Welcome, and thank you for standing by. All participants are in a listen-only mode until the question and answer session. At that time, please press star 1 and record your name as prompted. Today's conference is being recorded. If you have any objections, you may disconnect at this time. I would now like to turn today's meeting over to Tara Nokelby. Thank you. You may begin.

Tara Nokelby: Thank you. Good afternoon. Thank you for joining us today. My name is Tara Nokelby, and I will be facilitating your webinar. Today's webinar will be on Alzheimer's disease and related dementia in Indian Country. What do we need to know and share with others? From our speakers Cynthia LaCount and Erin Long with the Administration for Community Living, Administration on Aging. And at this time, I will pass it off to Cynthia. Thank you.

Cynthia: Thanks, Tara. And thank you, Erin, for helping us out one more time. And thank you Title VI and whomever else has called in. You know, we've talked about Alzheimer’s disease and other dementias before, and we've talked about what the disease is and how it impacts a person, and we've kind of gone in a maybe a more medical direction or a...different direction than we're going to go today. And what I asked Erin to talk about today and what I want you folks to think about as you're listening to her and preparing your questions, I want to know how we can best serve those clients who are maybe in the beginning stages of dementia and Alzheimer's and so they're still coming in to our facilities, they're still participating in our programs. But we're starting to notice some changes. How can we help that individual and what do we need to watch for, Erin, in how we're delivering their care and just how we're working with them? What do we need to be aware of and when do we need to help call those whistles that this person might need more care or different care than we're able to provide through Title VI? Alright, that was my question, and those were my thoughts on how I want us to think about this. And I'm turning it over to Erin, who's our expert. Thanks.

Erin: Thanks so much, Cynthia and Tara. I appreciate you guys, everyone that's on the line, I appreciate your being here to listen to me talk about what we can do in Indian country for folks living with Alzheimer's and their caregivers. Some of you may have heard me talk a little bit in the past, but hopefully this won't be too much of a refresher, maybe a little bit new information. So, today...sorry, I'm trying to move the...Tara, I'm not able to manipulate the...
story as a Title VI director, you, I'm sure, have encountered, you know you have an 83-year-old woman. She's living with her daughter. She's widowed, and she's a frequent attendee of your senior center. But then, she sort of slows down and starts coming a little less frequently. But when she does come, you're noticing that there's just something different about her, and she's changing. And, as we talk through the signs of dementia and things that you may observe, and that's the key to all of this is really being observant and understanding what the...what you can do to help people through this journey. 'cause that's what it is. So, dementia, generically, dementia is an umbrella term that covers very many different forms of cognitive impairment. Alzheimer's is definitely the most common kind, but dementia generically is memory loss and difficulty with naming things, doing things, recognizing things, behavior, thinking, calculating big, calculating especially with money. Money is the almost one of the first signs you know a person who could always balance their checkbook starts having trouble with just writing checks and having that ability to think through. Planning and organizing, and it really just, dementia is something that interferes with an elder's ability just to do things that they've always done.

And obviously it comes in different stages. So, they, in the beginning, it's just sort of little things and then it sort of snowballs a little bit. So, like I said, dementia is a umbrella term for a wide variety of impairments and it's, Alzheimer's certainly falls under that umbrella. I've heard estimates, there's well over a hundred kinds of dementia, but the most common is Alzheimer's disease. There's vascular dementia, Lewy body dementia, fronto-temporal dementia, and then there's other things like traumatic brain injury and even alcohol-related dementia. So, there's a couple that are reversible, but...or not dementias, but impairments that, when you're working with someone who you think may be impaired, one of the things you're gonna have to do is when they go to the doctor is determine if what they have is really a dementia or if it's just something else that may be a deficiency, a vitamin deficiency or dehydration, that could be repaired or restored. So, with a diagnosis in the most common dementias, you're gonna see patterns. And these patterns help you set the expectations, especially with a caregiver. You know, when someone has Alzheimer's, you can give sort of a broad understanding of what may...what is likely to occur through the different stages of that dementia. And the same is true for the other various types of dementia. Really, it's those setting of expectations for the families and the people caring for the elders that, it's so important, understanding the course of the dementia and the symptoms and setting expectations on them, and also on the healthcare system.

