

**OPERATOR:** Welcome and thank you for standing by. At this time, all participants are in a listen-only mode until the question-and-answer session of today's conference. At that time, you may press star-one on your phone to ask a question. I would like to inform all parties that today's conference is being recorded. If you have any objections, you may disconnect at this time. I would now like to turn the conference over to Mike Splaine. Thank you, you may begin.

**MIKE SPLAINE:** Thank you and good afternoon, or for anybody that might still be in a morning time zone, good morning! My name is Mike Splaine, and I'm here at the invitation of Cynthia and others at ACL to talk today about Alzheimer's and dementia. Just by way of background, I'll tell you that I've been working with people with Alzheimer's and their families since the mid-1980s, most of that with the Alzheimer's Association. I've been an independent consultant for the last decade. I've had the privilege, for the last two years, of being the lead staff person from the Alzheimer's side—Alzheimer's Association side—as a consultant for—[audio cuts out]—product developed jointly by CDC, the Centers for Disease Control and Prevention and the Alzheimer's Association called a public health road map for Indian Country on issues around Alzheimer's disease and caregiving.

So the way this is going to work is I'm supposed to be able to manipulate the technology, and Dr. Lewis there—hi, Dr. Lewis, all the way in Alaska—you won't be able to talk until we open the phone lines for what I hope is very vigorous Q-and-A at the end of my formal presentations. So I think it's important that you know this is a list—and this is for the record—a list of my current clients. They include, as you will note, work as a grant reviewer for the Administration for Community Living as well as being a program speaker at the recent Title VI. We also own an interest in two other businesses. And that's what you need to know about that, but more importantly, you also need to know that none of my clients have any control over this presentation, and I want to acknowledge and thank the Alzheimer's Association for their dementia umbrella slide that you will see shortly.

So the path today is short introductions and ground rules, I want to do some level-setting on Alzheimer's disease and related disorders, talk a little bit about what are some of the headwinds for you to consider as you think about possibly doing more about Alzheimer's disease in your community, and very practically, I'd like to make some suggestions based, obviously, on super limited knowledge of what your situation is on the ground, but maybe make some humble suggestions about, as a Title VI director or somebody who works in Title VI and related aging services programs, where could you start.

So I want to start with a level-set about dementia and Alzheimer's disease. I mean, today, even professionals kinda use these two words interchangeably. But I'll remind you, if you didn't know, that even the largest association devoted to these issues goes by the shorthand of being the Alzheimer's Association, but in fact, its full corporate name is the Alzheimer's Disease and Related Disorders Association. This signals one of the most important things to know about Alzheimer's and dementia, that dementia is a symptom. It's a set of symptoms that are characterized by the loss of cognitive functioning and behavioral abilities that interfere with daily life. People with dementia have problems with thinking, remembering, organizing tasks, like making a pot of coffee or handling their medications.

And dementia, that cluster of symptoms, has several causes, some of which are reversible, some in older people are not, and among them, Alzheimer's disease is the most

common form of dementia. This percentage is also holding true in the few demographic studies we have of American Indians and Alaska Natives, that Alzheimer's disease is the most common form of dementia in those communities, but there are others. There are large numbers of people with vascular dementia. This is due to either microlesions in blood vessels, millions of miles of capillaries in our brain that break down, or from stroke.

In the United States and other countries with advanced imaging, we see people being parsed out that have Lewy bodies in their brain. These are structures in the brain and are widely believed to create a different cluster of symptoms beyond the memory loss and the confusion, the disorientation that comes with Alzheimer's disease. Some people have frontal temporal damage either from disease, such as Pick's disease, or from head injury. And again, it can mimic some of the other problems in Alzheimer's disease. Parkinson's, in some cases, will create dementia. And, of course, being a good social scientist, we have to say other. Most, maybe even a majority, of dementia cases have multiple causes.

