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AUCD-Network Public Health Webinar Series on COVID-19 - Session 3:  
Advice from People who have a Disability on Dealing with  
COVID-19-(Adobe)

Association of University Centers on Disabilities (AUCD)



Redefining Communication Access

>> Ilka Riddle: Okay, great.

Well, hello, and welcome to the AUCD Network webinar series on people with disabilities, and COVID-19.

Today, is the third of four webinars. Today's webinar will provide advice from self-advocates. My name is Ilka Riddle, and I'm an associate professor at the university of Cincinnati and Cincinnati children's hospital. I'm also the director of the university of Cincinnati's center for excellence, in developmental disabilities. And in addition, I am the chair of AUCD's disability and health special-interest group. Together with Dr. Adriane Griffen who is the senior director of health and public leadership at AUCD, I'm one of the facilitators of this webinar. First, I would like to thank you all for joining us today. We know at everyone is very busy with being at home working from home, school at home and/or taking care of others in these challenges times. Before we begin with the actual presentation, I would like to address a few logistical details. Because of the large number of participants your audio lines will be muted throughout the webinar; however, you can submit your questions, at any point during the presentations, or after all the presentations have concluded, via the chat box, on your screen.

**CART FILE**

You may send a question or comment in the chat box, to the whole audience, so that everyone can see it; or privately to the Staff or Presenters. We will compile your questions throughout the webinar, and address them at the end, we have our discussants and Q&A marshal. Please note we may not be able to address every question and we may have to combine some of your questions into one question. This webinar is being captioned, and ASL interpretation is provided. This webinar is also being recorded.

And will be available on AUCD's webinar library. There will be an evaluation survey at the close of the webinar. We invite you to provide feedback on the webinar, and provide suggestions for future topics.

So why are we offering this webinar series? Over the last few weeks, now it's almost months, we have learned quickly that the needs of people with disabilities and their families during the coronavirus pandemic, are not very well-addressed; and we decided that information from experts in our field of developmental disabilities could be helpful to all of us. Therefore, we created this webinar series with the hope that you will find the information useful.

Now, I would like to welcome today's distinguished panel of speakers. And thank them very much for agreeing to present today.

All of them are self-advocates, themselves, or work with self-advocates, and we feel fortunate that they are with us today.

Ilka Riddle: Our panelists today include: Mr. Max, outreach director for green mountain self advocate and an experienced leader for self advocates, Dr. Kara Ayers, assistant professor and director of the university of Cincinnati UCEDD, also a parent and a person with a disability. We also welcome Ms. Sherice Smith, who is the disabilities program coordinator and disability specialist for the Arkansas disability and health program, and the safety project at Partners for inclusive communities. And we have Ms. Julia Atkinson, who at the center for human development, at the university of Alaska, anchorage, and does work in health, wellness and relationships.

In addition to our fantastic speakers, we have also invited great discussants, and our question and answer marshal, Liz Weintraub senior advocacy specialist at AUCD, Mr. Mark Smith, Monroe Myer institute, the Nebraska medical center university center for excellence in developmental disabilities and we also have Ms. Jeiri Flores, leadership education in neurodevelopmental and related disabilities LEND self-advocacy codiscipline coordinator at the strong university

center for excellence and developmental disabilities at the University of Rochester.

Our panelists will speak first, followed by remarks and thoughts from our discussants. Our question and answer marshal will, then, lead us to audience questions.

I will now pass the microphone, to Dr. Adriane Griffen, who will get us started with a few words about public health.

>> Dr. Adriane Griffen: Thank you, Dr. Riddle. I appreciate the introduction and welcome everyone. We are excited to be with you today.

We wanted just to take a couple of minutes, at the beginning, to talk about what public health is.

This is a term that you have heard a lot.

Over the last couple of months. So we just wanted to talk about how people define it; how AUCD applies it; and how we think about it with our national Center on Disability and Public Health. So public health, what is it? It promotes and protects health of people, and their communities.

So it's basically everywhere. It's where you live. Learn, work, and play.

Public health also prevents people from getting sick. Or injured. And it also promotes rather, wellness by encouraging healthy behavior. So that's everything from getting enough rest, sleep, to good nutrition.

And it's also a blend of science, as well as art. That's why, with COVID-19, you might hear recommendations change, or shift, because public health is a practice of science as well as art.

But how does AUCD think about public health? We think public health is for everyone. And that means everyone! So those of you who are on social media with me, we have a hashtag PH is for everyone. Public health is for everyone. We also see public health as a way to share tools for managing change.

And thinking creatively. So public health is our model for AUCD, national center on disability and public health. We also want to encourage all of our partners to work with us.

Collaborate with us; AUCD has a presence in every state and territory across the country through three different types of centers. I also wanted to share what these acronyms stand for with you. We have UCEDD, university centers for excellence and developmental disabilities.

We have LENDs, which are leadership education in neurodevelopmental and related disabilities and we also have I/DD RCs, which are intellectual and developmental disabilities research centers.

Together, the network, we work together to advance policies and practices that improve health as well as education, social and economic well-being with people with developmental as well as other disabilities, as well as their families and communities where they live. So thanks for letting me have just a minute to define what we mean by public health.

Next, I would like to turn the virtual podium over to Max from green mountain advocates, and I will be back as an anchor in between each of our presenters. Thank you, over to you Max!

>> Max Barrows: (No audible response).

>> Adriane Griffen: Max, if you are speaking, I am not hearing you.

Max Barrows: All right, now you can hear me, somehow it wasn't letting me connect to the audio, because I tried to get it on mute. Now I can talk. For those who don't know me... my name is Max.

And um, I work, for Green mountain self-advocates as said in the introduction.

Here in the great state of Vermont.

And I'm here to present to you, all, like, what I, as a person with a disability, myself, also speaking up on behalf of people with disabilities, have in sharing about how this time of uncertainty, with COVID-19, has been impacting the lives of people that I have met, throughout the work that I do; and speak up due to the work that I do. So if you guys are curious to know:

I would -- I will jump in to that right now.

And hopefully, this information will help you all... think about what needs to be done, to accommodate and support people with disabilities through this time of uncertainty. With a crisis going on in our country, and around the world.

So, I guess... next slide.

If there is a next slide here.

Mr. Max Barrows. (Continuing) :

Unless there's no slide, I can just go through what I've got.

