

The Atlantic

Who Decides Where Autistic Adults Live?

For many intellectually and developmentally disabled people, large campuses or farmsteads may be better options than small group homes. But new state laws could make it hard for big facilities to survive.



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MAY 26, 2015 | HEALTH

TEXT SIZE



In December 2014, I watched 24-year-old Andrew Parles fit wood shapes into a simple puzzle in the new vocational building at the Bancroft Lakeside Campus, a residential program in New Jersey that serves 47 adults with autism and intellectual disabilities. The task wasn't challenging for Andrew, but his team was taking it slow: Andrew was still recovering from surgery after detaching his own retinas through years of self-injurious behavior. A staff member stood nearby—not hovering, exactly, but close enough to intervene if Andrew suddenly started to hit himself in the head. His mother, Lisa, was hopeful that he'd soon be able to

participate in the programs he had enjoyed before his surgery: working in Lakeside's greenhouse, painting in the art studio, delivering food for Meals on Wheels.

I toured the campus, admiring the cathedral ceilings and brightly painted exteriors, thinking how perfect a place like this would be for my 16-year-old son Jonah, who is also severely autistic and will require round-the-clock supervision his entire life. Lakeside likely won't be an option for Jonah, because we don't live in New Jersey, but soon it may not be an option for Andrew, either. In 2014, the federal government asked each state to define exactly what types of vocational and residential settings would be eligible to receive federal funding. Large group homes, farmsteads, and campuses like Lakeside all face possible exclusion.

Congregate settings for people with intellectual and developmental disabilities (I/DD) have been discouraged for years. During the 1960s, around the time Ken Kesey published *One Flew Over the Cuckoo's Nest*, patient advocates began rejecting the idea of the mental institution, arguing that people with disabilities should and could live in their communities. Since that time, the institutionalized I/DD population has dropped by more than 80 percent.

It seemed pretty simple: community good, institutions bad. But these two terms have proven extraordinarily difficult to pin down. Is the difference merely one of size? In 2011, the National Council on Disability defined "institutional settings as housing situations in which more than four people with I/DD" live in a single home. Some autistic people and their families have embraced this definition: The four-person size limit was included in "[Keeping the Promise: Self-Advocates Defining the Meaning of Community Living](#)," a 2011 paper jointly issued by three self-advocacy organizations.

In some states, this guideline is poised to become law, which means such congregate settings may all be excluded from the waiver program. This

could prove disastrous for the autism community, which is facing a housing crisis that is only expected to get worse. Right now, 80,000 autistic adults are on waiting lists for residential placements that can be up to 10 years long, and the nonprofit advocacy organization Autism Speaks estimates that half a million autistic children will transition to the adult state-by-state funding system over the next decade. Shortages aside, there are plenty of parents who feel that large facilities like Lakeside are truly the best places for their children and bear no resemblance to the institutions of the mid-20th century.

This sounds like a technical debate, and one limited to a very specific community, which may explain the public's relative lack of interest. But it touches on a larger question: While many Americans may never need food stamps or unemployment, virtually everyone eventually benefits from Social Security and Medicare. What level of control should the government have over how these subsidies are used? In the case of disabled adults, who should decide what kind of housing best suits their needs? Should it be those individuals and their families, or should it be the state?



Andrew Parles in his room at Lakeside, a New Jersey program that provides care and housing for 47 adults with autism and intellectual disabilities (Neal Santos / The Atlantic)

There's no doubt that in the past, state schools and asylums were frequently rife with abuse and neglect. Clips of Geraldo Rivera's 1972 expose on the Willowbrook State School [can still be found online](#), as can truly horrifying facts about that facility: 6,000 intellectually disabled children crammed into a building designed for 4,000; staff ratios as low as one employee for every 40 residents; kids subjected to medical experimentation on the treatment of hepatitis A, which ran rampant through the wards because of poor sanitation.

That documentary, and the class-action lawsuit that followed, ushered in an era of policy changes. The Civil Rights of Institutionalized Persons Act of 1980 led to more thorough investigations of abuses, and the Americans with Disabilities Act of 1990 helped protect the rights of the mentally and physically disabled. In the 1999 case *Olmstead v. L.C.*, the Supreme Court ruled that forcible institutionalization violated the ADA.