And so, while it's important, differential diagnosis and how the path of the disease might be important, I think there's two takeaways here. First of all, Alzheimer's disease used interchangeably with dementia is probably a little wrong because Alzheimer's disease is a cause of dementia. I think the other takeaway is that sometimes it's not an irreversible dementia. What are some of the things that can create dementia-like symptoms? And in older adults, one of the most common ones of all, we can have people seriously looking like they have an irreversible dementia, are urinary tract infections. Just something to think about when there's a sudden change as opposed to a slow change that is very characteristic of something like Alzheimer's disease.

So what is dementia? Dementia are the symptoms, the cluster of symptoms. It has many causes, including some things that are reversible, such as a UTI or drug interactions. I think we all know, that work with older people, once you get above five prescriptions or combination of five prescription and non-prescription substances, that there are risks to our thinking ability, not just our bodily functioning, these are important things. Somebody just noted that they're on the CPU line. I don't know whether that was intended for me, but I will just take it that the [chuckles] problem is solved. So let me continue.

I think, you know, so a second thing that I want to do to level-set is to talk that we now have and now understand there to be—Alzheimer's disease and its related disorders to be life course diseases, but people don't get Alzheimer's disease all of a sudden in their older years. But that said, the public image of Alzheimer's disease and our thinking about Alzheimer's disease is right here in the middle and end stages on the righthand side of this handy little graph. This handy little graph is the only original thing I've ever done on Alzheimer's disease, and it's later been—you'll see another version of it, but what I try to characterize here is that the societal thinking and our planning and our health thinking around Alzheimer's disease, because of when people get diagnosed traditionally, is very, very focused on the middle and later stages of the disease.

In fact, in unaided public awareness polls, if you ask people, what does a person with Alzheimer's disease or dementia look like, you'll here that they must be old, they must be disabled and unable to make decisions or to manage their own lives and activities, and they are likely to be dependent on others for care, possibly even living in a nursing home or an assisted living facility. Well, I'm here to say that, with the evolution of our understanding of the disease

and with progress in how it's detected and diagnosed, there's this whole left-hand side of my curve here of early stage pre-symptomatic detection, and even people who are healthy who have a real opportunity—and particularly public health authorities have a real opportunity to guide us on what we might do to reduce our population risk of Alzheimer's disease.

Probably the biggest change in the Alzheimer field in the last ten years has been the emergence of people who get diagnosed in the early stages of the disease, and as one of my dear friends in the work says, it's not your mother's Alzheimer's Association anymore when the people with Alzheimer's disease want to identify what they need from their own perspective, what they want, how they want to be involved in either decisions about their lives or decisions about programs. This is just a very energetic part of the Alzheimer community all over the world, and you see it reflected, this change in the last 10 to 12 years of more people getting diagnosed in the early stages. You see it reflected in things like boards of directors of Alzheimer organizations, work groups, a number of states have state government Alzheimer plans and have been updating them, and probably two-thirds of the states in the United States have mandated the participation of people with Alzheimer's disease in those planning processes.

Moving further to the left here on this life course or comprehensive approach to Alzheimer disease, we have a phase in which, you know, people can be detected before their symptoms are evident. This is mostly through advanced imaging where we can identify people that have the characteristic buildup of plaque or the tangling of neurons and inflammation in their brain that is the physical characteristic at the cellular level of Alzheimer's disease. A number of clinical trials have been aimed at folks that may have that plaque buildup in their brains but don't yet exhibit the cognitive functions—cognitive functioning changes that are characteristic with Alzheimer disease.

Moving further out, we now have, I think, solid evidence that, from a public health, a population health point of view, because always with prevention or risk reduction from a public health point of view, individual results will vary, but from a population health point of view, there are sound things we can do to improve all of our chances of having healthier brains later in our life. I can summarize the evidence in a simple phrase, what's good for your heart is good for your brain. And besides, anything we do to improve our hearth health, whether it's getting off the couch, watching our cholesterol, managing our midlife hypertension, particularly as it relates to both Alzheimer's and vascular dementia, controlling and managing our diabetes, all of these health steps that we would do to protect our hearts are also protective of brains. And besides, they're not otherwise bad for us or, you know, expensive or intensive or risky.

