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[CAPTIONER ON STANDBY]

AUCD-All of Us Includes Disability (Adobe)

Association of University Centers on Disabilities (AUCD)

ANNA: Hello and welcome to "all of us, includes disabilities". My name is Anna and I am the resource dissemination manager here at AUCD. I would like to thank everyone for joining us today. Before we begin, I would like to address a few logistical details.

Because of the number of participants, your telephone lines will be muted throughout the call; however, we will unmute your phones, one at a time at the end.

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Karl Cooper is the director of public health programs at the American association on health and disability.   Meg Traci is a research associate professor at the university of Montana, rural institute.   And Tony Cahill is the evaluation director at the center for development and disability at the university of New Mexico School of Medicine.   I will now turn the mic over to Karl Cooper, who will start us off!

>>KARL: Thank you very much.   And good afternoon for those of you on the East Coast.   Good morning to the rest of you.   And I want to thank you for joining us today.   To learn a little bit more about the research program, and what it means for people with disabilities, and specifically, how the UCEDD network can get involved with this initiative.

For those of you who are unfamiliar with my organization, the American association on health and disability -- just wanted to do a quick synopsis of what it is that we do.   We essentially have five main objectives that we work on to promote our mission, which is to promote health and wellness, for people with

disabilities.   And we work across the life span and across disability.   We work to reduce health disparities.   We advocate for community inclusion.   We work to promote full accessibility.   We try to integrate disability into the public healthy agenda essentially finding the spots where there are public health initiatives and people with disabilities might not be getting included and making sure that you are.   And also work to advance knowledge translation, and disability research. In terms of what the all of us program is specifically.   The all of us research program is -- an initiative that was launched by NIH, last May, so it's -- not quite a year yet, that it has been fully operational.

And essentially, what it's trying to do is enroll a million or more people over a long study of the current plan is to run it for ten years.   And they're working to try and improve precision medicine.   And work in areas, where the -- to help individuals understand what it is about their uniqueness and how that affects their health and why do some people respond to certain medications in a way and why do others not?   And trying to further research areas to really see if they can find a connection that may be missed in smaller more clinical studies that are done many times, on a specific drug or conditions.   So that's what the goal of this project is, is to try and really see how....   the -- how the individual's uniqueness really plays into that.   So because of that, we're trying to make sure that the -- the -- program, itself, has an enrollment that really represents the diversity of America; and really includes all different types of individuals, both from a geographic standpoint, from an ethnic and racial standpoint; and from a health status standpoint, which, obviously, includes disability and many of the interesting conditions that exist within the disability community.   And for -- the UCEDD network, specifically, those of you who do a lot of research, there's a lot of great

research that's being done in the UCEDD network on specific conditions.

And we really think this sort of initiative can really help leap those efforts forward, especially if those conditions are represented in the sample size of the all of us research project. And I'll get into more detail on that later. In the presentation. But that's really where we think that your -- your group and your network can play a role in trying to make sure that that uniqueness is captured within -- the program. So what exactly is the NIH -- all of us research program from the NIH's perspective? NIH director Francis Collins has said among the most ambitious efforts ever taken that our nation has ever undertaken in terms of medical research. And really, it's -- when you think about it, it's a -- it's a huge undertaking, to try and get this many people enrolled and follow them over a long period of time to really sort of track how and see exactly what trends can be noticed and picked up, in areas that might get missed otherwise. And to do that, there -- they do need to make sure that the sample is representative and that the group is fully -- is fully committed to doing what needs to be done to make sure that we can reach the largest number of people and have the most diverse sample that we can get.

(Pause).

>>KARL: So for those of you who don't understand exactly what precision medicine is, it is an emerging practice. Disease treatment and prevention that takes into account lifestyle, biology and environment. And really, this is sort of a transformational approach for NIH. Those of us that do a lot of -- in disability and health, and research and understanding it -- we understand that really, you know your help as a person with a disability, goes beyond just the biology. It goes to the lifestyle that you are -- that you have, and also, the

environment that you face.   And as a result, we're really excited about the fact

that NIH is really sort of taking a look at these other areas that really do impact

health.   That goes beyond just sort of the medical model approach to medicine.

It really is looking at some of the social issues that do affect health and how

that -- what role that plays; and that's one of the reasons why we're especially

excited about this project, is because it is taking a look at many of those other

different... types of things.

Obviously, biology still plays a large role and an important role; but many

times some of those other factors, really can play a role in our health.   And

understanding that is a -- an important part of that.

In terms of the specifics of precision medicine, and, you know, examples

of precision medicine: The thing I like to use, as the most obvious example, is

those of us that use prescription glasses or contact lenses -- obviously, those are

created specifically for you.   You couldn't give them to your friend who needs

glasses, they would not work or not nearly as effective as if that person had a

prescription that was specific to them; and that is an example of precision

medicine on a very basic level.   Same with insulin pumps and blood transfusions

and hearing aids -- all of those are calibrated specifically for the individual, so that

the individual really is receiving treatment that is personalized for them.

