

Addressing Brain Health in the American Indian and Alaska Native Communities

Applications from the [GSA KAER Toolkit for Primary Care Teams](#)

Momentum Discussions Podcast from the Gerontological Society of America

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The Gerontological Society of America, meaningful lives as we age.

Jen Pettis:

Welcome to this GSA Momentum Discussion podcast episode titled, Addressing Brain Health in the American Indian and Alaska Native Communities. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Genentech, Lilly, Eisai, and Otsuka for their support of [The GSA KAER Toolkit for Primary Care Teams](#) and today's podcast. My name is Jen Pettis, and I'm the Director of Strategic Alliances at the Gerontological Society of America (GSA). I'm pleased to serve as the host for today's Momentum Discussion. I'm so happy to be joined by Michael Splaine, a Principal with Consulting and Managing Partner with Recruitment Partners, LLC. Mike is a contributor to the [CDC's Healthy Brain Initiative](#), along with a wide variety of communities of interest, including GSA and the [Healthy Brain Initiative Roadmap for Indian Country](#). Mike also consults with the [International Indigenous Aging Association](#) and the [Great Lakes Intertribal Council](#). Mike is not a tribal citizen but is a leader in addressing brain health and dementia in the American Indian and Alaska Native communities, as well as a great friend to GSA. Mike, I'm so glad you could join me.

Mike Splaine:

And a lifelong member of GSA, or as somebody said, so far.

Jen Pettis:

It is great to have you here, Mike. Thanks so much.

Mike Splaine:

Great to be here. Thank you.

Jen Pettis:

Mike, the American Indian and Alaska Native people have long experienced lower health status when compared with other Americans. How about brain health in this population? What disparities exist and what challenges do we need to overcome to promote brain health in this population?

Mike Splaine:

This is a tough one because the diversity between and among tribes about how our American Indian citizens live and where they live feel like they're infinite permutations. What I mean is that 60% of people who identify as American Indians live in urban areas. If the picture that immediately comes to mind when we say American Indians and Alaska Natives is reservation-dwelling Indians, that's only part of those who identify as American Indians. Diversity is a challenge. In many health studies, race is not necessarily a category. For example, when we look at Medicare data, for the older population and those with disabilities, Medicare doesn't track race.

In general, yes, American Indians and Alaska Natives do have lower health status when compared to other Americans, including their brain health. There are three perspectives on that. First, we are now beginning to understand and deploy resources toward risk reduction of dementia in late life. To the extent that risk factors like diabetes and untreated hypertension are high in American Indian communities. There's a story to be told about the greater risk, but also the greater opportunity for doing something about that risk in American Indian and Alaska Native communities. A second comment about brain health in the population is that trauma - historic, current, and actual trauma to individuals in terms of the rates of road accidents and lack of helmet use, adds injury to insult to the already existing higher risk factor for poor brain health in late life.

I think the third disparity that I would mention is that, particularly for reservation-dwelling American Indians who rely on the [Indian Health Service](#) and its components to provide their basic healthcare, all experts agree that the Indian Health Service has about 10% of what it needs to do its job. In that environment, brain health may be seen as a luxury and assumptions made that American Indians have shorter lifespans, therefore, issues of chronic disease in old age like Alzheimer's and related dementia aren't going to be as prevalent, which is turning out to not be true. The American Indian and Alaska Native communities, and the native Hawaiians, are aging rapidly. Concern and awareness about Alzheimer's disease and related dementias, whether it's risk or it's actual people with dementia, is justifiably coming to light. It's becoming a brain health issue in Indian Country.

Jen Pettis:

Mike, what are the underlying principles of your work with the American Indian and Alaska Native communities around a variety of issues, including brain health? How could these be applied to work around brain health with other diverse and underserved populations?

Mike Splaine:

A wonderful Ojibwe man, named Steve Chapman, who was my cultural guide when I started working on the Roadmap for Indian Country five years ago, told me through hand gestures, that I need to listen and see much more than I talk. The underlying principle is if you're not a tribal citizen, you shouldn't pretend that you understand. That doesn't mean you cannot be understanding or that you cannot be a sympathetic and good listener. Many people fail when they work interculturally because they're so full of their message about what they want to talk about. They don't leave room for listening and learning.