So there's a growing messaging, there's a growing body of evidence, there's a sound body of evidence that we can take action. Now, what do you do with this comprehensive point of view about Alzheimer's disease, this life course approach to Alzheimer disease? It's really hard because the people who are likely to ask you at a meal site or at a program or in passing because they know you work with older people, the people that are most likely to ask you for information or support or what do you know about or how can I get help are the people in the middle and end of life stages of Alzheimer disease.

But we have this wonderful opportunity across an entire spectrum or life course approach to Alzheimer's disease to take action, you know, across our entire communities, maybe even using this and using—and one of the real themes in the road map for Indian Country is about how can we use better knowledge about the life course approach to

Alzheimer's disease to bind the work we do in health and in aging, bind the generations together, and make this more of a familial and a multigenerational approach to Alzheimer's disease and not isolating it as those old people with dementia. Something to think about, something to think about. Another representation of this, this is the update of that slide done by Dr. Peter Reid and assisted by Mathew Bongard(?), but this shows the same thing, that in fact, Alzheimer's is a 20- to 30-year process, that there are different opportunities to get involved and doing something about Alzheimer's disease across a continuum and that it is not all about the middle and later stages of the disease.

I want to shift gears—and I hope you're writing down your questions as we go because we will have some time to chat when we get to about 25 minutes into the talk, so you don't have to listen to me very much longer—but what are some of the headwinds that we have heard folks in American Indian and Alaska Native communities that have started to take action on Alzheimer's disease in the community, what are some of the headwinds that they've run into. And in all communities all around the world, the biggest headwind that we face is stigma, that somehow we see people with severe cognitive impairment as other, as different, as scary, and that there's just real stigma associated with being a person with dementia.

It's interesting that we worked, as you saw—fleetingly you saw our client list, we've worked for many years doing public policy work at the global level with Alzheimer's Disease International. That's the international body that is the home or the international home of over a hundred Alzheimer's associations around the world, and this is World Alzheimer Month for those of you [chuckles] not keeping score. Every disease has got a month, and this is World Alzheimer Month, and it's content, ADI's content contribution to the work of the movement internationally this year is a major report on stigma and the kind of activities that are going on, such as dementia-friendly communities around the world to destigmatize the disease and, as a community, work to help people live well with dementia, even though they may be impaired and, in some ways, disabled, help people live their best lives with dementia. So if you're curious about how the rest of the world is thinking about stigma, there's a major report coming out this World Alzheimer Month about stigma. But it's a real issue and it's one we ought to acknowledge and find creative ways to deal with it.

I think another not unrelated headwind that we face when we say we want to do something at the local or community level about Alzheimer's disease is that, although there are huge prevalence numbers, we estimate over six million people living with Alzheimer's disease in the United States, we know that much Alzheimer's disease goes undetected, undiagnosed, and in some cases, even people with a diagnosis don't have that diagnosis disclosed to them. There are—so what do I mean by all this? Well, we estimate in the United States across the whole population, only about 40% of people with Alzheimer's or a closely related disorder have a formal diagnosis of Alzheimer's disease in their medical record. And of that 40% that have it in their medical record, one-third have not had that diagnosis disclosed to them. This may be terribly unfair with a group that may be more than 50% women, but I wonder what you would think of those numbers if I used similar numbers for breast cancer, that only 40% with breast cancer have it in their medical record, and of those that get diagnosed with it, one-third don't get told their diagnosis. I kinda suspect there would be a revolution of some sort.

