

Improving Care for Adults with Intellectual and Developmental Disabilities

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[Matt Hoffman](#)

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Seth M. Keller, MD, chair of the Section for Adults with IDD's at AAN, shared his perspective on the state of care for these individuals and the need to improve the difficulties they face when transitioning out of pediatric care.



Seth M. Keller, MD

In 2021, the American Academy of Neurology (AAN) announced the formation of a new group in the organization: the Adults with Intellectual and Developmental Disabilities (IDDs) Section at AAN. With the intention of providing resources and training to improve the care of children and adolescents with intellectual and developmental disabilities, the section is headed by Seth M. Keller, MD.

Infants, children, and adolescents with IDD are often faced with comorbid conditions such as epilepsy, cerebral palsy, and autism, and are most often cared for by pediatric neurologists. Although, when these young individuals become adults and transition into adult neurology care, they are often faced with challenges, as these neurologists have been historically ill-equipped and undereducated on how to appropriately care for them.

At the [2022 AAN Annual Meeting](#), April 2-7, in Seattle, Washington, *NeurologyLive*® sat down with Dr. Keller, a board-certified neurologist in private practice with Advocare Neurology of South Jersey, to discuss the needs of these patients and the goals of the section, the leadership of which also includes vice-chair [Bhooma Aravamuthan, MD, DPhil](#).

***NeurologyLive*®: Could you provide some background on the Adults with Intellectual and Developmental Disabilities Section at AAN?**

Seth M. Keller, MD: The section itself represents the patient population of adults with intellectual and developmental disabilities. For instance, this would be people that have autism, cerebral palsy, and Down syndrome, who have a whole host of neurodevelopmental disabilities ever since, basically, they've been born. Our section is focusing on the issues relevant to them when they transition from a pediatric to the adult world. Their types of complications—which are complex in this patient population—include epilepsy and various seizure disorders, but also movement disorders, and spasticity. I focus not only on epilepsy myself but on the aging population, those with the same type of condition, developmental disabilities, that are older adults. For instance, one thing that's very, very prevalent in the developmental population, specifically those with Down syndrome, is early-onset Alzheimer disease. In those with Down syndrome, it's a challenging and difficult situation—60% get Alzheimer by age 60. It's a real challenge and a tragedy when these difficulties arise in this population.

From your perspective in the field, as far as the neurologists and the clinicians are concerned, do you think that the patient voice still needs more of a presence in the room?

Let me put it this way. When children with intellectual developmental disabilities, they're brought in with their parent advocates, who have a very strong, loud voice for their children. And so, in pediatrics and pediatric neurology there's huge attention often for developmental disability because of parents being at the forefront and because pediatrics has education and training, it's got centers, and you can get board certification in pediatrics for developmental disabilities. The challenge is basically when they grow up, and they turn 18 years old, they go to adult providers—adult neurologists—and that's where basically things hit the wall. That's because the adult neurologists, basically, are not at all getting any education and training in medical school, they're not getting any training in residency or fellowship, in the care of the neurologic complications of adults with IDD. A big part really starts in the transitioning process, trying to find a so-called good or knowledgeable adult neurologist who understands those with Down syndrome, understands those with cerebral palsy, who understand those with autism who are developing neurologic complications, and are trying to find an adult provider. It's been very difficult. There have been papers written

about it by not only AAN, but other organizations like the [Child Neurology Foundation](#), that are trying to help figure it out. The problem is there's a lack of education and training for the adult neurologists.

How does that transition process different for this patient population? Are there ongoing efforts to address those challenges specific to them?

There's not enough. I would like to admit that there's a lot being done, but right now, the creation of a section was born in that situation to be able to address those issues. One would be the complexity of the seizures, and it would be several people who have syndromes. You and I were just talking earlier about the different ones: Dravet syndrome, Lennox-Gastaut syndrome, tuberous sclerosis complex—just to name a few—these different syndromes basically, are genetic. These genetic syndromes are not really appreciated or well-known by adult neurologists.

The other complexity is that adult neurologists may not really appreciate them as people with value or that need equity of care. And that's the other part about it. They may not be able to—because they're not really trained about seeing an adult with an intellectual developmental disability—to provide care for them. To care for someone—this is kind of a philosophical comment—and to care for a patient, you obviously can know a drug, you can know a disease, you can order a test, but to provide care for them, you have to be able to, at some level, connect with them as a person who has value. And I'm not trying to throw anyone under the bus about it, but you must really connect with them. There might be a disconnection between a neurologist or any other healthcare provider—not just neurology, really any healthcare provider—about connecting to someone who's not a little child, is not with their parent, someone who you may not have the “warm and fuzzies” for as much as you could with a child.

There are also a lot of common behavioral challenges. People might have autism, seizures, or other kinds of common behavioral problems. The physician and the neurologist may not have that comfort level and be able to deal with or cope or handle a lot of concomitant behavioral issues with their neurologic complication. The other part about it is that the caregivers sometimes may not be the mother and father. There's a decent percentage of adults with intellectual developmental disabilities that may not be living with their mother and father anymore. But if they are, they might be aging parents or they're living in a group home, and the healthcare provider or neurologist may not be able to appreciate who the supporting provider is with them. A direct support professional, who is that person? What do they do? What's their decision-making in terms of them being able to have a voice or proxy for them or not?

Then, trying to get feedback and trying to get information back from the patients, who you are not able to provide a lot of information because they may be poorly verbal or nonverbal. There are several complications that might make the neurologist not really feel comfortable, especially when they're not provided education and training at all, and they're trying to almost care for them like they would someone who does not have developmental

disabilities when there's a good number of difficulties or challenges that are different than normal, typical populations.

How do we go about addressing that?

Part of it is education. There's a very important and appreciated nature for equity of care for diverse populations at AAN, and there's no other patient population that really has as many challenges of equity and access to quality services as adults with IDD. Right now, we are working very closely, which is a wonderful thing, with the AAN in addressing exactly that. In our section and with the leaders in our section, which is really growing across the country and internationally, we are trying to be there as the voice. That's why we're a section, we're trying to be there as the voice for adults with IDD, so we can ensure that they have that voice in talking about what it means to get an education, and what it means to get training.

But how do we get it? Besides in our annual meeting, how do we get printed material that neurologists, through their training, can learn from? Also, we really, deeply appreciate the importance of advocacy, whether it's a parent organization or an organization that supports various syndromes, like the [Dravet Syndrome Foundation](#), [Lennox-Gastaut Foundation](#), or others. We appreciate that those foundations, those organizations are hugely, vitally important. We really, I would say, wouldn't do much without helping in education and training without working with them in partnership on to how we move forward. They live in that. They wake up, they go to sleep every night, and care for these individuals while we go to our next patient. So really, for us, we must make sure that everything we do is a discussion, talking to these various organizations and working with them across the board.

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