And that's really what we're trying to do with the all of us research

program, is to take some of these areas, where it's very basic and we understand

what needs to go into personalized medicine and take that to other areas of

medicine.   So for instance, in prescription drug treatment, and some other

areas -- where lots of times, it's sort of one-size-fits-all approach, where if you

have high blood pressure, the doctor prescribes you the basic statin drug.   And

you try that and if that doesn't work, they try other things and it's sort of a trial and error method until you find something that really worked.   Hopefully, with the all of us research project, areas like that and many other areas, the -- the hope is that they will really be able to understand more about the needs of individuals and what goes into that so that you won't have to do that wait and see approach. You'll be able to do -- you know, something that's much more personalized for that individual.

(Pause).

>>KARL: What happens when we have imprecise medicine?   Well, there's a lot of things that really end up becoming a problem.   If there is a lack of precision medicine.   Like I said, healthcare is often targeted to the average patient and not the individual; and then you just try a trial-and-error method; and that, obviously, we know especially with people with disabilities -- if they have physical conditions that are affected by this stuff, it can make matters worse.   Or it can just not improve as quickly as it could had there been a more precise approach to it.   Providers, many times, are, you know, sort of at a loss and not knowing exactly where to go with an individual if they struggle with some of the initial treatments and sort of that trial and error method becomes a challenging -- a challenge for providers.   And you know, the idea of trying to create, you know, electronic health records and keep them all in one place, is a great idea.   And that -- but that's still is an area that needs to be improved; and there's always an issue with time.   When you're talking about providers, and they're not having enough time to really do the analysis for each individual patient.

For researchers, the -- idea of doing any biomedical research can be a huge undertaking from a cost standpoint, both time.

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>> I can't get into -- um...

>>KARL: Hello?

>> (Pause).

>>KARL: Hello, yeah, in terms of the researchers, you know, there is -- there can be a huge investment in time and money that is spent into really building what is needed to do research.

And then the -- the data gets siloed; and it's based on -- going from funding opportunity to funding opportunity.   And many times you can't get the sample sizes you really need to be able to understand what it is you're trying to reach.

The -- I'll be talking a little bit later about exactly what those researchers can do with this opportunity.   And it is going to hopefully break down some of those silos and make it easier for researchers to get access to data that can help them further their research.   So what is exactly being asked of participants? Right now, there is an enroll consent and authorize process that each individual goes through.   Right now the program is open to all adults, who are of -- who can provide their own consent.   So for -- the one thing that we are working with the program on, is individuals with intellectual disabilities that do not have their own legal guardianship.

And cannot give their own consent.   Because we feel that that's a population that needs to be included in this project.   Unfortunately, right now, it cannot be included because they're working through protocols to allow for that consent, that process needs to be done, the other area they're also working on is trying to get children enrolled; and that's another thing that hopefully, will be coming this year that they'll be able to have the protocol set for children to get

enrolled.   But right now it is limited to adults who are able to give their own consent.   So people with intellectual disabilities are able to join if they are able to get their own consent.   Once they go through the enrollment and consent process they're, then, asked to complete several surveys.   These are all done online.   You can do them on your computer.   There's an app you can download for the all of us research program that those surveys can be done the app.   And when they roll out new ones they notify you by e-mail so you can go on and complete the new surveys.   If that's all you want to do with this project.   That's perfectly acceptable.   If you want to end right there and do the surveys and not anything else that is a perfectly valid way to be involve would the program.   However, there are other opportunities to get involved and that includes the physical measurements; and you can see all the things they look at in that instance; and also providing biosamples.

So, you know, blood and urine, and those are stored at that program's bio bank after they are identified to make sure things are maintained in a safe way so that information is not -- easily... used in a way that's inappropriate.   And then finally the final thing we're still working on, is they want to try and see if they can add so much with technology nowadays and health and monitoring.   A lot of people are using wearable and digital apps, whether that's, you know, using something on, you know, a Fitbit.   Or it's using it on an Apple watch, or whatever it is to sort of track your activity.

That is something else that they're looking to see if they can add to the program to get an idea of the activity levels of participants.   But once again, those are areas that once they -- once that does become available that was completely voluntary and that's not something you would want to do.   It's not

something you're required to do to be involved in the project.

(Pause).

>>KARL: Currently, they do have the six survey models in -- modules in place.