So, like I said dementia is different for everyone. There's certainly some common warning signs. The Alzheimer's association has a great presentation. They call it "The Ten Signs", and it's a great resource. But basically, if a person is demonstrating signs of dementia, it's little things like asking the same question over and over again or, you know, they've lived in the same place their entire life, but then they're getting lost in familiar places or forgetting where...starting to go somewhere and then forgetting where they were gonna go. The inability to follow directions, getting confused about time that often happens. Thinking the early evening is the early morning, challenges with self-care, bathing and safety perhaps, inappropriate behaviors. Other things would include difficulty completing tasks that they've always done. If they've always made pies since they were small, if the women that we described earlier had always made pies and she could do it by heart, and now it's becoming a little bit harder to execute that. Problems finding words. I experienced a great example years ago of a gentleman that had trouble finding words in either speaking or writing and when, where the one example with him was, he'd fallen down, and
an ambulance came to take him to the hospital and he couldn't remember the word ambulance, and he said you know that truck that comes to take you to the hospital. And he just couldn't get that ambulance word out, or microwave. He couldn't remember the word microwave, "That thing that cooks his food". So, it's just little things that are noticeable and worth paying attention to if someone comes in to your center and is experiencing those kinds of...or demonstrating those sorts of signs, it's worth taking a closer look.

So, diagnosis, as home and community-based centers, we certainly don't provide diagnoses, but we certainly can contribute to the story, as well as when a person is...how does the person get diagnoses? Well, the first thing is someone has to notice it. So, the elder may come with concerns or family members or other people that have regular contact with someone may come with concerns. Then, there are cognitive tests that can be done. They test memory, calculations. You might have heard of the clock test. There is a mini-mental exam, just a couple questions. And here at AOA, we talk a lot about dementia capability, and what we do is these little mini-assessments, and those assessments then lead us to recommend and refer people back to their medical provider to get the, on the slide, those lab tests that might be able to provide some more definitive information. Really, I mean just to ensure that it's not something else. A recent example of where a lab test might have been helpful is a person had been a celebrity, Kris Kristofferson, had been told for years that he had the beginning stages of Alzheimer's, and then it turns out he had Lyme disease. They did some extra tests and that was it, and he doesn't, in fact, have Alzheimer's disease. But...so lab test are very important, and not always, but sometimes a CT scan or an MRI might be taken through the medical provider.

So, who diagnoses and treats dementia? As with everything, I know you guys do, there's people that have all different kinds of specialties. It takes a team, and, you know, the primary care physician, the nurse practitioners, the physicians' assistants, and as well as the neurologist, psychologist, and psychiatrist. With all that expertise, we hope that you would eventually get to the appropriate diagnosis, and then also a plan of care. So, there's different organizations give the stages of Alzheimer's in...there's really two main ways that it's done, and the slide here talks about the stages of Alzheimer's as mild, moderate, to severe, and then the other way is there is a scale of 1 to 7 too that some medical providers use. But I'm gonna explain it using this mild, moderate, severe stages of Alzheimer's. So, when a person is in the earlier stages, which is mild, they can still be involved, however they could get frustrated. They...but they take part in decisions about themselves and they just things just take a little bit slower. But, eventually, they get to where they need to be. As the disease progresses, folks need a little more help, and when they're in the moderate stage, they need more attention, but they still can enjoy being involved and with their families and oftentimes stay in their homes throughout that moderate stage. Obviously, there are definitely people with Alzheimer's who remain in their homes throughout the course of the disease. And, but once it gets severe, then they need total care which I imagine you're probably familiar with, but...So, mild, moderate, severe are the three stages, and it looks different for everyone. There is...I've heard it said a million times, it's kind of a cliché, when you've seen one case of Alzheimer's, you've seen one case of Alzheimer's because it really does look so different in every person. And the experience is so different.

So, how is it treated? Medications: there are medications out there that. There is no cure for Alzheimer's, but there are medications thought to slow the disease in some people. It doesn't
work for everyone necessarily, but it definitely helps. There are also, along with Alzheimer's, you'll see when you hear people talking about dementia and Alzheimer's, they talk about behaviors. It's kind of a negative way to frame things, but sometimes, I mean, if you've ever known anybody who has suspected or confirmed case of Alzheimer's, you might say, "Oh, well. They get mad, or they do things." And that's what they mean by behaviors. They don't want to take a bath, or they act out, and they have medications that help people sort of calming. A lot of times they give people with dementia are also diagnosed with depression, and that sometimes they're medicated for that. But there are many interventions and ways to work with folks that are living with dementia to make their life better and to, as the disease progresses, to sort of work with them to meet them where they are and help care for them in a way that gives them a good quality of life. And a key to that is getting them the best care and in the right setting, and, and...giving them the attention that, as they move through their life and on to the next world, just ensuring that there is a high quality of service and care that they're receiving at the later stages of their life.

