MADDIE HALEY:

There will also be a short evaluation survey at the close of the webinar. We invite you to provide feedback on this webinar and also to provide suggestion for future webinars. In the interest of time, let's get started. We want to first acknowledge the health resources and services Administration as a funding source for the AIR-P. Now it is my honour to introduce our speakers for today. Doctor Stephen Shore and Teal Benevides.

Please join me in welcoming Doctor Shor and Benevides.

STEPHEN SHORE:

Thank you very much for the introduction, and we look forward to talking to you about promoting authentic engagement of autistic individuals and in doing so setting priorities to improve health outcomes. First we want to acknowledge,... Who funded our project and meaningfully engaging artistic stakeholders and identifying these priorities.

You can see the conflict of interest, that we have no conflict of interest. With the views presented here is solely the responsibility of Teal and I. So moving on. What we will focus on is being able to answer the questions, what preferences for engagement? What are the preferences for engagement for autistic individuals and what methods are successful in promoting the greatest amount of engagement possible?

And specifically as researchers. And then what are the health priorities that were identified by autistic adults. So on the next slide, the questions, why bother to engage autistic people in the first place in research and then how do you go about doing so?

If we took -- Take a look at the why on the next slide, we need to ensure that autistic people are involved in research before studying them. -- If we are studying them. I'm purposely using what is known as condition first language or identity first language because most autistic adults identify with being autistic, we don't see it as being bad or shameful. It just kind of is. Maybe like nationality or religious affiliation. I've never heard people with Americanism for example or with Christianity. It's just some things that we are, we are autistic. It affects major aspects and sometimes every aspect of our lives.

We so often have multiple and chronic and potentially preventable health care needs. Co-occurring conditions, sometimes refer to as core morbid. Document comorbid, kind of -- comorbid... So a lot of research is done but not much is done. In terms of involving autistic people. And setting these priorities.

So that was -- that is what this research is all about. So what is interesting to note is that there are continuing to be increases in artistic involvement in research. We are seeing that in the (unknown name) for example. More autistic people are being nominated as the government strides to promote interagency collaboration. Between organizations.

As we flip over to the next page, the backbone of authentic artistic engagement is authentic participation. So we engage in research design, that is participatory, the first thing we did is that we establish a project team of autistic, or diagnose autistic individuals and non-autistic individuals. And we like to look at it that way as opposed to artistic and neuro- typical.

Because someone way -- May not be on the spectrum but they may not necessarily our autistic either. When Teal and I first met, I did a presentation on strengths, on artistic strengths, we thought that we could do research and it could be so much better unauthentic to directly engage autistic individuals. So in doing so, we developed a paid community Council of autistic adults, 18 to be specific. Most on the autism spectrum. We also had the collaboration of various other organizations or stakeholders in promoting health for autistic individuals. Other stakeholders such as, asperger autism network, Autism Speaks, etc. And in that way we have the greatest diversity of people with differences. People on the spectrum.

So what are some of the things that we did? What could we do to enhance engagement? And that was the engagement on the two-year (unknown name) award that we received. One was to engage in scientific research and the other part was the engagement piece. And in doing so we developed and published an engagement guide ICC here! As you see here. And when I think about engagement compensation, for literacies come to mind, -- C's come to mind, (Reads).

Let's go a little more deeply into that as we go into the next slide. One phrase that comes to mind is I think about authentic involvement and enhancing that. Making that occur is what is good for the goose is good for the gander. So what we are doing for people and with people and engaging people who are not on the autism spectrum, we should be doing the same thing with autistic individuals. It also we can put that around, whereas we devise ways with input, with meaningful input from the community Council made up of mostly autistic individuals, the strategies also end up being helpful for non-autistic people.

