

Against “Community”

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The biggest buzzword in disability rights is undermining intellectually disabled people.

By Amy S. F. Lutz

When my severely autistic son, Jonah, was first diagnosed at the age of two, we were so hopeful. How lucky we were, to live in the 21st century! Instead of being institutionalized in snake pits like Willowbrook, Jonah and his intellectually and developmentally disabled peers now had the right to educational, vocational, and residential services in “the community”—the biggest buzzword in disability discourse for the past 50 years. It all sounded so warm and fuzzy—until Jonah broke a teacher’s nose when he was in kindergarten and it quickly became evident that his cognitive and behavioral challenges would require intensive, specialized services. Over the years, these have included autism schools, special needs summer camps, and now, having just turned 21, a disability-specific day program. Although Jonah is thriving, his future is

still terrifyingly uncertain. Disability rights advocates are fighting to close such programs, as well as others—like sheltered workshops, farmsteads, and campuses—they consider not in “the community.” It wasn’t until I returned to Penn to pursue my doctorate in the history of medicine, seeking to better understand the trajectory of these debates, that it occurred to me to ask: What, exactly, does “community” mean, anyway?

This is neither a rhetorical question nor an example of academic hairsplitting. Consider this statement by the National Council on Disability: “Living independently and in the community are preconditions for the enjoyment of human rights by people with disabilities and represent core values of the American disability community.” In the first use, *community* refers to a geographical location, like a neighborhood. In the second, it means a group of people that share certain characteristics, even if they don’t know each other.

There’s yet a third meaning, one that goes back to the beginning of community-based services. During World War II, psychiatrists discovered that soldiers suffering from shell shock—what today we would call post-traumatic stress disorder—were much more likely to recover if, instead of being separated from their units and sent to distant psychiatric hospitals, they were permitted to stay with their comrades. This conception of community—a set of meaningful relationships—would prove influential in civilian practice after the war.

Ideally, community would fit all of these definitions: a local neighborhood filled with like-minded people who really knew and cared about us. This is the romanticized version offered by disability rights advocates such as Ari Ne’eman, founder of the Autistic Self-Advocacy Network (ASAN), who has described the owner of a pizzeria who called to check in on an autistic man who typically ate in his establishment every day, but who had missed several meals due to illness.

Such moments of kindness doubtlessly occur—along with many complaints from the neighbors of autistic individuals banging their heads against the wall at 2 a.m.; NIMBY protests over the location of group homes; and, mostly, profound indifference. Today’s actual US communities are made up of strangers: according to economist Brian Bethune, 50 percent of Americans don’t even know their neighbors.

As these different meanings of community have unraveled, disability rights activists have latched on to place as the one that matters most. In a joint policy paper, ASAN and several other self-advocacy groups argue that “genuine community happens in inclusive, diverse and mixed neighborhoods” populated by “people who don’t have

disabilities, and this does not mean staff.” Day habilitation centers, gated communities, clustered group homes, and virtually all settings that serve more than four disabled people at one time are emphatically rejected as “not community.”

The perverse result is evident in a comparison of two sample days at real programs currently serving intellectually and developmentally disabled (I/DD) clients:

Program A: Client spends the day feeding horses, collecting eggs, and picking tomatoes at a farm-based program. At lunch, he joins 32 peers for a meal they have helped prepare using ingredients produced at the farm.

Program B: Client spends 1.5 hours in a van with two peers and one direct support professional (DSP) driving to a mall 70 miles away. The group walks around the mall for two hours, buys nothing, then returns.

According to an increasing number of policies, only Program B is considered “in the community.” In a statement issued last year, groups including The Arc, Autism Society, and others urged Congress to pass legislation stipulating that disability services funded through Medicaid be “provided in the community in inclusive and integrated settings.”

At the state level, many agencies have already moved to restrict disability-specific settings like Program A—either prohibiting them outright or creating nearly insurmountable financial obstacles, such as reimbursing “community-based” programs, like Program B, at a much higher rate. These sweeping policy changes often fail to acknowledge the challenges experienced by many I/DD adults. The very behaviors that preclude many of them from participating in the supported work programs overwhelmingly favored by Disability Rights advocates—such as aggression, self-injury, property destruction, and elopement, all of which Jonah has suffered for much of his life—also make many public spaces inappropriate or even unsafe. Program B is just one example of the logistical contortions many providers go through to meet community requirements for their most impaired clients. The mall—wide-open and not very crowded on weekday mornings—is fairly safe. But a trip to the local mall won’t take up nearly enough of the day, so staff members are directed to drive to the mall five towns over.

The same fight has unfolded over residential settings. Consider these two programs:

Program A: An apartment building for autistic adults in a major city. Rent payments include a suite of supports, including life skills and vocational training. Social skills are practiced during scheduled events, and more informally in communal spaces such as a gym, swimming pool, and game room.

Program B: An individual apartment in the same city. Client lives alone, supervised by rotating DSP staffers paid \$10.50/hour.

As a parent, nothing scares me more than Program B. My son is intellectually disabled and minimally verbal, so he could never tell me whether he spent his morning hiking through a state park, or whether his aide opted to let Jonah sit at home all day, watching the same 30-second clip of “Big Bird Doesn’t Fly” over and over again on his iPad. I also think Jonah would be safer from abuse—a scourge for I/DD adults—in a larger setting, with many eyeballs on him. Nevertheless, Program B meets the criteria of even the states with the strictest inclusion requirements, but Program A was the target of a campaign by ASAN to keep the state of Arizona from supporting it.

Jonah loves going to restaurants and amusement parks, and shopping at Big Box stores with his father on the weekends. But, importantly, the physical community is a means to many ends, including pleasure, fitness, and employment. The mistake advocates make is treating community as an end unto itself, and collapsing all the diverse factors that make life meaningful into that narrow measure.

A better policy would focus on maximizing ends: happiness, health, safety. Perhaps most importantly, interpersonal connection.

Disability rights organizations have rallied advocates, academics, and many policy-makers around the flag of community, to the point that virtually all services have come to be judged by this single standard. But the reason community has resonated so deeply with so many stakeholders is because the word still carries connotations of warmth and connection—even if, in practice, it now solely refers to a geographic location. Perhaps we need a new set of terms: *public space* or *commons* to describe the brick-and-mortar buildings where those of us with and without disabilities may or may not live, work, shop, eat, and play; and *social network* when speaking of the number and strength of the relationships that sustain us all. Too much is at stake to build our disability infrastructure on a foundation as amorphous, imprecise, and misleading as *community*.

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