And this includes some basic information, some stuff on overall health. Lifestyle.   Personal health history.   Family history.   And then your utilization of healthcare and access.   And they're also working where -- we've been working with them on creating survey module that would yield more specifically with disabilities so we can really get data that will allow us to understand what -- what people with disabilities are enrolled in the program.   And different functional levels and how that plays into -- in the issues as well.   So all those things are being worked on and that hopefully, will be another survey that will be added down the road; but right now, if you were to enroll, those would be the six surveys you could complete.   And you would, then, be able to -- as new surveys become available, you'll be notified and you can complete those surveys at that time.   The all of us program does have -- has created a set of value statements that they really think is important for the project to be successful.   And these really sort of....   reflect -- what they're trying to do with this program and the fact they want the program to reflect the rich diversity of America -- and they don't necessarily want it to be representative.   If anything, they want it to overrepresent those who have been left out of biomedical research in the past.   And for that reason they are seeking everyone's uniqueness.   So people that, you know -- there's a lot of stuff that's been written about, you know, how certain groups have been either excluded from research -- biomedical research; or the whole population groups have been abused as it relates to biomedical research in the past -- as a result of

that, lots of times there are biases within those population groups against getting

involved in something like this.

And they're trying to do what they can to sort of bridge those gaps to make

sure that all population groups are represented.

And that they are included. And the way I like to say it is, you know, the

last thing this program wants is another research study that's going to be done on

50-year-old white males. We don't really need something like that. We want to

make sure that this is purely representative of all of the whole country and it

includes all racial groups. It includes all health status. It includes all

genders -- and we -- for that reason we want to make sure that it does, you know,

reach out and do the appropriate thing that needs to be done to reach everyone.

And for that reason we really think this -- these value statements are important

and they do align with the disability... the disability community. And the is

disability community's values. There's a common saying in the disability

community of nothing about us without us. And we really think that it's important

that if we truly believe this statement that nothing about us, without us is the way

we want to really approach things, that we need to make sure that when we are

being called on to get involved in a project, and where they are seeking our input,

that if we believe this statement, we need to make sure we're answering that call

and we are actively getting involved in those programs so that we can really be

reflected in the outcomes that are.... are a result of the program.

So for that reason, we really think it's important. We've recently... done a

call to action to the disability community that we will be sending out and really

distributing in -- in wide circulation. To really press this idea -- in terms

of -- understanding exactly what it is that we need to reach so that individuals

can -- can be involved in the project and can, you know, actively make sure that
their information is included.

        (Pause).

        >>KARL: So it is -- a transformational approach to diversity that they're
doing that includes all people groups.   All health status.   All geographic
regions -- and all data types.   And they're trying to make sure that they are doing
that in a way that is going to reach everyone.   And it's for that reason that -- when
you take a look at geography when I'm talking about our partner groups later you
see that we try to do a very diverse approach in that way.   And we also,
obviously, want to make sure that we're reaching all the different types of health
status and all peoples with disabilities so that we're including everyone that we
can to make sure that all their data is captured in this project.

        It's also a transformational approach to participants and specifically,
the -- the -- not just -- they don't want to view these people as patients or even
research subjects but true partners in this process.   And that means that they
want to involve participants in getting information from them.   In terms of what
data is collected.   What lab analysis is done.   What research is conducted.   And
how the data gets returned to the individuals, because they want to make sure
that there is going to be value going back to the participants, themselves.

        And it's a transformational approach to data access.   So it's data-sharing
is a priority.   To both the researchers and participants so that everyone hopefully,
will be able to access this data.   And it won't just be limited to large research
universities, but smaller schools will be able to get involved; and we'll be able to
have access to this data that data collection will... obviously, going to start small,

but it's going to hopefully build over time.   And they're committed to making sure that privacy and security is done at the highest standards.

So they're trying to really make sure that this does level the playing field so that researchers are able to really get involved with this and be able to do the research they need and essentially allow some of the infrastructure problems and all that kind of stuff that can become a hindrance to research -- get that out of the way so the researchers just can get access to the data, and do the work that they want to do.

So what's the promise for each individual participant?   Well, it's an opportunity to fight disease and improve the health for future generations for people that are -- have a condition, similar to you.   It's a chance for them to learn about their own health, including their personalized risk factors or exposures. The ability and choice to access the... participants' own data including basically the rich health records that exist and really making sure that is put together in a way that the individual will truly be able to get some use out of that.   It's an opportunity to ensure that your specific community is included in studies that lead to new understandings and new treatments.

So that really, this will benefit future generations of people that have a condition similar to yours.   It's also a chance to learn about additional research opportunities that could be of interest.   And also -- there's going to be the chance to meet other individuals like you, should you choose, perhaps even joining them to propose and do some research in these specific areas.   So what's the promise for researchers?

Uh, the opportunity to save time and resources, and accelerate research breakthroughs by leveraging rich -- rich resource of data including bio specimens

and increasingly robust electronic health records; a longitudinal data set that will allow participants as they move, age, develop -- relationships get sick and try treatments; it will provide a diverse cohort of participants including people both healthy and sick from all walks of life and all parts of the country.   Both raw data and data that is already cleaned and curated.   It will include robust computing and analytic tools to support complex data analysis in a secure data environment. Also provides a group of engaged participants who may be eager to participate in ancillary studies, should the opportunity arise.