So one thing we do is we assume competence, we assume that people who don't speak, understand what is being discussed. And we see examples of that, say during team meetings or teacher and parent meetings or clinician and parent meetings. They will be talking about the autistic individual who has just been evaluated or is being discussed as if they weren't in the room. A common leasing! Saying -- saying deficit based discussion. Like this person can't do this, is unable to. Focused on the abilities and strengths. And to their surprise, the person who allegedly doesn't understand anything is suddenly engaging in some -- and challenging behaviours. They may not be able to speak in the same way that I am talking to you. About how they feel and to provide suggestions, they will communicate in a way that they know how and sometimes that is a challenging behaviour because that is the only thing that is left to communicate.

We also need to adjust our language. Talking more about differences as I think about autism spectrum disorder, ASD, the initials are very convenient. And we can instead refer to it as autism spectrum differences. And the differences can provide gifts to some individuals who are able to process information and do tasks that their people that aren't able to do or find difficult to do. And at the same

time, these differences can cause some very real disabilities. Some very real challenges that we must be cognizant of that. That there are significant challenges of being autistic and that is what part of this research is about is how can we provide support.

Being with the autistic person, not doing things too. Going beyond the awareness stage, which is sort of a foundation. Now we are aware of the person that is autistic, be it a medical situation, be it in school or at home or in the community or in employment. And to go into the next step towards acceptance. That's where we begin to work with the characteristics, we understand. That's where we have understanding of the strengths and the abilities that autistic can bring to the society and work with them.

Turning away from deficit-based language, disorder and disability, towards ability based language. And again the assumption that autistic people understand what is being said. Even if they are not able to express that understanding in no way that we expect or we are used to. So as we move on, to the next page.

Here is communication. Enhancing engagement through communication. And here's an email, a format for an email developed by (unknown name), that I think is helpful for everybody. And I know many autistic people or non-autistic people who have reported to me when using this format, now things become very clear because often when autistic people do not respond it is because we are overwhelmed with details. And before we implemented this protocol, we would email and more standard flower language, too much language manner. He got very little response. -- We had a very low response rate.

And when (unknown name) enlightened us with this protocol and using it as we see here, we are minimizing words. Every word is important and being clear about what this email is about and also clear about what needs to be done. And sometimes no action is needed but it is an update and we should be clear about that or there are certain specific steps that need to be done when we did this. Our response rate went up to 90-100%...

Another C is compensation. Equal pay for equal work. So for an autistic person is engaged in the research in some manner, they would be compensated so should the autistic person. And also realizing the importance of compensation on a very pragmatic level. There is a combined under an unemployment rate with autistic people that is 88%. At least according to the National autistic Society in the UK. What does that mean that there is only 12% of us on the spectrum in this regrettably rarefied position to be employed in our capacity. There's a vast under and unemployment which needs to be much reduced... We take for granted that if we need to go to a meeting in the city, we take the train which cost $12, and we make our way they are, no big deal.

But that $12 may be very significant for an artistic individual who again may be part of the majority of us who are under and unemployed. So we set a rate of $50 an hour for community member, councilmember time in their advisory roles. In some recent applications, we have been able to bring the compensation 200 hours an hour. -- $100 an hour.

One thing that we need to be aware of is the potential barrier where payment may interfere with disability benefits. So that's an area of future work. What can we do to make sure that the autistic person isn't penalized for maybe having $2000 in the bank account or exceeding some limit that a social support agency has created. So that is something that needs to be addressed, something we need to look at. People cannot afford to lose support benefits because they engage in research.

So considerations. So how do we measure compensation? Not compensation, how do we measure engagement? How do we know what level someone is engaging in? That's a difficult thing to do. We have come up with some areas may begin to look at, if you see positive action in these areas, then we are moving towards positive engagement. And promoting full and authentic engagement.

One area is trust. Do people feel free and safe to bring differing ideas, contrasting ideas without being shot down or called names? So in other words, can concerns be raised and also are they meaningfully heard and is something done to address those concerns?

So here's an example, initially we plan to capture priorities and discussions through Facebook. At that time, there was a lot of questions about confidentiality of communication that occurred on Facebook. And many community Council members were concerned, they raised these concerns and to be addressed these concerns that led to changes in our methods.