So, one of the biggest challenges, that we've been hearing is, there's a lot of information being thrown at us by the media, and it's

not clear, and it is not accessible for people to understand.

So think about, like, the words you use, people are using, many words, many new words.

And things consistently change, like, way too fast.

And it is too hard to keep up with the changes.

So we made a toolkit that is accessible for people, with disabilities.

And there are eight booklets to help people understand issues connected to the coronavirus.

If you go to, like, the Web site, our Web site, which is GMSAVT.org.

And I would be more than happy for someone to type it in the chat box, WWW.GMSAVT.org.

You can access the toolkit, that we developed.

And so, we have booklets on all kinds of things. We have booklets on, like, basic COVID-19 information.

Tips for working with support staff.

We have one on a sample advocacy letter about patients with intellectual disabilities having a support person with them when in the hospital.

We have one on COVID-19 medical information form. We have one on how people on SSI and SSDI get a stimulus check. We have one on getting unemployment benefits.

We have one on a coronavirus plain-language glossary on words to know.

So those -- those are what we had, and just to point out that the first booklet, the one with basic information on, you know, the -- the basic information on COVID-19, has been translated into 11 languages, and has been shared all over the country, in the world.

Let's see other things we've been doing, in this time of uncertainty, is we've been having a weekly meetings, on Zoom, weekly Zoom meetings, with self-advocates, to nationally, and one within our state of Vermont for people to share concerns about COVID-19 and getting updates about what -- what's going on, as things change, in this time of uncertainty, and through, the meetings that I've -- we've been having here. The concerns that I've sort of -- well, not sort of, but I come across, are, from self-advocates, are, you know, how it's going to affect them through money, through jobs.

As I have already stated, many concerns about lack of accessible

information. Information from the Center on Disease Control is sometimes different, than when agencies are telling people what agencies are telling people.

Also, also concerns around staff having access to masks and gloves.

Things around services that have been cut for some people.

Without really involving the person.

And also, we understand that best practices -- best practice means at that everyone who is getting services will have planned -- if they get sick or someone in their house gets sick, and a few people know what that plan is. And few have it in writing.

That's a thing I wanted to point out through our concern.

Another concern, is hospital visitation. It is still an ongoing battle for people with disabilities to have staff, or family members, accompany them while they are admitted into the hospital.

And the whole issue of some hospital policies limiting access, medical equipment to people with intellectual and developmental disabilities, is a big concern.

Max Barrows: (Continuing) next slide, please.

I guess... the one on self-care, if there's a slide on that.

So ideas on self-care:

I would like to take -- here's the thing. I like to take walks. That's part of my personal self-care routine.

But not everyone is able to do that like me.

I can do it on my own, and I feel like I am enjoying the little things that I -- you know, don't make or don't take time to do.

Before this.

But, we have been hearing, that people who use, like, wheelchairs, have not -- have not left their homes, in like two months, and it just seems easier, for people who move about their community independently to get out.

Max Barrows: We hope that Staff can help us discover strengths and interests that we don't think that we had; and also, I try to use this time to kind of, like, -- sort of, take it as, like, a social experiment.

Like, in other words, in this time of uncertainty, trying to do things that are out of my ordinary. I personally would like, to -- I personally live in the woods; so I would really like to make more of what nature has to offer.

One thing I can say is I'm really pumped that the seasons are changing. I am a huge weather -- extreme-weather fan, so the thunderstorm season is coming, and that is all that I would be paying most attention to. But -- in a time of uncertainty -- that would be something that I am definitely looking forward to.

I will say, for this time, this time gives us an opportunity to eat healthier and to save money.

I take advantage of foods inside my house, and from my garden.

And there are -- there are all healthy foods.

And we are seeing, a lot of ways that people with disabilities are dealing with this time of uncertainty. We are seeing that some people who have always been calm, cool, and collected; and having, like, their -- they're, like, having a harder time.

And on the other hand some people are coping better than expected in this time of uncertainty. This crisis is impacting us in new ways; so you can't just presume that someone will deal with it, based on how they have always coped with difficult situations.

An example of that, actually, quickly, I'll share is just, one of our leaders, is someone who just lost both of his -- their job support.

And all of their natural support.

And they used to get -- they, like, they are, like, basically in a situation, where what they used to get at work, they don't get anymore; and they are, like, having a hard time. And they... you know, they have not ever been someone who has experienced depression, and, you know, we are concerned about them.

And also, other things, developmental service agencies need to be in touch more often and listen to how the person is coping and it is important for people to be given crisis support lines that people can call or text, just as a back up.

Max Barrows: And next... slide, unless you're already there.

I believe there's another one, but I -- guess... there may be -- maybe isn't matching the ones I have. But I'll just go into this quick point here before I turn it over.

I am going to just spend the next -- just few more minutes, just maybe even a couple of more minutes, going over tips for working with support staff, during COVID-19.

And the first tip is, we need to keep reminding everyone, nothing about us, without us. Whatever decisions are being made about our lives, we need to be at the Table 100% and taken seriously. Some people seem to be forgetting the basics. Like talk to me directly. I want to be a part of all talks about me.

Tip No. 2: If an individual gets services, they should make a new plan with their agency, and that will be used now during the coronavirus outbreak.

They need to decide what they need help with; they also need to decide when it -- when it needs to happen.

And the person can ask themselves -- can I wait a couple of hours or a day or a week for this to happen? And it is important to -- for them to decide on what will help them.

And... pretty much can Staff help them over the phone?

Or does it need to be in person?

Also, make sure staff, or anyone assisting, are using words that the individual can understand.

And lastly, everyone -- anything -- anything that is being done needs to focus on what is important to the individual instead of what is important for the person.

What's important to is directly coming from the person in their experience --

[SIMULTANEOUS SPEAKERS]

>> Max Barrows: You can miss out, on things that may not be accurately directed toward -- to what the person needs.

So on that note: That is what I've been getting out of the work that I've been doing with self-advocates through my job on this -- during this time of uncertainty. During the coronavirus outbreak.

So thank you, so much, for letting me share my tips. And suggestions. And hopefully this will be taken into consideration as people move forward with their work.

(Max Barrows).

>> Adriane Griffen: Thanks, Max this is wonderful, thank you for the ideas for self-care, and those tips were great. Next we're going to turn the virtual podium over to Dr. Kara Ayers, take it away.

