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SPEAKER:

Hello, and welcome to #VaccinateByADA. We would like to thank you all for joining us today. Before you begin, I would like to address the number of participants, you can submit questions or comments at any time in the question box on your console. You can also send a quick chat, there is also a chat box. We have captioning, if you would like to access it, press the CC button to access the subtitles. You can make the captions bigger or smaller by hitting settings. You can also move your caption card around if you need to. In addition, we have sign language interpreters for this session, you can see their video by hovering over the screen and clicking the small dots at the top of the corner of the video. You can also use the top right corner to adjust the speaker preferences. This meeting is being recorded and will be available for the transcript and presentation slides. Please join me in welcoming Tanisha Clarke, the moderator for today's event.

TANISHA CLARKE:

Thank you, Anna, and welcome everyone. This is being presented by the University Centre for disability, National Centre on disability and public health, the Morehouse group of medicines, national COVID-19 resiliency network, and the Association of State and territorial health organizations. My name is Tanisha Clarke. I am a senior manager -- manager with AUCD and I will be your host for this event.

Today, we will be learning about common strategies to support COVID-19 for people with disabilities. From Lauren, our project manager with AUCD. Lydia from the Mailman Center for Child Development, Marcia from the University of New Mexico Centre for development and disability. Along with David, a disability inclusion specialist with ASTHO. We will leave time at the end for a brief panel discussion about ways to sustain inclusion, of personal disabilities in public health, and we will end with your questions. I will turn it over now to Lauren to introduce us to AUCD's vaccine work.

LAUREN BLACHOWIAK:

Hi, everybody, thank you for joining us today. Thank you, Tanisha. My name is Lauren Blachowiak, I am a manager for AUCD's COVID-19 vaccine access for people with disability initiative. It is through the Centre of disease control and prevention. This initiative has a simple goal, we want to vaccinate all accessible persons with disabilities with the COVID-19 vaccine to help keep everyone safe and healthy.

We are doing this work by engaging 23 of our centres across the country in rural and urban communities, all the way from New York down to Puerto Rico and Hawaii. We are really doing some local outreach efforts that spread across the entire country. We talk about individuals with disabilities, we are really taking a cross-disability approach in thinking about individuals with intellectual and

development of disabilities, physical or mental health. Also thinking across the age spans. Right now, we are focusing on 12 years and older individuals who are eligible.

To do this work, we are doing outreach not just with individuals with disabilities, but also to their family members, recognizing that family is an important support network for people with disabilities as well as doing outreach to the direct support professionals who work with individuals with disabilities every day. By focusing our attention on all of these groups together, we are hoping to keep everyone safe and healthy.

We are taking a two-pronged approach to this work. First, our outreach efforts are around building vaccine competence by ensuring that people with disabilities have the information in an accessible format and in ways that are applicable to make an informed decision, whether or not to get the vaccine. We are also thinking about ways to remove barriers of access to the vaccine, and accessibility in the vaccine experience. All the way from signing up on a website, making sure that a website is screen reader friendly, to an actual vaccination site, making sure that all individuals with their AES mobility can access. Recognizing that people with disabilities need to be included at all steps of this process.

I want to share with you now some of the resources that has come out of this work is part of our goal to vaccinate all eligible individuals with disabilities by the anniversary of the Americans with disabilities act. An ambitious goal, but we are working towards it. Our hope is that, by the end of today, you will learn some strategies that you can apply back to your own communities to help continue this work. Also, utilizing some of the resources that we developed as part of our work. I've highlighted here some examples that I will link to in the chat in a moment for you to access.

We have a series of short videos that you can look at and share from people with disabilities discussing their vaccine experience and encouraging others to experience it. We have a set of social media tools to reach out that are easy to read, and accessible. Finally, we have a set of vaccine competence talking points with questions and answers. Specific to individuals with disabilities who may have questions based on their disability status.

We will put the link in the chat and we encourage everybody to bring me strategies and tools back -- back to your own communities at the end of the day. I will turn it back to you Tanisha.