But for cognitive problems, for problems with thinking that are associated and stigmatized because they're problems to be perceived only of the old, it seems somehow that

this kind of state of affairs is okay. Having said all that, public health authorities, tribal, state, local public health authorities are deeply involved in trying to promote both access and resources for early detection and diagnosis all over the country. But it's a real problem because even within ourselves it's a problem. There is a national survey that the public health authorities that has the horrible acronym BRFSS, Behavioral Risk Factor Surveillance survey. It's a telephone survey that's done in every state every year in all five territories to try to get a fix on the basic health situation and perceptions about the health of the population. And for the last five years, there have been questions added to that public health survey about both cognitive impairment and caregiving.

And in fact, last year, and we're just starting to see some of this data come forth, the Office of Minority Health paid for an oversampling in the 11 states with the largest numbers of American Indians, Alaska Natives, so that we could get better data in the BRFSS system about those communities that would be more usable by those communities. Well, one of the questions in the BRFSS of people over age 45 is, has your thinking changed in the last year or two so that it changes how you live your life, does it change how you function? And about 45% of adults over age 45 say, yes, my thinking has changed in the last two years to the point where it's changing how I function. But a minority of them bring that to the attention of a medical practitioner.

So of adults over age 45 who say, yes, my thinking is changing, I have a subjective cognitive decline—that's what it's called formally, and if you go online to the CDC or other websites to see the reports on this, that's what you'll find, subjective cognitive decline—I know I'm changing, I know my thinking is changing, but I don't raise it with my medical practitioners. So this is an area, again, of great focus where—because it may very well be that the earlier signs of cognitive decline, as they are with other health issues, is how we notice how it changes ourselves. I don't have to tell this group anything. I have a lot to learn, constantly have a lot to learn, but with tutors like Dave Baldrige and Neil Henderson and others that have been in—that are of the American Indian community and have been involved in aging and American Indian issues for decades, it's really dangerous to say this, but we know that the American Indian, Alaska Native health system has some gaps.

It has some gaps in funding, in competencies, in access, and not unlike the rest of the health care system, it's not as prepared as it might be to deal with issues of Alzheimer's disease and related disorders. Some of the recommendations in that road map that I've mentioned are about doing a better job to prepare the health care workforce and health care systems for dealing with the large numbers that we have and the even larger numbers that we expect of persons with Alzheimer's and related disorders. One—and we learn this in the roadmap—and one other headwind that we really are working with some national organizations to begin to understand is we don't know an awful lot either from a caregiving perspective or from a person's living with dementia perspective on what the urban American Indian, Alaska Native experience is with Alzheimer's disease, getting help, getting diagnosis, getting referred to help.

We know very, very little, and we're very, very hopeful that fine researchers like Collette Adamson and others, and even the Title VI surveys that will be done this year, will start to shed some light on this. But it's a real gap in our knowledge. There are about three Alzheimer caregiver studies about people who go back and forth between reservation and urban settings to be long distance caregivers done by Dr. Turner Goins from North Carolina, formerly from

West Virginia, and we're even lacking some basic prevalence and diagnosis information about that. So these are all, you know, these are all some of the common headwinds that we're facing as we try to imagine somehow taking action on Alzheimer's disease. Nonetheless, people do try to take action.

In surveys of persons with Alzheimer's disease and their families, this slide, titled Bundles of Benefits, indicates in priority order what people are looking for when they are either receiving—upon receiving a diagnosis of Alzheimer's disease or being told that they possibly have Alzheimer's disease or a closely related disorder. You'll notice the first three are in blue, and I think those are ones that are within the wheelhouse, within the capability of a Title VI director or program or volunteer to handle. The others are higher level and require much more of a community response for the person with Alzheimer disease or their family. But first and foremost, when people get a diagnosis of Alzheimer's disease, and I would bet this is true of almost any disease, they're looking for information. They're looking for accurate and timely information about the disease, about how it's likely to impact their life, ways in which to talk about a disabling condition that will create some deterioration over time, people looking for information.