Other people call that cultural humility. I just call it respect. The first fundamental principle is listening more than you talk. Health people as a rule, whether it's a disease group or it's a health promotion of some sort, are on a mission to tell you something. Instead, they should take a minute take a breath, and listen. I am given respect for having white hair that I get nowhere else in America, except when I'm with Indian people. Another principle is that it's hard sometimes to understand that although American Indians and Alaska Natives are American citizens, they're also tribal citizens, and the word sovereignty comes into play.

When we work interculturally with American Indians, we should understand deeply that they are sovereign nations. They have their own laws, traditions, and police forces. You can get a ticket from a Chickasaw cop on the reservation. Sovereignty is important. When it comes to data and ownership of things like genetic information, there's been some real sins against tribes in terms of that sovereignty not being respected including in the Alzheimer's and dementia space in which I work. I remember when I was starting to go find case studies for the Roadmap for Indian Country, four years ago, I went to some of the Southwestern tribes. I said, well, I'm here to talk. I'd like to listen and learn what your experiences are with Alzheimer's and dementia.

I was stone-walled. "Oh, we know about that," they said. I got the crossed arms and that was the end of the conversation. I found out later that researchers had been in there to do their thing and hit and run and disrespected sovereignty. The flip side of sovereignty, respect, and listening is we have these wonderful opportunities to co-design solutions. I've never been anywhere in American Indian communities where my knowledge about dementia and related caregiving is not respected. That doesn't mean people want to be told what to do, or the solutions that come from the dominant culture. They want to discover their own cultures. We have these wonderful opportunities, whether it's basic research or understanding and supporting caregivers promoting brain health, to bring what we know as gerontologists or as aging specialists to the community but work with it in such a way that there's a respectful opportunity for co-design. I think that of all the adventures in the last three or four years with Indian Country, for me, it's these opportunities to build together, to collaborate in the literal words of Latin, to work together. That's exciting.

Jen Pettis:

You mentioned opportunity when you mentioned the great risk that folks face that creates opportunity. Then I heard how you can use sovereignty as another opportunity to allow folks to drive their own solution. It's so rich to hear you in this discussion.

Mike Splaine:

We have a silly project right now about culturally appropriate dementia food plating. We know that people with dementia have trouble with white-on-white. There's a whole body of knowledge about how to present food to people with moderate-severe dementia.

Mike Splaine:

How do we do that in keeping with a culture? It's just been fun to go out with open hands and say, teach me, what can we do together? Who's smart about this? It's just a different way of doing the work that's just so much richer than coming in, like the smart guy who knows everything.

Jen Pettis:

That must be so rewarding. I'd like to switch gears now and talk a bit about the [Healthy Brain Initiatives Roadmap for Indian Country](#). Mike, can you share a bit about an overview of the Roadmap, the broad approach, and its intended audience?

Mike Splaine:

In the words of my great friends from Virginia, "Public Health is the health of all y'all." The Roadmap for Indian Country is a document to provide guidance, action steps, and suggestions to Indian tribal and urban Indian health center leaders, and tribal leaders more generally, about public health approaches to dementia and related caregiving. It's not everything; it's not social service approaches, it's public health approaches. Our experience with implementing the Roadmap in the last four years is that because the structures and resources are different, public health actions are just as likely to be taken by somebody who is technically not a public health actor, as somebody who, for example, runs aging direct services. It's just important to realize that although the emphasis is activities that can improve the health of everyone, a lot of the folks who have picked up the Roadmap and run with it are folks who are not technically public health folks.

Public health is everywhere and often operating in the background. If you like clean water and clean air, you like public health. You just didn't know it. I think there's that to think about. Why did we write a Roadmap for Indian Country there? The Healthy Brain Initiative is a project that has been funded by Congress for almost 20 years now. It's a collaborative agreement between the Alzheimer's Association and the CDC. It has produced Roadmaps giving directions to the public health field for state and local public health officials. We went out to Indian Country with that Roadmap for state and local public health. It didn't connect. We realized between that and the growing risk factors, and the growing understanding, Some real early adopters of doing stuff about dementia in Indian Country, such as Jane Neil Henderson from Minnesota, the Banner Health System in Arizona, Dr. Blythe Winchester, and Bruce Fink from the [Indian Health Service](#), all of whom said you need to do something unique for Indian Country, which we did. We stopped beating our heads against the wall, bringing the state and local approach out to very different traditions and structures. The broad approach is public health. Its intended audience is [ITU services](#) as they're called Indian Health Service, Tribal Health Services, and Urban Indian Health Center leadership and Tribal leadership, more generally.

