

Association of University Centers on Disabilities (AUCD)
Policy Forum
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>> Hello, everyone. And welcome to AUCD's first virtual policy seminar event the AUCD seminar policy forum. We would like to thank all of you for joining us today before we begin I would like to address a few logistical details. Because of the -- your audio lines will be muted throughout the presentation. We can submit questions at any point during the presentation. Via the chat box on your webinar console. You may send a chat to the whole audience or to the presenters only. We will compile your questions throughout the webinar and address them at the end. Please note that we may not be able to address every question and may combine some questions. This webinar is being recorded and will be available on AUCD's webinar library. There will also be a short evaluation survey at the close of the webinar. We invite you to provide feedback on the webinar and also to provide suggestions for future topics. Please join me in welcoming today's speakers, John Tschida, acting executive director of AUCD. AUCD's emerging leader interims Meghan Breheney and Jazmin Burns, Liz Weintraub. I will now pass the microphone over to John Tschida.

>> JOHN TSCHIDA: Hi, Sarah and welcome to all of you and thank you for joining us today. It looks like we've got almost 300 participants and climbing. We are sorry that we can't be with you live, but we also realize that this virtual opportunity allows many of you to join us who otherwise could not. You'll hear more details about who we are and what we do at AUCD from our next speakers. I want you to know that our network is doing great things. In every state and in every territory. Serving as a vital link between the university for academic health center and the community. Our members are performing cutting edge research, exploring what works for people with disabilities as they transition from a world of education to the world of work, as just one example. There are interdisciplinary training programs, that many of you are a part of. Preparing the clinical leaders of tomorrow to better understand the disability experience, to serve people and families better.

We have some of the leading brain scientists in the world in our network, trying to understand the causes of intellectual and developmental disabilities. A few of these scientists have developed life-saving gene therapies that stop the progression of otherwise devastating diseases.

This is a world that you all are now a part of. A world I hope you will continue to engage with long after your training is over. Because without you the disability community is in

trouble. We need to build the bench. We need to build our bench of experts and advocates. Especially now, during this scary and uncertain time. Emerging leaders like you are our feature. People like Meghan Breheny a develop judgmental and behavioral at a children's hospital in New York. Like Jazmin Burns, a psychologist and LEND trainee at the university of California Davis at the mind institute. These are emerging leaders interns at AUCD and just two of the many across the country that we need in our advocacy and policy efforts. This entire forum was planned by emerging leaders. Some of them within our staff, some of them within our network. And I cannot stress the importance of these people enough. You bring passion, you bring energy, you bring new ideas, often asking how can I from where I am today impact the lives of people with disabilities in a positive way. Leaders don't necessarily have fancy titles of positions of power and authority. Leaders are those who recognize that regardless of where they sit within an organization, within a coalition, that there is opportunity. Opportunity for positive change to happen, not just for themselves but for others. And change is what we're here to talk about today. One specific kind of change, and that's public policy.

Why, you might ask, is public policy important. Think of public policy as the driver's manual that many, not all of us, got when we were in our teens. This is a document made by policy makers. It is filled with rules and regulations. Within it, it tells you who gets to drive. What conditions do you have to meet in order to drive at all. Where can you drive. How fast can you go. Where can you turn, when can you turn, where can you park? Think of public policy generally, especially for people with disabilities and their families. As the rules of the road that we have to live by in order to be successful in life.

And it's not just in the area of transportation. Those of us with disabilities often rely on a complex array of services in order to be independent within the community. Yes, we need transportation. We also need access to health care. Access to affordable housing. Access to employment, and of course access to an equal and accessible education. And who decides whether these policies are friendly or unfriendly to people with disabilities, the people who support them, and the organizations that serve them. It's the folks here in Congress and Washington, and where you live, within your state legislators in your state capitals. They are the ones deciding the rules that people with disabilities need to live by. Sometimes the rules work great. Often they need to be changed. And when they do, we need help from people like you. I said before that leaders aren't just people in power or with fancy titles. Each of you brings a unique set of experiences that can help people lead policy change. It may be your personal history, of someone living with a disability. You know what works. If you're accessing government programs or services, you know where the gaffes are, you know where you're not getting what you need. You probably have ideas on how they could work better in order to make your life easier and less complicated. You may be say family member of someone living with a disability. And similarly a witness to exactly what works and what doesn't and how things could be improved. It may be that you've seen during your training programs as emerging leaders how people with disabilities and their families often struggle to get the services they need, to get access to the health care that they need.

These are not all negative experiences, it can be a success story for you personally, within your organization, if you're working within one, that reinforces the value of the government-funded programs that you all are a part of. Today that experience, your experience is desperately needed. Especially given the difficult and confusing circumstances we now find ourselves in with COVID-19. Your voice is important. Not just your boss's voice or your parents' voice, your voice. You all can lead from where you are. And that's the focus of our time together today.

I'm going to turn it over to our emerging leader interns Meghan and Jazmin in a minute here, but before I do, you need to know that AUCD is here to help you and your colleagues.

Our policy team, Rylin Rodgers, Sarah Mueller, Denise Rozell and Liz Weintraub. Maureen Johnson, our public health team and our communications staff including Anika and finally our accessibility specialist without her constantly reminding us that all means all in the words of Liz Weintraub, we need to make sure people with disabilities, people of all abilities can access our information and resources. The people I've just named have made up the planning committee for this. They also serve as incredible members of our team at AUCD. I would stack these people up against any staff in Washington. Not just because they're smart, but because they see it as their job to help emerging leaders like you. Call us. Participate in our webinars. Join our monthly public policy calls like the one you'll hear about tomorrow. Visit AUCD.org to learn more about any of the things I just mentioned. And of course, please follow us on social media. But most importantly, stay engaged in this work. It is critical to our future. Especially given the uncertainty of the time that we are now living in. Your voice matters. Your voice is needed. I thank you for listening and for participating today, and I hope that you all are healthy and remain safe.

