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SPHARC COFFEE TALK  
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### Remote CART Captioning

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>> Good afternoon, everyone, and welcome to today's Coffee Talk where we will have Stephen Shore and Teal Benevides present on the "Meaningful Inclusion of People on the Autism Spectrum" in multiple settings, as well as open discussion among all attendees on this topic.

Hi, everyone. My name is Shanel, I'm excited to have an opportunity to speak with you all and moderate on this discussion today. I'm AMCHP's new program analyst within the child and adolescent health needs. Before we begin, we want to let you know that this webinar will be recorded and I will start recording at this time.

So before we begin our presentation, I do have a few housekeeping reminders. Please press Star 6 to mute or unmute your line. Please mute your fine lines now and adjust the volume on your computer.

If you are having any technical difficulties with your audio, please use the chat feature and AMCHP staff will be able to help you.

Additionally, to submit questions or comments, use the call-in, the chat box at the lower right-hand side of your screen or use the raise your hand function.

Before we get started today I want to remind you that the recording and slides will be available on the AMCHP website within a week after this broadcast.

Finally, you will receive a short evaluation survey after the webinar has ended. Please take a few moments to provide feedback, as your input is helpful in planning future events and learning opportunities.

>> Thanks so much. This is Paige. I'm the senior program management at AMCHP. I just wanted to provide a quick overview of our State Public Health Autism Resource Center, which we refer to as SPHARC. We're very excited to host this webinar. For those of you who are not aware, the State Public Health Autism Resource Center is a web-based resource center

intended to provide ongoing technical assistance and facilitate learning, particularly Title V programs in developing and implementing systems of care for children with autism spectrum disorders and developmental disabilities, technical assistance and peer learning.

We're very excited today to continue this conversation. So for those of you in attendance at the AMCHP annual conference back in February, we hosted in partnership with AUCD, we hosted the autism Town Hall event which we had different presentations from our partners. So from our partners at the American Academy of Pediatrics, they presented on partnering with primary care pediatricians for identification and diagnosis, family support and transitions of care.

Then we had a presentation from the American speech and hearing association on gender differences in autism. And then finally we had our wonderful current presenters today from the asset project talk about the meaningful inclusion of people on the autism spectrum. Because they only had a few minutes to present at the town hall, because we used an Ignite style presentation format we're really excited to have the time today to continue that conversation, as this is a very important one and something that is critical to our work here at AMCHP.

So with that, I will turn it back over to Shanel to introduce our presenters.

>> Thank you, Page. As you can see, we have a great agenda for today's webinar. We will have ample time for questions and answers and discussion throughout the webinar. Before I turn it over to our presenters I want to take a few moments to do introductions. Dr. Stephen Shore was diagnosed with atypical development strong autistic tendencies and too sick for yacht patient treatment. He was recommended for institutionalization, nonverbal until four and much support from his parents, teachers, wife and others, Stephen is now a professor at Adelphi University matching best practice to the needs of people with autism.

In addition to working with children and talking about life on the autism spectrum, Stephen is internationally renowned for presentations, consultations and writings on lifespan issues pertinent to education, relationships, employment, advocacy and disclosure. His most recent book College for Students with Disabilities combines personal stories and promoting success in higher education.

A current board member of Autism Speaks and the organization for autism research, a member of the Asperger's association of New England and the advisory board member of Autism Society, Dr. Shore serves on the Board of the Asperger's syndrome and high functioning association and other autism-related organizations.

So welcome, Dr. Shore.

We also have today, Dr. Teal Benevides. She is an occupational therapist, researcher, wife and mother. Currently she serves as associate professor in the department of occupational therapy at Augusta University where time is primarily spent in research in teaching of graduate occupational therapy students. Teal received her Ph.D. from Virginia Commonwealth University in 2014 and has been an occupational therapist for over 13 years. As previous LEND fellow from Georgia State University Center for leadership and disability, Dr. Teal is

committed to fostering access to services and supports for individuals on the autism spectrum. This access will help improve health outcomes and ensure participation in meaningful life activities. Teal has received grants from agencies including health resource and services administration and patient-centered outcome research institute. Teal enjoys collaborating to improve the autistic and non-autistic research settings to address pressing priorities faced by the autism community. Extension of this work aims to address ethnic and racial disparity and care for those on the autism spectrum in Georgia. When not working she enjoys reading, playing board games with daughter and husband and going to the beach. Please welcome Dr. Teal Benevides. Thank you.

