

## Addressing Brain Health in Adults with Intellectual and Developmental Disabilities

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

GSA Momentum Discussions Podcast from the Gerontological Society of America

Recorded November 10, 2023 at GSA 2023 in Tampa, FL

---

**Guest:**

**Lisa Comes**

Service and Support Advisor

Ohio Association of County Boards of Developmental Disabilities



**Host:**

**Jennifer Pettis, MS, RN, CNE**

Director of Strategic Alliances

Gerontological Society of America



---

**Announcer:**

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

**Jen Pettis:**

Welcome to this GSA Momentum Discussion podcast episode, Addressing Brain Health in Adults with Intellectual and Developmental Disabilities. Momentum Discussions highlight topics experiencing great momentum in the field of gerontology. We're grateful to Eisai for this podcast episode and their support of the new GSA publication, *Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities: A Companion to the KAER Toolkit for Primary Care Providers*. My name is Jen Pettis, and I am the Director of Strategic Alliances at the Gerontological Society of America. I am delighted to serve as the host for today's Momentum Discussion podcast episode. Joining me today for this podcast is Lisa Comes. Lisa is a Service and Support Advisor with the [Ohio Association of County Boards of Developmental Disabilities](#) (OACB) and a member of our expert review panel for the new GSA KAER Companion to the KAER Toolkit. We are recording this episode of our Momentum Discussion podcast in the podcast booth at GSA 2023 in Tampa, Florida.

**Jen Pettis:**

We are delighted to have OACB as a collaborating organization on the new Companion to the KAER Toolkit, along with the [National Task Group on Intellectual Disabilities and Dementia Care Practices](#), and the [Ohio Council for Cognitive Health](#). Lisa, thanks so much for taking time out of your busy schedule to participate in the GSA Annual Scientific Meeting here in Tampa and for sharing your insights around kick-starting brain health conversations with adults who have intellectual and developmental disabilities.

**Lisa Comes:**

Thanks for having me.

**Jen Pettis:**

Certain groups of individuals with intellectual disabilities and developmental disabilities (ID/DD) develop dementia at rates like older adults in the general population. However, adults with certain conditions such as Down Syndrome develop Alzheimer's disease at greater rates. Can you share some insights into brain health disparities in this population?

**Lisa Comes:**

Dementia and Alzheimer's are pervasive in people with Down Syndrome. Findings show that dementia can develop in 30 years olds adults with Down Syndrome, and the likelihood increases through their 40s, 50s, and 60s. Not only is it prevalent but it is earlier onset than for adults without developmental disabilities. The numbers that we've heard are 2% of people with Down syndrome develop dementia in their 30s and then 10% to 15% in their 40s, 20% to 50% in their 50s, and then by 60 years of age it can be 60% to 90%. There is a strong connection there.

There are many intellectual disabilities and developmental disabilities (ID/DD), and we don't see those same numbers in the aging community. But we really don't know, as people with intellectual and developmental disabilities are living longer than they ever have. Twenty years ago, there was not as high a population in their 60s and 70s. Our forecasts show that we're going to have twice as many people with intellectual disabilities in 2030 than we had in 2002. Through research collaboration, we can learn if there are any other developmental disabilities associated with increased dementia and Alzheimer's.

**Jen Pettis:**

This is interesting information and insight. We know that you have the "boots on the ground" experience working in this community, which is why your insights are so valuable to share things like unique challenges that we need to address to improve brain health and early detection of dementia for individuals in this community and in with intellectual and developmental disabilities.

**Lisa Comes:**

My background includes 20 years as a caseworker. We call them service and support advisors in Ohio. In addition, I have a 25-year-old son with developmental disabilities living at home with me. Recently, I've gotten involved at the state level in supporting those caseworkers. My love is helping caseworkers and people with disabilities have great relationships and thrive. The challenges that we see in diagnosing and early detection of brain health issues is that as people develop conditions that are more common in older adults, like dementia and Alzheimer's, very often they're not recognized as such because doctors assume it has to do with the disability.

**Lisa Comes:**

The primary care physician often doesn't know the individual well. Adults with ID/DD might change doctors often, and the physician isn't allotted the time to understand that the progression of dementia is something different for somebody who always has needed help getting dressed, for example. When the caregiver explains that the progression of disease means that the adult with ID/DD can't independently manage the tasks that they previously were capable of. From a doctor's perspective, what's the difference? I think that the idea that they attribute most things to the diagnosis of the disability is probably one of the worst things. Similar groups have those same issues around limited healthcare. Much of their care is done through a family practice physician that may or may not know them well, but they also may be being treated in hospitals and urgent care where you don't see a longitudinal relationship between the doctors and the adults with ID/DD.

The concept of aging for someone with intellectual and development disabilities is rather new. There's a stereotype that people with disabilities are young. Even if their birthdate shows that they're 65 or 70 years old, they may look like they're 40 or they may behave as if they're 40, or even 20. We're not thinking enough about asking those deeper questions around aging. Everybody calls my child such a good kid but he's 25, he's not a kid anymore.

**Jen Pettis:**

A whole different frame around really looking at folks individually is important. The second step of the KAER Framework is to assess cognitive impairment. What are some best practices in obtaining baseline functioning for people with ID/DD? I heard you talk about longitudinal assessments. Could you elaborate on that?

**Lisa Comes:**

In our field, it's important for caseworkers to interact with someone who has known the adult with ID/DD throughout their life. Getting baseline information from the caregivers and family about the adult with an intellectual or developmental disability is vital to learn about their behaviors and activities when they were 30 and identify the most independent period of their life. That tells us about where they are now in relation to their baseline. Are we in a good time or are we not in a good time? One of the more respected assessments to get good baseline information and start doing it early would be [NTG's early detection and screen for dementia](#).