And now I'm going to turn it over to Meghan and Jazmin.

>> JAZMIN BURNS: Good morning. My name is Jazmin Burns and I'm one of your emerging leaders interns. I know John briefly introduced us but I wanted to introduce us again. So as he said I am a clinical psychologist and LEND trainee at the U.S. Davis institute and I live and work in Sacramento California and I'm also joined by Meghan Breheney she is the developmental and behavioral pediatrician and LEND trainee as well and she lives and works in New York City. And we are very excited that you are all able to join us today.

I'm sure a lot of you have heard the term AUCD emerging leaders community, but what does that mean exactly? So this community is made up of thousands of trainees and early career professionals nationwide. And we're made up of a diverse group of people, many of whom identify having one or more disabilities. And there are family members in this community, educators, researchers, clinicians, the list goes on and on. And our community, we had a passion to serve, advocate and educate to make positive changes for and with people with disabilities. Now, AUCD has a lot of acronyms. And so I want to pass it over to Meghan to explain what many of those acronyms mean.

>> Meghan, we can't hear you.

>> MEGHAN BREHENEY: Can you hear me now? Okay. I apologize. My mic must have turned off.

So this slide seems very complicated when you first look at it, but I wanted to take the time to kind of help talk everyone through what makes up the different parts of the emerging leaders network. So if you start at the top, all of those things across the top are federal agencies. So starting at the left, you have MCHB, which is the maternal child health bureau. And they give money to AUCD, which is the Association of University Centers on Disabilities. And through that, they fund the 52 LEND programs which is the leadership in education in neurodevelopmental disabilities programs across the country. So these programs have different trainees who are getting an experience in learning how to work with individuals with developmental disabilities.

And then next over in blue, you have the office of intellectual and developmental disabilities. And that federal organization, again, through AUCD, the Association of University Centers on Disabilities, funds the 67 UCEDDs across the country. University centers for excellence in developmental disabilities. These are involved in a lot and do a lot of outreach work for people with developmental disabilities among other things.

And then you have the national institute of child health and human development, and that funds the 14 IDDRCs, which is the intellectual and developmental disabilities research centers. So those are the people that John kind of alluded to before, who are doing these sort of basic science to try and find treatments or causes for different types of intellectual

development disabilities. And then you have the department of education, which funds the TIPSD which is the transition and post secondary program which makes up some of our college colleagues who are here today. The important thing to take from this slide today is everyone, no matter which program you come from, you guys are all emerging leaders and are all part of this community, and we want you guys to really think of the emerging leaders community as your professional home.

I also wanted to show that if you need help remembering all of these acronym, and you might not just be hearing them today. In policy itself, all of the different bills have very acronyms, the ADA is the big one we know about, the Americans with Disabilities Act, but if you check out this link on the emerging leaders community website, it gives you a great list of what all these different acronyms mean. So if you hear something, not sure what it stands for, this is a great resource to kind of look at to find what these things mean. I'll hand it over to Jazmin. Who has her mic --

>> JAZMIN BURNS: Can you hear me now? Awesome. The emerging leaders has four pillars that we want to talk about today --

>> Can you raise your voice a little?

>> JAZMIN BURNS: Is that better? I'm going to talk about the first pillar which is Learn. The emergency pillars community is more where you can learn more about AUCD, you can also learn about what and who AUCD trainees are and what they're doing. You can also learn more about LEND, UCEDDs and IDCCs. Meghan did a lovely job but there's more that goes to it too. On the emerging leaders community website that's a great place to learn more about each type of agency in detail.

>> MEGHAN BREHENEY: The second pillar we wanted to talk about is connect. So the emerging leaders community is a place where you can connect with other emerging leaders across the country. You can connect on social media, which Jazmin will talk about the social media aspects towards the end. But one of the things I wanted to bring up also is the emerging leaders map which is a great way to learn what trainees around the country are doing. So this is the 2019 emerging leaders map. And all of the different pins here represent an emerging leaders from that part of the country. You can click on those pins and it brings up who that person is, a little about what they're involved in. It also has links to their center. But the very exciting thing is the 2020 emerging leaders map is coming very soon, hopefully by the end of March. So while I know with things going on, a lot of people training has been moved online, there's less gatherings and social distancing and because of that, people can feel disconnected from each other. And we hope that you guys can look to this year's map, which will be coming out in a few weeks, to see some of the amazing things that your fellow emerging leaders are doing. The theme for this year's map is enhancing access for and with people with disabilities. So it's focusing on what emerging leaders are doing in their centers or in their states to enhance access. So I hope you guys will pay attention to social media and check your email, because hopefully we'll be sending things out in the next couple of weeks about when the map will become live. And also something we added this year is some of the emerging leaders who are featured included their social media handle, and their email addresses. So it can be a great way to then get in contact from people across the country in a more virtual way.