The *Olmstead* case did something more, too: It required states to support disabled individuals so they could stay in mainstream society. It took several years, but in 2007, Medicaid began offering Home and Community-Based Services (HCBS) waivers, an alternative funding stream for those who “waived” institutional care. These waivers now help pay for the housing and care of [nearly 1,000,000 people with disabilities](#).

In January 2014, the Center for Medicare and Medicaid Services (CMS) issued a “final rule” describing how the waiver program would operate under the Affordable Care Act. That document didn’t disqualify any particular housing models. In fact, it noted, “It is not the intent of this rule to prohibit congregate settings from being considered home and community-based settings.”

But two months later, CMS issued a “guidance bulletin” to help states decide which settings should be deemed too institutional to participate. This document specifically cited farmsteads, gated communities, residential schools, and clustered residences as too isolating. The bulletin allowed for some of these settings to be approved through a process called “heightened scrutiny.” However, several states seem inclined to draft policies that are more restrictive than these federal guidelines.

[Massachusetts](#), for example, has opted to categorically exclude any settings that house more than five people; [New Jersey](#) crafted a density rule mandating that no more than 25 percent of the units in any development or apartment building be occupied by waiver recipients. So far, these are just proposals: The states are required to consider public feedback, and at the hearings I attended in New Jersey, so many parents and providers opposed the plan—which, like Massachusetts’, also eliminated large settings—that Governor Christie has already sent it back to the state’s Division of Developmental Disabilities (DDD) for revision. It’s unclear what the final versions of these policies will look like.

In Pennsylvania, the Office of Developmental Programs has restricted

group homes to four people since 1996. This is a frustrating and arbitrary limit for Stacy Levitan, the executive director of Judith Creed Homes for Adult Independence (JCHAI). Her Philadelphia-based non-profit provides a range of services for approximately 100 adults with intellectual disabilities, including operating 15 community-based, supported apartments and three six-person group homes, which were grandfathered in because they were licensed before the restrictions were introduced.

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“There’s nothing institutional about our homes,” said Levitan. “Our residents come and go as they please, they have their own rooms with doors that lock, they don’t have to sit down for meals together at the same time—although many times they do, because they enjoy it.”

I had dinner at one of the JCHAI homes with Levitan’s brother, Doug, who has Down Syndrome, and his housemates. I spent much of the evening talking with Jacob, an autistic 32-year-old who could have chosen to live in one of the JCHAI apartments but picked the communal house instead. I tried to talk to him about his decision, but, despite his relatively high level of functioning, he still exhibits many of the core deficits of autism. He perseverated on the directions between different locations: the different ways I could have driven to the JCHAI home from my house, for example. But through our conversation about transportation I learned a lot about how Jacob spends his time: working at T.J. Maxx, volunteering at the Jewish Relief Agency, going to the movies. The next day, he was planning to take the train to his ex-girlfriend’s 30th birthday party.

Jacob did list one advantage of living in the house that had nothing to do with its proximity to various destinations. “I get to hear Alex’s jokes and

riddles,” he said, holding his hand out so his housemate could slap it. Alex told me a joke, too, but his speech is very difficult to understand and I didn’t want to keep asking him to repeat it, so I just smiled. Jacob had no problem; he laughed and held out his hand for another high-five. They slapped hands all evening: over Alex’s new television, the birthday bash for Elvis Presley scheduled for that weekend at the American Music Theater, the brownies served after dinner.

Levitan doesn’t want to think about how Jacob, Alex, Doug, and their housemates would react if JCHAI had to sell their homes and force everyone into apartments. “Right now, if one of our residents moved out, whoever moved in would probably have to be private pay,” Levitan said. “We could fill several more houses if we could get funding for six-person homes, but we can’t.” Four-person homes cost too much to operate for an organization that—on top of the waivers and out-of-pocket fees it collects—needs to raise \$375,000 every year just to break even.



Residents in the art room at Lakeside (Neal Santos / The Atlantic)

A common concern about congregate settings is that they may be “so lovely when they start out,” said Nancy Thaler, the executive director of the National Association of State Directors of Developmental Disabilities Services. “They’re pretty good while the founding families are still around. But when professional management comes in, that’s when institutional issues, like neglect and abuse, come up.”

Thaler has an impressive 40-year history working with disabled individuals, a decade of it in public institutions. Between 2003 and 2006, she worked for the Center for Medicare and Medicaid Services, where she led the development of the waiver program. She is also the mother of an adult with developmental disabilities, whom she adopted as a 7-year-old from one of those institutions. Based on what she’s seen, she has concluded that congregate settings restrict choice, control, and individualized programming. As a facility gets larger, she says, it unavoidably starts to “segregate and isolate.” To her mind, this is what makes it an institution.