>> Thank you. This is Page. Before we turn it over to Teal and Stephen, there is the chat box enabled on the screen, in the lower right-hand corner. We had a few questions that came in via the survey we sent out to everyone who registered for the event. If you have any questions as they're speaking, please feel free to type those into the chat box and we'll be sure to address those after the presentation.

So with that I'll turn it over to Teal and Stephen. Thank you!

>> Stephen Shore: Well, I am honored to be presenting and working with so many people who are dedicated to promoting fulfilling and productive lives for autistic individuals. And in the area that we're focusing on at this point, the inclusion of autistic individuals in research and other aspects of life.

So let the fun begin. We're going to talk about our project, and once I can get this to... there we go!

All right. So our objectives that we're going to provide an overview of Autistic Adults and other Stakeholders Engage Together project and lessons we've learned. We've learned a lot of things that were incidental to the goal of the project, which were to find the most pressing medical issues facing autistic adults, and we are eager to share what was learned with you.

We're going to discuss additional key strategies for meaningful inclusion of people on the autism spectrum in multiple settings. And also supporting dialogue between all of you and us as the AASET project leads.

The one thing we need to take a look at is identity versus person-first language. You may have noticed that I've been using "autistic person," "autistic individual," "autistics" and that's considered identity-first language. Person-first language begins with the person first, might be a person's name or it might be referring to a student, and that's a person with autism, a person on the autism spectrum, somebody who has autism. And what I have found, the past several years, engaging with my colleagues, my autistic colleagues, about 80% of us prefer identity-first language because we feel that autism colors everything that we do, not that autism is all we are, but it is an ever-present part of who we are.

So, for example, autism isn't something that you can, for example, put into a bag and leave it at the door and when you're done hopefully you don't forget to pick up your bag of autism and bring it back home.

However, we do know that there are some autistic individuals who prefer person-first language, and that's perfectly fine with us too.

So the best way to go about it is just to ask, ask us, how do we prefer to be identified as? A person with autism or as an autistic person? As part of that, we also feel that we shouldn't have a meltdown or get into a tantrum because somebody uses the other form than what we prefer.

So as we go about our research, as we talk about improving lives for autistic individuals, we value autonomy and identity and above all mutual respect.

I want to acknowledge our funders, Autistic Adults and other Stakeholders Engage Together were funded through a patient care outcomes research institute, PCORI engagement award, and the views presented in the presentation, they're the responsibility of the authors, the two of us, and do not necessarily represent the views of PCORI, its Board of Governors or Methodology Committee.

So I will now turn you over to Dr. Teal Benevides, who will tell us a little bit more about what AASET is.

>> Teal Benevides: Hello, everyone. Thank you so much for having us today. We are excited to share with your our AASET project. And AASET stands for Autistic Adults and other Stakeholders Engage Together. We started this collaborative engagement award because there are many pressing health needs and poor health outcomes that affect many autistic adults. However, as research unfolds in this area, we don't know exactly what the autism community wants to see research on. So what are the most pressing health needs or outcomes that are priorities from the autistic perspective? And we don't know what interventions are acceptable to individuals whom we work with and whom research would be done in collaboration with. And so our project aims to engage the autism community in identifying priority outcomes and interventions to address health needs.

And so we were funded for two years, and our first year was essentially building up our capacity to engage the autistic community and in year two we're going to continue our priority setting activities.

I want to acknowledge that we have a fantastic project team, and Stephen will talk a little more about how they're involved later. Alex Plank is our social media coordinator, and runs our Facebook group. He posts interesting information about health. And Patty Duncan is our conference coordinator, and in year two we'll share with you we have a meeting to engage other stakeholders on the topics related to priority settings, and hopefully if you're interested you can attend.

So what do we plan to do in this two-year project?

Because it's an engagement project, it's not a research project, our first step was to establish backbone support. This involves things such as ensuring that the IRB was aware of our funding and had input as to what was considered to be research from the perspective of the IRB, and also ensuring that everyone who needed to be on the project was hired and paid appropriately.

