

Testimony of Amy S.F. Lutz

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My name is Amy Lutz, and I am the president of EASI Foundation: Ending Aggression and Self-Injury in the Developmentally Disabled, and a founding board member of the National Council on Severe Autism (NCSA), which just launched in January. Most importantly, I am the parent of a 20-year-old son, Jonah, who suffers from severe autism, intellectual disability, and epilepsy. This is my second time testifying before the Committee - I was also here two years ago to oppose a proposed change that would have forced waiver recipients in day programs to spend 75% of their time in fully integrated settings, which would have effectively closed sheltered workshops. I'm happy to be back, and grateful to the Committee for hosting this ongoing conversation about the Commonwealth's most vulnerable citizens.

Today, I'd like to talk to you about residential policy. I'm sure it's not news to you that nothing keeps parents like me up at night more than panic over where our severely intellectually and disabled children will live when they leave home. I'm thrilled to report that some of the most exciting projects unfolding all over the country are responding to this critical concern. In New Jersey, Arizona, Florida, even Arkansas, and elsewhere, families are collaborating with providers, medical professionals, universities, and local businesses to build beautiful communities designed to meet the particular needs of individuals with severe intellectual and developmental disabilities and challenging behaviors like self-injury, aggression, elopement, and property destruction, while at the same time ensuring that those behaviors don't preclude residents from enjoying a joyous and meaningful life.

But that isn't happening in Pennsylvania. In fact, just last month, Kristin Biddle – the mother of 22-year-old Will, who is severely autistic and suffers from aggressive and self-injurious episodes that require five trained staff members to safely manage – sent a proposal to ODP to build such a community. Her project, called the Lotus Mission, seeks to “create integrated, sustainable, walkable communities” of sixteen residents each that would serve the entire spectrum of adults with I/DD but were designed specifically for those with dangerous behaviors who require, as she writes in her proposal, “a more secure, autism-friendly environment in order to maximize their opportunities for community engagement.” These developments would feature a community center and a hydroponic greenhouse that would provide minimum-wage jobs to those residents that chose to work there.

Keep in mind that Biddle was not asking the Commonwealth to build these communities. The Lotus Mission would raise the funds for purchasing the property and constructing the buildings. She was just asking that residents be able to use their waivers to live there. This is a perfect example of the kind of public-private partnerships that our overstretched system – with a waiting list of almost 15,000 – should be eagerly pursuing. Instead, ODP officials flatly rejected her proposal, noting that they would not approve any new residential setting larger than four people, unless the percentage of waiver recipients was restricted to 25% – despite the fact that no obstacles exist to building peer specific communities for virtually any other population you can imagine – seniors, veterans, college students, religious orders, etc.

It's worth considering the reasons behind these standards. Doubtlessly, they are well-intentioned, reflecting the horror we all felt following exposes of abuse and neglect at megasyllums like Willowbrook and Pennhurst. But let's remember that Willowbrook had

6,000 kids and a resident to staff ratio of 40 to 1. Today, inclusion advocates have, in a truly dazzling display of discursive sleight-of-hand, re-defined “institution” to mean “any setting larger than four people.” From 6,000...to 4. This not only defies common sense, but - as the National Council on Severe Autism argues in its position paper on residential settings, it “imperils existing quality programs and sharply restricts the development of safe, robust, and clinically necessary programs and models.”

Well, surely inclusion advocates must have studies to back up such a draconian position? They claim they do, but the studies they point to are so flawed, so biased, that, in a review of the literature, David Mandell, ScD., Director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania, concluded, “Right now, our decision-making regarding which types of placements to pay for and prioritize is based on values rather than data.” Which is undoubtedly why CMS issued new guidance in January designed to ensure that adults with I/DD enjoy the same right to choose where and with whom they live that those of us without disabilities take for granted. (I used to say that adults with I/DD represented the only population that can’t choose where and with whom they live, until someone pointed out to me that, in some townships, convicted sex offenders are prohibited from living, for example, too close to schools. I think my point is still valid.) Gone from the guidance were the warnings that farmsteads, gated communities and clustered group homes might be “isolating” or “segregating.” Instead of the physical characteristics of settings, CMS has adopted an outcome-oriented approach, recognizing that - as those of us who followed the 2017 Blossom scandal, in which the Philadelphia-based service provider of over 30 community-based group homes was stripped of its license due to “gross incompetence” know all too well - abuse and neglect can and do happen anywhere.

Despite the fact that the data don't support restrictive residential policies, and CMS no longer encourages them, ODP has refused to budge, resulting in a residential policy that is among the strictest in the nation. We are asking you, our legislators, to intervene. The I/DD population is extraordinarily diverse, representing a broad range of needs, impairments and preferences. A one-size-fits-all model of service provision is not only absurd, but it is bound to fail. And it has failed, many times. There are parents in this room whose children bounced from group homes to emergency rooms to group homes to psych wards and back to group homes, paying with their unspeakable trauma for ODP's ideological intransigence. They know that allegedly inclusive settings like small group homes and individual apartments can be the most isolated and segregated of all for those with challenging behaviors that require more structure and more support than can be provided in those environments. We need to support a range of residential options - from ICFs, to intentional communities, to group homes, to supported apartments. This is the only way to honor individual choice and person-centered planning - principles at the core of disability service provision today. Choice is only meaningful if there are options to choose from.