And it also, is the ability to easily share workspace and analysis with researchers and partners -- with research partners and reviewers and the chance to learn from the pilots -- program's pilot and experiments, to leverage innovations for other studies and cohorts.

I include here the link for the researcher hub.   And this is a screen shot from that.   If you're interested in learning more about what, exactly, will be available to researchers as part of this hub, this is where -- this is the Web site that you can go to, to specifically get those answers to questions.   You can sign up to get e-mails and updates as that hub becomes available and the data starts to become available to researchers.   Now, obviously, with any sort of, you know -- project like this that's collecting a lot of data, that's personal to the individual -- there's, obviously, concerns about what exactly happens with that data and how that gets protected.   So... they do have an approach to privacy and security that has, you know, many points to it.

And really trying to make sure that the individuals' data is secure and protected.   So... they do have -- this approach to privacy and security -- I won't go through and read all this, but what I will summarize is this:

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They recognize that they're going to do everything they can to keep this at the highest level and the most state-of-the-art protections that could be in place for individuals' data.   They also recognize those that even with the best intentions and the best plans, sometimes things can go wrong.   It seems like every week, something comes out that, you know, some financial institution has had a data breach.   So they do recognize that stuff could potentially happen.

And if it does, they want to make sure that that are plans in place to let participants know what has happened.   And keep them in the loop so that they are fully aware if there is a data breach.   Like I said before, when things like biospecimens are done, that is kept in a bio bank but it is identified so that the individual's name is not associated with that information and -- it is done in a way that do protect that information should there be a breach in that way.

And so that is essentially, the approach that they're trying to take, to make sure that the data is protected and individuals' information is protected as well.

(Pause).

>>KARL: Obviously, like, this, though, does have a lot of building blocks to really be able to enroll the number of people they're trying to enroll.   Like I said, the goal is to enroll a million or more people in this initiative.   The last I heard they were at 150,000.   Not even quite a year into that project.   So there's still quite a ways to go.   But they do want to try and make sure that they can reach -- do what they can to reach everyone in trying to enroll them and -- and get the proper building blocks in place to do that.

So they do have this all of us research program consortium.   That includes a lot of different areas and a lot of different roles that all these organizations are playing from the data and research center, to the bio bank, to

people that are working with technology.   Also, the people that are doing direct

volunteer network and the participant centers.   Then they're also working with

health provider organizations directly to help do outreach.   And then the

communications and community network is the area where we are working in, to

work in -- do education and outreach for individuals so that they can be aware of

the project and what it is.   And this is the community and provider network that is

doing the outreach.   So you can see that there's a lot of different organizations

doing a lot of different work in this area.   In a lot of different population groups.

AHD is just one of the organizations that's doing outreach.   So you could see,

you know, similar messaging that, like, we're putting out from other organizations,

that are also doing a very similar work that's doing it specifically with their

population groups.

So what specifically is AAHD doing?   We have been funded to identify

and fund partner organizations which I'll be talking about in a moment.   Helping

disability focus rationale in the project which goes to the call to action I was

talking about earlier, which will be -- will be trying to get out in wider circulation in

the next week.   We also are reviewing the all of us program materials to ensure

that messages are appropriate for persons with disabilities and that it includes

imaging that reflects that.   And also conducting national education and outreach

on all of us in the disability community so for instance in the photograph on this

particular side you can see when I was at the April conference in October -- you

know, -- essentially working with the centers for independent living that work with

rural programs.

And doing outreach to them to let them know about the projects they can

tell their constituency about it and get them to learn more about it and enroll

individuals.

There are several materials that have been put out and like I said, we were working with them to make sure that people with disabilities are included in that. And we're trying to help them to even make that even more diverse to get even more imaging that includes people with disabilities. This is just a small sample size of the materials that we do have available; and some of the imaging that is being used. I mentioned the four partner sites that we're working with. And specifically, what we're doing with them.

We decided what we were going to do when we -- wanted to do this work is to really try and work with some organizations that we work with in the past, that have done outreach to their communities, and have done work specific -- and had sort of a local engagement strategy that they can use in their state and in their communities. So for that reason, we worked with the Lake Shore foundation in Birmingham Alabama, which many of you know runs the national center for physical activity. Physical health and activity. For disabilities. Or N C.P.A., they're involved in trying to do outreach there in the Birmingham area. Working with the two UCEDDs. We will be talking momentarily about the work that they're doing in both Montana and New Mexico. And also working with the center for the independence of disabled in New York, the Center for Independent Living in Manhattan. We wanted to get an approach we were looking at, you know, folks in rural areas like Montana and New Mexico. But also looking at urban areas and trying to see what messaging works maybe in some areas that might not work in others.