One of the other things, the last bullet on this slide is the bleeding into the next stage of my presentation, and that talking about caring for the caregivers. And that's a big piece of working with people with Alzheimer's or dementia is knowing who has a caregiver, who doesn't have a caregiver, because that's certainly a big problem. People that live alone, and it's harder to identify...you won't if someone doesn't have someone that lives with them, it's often harder to identify them as people who are becoming impaired. But caring for the caregivers is a huge piece of the puzzle in caring for individuals living with Alzheimer's and dementia. So, when we think about caring for people living with dementia, you have to care for the...don't forget about caring for the caregivers. And a big part about that too is just knowing who has a caregiver and who doesn't, and, if so, who is it? You know, in my life, my mother has Alzheimer's and my 90-year-old dad is her caregiver. And understanding the needs of a caregiver, no matter what age, and supporting and training them to relieve their stress and reduce their stress and burden is a key to getting the best care to the person living with dementia.

There's certainly, I'm preaching to the choir I'm sure. There's certainly tons of challenges that come with caregiving. Just understanding Alzheimer's and related dementias is, can be, overwhelming. So many people when they don't make the connection that there's this umbrella that's dementia, and then a person may have Alzheimer's, but they may not. And it's not one-size-fits-all that just because a person has some memory issues, it's not necessarily Alzheimer's it could be, and there's a good likelihood that it, I think, it's like 60% is the number of individuals with dementia that actually have Alzheimer's. Another thing that for in caregiving that is a challenge is actually getting a caregiver to identify as a caregiver. It's, I mean, a caregiver, I think sometimes there's a little bit of a stigma attached to it because people don't see it. They see caregiver as a job, and when we care for our elders, it's not, it's not a job. It's just what we do. Whether it's our loved one, it's just what we do. And so, having a husband identify as a caregiver, or a wife identify as a caregiver, I think people are getting better at it. You might hear someone, people out in the field calling it "carepartners" or "caregivers" or "carers". It's all the same thing thought. It's caring for a person that needs your help. So, as a caregiver, you know, one of the big things that is a challenge is adjusting to this person as they change. And how to respond to behaviors or actions that a person never would have, you know that your mother would never have done something rude or said something rude, and sometimes when a person is advancing in
their dementia, they, for lack of a better way of putting it, they sort of lose their filter. And so, they say things or do things that they wouldn't necessarily, that's not a necessarily a personality trait for them. And as a caregiver, especially as a family caregiver, recognizing those and responding to those changes can be really a huge challenge.

Challenges in the way you communicate. You just have to change it. You have to look for nonverbal communication. Oftentimes when, you know, I talked earlier about behaviors, the sometimes a person with dementia may not be able to explain something, they're feeling bad, if they have some sort of infection. And as opposed to trying to describe it, they just get cranky or they act out in some way. So, you kind of have to be able to understand those nonverbal communications and take into account what a person normally would do and if there is a chance that there's something else going on as opposed to someone just "being difficult". I always hear people talk about people with dementia being angry, and a lot of that, it won't always help, but it's just trying to understand what's behind that anger, and oftentimes it may just be something as simple as urinary tract infection that they're just uncomfortable. They have a headache, but they can't tell you what they need to get rid of it. Caregivers need to remember the huge challenge of caregiving is responding to their own stress and maintaining their own personal well-being, so that they can do what they need to do to carry on.