“It’s hard to be person-centered when you have large groups of people,” she told me. The phrase “person-centered” represents the aspirations of Thaler’s field: The CMS’s final rule used it 272 times, calling for individualized service plans that would detail each recipient’s desires and needs, giving them and their families more agency.

People with intellectual and developmental disabilities are certainly vulnerable: [One study](#) found that almost 70 percent of autistic adults have been abused. A huge part of the problem is “the lack of quality, quantity, and accountability in direct care staff,” said Desiree Kameka, the acting national coordinator of the Coalition for Community Choice, a network of more than 85 organizations advocating for adults with autism and related developmental disabilities. Direct-care positions involve a huge amount of effort and complexity, yet the qualifications frequently end at a GED and a

driver's license. And these jobs are very poorly compensated: 45 percent of workers live below the poverty line. Unsurprisingly, given these factors, the field has a 70-percent turnover rate.

However, Kameka points out that this issue affects every individual who receives support. "Even when living in their own apartments, people can be dehumanized through words or actions and involuntarily segregated by support staff. Physical locations don't do this, people do." In 2011, *The New York Times* reported that more than 1,200 developmentally disabled individuals had died of "unnatural or unknown causes" in New York group homes alone over the previous decade. In Georgia in 2013, 10 percent of those who had been moved to community settings died following their relocation.

Lisa Parles—a disability attorney who has spent years advocating not only for her own son, Andrew, but hundreds of others like him—feels that neglect and abuse are less likely to happen at Lakeside, precisely because of its size. "Andrew was at a group home before, and it did not work for him," she told me. "If staff would call out or not show up, you either had overworked, exhausted aides who had to stay, or substitutes sent over by the agency who knew nothing about him or how to handle his self-injury. At Lakeside, he knows everybody. There are so many eyes on him. And if there's a crisis, there's always other staff around who can very quickly come help."

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Ari Ne'eman, the founder and president of the Autistic Self-Advocacy Network, has a very different view on safety. Ne'eman himself has autism-spectrum disorder and is one of the most influential members of that community: In 2010, he became the first autistic person to serve on the

National Council on Disability. Although he faced bullying after transferring from a segregated special-education program to a mainstream school, he's outspoken about his belief that autistic individuals fare better when they're integrated into the wider community.

“You need meaningful relationships with those who don't have a custodial arrangement over you and no incentive to cover up abuse,” Ne'eman said. He told me about one autistic man who went to the same pizzeria every day with his care worker. When he couldn't go for a few days because of an illness, the owner of the pizzeria called to check in on him. Ne'eman's conclusion: “Safety is brought about by the opportunity to participate in the greater community and have relationships with people who can notice.”



Craig and Lisa Parles moved Andrew to Lakeside after having a negative experience at a small group home. “At Lakeside, he knows everybody,” Lisa said. “There are so many eyes on him.” (Neal Santos / The Atlantic)

But what, exactly, constitutes a community? This question is at the core of the debate over HCBS waivers. Consider Misericordia, a Chicago facility that treats 600 residents with a range of developmental disabilities and has over 400 families on its waiting list. Misericordia offers an extensive array of therapeutic services, including occupational, physical, and speech therapy. Its 31-acre campus has a greenhouse, a gym, a bowling alley, computer labs, and a swimming pool where the Special Olympics team practices. Residents can work in the bakery, the horticultural center, the recycling program, the commercial laundry, or the restaurant.

They also have a number of opportunities to interact with people off-campus. Residents are employed at local supermarkets, Loyola University, and U.S. Cellular Field, where the White Sox play. Those who like music can participate in two groups that perform all over Chicago: One is a dance troupe and the other combines singing and sign language. The artistically inclined can spend their time in various multimedia studios, creating ceramics and jewelry to sell in the gift shop or paintings to display at an annual exhibition at the Art Institute of Chicago. Misericordia also operates seven nearby homes for waiver recipients who don't need the 24-hour care required by most on-campus residents.