So some of the work that they have been doing: The Lake Shore foundation in Birmingham, they hosted a vendor booth at the launch event they

conducted in Birmingham.   The all of us research project had a specific launch event.   And they hosted the MEA, the mobile engagement asset, you can see in the picture, there is -- there are now two of these that are touring the country.   To tell people about the program.

And this was -- in May of last year, right after the launch of the program.

I had gone down there to help promote that within the community; and for people with disabilities to make sure they're aware of the project and let them know exactly what it is they can do to get involved.   So we were down there to sort of promote that.   And get people educated about it.   And potentially enroll -- enrolled in the program.   And that's what the -- this does, two of them specifically.   The first one, the one that you see pictured here... is just an education and outreach asset.   That's all it does, it just goes around and essentially has information and allows people to learn more and sign up and then they can go through the enrollment process on their own later.   The second one...

Is going to be focused on more rural areas.   As they have an issue lots of times with the second part of the enrollment process: Doing the bio specimens, doing the physical measurements.   And so what the second mobile engagement asset does is it allows them to essentially do all that right on-site.   And it is touring some -- the more rural areas of the country.   Where they don't have health provider organizations they're working with.   So that is touring and essentially, it's a lab that allows them to do all that.   Allows them to do with the bio specimens right there on-site.   And it allows them to do the physical measurements after the individuals go through the consent process and enroll in the program.   So it allows them to do all that right there in the rural areas where

they've had a hard time making connections with some of the hub provider organizations.

There are also Lake Shore is doing, what they're doing hosted the MEA in May.   Also working with local disability organizations to promote it.   They conduct webinars and, obviously, done a lot of posting on social media.

Our partner organization in New York, utilized their disability press outlets they work with, within New York City.   They also hold community workshops and they highlighted the all of us – in a community workshop and you can see in the image here where I was presenting at one of those community workshops.   They also host exhibit booths at some of the local community events.   They promoted all of us at their disability pride parade they had last summer and they've also done some webinars and, obviously, posting on social media.

As it relates to the work that's going on in Montana and New York -- I don't want to steal their thunder -- as they'll be talking momentarily about some of the work they're doing: But this is a shot of the state of Montana and the centers for independent living and the regions they work with, so Meg, will be talking about that in a moment.   I just wanted to give you an idea of exactly where it is, how their state approaches that; so that's what that image can show.   And then for Montana, in a similar way, they're also working with some of the disability organizations there.   Within -- and also within the state.   Some of the state... collaborations that they work with.   And some of the councils they work with at the state level.   To make sure that this project is the outreach is done to those individuals.   So that's what they're doing, but I don't want to take the -- the thunder away from them; so we do want to talk specifically with Montana and New Mexico about what they're doing and how UCEDDs can get involved with this.

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So at this point, I do have some questions that we're going to do a little bit of a Q&A. With Meg, and Tony, and the first question. I'll ask both individuals to answer this, but Meg, if we can start with you.

Q. In your role as a UCEDD, how did you use your unique position as a statewide resource to disseminate information about all of us?

A. (Meg) thanks Karl. I think that we really build on the role of the UCEDD to conduct research that is participatory. And involves the disability community as leaders in that research and... so we've been doing that work here in Montana. Through the rural institute for inclusive communities. And the research and training center on disability in rural communities for many years now; and so... I think we have at the -- at the base, the values of that approach. That you mentioned in your slides. You know, and of the community. Where -- first and foremost, we are working with the community to... put forward self-determination, choice, dignity, welfare and -- and freedom; so all of those are at the core, and so putting forward opportunities in a rural state is... you know value-driven as -- as UCEDDs have this kind of role in everything that we do.

And so I would say that's been really key. Logistically. We organize, the -- the research that we do here with a variety of partners. We leverage the systems and networks that support people with disabilities in the most rural parts of our state. To do that research. And ensure that -- even folks who live in some of our most remote, rural counties, are included in the research; so we're always look at the representation in the work and that their voices are a part of organizing that research from the beginning.

So those systems and that includes vocational rehabilitation, developmental -- developmental disability service systems, centers for independent

living -- and so on.

And I think through that research, we really grew awareness that, you know, there was this array of health conditions that the disability community wanted to be part of the public health agenda; that were not a part of it.   Those were the secondary conditions.

And describing those in the '90s and building out programs like living well with a disability, with our key partners as well as other programs to promote the health of people with developmental disabilities -- all of that is a part of what our UCEDD does. And has really been a part of our capacity to help promote awareness of the NIH's all of us research program.

I'll just stop there.

>>KARL: Okay.   Fantastic.   Tony, do you want to share a little bit about what you're doing?

>>TONY: Yeah.

I -- I think we use an approach similar to Meg, and rural institute.

Like most UCEDDs we are pretty well-connected with other disability organizations.