We also learned a lot about communication, which we'll talk about soon. So that was our first step., ensuring we had strategies to communicate effectively with everyone. Our second step was to build community presence. We'll share how we were engaged with other stakeholder organizations. Our third step was to build our community council, and that was an important part of the process that we'll talk about, our Community Council includes autistic adults who inform, advise and contribute to project-related documents.

Our step four was to engage in a year one meeting to identify priorities for future actions. And so right now, in year two, we're engaging in step five and step six to understand the literature related to priorities -- early priorities that the autistic community has identified and to develop an intervention plan, some of which we'll share today. This entire project used selective impact as the framework for building our mutual understanding of the stakeholders that are involved. And so collective impact by Kanya and Kramer was published in 2011 and identified a framework for engaging all of the relevant people and organizations that might need to play a role in solving challenges related to something like building priorities and addressing priorities for health outcomes.

This is not something that our project team can do alone, and collective impact is a framework for making sure that as many stakeholders that need to be involved are, and so that's something interesting we could share, those resources with you about collective impact if people would like to learn more about that.

So, what we did in step one was learn how to communicate effectively with each other. So it looks like part of the slide got cut off on the left hand there with our bullets, however, what we learned is that our project team and our Community Council hear and understand things differently when they're shared. And we attempted to ensure that people's communication needs were met by asking what preferred methods they had in communications. Was it email? Was it through a video conference call? Was it a regular voice mail or phone conference?

And through trial and error we used different methods and we learned a lot about how people communicate and ensuring that there are opportunities to express preferences and also change one's preference during a particular meeting. So, for example, this particular webinar allows people to participate both through chat, text chat, and through auditory listening to what people are saying.

There's also a transcriptionist who is typing out the words, so somebody could visually read what is going on.

Those are all appropriate methods for a meaningful inclusion, and ensuring that everyone has an opportunity to communicate in the preferred manner was a very helpful thing to consider before launching other project activities.

So we determined the best way for our Project Team and our Community Council to communicate. One of the things that we learned was about email communication. I have been described as writing and speaking in manifesto. So Stephen called me a manifesto writer, which means that I often include too much information in my emails. What we've learned is that using an email template, which uses bullets, a clear structure for every email, and reduced words will help everyone, and it helped me organize what I need and what others need to communicate back during Project Communication.

So thinking carefully about how to communicate and using it consistently is an important lesson learned.

I would like to share with you our email template that we used to communicate with our Community Council. And unfortunately it looks like a lot of these slides, the bullets have been cut off on the left-hand slide, so I apologize. But Elesia Ashkenazy, a Community Council member created this template to use when communicating with the Community Council.

So our template always has at the top a greeting "hello." Then it has underneath that bolded, underlined, purpose of the email. And usually we have no more than one or two purposes that we share with the Community Council in any given email.

The next part of the email structure are the details. We provide any kind of information people need in order to enact the action step, which is the last part of the email template.

So the action steps are very clear, specific actions that we need the Community Council to do, and what is not shown on this slide, the actions were to read the conference summary. The second action was to use track changes or comments to share feedback about the conference summary. And the third action was to send that feedback to a particular person on the Project Team.

We always include a deadline, which is clear, specific, and includes both a time and time zone, so people know when something is due. This helped us create open communication systems with people and ensure a functioning team.

I'm going to turn it over to Stephen to talk about other things we've learned.

>> Stephen Shore: All right. So we're going to take it step-by-step. We'll begin with the Institutional Review Board, the IRB. And what we found is that IRBs don't always understand what the specific needs of project partners are who may not be scientists. So one challenge that we faced was a lack of understanding of the spectrum. And it was assumed that all autistic adults had diminished capacity, which has important implications in terms of gathering data for research. And what we needed to educate the IRB on was that not being able to speak doesn't mean that we don't have something to say, and that non-speaking individuals

can be very competent and perhaps maybe even more intelligent than we are. So speaking isn't correlated -- necessarily correlated to substance.

Also, the type of the project. This is not a research project, per se, but it's an engagement project, and it's highly participatory and highly constructionist, as we learn things, that guides us, as we continue through our project. And also we found many -- a number of us partners being challenged by the lack of accommodations for CITI training. The CITI training on human subjects is a rigorous course with rigorous assessments and essentially requires that one memorize huge blocks of text before answering various multiple choice questions on them.