Is Misericordia an institution? For financial purposes it is considered one: Most residents are funded not through the HCBS waiver but through the much older Medicaid benefit for Intermediate Care Facilities for Individuals with Developmental Disability (ICF/DD). Still, residents and their families bristle at the word. "It's not like living in an institution," Bob Bourke told me. His 29-year-old daughter, Molly, who has Down Syndrome, has been living there for the past eight years. "Misericordia is a far deeper and richer community than we could create for Molly," Bourke said. "She's part of a variety of communities, actually: One is the Heartbreakers [the dance troupe], one is her housemates, one is the other houses she visits for barbecues and parties. If she didn't have Misericordia,

she wouldn't have access to any of that.”

“Misericordia is very much a community,” agreed Gail Schmidt, whose son Dave, 26, has [Fragile X syndrome](#). “The campus atmosphere is like a college. There's a collegiate, small-town community feeling.”

Many parents and providers I spoke to at congregate settings across the country prefer the term *intentional community*, which likens a place like Misericordia to any planned residential development in which people choose to live together because of certain shared characteristics. That sense of common ground is what's often lacking when individuals with I/DD live in integrated housing, surrounded by neighbors who don't understand them.

In an era when 50 percent of Americans don't even know their own neighbors, living in a small home can be especially isolating for a person with I/DD. Micki Edelson, the founder of the Delaware non-profit Homes For Life, built her first group home in 1989 for four men, including her son Robert, 42, who has an intellectual disability due to a birth injury. Since then, she has established 25 similar homes all over the state, as well as several completely integrated apartments that meet the most stringent interpretation of the CMS final rule. Her verdict?

“Community integration is a myth,” she told me. “My homes are in nice neighborhoods—do you think the neighbors are asking the residents over for barbecues or to go to the movies? Of course not. There has been no real interaction between the neighbors and the people living in the homes besides the occasional wave.” After building group homes for a quarter of a century, Edelson told me, “Before I die, my son will be in an intentional community.”



Personal lockers at Lakeside (Neal Santos / The Atlantic)

Even advocates of community integration agree that developing meaningful relationships with non-disabled neighbors can be “a challenge,” as Ari Ne’eman put it, and this is especially true when it comes to the most severely afflicted. It’s not a small group: A 2013 study found that over half of autistic kids exhibit aggressive behaviors, which vary in intensity but can be very difficult to treat and tend to continue into adulthood.

Perhaps it was this population that Supreme Court Justice Ruth Bader Ginsburg was worried about when she carefully crafted her opinion in the 1999 *Olmstead* case to make it clear that community inclusion might not be right for everyone. Such integrated settings, she wrote, should only be required “when the State’s treatment professionals have determined that community placement is appropriate” and “the transfer from institutional care to a less restrictive setting is not opposed by the affected individual.” In other words, forcing developmentally disabled individuals into

dispersed community settings that don't meet their needs is as much a violation of *Olmstead* as forcing them into institutions.

Dennis Rogers founded Safe Haven Farm in Ohio in 2009 after buying two different houses for his autistic daughter, Emily, now 34. "Our goal had always been for Emily to live in the community, and we set her up exactly as we had envisioned—in her own house, with a roommate, and staff to help her participate in different activities," Rogers said. None of this worked out as planned.

"The first house we bought was next door to a couple who had a puppy Emily loved. It got to the point where Emily would sneak away from her staff to go look for the puppy. The couple refused to lock their front door, so Emily would just walk right in. We begged them to lock the door so we could teach her not to do it, but they refused."

This didn't mean, however, that the neighbors welcomed Emily's visits. "One time, the husband—he was a policeman, if you can believe it—met Emily as she was opening the door and slammed it on her hand, smashing her fingers. Her staff found her sitting in their driveway, covered in blood. Then the neighbors sent us a bill for \$1,000 for damage to the door." After that, said Rogers, "We just moved. It wasn't worth it."

Emily lived in the second house the family bought for six years. "She didn't have one interaction with a neighbor during that time, good or bad," Rogers said. "We learned that the human community is all that matters, not the physical community."

Like many individuals with autism, Emily also has profound auditory sensitivities. Rogers wanted her to go out and be active, with the help of an aide. "But most places were too loud for her to tolerate. We found a good sheltered workshop [a day program where low-functioning disabled people can do small jobs or crafts], but it had 100 people and concrete floors, so it was just too loud. After two days, she started attacking the staff in the van

if they tried to take her there.” Rogers and his wife decided to enroll her in a group program that took participants to malls, parks, and restaurants. “But Emily had so much anxiety, she wouldn’t go into any buildings,” Rogers said. “She has a phobia of ceiling fans, she can’t stand hearing people cough or clear their throats. She would agree to go to the park, because she likes the swings, but after a few minutes she would want to go home.”

