

2021 Online KT Conference: Research Results for Policy Outcomes

Grassroots Policy Change

Liz Weintraub, Jeff Johnson, Clark Rachfal

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JOANN STARKS: It's time to get started with today's activities. Motivated individuals and community organizations are the engines that can drive grassroots policy change. And in this panel, we will hear from three leaders in the disability community who have been leading the charge of creating policy by and for people with disabilities. These experts will discuss the role of stakeholders in all parts of policy development and implementation.

First, we will hear from Liz Weintraub with the Association of University Centers on Disabilities who will discuss the impetus for the Tuesdays with Liz weekly video series. Next, Jeff Johnson will discuss his efforts at Missouri People First and will describe a project on segregated education and the school to prison pipeline. Clark Rachfal will round out the panel by discussing his policy role at the American Council of the Blind.

So, let's get going with Liz. Please welcome Liz Weintraub. Liz, can you turn your camera on now? She is Senior Advocacy Specialist at the Association of University Centers on Disabilities. She is also the host of Tuesdays with Liz, Disability Policy for All, and her presentation today is "Why Policy Needs to be Accessible for All." Go ahead Liz.

LIZ WEINTRAUB: Thank you, Joanne, and thank you, everyone, for inviting me to speak to you today. My description is I'm a short white woman with black hair, silver glasses, and wearing a blue jacket with a purplish reddish blouse. So that's my description.

This presentation is called "Why a Policy Need to be Accessible for All." I mean all. Who am I? Well, I am a self-advocate. I advocate for myself. I advocate when I want something, to what I want for dinner to my husband. And that's a picture of him. We were in Vermont where his family has a house.

On top is my sister. I'm a sister of three amazing people who helped me every day. And then, am I'm a wife to my husband, I'm a daughter to my parents, on the below-- and I'm not good with

left from right, on the below right, on the right side. And they're no longer here, so I miss them every day. And I try to be a friend to all. I say, I try, because that's up to you whether I'm a friend to all.

The backstory of Tuesdays with Liz, it started when I was young with my family. The discussion, and maybe my family is different, but they're my family and I love them. All of the discussion was about policy and politics. So, I didn't understand it. And I kept on saying, what did this? What did that? How is this? What did this? And no one would answer me. And their answer was, well look it up. Look it up. Well, that doesn't work for me.

So, when I got to AUCD and when I had a chance to make a video, I wanted to make sure that-- I wanted to make a video where my friends, my friends and others, could go up to the hill and talk to our legislators about policy. Like for example, I explained, I talked about home community-based services. I talk about the ABLE Act and they explained those issues. Because I didn't know what they were until I learned. I learned what they were.

So, I could go up to Capitol Hill. I could go to Annapolis, the capital in Maryland and talk to our legislator. Rather than someone coming to, rather than getting support from our supporters, like John Tschida at AUCD, or my supervisor at AUCD.

So, I worked with our former director, and our former policy director, there knowing at AUCD net at this time to make Tuesdays with Liz happen. And I didn't know what it was called, but that's the kind of vision that I had. I work with my producer to choose a policy topic. And we'll talk about what I want, or what's timely. So, for example, in late summer, we were talking about having HCBS as a hot topic.

HCBS stands for Home Community Based Services. The President wanted \$400 billion in the Build Back Better agenda. So, he-- in there to support home community-based services. So that was a big topic. So, we would talk about who I could interview. And either I would find someone to interview, or present by myself. Sometimes I'll just talk about home community-based services on my own.

And then she also will film the video. She'll also caption the video. It's very important to AUCD that our videos are captioned. So, everyone can understand and can participate and listen to the videos. She'll also edit the video. And she also posts the video to our social media platforms.

And since 2015, we have made over 200 episodes of Tuesdays with Liz. I think up to now we probably are up to 300 or 400 videos. We used to have it on a weekly basis on Tuesdays, but now we're just doing it on a monthly basis. So, every first Tuesday of the month.

The purpose of Tuesdays, and I think I went over this, but I'll talk again, is to educate about policy. So, someone can go up to Capitol Hill and say, oh yeah, I understand what HCBS is, or what ABLE Act is. To advocate, to make change on our own, and to help everyone understand policy, not just about people with disabilities. Started originally in 2015, but it's a big deal for self-advocates or people with disabilities.

But now, now a lot it has grown so much. So many people, trainees, trainees and in their network, people who are learning how to be in their network, who want to be doctors, who want to be researchers, who want to do this or that. So, it has grown.

And one of our favorite sayings is, "nothing about us without us." So, there's a saying. If there's a discussion, I demand to be at that table, or my friends demand. It's not a question about can we be at that table, but demand to be at that table, because it's our life.

And if there's time, I'll share a story about that, but I don't know if there is time. This is a video, live video, of our latest video, one of our latest videos with Senator Casey from Pennsylvania.

[VIDEO PLAYBACK]

- As for so many with so many important issues for families, for seniors, for people with disabilities, for workers, but the so-called HCBS part of it, as you noted, the policy is contained in the Better Care, Better jobs Act. What we're trying to do there is to make sure that, if you're a person with a disability, and you want to have care in your home or in the community, you should have, not only the right to have that care delivered in the home, in your home or in the community, but you should have access to the opportunity to have that kind of care.

