

Testimony of Amy S.F. Lutz
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Disabled
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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, a non-profit that supports autistic and other intellectually disabled individuals with dangerous behaviors and their families. First of all, thank you so much to the members of the Committee for including me in this critical conversation concerning the Commonwealth's most vulnerable citizens. I am particularly grateful that this hearing was still held even though ODP has already revised its proposal to force waiver recipients in day programs to spend 75% of their time in fully integrated settings – a regulation whose virtually unanimous opposition was the catalyst for today's meeting. It would have been so easy for the Committee to thank ODP for its quick response – for which the agency should be commended – and to cancel this hearing, considering the matter resolved. But there is still a massive disconnect between the ideological policies of ODP and the needs and preferences of those with I/DD and their families that demands your attention, and – I hope – your intervention. Consider the fact that this 75% rule was floated in the first place, even though the exact same requirement was included in the initial draft of New Jersey's State Transition Plan. Surely, ODP could not have missed the massive protests from individuals with disabilities, their families, advocates, providers and legislators that forced the state's Division of Developmental Disabilities to submit a significantly revised STP just this past December removing this requirement, among other changes. Yet ODP still persevered, causing completely foreseeable and avoidable panic and wasting

precious time and money while more than 13,000 Pennsylvanians with I/DD languish on waiting lists. Why?

The fact is, ODP's bias against disability-specific settings is reflected across the board, not only in regulations concerning day, pre-vocational and vocational programs but in those pertaining to residential options as well. New residential projects are limited to three people, which means waiver recipients can't choose to live in intentional communities, clustered group homes, farmsteads or campuses, even if those models most meet their needs.

I feel like I should pause for a moment and say something I hope is completely obvious: no one is opposed to competitive, minimum wage employment, or dispersed apartments in the community. All people with disabilities of any kind who choose these options should get whatever supports they need to succeed. But the I/DD community is very large, and very diverse, and it's absurd to think that one service model will work for everyone. My own son Jonah, now 18, will require round the clock supervision his entire life due to his history of violent behavior, as well as his compulsion to wander. His profound impairments preclude him from holding a minimum-wage job or life sharing, both pet programs of ODP. At EASI Foundation we work with many families with children like Jonah. This is the population most affected by ODP's restrictive policies; these are the parents who are rallying outside while I speak. And lest you think that we represent only a small group, I want to give you some numbers: 40% of individuals with autism also are intellectually disabled; 20% are nonverbal; more than 50% exhibit violent behavior, including aggression, self-injury and property destruction. Autism Speaks estimates that more than a third of autistic adults need 24-hour supervision. So how many

people is that? Well, the 2014 Pennsylvania Autism Census estimated there were almost 200,000 autistic individuals in the Commonwealth, which translates into approximately 65,000 Pennsylvanians who can't be safely left alone, ever. And that's just the autistic population – it doesn't include those with other kinds of developmental and intellectual disabilities, like Down syndrome or cerebral palsy.

You may wonder if you even have any control over this issue; I'm sure you've heard many disability advocates and even some policy makers referring to the *Olmstead* Supreme Court decision or even the Americans with Disabilities Act as "inclusion mandates." But these important documents are more accurately described as "choice mandates." They defend the right of the disabled to live and work in the community – a critical right, representing a landmark achievement of the Disability Rights Movement. But they never suggest this should be the only option. In fact, the majority in *Olmstead* specifically wrote, "States are required to provide community-based treatment for persons with mental disabilities when...such treatment is appropriate, **the affected persons do not oppose such treatment**, and the placement can be reasonably accommodated. In his concurring (and prescient) opinion, Justice Anthony Kennedy warned, "It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act...to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." This is exactly what is happening in Pennsylvania, right now.

But what about CMS? Doesn't the Final Rule require Medicaid dollars to be spent exclusively in small, integrated settings? Actually, there are no numbers in the Final Rule

either – no size limits, no density restrictions, no 75% rule or anything that looks like it. On the contrary, CMS itself acknowledged in the Final Rule that regulations should be more “outcome-oriented...rather than based solely on a setting’s location, geography, or physical characteristics.” **What this means is that Pennsylvania’s policies are significantly more restrictive than required by CMS.** Just look at the exciting residential projects going up in other states, such as Massachusetts’ Riverbrook, a community of 26 women with intellectual disabilities; or First Place, a campus in Phoenix that includes more than 50 apartments, a transition academy, and a research and training institute; or the Arc Village in Jacksonville, Florida, which includes almost 100 rental apartments for adults with I/DD. The demand for intentional communities such as these shouldn’t surprise you. Many neurotypical adults also choose to live with peers in gated retirement communities, religious or ethnically concentrated neighborhoods, or college campuses.

If any of Jonah’s classmates graduating this year are lucky enough to find themselves with a Consolidated Waiver, what choices do they have about where they will live? There’s group homes...and that’s about it. This is so despite the fact that there is no research establishing that residents of group homes are more integrated into their broader communities or have a higher quality of life than adults with I/DD who live in larger settings like those I just mentioned. As recent group home exposes in New York and Chicago prove, abuse and neglect can happen in residences of any size. And these atrocities are happening right here in Pennsylvania. I took the following excerpt, with permission, from a Facebook group for Pennsylvania families of adults with I/DD: “My sweet 35 year old daughter lives in a group home. Please let me tell you that if I found

out I was going to die in 6 months, I would commit suicide and take her with me....The state of PA puts out \$212,000 a year for my daughter's care...Almost every time I speak with her she says the staff put a movie in for her and the staff is outside on the phone smoking a cigarette...She has fungus on her feet. Her once bright white teeth are rotting out, her belongings are either gone or destroyed. When she wets the bed, they flip the mattress to the other side; when she pees on the floor due to a night-time seizure, they just put a plug in air freshener in the room to mask the smell."