So we needed strategies to address these challenges. Is there expertise on board for participatory projects.

We also feel we need to reach out early, reach out to collaborate with the IRB early in the process, and also educating IRB about the nature of the spectrum, and in this scenario I see a lot of opportunity as the IRB at my university, Adelphi University has reached out to me to help educate them on various aspects and particularities of the autism spectrum, as we're doing more research on campus related to autism as well. So I find that very exciting.

Step two was to build a community presence. So contacting related organizations in the area of autism and advocacy and education in year one to get their involvement and get their support. So, for example, Gersh Academy, they were the first to put something on their website promoting our project and describing it, and now you see here the partners to help us along in our research. Also we will be asking them for collaboration and assistance in year two where we will provide them more regular updates and involvement, more significant involvement in our process.

And I want to give a shout-out to our sponsors, AUCD, the State Public Health Autism Resource Center and the technical assistance center, and we hope to continue our work with you as we move into year two of our project.

As we continue on to year three, now it's a matter of engaging the community, where we've assembled a Community Council of mostly autistic adults, 15, to be exact. And it's this Council that we've been -- that Teal has been talking about. We're learning best practices you might say, or at least very good practices in terms of meaningful communication where we can engage with our community to best enable them to provide our needed input.

So that's through email, could be through phone, could be through text-based meetings. The nature of discussion, what we're talking about, often determines how we will communicate. And also what is exciting is our ensuring and promoting opportunities for connection with research between autistic adults and the research community, and that way we're promoting meaningful and authentic and complete collaboration in research and all phases of research. And we find that very exciting as well.

So year one meeting, we had about 50 people, 50 stakeholders. So that was a good group. We had that out in Milwaukee last summer.

What else did we do? We also continually did iterative action steps to build knowledge. So conducting research through surveys, all to be reviewed and approved by the Community Council, engaging in face-to-face focus groups, and also making use of Facebook to obtain additional knowledge.

Now, we're moving on to step four. And in step four, we're looking to prioritize specific positive healthcare outcomes that are desired by autistic adults. And this is what we're looking for. We want to identify potential evidence-based interventions from the perspective of autistic adults, and involve other stakeholders in identifying those interventions in progressing priority topics.

What we learned during this meeting is that we need to work on developing mutual respect and trust, because without that participation is inhibited and it interferes with valid and reliable involvement in research activities. So some of the things that the Community Council -- I should say the stakeholders identified in particular were a lack of reporting results in a way useful to autistic individuals.

So, in other words, developing a layman's summary of the research is -- can be very helpful to us as an entry to getting an idea what the research is about. And then our making decisions if we want to go deeper into it.

Compensation is another big issue. So often us autistics are just so happy to engage with researchers in any way possible, and usually it's as a subset, because often we feel that's the only way to help people understand the challenges and particularities of the autistic. However, just like with any other type of research or whether it's in developing the research or being a participant as a subject, it's important to provide compensation for our time. We have data and every other situation data is purchased in one way or another. There's a cost to this data. And we often need to respect autistic individuals' time in terms of their own activities in earning money and you might say the opportunity cost of not earning money or taking time off of a job in terms of engaging in research.

So we have developed a compensation factor as part of our engagement guide, and with the help of the Community Council have put together a pretty specific details as to how to think about fairly and appropriately compensating autistic individuals for our participation in research, whether it's in the development of, writing of, proposing of, actually implementing the research, analyzing it, and then at the other end dissemination. Involvement in research decisions, making sure the autistic individuals are appropriately and fairly involved as there's research being done about us. I guess the best thing to do is "nothing about us without us."

And also continuing the trends of focusing on strengths. Turning away from what I call a deficit-based model of how we think about autism to an abilities-based model, and we need to be asking questions. What can the autistic individual do? So, for example, when we think about sensory issues, they're so often thought about as deficits. However, they can also be some very powerful strengths depending upon what the individual is doing. So, for example, I know an autistic individual who is a sound engineer. His hearing sensitivity is an acuity that really helped him in order to do his job well. And this is what we need to be looking at.

With that said, there are significant challenges to being autistic, and they do need to be addressed. We can't ignore them. However, we do need to keep in mind the stakes.