So, the only way to do that and to help seniors as well as people with disabilities, is to pass a bill which allows states to have more Medicaid funding so they can expand these services. And our bill can expand services for seniors and people with disabilities by more than 3 million Americans.

[END PLAYBACK]

LIZ WEINTRAUB: That's just a snippet of the videos, and on the website there's many, many more of videos. And these are some how people can help people with disabilities can advocate for change. We'll learn about policy that affects them. As I said, Tuesdays with Liz, you can subscribe to our Disability Policy News. And what I like about the Disability Policy News is, it comes out every Monday, there's a section about a plain language section.

So, there is a section there's the wonky, what I like to call wonky language, and then underneath that section-- I write the section about what does that mean in plain language. We invite you to write a "Policy Talk," if you're interested. In "Policy Talk" it's just basically a policy block. And if you're interested in a subject, please contact me and I'll put you in touch with the person that is in charge of the "Policy Talk."

You can also write letters, make calls, or visit legislators. And you might think that you can't go up on Capitol Hill now, because of the pandemic. But you can make a virtual visit. I have had many virtual visits just within the last month on 14C. So, you can do that, or you can also go to your own capital and make an appointment.

So please do that. It's really important. Or you can make calls. They also like to put on you and do social media. So, tag your senators or your representative about an issue that you care about.

And then on our website, on their my "Top 10 Tips" to build a relationship with your members of Congress. It's important to build those relationships. And my dreams for the future of Tuesdays with Liz, more people with disabilities explaining policy.

I would love someone to write-- do a Tuesdays with Liz, it might not be called Tuesdays with Liz, but people can call it whatever, "Fridays with Martha," or Tuesdays with-- Wednesday with Jeff, or whatever, to explain policy.

When more people with disability advocating with their legislators. I can't be the only one who advocates because nothing about us without us needs to be true for everyone and everywhere.

This is my information if you're interested. And have to link to subscribe to Tuesdays with Liz on my YouTube channel.

Thank you very much. And I'll be glad to answer questions later.

JOANN STARKS: Thank you so much, Liz. That was great. That was very interesting and I really appreciate that. I was looking at some of the videos from Tuesday's with Liz and you've

got some really great stories there that you've shared. So, we really appreciate you coming. You did say you had a story that you wanted to tell if there was time. And I think if it's a short story we do time.

LIZ WEINTRAUB: Yes.

JOANN STARKS: --that's fine

LIZ WEINTRAUB: Yes. This is about, this goes back to nothing about us without us, when it was probably on 2020, 2021, I was at Thanksgiving with my family and our Thanksgiving is with cousins, aunts and uncles. And I'm telling you all of that because it relates to the story.

My parents called the business meeting, and guess who wasn't invited to that meeting? And to make it worse, my cousin who was there for Thanksgiving, my parents asked him to quote, "babysit" me. Who would babysit the 21-year-old person?

But they wanted-- what they wanted, was that I would not go downstairs and hear the discussion. Well, yes, I would not understand that discussion, and to this day, I still don't understand the discussion. And I know what the meeting was about. But so, I would not understand that discussion, but that's not the point. The point is that I was part, I am part of that family. I'm part of the family and I deserve to be at the table and that meeting.

So please don't think that even people with disabilities cannot understand there, or you don't think that people are people. Told you then that we can't understand the discussion. Don't invite, it's important to still invite us to that meeting.

JOANN STARKS: Definitely, definitely. Thank you for sharing that. I'm sorry that happened and I'll bet your family was very sorry when they realized what they had done to you.

LIZ WEINTRAUB: Yes, I think I taught them something.

JOANN STARKS: You definitely did. I'm sure they will never forget that either. Thanks again to Liz for her excellent presentation. And now we're going to move on to welcome Jeff Johnson. So, Jeff, if you can go ahead and turn your camera on.

And Jeff Johnson is President of People First of Missouri and Vice President of Columbia, Missouri People First. And he will be talking about a project on "Segregated Education and the

School to Prison Pipeline." So, Jeff, we're going to share your slides, so you can let us know when you want to go to the next slide.

But if you could go ahead and say a few words to describe yourself, and anything else you want to say about yourself, and then get started. Thank you.

JEFF JOHNSON: Sure. Thank you, Joanne. My name is Jeff Johnson, and I describe myself as an African-American, six feet tall. I'm wearing black eyeglasses, and I'm also wearing a light blue shirt. And I'm bald headed. I cut my hair short. So, I'm from Columbia, Missouri. So again, I want to thank everybody for allowing me to be part of you guys' conference this year.

And by the way Liz, great presentation.

So, I'm going to talk to you today about a project that I put together called the school pipeline to prison by SARTAC. And what SARTAC stands for Self Advocacy Technology Assisted. About the fellow again, as I told you, my name is Jess Johnson. I'm from Missouri.

And the segregated project that I put on was due to the fact that I wanted to do something about the school pipeline to prison. And I also had a host, by the name of Mark Satterwhite, which you see his name there. He works for organizations that deals with people with intellectual disability. And that organization is named Boone County Family Resources.