It's a different function, it's a different benefit that people look for, but people do also look for referral. Can you, as a trusted person in the community tell me who else I can talk to? Are there organizations that work in this area, are there services or sources of support that I need to know about as I'm dealing with Alzheimer's disease or other dementing illness? Folks with a diagnosis early on and a diagnosis of Alzheimer disease and their families are looking for emotional support and connection. Will having a disease that makes it more and more difficult for me to communicate disconnect me from my community? Will I still be able to—one of the important ones that plays out in our community that we live in here in Maryland is, will I still be able to go to my faith community and participate as I have, or will I be seen as somebody who has to be disconnected from the community? And emotional support, you know, people upon—if they really understand that Alzheimer's disease might be a four-, six-, to eight-year process, how can I and who can I rely on for emotional support?

Respite refers to anything that can give a caregiver a break. Long term services and supports take a variety of forms, from home care to some forms of residential care and supported living. Interestingly, very low down on the list, but nonetheless very important, some folks, upon diagnosis, look for opportunities to participate in biomedical research. And only last do people look for medicines. I believe this is because it's well understood in the community that so far we have—although we have medicines that give people more light longer, we don't have any medicines that actually change the underlying course of the disease. So when you think about, you know, what might people expect if visibility is raised about Alzheimer's disease and related dementia in our community, what might they expect of me, who is well-known as a tribal leader in aging services, I think these first three in blue are really—not surprising. I think these would be priority expectations that people might have of you or of people that you—other people that you work with on your broader team. And they're a need, they're a benefit that I think you're uniquely able to provide.

Well, this is not a partisan joke, but—and nobody can answer because you're all muted, but I'm sure you all know the answer to the question, how do you eat an elephant? And the answer is one bite at a time with lots of chili sauce. So this is just a slide, and these slides are

going to be posted so that you can have them, this is just a slide that takes those first three items that I suggested, you know, what's the bite of the elephant that an ordinary, busy Title VI director might be able to take? I think the—if you are willing to take a stand or take some steps about Alzheimer's disease and think that one of your roles is to provide information and support, here's links to a couple of websites.

The Alzheimer's Association, first and foremost, spends more time, talent, and resources trying to be the most current, the most up-to-date, and the most available. The Alzheimer's Association also maintains a 24/7 contact center and helpline that provides information as well as social work support to help people deal with care issues. Its number is 800-272-3900. If any of you are dealing with some of the related disorders, you can contact me offline, but you should know that there now is a Lewy body as well as a frontal temporal dementia association that works on those narrower forms of dementia. The second link here is a link to the public health tribal road map that I've referenced. This is not only basic information about Alzheimer's disease, such as the stages of the disease and the wedge and the umbrella that you saw earlier in the slide deck, but also has some suggestions on community-level action steps from a public health perspective that might be able to be imagined by tribes trying to face the challenge of dementia in their communities.

Not unreasonable, as a source of—trusted source of information, people may ask you, how will I know if I have Alzheimer's disease, and one of the great classics in the field is something called the 10 Warning Signs. This is a handy document that's evidence-based that walks through in a very visual and a very easy-to-understand method, what is it that I need to be worried about if I know my thinking is changing, and more importantly, how do I talk to a medical professional about that. As somebody said once and has said over and over again, Alzheimer's disease is not forgetting where you leave your keys. We all, whether we're deeply forgetful or only mildly forgetful, from time to time, may space out on where we left our keys. It's forgetting what keys are, and this 10 Warning Signs is a very helpful document to have around and have handy if people have curiosity or questions about whether or not changes in their thinking are, in fact, a sign or an early warning sign of some possible dementia.

