VIEWPOINT

Adults with disabilities deserve right to choose where to live

BY **AMY S.F. LUTZ**

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In two years, my oldest daughter will go to college and move into a dormitory with other students. My mother loves her gated retirement community. My son, however, can't make a similar choice to live with his peers. Jonah, now 18, has severe autism and is part of the only group of people in the United States denied the basic right to choose where and with whom to live: the intellectually and developmentally disabled.

An increasing number of states are refusing to fund large residential communities that are specific to disabled people — despite the popularity of these models both among people who want a readily available social network and those who have medical or behavioral challenges that require extensive support.

Sounds like a case for the American Civil Liberties Union (ACLU), right? What's baffling to me is that the ACLU supports these housing restrictions. ACLU officials maintain that large communities designed for people with disabilities are isolating and tantamount to unlawful segregation. I think they miss the point.

I am a member of a nationwide coalition of more than 30 organizations, representing tens of thousands of adults with intellectual and developmental disabilities, and their families. We wrote a letter to the ACLU explaining why people with intellectual and developmental disabilities need a broad range of housing options to reflect their diverse needs and preferences. But ACLU's executive director Anthony Romero wouldn't even grant us a meeting.

The idea that one residential model is appropriate for the entire spectrum of intellectual and developmental disability — from college-educated self-advocates to profoundly impaired individuals at risk of detaching their own retinas or bolting into traffic — is patently absurd.

Legal limits:

At the center of this issue is the 'final rule,' issued by the Centers for Medicaid and Medicare Services (CMS) in 2014, to specify the types of residential settings in which individuals with disabilities can use their Home and Community-Based Services 'waivers.' These waivers — paid jointly by state and federal government — cover the cost of housing that would otherwise be prohibitively expensive. (We expect Jonah to require more than $200,000 a year once he leaves home.)

CMS **initially set no size limits** or density restrictions on the residential settings in which people can use the waivers. According to a 2014 fact sheet, its rule followed an "outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics." This indicates a focus on results — such as whether waiver recipients are happy and safe in their homes — rather than what those homes look like.

However, as the states prepared to comply with the final rule, CMS seemingly forgot about its focus on outcomes. It issued a new document that called out farmsteads, disability-specific communities, campuses and clustered group homes as potentially "isolating" to disabled individuals, and thus at risk of losing federal funding. Several vocal self-advocacy groups, such as the **Autistic Self-Advocacy Network**, also issued statements demanding that public funds be used exclusively for small, dispersed homes in the community rather than on these larger settings.

As a result, a number of states — including Delaware, New York, Pennsylvania, Massachusetts, Oregon and Ohio — proposed policies that effectively ban residences that serve more than five or even four individuals. The ACLU has publicly supported these restrictive rules. It has also opposed the current administration's plan to indefinitely postpone the deadline, originally 2019, by which states must implement their plans.

Fundamentally human:

As our coalition wrote to Romero, "The desire to live with peers is fundamentally human." This isn't the projection of deluded parents: A 2013 Autism Speaks survey revealed that nearly 30 percent of **people with autism prefer to live** in a planned community.

In his response to our letter, Romero warned us that he regards such "segregated" settings with great suspicion. He added: "Indeed, federal law and Supreme Court rulings support our position. Both the Americans with Disabilities Act and the Supreme Court's 1999 *Olmstead* decision view the

unnecessary segregation of people with disabilities as a violation of their civil liberties."

Romero's statements misrepresent these landmark decrees, however. *Olmstead* requires states to provide integrated settings when "community placement is appropriate" and when "the transfer … to a less restrictive setting is not opposed by the affected individual."

In fact, the justices expressed concern about this exact misreading of their decision. In his concurring opinion, Justice Anthony Kennedy wrote, "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."

In his letter, Romero further claimed that research supports his opposition to large group residences. In truth, the literature examining residential size is inconclusive. "There are remarkably little data available to support which housing options work best for which individuals," says **David Mandell**, associate professor of psychiatry and pediatrics at the University of Pennsylvania. "The largest challenge to conducting rigorous research on housing is disentangling the severity and needs of the individual from the housing option in which they are placed."

Push-button locks:

Jonah has a tested intelligence quotient of 40 and a history of challenging behaviors, including dangerous aggression and **self-injury** that precipitated a 10-month hospitalization when he was 9 years old. He has run away from our home so many times that we now have push-button locks on our doors that require a code to enter or leave.

My son isn't alone. The 2013 Autism Speaks survey revealed that more than one-third of individuals with autism require 24-hour supervision.

Some adults with disabilities and their families are attracted to large, disability-specific communities because of their social benefits. But others — like Jonah — need this option, as they require more support than can be safely and consistently delivered in dispersed settings. One of my greatest fears is that when my husband and I can no longer care for Jonah, he will end up in his own apartment with a minimally paid, minimally trained aide who will let him stim on his iPad all day rather than risk taking him out.

Good housing policy would take his needs — and those of all others with a disability — into consideration.

Troubling paternalism:

Throughout its history, the ACLU has protected the freedom to exercise fundamental rights — even

if those choices are not ones that most ACLU members would make. Over the past century, its actions have involved defending the Ku Klux Klan, confederate flag license plates, and the homophobic and anti-Semitic Westboro Baptist Church.

The refusal of the ACLU to defend the rights of adults with disabilities and their families to choose from the same range of residential options enjoyed by non-disabled Americans is not only a shocking departure, but a troubling display of paternalism. The doctors who founded the first public institutions in the 19th century believed they knew what was best for people with disabilities, too.

The ACLU has embraced a fundamental hypocrisy. In his reply to our coalition, Romero wrote that individuals with disabilities should have “the same choices and freedoms as others.” Yet in the same letter, he reiterates the ACLU’s support for policies that strip this population of those liberties.

As we explained to Romero, “The right to choose is meaningless if every option but one is taken off the table.”

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