>> Thank you, and thank Max, you gave some great ideas I'm going to try out with my family as well. I'm Kara, and for many of us there have been many roles in my life impacted by this pandemic. It's already been shared a little bit about my professional roles, but I also have personal roles as well.

So I'm an individual with a disability, that I'm at higher risk for serious complications, or even death -- if I contract COVID-19.

So, my disability primarily, impacts my bones, but it's the pieces that make up our bones, that are specifically impacted. And those are the same pieces -- collagen, that make up lungs.

So I have been learning more about my own disability through this and in that process, learning that I'm at high risk, if I were to contract it. So our family is pictured in this slide, there are 5 of us, my husband also has the same disability I do. Osteogenesis imperfecta, and we are both wheelchair users and we have three kids,

we have our 12-year-old is going to turn 13 on Friday and he does have a disability. And then we have two daughters, 9, and three, who do not have disabilities.

So for us, it's a lot of complicated decisions about our family, but with the primary goal, to do everything we can, not to contract COVID-19. As so many of us are doing as well.

So I've been -- I've found it a fortunate outlet that I've been able to channel some of my worries and concerns about the pandemic and its impact on people with disabilities, into my work.

So specifically, my work as the director of the center for dignity and healthcare, for people with disabilities.

Has let me focus in with an incredible team of people on issues on medical discrimination.

So our disability community has always had difficulty accessing healthcare and especially quality healthcare. But now we see these issues in a different light with the COVID-19 pandemic.

So for me, it's been a helpful coping strategy at times to be able to really dig in and learn more about these issues, and talk to policy-makers about what we can do to counter them, and also hear others' stories from people with disabilities, who are trying to access treatment, whether it's successful or not.

While this can be helpful for me, from a professional standpoint, it can also become kind of all-consuming.

And it's a scary time for us, as a community. And I'm really glad that we have a chance to talk about that today.

Kara: (Continuing) so one of the first impacts that many of us have felt with the pandemic, were changes to our everyday supports, and so for some of us that might be formal supports, like, paid caregivers, or places we go to get services. And for others it might be more informal or natural supports.

So for our family we rely more on those types of informal supports, so for us, that might look like family members who occasionally help out with childcare, or things around the house, that are difficult for us to do or reach.

So we've really had to make decisions, based on what these supports -- what supports can we live without at this time?

Because, again, we're really trying to reduce or exposure.

But we have to ask difficult questions like, you know, how can we make this work in the meantime?

And for how long can this work?

So I think our disability community is fortunate that we're really skilled at problem-solving and creativity.

So my husband and I have thought back to the days when I was in graduate school. We moved out of state and, you know, before we had made good friends, we really were quite alone for a while.

But now, you know, we have added three kids to the mix, so our needs for support do differ in that way. I'm really trying to learn from efforts that I'm hearing about within the disability community, where we're helping each other.

So one of these stories, is their logo is shown on my slide. Is the disability justice culture club; and they are a coop, that is co-led by a friend of mine, Stacy, out in California, and they use collective action to really try to figure out what basic needs are unmet with people with disabilities in their community. And how can they work together to get those needs met.

So they started out by, in the first few weeks, trying to collectively gather what hand sanitizer they could and share it with people, who couldn't get it when it was off the shelves too quickly.

(An interruption) since then, they have really moved to figure out what other basic needs people need met and how can they make it happen? So I'm trying to learn from that and give some inspiration at a time that we're all hopefully trying to look for ways we can help each other.

Kara Ayers: Another way that I'm trying to think about collective action, is through Advocacy.

So I've always been a policy Wonk, I like the process of thinking about policies and how they impact us and thinking about ways that we can make policies more equitable or fair.

So it's an exciting time, if you like advocacy, because there is policy-making happening everywhere.

So, you know, schools, are having to make decisions about what to cancel, and in our case, school is cancelled for the remainder of the year.

But they're already talking about how -- what will school look like next year? And so I participate in those conversations, not only as a Mother, but also, as someone who advocates for children with disabilities, and their education.

So there's ample opportunities for joining conversations like that, and some of the barriers that have held us back in the past, like

transportation, have somewhat come down in terms of -- many people are holding these conversations virtually. Even grocery stores and places where you like to shop are making different policy-decisions paced on when we can safely shop or rules about masks -- so I would encourage you to express your needs, as people figure out these different ways of life.

Another point is, that for me, it's important to stay informed, both for my work, but also in my personal life. But I have to be careful about where I get my information.

I look for sources that are accurate.

But for me, I try to cut down on all the banter or the comments that go along with it.

I find that much of that banter is what's filled with ableism, and that kind of erodes my mental health. Doesn't help me stay in a positive mindset and can be pretty depressing and discouraging.

So I'm increasingly looking for ways to find these reports or summaries of the press conferences that don't allow me to be sucked in to the -- to the comments section.

And I want to finish up by talking about maintaining well-being. For this last point, I've been closing out a lot of my e-mails and saying frequently, for my wishes that people will stay well.

But I also mean that in an emotional sense, for our disability community. I think that some of the things -- the conversations that have happened can take an emotional toll on our community. Collective toll. And so one of the things that I've noticed is that, when a media story shares about a death, it's attributed to COVID-19.

You'll see people's immediate question will be, "But did the person have a preexisting condition?" Or something along that lines, especially if the person is not in the higher-risk age group that has been defined. And it seems if the answer is yes and people say oh, yes, this person had whatever disability it is -- there seems to be a more immediate acceptance or the idea that it's completely understandable that that loss of life has occurred.

And, you know, this is discouraging because there is noticeably more distress or outrage over the loss of these lives without disability.

I think it's important for us to talk about that our lives are just as valuable, and no less upsetting when someone with a disability dies.

So I think we need to talk about what it feels like to see these messages, that our lives have less value over and over; and that toll that it can take on us. And I hope that we'll reach out and support

each other on this. This type of support isn't a formal service, so you don't need a waiver or a co-pay, which is good; but it's also a little bit harder to define. It really, for me it comes in the form of talking with other people, who understand what it feels like to read those messages and think about how valued the people in our lives are, and we should be equally upset about the losses that are happening. And not kind of dismiss some.

Kara Ayers: Another example of this collective toll, has come for me, as we look at ways that our states are reopening. So some of the dialogue that I've seen around this, has increasingly, what I would call "othered" people with disabilities. So in my state of Ohio, we seem to now be referenced as the "vulnerable folks" -- so I know the intention of this is to continue to point out that people with high-risk concerns like myself and my family, have to take different precautions.