The reason why I wanted to do this project is because I wanted students with disabilities, students of color, and their parents to know their rights and to know where to turn for help. Because a lot of people didn't know where to turn for help when it comes to their kids being pushed out. I also formed a steering committee to make a plan. We held a focus group and did some research. So that's why that I wanted to, before I do this project, I wanted to put this committee together.

And the project went as planned except one part, is that the school would not let us in to do a survey. And we also did the National Research showing that there were more Black students with disabilities, are nearly four times more likely to receive multiple out-of-school suspensions, and almost 2 times more likely to be expelled than white students with disabilities.

But anyway, back to what I was saying about the students that were being pushed out. There were more African-Americans that were being pushed out. And those kids with intellectual disabilities that were being pushed out of the school, so that was one of the reasons why I put the panel together. And as you can look down below, where I was talking about the students with

disability as well, as a whole, are more than twice as likely to receive out-of-school suspension compared to students with no disability.

And here's my steering committee that I had put together. As you can see some of the names here. I'm going to call them out. The lady on the left here, some of you might see it on the right, Cheryl Miller, which is an attorney, a great, great friend of mine, that we worked together years ago, back in 2000, to where there was an organization called Grassroots Organizing. And what that group did was to advocate for those that couldn't advocate for themselves. We dealt with housing issues, we dealt with Medicaid issues, we dealt with Social Security issues. We dealt with a lot of issues that was brought before us.

And Mark Satterwhite, which you could tell there. He was my co-host that I just named. He works for what people with intellectual disability. And Christina Devine, there, which is an attorney for that same organization. She's an attorney there, and she was part of my steering committee as well, which is her husband just became a judge for the Columbia Boone County Court here, in Columbia, Missouri.

And what you can see Katie Kinder, which is our President for People First of Boone County. She was also part of the committee. And as you can see down below her is Kevin Williams. Which he is a parent of a family member that has intellectual disabilities. So, he was also part of the committee. And as you can see Nicole Seaman. She is a parent of a child that had intellectual disability, and also her husband sits on the School Board here in Columbia, Missouri.

So, these were the steering committee diversity that I have picked for my steering committee because I wanted somebody that I knew I can trust, somebody that I knew that would help me get the project done and find a lot of great information. So that's why I put the steering committee together.

And also, you can see there, information here to where we put a flyer together, which, the invite, the focus group. And the reason for that focus group was I wanted parents, youth, and other people that was at that focus group to be able to give me some information to help me with the project is working. Some of those are parents and youth that were there, and other agencies that were there at the focus group.

They provided me with great, great information, and we jotted it all down and we put it towards the project. And one of the things that I liked it about the focus group is that most of those parents, besides myself, wasn't the only one that had a lot of issues with the school. But one of

the things that we did make sure of, that we didn't want anything like to where the school versus us, us versus them. You know, we all wanted everybody to kind of work together, and come up with better solutions.

And that's what those parents, and the youth, and other agencies that was in that focus group did. They came up with some great information for this project.

And here you can see focus group 1 here. Where we held it on October 26 '19-- I mean 19, the year 2019 at the Columbia Library. Parents, grandparents, students, and representatives from Mid-Missouri Legal Services, SEPTA, that's another organization. Race Matters, that's another organization, and the ACLU, and People First of Boone County all participated with this focus group.

As you can see in the picture, especially on the far left there, where I'm listening to what the parents and other agencies were wanting to put into this project and group gave great information, in which they've done that. That was a really awesome group.

And here there was another focus group as you can see. Some who were at the first focus group wanted to continue the discussion. We met again in November at the host site at Boone County Family Resources. And as you can see in that picture, you see my wife, and my daughter, and some other members from the first focus group. We were still discussing some of the things that we would like to see put into the project which was great.

And we're still continuing that. We're just not doing it right at the moment due to the focus of-- I shouldn't say focus, but due to the fact of the pandemic. So that's why we haven't really been meeting. But we're going to try to pick this back up so we can get this back going again.

And what the focus group finding was is that parents needed to know where to turn for support. Students and their parents needed to know their rights. Teachers need special training and support in order to handle behavior definitely. School policy needs to change so it isn't so easy to kick students out of school or reference them, to refer them to juvenile authorities.

These should be last restored. So basically, this came from parents that was involved in that focus group. And then they were right about the support, and they was also right about coming up with something about their rights, because if you look at it, most people with intellectual disability, of kids of color, they just don't know who to turn to or who to talk to about the issues that they might be having within the school district.

And sometimes it might not just be the school district it can be also in the court system as well. So, this was something that I definitely, really was passionate about, is trying to come up with some solutions to help these families, and the students as well, to make sure that they had something to go on to where if they needed to talk to somebody, these were the resources that we can provide for them.

And basically, what I learned as a fellow, I learned the problem is real in our community, and also in our school. I also got to know others who are concerned about the problem and want to help. I also learned students and parents need support, and teachers need training. I also got to meet with other local groups like the Special Education Parent Teachers Association who I'm willing to partner with. I built all my leadership skills as well.

And the resource that was created, as you can see, this is out there on the website about the school pipeline to prison, as to we created a resource guide for parents and the community to be able to go through and find some of those resources like the ACLU, or Partners in Policy Making, things like that. So that way those parents will be able to go and find those type of resources. So, it's at their home on the SARTAC website as well.