Rogers said Emily ended up spending two years sitting in the basement of her house watching the same five minutes of the movie *Speed* over and over. “Her behaviors escalated, the police were called, and twice she was taken to a psychiatric hospital and locked up for over a week,” Rogers said. “It was very traumatizing. Each time she came out worse. After her second hospitalization she was discharged on antipsychotics, antidepressants, and anti-anxiety meds. It was at that point that my wife and I decided this was no way for Emily to live.”

Rogers was familiar with Bittersweet Farm, the first farmstead created for people with autism; it was just a couple of hours north of the Rogers’ home in Whitehouse, Ohio. Thirty-two residents live there on 80 acres, where they care for animals, weave placemats and rugs to sell, and work in the fields and greenhouses, which yield enough produce for a community-supported agriculture program that provides weekly boxes to a hundred local families. Since Bittersweet was founded in 1983, more than 35 similar farm-based opportunities have been built around the country for this population. Rogers thought Emily might do well in such a tranquil environment.

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To focus on creating Safe Haven, Rogers retired from his job as a general manager for General Electric. “First it was a need, then it became a passion,” he said. “Someone has to be the champion. My corporate background gave me a lot of the skills necessary to coordinate a big project like this. I determined my purpose wasn’t to help GE make more billions; they can do that without me. This became my purpose, to maximize Emily’s quality of life.”

After three years of planning, the farm opened in May 2010. Rogers said Emily is thriving there. She picks pumpkins all autumn long and takes them back to her room to paint. She spends a lot of time with the animals—Safe Haven has alpacas, chickens, and dogs, but Emily especially loves the miniature horses, which she calls “horse puppies.”

Emily’s maladaptive behavior levels have dropped, and her parents are starting to wean her off her medications. Even her auditory sensitivities no longer seem so acute. “We have dances once a month, and she’ll come, even though it’s loud and crowded,” Rogers said. “And she would never go into public pools because she couldn’t stand the lifeguard whistles. Now she loves swimming in our pool.”

Emily and the other residents don’t spend all their time on the farm. “Emily still goes into town and does everything she ever did when she lived there,” Rogers said. “She’ll go into small stores, like the Dollar Store, or go through a drive-thru for fast food. She comes to our house for lunch once a week. She likes to go see trains and she loves to get coffee. We’re not isolating anybody.”

Of vital importance to Safe Haven’s success is the support it enjoys from its state’s lawmakers—so much so that in January of this year, 14 of Ohio’s Congressional representatives, including Speaker of the House John Boehner, sent a letter to Health and Human Services Secretary Sylvia Burwell urging CMS not to take any action that might threaten farmsteads, which, they wrote, “provide unique support for individuals with autism,

enabling them to maximize their potential.”

Compare Emily’s story with that of Tyler Loftus, a 23-year-old from New Jersey. Diagnosed with autism, intellectual disability, and bipolar disorder, he also suffers from aggressive and disruptive behaviors that resulted in his placement at the Woods School in Pennsylvania when he was 14 years old. “For four or so years before that, he was going to the ER five times a week in a cop car, where they would keep him in four-point leather restraints until the Haldol kicked in,” his mother, Rita O’Grady, told me. “I was a single mother, working three jobs at times to pay for all Tyler’s therapies. There was no way I could handle him.”

Loftus did well at Woods, and O’Grady assumed he would transition to the adult program there when he graduated. But in 2010, the New Jersey Division of Developmental Disabilities began moving out-of-state people with I/DD back through its Return Home New Jersey program. Just before he turned 21 and his educational entitlement ended, Loftus was relocated to a supported apartment. It was the first of five community placements where he would fail over the next two years. “When Tyler eloped or got aggressive, all the staff could do was call 911,” O’Grady said. “The cops would come, and take him to the ER for a psych eval. This happened every day, sometimes more than once.”

Tyler Loftus’s story made the headlines after September 18, 2014, when he was picked up by a police officer for running away and arrested for carrying a three-inch pocket knife. The prosecutor wanted to drop the charges immediately, but couldn’t because there was no place for Loftus to go—the director of the agency that managed the group home he lived in at the time showed up at the arraignment to inform the judge that Loftus had been officially evicted. As a result, this young man with the cognitive capacity of a 5-year-old spent almost three weeks in jail.

