

Good morning. Thank you for allowing me to speak this morning from a physician's perspective on behalf of an ever-expanding group of individuals who don't have the capacity to advocate for themselves, but whose needs demand our immediate attention.

I am a psychiatrist specializing in the care of youth and young adults with autism and other neurodevelopmental disabilities, often in tandem with intellectual disability ranging from mild to profound. I am the Medical Director of the Neurobehavioral Unit and the Kennedy Krieger Institute in Baltimore, Maryland, which is an inpatient service dedicated to the care of children and adolescents with neurodevelopmental disabilities who present with what are known in the field as "severe challenging behaviors," and largely include various topographies of self-injurious, aggressive and disruptive behaviors. My unit services patients from across the US and abroad, and typically represents the "end of the train line" for individuals who present with the most horrific, intractable behavioral presentations that have literally brought their lives, and those of their caregivers, to a grinding halt. My patients, if you will, are the ones who have hit themselves in the head so many times that they have caused retinal detachment, traumatic cataracts and concussions, whose bodies are often covered in open wounds and/or wounds in various stages of healing and scarring, who have sent caregivers to the emergency department in the aftermath of assaultive behaviors, who live in full-body protective equipment while hulking in-home workers – or exhausted parents – attempted to block their most dangerous behaviors and simply live to see the next day without another medical crisis, fruitless call to the police or ambulance, or useless trip the local ED to be informed that nothing can be done to help. These kids, and their families, are the black sheep of the autism and disabilities communities, and often don't have a place at the table in autism advocacy circles, as they sadly don't represent the currently popular "neurodiversity" movement where "everyone is a little bit autistic" and autism/developmental disability are presented as gifts to be cherished and embraced, rather than major health concerns that no parent in his right mind would choose for his child, anymore than he would choose for his child to have cancer or organ failure. In fact, if you discussed the alleged gift of autism with most of the parents I see, they'd probably ask if you'd like to take it outside so they could punch you in the face. Or, perhaps more charitably, ask if you'd like to come live in their house, wear protective equipment worthy of an ice hockey goalie, sleep say, 2-3 hours nightly, and clean up the blood, urine, feces and vomit as it accumulates around the house, while you also try to take care of yourself and the other kids living in your home, and maintain employment so you can keep the electricity and water on.

You see, the fact of the matter in the real world is that people exist on the entire range of the autism and neurodevelopmental disability spectrum, including those who aren't "nice" to see and who don't represent what every parent with a toddler who has just received an autism, Down syndrome or other developmental disability diagnosis is hoping to have 20 years down the road. These people, citizens of your state, citizens of the US and world beyond, deserve our care and attention just as much as those on the much higher-functioning end of the spectrum might need special initiatives so that they can be mainstreamed in classrooms, participate fully in sports and community activities, or attend our universities with necessary supports. Helping those at the most dire end of the spectrum neither obfuscates nor negates assistance and attention to the less-afflicted end of the spectrum.

I've mentioned that I work largely with youth, or people under age 21. But I am here today to speak specifically on behalf of all of the severely afflicted patients in my career who have already become adults, and those who are heading into adulthood. A lot of resources are focused on *children with disability*, but at the end of the day, these children are going to spend a much greater percentage of their lives as *adults with disability*, and most likely they are going to have the same degree of impairment and associated needs as during their childhoods. Only as adults, now they are faced with older parents, diminished resources and programming options as they no longer qualify for school services, diminished safeguards such as substituted decision-making from parents or appointed proxies, and often most importantly, an all-too-infrequent lack of quality, safe and meaningful living options. This is a public health concern for a segment of our adult population that cannot be dismissed simply because their challenges don't warm our hearts like the story of the autistic adult who ran the Boston Marathon this year in 2 hours 46 minutes.

"Choice" is a keyword in the adult disability world, and is often invoked with more than one false notion. First, that everyone with a disability would necessarily make the same choices as those on the higher-functioning end of the spectrum, and secondly, that everyone is capable of making an informed choice. The fact of the matter is that while some autistic adults can engage in discussion and analysis of living options, there are others whose ability to choose doesn't extend beyond a M&M or Skittle as a reinforcer. While some adults with disability could manage basic household tasks and take a bus to work, others cannot toilet themselves or brush their teeth independently. And some continue to engage throughout their lifespan in very dangerous behaviors that are a function not only of their disability, but the frequent comorbidity of additional psychopathology. These might not be politically correct statements, but they represent the hard truth, and PC behavior and fantasy thinking cannot change biology. Regardless of the severity of said biology, every one of these individuals should still have access to safe and dignified adult living solutions as they transition away from the primary childhood home – because truly no one can live at home forever – that allow as well for meaning and joy according to each person's unique attributes and potential. I urge you to listen carefully to the families and other providers who speak here today on behalf of those who will never have their own voice in this Senate chamber, and move towards meaningful change to better their lives, and those of the families who hold them dear.

Public comments from Kennedy Krieger Institute psychiatrist Dr. Lee Wachtel to the IACC (Interagency Autism Coordination Committee - a federal advisory committee on autism)

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**Second, the IACC (Interagency Autism Coordinating Committee) must promote a CHOICE BASED APPROACH to service provision that ensures adults with aggressive and self-injurious behaviors have a place to go when their families can no longer safely care for them. Some autistic adults have severe behaviors that cannot be managed in community settings. They may not exhibit them all the time, but they need to be somewhere with experienced caregivers who can manage dangerous behaviors when they do occur, with access to professionals who can treat them, as well as structured programs to maximize community**

**access as well as providing satisfying site-based programming. This population needs to be surrounded with well-trained, well-paid aides, because the health and happiness of these adults depends almost exclusively on that one variable. The IACC should write a white paper focused specifically on the service needs of this population.**

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