And also, my partners, that they were helpful. As you can see that I'm talking with one of the members of the Special Education Parents and Teachers Association, with the attorney there. And also, I also partnered with Community Partnership of the Ozarks, which is out of Springfield, Missouri. And I also worked with them along with similar to the same project that I was working on the school pipeline to prison.

And also, you can see again, here, where I was talking with family members at the steering committee meeting. You can also see on the right, there, where I'm talking with the ACLU there about this project, and they gave great information for parents and also for my project as well.

And also, if you can see right here while networking at the MoDE, at the Missouri Disability Empowerment event that they put on for parents. And as you can see on the left, and some of you might see it on the right there, where I'm introducing myself and shaking hands with-- now, he's a judge now-- and he was one of the persons that told me that if I needed anything from him, that he will help me talk with other judges about this special project that I was putting on, the school pipeline to prison, that he will be assisted to that.

So, I'm still reaching out to him as well. And as you can see, myself and another former colleague of mine, with People First of Boone County. We was also invited to that event to give out information about my project and how I was doing.

The leadership and policy resolve, one of the things that I am interested in working with legislators to file bills to stop restraints and seclusions and limit out of school suspension. Just to go back a little bit about the restraints. I do know Missouri has passed a bill about the restraints and seclusion on that. I haven't really seen the bill, but I know it has been passed. But one of the things that I do want to work on, and talk with legislators about, about the out-of-school suspension.

I also want to be sure, and have a voice with the school board, in which I did talk with one board member before he became a board member. Now he's getting ready to run for the City Mayor here in Columbia, Missouri, so I'm still going to be trying to talk with him more to see where we all at about the school pipeline to prison, before he decides to leave the school board.

During the spring, I used my leadership skills to help with the Disability Rights Legislative Day at the State Capitol. This is something that we put on every year, as Liz mentioned in her presentation about going and talking with your legislators and all that. This is the same thing that we do here in the State of Missouri every year around March or April, one of the two, is that we'll go and talk with our legislators about issues that is more important to us and trying to get them to jump on board to get some of those bills passed.

And the local advocacy for school policy, as you can see, my wife and my son, and some other People First members. We met with David Seaman. He was a candidate for the school board. He is now on the school board. This is the gentleman on your far left over there, some people might see him on the right, just by looking at the PowerPoint here. But like I said, he's now on the school board, but now he's getting ready to run for city council, or not city council, excuse me, but City Mayor here in Columbia, Missouri. So, I'm hoping that I can meet up with him again if he decides to be elected as our next City Mayor.

And here where you see where I'm in the background, I was introducing some of the representatives, kind of talked about the restraints and seclusion bill. These guys, they did sponsor that bill, and because if you look at it, my son has some experience about being in restraints and seclusion in the school classroom. During the time that he was in school, but now that he's out of school, he's been out of school for the past, say, two years now. So, but like I said before, that bill did get passed.

The role of the host, the role of the host of my project, as a host, Boone County found a resource providing meeting space, usable equipment, and their paper. Mark Satterwhite took meeting notes so I could focus on leading or facilitating the meetings. The host also-- you can see right there some of the names that I already mentioned before. They helped develop the resource guide. Boone County Family Resource supported people with I/DD.

They also included public school students who may be experiencing the issue. And I also focused on it. The project helped bring us into better touch with the issues. So, this whole project, it just brought us all together to continue the work. And to be honest with you, I've been getting a lot of calls, and a lot of invitations to come and talk about this same project.

And about the employment results of the goal, well, I have a goal to be self-employed as a consultant and advocate for students' rights. My research during this project has helped me prepare. I am currently the co-chair for the Real Voices and Real Choices Conference. And when I say Real Voices and Real Choices Conference, it's a conference that the State of Missouri has put on through the Department of mental health due to the fact, this was something back in 2008 that we did a summit on, and then we put a committee together. And then we also, a year later, we put on a conference.

And I'm going to save my questions and answers for later.

JOANN STARKS: OK thank you so much. That was great. That was excellent to see all the participation you had, lots of helpful partners, lots of participation throughout the community, and a very interesting, and sounds like successful, project. So, thank you so much for sharing that.

And if you want to turn off your camera, we'll now ask Clark Rachfal, Director of Advocacy and Governmental Affairs at American Council of the Blind to turn on his camera. And a reminder there's no slides for Clark's presentation, but he will be talking to us about his many policy experiences in his role at ACB and other organizations. So, Clarke, if you would like to say a few words to describe or introduce yourself, and then go ahead with your presentation.

CLARK RACHFAL: Absolutely thank you so much. Hello, everyone. My name is Clark Rachfal. I'm the Director of Advocacy and Governmental Affairs for the American Council of the Blind. ACB is a nationwide membership organization that strives to increase the security, independence, economic opportunity, and quality of life for people who are blind and visually impaired.

So, I, myself, I am a light-skinned male with short brown hair, what I believe is a medium gray shirt, and with a purple wall as a background behind me.

Thank you so much for the opportunity to present here on this great panel and speak with you all today. Primarily, I'm going to focus on accessibility of health and wellness, and how that relates to people who are blind and experiencing vision loss.

So, the leading cause of blindness in the United States. We'll start with older Americans, which is age-related macular degeneration, but also includes things like glaucoma and cataracts and many other conditions. Roughly 1/3 of seniors over the age of 65 will have some form of vision loss. For working age adults, ages 18 to 64, the leading cause of blindness is diabetes, and complications related to diabetic retinopathy.