The state finally arranged for Loftus to be released to an emergency group home on October 6, but that placement didn’t last even one day. “As soon

as we got there, Tyler started flipping out,” O’Grady said. “He kept saying, ‘I’m not staying here, I’m not staying here.’” He ended up at Trinitas Hospital, on the only unit in the entire state that treats individuals with autism and intellectual disabilities, where he has been admitted multiple times. Loftus has now been in group home number five for about three months, and after a rocky start, O’Grady reported that he is “settling in.”

When I asked O’Grady if she had ever considered Lakeside, where Andrew Parles lives, she told me the state had never presented it to her as an option. But when she described her ideal setting for Loftus, it sounded very familiar: “I’d want counselors and therapists available on-site, and lots of opportunities for exercise ... Residents would have their own rooms, but live with like peers. And there would be decent security, for Tyler’s elopement issues.”

“The folks we struggle with the most are the ones with challenging behaviors,” Nancy Thaler, of NASDDDS, acknowledged. “So we say everyone can live in the community but we haven’t figured out how to do that really well for everybody yet.”

Isn’t this an argument for congregate settings like Lakeside or Safe Haven? Not necessarily, says Thaler. “Having people with challenging behaviors living together compounds the problem. It’s important to be responsive to these behaviors when they occur, and it’s hard to do that when you have a large group of people.”



The communal kitchen in Parles's residence building (Neal Santos / The Atlantic)

Something rarely mentioned, as advocates and policy makers clash over the meaning of “home and community based,” is how few adults with I/DD will actually receive waivers. My state, Pennsylvania, just announced that this year it will award 200 additional waivers to a waiting list of more than 17,000 people. A February 2014 headline from *The Connecticut Mirror* sums it up: “[For CT Adults With Developmental Disabilities, Housing Help Unlikely Until Parents Die.](#)”

Nancy Thaler explained the math to me. There’s “one big pool of money shared by the aging and the disabled,” she said. Both groups are growing, but the aging group is growing much faster: 10,000 baby boomers are entering Medicare and Social Security every day, while 500,000 autistic children will become adults over the next 10 years.

Facing these unsustainable numbers, states have increasingly pushed models that support individuals with I/DD in their family homes—or in the homes of other families. Euphemistically called “life sharing,” this latter

program is really adult foster care, for which participants are paid approximately \$25,000 a year.

“The provider agencies are having a hard time recruiting families—there are less than 1,600 families in Pennsylvania that do it,” said JCHAI’s Stacy Levitan. “My understanding is that more people were signing up when they thought it would be easy, just some extra income and a way to help people with disabilities, but then they found they often had to quit their jobs to stay home and care for their charges, who were not that independent.”

And there’s very little oversight to make sure hosts are planning activities for their charges or facilitating community involvement. Although many of these placements work out well, most of the parents of I/DD kids I know—myself included—are terrified at the prospect of their children languishing in a stranger’s basement watching YouTube all day. Or worse: In 2008, 28-year-old [Tara O’Leary starved to death](#) in a New Jersey foster home.

You might think, given the rising numbers and shrinking resources, the states would welcome partnerships between the public and private sectors. There are many, all over the country, started by parents or providers who were able to use different funding streams—including private donations, tax credits, municipal grants, and low-income housing allocations. By the end of 2015, Madison House Autism Foundation is expecting to launch the Autism Housing Network, a website that will help those collaborating on similar projects find one another.

But if larger, disability-specific settings are prohibited, many of these programs will become unfeasible. The Bergen County United Way, for example, has built several intentional communities in New Jersey for individuals with a range of disabilities. It oversees every stage of these projects, funding all the initial assessments, designs, and plans with its own capital. The New Jersey Housing Mortgage Finance Agency offers special loans that allow the United Way to purchase land; other sources

include local county-government community-development departments and the Federal Home Loan Bank. Private agencies provide direct care to residents.

I visited one of these projects—Airmount Woods—and was struck by the number of elements tailored to the needs of this population. The organizers had consulted well-known autism schools to create a therapeutically designed environment that would reduce sensory triggers such as light, noise, and vibration. The walls were built of tempered glass and heavy-duty wallboard, materials that could withstand violent meltdowns. Clear sightlines allowed staff to see almost the entire house from the kitchen.