And then I think Jazmin was going to talk about --

>> JAZMIN BURNS: Yes. Making sure my mic is on. Hopefully everyone can hear me. Get involved is the third pillar. The emerging leaders community is a place where you can get involved. You can learn about disability policy, you can learn more about the conferences that go on throughout the year, like AUCD conference and DPS. And then you can also get involved with the leadership positions here at AUCD and I wanted to talk a moment to briefly talk about some of the leadership position that's we offer. So the first one being the

emerging leaders intern, that's the role that Meghan and I both have. Another role, and I've seen a lot of trainee liaisons already in the chat. Is trainee liaison. Trainee Lee a ones are trainees who volunteer for the year, and they engage in information involving sharing and kind of having a dialogue with their program, their trainees at other sites, and the AUCD national office. So they're kind of like the bridge between their program and the national office. And they play a really vital role in building the community aspect of the emerging leaders community. So that's one leadership position. The other one that's fairly new is the council trainee represents. There is one council trainee representatives per council, there's a total of five council trainees, and they are paired with a council mentor and they work with a mentor to learn and share information and strategies, develop appropriate and relevant training leadership opportunities, promote the role to future trainees. They also attend council calls, in-person meetings at the AUCD conference, all kinds of great things. So while we're no longer accepting applications for that, look forward to that being posted later on this year. But those are just great examples of leadership opportunities that AUCD offers and great ways for you all to get involved. Pass it back to Meghan now.

>> MEGHAN BREHENEY: Finally the last pillar is grow. Which is what we hope that your time as an emerging leaders and what you've learned through your training is that -- and what you learn helps you to grow into whatever your next step may be. And the emerging leaders community wants to help with that, and on our website they have information about different fellowships or internships. Also information about certain scholarships, especially scholarships to upcoming conferences. And kind of the hope is that being part of the emerging leaders community we want you to stay connected to AUCD and stay connected to the network, even as you go on to do bigger and better things. And I'm going to give it back to Jazmin.

>> JAZMIN BURNS: So like Meghan mentioned, we have a lot of social media options. And so after checking out the AUCD emerging leaders website you can follow us as well. There's different options, there's Twitter, there's Facebook and there's Instagram. So Twitter the handle is @AUCDNews and Facebook is AUCD and Instagram is @AUCDpix. Go on social media and start conversations. Conversations about disability policy and how we can help the disability community during this time of uncertainty. And one way to really get involved and stay connected through social media is by using appropriate hashtags so we can all find each other. For DPS you can use #DPS2020. If you're talking about emerging leaders you can use #AUCDemerging leaders or just #AUCD to make sure you're using hash tags to keep us connected and be able to communicate in a clear fashion.

>> Thank you so much Meghan and Jazmin. You truly have embodied the connect, learn, lead and grow this year as emerging leaders interns and we can't thank you enough for your leadership today and throughout the year. We now turn it over to Rylin Rodgers, who is the director of public policy at AUCD, to give you an update on what's happening in DC and how as emerging leaders and members of the AUCD community you can connect with policy.

>> RYLIN RODGERS: So, good morning or good afternoon, depending on where you are coming from in this country. We are thrilled to have you with us. I'm sorry we are not face to face, but grateful for the work that's happening all over in this time of social distancing and in this time of significant need. It turns out that the disability policy seminar this year was at perhaps the most critical time in our lifetime, in terms of impacting disability policy and American policy to make sure that it works for people with disabilities. So I'm grateful that you're here, that you're engaged. I'm grateful for the virtual Hill visit that you will be going on in the next few days, and all of the ways that you will educate and raise your voice.

To say that the last several weeks have been overwhelming is a significant under statement. It's critical for us to stay on top of what's happening, and in some ways it's helpful to take a step back and a deep breath to see where we are, what's happening now, and what

we can do. So I wanted to help us know what's happened so far on Capitol Hill, what's going on today, and what we expect to happen in the next couple of weeks.

The very important thing to remember is that two bills related to the coronavirus pandemic have already been passed in Congress. So significant efforts are already under way. The first one became law on March 6, 2020, which at this point feels like a lifetime ago. That was an emergency appropriation to provide money to the states. And to programs to meet the crisis need. We didn't yet fully understand how large the crisis was. One of the things that's really important with the disability community in that very first bill is that it actually paid back some of the money that had been taken from other programs to start to respond to the crisis. So it's a very technical way that Washington operates, that federal agencies can claw back or move some money from existing appropriations to deal with an emergency. When that started to happen, people were concerned about those programs. In particular, some of the research programs that came out of NIDILRR and really important to note some of the emergency programs that offered assistance for heat in the winter. Received some temporary cuts, but that was paid back on March 6th.

The next set of action that again has already become law, was the families first coronavirus response act and that became law just last week on March 19th. And this did several things pretty quickly. It gave a giant pot of money to a variety of different programs to make sure that access to pay for the test wasn't a barrier to taking the test. We have people who are uninsured and that was part of the bill that became law on March 19th. As you have seen in the media, that hasn't addressed the challenges of getting all of the people tested who need to be tested, or the other issues in our system, in terms of supplies that have created barriers to testing.

The other thing that it did immediately was give states some emergency money to address what they knew would be rising rates of unemployment to allow their state systems to respond to new unemployment insurance claims. And then it also started the increased funding for food security program. We have seen across the country there has needed to be a change in the way we offer some feed, particularly to children who previously received food as part of their school day and are no longer in school. So emergency programs to allow schools to deliver food outside of the school building, and communities to respond receive funding. One of the pieces of that law that did pass but was not completely meeting everyone's need, was the expansion of paid leave. The ability to take time off from work and still get paid. In the United States that has never been a right. That's something that different employers offered as a benefit, but it's not something that's been guaranteed. The law that passed on March 19th allowed for increased access to some people for some of the time off they would need because of the virus, but in many ways it didn't meet all of the needs. The disability is aware that it did not include the ability to take time off to care for someone that's in your life with a disability, who is not a child and needs care. So there has been lots of unmet needs in that space.