Why is this important? About roughly 60 million Americans have a disability. Roughly half, 30 million Americans, have severe vision loss, vision loss that impacts one or more major life functions. However, our medical system, as many of us know and have experienced over the past year and the COVID 19 pandemic, is not necessarily accessible, or set up in a manner to consider the needs of individuals with disabilities.

So, for our seniors with disabilities, there are estimates that for medical conditions for adults over the age of 40, there is roughly a \$50 billion burden on the US economy. And that's from the Vision Health Initiative at the Centers for Disease Control and Prevention, CDC.

With that being the case and knowing that routine eye exams can help to mitigate the deteriorating lifestyles of our seniors experiencing vision loss, it may come as a surprise to some, likely not all, that Medicare actually has a statutory exclusion of providing vision coverage.

And in 2008 the Centers for Medicare and Medicaid Services went a bit further and extended the vision coverage exclusion. They interpreted it very broadly to include everything with a lens, so low vision devices, magnifier, video magnifier, anything that can augment the magnification, color contrast, whether a wearable handheld or table mounted low vision device, is not eligible for Medicare coverage.

Why does this matter? Well, as I mentioned, our seniors, and this population is anticipated to increase as the baby boomer generation ages, roughly a third of them have vision loss. But also, around 25% of seniors are, not anticipated to, but statistics show that roughly 25% of seniors

over the age of 65 experience a fall every year. This more than doubles if you are a senior with visual impairments or experiencing vision loss.

Some of the things that the CDC has documented to reduce these numbers include routine eye exams, corrective lenses for eyeglasses, as well as low vision aids and devices, all of which are not covered by Medicare. It's estimated that adding a Medicare benefit, excuse me, adding a vision benefit to Medicare, as is attempted to be being done right now in the budget reconciliation package, would cost about \$20 billion.

However, the Medicare, Medicaid, and insurance companies currently spend far more than this, and the burden to our economy is far greater from the health conditions resulting from a lack of vision coverage, and the costs of seniors' experiencing falls each year.

Going back to our working age population, who is experiencing systemic rates of diabetes, a condition that we know disproportionately impacts people of color, African-Americans, Hispanics, Asian-Pacific Islanders, and Native Americans. This is-- excuse me, I always get a little tongue-tied here, because it just baffles my mind.

So, knowing that diabetes is a leading cause of blindness for working age adults, and knowing that diabetes is a preventable condition, how can diabetes or diabetic retinopathy be prevented? With routine eye exams, managing one's blood sugar, routine exercise and fitness.

However, there are no requirements that durable medical equipment be accessible. Again, so the leading cause of blindness for working age adults is diabetes and diabetic retinopathy. Some of the ways to reduce the risk of diabetic retinopathy, routine eye exams, as we just stated, not covered by Medicare, and typically an added bit of coverage for insurance policies.

Regular monitoring, testing, and management of one's blood sugar levels. However, there are no requirements for durable medical equipment, including continuous glucose monitors, as well as insulin pumps, to be accessible for people with disabilities, including individuals who have lost their vision due to diabetes.

And then the third, exercise and fitness, which is also an interesting one. Because, although the international standards setting body, ASTM, in 2013 created international guidelines for inclusive and accessible exercise and fitness equipment, which includes tactile user interfaces, as well as audio output for people who are blind and experiencing vision loss, there are no regulations to enforce these standards.

In my view, and the view of our members in ACB, as well as our affiliate ACB Diabetics in Action, this is not just an oversight, but it's wrong. So, what can we do to remedy these problems? Well, I mentioned that there's efforts to get Medicare vision coverage in the budget reconciliation package. There's also efforts underway to require the accessibility of durable medical equipment.

And again, I focused on diabetes and diabetic retinopathy, and equipment for monitoring, managing, and testing for diabetes because it's the most prevalent cause. But that's not the only thing that these regulations would apply to. They would apply to heart rate monitors, pulse oximeters. Everything that we've experienced over the past year with the growing of remote monitoring in diagnostics of telehealth, remote health care, in-home monitoring and care.

In addition to these durable medical products, we need to ensure that telehealth is accessible for people with disabilities, and people who are blind and visually impaired. This would allow our folks to maintain independence, remain integrated in their community, and take back control of their health.

So, we talked about the impact of vision loss and falls on our senior population. And according to the CDC, diabetes and diabetic retinopathy has a \$50 billion a year burden on our economy for medical costs, for Medicare and Medicaid costs, and lost economic potential.

For ACB, another key driver of us being able to, and people who are blind and experiencing vision loss, to take back control of our health, is ensuring the accessibility of exercise and fitness equipment. So, we certainly want to make sure that our friends, and family, and community members can independently manage their health conditions. But we also want to provide individuals the tools and the resources so that they don't become subject to diabetes, they don't acquire diabetic retinopathy in the first place.

So, we're also working with Congress, as I mentioned, for regulations around durable medical equipment. We're also working for regulations around accessible exercise and fitness equipment. So, at this point, I'm glad to say that there have been bills introduced in the US Congress for accessible exercise and fitness equipment. Bills have been introduced in both the House and the Senate, the Exercise and Fitness for All Act. It's S 2504 and HR 4756.