In different ways, and at different levels.   But we -- we know who to contact and in our case, you know, we've used organizations like the governor's commission on disability; commission for the blind; commission for the Deaf -- the DDPC -- disability rights New Mexico.   And so on...

Using a -- an approach, which gets their staff familiar with the program.

So they can in turn disseminate information to others.   That's No. 1.

No. 2:   We have a -- a library and information center.

That is statewide.

And one of the things they do is they exhibit at conferences, and meetings; so the information network will take an exhibit table.   And we have got some tabletop display cases and had some of the fliers printed off.

Gave our information center staff some training so they can do talking points.   And so far, they've exhibited at -- I think between 20 and 25 meetings and conferences around the state.

So that's the -- the other approach we use.

Social media is not a -- a major factor here in New Mexico.

We... for example, the independent living centers -- there are five -- only two of them have Web sites.   Even.   Which isn't social media; but -- so, we have deemphasized, you know, social media contacts and Facebook, and Twitter and all that -- relying on face to face contact.

And there you go.

>>KARL: Okay.   Great.

Meg, now, some of this you might have already answered.   But maybe you might want to elaborate a little bit more.

Q.   What type of dissemination activities did you use and which were the most successful and which were not as successful, did you find?

A.   (Meg), thanks.

I think there are key communication strategies that we stand up that really, you know, have some -- some -- we organize through the UCEDD to be able to do these for a variety of reasons.   And, you know, we've done a lot of small media kind of communication, even starting in the '80s, you know, with some of our first activities as a UCEDD here.

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But I would say the four strategies tend to be that we're -- just -- to reiterate.   We're leveraging the disability and our health partners and systems and all of the communications that are ongoing through those partners.

To include all of us messaging.

And so that can happen by adding messaging to their Web sites, their social media -- the programs they're running.

And each one of those organizations also, they tend too as do we -- we leverage local events.   Whether it's sporting or art, or health fairs or community events to promote our own messages.

And so, again, in that strategy -- we're placing the all of us messages within the Community.   And that tends to be the -- the small-print media and conversations and we've built out scripts for our partners.   And for ourselves so that we can be accurately representing what the "all of us" research program has.

And... and then, I -- you know, one of the things that's really important is for us, is that, you know, as a UCEDD, you -- you kind of know who's who in your Community.

In your state.

And who has the ear of the disability community.   And you can bring them in... to amplify nuances of the communications that are of most concern to the Community; and so we've been able to engage Bob in several ways in amplifying the "all of us" research program messages, as well as Steve, who we got to know through the "all of us" program through blogs and webinar, and then we were able to bring in, you know, one of the roles of the UCEDD is to leverage the resources of the university; and so we learned about Erica Woodall, who is a lead researcher in precision medicine here at the University of Montana.   We were able to bring in her voice,

and -- and with her partners, some of her understanding of conducting precision medicine.

With tribal communities.

So all of that is part of that strategy, where we're really trying to -- I guess nuance the message from the community perspective, with leaders' input and then the fourth is that we're....

We're building -- we're trying to add resources to our partners' work to strengthen some of the relationships they have with other regional partners outside of kind of our traditional partners.

So the secondary partners, so they're beginning to engage those partners; but I would say that that's been the most difficult.

Karl, you alluded, that NIH is building capacity to do some of this enrollment, and on-site data collection in rural areas and at this point, you know, Montana doesn't really have one of those sites.

Yet.

And so I think once NIH organizes to build the capacity of our -- of our healthcare partners, to play that role statewide, then our disability partners will be able to implement this strategy a little more effectively. But we have started to prime those conversations and we're excited about them for sure.

And hopeful that the mobile unit will be coming to Montana and -- and really start to build out some of -- of our capacity for individuals who want to do "all of us" on-site data collection and enrollment.

So um... those are our dissemination.

And I -- you know, I just can't say enough about the independent living centers and how they've organized really elaborate -- their advocacy work that is

ongoing in social media.

And they've done so much to build their capacity to get messages out and to get people to act.

Through social media.

And we really benefit from our partners, with our centers here in Montana.

>>KARL: Fantastic!

And we're still hopeful that, yeah, we can get that mobile asset up there to Montana.

Hopefully in the near future so that that -- other work can be done.

Tony, do you have any -- do you want to talk about some of the dissemination activities you've done?   And we've had comments asking you if you could speak up a little bit more.   They're having hard time hearing you the last time you were speaking.

>>TONY: Oh, God!   Usually projection isn't one of my problems.   I will indeed!

[LAUGHTER]

>>TONY: I -- I think I really talked about kind of our dissemination strategies earlier.   We have varying levels of success.

One of the organizations we contacted, just -- disability organizations just flat-out said, no, they wouldn't participate with us.