TANISHA CLARKE:

Thank you, Lauren, thank you for sharing efforts across the country to vaccinate people with disabilities, their families and the professionals who support them. We will begin our discussion today of successful strategies by hearing from Maureen, Director of the MC DD, and their successful drive-through clinic in Baltimore city.

MAUREEN VAN STONE:

Thank you, Tanisha and Lauren, I appreciate the opportunity to share our important work here in Maryland. We have created the team at Kennedy Krieger of interdisciplinary professionals across various professions and programs to address COVID-19 vaccine access and confidence with excess abilities, including representatives from the Merrill Lynch Centre for Dell developmental disabilities, our Centre for diversity in health leadership training, our Centre for Child and family genetic stress, self advocates from people on the go in Maryland as well as other people with disabilities, parents and legal guardians and we've included a number of trainees from our Ellie ND, and CDD, and Centre for diversity in public training.

In terms of Kennedy Krieger's outreach, we have posted free drive-through vaccine clinics in downtown Baltimore. These clinics were held on May 1, May 23, and June 13. I am proud to share with this group that we successfully vaccinated 580 people in total, individuals 12 and older receive their first or second instance of the vaccine in part of the reason we've posted these are out patient centres in downtown Baltimore was to promote accessibility for folks and provide much-needed accommodation. We have language and Ace SL interpreters at the sites, ability to handle oversized vehicles like medical transport as they went through our outpatient garage. We also use these clinics as an opportunity collect success stories on why people are receiving the COVID-19 vaccine.

I had the opportunity to talk about this with a local news segment, in early May. This coincided with the day that children in Maryland could start receiving their vaccine. It was a really exciting day and give us an opportunity to talk about the importance of children receiving the vaccine. Additionally, we issued a press release about this work later in the month of May.

In terms of COVID-19, our Centre has been extremely involved in all different aspects of COVID-19 work. Throughout the course of the pandemic. I have served in a number of COVID-19 taskforces, I had this privilege of serving on the Johns Hopkins scarce allocation of resources committee, for the last 16 months. This really brought a disability perspective to plans for our larger healthcare system in Maryland, and advised our governor in terms of ways to think about a framework for the allocation of scarce resources such as ventilators, ICO beds, plasma, the COVID-19 vaccine, etc.

As you can see, we have done a lot of work surrounding COVID-19 in the vaccine including webinars and trainings for school closures and how it impacts students with disabilities, and now we have shifted gears in focusing on the need to advance confidence and access to the vaccine. When you receive copies of the slides, you can like to any of the resources we developed over the course of the pandemic.

One thing that we recently added was my colleagues in Puerto Rico mentioned that they were creating

a vaccine holder, so what I did was go ahead and order 5000 of these vaccine cardholders for students, and their family members. These will be disseminated at our clinics, what we're doing right now is hosting clinics every Friday beginning on July 9 in our outpatient centres. If a patient or caregiver is coming from outpatient appointment, we are going to offer them the COVID-19 vaccine and if they receive the vaccine, they are also going to receive this vaccine cardholder with the logo.

Additionally, the M said is proud to be one of the eight national partners in the centre for dignity and healthcare for people with disabilities. We have been able to leverage our advocacy around the vaccine through the Centre for dignity with people with healthcare people disabilities. As many of you know, we are one of eight collaborators. The centre had the opportunity to host a COVID-19 workgroup, at the outset of the pandemic. Two members of our staff have been serving on that workgroup, initially we were meeting weekly and then we shifted the biweekly and on Friday, we made the determination to shift monthly. We also worked very closely through the centre with the Johns Hopkins disability health research Centre, to create a vaccine allocation plan for disability tracker. That tracker was utilized by individuals across the country to track when they were eligible to receive the vaccine. It was updated every week, and it was last updated in late April when vaccines were open to everyone.

Additionally, we have been working to create social stories to help individuals with disabilities receive safely and effectively the vaccine. We created a document about commonly asked questions and then we created social stories in English, Spanish and additionally a British version.