And there is also a bill, the Medical Device Nonvisual Accessibility Act, that has been introduced in the House of Representatives that would require accessibility for durable medical equipment. And that bill is HR 4853. As we work with Congress and the federal government to

implement legislation and regulations requiring accessibility standards for exercise and fitness equipment, as well as durable medical equipment, we're also attempting to work with industry, and collaborate with our corporate partners.

Because we know sometimes it can take a long time to pass a bill, it can take a long time for a rulemaking, and we know that our partners in the broader community, they want to be able to serve as many consumers as they can and reach as many potential customers as possible.

So, in 2020, ACB was proud that through our collaboration with Peloton International, the Google TalkBack screen reader was enabled on the Peloton Bike and Bike Plus. Much like we see in the medical industry, Peloton is using an Android based, Android operating system-based tablet, for their user interface.

The beauty of when an off the shelf product, like a tablet using the Android operating system, Microsoft, Apple's operating systems, is that accessibility is already baked in. It's there in the operating system. It just takes some education on the part of the disability rights community, at ACB, at our partners, and across disability community, to work with and communicate the availability of these technologies to these companies.

So, we've noticed the same thing in the medical device space, whether it's for continuous glucose monitors, or for remote monitoring of heart arrhythmias, tachycardia, irregular heartbeats. A lot of times it's a wearable sensor that then connects to a smartphone. A smartphone that already has accessibility built into it, but that the creators of the app didn't know about or unfortunately sometimes, just coded around.

So, what can we do to raise the profile of the fact that these features are built in? How can we work with the research community to show the ease of access for engaging, or in some cases, like exercise and fitness equipment, and other durable medical good products, the ease of including these features?

To ensure that these products, these devices, are accessible, making sure that they're accessible so our folks can take charge of their health, live more independently as engaged and active members of their community, and contribute to our society more fully.

In addition to working collaboratively with industry, and across disability community, and working with government, at ACB we are also launching a multiyear campaign. We're calling it our Get Up & Get Moving campaign. Because we know that throughout the pandemic, as our

folks have been socially distant in many cases, not just distance, but isolated, that we've led stagnant lives as well. With impacts on our social inclusion, on our mental and physical well-being.

So, we are working to create greater public awareness, increased partnerships, and raise more knowledge of our advocacy efforts in the health and wellness space. I encourage all folks to visit our website and learn more about our Get Up & Get Moving campaign as we embark here into 2022. And I hope that everyone can get up and get moving. A little bit of movement, especially with accessible exercise and fitness equipment, and accessible durable medical equipment, will do us all good as we come out of this pandemic and embrace living life to the fullest.

So, thank you very much for the opportunity to speak here with you today. And I'm happy to answer any questions.

JOANN STARKS: Thank you so much, Clarke. That was sobering and very interesting. Being on Medicare myself, I'm learning about some of those things that you talked about and do agree. I find it quite shocking that some things are not covered, like vision and dental, which are issues that everyone has, and especially as one gets older.

So, it's great to know that you're working on these policy issues, and these changes to some of the laws out there. And we really appreciate your sharing that information with us.

So, we do have time to take a question or two before we go on to our discussion session. We have a comment from one of our participants. "Another factor is to remedy the food deserts, or lack of access to grocery stores with robust food options." So, I'll take your comment on that, Clark, as part of what you've been talking about.

Well, you're on mute. Sorry.

CLARK RACHFAL: Great, thank you. Just making sure. Yes, so certainly for ACB and our members, the things that we've heard about the most throughout the pandemic are transportation access and information access. A lot of our members rely heavily on delivery services, either because time or money, right? Things that are in short supply for everyone, especially people with disabilities.

And as it became more difficult to, whether due to food deserts, or due to lack of accessible transportation options, many folks have relied on food delivery services. However, during the pandemic these services became very popular. Much like we've noticed a lot of accommodations

and things typically adopted by people with disabilities, like remote work and distance learning, accommodations you used to have to fight tooth and nail for, became popular by the general public.

So, these services typically had much longer delays, which made it more difficult for folks to gain access. And these are for folks that A, can afford access, but also had access to technology as well as well as these delivery services. Certainly, a much larger issue is raised by the question of fresh food, grocery deserts, for people with disabilities, people who are low income, and other socioeconomic groups. It's a major issue that can have long lasting and deteriorating impacts on one's health and wellness.

JOANN STARKS: Thank you, Clark. We do have one other question. I think we can squeeze it in. Does ACB-- this is Jess Chaiken, who is one of our reactors. "Does ACB do any work with University programs pairing developers and designers with members to get the concept of accessibility ingrained early?"

CLARK RACHFAL: Absolutely. What a great question. So yes, ACB does work with universities and developers. We are actually a member of Teach Access. If folks aren't familiar with TeachAccess.org, but it was an organization that was founded to introduce accessibility professionals to the STEM university curriculum structures, along with professors and students, so that students can be exposed to universal design, accessible by design in the classroom.

Because one of the things that companies and industry partners have been noticing is that when they're going to hire someone for accessibility, if they are fresh out of a degree in software engineering, or cybersecurity-- not cybersecurity, but computer information systems or something like that, they don't have a background in accessibility. And they have to be coached and taught on the job to design with accessibility in mind.