What's happening right now, and by right now I mean being debated currently on the floor of the Senate is what's being seen as phase 3 or part 3 of the relief. It's currently called the coronavirus aid, relief and economic securities act. The acronym for that is a little confusing to those of us in the AUCD community, because they're calling it the CARES Act. And many of us work really hard in the last year to reauthorize Autism Cares. But this is a different bill, and it will address the needs of Americans related to the coronavirus. It's really important to know that there is not yet agreement about what will be in that bill, and this is exactly the right time to raise the needs of people with disabilities, to raise what you're seeing as unmet needs in your community, as impact of the virus on systems and services, and to be educating members around that. That's what's being debated right now is phase 3. After we get through phase 3, it is almost an absolutely certainty or a thing we know for sure, that

there will be a package 4 an additional bill moving on. Let's talk about what some of the needs are that we can be actively advocating for and educating about.

We're hearing from you all over the country as family members, as people with disabilities, as emerging leaders who are learning about systems, as UCEDDs and LENDs seeing what these changes have meant, that there are some critical unmet needs. The number one thing that we're hearing about is the need to make sure our home and community-based service system remains able to function and have the resources that they need to move on. So many policy makers are aware that in package 2 there was some increased funding that went to Medicaid programs. But it's important to know that that funding was not directed to the home and community-based service part of Medicaid. So there's unmet needs in meeting the needs with people with disabilities. We think about this in a variety of ways. It's important, many of you are sharing with us that the options to get services in the community are in jeopardy because the workforce, direct support professionals are having a hard time getting to work and in some cases don't have the information or the protection in terms of their own physical safety, and the safety of people they're providing support to, to be able to continue to provide direct support. We're working hard to raise that issue.

One really important issue that's been part of advocacy for a long time around home and community-based services is making sure that direct support professionals who have relationships and partnerships with individuals with disabilities, can continue to provide the support when an individual with a disability becomes ill and has to be in a hospital or other setting. One of the emergency asks around home and community-based settings, is to make sure that we are allowing the direct report workforce to continue those partnerships with people with disabilities and whatever setting they're in in this time of emergency.

We're also aware that there are many people who are eligible for home and community-based services who are not currently receiving services. In some cases that's because they're on a wait list, and other ways it's because they haven't yet applied. The reality is that this emergency will likely cause an increased need for some of those folks to have home and community-based services. That need may occur because their primary support or caregiver becomes ill. In some cases it may also occur because their primary support or care divides giver loses their life. We need to have resources to make sure that we can respond and are able to meet people's needs. That's our number one ask. And when you're thinking about that ask, you can think about advocating directly for that, or if you're not in a position to make an ask because of your funding through your training program or your professional role, it's still incredibly important to educate about that issue. To let members of the congress and their staff know what you're seeing, what you're worried about, and what this coronavirus can and will impact in our home community-based service system. That education helps inform and elevate the issue for policy makers.

Over the weekend I heard from quite a lot of you, and I'm grateful for your engagement, with lots of questions around what's happening for students with disabilities. And getting the support they need to access education as schools are moving to a virtual system. There was some deep concern that the coronavirus bills included language that would limit students' rights and protections under the individuals with disabilities in education act and there were a lot of questions around that. In a very unusual move, something I don't think I've ever seen, the department of education released additional guidance around supporting students with disabilities on Saturday night. Late Saturday evening, additional guidance was released. We'll share a link to that on our talking points page as a reference point, and those pieces of information.

So individuals have asked me what does it all mean, in terms of what we need in the relieve package. Schools need additional dollars to support access and universal design and accommodations as they move to virtual education for students with disabilities. In some

cases students will need captioning or CART for their virtual classroom. They'll need ASL interpretations. Schools will need additional resources to make sure that the materials that they're sharing electronically are accessible. That screen readers work. Schools will need additional resources to help students access the technology that they'll need to make education individualized. In some cases there will need to be significant individual supports that are delivered in unconventional ways. So those are resources that we need to be informing our policy makers that we need. And resources that we are asking them to consider adding into the coronavirus relief package. I used a term there around a accessibility feature called CART and CART is the ability to have captioning or the words that are being spoken in an online classroom or in a Zoom meeting on the screen. Very similar to the captioning that you are seeing as part of this meeting.

One of the other big pieces that individuals with disabilities have been asking about and are advocating for and are educating their members about is the need to have access to emergency supplies. We are growing -- there's a growing awareness in our country that health care supplies are hard to get. Our system hasn't been able to meet the demand at this point. And we give people a lot of guidance that say in order to shelter in place, and be able to respond to the emergency actions of your community, you should have a month or more medication that you currently take on hand. One of the things that we have not fixed yet in our policy space is that we give people that direction, but our health care systems and our funding systems and our reimbursement systems, don't let people get the medicine they need in a supply amount that they need. So in order to let people be safe in that you are communities and be able to get their supplies, we need to change the rules so that people have access to an emergency supply of medication at this time. It's a really good example of sometimes an emergency or a crisis helps us see what's broken and this is something we need to fix for right now, but we really need to fix this for the future so that individuals with disabilities who are preparing for any type of emergency, whether it's a hurricane, a wildfire, a flood, or a global pandemic, have the ability to have a supply that needs their needs.

Another piece that is really important is we're hearing a lot of information about individuals getting checks in the mail or economic stimulus payments. Over the last 48 hours there have been lots of questions about how big will the checks be, will it be more than one time. The reality is we don't know that. We know that with people with disabilities two things are really important. A, that they get the check. That all means all. And B, that we make sure that getting that check does not impact someone's eligibility for any existing income-based or asset-based program. So knowing that we're going to give people additional funds and additional access to food, but that we don't make that access to other pieces. There's more detail on all of this. But I think we're going to pause there knowing that we have chances to do questions and answers and we also have a chance in checking out today's disability policy news for lots of details about everything I went over. And we'll talk about it again tomorrow for an hour on our policy committee meeting. So all the details we can do questions and answers and other pieces. So I'm going to pause and pass it back to Sarah. Sarah: Thank you, so much, Rylin. That was super informative as a reminder to everybody, we have the opportunity tomorrow to go into a deep dive into these policy needs that are rapidly evolving here in Washington.