Then we created fact sheets about the questions, about COVID-19 vaccine. These are a list of other fact sheets that were created and links to those fact sheets. As well as my staff attorney, Tracy Waller, created an info graphic on discrimination in healthcare during the COVID-19 pandemic which was very useful at the outset of the pandemic and highlights types of discriminations, and discrimination remedies available to individuals with disabilities. As you may know, the Centre for dignity as well as AUCD has been really great in posting blogs about these really difficult and challenging issues that we face over the course of the pandemic. As you can see, we have four blogs that have been posted, if you haven't yet had the opportunity to read them, I encourage you to do so.

This is our information at Kennedy, I am happy to field questions at the end when we have the panel. And I want to thank AUCD for the opportunity to share our work here in Maryland, and I look forward to continuing our work on this project for the remaining months. Thank you.

TANISHA CLARKE:

Thank you so much, Maureen. We know you are only getting a little bit of time to share the great work you are doing. Feel free to reach out and stay connected with Maureen and the Centre in Maryland. Next, we will hear from Lydia and Jeff on their outreach at the centre in Miami, Florida.

LYDIA OCASIO-STOUTENBURG:

Thank you for having us. We are from Miami, Florida and I would like to hold space for a moment for a tragedy that has happened in Miami, Florida for all of the people who have been victimized by the big building collapse. We recognize that many of those individuals were persons with disabilities as we share this morning our community meeting. I would like to hold space for that for a moment and recognize that is part of our responsiveness is to recognize when there are emergencies.

This is -- these are the members of our team, we have a very diverse panel who are working on this. We would like to highlight the fact that we have advocates as part of our team, and our NPH students. I know you hear that all the time, but we are preparing our next generation of leaders and getting them involved in some of these efforts. Our generation leaders have been involved in developing our vaccine model which I will share with you in a few minutes, as well as sharing our social media efforts, so they have active roles and responsibilities. We have this talk about diversity, equity and inclusion, right? It is really part of our culture and embedded in our world. -- Work. If we think about Miami community and how diverse it is, culturally, ethnically, it is really embedded in our culture to be responsive to that. Of course, we will develop resources in Spanish and English. (Speaking Spanish) we will make sure our resources are that responsive. But also embedding that into our leadership as well. Because our leadership is diverse, we will ask the questions that need to be asked and be responsive to our communities who will identify those who are at those intersections. We know that those with disabilities also have intersecting identities and culture perks that they are part of. We also have advocates who have intersecting identities who are part of our team. So we embed this from the beginning of our initiatives all the way through.

We are talking about our logic model. This is something we have developed in identifying what are the issues around vaccine confidence, what do we need to identify about access. How can we be responsive to that? We will share those in a minute, but we have been responsive in terms of garnering stakeholder information, and we shot this around to all of our collaborators to get their feedback on how we can develop this model. The language that we use, and if any of our features are responsive to the needs of all of our communities as we address diversity.

This is our conceptual model for vaccine confidence and people with disabilities. As you can see, the centre of this model, which is the hallmark, is the decision-making about vaccine. We are censuring the people with intellectual disabilities but also acknowledging the cross disability perspective. These are dotted arrows, and trust is really immediate or all across this model, looking at all the historical and political social content, looking at accessibility which is something that is really important, especially at the beginning of this. It really continues throughout. Our healthcare professionals and recommendations as we think about direct service care providers and communication in media, vaccine policies that are also important. Again, trust is also important which we have garnered through

our perspectives, but also listening to the voices of people with disabilities about their concerns.

What we have done is partner with the Department of Health, it has been really key in developing how we can be responsive to those needs. Our resource list for clients with disabilities has been an important part of our initiatives. We have also partnered with Puerto Rico and also utilizing those networks for disseminating information.

Just sharing what we have done. So in March, we developed a panel called asking expert where we had individuals with developmental disabilities who are part of our card partnership to ask an expert. So we had practitioner able to of vied information about the vaccines, about all the differences between the vaccines, and our panelists who were able to be that in order to moderate the panel. It was really centred around our centres for disabilities. They were able to ask all the questions that they had and they were relevant questions. In response to that, we developed this info graphic. And change the narrative around. Instead of asking an expert, how about have a conversation with people with disabilities. What other concerns about the vaccine? We listed all of these questions and included these in the narrative.