We have had difficulty -- the Albuquerque public library system, has a huge multiyear grant from the national library association, to disseminate information about "all of us."   We tried setting up a collaboration with them.   The result was underwhelming.

And we're not really sure why.

And that really revolved around the band coming to Albuquerque in the civic plaza.

I think that what might be more useful is to -- to let people know some of the objections, we get.

The -- or some of the barriers, and maybe I'm jumping ahead.

>>KARL: Yeah, you mentioned the one group that refused or didn't want to participate. Can you tell us why?

>>TONY: It has to do with -- you know, as you know -- and I'm -- as -- some of you know, at least, I am a researcher.

I'm a statistician.

There's a tremendous amount of uncertainty about and suspicion about the research end of this, when people hear about all the data that might go into this -- this database, and the distant city from -- maintained by people they don't know -- given out to people, they have no idea about.

Some people are just very reluctant to participate in a project like that; and, you know, for those of you who aren't researchers, you know, we -- we're having increasing difficulty getting people to answer telephone surveys.

There's just a real suspicion out there about gathering information.

So that particular organization that was the reason they gave -- but we're -- we're finding out that... a lot of people once they hear about it, are -- are declining to participate, based on those concerns about, you know, personal -- PII.

And protected health information.

In a big way. That's going out and they're concerned about that.

The other observation I make, really quickly, is that precision research -- is

not a concept that has been popular.   You say, "precision research" and try to
describe what it is.   And people's -- many people's eyes just glaze over.

We have actually down-played the -- the whole precision research
approach.

And we talk about the -- you know, nothing about us without
us -- that -- it's critical, with this database.   Be reflective of the population of the
United States.

And disability plays both physical disability and IDD plays a significant role
in that.

And we don't want to be excluded.   We don't want people with disabilities
to be once again, excluded.   That argument resonates much better than an
explanation of precision research.

>>KARL: Yeah.   And so the next question I had... I'll speak with you,
Tony, since you already started to answer it.

Q.   Major obstacles you had and how did you over -- what did you do to
overcome them?

A.   (Tony) well, -- (laughing), I mean, we -- we learned early on, that there's
no point, once somebody starts -- their eyes glaze over about precision research.   We
just drop it.   Right away.   I mean, we -- we deemphasize that, as I said.

The most success we've had are these exhibits at conferences and
meetings.   People, you know, are engaged.   They take the brochures.   They talk to
the staff, who are staffing the exhibit table.   And that seems to be our most positive
thing that we've done out here.   Again, taking social media off the table for us.   So, you
know, the -- the barriers, obviously, like Montana -- we're huge, we're rural.   We have a

large -- you know, one population center.

We're going to -- as this moves forward, we want to try to reemphasize the independent living centers; but that's actually going to require visiting the independent living centers.

Our statewide independent living council is -- is not an active and vibrant organization.

They -- they did have a Web site.   And it was last updated in 2015.   Now we can't even find the Web site.   We're now going to visit the independent living centers trying to make a big push on them as well as several more statewide conferences and meetings coming up.   So that's it.

>>KARL: Okay.   Go ahead.

(Pause).

>>TONY: No.   I was done.

>>KARL: Okay.   Sorry.

Meg, what about you in terms of obstacles you've faced and what did you do to try to overcome them.

>>Meg: Any time we're kind of relying on small media or pushing out information others have prepared.   We're always -- thinking about the accessible versions and making them available as -- as part of our communications and not as -- you know, an accommodation or someone -- if they request it, then we'll get it out and in an accessible version.

And this has been the -- I would say -- you know, one of the exciting things about NIH: Is that they are thinking of this as transformational.   They do want to change how they do things.

To be reflective of the disability community's culture of -- of, you know,

making everything available to people in formats that will work. For

every -- anyone, so when we've run across -- I would say, you know, small media

brochures, that are too dense, or not organized really, with the -- the principles

of -- of clean design for people who might have visual, low-vision or are

blind -- we've been able to give that feedback, back, through AUCD, and up

through NIH and now through our relationship with Steve, who is our participant

on the steering committee.

I think that's been really important. So how do we get the electronic,

accessible versions of what we're providing through any of those strategies? I

mentioned.

And that's been something we worked on, and it was a little wonky at the

beginning, we put them on USBs and just made them available and then we were

able to get them on our Web site and create some links on the fliers and so on; so

that's been -- logistically, you know, one of those obstacles that you just are so

happy to have a partner who's willing to work on them with you.

And we've similarly been reviewing all the videos; and the materials that

are coming out from NIH, making sure that they're captioned. If they're not, you

know, at the beginning we let folks know right away. And I would say we haven't

really been seeing any that have not been captioned anymore; and then just

looking for the representation of stories that are authentic in the disability

community. And whether it's just in the photos, or in actual -- some of the

multimedia components of the campaign.

And giving that feedback up.