So that is an example of number one, trust, not getting shut down, hearing words such as, know everything is fine, don't worry about it. If someone is worried about it then that concern should be met and meaningfully heard.

So respect, equal value of contributions that made. Equality of voices and in making decisions. Not getting caught up on how many letters or kind of alphabet soup at the end of a person's name. And that experience, personal experience of being autistic is valued. And these contributions, we see meaningfully included throughout our work and also recognize to making sure that we recognize the contribution. Of everybody. Autistic or otherwise that's why am making a big deal about mentioning (unknown name)'s name because she made some significant contributions and we want to make sure it gets awareness about that. On that.

And relatedly making sure that community council members are often given the opportunity to author and co-author products and being supported in doing so. So perhaps, the standard academic process of collaborating when engaging in research and writing up the results, maybe we need to make some modifications to that. And indeed, we did and we continued to do so that the opportunity continues to be provided. So multiple options for remaining engaged, some of us are talkies and talk to the way -- like the way I talk to you. Some committee through devices, some people need additional time to process and communicate. We need to make sure that support is provided in all of these areas.

So moving on to slide 15. Here are some recommendations that we have for enhancing engagement, making sure that we have full and meaningful inclusion of autistics in all aspects of research from the initial discussions all the way to the -- dissemination. Ensure the proper accommodations are made for participation. And whether that is the accommodation of time or style or the process that participation

takes place. We need to be continually consulting the community Council of autistic people, how can we make sure this happens?

Assuming that as I mentioned before, that the autistic person understands what is being said and we already know that receptive language tends to be better than expressive. That means we need to focus on the abilities of that individual to express what needs to be expressed, however that is done.

Valuing autistics is an integral part of the team. So avoiding tokenism, going way beyond tossing in an autistic person onto an advisory board for example and protecting their being listened to. But having that autistic person actively engage in every aspect of research.

Presenting research results in different modalities to accommodate different communication styles. Some of us are word-based, others are visually based. Part of that also includes the development of presenting information in layman's terms. So in other words, people who don't necessarily have fancy degrees and have done a lot of research. So we can process information presented in that way. And what about everybody else? Who have not spent years engaging in research and meaning that type of language. We need to make sure that everybody who is reading and engaging in this material can do so, we talked about compensation, for time and experience and that goes into valuing that time and experience.

Then finally, at -- as we always do, consulting autistics regarding all aspects of research and systems change.

So as I close my portion of the presentation, we also have some statistics on this slide describing how respondents wish to be engaged in research. In being a participant, that's way up there and as you can see here, it's that real desire for meaningful engagement in all aspects of research. And then I will close with some related publications that focus on listening to the artistic voice. -- Autistic voice... We need to be involving autistic people in all aspects of doing so.

At this point, I will turn you over to my partner of crime -- in crime, Teal Benevides to talk about priorities and health and research.

TEAL BENEVIDES:
Thank you very much. It's been such a pleasure to hear the various ways we can engage autistic people and projects. It really was such a collaborative way and I do want to just J -- give a shout out to our community council members who are an integral part of our team and who are continually being involved today and continuing this work.

So we are presenting on their behalf and on the behalf of those who participated in this project. Some of you may have joined us in some of our approaches. I will briefly share about how we engaged the autism community and setting this priorities.

We used a variety of approaches so we can reach the maximum number of people possible. Across both the United States and beyond. These iterative steps were developed as Stephen mentioned with

the input and continual thoughtful revision by our community Council. So each decision point was made in consultation with them.

We started off our priority setting approaches with large group stakeholder meetings. We brought together autistic adults, caregivers, researchers, and other healthcare providers, the day before a large autism meeting. And in this large stakeholder meeting, we had people break out into different topic areas and we discussed what research had already occurred within autistic adult areas of focus. And we ask people to identify those areas that they felt were missing from the current research narrative.