As a partnership with our Puerto Rico youth set we also develop this in Spanish so it could be accessible to our clients in Spanish. We will continue forward developing real talk to, we will also do ask an expert featuring Doctor (Name) and we will also continue along those conversations as we transition into our client's concerns about children receiving vaccine, about transitioning into life now and about the variance. All the different concerns will be included in that upcoming panel.

One of the things we've also done, I would like to highlight efforts of our self advocates, is developing this letter. They wrote a letter to our local leadership and politicians asking them to please be mindful of the concerns of individuals with disabilities who are not going to be left out of the conversation. We want to highlight this as an effort because it is really important as we garner individuals with disabilities in their perspectives and their concerns and make them Central. And make them -- our politicians responsive to that. Also, in response to what I mentioned earlier about what we do in response to an emergency? One of the things COVID did was expose our faultlines. Where are the areas we need to be responsive to people with disabilities? We developed this flyer, which you can see is developed in high contrast materials. We also talked about who we can reach out to, so it is not just having accessibility but having a person on the other end of the line who they can talk to. So again, this is responsive to our clients who are deaf and hearing impaired, clients who are visually impaired and clients with intellectual and developmental disabilities and autism to make additional supports in getting the vaccine and exactly who our support professionals can turn to in order to get support.

Here are our contact information. I will turn it over to Jeff who has additional comments for you.

SPEAKER:

Thank you, just want to emphasize one additional point. This might be an size and other places. Our Department of Health keeps its disaster list. For us, it is hurricanes, but wherever you live it is some other natural disaster. People who are electricity dependent, who don't have good mobility, who might need help in case of an emergency. It is about 60,000 people. The department is going to the list one by one, calling those folks and asking, "Have you been vaccinated?" The fly that Lydia just showed you was our partners for Department of Health staff, if you call someone and they have a mobility disorder order -- or a visual impairment, here is what you can use to make sure that whatever that need, there is someone in our community who can reach them. What can we do, we don't have a lot of resources but we do have connections to the disability community and we can connect them with the Department of Health which has a huge staff. So just an idea of the kind of things that we think we can all do across the country to improve vaccine confidence. Thank you.

TANISHA CLARKE:

Thank you, Lydia and Jeff for sharing your amazing work with us. We really appreciate hearing from you. Again, feel free to reach out to Jeff and Lydia with additional questions. Last from the AUCD network, we will hear from Marcia about the many successful vaccine efforts in New Mexico.

MARCIA MORIARTA:

Thank you, Tanisha. We will focus today on one there he successful culminating effort in our vaccine efforts. I really appreciate what Jeff just said about being a you said, we have a lot of links and connections but not always the resources to do what needs to be done. We certainly can make the connections and leverage. Leverage, leverage, leverage. What I will talk about today is our town hall for youth with disabilities related to covert vaccination -- COVID vaccination that place on June 10 of this year. I want to thank my colleague, Pat Osborne who was our associate Director and was the organizer, spearhead and Jack of all trades to get this event pulled off with a number of other collaborators who were listed on the slide. Primarily, with our Governor's commission on disability which is representative of broad disability, and of course, as Lauren pointed out, these efforts are broad disability focus. Our partners in this town hall, which had the purpose of bringing information about vaccines to the forefront coinciding with kids 12 and up being able to access the vaccine to really kind of jumpstart motivation and answer questions, lots of questions that families have had about children, particularly children with disabilities as well as special healthcare needs. Our partners were our new Mexico governors commission on disability. But additionally, we had our aging and long-term services division, the commission of deaf and hard and it hearing. Commission for the blind, our developmental disabilities Council, our department of health, parents reaching out which is our parent support advocacy group in New Mexico, our public education department, because we were focusing on youth, and children, youth and families department which is our New Mexico child healthcare agency.