In our in-person -- I'm going to actually turn it back to our emerging leaders on who are going to share a little bit about who they are and why they are here and give you all a chance to share with us who you are and why you are here.

>> Hi, this is Meghan back again. I think we were really hoping for this in person to be as interactive as possible. But I think we wanted to give you guys as much as we can on a virtual platform to have some way to communicate with others. So the first thing we wanted to know is for you to tell us who you are. So there should be a poll where you can kind of

enter a one-to two-word answer telling us are you a person with a disability, are you a family member, a trainee, a researcher, educator, et cetera, and then hopefully after we get some answers we'll be able to kind of share it with the group.

All right. So it seems like the poll has ended. We're still going. If I end the poll, will it then show? Are people able to results as they're coming in?

>> People are able to see the results right now.

>> Okay.

>> MEGHAN BREHENEY: So it seems like we have a lot of LEND trainees, physical therapists, a whole great diversity of people. Psychologists, we have students, we have a person people with disabilities, family members, parent consultants, self-advocates. Basically it's great to see the big diversity of people we have here. We have some special language pathologists, just going through. And then we also want to know sorry. I'm trying to move this out of the way. Why are we here. We wanted to explain a little about why the AUCD emerging leaders community is here. And we as a whole we want to make positive change for and with people with disabilities. We want to learn and we want everyone to learn from all of our past experiences. And we really feel like today in going forward when you're speaking to Hill staffers on your virtual Hill visits, we feel everyone can contribute to the learning today. Everyone has their own unique story and their unique viewpoints and it's really important that our policymakers hear from everyone. Another quick polling question we wanted you guys to answer with one or two words is tell us why you're here. Are you here to learn more about policy? To become better at educating about policy? Are you here preparing for a Virtual Hill visit or are you here to connect with others. So it seems like that poll is up. So we've got people looking to learn more about policy. Some all of the above. Some people looking to connect or as part of their LEND experience. Got a lot looking to learn more about policy, and I think that was a lot of what drew me to this role as well in AUCD was to learn more about policy and how we can educate and sort of advance what we feel is important and kind of learn more about how we can improve the lives for and with people with disabilities. And also someone looking to learn more about resources, that's great.

So it seems like everyone is here for very similar reasons and hopefully through this we can learn more about policy and become better about educating others about disability policy.

So one of the things we wanted to talk about is kind of when you're doing these Hill visits or when you're meeting someone in a professional environment to kind of have a short way to say who you are and why you're here. And some people call this an elevator speech. And what that is is sort of a short introduction and it's called an elevator speech, because it should be quick enough to say during an elevator ride. So you kind of want to get to the point of who you are and why you're here, so that person you're trying to educate, whether it be a Hill staffer or someone else in a professional environment, understand kind of what motivates you in a quick way without them losing their attention. So like I said, this would be very helpful during Hill visits to help staffers know more about you and why you're visiting with them. So Jazmin and I, we put together this sort of structure that you can use to kind of create your own elevator speech. So I don't know if anyone has ever played Mad Libs in the past, but it's a game where there's parts of a center and you kind of fill in the blanks and fill in the rest of the words to create a story. So that's kind of what we did here. We've created an outline and where there are blanks, you can fill in what makes the most sense to you. So to kind of give you an example, Jazmin and I are going to use this structure to give you our own elevator speech.

So mine would go: Hi, my name is Meghan Breheney. And I'm a developmental and behavioral pediatrician. I'm at fellow at Montefiore medical center and I live in New York City

and work in the Bronx. We thought it was important to include where we live because that's who the legislators are working with. They want to know that you're part of their area. I have experience with diagnosing and treating children with autism and other developmental disabilities. I care about increasing access to diagnosis, treatment, and services for my patients. And then Jazmin will give her example. And we also want to let you guys know that this template is in -- you can download it as well. It's in the download box.

>> JAZMIN BURNS: Hello. This is Jazmin. This is my elevator speech. Hi, my name is Jazmin Burns and I am a family member of a person with disabilities as well as a clinical psychologist and LEND fellow who works with the neurodevelopmental disability and intellectual disability community. I am part of the AUCD mind institute and I live in Sacramento, California. I have experience providing intervention services to families who have children with neurodevelopmental disabilities and intellectual disabilities. I care about education and access to mental health care, policy, as well as providing mental health care and support services to children and families, especially those from underrepresented communities.

>> MEGHAN BREHENEY: Great. As you can see this is sort of a short way that you can get across to Hill staffers who you are, what experience you bring to the table, and what you care about. And you can kind of add on to this as you want. You can add on at the end of this if there are any specific bills or policies that you want to educate Hill staffers about as well. And like I said, this is available to be downloaded.

But I think now we are going to move on to do a virtual Hill visit example. So I'm going to pass it back to Sarah.

>> Sarah Mueller: Thanks, Meghan and Jazmin I hope the template you guys provided will help new trainees craft their elevator speech so they feel comfortable building their relationship with their members of Congress. We wanted to provide an example for you of what a phone call would sound like or a meeting would sound like with your member of Congress's staffer. So as a former trainee in our network, as well as Rylin being a former training director in our network, we had a phone call with Gilbert Ruiz who is a legislative assistant in Senator Gillibrand's office. Doing negotiations in the Senate giving paid life. We have a recording for you to share what are the different pieces and elements of a successful Hill visit.