We used a variety of approaches that involve spoken language as well as non-spoken language approaches, using stickiness to allow people to vote on different areas. And somewhat modified (indiscernible) to allow people to share areas that they felt strongly about for future research topics and outcomes.

Then we moved into working with our community Council to create a way for the autism community to be involved in setting those priorities. The broader community, not just those who attended the meeting in year one. And as Stephen mentioned, our original approach involved setting up a Facebook group and a safe private spaces in Facebook for people to share their thoughts.

From input from our committee counsel, they were concerned with the Cambridge (indiscernible) at the same time of using this approach. We immediately heard those concerns and said, what should we do, what would we want to do? And our community Council said, a survey is nice but not everyone can participate in one. So we also need to engage with people face-to-face to allow folks with augmentative and assistive communication devices or people who may not be on the internet to share their priorities. And so we engaged in using an online survey as well as face-to-face focus groups in rural and suburban and urban locations in the state of New York.

We held small stakeholder meetings with folks to identify both what they felt health research so focus on -- should focus on... The outcomes that were important to people and the headlines. What those should be saying?

The service and the focus groups were submitted and then we held a large year to meeting, supported by others in various organizations and they want to give us out out -- Shout out to AUCD.

And so, this meeting, we again assured what we had learned through our priority setting process. We shared quotes and direct information about the priorities and outcomes that people shared. And people who attended this meeting, again engaged in a modified (indiscernible) approach, using sticky notes and both interactive spoken and non-smoking approaches to allow people to share what should be the top priorities.

Until those priorities revolved around three areas. The first overwhelmingly was mental health intervention and outcomes. The second was how people access healthcare and those accommodations needed to receive healthcare. In the third area was on gender and sexual health and well-being resources and supports as people are aging into adulthood.

Our first priority area on mental health was important that we have published on this already, published last year, listening to the autistic voice (Reads). Because this is a AARP physical webinar, I spent a lot of time on our mental health priorities, but I encourage you to read, it provides details in our methods. And I do want to point out that many people met their -- link their mental and physical health needs...

Please keep in mind that among our mental health priorities, we had priorities related to addressing trauma, PTSD, well-being, social well-being and how does self manage one's own mental health and not have to see a doctor. What are ways that I can self manage on my own? A lot of these have importance for physical health and well-being. And I encourage you to take a look.

Also since we don't have a lot of time to focus on these mental health priorities, I will briefly highlight because it will come up later that among our outcomes of people felt were important for our mental health, quality life and sleep were among those top five mental health outcomes that people felt were important to measure. And we will see that those are also important when we look at physical health and well-being.

So what about physical health? We asked a number of questions in different ways, and both our surveys and focus group responders. Use open ended and forced choice types of responses to get at what outcomes matter to people and what does being healthy mean? He also inquired what health professionals should be involved in future research as well as if people could wave a magic wand, what they want to change above -- About healthcare?

This last question about a breaking news headline, it tended to focus on that were actually health-related. So when we think about physical health outcomes, people are asked and to -- to click and drag the outcomes that matter or not. And among those physical health outcomes, the people clicked and dragged into outcomes that matter, sensory integration and processing as well as quality of life were endorsed by more than 70% of people who took our survey.

These two physical health outcomes are interesting, number one because sensory integration and processing is something that is being addressed in childhood but less frequently is discussed when we take a look at the health literature for adults. But people did bring up the important of sensory processing practically in the environment of care that will identify as related to access to health care and services.

Quality of life and sleep are both consistent outcomes for physical and mental health. And people also identify as important to them those interpersonal relationships and being able to socialize with other loved ones as well as being able to engage in daily activities such as ADLs and other things in their community.

Why people's physical health was compromised, imagine not being able to participate in social activities or events or in those daily activities that they find reassuring, routine based and meaningful. We provided people not only a forced choice option but also gave an open ended option to share what other things matter to people.