So we continue in step four the results of year one meeting. We found that what bubbled to the top are mental health outcomes. So the greatest concern was, what are we going to do to address the mental health challenges that we face on the autism spectrum?

And I find this very interesting and also I found it to be validating in my discussions with others, other autistic individuals who were not part of a study or involved in our research, and they also agree. And as we think about mental health and as we think about co-morbidity or, for example, depression and anxiety, one interesting thing to think about is what would the -- how would the rate of anxiety and depression compare in non-autistic people to autistic people and non-autistic people faced with the same challenges, social interaction and employment success and many other aspects of life that autistic individuals face?

So I think that's an interesting thought experiment.

So we're looking at year one meeting. We asked people to put their money where their mouth is and asked, where would you spend your dollars? Where would you spend your research dollars? And related to my discussion in the previous slide, social wellbeing, that bubbled to the top, as well as mental health interventions.

So what we want to do is take this information and see what we can do to make interventions more appropriately focused to what the needs -- what us as autistic individuals identified as our needs.

So in our work we've found, in collaboration with our Community Council, is that we need to include autistics in the development, implementation and dissemination and every other aspect of research in between those words. To increase reliability and validity of research. We need to ensure participation through appropriate accommodation. So for people who communicate in different ways other than speaking, like I'm doing now, and as Teal so co-gently pointed out, there's a number of ways audience members can get information through the presentation. It can be through listening. It can be through watching later on in a quiet location. It can be through reading the words that are being typed out in the transcript below. And we find that very encouraging.

Three is presuming competence. So assume that a person can do what we're asking them to do. For example, when talking with a therapist about a student, and if that student is in the room, we need to assume that that student can hear and understand everything that is being said. So often I've heard stories of where deficit-based discussion and negative talking about a student while a student is in the room, and then suddenly a lot of challenging behaviors suddenly occur and nobody can understand why that is happening.

So we need to presume their competence and understanding. And also focusing on what we can do. Nobody builds a career out of remediated weaknesses, and shouldn't expect autistic

people to do the same. Valuing autistic people as an integral part of the team. So, in other words, avoiding tokenism, as we look at our Project Team, we have two autistic individuals and two people who are not diagnosed as on the autism spectrum, and that's an example of complete and authentic collaboration between the autistic community and people who aren't on the spectrum.

Presenting research results in several modalities. So with spoken word, the written word, graphics, to accommodate different communication styles. We talked about compensation. Many of us have a lot of experience, certainly have a lot of experience being autistic, but we have experience in other areas, maybe academic, maybe somewhere else, and autistic people should be compensated just as anybody else would be compensated for our contributions.

And then finally, consulting autistic people regarding priorities for research and systems change, as who knows best about what autistic people need but autistic individuals.

So in looking at these seven areas of promoting authentic collaboration in research, these look like things that we would do for anybody, whether they are autistic or not.

Perhaps we need to be a little bit more focused and a little bit more intense in our efforts in making sure that autistic individuals are authentically included in our research efforts, and by extension every aspect of life.

So as we look at examples of how we can support autistic engagement, I mentioned our four members of the Project Team, two of us who are diagnosed as autistic and two of us who don't have a diagnosis, are not on the autism spectrum, and in doing so we make sure that all communication to the community is autistically vetted, is probably the best way to put it.

And an example of that, as Teal mentioned a little earlier, de-manifesto-izing Teal's communication.

So moving on to part two, the appropriate accommodation example. We use preferred communication styles of an autistic adults individual and do what we can to reduce verbiage, back to the idea of de-manifesto-izing communication, and we really like to work in terms of their material on teaching and then assessing for a person's competency in the protection of human subjects. As we get to compensation, which is somewhere off the slide, one example is that Community Council members determined that we should be paying Community Council members \$50 an hour for their expertise and their time and their efforts.

So, getting on to the presumption of competence and strength, another important aspect, we should assume that people who don't speak understand all verbal language. And if for some reason, for example, if there's an issue in central auditory processing disorder and hearing doesn't work, then it is on us to make sure that we communicate with the person -- with that person in the way that they best communicate.

