

CAN THE U.S. EVER
MOVE BEYOND SLAVERY?

WILL LOCKDOWN LOSERS
FINALLY FIND RELIEF?

HOW MUCH PROTECTION
DO COPS REALLY NEED?

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George Orwell's
Nineteen Eighty-Four
in Full Bloom Today

IT HAS BEEN almost 50 years since “One Flew Over the Cuckoo’s Nest” debuted and cast light on life in a mental institution, leading many to argue that people with disabilities should and could live among their communities. However, the issues brought out in this film seem as relevant today as they were back then. Studies have found a staggering 70% of adults with autism have been abused while in “care.” Even without abuse, reports of this population feeling lonely and misunderstood are common. However, we continue to evolve to a point where more and more options are becoming available to them.

Although there are large institutions trying to provide quality care, there are many more choices for adults with special needs and, as understanding increases, so will hope for this fragile population.

The Civil Rights of Institutionalized Persons Act of 1980 led to more investigations of abuse and neglect. The Americans with Disabilities Act of 1990 began protecting the rights of both the mentally and physically disabled. The well-known 1999 case of *Olmstead v. L.C.* concluded with a Supreme Court ruling that forcible institutionalization violated the law. The thinking about the care of those with disabilities slowly was changing to involve two crucial choices for the intellectually disabled: where I want to live and how I want to live.

Olmstead required states to support disabled individuals so they could remain in mainstream society rather than be hidden—which was a giant step forward in caring for the disabled. Soon, Medicaid began offering services for those who did not live in institutions—“waivers” that assist people with disabilities in housing and care. Even the way people with developmental disabilities are identified has changed: Pres. Barack Obama signed a law in 2010 mandating that Federal statutes no longer will use the term “mental retardation.” The replacement phrase is “intellectual disability.” It is known as “Rosa’s Law.”

In a landmark move, the Center for Medicare and Medicaid Services called out how the waiver program would operate once the Patient Protection and Affordable Care Act protections were implemented in January 2014. It said that no particular housing models would disqualify residents. In other words, it would not prohibit “congregate settings”—community-based settings that many advocates for the disabled were calling for. It also gave the states the freedom to decide what was “institutional,” as well as how many people could live in each setting.

These rulings have helped “intentional communities” thrive. An intentional community is defined as a group that has chosen to live together with a common purpose, working cooperatively to create a lifestyle that reflects their shared core values. In the case of the intellectually disabled, it means creating and sustaining safe, accessible, affordable, and integrated housing—and within that structure it means providing as much peer

support as possible. Groups of parents and advocates have conceived of and planned new living spaces with a mission to heal this population from the inequities they have faced.

One of the newest organizations to break ground is The Big Wave Project in Half Moon Bay, Calif. In the western U.S., California and Texas have more disabled Americans living in institutions than all other states. Big Wave co-founder Jeff Peck, a father of an adult with special needs, began to interact with his community 20 years ago with the mission of providing a purposeful and independent life for both his daughter and her peers with develop-

mental support has been crucial, as it has taken 20 years for them to break ground due to opposition from a few residents who were known to oppose building on the coast. Although the delays have made the project more costly, the Bay Area families persevered, and Big Wave finally was granted its permits, breaking ground on Aug. 15, 2020.

Other intentional communities are building on earlier models. Madison House Autism Foundation in Maryland was founded to identify the lifelong needs of adults with autism through education, awareness, and advocacy and then seek to fulfill those needs. They now

IT'S INTENTIONAL

BY SARAH SHERWOOD

Adults with special needs are benefiting from intentional communities.

mental disabilities through affordable housing, meaningful employment, and a supportive community.

Across the country, many parents and professionals are working together to design intentional communities. “Parents are understandably especially sensitive to the needs of their children as they grow and develop,” says David Spiegel, associate chair of psychiatry at Stanford University, “but when we reinforce their recommendations with good research, we have a better chance of providing what is truly needed. In this case, there is no question that peer support for adults with special needs is very important.”

Peck, a professional in construction, along with his wife, had two goals: to provide a place for adults with special needs so that they can reach their full potential and to support Big Wave through local businesses (those who would provide jobs and resources so that the organization could be completely self-sustaining).

In the last two decades, parents, along with donated land from Peck and his business partner, Steve Barber, have provided the bulk of support, forming a co-op to encourage and sustain family control of Big Wave. That fi-

are developing an “agrihood” as part of a 400-acre farm just 30 miles north of Washington, D.C. It will include housing, education, riding, and employment opportunities for neurotypical populations, adults with autism and other developmental disabilities, and groups such as wounded veterans, who can use the farm for specialized programs, volunteer in support of adults with disabilities, or share in benefiting from existing employment and service programs.