Jen Pettis:

I understand there are eight public health strategies outlined. Can you share a bit about them?

Mike Splaine:

The eight actions are divided into categories. One of the categories is strengthening the workforce, and one action item that will sound very noble and doable is to educate healthcare and aging service professionals in Indian Country about the signs and symptoms of dementia and about caregiving for persons with dementia. That would raise the public health approach to education. Educating the workforce about the signs and symptoms of dementia seems doable and practical.

Mike Splaine:

As the prevalence is on the rise and as awareness that dementia is not normal aging, it's almost as if every community must go through this phase of thinking about dementia and related caregiving so that they get to understand it in a felt way and act on the fact that dementia is not normal aging. Not all of us need to lose our faculties before we pass on or walk on. This community's learning that lesson, too. That's an example of public health action because it affects all of us that comes from the Roadmap. It can be done at many levels. That's the other thing I love about a public health approach. It could be done locally, on or off a reservation, or nationally. We work with the [International Indigenous Aging Association](#) who also have funding from the Centers for Disease Control. They have created a whole body of culturally appropriate dementia tools that are now available to the whole community that didn't exist four years ago.

Jen Pettis:

You mentioned a few organizations and people that have done some great work. Can you share a couple of success stories with Indigenous communities looking at dementia issues?

Mike Splaine:

In Wisconsin, the state funds through their aging network, several dementia care specialists, who are folks that work at the community level to do dementia awareness, to mobilize concern, and to bring people together around what can be done locally about dementia to help people with dementia and their family caregivers live better lives. Three years ago, the state added to its body of dementia care specialists a position for every tribe. Now we have tribal dementia care specialists. They work side by side with their non-tribal folks. They get the same background in education, and support, and work statewide, but they work in their own way, within their tribes or in their multitribal organizations. That's a living example of a very high level of commitment to do the right thing, but to do it in a culturally appropriate way. In some of those tribal organizations, they're not called dementia care specialists because it doesn't click. One great example of action that's been taken is how my friends at the [Great Lakes Intertribal Center \(GLITC\)](#) have adapted the job description to be more meaningful for the Upper Great Lakes tribes.

Another one is our friends in Nevada, the [Pyramid Lake Paiute](#); go to Reno and go 80 miles inland to the Great Basin. Five years ago, the Pyramid Lake Paiute found out about dementia-friendly communities, and how they could get trained in using those awareness tools on their reservation. They're wonderful implementers of all the principles, but also all the activities in dementia-friendly communities. Using the tools of [Dementia Friendly America](#) to raise awareness are some examples.

The Alzheimer's Association holds a leadership role in a Healthy Brain initiative, and a leadership role in trying to bring diversity, equity, and inclusion to the world of dementia and related caregiving. Through its chapter network develops partnerships to work at the tribal level or within the Urban Indian Health Centers to provide information referral first-level support for people dealing with Alzheimer's or thinking they're dealing with Alzheimer's disease. It tracks where tribes are.

Mike Splaine:

There's a lot more activity in Oklahoma than there is in Maryland. That's because there are 39 tribes in Oklahoma. We have two tribes that have headquarters here in Maryland.

Jen Pettis:

You've told us a lot of things that folks have learned, but I suspect that there are lots more questions to be answered. What are some of those open research questions that need to be answered for the work to be more successful?

Mike Splaine:

We're in the process and a wonderful leadership committee. There'll be a Roadmap for Indian Country II, coming out at the end of this 2024 calendar year, hopefully in time for GSA in November. There's work underway on a new Roadmap, which is why these kinds of ideas about open research questions as well as success stories are so important. One thing that troubles us all is understanding the pathway to support, care, identification of dementia, support, and care for family caregivers for those 60% of American Indians and Alaska Natives who live in urban areas. Our friends at the University of North Dakota have recently published something called the [NUENAS](#) Study, which was based on surveys of about 1500 urban-dwelling American Indian elders.