Stress comes in a variety of ways. The next bullet: financial challenges. Caring for someone with dementia can be so costly whether it's the cost of prescription medications or getting someone to come in and help. And if you don't have that extra income or that, the ability to access someone to come in and give you a break and pay someone to give you a little bit of respite. That can be a huge problem. And it can take a toll on a caregiver that might be avoidable if some services can be made available. And also, a challenge with caregiving is being able, oftentimes, there are other health conditions that are accompanying the dementia, the Alzheimer's. A perfect example is diabetes that, you know, a person with diabetes has could very well develop that and then that could contribute to their symptoms as they forget to take their shots, they eat something they're not supposed to eat. All of those different things come into play and, even for the person with dementia or the caregiver, sometimes caregivers get so busy taking care of their loved one that they forget to take care of themselves. They forget to take their own medications. They forego their doctor's appointments so that they, because they're so worried about caring for their person or they can't be left alone, and they don't have someone to take care, even if it's just sitting with a person so that the caregiver can go to the doctor's. It's a real challenge of caregiving.

So, this is a different kind of depiction of the challenges that a person with...calls it challenging behavior. A person living with dementia or Alzheimer's might be living with, but might be experiencing trouble communicating. It's all the things that really talked about, unfamiliar with the environment, physical discomfort, they get bored, if you're a caregiver. I mean, people just like we can...If someone is upset or unhappy, if someone has an agitated caregiver, that would impact the person with dementia. Sometimes just an overstimulating environment. If you go to a restaurant and there's dishes clanging and that can really be disruptive for a person with dementia, just being in a really noisy environment. And then they can't tell you why they get frustrated or confused.
So, I wanted to share with you some...I talked a little bit about challenging behavior, and I wanted to share with you. This is just a screenshot of a...we have this great resource here at AOA, at our National Alzheimer's and Dementia Resource Center, we have these fact sheets that are really helpful on topics that are relevant to caregivers, and so they're easy to read with just little tips on...right now we have six of them, but we're expecting to have more soon. And the topics that they cover are Anger and Frustration on one, we have one on Bathing (Bathing is a real challenge with people with Alzheimer's and dementia. And you really do, you have to learn sort of tricks to, not to trick the person, but just tricks to make things happen and make sure people are comfortable and safe. You know, there's a problem with people getting lost. Some people that have dementia actually have hallucinations, and how scary is that?) There's a tip sheet for making your home safe. There's a tip sheet for medications. We just have...these are six very, very common issues and we feel like it's...this is a great resource. It was created in Los Angeles by Alzheimer's Greater Los Angeles, and they have been so kind to make these available to anyone, and even if your organization wanted to put your name on it and put your brand on it, they would help you do that, so that it could come from you because you are a trusted source in your communities and that's so important. And they would be happy to...you could go to our webpage and get these fact sheets and just have them around at your senior centers so that if someone does come in and they say, "Oh, gosh, you know, I can't get my mom to take a bath. It's the hardest thing", you can give them the tip sheet, and that might give them the little bump of help that they need to make that happen because that's a very common challenge that people experience.

So, I'm gonna go into three actual resources that we have available now that have been translated to be culturally appropriate for Indian country. And you may or may not, we have been talking a lot about all three of these late in the last couple years, so you may or may not have heard of them all. But, hopefully, this will just, if you have already heard this will just reiterate that we've got good stuff available to you. And, if not, it will hopefully help you have something else in your toolbox that shouldn't cost money. Other than time, I mean time is money though, I get it. But these exist, and they might be able to help you. So, for the last two and a half years, the Indian Health Service and ACL have been working with the Veterans Administration on resources for REACH into Indian country, and it stands for Resources for Enhancing Alzheimer's Caregivers' Health. It's REACH into Indian Country. They've had many iterations of REACH. It was started in VA and the folks at VA have been helping us to implement it. They had a three-year grant from the RX Foundation that, it trains...we've been doing public health nurses and Title VI directors and Title VI staff to become caregiver coaches, and they help...and basically, we train the staff members to be able to help caregivers with problem-solving and positive thinking and stress management, and it does, it is proven to decrease stress in caregivers if they can just get them to do it. It shows improvement in caregiver depression, burden, frustration, and also reduction also, once again, those challenging behaviors. Presently, so the REACH intervention, as we've been doing it, has been free training. They've come to the Title VI conferences. I know that they've done some other workshops across the country. They have, we currently have certified interventionists, or they call them caregiver coaches in Arizona, Colorado, Montana, Michigan, New Mexico, Utah, and Wisconsin. And that list may be short. There may be other. I think they were in Oklahoma recently, but I may be wrong.
The training is flexible. You can do it online. I'm gonna give you later the phone number or the email for the folks at the VA that are doing the trainings for us if you were to think that maybe you would be interested. It's free. It's a program designed to meet the needs of individual caregivers, but it also can include extended family members if the primary caregiver is inclined to have that person help. And then, in addition to giving the training, the VA has, they also have ongoing support for those that have been trained. So, just a little bit about the intervention, or the training for the intervention. It's for...what we do is we train staff to work with caregivers of elders with dementia. It's a three- to four-hour web-based training. You get, there's a notebook that comes with it that gives you scripts and tells you how to talk and talking points. But it also gives a notebook for the caregivers to have at home and take notes and look things up if they're experiencing something they have it in their notebook to be able to look things up to help them solve based on the training that they've learned from their coaches. The coach meets with the caregiver for four sessions, but then makes themselves available so that if the caregiver needs a consultation, they can get it. And then we're not having as many training sessions, but I think that they do still have online training available.