So, we are working with Teach Access to provide the consumer, the end user, but also the potential employee perspective on why accessibility matters. But for ACB's part, we're also trying to educate the broader public on why accessible media and content and information is important, like audio description, like using alt text to provide information about your images in posts on social media and everywhere else.

JOANN STARKS: Great, thank you so much, Clarke. And I want to thank all of our panelists today for sharing their great grassroots policy experiences. And we're going to get ready to move on to our discussion session that will be led by our KTDORR Director, Kathleen Murphy.

So, I'd like to ask all the presenters to turn their cameras on, as well as the three participants who have volunteered to be reactors to today's session. So, Kathleen, are you ready to take it over and start facilitating our discussion session to follow up the panel?

KATHLEEN MURPHY: I am. So, thank you, Joanne. And I did pop it in the chat earlier today, but for those of you who missed that, I'm Kathleen Murphy. I'm Director of the Center on Knowledge Translation for Disability and Rehabilitation Research, the center in KTDRR which is sponsoring this conference. And I am a white woman with shoulder length blonde hair, wearing kind of an off-white sweater and glasses. And my background is blurred, so there's not much to see there.

So, we are excited that we've got some fantastic reactors lined up for today. So, I will let-- I'm just going to list each of them and then I'll go to each of you and you can add any information that you might want to add to your bio, describe who you are, and then we'll go back around once just to see if you have some immediate reaction to any of what you've heard so far today.

So, I'm going to start with Jess Chaiken, from the National Rehabilitation Information Center. Many of you might have known or heard of that as NARIC. You want to say Hi Jess?

JESS CHAIKEN: Yep so, I'm Jess. I identify as a cisgender white woman. I've got glasses with little flowers on them, and a blue sweater and a blurred background, wherein a cat or two may appear. And most of you know me from NARIC.

KATHLEEN MURPHY: And we have Jessica. We have two Jessicas, so Jess Chaiken has agreed to be Jess for today. And Jessica Lukefahr, who's joining us from Portland State University, is our Jessica. So, Jessica, do you want to say Hello?

JESSICA LUKEFAHR: Hello. Yes, I work for Portland State University, but I actually live in Texas, so it's a lot too, it's kind of confusing. To describe myself I'm light complected, female, in my 30s, and I have long, blonde hair. I'm wearing a blouse that has navy blue in the background and then white flowers on it. And it's kind of blurred, but I am in a wheelchair. I have cerebral palsy. So, my head rest is kind of blurred for some reason.

And so currently the work that I do is for the Regional Research Institute at Portland State University. And what I'm focusing on right now, I work on a project for supporting working caregivers. So--

KATHLEEN MURPHY: Super important, as we've heard from Liz, especially. And our third reactor for today is Regina Rice who is with the Vocational Rehabilitation in Florida, which is housed in their Department of Education. Regina, do you want to say hello?

REGINA RICE: Hi, everyone. My name is Regina Rice, and I am a white woman with medium length brown hair. I'm wearing glasses and a black and white striped shirt.

KATHLEEN MURPHY: So now we're going to go around once again. And all of our reactors have seen the information, or had some information about this panel, so compared to those of you who are attending, and are just hearing this for the first time, they have had a little bit of time to think about it.

So, you don't have to, Jess, Jessica, and Regina, say anything right now because we do have other questions from the participants. But if you would like to say some thoughts that you had, this is your opportunity. So, I'm just going to go back around. So, Jess, is there anything that you wanted to add or ask?

JESS CHAIKEN: There were-- so a couple of things struck me. One is the importance of local advocacy. We certainly learned in the last few elections that change happens locally. With local elections, local school boards, and we're certainly seeing a lot of advocacy in local school boards, local health boards, and things like that. So, I was really struck by the importance of acting locally if you're going to be an advocate.

And the other thing that struck me is again, lately we've seen this resistance to science, and as part of the conference we're talking about how do we get science into the mainstream, into practice, and into policy.

So, I think the idea of having local advocates, people who are in the community, who are visible in the community, fostering, pushing the science into policy may be one way to get past some of that resistance to science that we're seeing lately.

And the third thing that struck me was listening to Clark. The idea of personas for developers, giving developers and designers a person, the idea of a person, to hang on as they're creating and developing tools, apps, technology, seems so important.

That it's great to have an idea of it, would be great if we had an app that did this. But for whom, and how are they going to use it? And having those personas, I think, can be really key. So those were my initial thoughts.

KATHLEEN MURPHY: And that's actually interesting because it's another way of, the personas and being local, are both ways against being general.

JESS CHAIKEN: Right, and you're giving people a person to hang the idea on, whether it's an actual person, an advocate standing up and talking, or having this idea of this persona.

KATHLEEN MURPHY: Exactly. So, Jessica, how about you? Did you have any immediate feedback?

JESSICA LUKEFAHR: Sure, the way I arranged my questions was I did it by presenter. So, I have I have a question for each of you. If this is too long, please let me know.

So, for Liz, as I'm doing my own research, and I know that your show does talk about disability and policies, is there another source that you would recommend just to get a general knowledge of the policies that affect disability right now, or the current ones that are being researched? So, I can kind of get a handle on that. So that when I come into these policies that are in the research-- that the research project is working on, I can have a better understanding from that perspective.