The goal is to become a national prototype, “directly meeting the needs of adults with disabilities, veterans, and residents wishing to reconnect with and help preserve our rural treasures.”

In Chicago, through a spectrum of residential options on its 31-acre campus and in the community, Misericordia currently serves more than 600 children and adults residentially, from diverse racial, religious, and socioeconomic backgrounds. Twenty percent of its residents either come from impoverished families or have no families and are wards of the state.

Geana Connelly, who runs clinical services for the organization, says those who criticize intentional communities claim that they are

isolating and segregating adults with special needs. Connelly, who has been with Misericordia for 28 years, argues that while they are congregating together, that does not mean they are not involved in the community; rather, they need a place where they have opportunities for meaningful relationships where they can feel safe and understood.

They volunteer through a program called "Engage Chicago." They rely on more than 10,000 volunteers to help them with fundraising, enhancing relationships, staff support, and help with critical services. "It's a mutual partnership with the community," she says.

a time and lets it dictate the song. He uses color-coding and precautions around sound to help them learn in their own way. "By the end of that first day they wanted to start their own band. I watch them light up every time and eventually they begin to believe that if they can play an instrument they can learn, and they even have more confidence that they can work."

Indeed, one of the many needs of this population is the dignity of work. It is estimated that 87% of adults with special needs are unemployed. That, too, is just beginning to change. Employers like Safeway and Microsoft have been hiring adults with special

has taken them to exciting venues where they can play for the public, sees the support of the audience and thinks, "I am lucky to be standing on a stage with them." One Step Beyond's retention rate is 95%. "We like to make staff feel like they are members of a family," says founder and former CEO Mimi Rogers.

Rogers is adding to her programs in Arizona and California in an unprecedented way through Big Wave. "We have developed a method of teaching music and other skills to adults with special needs. Now we are going to bring culinary skills to the San Francisco Bay Area in a way we have not done before."



Despite new ideas for supporting adults with special needs, nationally, they often still are marginalized and many remain outside of intentional communities; their only lifeline is a strong day program.

Peck and a co-op of dozens of Big Wave families are "focused and driven" to create a safe and nurturing place not only for their sons and daughters, but for the entire community. With these priorities they have partnered with One Step Beyond, an organization that provides developmental programs that are the first of their kind for adults who have intellectual disabilities.

One of those initiatives is led by Jared Woosley—a musician who designed the music program at One Step Beyond in Arizona—who once had a band that toured with Virgin Records. Woosley brought his skills and connections with him to offer a comprehensive music program, and also to give himself a greater quality of life: "Although I had a friend with Down syndrome, when I first took the job I didn't realize what it would mean for me or these students, but I was happy to bring the curriculum in."

With his students, Woosley takes one key at

needs with an eye on the research that says not only can they work, but it can be good for business. Big Wave estimates that most of their residents will be able to work on campus with local businesses and that serves other purposes as well, including integrating adults with special needs into the larger community. More importantly, though, it gives this population more confidence and fulfillment.

That is precisely what many group homes do not do. It is emblematic of a system that lacks quality and stability to be accountable. Many of these positions require strong effort and complexity, yet the qualifications frequently involve a high school diploma. Unsurprisingly, given these factors, the field has a 70% turnover rate. "One of the problems with so many of the older institutions, and even some of the group homes, is a lack of quality day programming and insufficient staff," says Peck. "One Step Beyond has that which will encourage peer support through a variety of very creative programs, taught from qualified staff."

Woosley says he gets real fulfillment by observing how music gives his students the confidence to communicate with their peers. He

Big Wave will take the Bay Area's developmental disability population out of a game of just a few people where loneliness is more often the norm. Instead, they will integrate in a larger manner with dozens of units of living space and a Culinary Academy on campus that will train these adults in safe culinary skills, helping them to work on events with catering and support. Big Wave's local flower business, Bubbles and Blooms, also will help support Big Wave. In fact, integrated employment opportunities for the residents is an integral part of Big Wave's broader business model.

The times are changing. Society is hiding away these vulnerable human beings less than it used to and, instead, we are learning that they have quite a bit to teach us. "Mom and Dad have been too much the center of their day," says Rogers. Instead, they soon will live with their peers—and Mom and Dad will come to visit. Rogers and the others who work closely with this population say it is time to shine a light on the abilities of adults with special needs. ★

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