But I do worry that it seems that we're drawing this line, between us, and the rest of the world, that is not even accurate, based on what we know about COVID-19.

So we know that people can be asymptomatic, and still carry the infection, we also know that it can impact people seriously, in unexpected ways.

So, you know, I'm concerned about comments when I see things like well, they can just stay home.

Which is in my speech, well, the sick and vulnerable will just have to stay home.

And there seems to be no thought around when this recommendation would end.

And some of these people who say this seem to think forever would be fine. So that worries me.

I think that we have to consider that, yes, people with different risks, are -- many of us are sheltering in place for longer, but we also have to make sure the supports that popped up when everyone was at home, are still available for us.

So things like curbside pick up. No-touch interactions or deliveries. Those things can't go away if -- if it's expected that many of us continue to shelter in place for longer.

Kara Ayers: So these are all considerations that are evolving. You know, my thoughts around this, as I was preparing have even changed since last week.

But, a theme has struck me, and this might be because I've had

a good bit of time to catch up on my Disney +, and if you also have little ones or if not in this case, you may have caught "Frozen 2", so there is a song that is equally catchy as "let it go" but a little more annoying, this song is called "into the unknown" and I think that's really where we're moving with ideas of what does social distancing look like for us as we go forward? It's one thing for us to try and practice social distancing, but a factor that many people don't consider is that when we go out into the public, other people often don't allow us to practice social distancing.

You know, I've spoken to many of my blind friends, about how frequently they are approached and touched by strangers when they're trying to navigate the world; you know, just last week my husband was sitting outside in our driveway brushing our dog and someone pulled off the road and was concerned about him and his wheelchair. And I know the person was being kind and had my husband needed help and had he been flagging down people, that would be a different situation.

But this is just an example of how people's helpfulness, is really going to complicate our ability to stay safe with social distancing, even if we try to do so. The issue of masks is going to be one that our disability community needs to talk about.

Exceptions to wearing masks should definitely be considered a reasonable accommodation. But we need to figure out how we can communicate this.

I know for myself, I'm not happy to see this issue becoming political.

I've seen people describe themselves as quote, not mask people; and that's not in line with what is being recommended, unless you have a disability, that makes it a reasonable accommodation, not to wear a mask.

So we need to come together and work on these different -- different questions.

And there aren't just singular, right answers. We'll have different approaches to these complicated questions.

But I really hope that we can still support each other along the way and truly still be in this together.

Kara Ayers: And thank you so much, for the opportunity to be here with you today. I'm happy and look forward to your questions, when it's time for questions as well. And here are two resources related to what I spoke about today. Thank you.

>> Adriane Griffen: Great, thank you so much, Kara! Really appreciate that. Next up we will hear from Sherice Smith, who will share some other thoughts, and tips on dealing with COVID-19.

I'll turn it over to you now, Sherice!

>> Sherice Smith:

-- Adriane Griffen: Sherice, if you are talking, we are not hearing you, make sure you are still not on mute, please.

(A pause) Adriane Griffen: We'll just give Sherice another second and then if we're not able to connect her audio, we can keep going. We'll loop back...

Sherice, we're still not able to hear you.

Doesn't look like you're connected.

Okay.

[An electronic tone], Adriane Griffen: All right, we will, in the interest of time, loop back to Sherice.

Going forward in the slide here, I do not see she is connected to audio, apologies to everyone. We'll come back to her.

So we will switch over to you, Julia, if you can take the virtual stage to share some tips on maintaining relationships among, you know, all of these changes with COVID-19.

Julia Atkinson: Hello?

>> Adriane Griffen: Hello.

>> Julia Atkinson: Oh, there we go! I'm sorry (correction, Sherice Smith).

>> Sherice Smith: I'm sorry, I don't know what was going on there.

>> Adriane Griffen: It's, like, like TV. We're here, together live. All right.

Sherice.

>> Sherice Smith: I am so sorry! Adriane Griffen: No worries.

>> Sherice Smith:

-- Adriane Griffen: Sherice, your audio has cut off for me. Now we lost you again, Sherice.

It does look like you're connected, though, all right.

Let's -- let's give Sherice a minute to connect her audio again.

Julia, I am going to switch over to you, let me pull your slide deck up, and then we'll get Sherice connected.

(A pause).

Thanks everyone, for your patience.

All right. Julia,

If you could, share your tips on maintaining relationships during COVID-19 and strategies for dealing with social distancing. That would be great.

>> Julia Atkinson: (Taking the virtual podium.).

Julia, are you there, we're not hearing you either. Maybe it's just me. Can folks use the chat to let me know if you're hearing me? (Adriane Griffen)

>> We can hear you now.

>> Adriane Griffen: Okay, thank you.

>> This is Julie, can you guys hear me.

>> Yeah, we can.

>> Julia Atkinson: I was talking to myself.

>> Adriane Griffen: Thank you, Julie.

>> Julia Atkinson: No worries, I was saying, what I was saying to myself is that I'm excited to be here, and to be with this great panel.

I've been working at the university of Alaska for the last 12 years, and have focused a lot of my work, on relationships and the importance of relationships.

And over that time, um, I spent a lot of time really looking into the health benefits of having strong relationships.

Why they're important. And, you know, probably everyone right now is definitely feeling.... the pinch with social distancing. And stay-at-home orders, and -- a lot of the things that are going on right now, definitely creating barriers in the relationships that we have with our friends; our families.

The agencies we interact with. Community members. And so I think across the board, it -- it's really hard right now. But I don't want to focus on necessarily the negative. I think that, this is also an opportunity where we can find new ways, and I think Max talked about this a little bit as well -- we can find new ways to strengthen, and grow relationships with those around us.

So that's what I want to focus on, this afternoon is to talk about a few ways, that we can maybe work to maintain and strengthen the relationships that we have.

And potentially look at other opportunities.

So I think the first place to start, is with those that you are around; that you live with; and that you're able to interact with on a

regular basis.

I know that in talking with Agencies and folks across the state, in Alaska, um... people are talking about how, you know, they -- that social network has been shrunken down, and there is not as many people that they get to interact with.

But for those that you are around, it's important to look at those relationships, and I know that we -- maybe after two months, nearly -- a month and a half of being in close quarters, are starting to want a little distance. But, it's important to look for things that we have in common with one another. Or the ways that we can connect and strengthen that relationship.