[Video playing]

>> Sarah Mueller: So, thank you so much to Gil Ruiz who was able to give us some time for busy time for his office and for Senator Gillibrand. We apologize for any audio issues that anyone experienced. The transcript and the YouTube video will be available for download after our webinar today. I did want to give folks an opportunity to ask questions based on our example. You can type in your questions in the chat box. I will ask the questions to Rylin. In the meantime, Rylin, if you could give us a highlight of that example and kind of point out the key areas that we want to make sure that we're emphasizing for trainees and professionals who will be having phone calls or doing Hill visits in the future.

>> RYLIN RODGERS: Thanks everybody for being patient. It feels like I'm getting feedback. Sarah do you hear feedback from me or am I okay? Okay.

So obviously if you were able to hear that or later when you get to watch it again or read the transcript, you'll understand that it's one experience to talk to an office of a champion, which Senator Gillibrand is certainly someone in the past has been friendly to disability issues, and it's interesting that she's really growing in that area right now. I think what I take away is that it's a lot about relationships. I think Gil's experience the fact that he shared that calling matters and he knows that because he used to be somebody that answered the phone calls. Really reflects on that all kinds of communication with policymakers and their staff is critical, and it really helps to build the understanding of staffers. Gil is a real partner to

lots of disability communities, but he is not someone that came to this work with lots of expertise around disability and he relies on hearing directly from constituents in that state and from partners in the disability space. So really knowing that your expertise matters, and how critical it is to not just call once or -- [frozen]

>> Rylin, you froze.

>> I'm going to finish up that thought for Rylin as she is experiencing some difficulties. Her point is that you should be following up with staffers as often as you can. So once you have finished a phone call or a meeting with your staffer, immediately send a follow-up email to thank them for their time and to provide the extra resources that you mentioned in the meeting. And then periodically it's best to continue to follow up with your staffer as you're conducting research. And research has been published or if you had a great project that happened in your community to share those links and those stories and successes with a staffer to keep you guys engaged with the staffer and a member of congress. Welcome back, Rylin.

We have a question about a one-pager being available on talking points for the disability community's needs during COVID-19. Is that something that could be made available or is there resources already out there?

>> RYLIN RODGERS: That's a great question. And on the landing page for our virtual DPS resources, we have talking points that we are updating daily with key messages. So there are examples of what to say and how to say it and what the key issues are. Also, great to check back on AUCD's social media and other channels. We have put out an action work that has four critical asks highlighted so you can refer to that in order to get to your talking points. And if you wanted to see an example of a person sharing more details around that, our acting executive director John Tschida did a policy blog over the weekend talking about the critical needs of the disability community right now.

It would be good for me to talk a little bit more about the virtual Hill day and our next steps.

So we conceptualized moving the seminar to an online experience, we would like the opportunity to keep Wednesday as our Virtual Hill Day. And many of you talked about that it would be -- I'm sorry. So if you had an existing in-person meeting, we recommended that you see if you could change that to a phone meeting. And many of you have been able to do that. But if you did not already have that, there's still ways to engage. So the thing that's the truth of the matter right now is you don't need to wait until Wednesday to engage. I saw some great questions in the chat box about how often should I be communicating? How often should I be raising these issues? If I did it over the weekend, is that enough. And the real answer at this point is that this is a critical time in the disability community and for our country, and really communicating once a day with your policymakers and their offices is appropriate. Sharing about what's happening moving forward, sharing the resources that you're hearing about, letting them know what the needs are on a regular basis, and sharing what you're hearing in your communities and states about those meetings, really can't happen too much or too frequently at this moment, because things are changing so rapidly. So we encourage you to do a couple of things. To look at the talking points and reach out today, whether that's by phone or by email to a staffer or by social media to your members of congress, or all three. And then stay engaged, check in with us for our virtual policy meeting tomorrow. Reach out again. And if you've got a full phone meeting on Wednesday, use these talking points as part of your discussion for that. But also if you don't, reach out and raise the issue and elevate things for Wednesday.

There's lots of ways to really move the conversation. Things are changing really frequently here in Washington, and one of the things that's changing is where people are, including members of Congress and their staff. Most of them are no longer on Capitol Hill but like the rest of us are working virtually. That's created challenges in reaching them by

phone or some of the typical ways that we do, and it's actually created an opportunity where they're looking for what is the noise or what are the issues being raised on social media. So it's a change to let members of Congress know that as they're working on these relief packages, that there are critical issues for the disability community. As our virtual emerging leader interns referenced, we can elevate each other's voice on the social media space by using hashtags. The DPS2020 is a hashtag we can use. Some of you may also be aware that the disability community started to use a hashtag that's related to the current discussion, and it's called #whatweneed. All of those words blended together as a way of to talk about what do we need for people with disabilities to get the systems and services working in this emergency. So really thinking about who am I and what am I do today, tomorrow and Wednesday to build on what I'm learning at DPS virtually, to make a change and to make an impact going forward.

I often think about that we have the greatest impact as a disability community when we work together. We also have a great impact on disability when we ask other people to join us. So as you're learning some things about critical issues in your community and you're speaking out, if you can ask others in your social circles who may be self-isolating but looking for an action step or a way to help other people, this is a real chance to ask people to join us in speaking out in partnership with the disability community.

I'm looking to see Sarah, if there's any critical questions.

>> Sarah Mueller: I have a question about should our AUCD network be sharing what they're hearing from their staffers and members of Congress with AUCD.

>> RYLIN RODGERS: That's such a good question. And you can see just the beaming smile on Sarah and I's face by asking the question. It's incredibly helpful for us to hear what you're hearing and to be able to use that for follow-up and for connection. And really that's across the board. This morning I heard the governor of Illinois in a media interview talk about that what he did and really packaged for his states was to meet the needs for people with disabilities. Actually I didn't hear that, but a member of our network sent me the clip from the Today Show because they wanted me to know that the governor had raised the issue. That gave me some information to follow back up with Illinois' Congressional team to say we agree that it's critical and here are some of the issues and ways that you can do that moving forward.

