Amy Lutz, PhD
Size and Density Restrictions Testimony
June 9, 2025

Good morning, Chairman Coleman, Chairwoman Tartaglione, and other esteemed members of the committee. My name is Dr. Amy Lutz. I'm a historian of medicine at the University of Pennsylvania with a research focus on the history and ethics of autism and intellectual disability policy and practice, as well as a founding board member of the National Council on Severe Autism. And my research, writing, and advocacy are all inspired by my most important job of all: being the parent of a profoundly autistic son, Jonah, 26, who is the oldest of my five children. Jonah is extraordinarily disabled by his autism: he has a tested IQ of 40, minimal language, and a history of very aggressive and self-injurious behaviors that necessitated an almost year-long hospitalization when he was only nine years old. He will require intensive and lifelong supervision and care.

Thank you so much for the opportunity to participate in this very important hearing. I have been advocating for the elimination of ODP's size and density restrictions for more than a decade. In 2015, I wrote an article for *The Atlantic* called "Where Should Autistic Adults Live?" in which I made the case that intellectually and developmentally disabled adults should have the same freedom to choose where and with whom they live as non-disabled adults. This seemed like such a common-sense argument then, I honestly can't believe we're still fighting for this in 2025. If you have any doubt about how discriminatory and ableist these restrictions are, just substitute any other minority group and imagine the uproar if the Commonwealth decreed that no more than 25% of an apartment building could be occupied by...African Americans. Or Jews. Or queer people. Or if no more than four unrelated members of these groups were allowed to live together. Somehow, the gross civil rights violation is immediately obvious when the restrictions are applied in these other cases – but not, for some reason, when they're applied to the intellectually and developmentally disabled.

There's no doubt that this population is exceedingly vulnerable due to an almost complete dependency and inability to report abuse or neglect. As a historian of medicine, I am very familiar with the inhumane treatment people like my son received in mid-20th century institutions, and I completely understand the insistence that we never go back. But Willowbrook and Pennhurst are red herrings in this debate. Willowbrook, at its peak, housed six thousand children (in a facility built for half that many) and had a staff-to-resident ratio of 1-40. Obviously, compassionate and effective care is impossible under those conditions. But that doesn't mean that compassionate and effective care can't be provided in settings larger than four. In fact, there is no evidence that small, dispersed settings have better outcomes or fewer incidents of abuse than congregate settings (as evidenced by the exposé of abuse in New Jersey group homes published just last month). The research on the relationship of setting size to outcomes is so sparse and shoddy that my Penn colleague David Mandell, Director of the Center for Mental Health Policy and Services Research, has concluded, "Our decision-making regarding which types of placements to pay for and prioritize is based on values rather than data." In other words, ODP's size and density restrictions reflect ideological biases rather than evidence-based practice.

Larger and disability-specific housing definitely won't appeal to every adult with autism or other intellectual disabilities in the Commonwealth – which is fine. The fight to remove size and density restrictions is about expanding options, not taking anything away. Waiver recipients who want to live and work in the community should absolutely receive whatever supports they need to thrive. But I have never understood the logic that informs ODP's position: I don't like X, so therefore no one should have X. Or the insistence that a one-size-fits-all approach could possibly meet the needs and preferences of such a heterogeneous population.

The fact is, it can't. And perhaps the most heartbreaking part of all of this is that ODP knows these restrictions are failing the most severely impaired, and the only explanation I can come up with for the agency's failure to act is that they just don't care. Let me describe what "community living" looks like for one profoundly autistic young man whose family I've been working with: Nick Pirozzi, who is 23. Nick is so aggressive he requires two staff at all times to keep everyone safe. Because of the risk he poses to others, he lives in his own "group home" with no other residents, just a rotating stable of direct support professionals. His house is in a very rural part of the state, down a long driveway, surrounded by fields. No day program will take him because of his behaviors, so Nick literally spends all day, every day, with two aides who are not required to take him out, play games with him or engage him in any way. They are, his mother Donna told me bitterly, "Just there to keep him alive." According to ODP, this is living "in the community," simply because no more than four intellectually disabled people live there. According to my husband, who wanted to know why I was so shaken after returning from a visit with the Pirozzis, this is more like "solitary confinement."

This is not the first time I've been involved with legislative efforts to assess and intervene in Pennsylvania's residential policies for the intellectually and developmentally disabled. Between October 22, 2022 and November 23, 2023, I served on a task force and advisory committee on "Services to Individuals with Intellectual Disability, Developmental Disability, or Autism through the Pennsylvania Office of Developmental Programs," that was convened at the request of then-Representative, now Senator Frank Farry. The first recommendation in our 150+ page report? That the Commonwealth should "promote freedom of choice. The desires and needs of the individual should be paramount in all decision-making." We go on to specify that "Multiple alternatives for any and all services should be presented to the individual…One type of service should not be given preference over another. Choice is illusory if the decision is between no service or the only one being presented to you." In short, this report concluded that ODP's size and density restrictions should be eliminated to allow parents, providers, and developers to collaborate and build the kinds of innovative farmsteads, campuses and other larger models that are so popular in other states – so popular, in fact, that one new HCBS-funded program in Wisconsin, Matthias Academy, had to cap their waiting list at 500 families.

Deputy Secretary Kristin Ahrens was on that Advisory Committee with me. Still, eighteen months later, ODP has not adopted any of these recommendations. Although Donna and her husband Chris would love to see their son in a vibrant intentional community – one large enough to support on-site specialists in behavior, speech, occupational therapy, and nursing; host a range of activities for those times when Nick's challenging behaviors preclude community outings; and maintain a large and flexible workforce that can be shifted to provide extra help during meltdowns or faded to encourage independent skill development – that is not an option in our state. The only decision that they have is still "between no service or the only one being presented to you." If they don't like Nick's isolated "group home," they can take him home. For these aging parents, who can no longer manage their son's aggressive behaviors, that is no choice at all. Pennsylvania's most impaired citizens and their families deserve better. Thank you.