And it's a uniquely -- the privacy confidentiality issues are always a big

thing. If you're in a rural state, at my rural locations, my condition or impairment

and you know who I am. You know. That rural piece of my identity, really makes it a little more difficult to say, who I -- to protect my identity.

And so just wanting to always keep this line of communication open with NIH about that and then, also, the beneficence message, will this research really come back and benefit me and my neighbors? We learn to do precision medicine, that either improves my condition, that's associated with my disability; or my outcomes from health conditions -- such as cancer, or mental health -- it might -- I might, like, anybody else might experience, but my disability should be taken into consideration as treatments are targeted for me.

Knowing that that will be available in rural communities is really important. That the knowledge will come back to practice in rural.

And... but so, really, I think for us it's just keeping that dialogue going.

One of the things that we've learned through our partnership with Erica Woodall, is at the end of the day the data becomes available for researchers, how do we assure that the core values that guide some of that participatory work that I mentioned at the beginning, are part of the values of the researchers who gain access to the data that are provided by the disability community members.

And so, for example, who -- who from the disability community, will continue to be a part of reviewing applications?

From researchers to do the work and make sure that it is sensitive and -- and value-driven from the disability community?

So those are some of the -- some of the ongoing considerations -- I'm not sure I would say "obstacles" but I would say, again, how NIH is organized to really involve participants in their steering committee -- it's important.

And I think reflective of their commitment to be transformative in the work.

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>>KARL: All right. Well, thank you very much for all your input on that.

I do want to talk just real briefly about what people can do, if they do want to get more involved. If you do want to enroll, you can go to joinallofus.org, and this is a screen shot of the Web site when you go there. And you go there and that's where you can learn more about it. And go through the enrollment process and the consent process for that.

They also have social media they are using, that they are doing. That's sort of to educate people about the program so you can go to the Web site as I mentioned. But you can also follow them on Facebook Instagram, YouTube, and Twitter. The handle is all of us research and using the hashtags join all of us, and all of us, inclusion is one that we've used on some of the posts we've been doing.

So that's if you want to learn more about that, that's how you can do that.

I do want to open it up to -- to questions from the audience. We don't have a lot of time left. And I do have one other question, I can ask to -- or to Meg, and Tony, if there are no questions, but first, I wanted to see if anyone else has -- has any specific questions.

ANNA: So Karl there looks a question from Lynn Ann: Does the project have personal stories on thou the precision medicine will benefit the participation? Having those examples are more tangible to participants you want to reach with the all of us project.

>>KARL: That's a great question, and they are working on doing some sort of testimonial things.

Meg, also mentioned the blog they did with Steve, that it gives his sort of

personal perspective on it; and the benefits that he sees -- or that he hopes will be coming down the line, for those of you who don't know Steve. He's a personal with a physical disability, himself; so those are all stories that are out there, and we're working on that.

In terms of actual benefits known right now, I don't know there are any right now that they're able to really push out, because the research really is just getting started. But as those stories come out, I'm -- we'll do what we can to push those messages out as well. And I see Meg just put in the chat, the interview they did with -- with Steve, the link is there that you can access that.

(Pause).

>>KARL: I'll spin one more question to Meg and Tony, what suggestion do you have if other UCEDDs decided they want to join the "all of us" campaign? And Meg, we'll start with you.

>>Meg: You know, I -- again, I think people who are in the UCEDD network know this, but, you know, to start to organize and move carefully, and slowly, and be thinking through all the ethical considerations.

With the partners from the disability community.

And I know that there are many -- in the UCEDD network who are working in this area, and this way; and so to network to those folks and to learn from them -- I think -- is -- you know, really important.

And... you know, to -- to... yeah, just move slowly and using participatory approach and values.

(A pause).

>>TONY: This is Tony. What I'll say, is tap into things you already do.

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You know, we have tried, as -- as best we can, to -- as I said, you know, we're distributing information about it to our existing dissemination mechanism. Going to these organizations, seeing what they'll do, that -- but those are things we would have done anyhow.   So it can be -- it doesn't have to be a huge effort. It -- it can be just looking at your existing relationships, whether it be community advisory committees; or trainings that you do; or professional associations within the state that you're working on.   And integrate it into things you're already doing. That would be my suggestion.

>>KARL: Okay.   Well, thank you very much.

We are out of time now.

But if people do have more questions, my e-mail is on the final slide and you can reach out to me with any other questions you have, and I'm happy to answer those for you.   We want to thank you for participating today; and Anna, I don't know if you had any final words you wanted to share with everyone.

ANNA: Thank you to our presenters.   This was a great presentation, I would like to thank everyone for attending, this webinar has been recorded and will be archived in the webinar library at AUCD.org.   And once you close out take a few minutes to complete our survey.   It will pop up on our web browser, a short survey.   And thank you, again, for attending and have a great rest of your day! Bye now!

>>KARL: Bye-bye!

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