Also I've heard from folks who felt like they got a really positive answer from a staffer, and that didn't match what we were hearing in terms of how a member would vote. So it gave us a chance to follow up and say can you tell me more about the fact that you told folks in your state that you were going to meet these needs. Let us know how that will work.

So it's really incredibly important for us to hear from you, and to be able to go for next steps.

I saw another question about how do we know what is a state issue, in terms of getting it solved right now, what's something that the administrative action can do, and what do we need to ask Congress for. And it's such a great question. It can always feel complicated in the disability space to understand that. Most issues that impact people with disabilities have a state part and a federal part. That's because systems like Medicaid are state and federal partnerships. Systems like special education have state and local and federal pieces to them.

So I think the best thing to do at this point is find reliable information, in terms of what's happening and what's moving. Things like the analysis that we provided in disability policy news can show you what happened at the executive level from the president, which, for example, with things like moving the deadline for taxes, and what's happening in Congress. And also if you have an individual question about an issue, you're trying to get to the bottom of it, ask us. We're happy to be a resource.

>> Rylin, we have a question about how do we advocate and community with members of Congress and our staffers who are not disability-savvy or haven't done a lot of disability policy in their agenda.

>> That's such great question. What we've learned over time is that using plain language and making things as clear as possible works really well in the disability community and it also works really well with Hill staff. So what I mean by that is if you can explain an issue as clearly as possible. Try not to use acronyms or jargon, but explain who it impacts, what the problem is, and what the need is. If you can do it at a basic level for a Hill staffer, they will appreciate it and they will find it accessible and able to act upon. Sometimes we think that in order to talk about policy we have to be super y or use technical law terms. In fact, in order to be accessible and effective in advocating with Hill staffers, we need to be clear and use plain language to make sure they understand a subject area they might not be expert in.

>> We're getting really specific questions around the disability community and the COVID crisis and how it's going to impact programs. Can you share a little about the opportunities for our network to stay engaged with AUCD on the developments here in Washington and how to stay up to date with the current news?

>> RYLIN RODGERS: Yes. The reality is that we don't know how everything is going to play out. We don't have a way to know how long we'll be in a crisis. How many emergency packages will come out. And then what will happen to the budget of some of the systems that we rely on on a regular basis which our country is not in crisis.

So first of all know that there are lots of ways to stay engaged, and to be asking the questions on an ongoing basis is an important way to make sure all those details do get addressed. It may not be that they get addressed in this next package, but we need to continue to ask and advocate. AUCD is here for the long related to figuring this out, raising critical issues and asking critical questions. As Sarah and I had mentioned, every Monday we have the disability policy news, where we put out a summary of what's happening in Washington. We tried really hard to let you know what's happening, and what you can do about it. What an action step is to raise your voice and engage in a system. We also have a policy committee at AUCD that meets monthly. It's a great way for our network to engage. We, because of this critical time and virtual environment, have decided to make it open for all tomorrow in 4:00-5:00 time eastern, where that's another part of our network where people can be engaged in a regular basis. And there is Tuesdays with Liz which many of you know and love as a great resource for those of you that may prefer a video or like to have a deeper dive in a video of issues moving forward. So lots of tools to stay involved.

Another great thing to be doing in this conversation that you're having over the next couple of Virtual Hill Days is ask the staffer that you're talking to to get back to you to update you. It's fair to acknowledge the fact that things are moving fast and we don't know, and we know that there are really struggling themselves, but let them know you'll follow up and check back in on issues and ask them to keep you in the loop. It starts to build relationships and it going to be part of the work we need to do for the long .

>> Sarah Mueller: Rylin, we have a question on how do we find reliable news sources right now when there's so much information coming out.

>> RYLIN RODGERS: That's a great question. I will have to confess there have been times over the last several days that I myself have just been overwhelmed and tried to -- in trying to keep up. So it's great to have a couple of trusted sources to go back to. I always recommend finding something that you can get a digest about once a day. I really like, in terms of news source digest, I like Kaiser Health News. They tend to really talk about our health care system and other disability policy issues. You can sign up for free daily email from them. There's also DC-based journalists. So Politico and the Hill that offer daily

summaries. AUCD offers a once a week summary. And you also may have a professional or advocacy home that really is a great place to stay in touch with. Whether it's the American association of pediatrics or an association -- the national association of social workers or family voices. Finding your discipline-specific home and connecting for resources moving on. Really thinking about what are one or two places that you can go on a regular basis and move information forward. One of the other pieces that you may note is some of the pay walls are barriers to large newspapers to our country have been temporarily suspended. Many of us for whom our budget was a barrier for having as many subscriptions as we have, get access to things on the Washington post and the New York Times. I think the trick is to find one or two places to get consistent information so that you're not overwhelmed.

>> Sarah Mueller: Rylin I want to give you an opportunity to wrap up and remind and synthesize with people what we need from them today and moving forward as we have a nation virtual hill day on Wednesday.