A great way to I think, work on relationships is the give and take and relationship, is you might take turns picking activities. Maybe it's the movie that you're going to watch. Games that you're going to play.

Where are you going to go on your walk?

So just taking turns, and -- and working on that mutuality, and the give-and-take of relationships -- we're all probably making some compromises. But, like, Max said, along the way you might find that you have new interests, and new strengths that you didn't know were there, because we're being pushed in some different ways, that maybe we didn't know were there.

Julia Atkinson: It's also important to -- to be assertive and to let those around you know when you need some time to yourself.

You may be have a roommate or a family member that would love to spend all of the time with you. And you, yourself, might need some time alone to recharge and to refresh. And it's important to ask for that or to say, "I would love to play with that game with you later on today, but right now I need to take a half an hour. I need to take an hour to myself," and let yourself recharge.

I think that's really important.

Julia Atkinson: Another great thing we have right now, is technology:

There's so much technology in our world, and hopefully, there are ways that you can connect to that technology, and to use it to help your relationships.

You know, just a quick text-message to someone -- "Hey, I'm thinking about you today" will certainly brighten their day. Will probably start a conversation. And even though you don't get to see them face-to-face, but it's a way to still maintain that relationship.

Video chats are also superhelpful.

You get to see one another, and I think that face-to-face connection is -- is really important, even though it's not tangible and not in-person, being able to make use of that technology is really important.

There are so many online games, there are apps that you can get together; and interact with your friends and your family.

I know there's one called "House party" and the other night my husband and I and our brother and sister, we all got online and played Pictionary together and it was a blast. It was really fun to be able to connect with them, and that's one thing that we like to do is to play games, we keep talking about games, but we really do enjoy doing in our home, and able to be able to do that even in a time when we're social distancing.

There are so many opportunities, and I'm sure, like, if -- other people are out there, I'm sure they can talk about other apps that maybe they're using to connect with people in the chat box. But I know that folks are using CAST, which is a movie streaming app, where everyone logs into it and you watch a movie together but you can make comments as if you were sitting in the room with your friends, you can make comments about that movie.

My only caution is certainly, that if you are using technology, is to certainly make sure you're looking at the privacy settings, and making sure that you understand those. And if you don't, to ask for some help around privacy, to make sure that you're being able to use that technology in a way that is safe, and not putting you at risk.

I also just want to briefly touch on, well, what if you're not big into technology or you don't have a smartphone or a computer?

There's still ways to connect.

Just calling someone up and having a conversation is a great way to.... to continue that relationship, and to -- and to, you know, let someone know that you're thinking about them. And talk about what are you experiencing?

And we all have this shared experience right now, in this pandemic.

That we're all experiencing things that we didn't understand -- we didn't know that were going to happen. And so we're all in a place of... a little bit of a place of uncertainty. And so you're able to talk about that. And what things are working well? What are you enjoying doing? What are you finding that you didn't

know you wanted to do?

You can always write a letter. Or a note to someone, send someone an e-mail.

One way that we -- my family has certainly enjoyed being able to still connect with friends, is that when we go out on our walk, we're able to say Hi, to our neighbors. And to stop, and -- from the street, you know, at their front door, we can still say Hi, and have a conversation, check on them, see if there's anything they need. And we're able to maintain a distance that's recommended; but then also be able to still feel like we're connected to our neighbors around us.

And I feel that -- I see more and more people outside right now, than I have in quite a while.

And then last:

I know that Sherice and -- is going to speak to this a little bit, and Kara also talked about that there are things that we can do to keep us safe right now.

And it's important to remember in our relationships, while we want to be able to be with our friends, and to be with our family, it's important that we're making decisions that are going to keep us safe, and not put ourselves or others at risk.

Of getting sick.

In terms of intimate relationships. This also opens a whole other conversation around what does this look like? But just a few tips, are certainly to be selective and who you kiss, who are you --... you know, interacting with?

There are a lot of resources out right now around intimate relationships, and staying safe.

And a lot of them are talking about that you are your safest partner. So maybe not engaging in sexual relations with -- with a partner, or with someone else right now.

Are there ways, that you can meet your sexual needs that aren't going to put you at risk? And certainly, if you are in a relationship with someone else, just making sure that you're practicing safe-sex practices and trying to make decisions that, again, are going to minimize risk.

All right. I'm going to hand it back to you and hopefully we can get Sherice on.

>> Adriane Griffen: Thank you so much, Julie, these are wonderful tips! So let's see if Sherice was able to troubleshoot her connection here. Sherice, are you able to take the microphone?

And say a few words?

>> Sherice Smith: Can you hear me?

>> Adriane Griffen: We can hear you now.

>> Sherice Smith: I just love technology.

I'm sorry, everyone.

Okay.

Thank you, all for being patient with me, and I do apologize for earlier. I don't know what happened.

But as I said, my name is Sherice Smith, I am with Partners for Inclusive Communities, which is through the university of Arkansas at Fayetteville.

And we -- and I do -- disability and health, as well as the safety project on domestic violence and sexual assault.

And our primary goal -- we're a UCEDD, so we do health and wellness as well as Access.

And Access, to care and services and just our environment has never been more important than it is right now.

We have a lot of programs, where we get in touch with the public, and now we're not able to do that. So we have been creating videos, trying to create videos, to still offer a level of engagement, as well as -- but still adhere to the recommended social distancing.

Next slide, please.

Sherice Smith: (Continuing) one of the things that we, want to stress is good hygiene, and good strategies for hygiene.

Washing your hands is very important. I have become an expert on -- if nothing else, hand-washing.

Especially because I have spina bifida, and I use a wheelchair, so my hands get dirty a lot.

And also, like, a previous presenter, Kara, stated -- I am at a higher risk for COVID because I have spina bifida, and I'm not -- my lungs are not as healthy as they probably should be.

So I just wanted to have a little fun.... with it, and I tell people to wash their hands.

It isn't important so much as the temp, as it is doing it for 20 seconds. Sing a song to make it fun. I've been doing all kind of things to amuse myself.

So I have a couple of my favorite songs that I came up with.

Shake, shake, shake your booty, with KC and the sunshine

band. "I saw the sign" by ace of base, and row, row, row your boat is one that you can use with your children, also, of course, the ever-popular birthday song.

Be sure to just make sure you wash, you know, between your fingers, under your nails, and your palms, again, if you're a wheelchair user -- you're touching the ground, that people are walking on.