“Now other municipalities are calling, looking for similar projects,” Toronto said. “Some of the most wealthy towns in New Jersey want to donate land or use their trust funds to build affordable, supported housing and suddenly DDD [the Division of Developmental Disabilities] has changed the name of the game, telling us that residents may not be able to use their waivers.” A pipeline of 350 units has now been effectively halted, as Toronto waits to see the final version of New Jersey’s regulations. “The Rockefeller Group wants to donate the land right across the street from Farleigh Dickinson University and next to the headquarters of the New York Jets. It’s close to public transportation, employment opportunities, shopping. They want us to build 40 units,” Toronto sighed. “But if the proposed changes go through we’ll only be able to build four.”

Prospects look brighter for The Arc Jacksonville, a provider in Florida that serves those with autism and I/DD. It’s months away from opening The Arc Village, a community that will include 97 one- and two-bedroom units for approximately 120 residents. Jim Whittaker, the president and CEO, told me how the project was funded. Florida provided many millions of dollars, including \$10 million in low-income tax credits, which The Arc sold to an investor. “Plus, we put up \$2.4 million in owner equity matching

funds,” Whittaker said.

All this capital means The Arc Village will have no mortgage, resulting in low operating costs and rents as much as 70 percent below market value. Residents can use waivers if they have them, but the community was designed to be affordable for those paying out of pocket. Whittaker said inquiries have been pouring in from all over the country. “Some of them are coming from traditional supported living, where they live in apartments with some assistance, but they are so, so lonely. What they want is a welcoming community. The Village is the best of both worlds: Residents can work, play, and worship in Jacksonville, but come home and hang out with peers in a safe environment.”

It’s this level of community engagement that convinced Florida officials that this large project meets the intent of the CMS final rule. “The state has looked at CMS requirements, and they don’t mention numbers. What they’re looking for is integration, control, and choice, and we meet and exceed those standards—we’re off the chart on most. There isn’t a group home in the country that’s going to be less restrictive than our apartments,” Whittaker said. In fact, the state is considering providing special funding to move some of the 20,000 individuals on Florida’s waiver list into apartments in The Arc Village.



As part of the Lakeside program, Parles volunteers for Meals on Wheels and works in the campus greenhouse. (Neal Santos / The Atlantic)

Nancy Thaler accused me, in the nicest way, of being “overly optimistic about the potential for good in congregate settings and really naïve about the potential for evil.”

Perhaps. I was not a parent during the era of Willowbrook. But I’ve read enough contemporary news stories to know that similar abuses continue today. In 2012, for instance, *The New York Times* reported on two lawsuits at large facilities for I/DD adults. At one, in Brooklyn, a resident left in the care of a teenager nearly choked to death. At another in Albany, *The Times* reported, “employees restricted a man to a small mat on the floor, intentionally starved him, and beat him with blue painted sticks they called magic wands.”

But it’s not clear to me why thriving communities like Misericordia, Safe Haven, Lakeside, and The Arc Village don’t play more of a role in this debate. “People really do deserve the care that best suits them,” said the

University of Pennsylvania ethics professor Dominic Sisti. “I don’t see how that’s even debatable.” Sisti received national attention in January 2015 when he and two colleagues published a viewpoint in *The Journal of the American Medical Association* with the provocative title: “[Improving Long-term Psychiatric Care: Bring Back the Asylum.](#)” I reached out to him because although his paper is about the care of patients with chronic psychiatric disorders, his description of individuals “who cannot live alone, cannot care for themselves, or are a danger to themselves and others” reminded me of my own son.

“We were trying to rehabilitate the term, bring it back to its original meaning, which is a place of sanctuary and healing,” Sisti said. “But it turned out to be too distracting. Everyone focused on that instead of the ethical imperative, which is clear: We need settings that match up with each individual’s needs.”

Which brings us back where we started: Who decides what’s best for those with developmental and intellectual disabilities?

Thaler argues that states that set size limits won’t really be taking options off the table. “There’s a difference between people being allowed to do something and compelling the government to fund it,” she told me. But this would imply that the full range of residential options should only be open to those who have \$4 million in trust funds to pay for them. Besides, that market is so small it can hardly drive innovation in the field. As Tom Toronto of the United Way told New Jersey DDD officers following a public comment forum in February, “We can’t build on spec. We need to know residents will be able to use their waivers.”