Though we received a number first class, I want to highlight those that are here on the screen. First, pain, chronic pain, migraine specific pain were mentioned frequently by respondents. These were often mentioned in the same words or sentence as fatigue. So pain and fatigue were common outcomes that people wanted to address in future research.

Also people identify gut and bowel health were important to them. They mentioned seeing people for their gut and bowel health and not finding relief through diet and other sources of intervention. And they wonder what else could be done to address this. This is certainly happened that can affect physical health but also was brought up as being related to someone's mental health in many of the comments that people submitted.

Also dyspraxia, mobility, joint and muscle issues, people mention not being able to move the way they wanted to. He related to things such as falls, or worry about falls or other outcomes. Although dyspraxia and mobility in childhood is frequent the address, again, we don't see this as an outcome that is addressed among adults and is something that people do bring up.

People also brought up the idea of stress, cortisol and other stress-related hormones. Although these are strongly linked to mental health outcomes, we also want to point out that people brought this up in the same as other chronic conditions. They wonder how stress hormones can be related to things like diabetes and cancer and other autoimmune... How can it impact their physical health and well-being in ways to improve their health and reducing these hormones...

To communicate what being healthy meant, included some interesting quotes. These are representative of a variety of different close the people submitted to us. People thought that being healthy meant the absence of chronic illness, it also meant being able to access resources to help them manage their own health and well-being. People want to be able to do things with little to no assistance. Again, being able to rely on one's own ability to manage their own health and well-being. Being comfortable in one's own abilities, having self-esteem, being in tune and understanding one's own body. It is an important outcome and being healthy.

It's all! It also means not being sick or in pain. Being able to sleep, being able to eat with energizes you and being able to contribute to the ability to regulate and self regulate one's own mind and body. People also mentioned that being healthy meant having lower stress levels and being able to manage one's own stress.

All of these things contributed to our future discussions about specific ways that people manage their health. So following these questions about what mean -- what being healthy meant, what are those things to help them do so? As well as ideas to -- for future research to help address these needs.

One of the things that we asked was whether or not there were certain providers that should be involved in future research. And although number of different providers were mentioned as being important to future research in autism, we learned that primary Kia -- care providers, cancer and psychologist and dental professionals were critical people who deeded to be involved in the future

research process.

So let's go over some of the access to care priority topics. I will share first the priority topic areas that were set in our year 2meeting and then go back and identify specific quotes...

The first topic was trying to understand how system navigators, or other people as well as technology portals, apps or other technology could help autistic individuals navigate and achieve better health and well-being. This is an interesting one, prettily says -- particularly says... Reimbursed at regular rates. So people wanted to know how can somebody help me navigate the systems, these complex systems of care, all are perceived as overwhelming and particularly for those who need to see a variety of providers that it was too much to handle. In some cases.

Other mentions barriers in the environment where they sought out care, and actually getting to those providers. People asked how nonemergency medical transit might be useful for helping people achieve access particularly in those rural settings where there are no local providers that understood autism. This is particularly important because many people mentioned having a local provider may be up primary care provider was -- is within reach but they didn't understand autism... They found the communication with the provider was challenging. And this is not surprising and has been addressed heavily by (unknown name) and colleagues.

This continues to be a top priority, how can we improve communication between patient and provider? And last but not least, many people felt that the environments of care were not friendly leases to be. The sensory environment was overwhelming, the other people in the environment, the repeater request for the same information, you have to fill out the same types of forms every time. These types of environmental challenges were thought to be a barrier for many people. We proposed how can we implement sensory friendly optimal healing environments on how people access and receive care?

So when people told us what they would change about healthcare, attack about communication. Seeing many of the heavenly easier to tell your Doctor (Reads)... I would like a written summary at some point, word for word. Provider understanding and presumption of competence came up not only in our research engagement but also in engagement from providers in the healthcare setting. People said, I would wave a magic one -- Want to stop doctors from treating (Reads).