So, these are the types of, the roles that people that have been trained as coaches are playing within Indian country. The senior center staff, caregiver support staff, public health nurses, CHR's, and basically there's, if you know people that have already done the training, you'll know that we've trained a lot of people and we, they're actively looking for caregivers, even if you don't want to be the person to be trained, you might have someone in your community that has already received the training and is looking for caregivers to, is recruiting caregivers to benefit from the program. That's a different way to look at it. It would certainly be a great resource in your community if you had a REACH coach to help your caregivers.

Another resource we have is the Savvy Caregiver in Indian Country. It was in 2014 Nikoa received a grant from ACL to take the Savvy Caregiver, which is a longstanding dementia caregiver intervention and make it culturally appropriate. They worked with some consultants to develop this new appropriate tool or training to teach caregivers to understand the stages of dementia. And really, in addition to understanding the stages, it's a understanding what the abilities of the elders are at certain, at the stages and what kind of activities are...they'll benefit from. And it also, it's another one, it shows caregivers to ways to have less stress by keeping the elders involved in the daily life, but in ways that fit, align with their change in abilities. It's six classes. We've done it, Savvy Caregiver, I manage ACL's Alzheimer's programs and we've done Savvy Caregiver across the country, and the great thing about this program is it is very cost-efficient. And people, caregivers really benefit from it. It's certainly worth considering. I know [unintelligible] has been talking about this for a couple years, and they have the manual that's free on the Nicoa website. I put the link in this presentation, so if you wanted to go and take a look at it. It's really well done and easy to follow, and just a great resource to have even if you don't have the manpower to do the classes, just to make this manual available to staff that might benefit from seeing the curriculum that's there.

And the last item I want to talk to you about is music and memory. We've been talking about this a lot at conferences lately. It's sort of all the rage. In Wisconsin, this is basically an intervention for, again, those behaviors. But it demonstrates the value of music and what it brings, what part of your brain it stimulates. But it helps, essentially, people...the way they do it is you get a iPod
and you load up on it all of the music that was meaningful to the elder, and when they are anxious or having, demonstrating these behaviors, oftentimes the music can soothe them. I know we've had some in the work that they've done in Wisconsin, they've used drum music. They've used Powwow music. They have, I had someone...I was at a meeting, and she recommended considering putting the sound of nature on an iPod and playing that as to soothe an individual when they become agitated. And it brings back happy memories. It's, there's a link there for a documentary. If you have, I think the clip is like six minutes, just to see what the impact of music can do for an individual. It's really astounding and uplifting to...because a person can come back. We hear story after story of the benefits of the music and how not only does it help the caregivers to be able to...as simple as if you want to make you're caring for your mom and you just need to be able to make dinner, because so often caregivers not only are caring for their parents, but they're caring for their own families and their own children. And just to be able to know that someone is occupied and happy. You can use the music to sort of distract the person with dementia and be able to make supper for the rest of your family without worrying that mom's gonna be upset or might wander off. So, it's a wonderful tool. Something that we all have around. I mean you really don't even have to do it with an iPod. You could...I mean that's certainly the intervention is with the iPod, but if ever you need something to just sort of bring the person down, some good soothing music, and especially things that make have memories for the elder from their youth oftentimes. It really is beneficial.