That they're spitting on, that they're sweating on, so it's important that you keep your hands clean.

Also like other presenters, I've had all these thoughts, since I submitted my slides, so I feel like I'm going to miss a lot of things. And I do apologize.

So next slide, please.

Sherice Smith: You know, mental health, and mental illness is -- has hit the worse, I think, during this. Stress and anxiety, which is something I have an issue with, and depression has spiked during COVID.

Affecting sleep, and eating habits.

I can get treated for depression and anxiety, and stress disorders so I have had a hard time coping. I've slept more than I ever have. My eating is out of control.

And people with disabilities, who already live an isolated life, in some cases, especially in a state, like, Arkansas, where it's very rural, don't have access to a lot of activities or being told to isolate even more, by not having friends and family.

And people that are used to having in their lives; and it's really difficult when you have this -- there's no way to get out of it, because supports are very limited. Even in the best of circumstances.

So -- I always say, what's a good way to combat that?

Is, you know, maybe you can find a new hobby.

Dance, listen to music.

I do a lot of listening to music. It makes me happy. Social media, and people have taken to doing Zoom a lot to do, social interactions. One thing that we do here, in Arkansas, is we have something called "a hog call" where we get advocates and allies together, and we chat about things that do not have to do with COVID, to kind of big people an escapism.

And so -- and then we also have other calls that we can discuss their concerns, but we also want to just give people a chance to forget about it; and have a good time, and get relief from all of the media, and being bombarded with news stories and e-mails and all of that.

Next slide, please.

Nutrition, and exercise is -- is wildly important during this time, because if you're like me, you're eating more than you ever have before.

[LAUGHTER] Sherice Smith: You are sleeping more than you ever have before, and that's not really great for nutrition.

So, lots of gyms, now, are -- all the gyms are closed, but there are some gyms that are offering online classes, for free.

So that's one way, you can stay in shape. Some places are even offering nutrition programs that you can do online, that is accessible.

Our disability and health program will be offering free online exercise videos by advocates, designed specifically for people with disabilities, and the people that support them.

If you can't go outside, walk around your yard or your neighborhood. Try doing laps, in your apartment: It's better than doing nothing. You know, I -- I roll around my apartment a lot. I have a iwatch.

So, it tells me when it's time to roll.

And I roll until it tells me, I've reached the goal, and it makes me feel, like I've accomplished something, when it feels like I can't do anything.

So it can be very frustrating, but, you know, I -- I have a dog, and I take walks with her all the -- all of the time. She's gotten sick of me. But doing things like that can.... help you with your nutrition and exercise.

If you have a person with a disability, or a fellow advocate, or someone that you know or support staff -- ask them to -- to do a workout with you. A lot of places are offering programs like Zumba and yoga, they're offering free classes, and right now I would take advantage of that.

Next slide, please.

Sherice Smith: So, one of the biggest issues, even in the best of circumstances is personal care attendants and support staff.

And that's even more challenging now; and so one of the things I would say is make sure your support staff, wears a mask and gloves. If they can't provide their own, work with a disability organization to see where you can get supplies.

A lot of organizations are stepping up and offering free

supplies.

So just ask, if -- if your personal care person can't provide their own, make sure your staff -- make sure that you have staff that can take their temp every day. I mean, I know a lot of places that won't even let you in.

If you don't take your temp at the door.

So, ask your staff to take their, and ask them if they're having any symptoms.

Make sure to have back up staff.

If your staff gets sick, because this is happening so rapidly -- ask them not to come in and try to find a back up person.

Ask your staff to set up meals, and meds and things in advance, so that they don't have to come in every single day.

I don't use a support staff, so I'm going off of --... things that other people have told me, like, Kara, I usually use family and friends.

And I usually have them set up things that I need, beforehand.

And so that they don't have to come in every day.

Next slide.

Sherice Smith: No other slides.

>> Adriane Griffen: That is the last one.

>> Sherice Smith: Okay, and in terms of relationships:

I just wanted to say, you know, Facebook has become a great resource for me to keep in touch with people.

In terms of mental health. And -- and in terms of talking to people, and having a good time. Doing Zoom parties if you have access, to online, is a really good way to just sit and connect and see people that you haven't seen or can't see right now. And I thank you all, for this space to give some things that I came up with. I had a billion more, but it just didn't have the room. So thank you.

>> Adriane Griffen: Thank you, Sherice, thanks for being a trooper in dealing with the technology. Really appreciate you.

So next up, I will forward this slide. Next, I want to invite Liz Weintraub to the virtual stage here to share your reflections on what you have heard so far, and also throw out a question or so, to the speakers today.

So, we'll have Liz first, and then, mark smith shares in the discussant role and wrapping us up today will be Jeiri Flores serving as our Q&A marshal taking charge of that. Let me turn it over to you Liz, take it away please! Liz Weintraub:

(Taking the virtual stage) Adriane Griffen: Liz, this is Adriane,

I'm not hearing you, if you are connected to audio.

Liz, I'm going to move back to you, we'll troubleshoot your audio.

I will flip over to you, Mark, if you could share your reflections on today, and also, throw out, maybe a question or two to the speaker panel, and then Liz will connect back with you, so take it away.

>> Mark: Can you hear me.

>> Adriane Griffen: We sure do.

>> First to start out, boy, are we living in a time where there's a lack of predictability. I am not a young guy, and I can never remember anything like this in my lifetime and certainly, you know, as we enter what they're calling this "new normal," which is kind of a -- you know, code word for things that I am not really very fond of, when we talk about persons that experience disability -- there's just so much stress, and so much what's coming next? I noted -- going to go back to some of the speakers, Kara talked about the reopening process and how that's going to impact the folks that we care about.

That has really been on my mind, as I'm also someone, who really shouldn't be catching this.

When they take about, you know, some of the approaches to -- who can and who should and shouldn't be catching this.

Let's see:

You know, the -- in terms of the self-advocates and the people that support them, you know, have worked so hard in my mind, to get to the point, where their voices are increasingly heard and their lives are increasingly their own. That what they say is included and respected.

You know, the world is not perfect, you know, as we know.

There's a lot of work to do.

But, as we move forward, how do we deal with this huge issue? This life-changing issue?

And prevent slippage from occurring in terms of the progress we've made?

I noted a couple of folks, especially Kara mentioned the issue of ableism and that being an issue that we're currently trying to address, and combat.