Actually, it's not exactly true that this mother has no other choice for her daughter besides the group home. She could do what most parents do: keep her at home. Nancy Thaler has repeatedly stated that ODP's focus is to support families in keeping their intellectually and developmentally disabled loved ones at home as long as possible. **As elected officials, you should know that this isn't the focus of any parent I know –** whether their children are disabled or not. Intense caregiving of the kind often required by adults with significant I/DD is physically and emotionally exhausting. A 2009 study reported that the level of chronic stress experienced by the mothers of autistic children was comparable to that of combat soldiers, which is almost certainly why a 2016 study found that mothers of autistic kids were at increased risk of heart disease. Setting aside for a moment parents' desire to work, care for their own elderly parents, or spend time with their other children – normal mid-life plans that I suppose ODP considers unnecessary luxuries – any plan dependent on the ability of aging parents to provide round-the-clock care for big, strong adults – often with aggressive, self-injurious or other dangerous behaviors, such as elopement or property damage – is broken from the start. **Every one of these situations inevitably ends in crisis:** the parent dead or physically

incapacitated, and the disabled person – already traumatized from the loss of the only constant caregiver he or she has ever known – dropped into the first empty bed in the state, ripped away from everyone and everything that had made life meaningful.

We can do better. Nancy Thaler argues that her family-based plan is necessary because group homes are so expensive – as we heard, \$212,000 for neglectful care that demands a state investigation. But that’s because ODP prohibits the development of larger, more cost-efficient projects. We don’t even need to look out of state for an example we should be following: Camphill, which serves 200 residents in an absolutely lovely farm-based community in Phoenixville at an annual cost of just \$40-70,000 a year, less than a third of what the Commonwealth is paying for that group home. Yet that mother could not move her daughter to Camphill, because ODP won’t pay for it.

Obviously, Camphill isn’t for everyone: people may not want to live and work on a farm, and the less structured environment isn’t appropriate for those with severe behaviors. But all around the country, creative parents and providers are designing projects that leverage tax credits, microbusinesses, or public-private partnerships to build affordable, state-of-the-art communities that maximize residents’ safety and promote peer relationships as well as facilitate engagement with the greater community through supported employment and leisure programs. Pennsylvania should be encouraging that type of development – or, at least, certainly not blocking it. Not only for the economic reasons I’ve just given you – which in and of themselves are critical, given the, again, 13,000 adults on waiting lists who are currently getting no services – but because the right to choose where and with whom we live and work is a civil right that Pennsylvania denies only to this population. I’m asking you today to stand and defend that right: the

right to choose to live with friends; to choose a safer, more structured environment; to choose a more cost-effective option. And that right to choose is only meaningful if the system supports a range of different choices. Thank you.

Please don't hesitate to contact me with any questions or comments about this issue at

amy@easifoundation.org. For further reading on this topic:

The Coalition for Community Choice (coalitionforcommunitychoice.org) has tremendous resources on its site, including important statistics and details about CMS and state transition plans, but start with these:

- “Policy Brief: HCBS Final Rule”
http://coalitionforcommunitychoice.org/wp-content/uploads/2014/12/CCC_PolicyBrief_1114_LL.pdf
- “HCBS Final Rule: Frequently Asked Questions”
http://coalitionforcommunitychoice.org/wp-content/uploads/2014/12/CCC_HCBS_FAQ_1114_LL.pdf
- “Intentional Communities Overview: A Sustainable Housing Option”
http://coalitionforcommunitychoice.org/wp-content/uploads/2014/12/CCC_IntentionalCommunities_1114_LL.pdf
- “Home and Community: An Individual Choice, not an Ideological Debate,” posted on February 26, 2016:
<http://coalitionforcommunitychoice.org/2016/02/home-and-community-an-individual-choice-not-an-ideological-debate/>

Jill Escher, “The Federal Government’s Quiet War Against Adults with Autism,” posted on the Autism Society of San Francisco’s website on April 19, 2016:

<http://www.sfautismsociety.org/blog/the-federal-governments-quiet-war-against-adults-with-autism>

Jill Escher, “You Can Choose Where You Want to Live...Unless You Have Autism,” posted on the Autism Society of San Francisco’s website on September 21, 2016:

<http://www.sfautismsociety.org/blog/you-can-choose-where-you-want-to-live-unless-you-have-autism>

Amy S.F. Lutz, “Who Decides Where Autistic Adults Live?” posted on *The Atlantic* website on May 26, 2015: <http://www.theatlantic.com/health/archive/2015/05/who-decides-where-autistic-adults-live/393455/>

Amy S.F. Lutz, “Ideology, not Data,” posted on the *Psychology Today* website on January 22, 2017: <https://www.psychologytoday.com/blog/inspectrum/201701/ideology-not-data>