Ne’eman made a different argument: He said that HCBS waivers were designed specifically for home and community-based settings, and pointed out that the government also offers institution-specific funding. “Nothing prevents ICF funding from being used to fund campus models,” he told me, referring to the Medicaid benefit many Misericordia residents

use. However, just a few minutes later, he acknowledged that several states had eliminated ICFs altogether. Even states that still have ICFs spend the bulk of their Medicaid dollars on HCBS waivers because they offer much greater flexibility: Rather than attaching to beds in particular facilities, as ICF funding does, the waivers attach to individuals, allowing recipients to change residences or providers and take their money with them.

It may be another form of discrimination to suppose that intellectually disabled adults can't thrive in a community of their own making.

What's more, Ne'eman's organization was one of the three self-advocacy groups that coauthored the policy paper "Keeping the Promise: Self Advocates Defining the Meaning of Community Living" in 2011, and that paper makes no mention of ICFs. Instead, it emphasizes that people with autism-spectrum disorders "should live in apartments, houses, condominiums, trailers, etc. located in rural, urban, or suburban communities with typical public resources such as shops, houses of worship, places to work, and accessible transportation systems." The paper makes it clear that no larger accommodation of any kind meets its standards. "Gated communities, farmsteads, and clusters of group homes—even those that include both people with and without disabilities—are not in the community. When we live in those settings we become segregated from the general scope of community life."

Ne'eman said he and his colleagues didn't base their opposition primarily on horror stories from the past. "We drew from a growing body of research literature on integration," he told me. "Research shows that choice and control increase when setting sizes are smaller."

Ne'eman sent me a [study](#) comparing the degree of choice individuals have

in HCBS programs versus ICF-supported facilities. That study did show that HCBS waiver recipients, on average, had more control over their lives. But the HCBS recipients were also, overall, significantly higher functioning than the ICF residents. The study authors were careful to point out that people who had higher levels of intellectual impairment, self-injury, and disruptive behavior had much less choice, even when they lived in smaller residences. The data source for the study—the National Core Indicators Consumer Survey—focused on personal decisions like when to get up, when to eat, and what to buy. It's hard to prioritize questions like these when an individual might blind himself, attack staff, or compulsively eat inedible, possibly toxic, substances (a behavior known as pica). Nancy Thaler acknowledged that some of the core indicators in the survey represent “luxurious outcomes” that can only be considered once health and safety needs are addressed.

It may be true that those in smaller, integrated settings do have more control over every aspect of their everyday lives. But for those who believe in expanding residential options, this seems like one element of a cost-benefit analysis—not a reason to rule out congregate settings altogether. For some individuals with I/DD and their families, scheduled, communal meals might make more sense than eating alone with an aide in a private apartment. These are matters of personal preference; neither is a bad choice.

The larger problem is the limited way “community” is being defined as exclusively the neurotypical community by CMS, the states, and, most surprisingly, by self-advocates such as Ne'eman. We are all part of many communities, and the government is generally not in the business of legitimizing some over others. The push for fully integrated housing comes from a desire to avoid discrimination. But it may be another form of discrimination to suppose that I/DD adults can't thrive in a community of their own making.

Vicky Blum is an autistic woman who bought the first house in what is projected to be a large intentional community for people with autism and their families in Pueblo, Colorado. She feels that immersion in the neurotypical community has left many young people with “the feeling of hopelessness, of being ‘less than,’” as she wrote to me, leading to increased rates of [unemployment](#), [homelessness](#), and [suicide](#). She said the Pueblo community would be a place where residents don’t have to “fake being neurotypical,” but can “embrace their awesome and authentic Autistic selves.” (Throughout her email, Blum capitalized “Autism” to underscore that sense of community.) She’s excited about watching children grow up “surrounded with incredible Autistic role models and mentors.” She also looks forward to hosting activities “that will teach non-Autistics who we are, which will make acceptance much easier.”

Blum’s community sounds lovely, but it would never be an appropriate home for Jonah, who will always need much more structure and supervision. That’s why it makes sense for waivers to support a range of settings that’s as broad as the range of challenges faced by this population: single apartments or small group homes for some, farmsteads or intentional communities for others. I had a tough time explaining this issue to Jacob during my dinner at the JCHAI house—frankly, he preferred to talk about the *Paddington* movie he couldn’t wait to see. But when it came to the question of where he himself should live, he did have one strong opinion: “I think I should get to decide.”

ABOUT THE AUTHOR

AMY S.F. LUTZ, a Philadelphia-based writer, is the cofounder and president of the [EASI Foundation](#) and the author of the book *Each Day I Like It Better: Autism, ECT and the Treatment of Our Most Impaired Children*.