KATHLEEN MURPHY: So, Liz if you want to go ahead and answer, that it's fine.

LIZ WEINTRAUB: It's got that, it was on mute. Thank you, Jessica, for that question. I don't know of a policy show like mine. There are other self-advocates who are doing policy. There has been a person in Georgia, named Martha Hayworth who has done a show like mine.

But the organization that has done a lot of policy work who is people with disability is the Autistic Self Advocacy Network and they have done a lot of the policy work around the same issues that I talk about.

I also know the Arc, but and I may put in the chat on tape. Self Advocates Becoming Empowered, is another self-advocacy organization. I don't know if they have done a lot as of right now around policy per se, but they are a self-advocacy organization around the country.

And every state has a chapter. They're not all named Self Advocates Becoming Empowered. And that's what they are called. it's the People First groups around the country, like Jeff has talked about. And I think Jeff is a member of People First of Missouri. And the reason why Self Advocates Becoming Empowered isn't called People First US, is because not every chapter's called People First.

KATHLEEN MURPHY: Thanks for that clarification, Liz. Jessica, I'm going to turn to Regina, and then we can come back to your other two questions. OK?

JESSICA LUKEFAHR: Sure.

KATHLEEN MURPHY: So, Regina?

REGINA RICE: I just had-- the one thing that really struck me was when Liz was speaking, and she was talking about being able to talk to legislators virtually, because I know during the pandemic, that's all how we worked and that's how we kept in touch, and I hadn't thought about that. And it just made me think that it opens up the door, a lot, for people who might not otherwise have the opportunity to get in front of people, to get in front of them.

And I just wondered if she found the virtual meetings to be as effective as in-person meetings were.

LIZ WEINTRAUB: Thank you for that question. I myself don't like virtual meetings as well. I have gotten used to them over the last 18, 19 months, however long we're here. But I don't think they work as well for people with disability because you can't hear very well, you can't be part of the conversation as well.

Sometimes people have come in with computer issues, like I do. It's really hard. I have learned a lot within the last 18, 19 months. But I can't say that I like working on the computer.

On Nate, I just saw the chat. He put AAPD, the American Association for People with Disabilities, how can I ever forget them? They're one the best organizations that are working on policy issues, mostly on the burning issues.

And NCIL, a really wonderful organization called National Council on Independent Living, and the organization's for shows around the country. So those are two of the other organizations that are run by and for people with disabilities.

KATHLEEN MURPHY: And yes, that's so important. So, Jessica, you mentioned that you had a question for Jeff.

JESSICA LUKEFAHR: Yes, so thank you for your presentation as well. I had a question that went beyond your study because you were talking about focus groups and how people get to a place, and they don't know where to turn to.

I was going to go off a little bit on that and ask if anyone knows like a peer group focus group? Especially for kids with disabilities, maybe older kids that are closer to teens, getting ready to transition to college, things of that sort. Because I know when I was growing up, I didn't have access to that.

So, what was told to me was like a rosy, cheery version of there's always going to be some agency or something to help you. And so, I would think something like a peer group, because I know there's some for people with mental disorders, they kind of peer talk to each other. And I haven't heard one on people with disabilities.

KATHLEEN MURPHY: Really helpful resources, Jessica. So, I want to give Jeff some time to answer to your really fantastic question, so maybe take about a minute, Jeff, and address some of what she's raising.

JEFF JOHNSON: To be honest with you, I notice you're in Columbia. I mean there are some peer groups here. And some people I do know that they do have a-- but they just put this in place a few years ago. It's called the Youth Commission. That was designed for students by the City Council here a few years ago. But I guess where I was kind of going with that, due to the fact that mostly people that lives in a low-income area, they don't even know that those groups even exist.

They don't even know that the resources is there. So, I was going through this with my son when he was in school. Because we've been dealing with this for years and years. I mean, ever since he was probably three years old. So, I just kind of made it up on my own, decided to say, OK, there's something, I have to do something.

So, after the years have past, so I decided that I wanted to do something like this, because you just get tired of trying to fight by yourself. So, I decided that I wanted to get some more people involved that will be able to help me with this. And that's what I've done. But you're right, there are some groups out there.

But a lot of parents just don't know that they even exist because, again, they want to try to find somebody that they can trust, that they know that's going to be willing to help them and not fib to them. Because sometimes people say they're going to do something, and they don't do it. And then you go back and say, I thought such and such was going to help me with this. And they never followed through.

So, it's just that trust, that I look at. And I think that's what parents and youth, sometimes they look at. They look at that trust. So, if they feel that, well, Jeff said he's going to do something, he's going to do it. So, they're going to always look to me, and say, hey, I know somebody. Jeff, he's going to do it. So, there is something out there.

KATHLEEN MURPHY: Thank you, Jeff. And we all know that such an important part of knowledge translation is relationship building, and trust is essential to that. And so, I think our participants trust we're going to stay on our timetable. So, we are going to close out this discussion, which means everybody who has been voicing anything right now is going to not only turn off your mic but turn off your camera. So, the two little icons at the bottom. And we will be joined, again, by Joann Starks, and new face to our attendees, David Gough.