And how do we ensure that, you know, that what appears to be an overwhelming and constant challenge is something that we can continue to make progress towards.

Another thing I'll mention in terms of my work is, the whole piece of cultural equity and access to services as we notice that COVID-19, has really I guess singled out our communities of color.

And that, you know, we're seeing a lot going on there. And in my mind, this is exposing issues in our society that otherwise just kind of don't always get noticed.

And for me, like, as I deal with for example, parents who have children in special education at home, who are trying to ensure their children get services, that they don't regress in their skills.

It's and that's probably my son calling me right now -- (referring to cell phone interruption) mark Smith: At least there's a plan in place, and that there are directions that we're going, as a community, and as a society, that ensures that the folks that we care about don't get left behind

Because that, you know, in past circumstances, where we've experienced crisis as a nation, you know, it's, like, who doesn't really get what they need?

First?

And so, I'm just saying, from my perspective, we have, you know, worked very hard, to ensure that the needs of those who experience disabilities, and the progress we've made in terms of our advocacy and work, is not lost. And that, in fact, it's time to even push harder, which is not really the message that a lot of folks want to hear, because I think folks are a little fatigued and a little tired right now. And I understand that. And I think a lot of what was discussed -- Max, Kara, Julia, and Sherice, all mentioned, you know, little aspects and pieces of -- of -- you need to take care of yourself.

So, I just really picked that up as we are going through this. There was a lot of, you know, taking responsibility for your own care.

But how to do that. And there were some great tips. So I have some questions. They would be for any of our presenters today.

I guess it might be best to ask one question, and here's some answers, and then I have a second follow-up question.

So my first question, would be --

Q. There was a lot of discussion about how important it is to get information.

To understand, you know, as best we can what's coming in an environment where that -- that's not the easiest.

And so I didn't know if folks that were presenters, had any ideas in terms of what -- what they would recommend as being stable, predictable reliable resources, to stay informed about what's going on with COVID-19.

And its impact on the disability community.

Sherice Smith: Anybody can go?

>> Yeah, I can try to start with this one.

A. Kara: I think for me it varies a little bit, between whether -- like, I sign up for a few e-mail lists that give me a summary of kind of the top news of the day.

Sometimes I like that in that it's not only disability-related. So I like to get the general story first, then I turn to some trusts organizations within our disability community.

And the AUCD Network does a great job of sharing those on social media.

So, like, I kind of, like, to look both places in terms of general and then disability-specific.

And I've also found a few people on Facebook, actually, that provide daily summaries of some of the press conferences, so our governor does one almost every day at 2:00 p.m. and then the White House has one most days as well so I've found that I don't like to watch those in their entirety anymore, because they're very long if you watch all of them. But I like those summaries that that just give me the main ideas, but you have to make sure that the summaries capture everything that was said in a neutral way.

>> Sherice Smith: We have a newsletter that gives out a lot of information, and we get most of our information from AUCD, CDC. So I -- we give out that. And also, I would -- piggyback on what Kara said, you know, go to your organizations like your Centers for Independent Living, and any other DD providers and they can usually give you some pretty good information.

Unfortunately, for a lot of people with disabilities, there is no Internet access; or they don't have it to where they can get it electronically. So, you know, they unfortunately have to rely a lot on TV, which is -- not the best way, but I would always say go to your centers for independent living, or any DD providers in your area, to get good information, because they're getting theirs from the CDC and AUCD.

>> Mark Smith.. great, great. Thanks.

I'll go on with my second question, those are terrific answers, thank you.

Q. The second question I have, was, again, for the entire group. You know, I shared a couple of thoughts that I had about things that we're -- we've been dealing with as a community, and trying to address

in terms of equity, and trying to combat ableism.

Personally. But I wanted to hear from the presenters, like, if you're going to put your -- your top priority or your top couple of priorities, you would be -- you know, your opinion in terms of what are -- we should be advocating for as a disability community across the country. What would that be?

Advocacy for blank, question mark?

>> Can you, like, repeat that again? Just so I can get a little bit of a gist of where you're going?

>> Mark Smith.. I can. There are a lot of issues out there for people with disabilities, for people who don't have disabilities.

But, for people with disabilities, you know, I would say a hallmark of our community historically, has been, that, we've had to be strong advocates.

And given that we're in this pandemic, and public health crisis, what do you think, is the top item that we should be identifying as a community, to advocate for? Or against? Or if you like, a couple of priorities.

Is that helpful?

>> Max Barrows: Yeah, that is.

>> Mark Smith: Okay, very good.

>> Max Barrows: Well, I think I presented this in when I was going before, but I think what it starts with is, I would say, you know, check in on us more often. I think there needs to be work in place, where people with disabilities, are listened to more. And a lot of the information that is being thrown out there about this time of uncertainty is just, right now, not as helpful in terms of where people would commonly pay attention to... when it comes to getting information.

I think, honestly, it just -- right now, it's, you know, we're being still seen as, like, we don't matter as much.

And that, to me, is not okay.

I think we matter as much as everybody else.

I think keeping that in mind to combat that we are seen as less than, I think, really is where it -- it starts.

>> Mark Smith.. thank you.

>> Sherice Smith: This is Sherice.

I think there are so many issues, but one of the biggest issues

that I've come across, is people don't have -- with disabilities, don't have access to supplies.

There is a problem with getting access to food, and it's because by the time they're able to get to the store, they -- there's nothing there because people have been hoarding it. And people -- because, like, for me for instance, I don't drive. So I have to set up transportation 24 hours in advance, so if someone tells me, oh, there's -- detergent or bread at the store today, I have to wait 24 hours, to get to the store, and then it might not be there anymore.

Luckily, I have -- there are delivery places, but not everybody can afford those.

So just getting access to supplies and food, is -- is huge for people with disabilities. Who may not have adequate transportation.

>> Mark Smith..

>> Thank you.

>> Kara: My top priority would be pushing back on the ableism that we see, I mean, this crisis has really highlighted how it can, literally, be life-or-death.

And, you know, the ableism that we see in healthcare in terms of discrimination, that is often based on the idea as was mentioned that our lives are less valuable, or the assumption that we have a lower quality of life.

And as Sherice just mentioned the ableism that, you know, that we deal with preCOVID-19 is just magnified now.

So as we figure these things out as a community, we can't allow people to not consider our needs, but also, we -- I think we need to push back against the idea that we should all have to come up with just one way of approaching things.