So helping train providers in autism and how to communicate effectively would be an important next step to improve access to care. When people talked about the environment of care, we wanted to share what one person said about the waiting room. One person said, (Reads).

So we have technology and solutions to improve the waiting experience or other aspects of the care environment but we may not have translated them to healthcare settings. I believe that COVID has fundamentally changed the types of care that people receive and I think the new technologies would be useful to investigate access...

One individual said, I have to do everything myself because (Reads). So', we heard aspects of transportation, communication, provider presumption of competence as well as cost of financial

barriers. All of these things that people shared with us is important to consider when we think about access to care. Our last area of priority was on gender and sexual health. Specifically there were three topic areas that people wanted to focus on in future research and practices. First was how can we improve autism diagnosis in females and not by ordinary individuals on the spectrum? We had a number of individuals about 21% of our survey sample identified as non-binary. An individual's reported that the diagnostic process was complicated, mainly because the signs and symptoms and standard assessments tend to focus on those identified primarily in males. Are those assessments have been validated primarily in meal samples.

Understanding how autism symptoms... Second individuals wanted to know and explicitly ask how more hormonal changes across the lives -- Hormonal changes affect their lifespan. How does it affect their skills, memory, their ability to be a parent or have children, how did this sensory system change and how can it affect their work or their daily lives. Last but not least, people talked about experiencing trauma and sexual assault quite frequently. This was our top priority for mental health and well-being. However it also shows that gender sexual health, people noted that there were very few resources for supporting autistic individuals and learning about and understand their own bodies and sexual health needs. When people are denied access to information and resources, that guide them, and something that is a normal adult function, problems are likely to occur. People mention not having access to the same sexual health development information as a child or adolescent and they did not understand when sexual assault happened to them. They were expressing fear and also lack of understanding of what needed to happen in those situations.

This is an urgent party because sexual assault is much more common among autistic individuals and individuals with intellectual disability. So we want to make sure that people understand that this is happening and we need to address it.

I'm running short on time so I would like to allow people access to the size at a later time and and with our limitations and discussion questions. So we have enough time for questions. We did have a convenient... Who attended our year one and two meeting. These priorities should be confirmed by others. We also relied on people who didn't say that they self identify as autistic. Not only do we have people with a diagnosis and confirm diagnosis, but we did allow people to indicate if they had self identified without formal diagnosis. We think that future priority setting work need to occur with individuals would've had limited ability to consent or participate in these activities. So people under guardianship, were not participating in these activities.

We did have some racial and ethnic diversity in our sample, but not sufficient. More work needs to be done and different communities. And when they mention when we had 21% of our survey sample entity for as non-binary, more rookies to be done here. Moreover because one of the prairies is gender and sexual health. So I would like to invite Stephen to share his screen at his face again so that we can discuss with you any questions, concerns or thoughts you have about this work. Thank you so much for being here today.

MADDIE HALEY:
Thank you so much for your presentation and for your work in this area. As they mentioned, we do

have some time for questions and answers from the audience. Doesn't look like anyone has typed anything in the chat yet but please feel free to go ahead and ask any questions and they will be available to answer.

TEAL BENEVIDES:
If there aren't any questions, I invite people to contact Stephen and myself through email. And we look forward to...

STEPHEN SHORE:
Often questions later come -- Later on as people process.

MADDIE HALEY:
Was the registration information, on the side as well?

TEAL BENEVIDES:
Yes.

MADDIE HALEY:
Perfect. So feel free to contact us at this email address and then there is also a feedback survey can provide the link in the chat as well.

So this is the next month's August webinar, it's going to be with Doctor Jennifer (unknown name) who work closely in the gender, sexuality, and representative -- reproductive (indiscernible). I will put in the chat the link to register for that as well.

TEAL BENEVIDES:
Thank you so much for having us.

MADDIE HALEY:
Thank you everyone. Have a good rest of your day.

Live captioning by Ai-Media