Modifying our language. Autism spectrum disorders, what if we referred to this condition as autism spectrum differences? We can even keep the same initials in the process. And

likewise with sensory dysfunction, maybe it's better to describe as sensory differences. And likewise with communication, you know, there are times when autistic communication is much more helpful in a situation than typical communication, say, for example, providing directions to lost patrons in a train station. You want these issues to be very direct and factual and accurate.

And that's characteristic of our communication.

We also need to teach others who communicate with autistic individuals to assume they understand what we're talking about and to avoid engaging in deficit-based language that is detrimental to one's mental health.

So those of you who are listening, if all you heard was discussion about the things you're not good at and what you needed improvement on and little to no discussion as to what you can do, that's not going to make you feel very good, and the same for autistic individuals.

So, as we move along, as we look to the future, what are we looking at as we continue our work? We plan on continuing to work with the autistic community to focus on and hone in on priority areas for future research. We're looking forward to our year two meeting in Washington, D.C. on Saturday, November 10th, 2018, where we're going to bring researcher, autistic stakeholders and other to look at an action plan to address priorities by the community and stakeholders and then we look forward to completing our engagement guide to be used by stakeholders when planning and implementing future research.

So as we continue, as we continue on to our discussion session, some things to think about. Whether you engage in some of these practices, most of these practices, how many of these practices do you engage in and what is successful and what challenges do you encounter? Also what can be done to modify the work you do or your organization does or research if, if you're involved in research, to be inclusive?

And then what systems change needs to occur in order to make authentic and complete inclusion of autistic individuals in research, the rule rather than the exception?

So I take it now we are in the Q&A portion of our time together.

>> Wonderful. Well, thank you so much Teal and Stephen. That was very eye opening. I feel like I learned a lot. I hope everyone else learned a lot as well.

So, we did have some questions that had been submitted beforehand. So we wanted to make sure that we give our speakers a chance to answer those questions, and in the meantime I know we've got a few questions as you all were speaking, but please feel free to type in your additional questions in the chat box on the lower right-hand corner.

So, I think the first question we had received was: How do we get organizations to include people on the spectrum in their decision making and how do we get them to pay these wonderful individuals for their valuable time?

>> Teal Benevides: Stephen, did you want to answer that or do you want me to start and you finish?

>> Stephen Shore: Why don't you start and I'll jump right in.

>> Teal Benevides: Sounds good. So I think... thank you for that question. Organizations can start to think about meaningful inclusion by addressing this compensation issue. So often autistic individuals are asked to donate their time by coming to speak at classes or seminars, and sometimes, for example, in our -- in a teaching environment, adjuncts are paid, and so should autistic speakers who are talking about their life experiences.

So when thinking about organizations change, we need to be thinking of that experience, that life experience as expertise, and so you're paying an expert. Compensation is a little bit tricky, though. Some individuals may be impacted financially or through tax reasons based off of the amount of compensation that might be given to them, so we always encourage organizations to often compensation, what the Community Council identified, as Stephen mentioned, was \$50 an hour for their time. But if the monetary compensation will impact disability insurance or income that they offer alternative forms of compensation. Those could be dependent upon the organization, gift cards or if it's a health environment, visits to a physician or something legal or ethical in that organization structure. So we encourage organizations to find out what that might be. But compensation would be important step to meaningful inclusion, to not take people's time for granted.

And also think about the time that it takes somebody to travel and prepare for a speaking engagement or a talk, because that is also something that we learned about as well in talking with our community.

>> Stephen Shore: And another way to promote the idea of compensation -- and this is something that a colleague does. She's chair of occupational therapy at NYU, and when people go to her looking for autistic people, either for engaging in research or as subjects, her first question is: What have you budgeted for compensation?

So bringing it up front and center that autistic people need to be compensated, just as anybody else might. There are some research efforts that are compensated very little. And sometimes it's purely volunteer. And in that case we need to be clear about that. So, for example, whatever other people are being compensated for their time and efforts in research, so should autistic individuals.

>> Thanks for those responses.

So, I think that we had -- so I know you touched on this a little bit, but Brian had asked a question while you were speaking. So as an autistic, how does one participate in this research?

>> Stephen Shore: Well, you can contact one of us. That's one way to do it. Also, searching online to see what research activities are occurring. Another idea is -- however it's kind of

expensive, is to go to a research conference, NSA or other conferences dedicated to research. Teal, do you have other suggestions?