That information is very easily available and generates new questions about whether people are more at risk regardless of whether they get health care. Are Urban Indian Health Centers deploying tools like the [Medicare Annual Wellness Visit](#) or the [GSA KAER Toolkit](#) as part of the routine care that they're delivering to older adults? Are Urban Indian Health Centers taking advantage of the billing tools in Medicare to both promote brain health, identify dementia, and support people with things like care planning? Those are some of the mysteries. Those are some of the research questions. There's a wonderful researcher that's onto this, that's a lot of commuting. My friend [Turner Goins](#), who I know is a GSA member from down in North Carolina, coined the term "commuting caregivers" because there are people who live off-reservation and yet go back for caregiving duties.

There are four young adults that I met in Las Vegas who own a crappy car and live in a terrible apartment in Las Vegas four nights a week because that's where the work is. On Friday night, they all pile into the crappy car, pool their money and go back to the reservation to take care of the grannies and grampies. It's a commuting caregiving. I'd like to understand that more. That's taking your citizenship really to another level, but it's also family. That's the great story about Alzheimer's all over the world. The care system for people with Alzheimer's and dementia first and foremost is, and in many places is only, families. It is just a different expression of that same dynamic that I think is an open research question.

Jen Pettis:

I had not heard the phrase "commuting caregiving," but it makes a lot of sense. I could go on and on with our discussion today. I enjoyed this discussion so much, Mike. I've learned so much as I always do when I listen to you, I am just going to mention a couple of things that really stuck out for me. You started talking about the diversity of where and how American Indian and Alaska Native people live and about the overall risks of the individual's health and why there is greater risk, there is also greater opportunity. I always love to hear you talk about, "listen more than you talk," and the idea of that listening and the respect and the coming up with solutions together so resonated with me. What are some key points you want to leave listeners with that I didn't mention?

Mike Splaine:

There are flocks of resources here. I mentioned the KAER Toolkit, which I know GSA is super proud of. It works if people apply it. There are resources here: [International Indigenous Aging Association](#), the [Alzheimer's Association](#).

Mike Splaine:

There's no lack of resources, and there'll be more as we take this public health approach. For the GSA research audience, think long and hard about how you include or could include people in an advisory or in a driver's seat basis about your research. If you're curious, whether it's about biological sciences or the social sciences, I think you will accelerate the pace and the quality of research, not to mention recruitment, if you get your sleeves rolled up and sit there and listen when people say that's an impossible protocol, can we work on that together to make it more possible?

I think there's some wonderful science opportunities here. It begins with that respect and listening. The last thing I would say is don't assume that American Indians and Alaska Natives don't know about these issues but do know that they have their own way of knowing and their own way of talking about it. It's important to know that and respect that there is an Indian way of knowing that may be far beyond just what we can physically count and understand empirically. That's what culture is.

I need to end with a story there. I'm of Irish Catholic culture. When people ask whether I'm tribal, I say, no, but I'm Irish Catholic. That's close. Believe me, it can be. The next part of the story is do you know about the Irish Catholics and the American Indians? Some people don't and some people do. It turns out this gets to the Indian way of knowing. In 1847, at the end of the Trail of Tears, which is when our American government forcefully took all the people who were living peacefully in Georgia to Oklahoma and relocated the American Indians from the East to the Midwest, was also the first year of the Irish Potato Famine, which ultimately led to over a million people dying or immigrating out of a population of seven and a half million on that little island. The Choctaw heard about the famine. We don't know how, but they raised money. At the end of the Trail of Tears, they raised \$25,000, and they sent it to Ireland so that the Irish could buy food to keep from starving.

That money went to a village on the Skibbereen Peninsula, which is one peninsula away from where my people, the Salons are from in County Cork, Ireland. There is a magnificent monument in Midleton, County Cork, Ireland to the Choctaw, even though they were flat on their backs themselves, responding compassionately to the people who were so troubled and starving in Ireland. It's just part of the interconnectedness of mind, body, spirit, and solidarity that we all ought to treasure and appreciate. You could look it up, Midleton County Cork, Ireland. It's a beautiful monument, stainless steel, and it's 20 miles as the crow flies from where my grandfather is from.

Jen Pettis:

The story is a great way to end. Mike, thank you so much for your time with me today. I have enjoyed this discussion a great deal, and I am sure that those who listen to it will enjoy it and find it extremely informative. Thank you for all your contributions to GSA's work, Mike. I appreciate it.

Announcer:

The Gerontological Society of America was founded in 1945 to cultivate excellence in interdisciplinary aging research and education to advance innovations in practice and policy. For more information about GSA, visit geron.org.