Again, our overarching goal in this event was really to try to capitalize on the momentum of the announcement that children 12 and over were now safe to get the vaccine and intersect that with the reality is that we were hearing in the disability space around broad access, in the adult population and try to use this as an avenue to pull some loose threads together and get some momentum that our state agencies and the Department of Health were providing these vaccines, certainly our institution at U of M, we sit within the health system. We were not unlike Maryland, I wish we did in clinics, but our university and our health system has been doing clinics. We were the initial providers of vaccines, so we have dovetailed with that effort over time and given them information about how to support folk with disability, support anxieties around needles etc. So this was a way to take what had been done in disparate spaces and some of you know him -- from the news media, our governor was very aggressive about vaccinating the state of New Mexico and has been successful, in large part. But what was happening around the announcement of you 12 and up, was a waning. Fewer folks accessing the vaccine. So trying to jumpstart interest, alleviate concern and get stories out. The goal was to do this Townhall, we really wanted to be statewide and reach the entire state, have a diverse panel that was youth self advocate and family focused, have testimonials with a moderated structure discussion as well as information from health providers and state officials responsible for the COVID vaccine effort. We wanted broad access, so now you know the next slide.

The town hall was presented in the evening from six to 7:00 PM, to accommodate folks that might be working. It was quickly turned around, I wish we had the chance to do more marketing but it will not be broadly available and we can market the video we made. We quickly turned it around and about a three week period. It was presented on Facebook Live, it was posted on a YouTube channel that the Governor's commission holds and it was also accessible via a direct Zoom link. During the Zoom meeting, we had probably somewhere between 40 and 50 participants, it was hard to track in real time who was getting on on Facebook, I don't have the stats for today.

All advertisements and marketing were able to do was to make excess will formats in other examples. Our panelists were chosen specifically to our present our state, we did ASL interpretation, CDI interpretation, Spanish-language interpretation was happening, and real-time captioning.

This was the flyer that went out advertising what was happening, and this is our panel. I was on a member of the panel but I was the host keeping everybody moving along, our Centre was the core host. Zoe love your is a 17-year-old youth advocate with autism spectrum disorder who was a cofacilitator and she was amazing. Katie Stone is the parent of youth with two children with autism spectrum disorder, she is a local celebrity and runs a children's radio hour, she was a known draw and she and Zoe worked together to facilitate the meeting.

It was really a professional and family and advocacy partnership. Dr Martha Muller is our infectious disease expert and division chief, she provided a good context to start the panel by sharing not just the

lack of risk or the concern about risks around the vaccine, but the alternative, the risk of contracting COVID, particularly if you have vulnerability because of your disability status or health status. She did a remarkable job and she was available for questions that the panelists were able to direct towards her and were coming from the audience live.

The four folks at the bottom of the screen represent the lived experience. Lynette to Revo is a member of the (unknown name), she is the parent of a child the significant's abilities -- disabilities and she was able to speak to why the vaccine is important. Even though there is concern given her child's health status, it was overridden by the love for her child and was incredibly moving. I am not doing injustice. Dana Mullen and her son Daniel, who is a young adult at this point, just out of adolescence who has significant disabilities and medical fragility, spoke as a physician. There is a lot of discourse between her and Martha about how it was playing out in real life. JoJo Lopez is an individual who is Deaf, who is an advocate in our Deaf community, and Katie is vision impaired. They were both able to speak to their experience with the vaccine but more portly, white was so important for them to obtain it.

The format was I did a welcoming, we had a scripted moderation between Katie and Zoe, I do want to say was so critical and we spent hours with Pat Osbourn, my colleague, the labour of love person behind this, with the script and mapping out what her role would be. At one point during the course of this, so we got cold feet and didn't think she could do this, it was overwhelming. She was able to advocate for herself and work with Pat and really did a beautiful job. We have a professional facilitator, Katie, who had points was overrunning her and so a weighted say, "I think that's my part," And continue. It was really powerful. For her to be a facilitator. She also spoke about her experience of taking the vaccine.

Jason Cornwell is our Director of development disabilities at our department of health, and he provided simple information, simplified information around how to register for the vaccine including what to do if you or a family or individual with disability, impacted by disability, and are having trouble getting accessible vaccine. He provided information going up the broad audience about what people can do to get networked through the Department of Health, it was very well received. I mentioned Martha Muller, my colleague in pediatrics, providing an overview and did a remarkable job and accessible job expanding the vaccine but also rased -- lack of risk in vaccination and the increased risk in contracting COVID.