So, that is sort of where I am with my presentation. I just would encourage you, a lot of times when I do these presentations I put in a pitch for ACL's grant programs. I didn't do that today just because there's nothing available at the moment. I definitely would encourage all of you to think outside the box when it comes to getting programs into your communities whether it's funding opportunities from ACL, from private foundations. With the music and memory stuff, you could easily, I bet, I would imagine, do a call for people to donate their old iPod. How many of us have two or three iPod that we thought we lost and we bought a new one, and then we have a spare one sitting around and just have those iPod at your center to make available to the folks there. Build partnerships with the surrounding communities, with whatever if there's something in your community that you could build on, work that is already existing, if they're doing falls prevention or CDSME or just finding ways that you can partner with people doing relevant work. Finding those free resources, the Nikoa manual, the REACH VA, and using those learning opportunities to your advantage. I just can't stress enough that some opportunities are there. We at AOA are certainly always, always very happy to try and help guide you to whatever opportunities we're aware of, or if you're aware of something and you want us to try and help you think through something for your community, always feel free to reach out to...I'm gonna speak out of turn for Cecilia and Cynthia, I know that if they don't know the answer, they always know where to go get it. And certainly, the same goes for me. If you have something that you're thinking might be right for your community, and you just need a little bit of brainstorming to figure out a way to get you to what you want, we're always happy to help. And, last but not least, I just had a little list of the different kinds of resources that are out there. This is certainly a short list. It is not everything that is out there. The ACL we have the National Alzheimer's and Dementia Resource Center that is populated with information that is tools that have been created through our grant program, papers, just different resources that have come out of ACL and our grantees that we think that the larger public would benefit from. Nikoa has the Savvy manual on their webpage. The Older Indians, I know you guys know all the resources that are there, Brain Health,
Alzheimer's.gov, and then of course always the Alzheimer's Association. I should have put it in there. It's alz.org. And they certainly have a tremendous amount of information on Alzheimer's and related dementias on their webpage.

So, with that, I've talked long enough. I don't know if anybody has any questions for me. We have a couple minutes left. If you have anything that you think I might be able to answer, I'd be happy to try.

**Operator:** Thank you. We will now begin the question and answer session. If you'd like to ask a question or make a comment from the phones, please press star 1, make sure your phone is unmuted and record your name to introduce your question, and to withdraw that request, you may press star 2. Once again for a question or comment from the phones, please press star 1 at this time. And I will standby for questions or comments.

**Tara:** And please feel free to also enter any of your questions into the WebEx chat. I do have one here from Lacy. It says, "Hi Tara, can you ask Erin if she has any thoughts about dementia-friendly communities for tribes or the dementia friends program through Dementia Friendly America?"

**Erin:** I am not aware of any specific initiatives on dementia-friendly America that is tribal specific. It's certainly a wonderful resource. Dementia Friendly America comes, I think it's actually being managed now by the N4A, the National Association for Areas Agencies on Aging. They have wonderful resources on building dementia-friendly communities. We did a presentation about a year ago with the folks from Dementia Friendly America for, I believe, this series, and but I can certainly get folks more information on Dementia Friendly America. I don't have the website at my finger...let me, I can look it up real quick and tell you what the webpage is, and they have great little videos that they've created. And it's definitely sort of the crossing the nation to...and more and more communities are building...and they have a toolkit. So, it's www.dfamerica.org. And I do believe that they have an agreement with the Dementia Friends program to build, to make Dementia Friends and there's a video so that members of your community can learn enough about Alzheimer's and dementia so that they can share it with other members of their community.

**Tara:** Thank you. And again, if you have any questions, please press star 1 to patch your line through, or you can type it in the chat. Also, if you would like to have your, the presentation sent to you via email, please feel free to put your email address in the chat as well, and I will get that over to you shortly after the presentation is completed.

**Operator:** And I'm standing by for questions or comments, and I currently show none from the phones at this time. Again, please press star 1.

**Tara:** Alright, it looks like I don't have any on the chat either. So, Erin thank you so much for your presentation today. And again, for all the folks that would like the presentation sent to them via email, please feel free to put it in the chat or you can email me as well. And just a little note, we will not be having the presentation, the webinar next week. We have cancelled it due to it being holiday season. So, please feel free to contact me if you have any questions. Thank you.
Erin: Thank you.

Operator: That concludes today's conference call. Thank you for your participation. You may disconnect at this time.