Moving into more of kinda the prevention and public health risk reduction area, I do want to point out that the Centers for Disease Control has funded the International Indigenous Aging Association, IA<sup>2</sup>, to partner with ASTHO, the Association of State and Territorial Health Organizations, to create a number of brain health materials to be used. These include public service announcements for radio, television, or video public service announcements to be used either in meetings or as links on your website and a number of posters and handouts that talk about that heart health, brain health connection so that we can begin the conversation much, much earlier, much, much more upstream, as the public health folks like to say. So these are my suggestions to you with, as I know, very incomplete knowledge of what your daily lives might be like, but I think, as I said on the previous slide, I think, as a trusted elder and a trusted person involved in services to older adults, people might turn to you about questions about both emotional support, direction in terms of getting a diagnosis, and just basic information and support about the disease. And, as I said, the first bite of the elephant might be one of these, it might be all of these.

This picture is recent. I'm very proud to have been a speaker at a summit. Some of you may recognize, in front right, a wonderful lady named Carla from the Pyramid Lake Paiute Tribe,

who, working with a professor at the University of Nevada - Reno, has been in the forefront of helping that tribe become a dementia-friendly community. And by extension, this wonderful shot is a picture of, I believe, the 11 tribes represented two weeks ago when we had first ever Dementia Summit hosted by the Pyramid Lake Paiute with brilliant ceremony, good heart, unbelievable food, and the friendliest people on Earth.

You may notice a couple of gentlemen in the picture. The gentleman in the back, hiding, is Dave Baldrige from Albuquerque who is Cherokee, and on the far right is Dr. Neil Henderson, who is a damn genius about dementia and diabetes. He's Choctaw and he now works at the University of Minnesota in Duluth. And the ladies here are all representatives of the other tribes of Northern Nevada, and one from as far away as Omaha, from Iowa, who came to this summit to learn, to plan, and to begin to think about what they could do as leaders in their communities about the growing challenge of dementia. I'm real proud of these guys and really love the picture. Anyway, I think this is the point—here's my contact information, and this is the point where I would ask our moderator to come back on the line and manage questions and answers.

**OPERATOR:** Thank you. We will now begin the question-and-answer session. If you would like to ask a question, please press star-one, unmute your phone, and record your name clearly. Your name is required to introduce your question. If you need to withdraw your question, press star-two. Again, to ask a question, please press star-one. It will take a few moments for the questions to come through. Please standby. [Pause] I'm showing no questions at this time.

**MIKE SPLAINE:** Camille(?), your name is on the roster here. Good afternoon, Heidi and Jacque(?). It's like I'm on television reading a list of who's who. Well, you know, there's no reason—I don't know [chuckles] what Cynthia would say, nobody ever died if a meeting ended early. I think Cynthia would agree with that. If, after the call, you've got my contact information here, I'm pretty easy to find because, you know, in terms of sending me along—you know, or feel free to send your questions, any remaining questions or questions that come into your mind after we're done, sending those either to Melissa or to Cynthia LaCounte and her team, that includes Cecilia Aldridge, sending them on to the team for action. I have—you know, I prepared this to be short and dialogical, and if we're done, we're done. So let me ask one more time, if nobody has—let me ask the moderator to ask one more time or hold for any remaining questions or any questions.

**OPERATOR:** One moment, we have one question.

**MIKE SPLAINE:** We have one question, okay.

**OPERATOR:** Dave Baldrige, your line is now open.

**DAVE BALDRIDGE:** Mike, thank you for a great presentation. This information is really helpful, and I don't think it could go to a more important group than our Title VI directors. I just wanted to add a quick mention that we're working on a dementia chapter for the upcoming Title VI Manual, and it will be—it will include much of the information you provided and hopefully be a



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lot of help to the directors, and I'm really excited about it, and thank you for your leadership in helping put all of this initiative together.

**MIKE SPLAINE:** Yeah, well, wisdom of elders like you have been a big, big, big part of why I've been able to do this in the last couple years, so thank you, Dave. Well, Melissa, I'm going to sign off. I see no reason to keep people on the phone if—as I said, if people have further questions, they know who to be in touch with, and we thank you for your time and your support and for what you do every day to make older persons' lives better. I'm going to sign off and that will end the call.

**OPERATOR:** That concludes today's conference. Thank you for participating. You may disconnect at this time.

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