Our testimonials, Lynette, JoJo, Dana, Katie provided stories that were incredible and powerful. I was so moved by the stories, and I think this is critical, how people change behaviour is through moving them emotionally. We are going to disseminate this, we will share with the AUCD and hopefully these testimonials can impact folks towards feeling comfortable to obtaining a vaccine. I think at that point, Pat put together the slides... This is an example of the panel during the panel discussion. I am facing

your left, Katie and Zoe were our facilitators, you see our ASL and CDI interpreters, some of our folks are part of the panel. Technology works when it does, a few people got dropped off so they had to get back on. This is our full crew of the panel.

I actually think, in this Zoom world, the impact of being able to see of rebutting this way was action pretty powerful in a way I would not have anticipated. We had our scientific expert, we answered a lot of questions, these were the kinds of questions that were coming up. Is it safe? Is it effective? Martha Muller address that. What are the side effects? Stuff that comes up about DNA infertility, a risk of heart issues that come up in the media for people with heart conditions, etc. What if a child it's very ill after the COVID vaccine? What to do, but the big question is when will kids under 12 be able to access the vaccine? Martha was able to impress that with her studies and saying some point later in the fall, but not in time for school to start in August.

I think the reality is that we wish we had more time, the voice of the advocates was critical, and really supporting our advocate Zoe to have this facilitator role was a really empowering piece we hope to continue to do. I think that is the end. Thanks.

SPEAKER:

Thank you so much, Marcia and Pat. We have heard some wonderful lessons, we are learning some wonderful lessons, if you guys have questions, please feel free to add them to the chat box will stop if it is problematic, Lauren is moderating and will respond to you. If it is questions for our panelists, we will get to them in the Q&A portion of the webinar. Now we will hurt here from important partner in our organization named David, a disability inclusion specialist to share the vaccination they are supporting in Arizona. Hi, David.

DAVID CAREY:

Can you hear me?

TANISHA CLARKE:

Yes.

DAVID CAREY:

My name is David Carey, I am the COVID-19 inclusive security educator for the Arizona statewide Independent living Council. Arizona State white in a minute living Council-isms organization which promotes resources, supports and services which empowers people with disabilities live independently. There's a statewide Independent living Council in each state that were close with a network of centres for Independent living partner agencies and other...

(Reads) I'm sorry, the Association of State and territorial health officials. (Reads) And I was hired as its

COVID-19 inclusivity educator. (Reads) (Reads) (Reads) Some successful strategies we have implemented (Reads) Each quarter we have come a disability community form, a disability lifeline pulse check, a DHS quarterly address, for all those three webinars we have ASL interpreters and cart captioning is providing. We do the disability community forum, it is individuals, and we invite people to provide information of how they have been impacted by COVID-19. A common theme with disabled individuals is lack of transportation, lack of access to PTE, and they may not have their caregivers go with them. People who have to munication difficulties were not able to have their caregiver with them. Because of COVID-19, finding caregiver sometimes could be quite challenging.

Many places of The doors open, and what they did was put in plans to mitigate the spread. Some people have been working from home, some were provided a stipend to upgrade their service presume calls like this. Some are provided technology which may be a laptop, to continue to provide services Some of the challenges that people encountered was working with individuals that had no access to internet, technology skills were not that great, and working with youth could be quite challenging for many reasons, especially (indiscernible). In regards to a DHS, we would take it to our partners at ADHS and they would come back and provide feedback on what they were doing on how to mitigate the spread, and hopefully at some point go into recovery phase. But anyway, please. Successful strategies for disability inclusion. Partnering with local agencies to provide vaccinations to disability community. The site must be accessible, both structurally and by transit. For example, Dial-a-ride, buses, light rail etc. Bathrooms, ramps, those types of things. Keep in mind, I worked for statewide inclusivity counsel, we don't provide services, we provide resources. So some of these things are quite challenging in the rural communities. For example, there is no public transit, in rural communities. Also, we provided volunteers to assist individuals with vaccine night -- registration. We provided ASL interpreters to the vaccine site. As of today, more than 2000 vaccinations have been provided since April.