>> Teal Benevides: So one recommendation I would have is to learn about adult research activities that are going on. There's a new journal called Autism in Adulthood published by I think Mary Ann Liebert Press. It was just released. You can look for Autism in Adulthood Journal, and it will ensure that summaries are available to stakeholders who are non-scientific readers, and through that journal I'm sure you can get a sense of what research is going on. If you wanted to get involved in our asset project, as Stephen mentioned, let us know. This summer we'll be doing surveys once it's approved by the IRB to understand about the priorities that people want for future outcomes and interventions. If you're asking about ours, just contact one of us.

>> Wonderful. And thanks so much, Ben. Ben provided the link and we'll make sure that goes out in the post webinar email as well.

So we have about six minutes left. So I just want to open it up to folks in the audience. So if you just want to -- if you want to ask a question, you can unmute your line by pressing \*6, and please just ask your question and we'll try to answer it.

>> Ben: This is Ben. Can folks hear me?

>> We can hear you, Ben.

>> Ben: For both Teal and Stephen, one question that I had is about -- you know, you guys provided some wonderful strategies for engagement, and I'm thinking about early career professionals who want to be more inclusive with their practices, whether they're clinicians or working in public health, and I'm wondering, do you have any guidance for those individuals on how to start developing relationships with the autistic community in their areas and how to develop a network that they can collaborate with?

If they're not familiar.

>> Stephen Shore: Well, you can start out by contacting one of us to bring you into the network. Also, as Teal mentioned, Autism in Adulthood Journal, you go to their website and you'll see a number of articles written by autistic individuals, talking to them. These would be good starters in terms of connecting to the autistic community.

Other possibilities might be connecting with organizations that promote autistic involvement, authentic autistic involvement in research, any one of the organizations that we have on our PowerPoint slide, they would be a good stepping stone in which to connect with autistic individuals as well.

>> Teal Benevides: I also think that if people are interested in research, as Stephen mentioned, there are many autistic-led organizations that are mentioned on our slides, but if people were interested in public health or other disability organizations such as AUCD, there are many LEND training programs that exist that also have community partnerships. So reaching out to those organizations or university centers might be a good way. Many

attendees I know are part of that network already, but for early career individuals, often those networks are established in some sense. I do think we need to do a better job of connected with autistic-led organizations, as Stephen pointed out, our slides have many of those listed.

Autism Society of America sometimes has regional groups. Those are dependent upon that region as to whether they're autistic-led or more parent driven, but they do have an autistic panel that they involve in decision making too. So that might be another resource.

>> Great. Thanks so much for weighing in on that.

So we do have two minutes left. Are there any other questions from the audience, or anything else maybe that Teal or Stephen want to weigh in on?

>> Stephen Shore: Well, one thing I'll say, entering a new era, where we're beginning to see autistic involvement, be in research or employment or education or other aspects of life, people are beginning to recognize the contributions that we can make to society and value autistic people for who we are, and, you know, we ask you to join our efforts in making this involvement the rule rather than the exception.

>> Teal Benevides: Agreed, and I would say the final concluding thing is listen. Listen what they are sharing with you. It may not be what you thought you expected to hear, but we need to do a good job listening to the community. So I appreciate everyone attending today.

>> Stephen Shore: Thank you very much for listening and all the work that you're doing to make inclusion happen.

>> Great. Thanks so much. So it is 2:00. So we are at the close of our Coffee Talk.

I just want to thank our presenters and our partners at AUCD for helping make the captioning accessible for today. We really hope that you all found this to be value-added for your work, and that you'll share this with your colleagues. As mentioned, we'll follow up with all of the resources, the slides, the recording, which will include the captioning. And other resources that others mentioned today. So at this time, if you could please fill out the short evaluation survey just to let us know what you thought about the Coffee Talk and let us know if there's any other information that you would like to learn about this topic.

We do have Stephen and Teal's emails here, and that's actually a mistake, Teal works at Augusta University, sorry about that. And so feel free to reach out to them, as they mentioned. But with that we'll let you all go and enjoy the rest of your day!

Thank you!

Thank you so much, Stephen and Teal!

>> Have a great day!