>> RYLIN RODGERS: Yeah. I would really love if we could all collectively think about the National Virtual Hill Day for DPS2020 as the next three days. If we can each individually find ways to advocate, raise our voice, and educate today, tomorrow, and Wednesday, it may turn out to be in the most critical period for disability policy in our lifetime. So for me, that means that today I started my day by sending emails to each of my Congressional delegation based on where I live, to let them know what I was concerned about. I also used my social media to share John's great blog from over the weekend, to share that this event was happening, and to share the talking points from AUCD, what we need, action alerts. That's what I did today. I will do similar actions tomorrow. And I'm lucky enough to have some phone calls scheduled tomorrow and Wednesday where I will ask questions of the Hill staffers about what they're hearing, share what's most important to people with disabilities and the systems that serve them, and really work on raising those issues and the next steps. So please, please --

>> Sarah Mueller: Thank you so much Rylin. We are going to pivot to our last section of our webinar today which I'm very excited about is a virtual Tuesdays with Liz live. Where our friend and colleague Liz Weintraub will be interviewing somebody who's known as respected in our network, Michael Gamel-McCormick who works for Senator Casey. We appreciate his brief time today to be able to share with us how as a network we can continue to build relationships with our members of congress and tips and tricks on having successful hill visits. So I'm going to turn it over to Michael and Liz.

>> Liz Weintraub: Thank you, Sarah. I wanted to interview Michael. So hello and welcome to another Tuesdays with Liz disability policy. Today I have the great fortune to be talking to my friend, dear friend as well, Michael Gamel-McCormick who is the disability advocate for Senator Casey. So welcome Michael.

>> Michael Gamel-McCormick: Thanks, Liz. It's good to be hearing your voice.

>> Liz Weintraub: The first question is who do you work for? The member of Congress or the voter?

>> Michael Gamel-McCormick: Liz, that's a little bit of a complicated question. The first answer is I work for Senator Casey, he's my boss and I have to make sure that I follow his priorities. But he works for the people of Pennsylvania. So in many ways I work for the people of Pennsylvania too. And as he's the ranking member of the special committee on aging and a senior member of the senate committee of health education labor and pensions and also a senior member of the finance committee, he works for the whole countries. In many ways I have three sets of people I work for. Bob Casey, the people of Pennsylvania, and the people of the country.

>> Liz Weintraub: Great. Thank you.

As a staffer have different kind of roles what are they? I think you've already explained

that but if there is something else you would like to share.

>> Michael Gamel-McCormick: Sure. I'm happy to talk about that. Advocates clearly bring to Congress and to senators and representatives their point of view and good information and knowledge from the field and from the grassroots. A staffer's responsibility in many ways are to pull together all that information and then present it to our bosses. So that in my case, Senator Casey knows what's happening at the grassroots level, and what the possible effect is of certain policies on the people that he serves. So my job in many ways is to make sure that people that my boss understands what is happening to the people of Pennsylvania and the people of the country. But I can't do that without hearing from advocates and the stakeholders.

>> Liz Weintraub: Thank you. The next question is what types of ways are the most effective ways to communicate with a staffer during a Hill visit? On the phone or on email or in person in a Hill visit?

>> Michael Gamel-McCormick: Sure. All of those ways are good ways to communicate with staff. And I would also add in you can still write a letter as well. We love that. But I think there are two things to include in any of those communications, whether you're emailing or calling or you're visiting in person or you're writing a letter. What you should include is information some data in terms of what is happening with the issue that you're worried about. If you're asking about -- let's say you're asking about the access to mental health services. Talk about the accessibility of services in your community and bring how many people need it and what the effect would be of the policy that you're asking for. So there's some data that you need, but you also need some stories as well. You need a story to illustrate what the effect of that policy would be. So communicating with the data and with the stories is really important.

>> Liz Weintraub: Thank you. How can people build relationships with the members of Congress and staff?

>> Michael Gamel-McCormick: That's a great question, Liz. I think the best way to do that is to become a trusted communicator, and that means when you're bringing information, that you're bringing solid, reliable, truthful information that's grounded in fact. It doesn't matter if it's large-scale data. Lots of information about say everybody in -- the other is more frequent communication other than just one time you come to visit on the Hill in Washington. It's okay to send -- I always work by the rule of three. Contacting a staff member three times a year at least to give them good information is really helpful. And then they learn who you are and then they also then learn that they can come to you directly if they have a question about things. And I have a long list of people in Pennsylvania and I used to have a long list of people in Iowa to talk to about the possible effect of a policy that we were thinking about.

And the last thing I would say about that is, don't forget about state staff. Every congresswoman or congressman or senator has a set of state staff as well, and they're important people in reaching out to them and getting to know them is just as important as talking to the people who are in Washington.

>> Liz Weintraub: Thank you. And can I also add one more tip. Writing a birthday greeting to members of Congress. You know some birthday of members of Congress. Everyone really enjoys having a birthday greeting. And just to say happy birthday. Thank you very much for all your work. I appreciate you.

Thank you. And we really did -- we do really appreciate --

>> Michael Gamel-McCormick: That's a great idea, Liz.

>> Liz Weintraub: What? I'm sorry.

>> Michael Gamel-McCormick: I was saying that your idea about birthday greetings is a great idea. It's a very nice thing to do. And it's that's a wonderful idea. And just saying thank you when something has happened is also really useful too.

>> Liz Weintraub: Thank you. We appreciate all your work, all your boss's work. Senator Casey is one of the champions on the Hill. I know during this difficult time, he is trying to advocate for us and fight for us. So thank you very much. And have a wonderful day and I'll see you next week. Bye.

>> Sarah Mueller: Thanks, Liz and Michael. We really appreciate it.

>> Michael: Thank you, Liz.

>> Sarah Mueller: We appreciate you sharing your expertise and knowledge.

So that is -- we come to the end of our webinar and we want to thank all of our speakers today who have joined us. And we want to thank all of you in the network for joining us to learn and connect and lead and grow together. As a reminder this webinar was recorded. We will archive it on our website at AUCD.org. And we ask that you take the survey that you will receive after the webinar is completed. A reminder to locate all of our resources we've referenced throughout our webinar on our website. We thank you again and please take the next three days to contact Congress and lift your voices for the people -- for people with disabilities and our communities.