Lessons learned, home vaccinations. Criteria for in-home vaccinations were too stringent, I thought. Would have liked to see more vaccinations offered in the home to those with limited mobility, limited access to accessible transportation, compromised health, mental health, anxiety of leaving the home because of the pandemic. Fear of getting COVID-19. Those are just a few, but I would have liked to see a lot more given out, and some issues they had was people not answering their phones, and they also day on today vaccinations (?) they had a pause on that. They could have been more lenient, not so urgent to get the vaccination. As a whole, the criteria was too stringent. Next time they should lose those reigns out to get more vaccines.

Lessons learned: transportation. Transportation always presents a barrier for people with disability. COVID was that times 10. Many individuals don't qualify for Dial-a-ride services. Door-to-door services for those that are ADA qualified, so basically, there is a vehicle that goes onto people's homes and workplace and takes them door-to-door. It can take you to work and drop you off and vice versa, take

you from home and drops you off -- takes you from work and drops you off at home. Many individuals especially in rural communities do not have access to transportation. Including public transportation. Many are not on Medicaid and therefore do not qualify for medical transportation through their health plan and are medically fragile with no means to access a lifesaving vaccine.

Before I wrapup here, I know it seems annoying, it seems like it has (indiscernible) in Fabry, we had advocacy, that was hosted by (Name). Lori, if you could folk -- post that into chat, that would be great. This year, we had to go virtual, and we had several thousand participants on the conference call, many of those workshops will workshops dealing with COVID. We could put the linkup, I think the link... That way you can watch some of the videos on the website.

TANISHA CLARKE:

Thank you for joining us, David. Thank you for sharing the important work you are doing in Arizona. Lauren just shared the link that David was referring to, the workshop. Feel free to check it out. To kickstart the Q&A portion, we will start with a quick panelist discussion on this question. We will ask each panelist to just provide a response in a minute or less. And then we will open the floor for a few minutes for some questions. Anything we are not able to answer, we will figure out a way that we can provide some answers for you. But definitely, you will have the contact information for our panelist as well.

What are your strategies for working with public health policy makers to sustain disability inclusion in emergency responses? We will go in the same order in which our presenters went, so we will start with Lauren in Maryland. -- Maureen in Maryland. What are some strategies for sustainable inclusivity?

MAUREEN VAN STONE:

I'm very pleased that I was included very early on in the Johns Hopkins scarce allocation of resources committee which really brought the disability perspective to the healthcare system. We used that forum as an opportunity to educate not only elected officials in the state of Maryland, but other organizations and agencies that are engaged in public health policy to help them really understand the issues that the individual with whom we work face in this pandemic and may face -- face in future pandemics. Sharing a lawsuit that was filed or a complaint that was filed, constantly sharing the issues and discriminatory practices and procedures that people with disabilities faced during this pandemic. It was really a crash course in educating public policy makers about some of these issues. I think that now we have their attention, we will continue to move forward and do so to try to help mitigate any future emergency responses in our state.

TANISHA CLARKE:

Thanks, Maureen. How about Lydia and Jeff in Miami?

LYDIA OCASIO-STOUTENBURG:

Our approach is really inclusion as part of our culture, really embedding that into all of the efforts that we do, sintering the voices of persons with disabilities. You have a really amazing self advocacy team who meet monthly and are able to express concerns that they have and have driven this effort from the beginning of the rollout to the vaccine to now, and it is ongoing. They are really the one who galvanize our efforts and mobilize everything around their voices because their perspective is really important, our international -- interpersonal communications are also key and provide a caregiver perspective. They are also involved in other networks, disability network throughout the state and throughout our local community. It is very important to continue these conversations and sent to these conversations among individuals with IDD and their support providers, and their social networks, they are very key in keeping that momentum going and keeping our policymakers aware of the disability issues that exist.

TANISHA CLARKE:

Jeff, did you have something to add or shall I move on?

SPEAKER:

That would be unfair. Lydia handled it just fine.

TANISHA CLARKE:

Marsha, New Mexico.