And I think the mask issue is an example of that. You know, some of us will need to advocate for not wearing a mask so that we can do something that we need to do, but with our disability. We're not able to wear a mask. Others of us, including my family, will hope that most people do wear masks to protect our communities.

So, we're a diverse group of people, as people with disabilities.

We don't have to give in to the idea that we have to decide one way of doing things, because we all have different needs and that's okay.

>> Mark Smith: Thank you.

So, at this point, I -- are we able to get Liz up?

Adriane Griffen: Thanks Mark, we can try to see if she was able to reconnect on audio.

>> Mark: Okay, while I have the floor, I would say, it's really an honor to be able to present with such an esteemed group, and thanks for the great information on this call.

I appreciate it. I'm sure as everyone does.

Adriane Griffen: Well, thank you, Mark. That was great. So we are going to just move on to wrapping up. We have Jeiri Flores with us to wrap us up.

And serve as our question-and answer-marshal so I'll turn it over to you, Jeiri.

>> Jeiri Flores: Can everybody hear me?

>> Adriane Griffen: Yes, we sure can.

>> Jeiri Flores: Good afternoon everybody, I'm so happy to be with you-all, and I appreciate everyone so much who has presented thus far.

We make a dope team!

There weren't a lot of questions but someone asked about the SSI stimulus check and I passed that question to anyone else that was a part of this group that can answer that in a more intelligent way.

I wouldn't want to answer that, and not provide clear information.

From what I do know, is that some folks are... receiving this stimulus check, and that receive SSI, but I think that the eligibility varies.

I know that there are some Web sites out now from the IRS that you can check for your eligibility.

(A pause), I'm not sure what more information we can really share.

Outside of those Web sites.

Jeiri Flores: Maybe I can post them in the chat. I don't know them offhand, and maybe if someone does, they can post them. There was another question about visits. I think that they will be done over the phone.

I have my visit coming up, soon. Well, you can see me in the picture. I'm also a person with a disability. There is my chair. For now, I think that all of them will be over the phone. They're checking

in more often than not now. They're required to do so.

I don't know when they'll be back to face to face, but I think for now, they're just going to do everything that they can over the phone, and try to be as honest and open with your care coordinator as you can be. As they sometimes have more connections to resources, or know of a place that you can go for resources.

Jeiri Flores: These presentations, I believe -- there was another question about, the recordings of these presentations.

These presentations most likely will be up on AUCD Web site, so you can, then, see the recordings, they'll be archived and they'll be shared with everyone who has access to the AUCD Web site!

I don't know how to answer this last question that I saw, it's -- the question was about mapping out the impact of COVID for people with disabilities, with the use of international classification of functioning. I'm going to be real, I don't even know what international classification of functioning is.

[LAUGHTER]

>> Jeiri Flores: So if someone who knows can answer that for folks. That's all that I caught on.

>> Adriane Griffen: I could respond to that real quick.

So the -- the international classification of functioning, or ICF, is a system that the World Health Organization, has developed to talk about how disability impacts different people in different communities, so McKenzie Jones the person here in the chat is asking if that could somehow be used as a framework to talk about how COVID-19 is impacting the disability community.

I think that's a good idea. I'm not aware of a lot of groups talking about it. Like that yet.

The American public health association disability section, is starting to look at it that way, and I know AUCD's national center on disability and public health is also looking at resources like that for ongoing public health research so that people with disabilities are always included in public health efforts and programs.

So I hope that helps Ilka: Can you guys hear me?

>> Yes.

>> Ilka Riddle: Great, I think the other thing is AUCD, is also, collecting stories, right now.

More so, for policy issues, however, if people provide stories to AUCD, about their experience, how COVID has impacted their lives, I think that would be helpful, not just on the policy end, but can be a

good resource, for all of the UCEDDs and for prodder information dissemination to others about what do people with disabilities experience during this COVID crisis?

So I would strongly recommend, and Adriane, if you can put the link to where people can put their stories, that might be helpful.

So feel free to share, too, positives as well as challenges that you have experienced.

>> Before we end, I just wanted to answer Mark's question, really fast in terms of what we should continue to advocate for. I know I wasn't -- one of the main presenters, but I would just like to say that I think that, you know, we're in a -- weird time, of course, (Jeiri Flores) so we're also in a time of change.

As we see a lot of accommodations come to light, and kind of be rolled out, I think we're in the primetime to make sure that those accommodations don't go away, once this is over.

That people understand that they're still important to us, and that may have made such a huge difference, in our lives, personally, but that they should continue to exist and be used and that we should still be, you know, personally involved in -- and included in all the things, with the use of these new -- I would call them new discoveries, even though they've existed forever; but, you know, in terms of how we're being more inclusive to folks with the use of -- Zoom and things and how we can all work from home, and it still be successful.

Thank you so much, for the opportunity, and I appreciate you-all, so much! (Jeiri Flores).

>> Thank you, so much, Jeiri, and for leading our Q&A, and thank you to Mark, for his comments and questions. Sorry we couldn't reconnect to Liz. I also wanted to apologize it took a while to get the interpreter going, as you probably know, there are lots and lots of people on these calls.

And sometimes we run into some technical challenges, so my apologies for that.

But you have in the bottom, we have the realtime captions.

And, before we go...

I would like you to take a look at this last slide Adriane just put up. We have two action items for you guys! We would love for you guys to look at the public health is for everyone toolkit, and add resources that may be really helpful.

And then the second ask, is for you all to attend tomorrow's

webinar, which will be the fourth, and last of our four-part webinar series on COVID-19 for right now.

We have a great panel that will address, and answer all kinds of questions. We collected questions from the last three sessions that we did; and from -- and so we'll answer those, as well as questions that people will share with us on tomorrow's call.

So if we weren't able to answer your question, or if something comes up tonight and you're, like, hmm! I really would like to know the answer to this question -- please join us tomorrow at 4:00 p.m. eastern time. And we will try to provide answers to your questions.

Again, this webinar has been recorded, and will be archived in the webinar library at AUCD and should be available in the next few days a reminder to take a few moments to complete our survey right after the webinar concludes. Thank you, everyone, have a great morning, afternoon, or evening, depending on your time zone.

Thank you, for calling in, and have a good rest of your day! Or evening.

>> Thank you very much.

>> Thank you, all!

(Transmission concluded)