It's an opportunity to review the skills, abilities, and weaknesses and determine what has always been a difficulty compared to a recent decline. Using dressing as an example, if an adult with ID/DD has always needed assistance with buttons and zippers but didn't previously need help with putting arms in or the coat is now being put on backwards then there is a notable decline in self-sufficiency. It's important to be aware of whether this a new symptom in the past year or is this something that is not an issue? I love that tool and I think, in the ID/DD area, we'd really like to start using that tool earlier in the detection. I was at a conference in the Spring, and we talked about adding an initial column to document the first time we notice a change in abilities. Whether somebody is 20 years old or 30 years old, let's document that earlier to have something to build on. That's certainly one of the more standard things that we like to think about. The other factor in obtaining a baseline is to consider from whom information is being sought.

**Jen Pettis:**

Perhaps with the idea of obtaining information from an individual that has the intellectual or developmental disabilities, but at their baseline they have that significant communication or verbal impairments, and perhaps they don't have a caregiver that's been consistent in their life. How are you able to deal with obtaining that information?

**Lisa Comes:**

It's hard for all of us and one of the biggest struggles in our system for caseworkers is just getting to know their clients. I think the most important thing is to slow down and spend some time with them. It's best if there is time for somebody to do an activity with a client. I understand medical professionals don't have that time, but even just sitting down and writing your name with somebody or drawing a picture with them, finding out if they can draw pictures, and watching them. Learning from their caregivers if they use any kind of augmentative communication. Unintelligible speech is a common symptom which my son exhibits with about 50% of what he says being incomprehensible.

One of the accommodations that we've made for him is to use text to speech since he can text very well. Improved technology has become more user friendly and a great asset for communication. While there are communication devices, we must continue to rely on caregivers and work with them regardless of how long they have been working with the adult with ID/DD. It would be useful to provide the caregiver with the NTG tool to review and ask them to observe their clients and report any behavioral changes. Caregivers may not initially be aware of changes because they are focused on helping with daily activities but not necessarily taking on an observation role of progress or decline in capabilities. It's going to take somebody doing a lot more observation, a lot more listening. Many folks that I work with who don't have speech are able to nod their head in consent or shake their head in dissent. They can smile, they can tell you no. There are multiple ways for them to communicate, but the communication process does take a little bit longer and requires a little more patience.

**Jen Pettis:**

In the third step of the KAER framework a clinician evaluates dementia. Can you share some key tenets of assessment for dementia in an individual with intellectual or developmental disabilities? I want to stress that it's important that the baseline for those individuals is captured and we're looking longitudinally over time. What are some other key tenets you might want to share?

**Lisa Comes:**

One of the cool things that's going on in the developmental disability system in Ohio is that we are doing a lot more to help families with planning. We're offering families more support by asking them to write letters of intent and videotaping important days or times in their person's life. One of the popular tools that we deal with in our planning is 'a day in life' where we go through and just talk about what kind of supports a person needs to get through the day.

Those tools are useful for professionals who are working with adults who are developing dementia. We have had these plans for years. We start serving people anywhere from birth to 22 years old, and we keep their plans until they are well past their 60s. There should be some good historical information as we continue this model of planning and documentation, which is another important factor in creating a baseline of information. It's important to remember that adults with ID/DD are individuals as are their capabilities, communication, and needs.

**Jen Pettis:**

Lisa, the final step of the KAER framework is to refer for community resources. What resources are available to assist medical professionals or state aging agencies in creating more support for people with ID and DD in their state?

**Lisa Comes:**

It is vital that we all work together on these processes. We have some large systems that support people with intellectual disabilities and developmental disabilities. I don't think we can do it without each other. I think we need to really make sure there's some great resources. You can go to the [National Association of State Directors of Developmental Disabilities](#) and you can click on your state, and they will give you the state's intellectual/developmental disabilities agency. It's important to find out who in your state is the agency that works with that field, and do they have ongoing case management and work, and did they know this person, do they know if there is somebody we could talk to from there?

Developing collaboration is essential. A lot of the state agencies on developmental disabilities now have medical directors and connecting with them and starting to collaborate with them on how we could get more information across the systems would be helpful. That's something Ohio's been doing by utilizing the resources of the National Task Group on Intellectual Disabilities and Dementia Practices. It was amazing to have them able to provide as much support as they have.

[Dementia Friends](#) is another great program providing support. Dementia Friends is good for the community at large. It's good for everybody. It crosses all types of people and is an opportunity to think about how we live as a community and support other people in our community who might have dementia. It's kind of that idea of universal precautions. You never know who you're talking to if they're over the age of 60, let's just be kind.

The other website that I really like is the [Ohio Council for Cognitive Health](#), which offers resource tools that can be shared with caregivers, families, and the community. Bonnie Berman, who heads the Ohio Council for Cognitive Health has been super helpful.

The last thing I was going to talk about is the GSA KAER Toolkit. I've had the privilege to work with Jen and some other folks from both NTG and the Ohio Council for Cognitive Health who are working together to develop a Companion Guide for the KAER Toolkit, focused on intellectual disabilities and developmental disabilities. We're excited to roll it out in Ohio. There's a lot of opportunity now to support those caregivers and the people with dementia.

**Jen Pettis:**

Thank you for joining me. This has been a fun discussion, and we are very excited that GSA will be rolling out that companion document in Ohio very soon. It will be freely available at [geron.org/brainhealth](https://geron.org/brainhealth) where all our brain health resources are available for free. Folks are welcome to download them and use them in their practice. Thanks again, Lisa, for joining me for this podcast episode and for joining us here in Tampa at GSA 2023.

**Announcer:**

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