MARCIA MORIARTA:

I think I would add two things: one is leveraging existing partnerships and using them as a platform to expand. This has provided a forum for the disability community to have a focal point to come together around. And the second is that it really mattered that we had this funding from AUCD, for this community of practice to bring a little bit of resource to the table and say we know our DDC had resource as well. As we initiate these conversations to ask how we can pull it and do more together. So I want to thank the CDC and the AUCD for that. That mattered. It helps policymakers see that the feds are investing in this community as well. Last but not least, I want to underscore that it has been an opportunity to centre the voices of people with disabilities and is powerful in getting attention in our state as well, so let's keep doing it.

TANISHA CLARKE:

Thanks, Marcia. David, what are your strategies for sustainability?

SPEAKER:

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DAVID CAREY:

I used to work as a disability advocate and part of my job was public policy. Answering questions. I'll keep it simple: my messages get involved, go to meetings, ask questions, answer questions, get to know who the players are, sit in on committees, expand your network of individuals that make public policy, do your homework, and be educated on the subject. I have a bit more experience in doing this, but when I started doing it, I had no experience how policy was made. Over the last 20 years, I have been able to understand the process and be involved in the process. Get involved in the process, vote. Be -- your policy mochas -- makers, if you do not vote, you cannot make a difference. Now you can implement the policies that you believe in.

TANISHA CLARKE:

Thank you, David. Appreciate all of your responses. I do want to give just a few minutes to throw out a couple of questions that came out in the chat box. Marsha, I will throw out an easy one for you. Was the town hall recorded and is it accessible? Is it something you can share a link to?

MARCIA MORIARTA:

It was recorded and it will be. The Governor's commission is taking responsibility for that. I will get you the YouTube link and we will get you all that information.

TANISHA CLARKE:

Thank you. We will try to add that to the archive page as a resource. Once it's available. There is a question in regards to just how you guys are addressing fear or different beliefs of people who have comorbid issues, blood disorder issues and are scared of the vaccine. How are you working around fear and different beliefs around vaccines? And addressing the trust issues.

DAVID CAREY:

That is a difficult one to answer. I just keep trying to... I try to educate on them, I don't have an answer to it, and... I just try to educate my friends and people I come in contact with in regards to the benefits and the risks of not doing so.

TANISHA CLARKE:

Thank you, David. Do you all have resources related to vaccine confidence that could support this? Any of the panelists?

LYDIA OCASIO-STOUTENBURG:

We are developing our confidence model that we have really been working hard on developing in response to those issues. One of the things I would say is we don't really work around fear but we address fear. We understand those and we really emphasize meeting people where they are and understanding their concerns which may be both historical and current. Understanding the different

issues that they may be facing which really need to this trepidation. But we also know that that trepidation doesn't mean absolute refusal. So we continue those conversations, and once we develop the model we can share that out as well.

TANISHA CLARKE:

Thank you. I know the national centre continues to populate their website with resources so feel free to visit the National Centre's website which Lauren shared in the chat box. There are several vaccine resources that may be able to assist you on this. Another question: are the statistics for how COVID-19 has impacted people with disabilities by type of disability? Deaf

JEFF BROSCO:

I love that question, this is one of the things that we should be trying to think about. We don't know, we don't have that much information neither as individuals or as a group with disabilities. If there is one thing we can change going forward that can be really affected, if we had data on these sorts of questions. It is an ongoing issue for us in pretty much every state, I think it is a great question, but I unfortunately don't have the answer. It is a great advocacy issue for all of us.

TANISHA CLARKE:

Thank you, Jeff. Lauren, was there any other question that we need to bring to the forefront?

LAUREN BLACHOWIAK:

We are out of time right now for questions, thank you for checking to niche and for feeling those. I will put my email address in the chat for any additional questions, you can send them out to our other panelists as well. You can also contact Adriane Griffen, from the disability National Centre for Public health. Denise Rozell, she can explain more about the national COVID-19 resiliency network, or Cassandra Thompson. Thank you, everybody, for joining us today. Thank you, Tanisha, for leading us through it. Goodbye, everybody.