SPECIAL PEOPLE WITH SPECIAL NEEDS

A MULTI-PRONGED LOOK AT U.S. ECONOMY CANCEL CULTURE CREATING CHAOS

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Advigating the Never-Ending Maze of COVID-Related Policies, Regulations, and Laws-

AHOME THAT IS SPECIAL

BY SARAH SHERWOOD

"The population of adults with special needs is growing, while the funding is decreasing. . . . Federal and state policy leaders [are working] on strategies to solve the problem, [but since] these leaders often are not touched personally by the problem, the design of these programs can fall short."

ULIE LENING was born into unfortunate circumstances. Her biological mother was addicted to a variety of drugs and struggled all of her life with depression. When she realized she was pregnant, she was too far along to terminate the pregnancy and chose instead to have her daughter adopted. While Julie could have had a better life in a new family, she did not. The family who adopted her could not and would not take care of her properly. Julie, now 32, was born with IDD (intellectual and developmental disabilities), and her adoptive mother chose to ignore it rather than seek the help she needed. Angry and confused throughout her childhood, Julie often demanded that her needs be met, but that only strengthened the family's resolve to ignore her, inconvenienced by her suffering.

When Julie was 14, her adoptive mother gave her back to the State of California. Julie, who is suspected to have a diagnosis of Asperger's Syndrome—part of the autism spectrum disorder—languished in group homes. As an adult with IDD, she dealt with the abuse from staff, shortages of money due to being on welfare, and, worst of all, severe loneliness and rejection.

"I want be around people who care about me," says Julie, with a tear in her eye. "I want a loving family of my own."

While Julie's story is extreme, her feelings of isolation and frustration with being misunderstood are not uncommon. The vast majority of adults with developmental disabilities live with a family member who cares for them and provides a nurturing environment, oftentimes with the help of programs offered by both public and private companies. There are, however, times when family love is not enough, and many parents worry about the very feelings that Julie has experienced—and so are determined to see that this does not happen to their own vulnerable sons and daughters.

"Through Big Wave, we are raising not just our sons and daughters, but a larger community as well," says Jeff Peck, CEO of the Big Wave Project in Half Moon Bay, Calif. "The fact is parents need each other, and so do our kids—they need each other, too. Peer support is most essential for this population." The science is clear: we all need community in order to thrive.

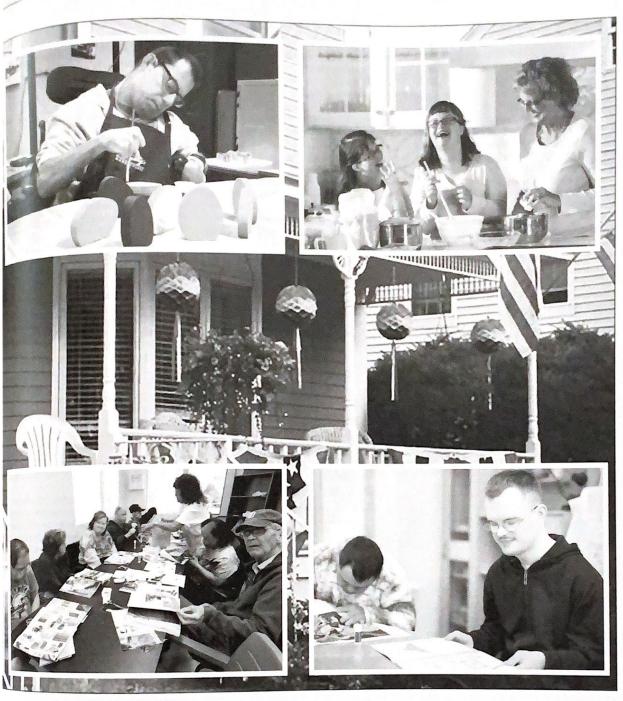
Peck had the foresight 21 years ago to realize that there would not be enough housing for the fast-growing population of adults with autism and other special needs. When he was told that his daughter had a developmental disability, knowing he would not be around forever, he did his research and discovered that, for these individuals, having a "home" sometimes is almost impossible. Today, hundreds of thousands of adults who have disabilities across the U.S. sit on waitlists for housing and community-based services. Even if they are ready to move out of their parents' home into independent living communities, their options and funding for it often do not exist. When parents die, their children can be in crisis.

In Oregon, a study by the Kuni Foundation, an organization that works for the inclusion of



individuals experiencing IDD, suggests "a growing risk of homelessness for Oregonians with intellectual disabilities, as government support fails to keep pace with rising housing costs for a population that often needs support." The report estimates that "around 24,000 adults with intellectual and developmental disabilities in the region face housing insecurity."

The population of adults with special needs is growing, while the funding is decreasing, and Federal and state policy leaders work on strategies to solve the problem. Because these leaders often are not touched personally by the problem, the design of these programs can fall short.



As a result, parents have taken this crisis into their own hands. In many cities across the U.S., they literally are coming to the rescue. In Maryland, there is the Madison House Foundation; in Arizona, First Place; in Ohio, Bitersweet Farms. These "intentional communities" of varying models aim to address the severe shortage of housing options for those with developmental disabilities.

Big Wave's model strives to be independent of government funding. "This is very important, because we want it to succeed forever. This will set us up for success for the long term," Peck emphasizes. "Our model is sus-

tainable in this way. We do not want to be vulnerable to cuts in funding, ever."

Whatever the model, parents who design these intentional communities understand the connection between a place to live and one's happiness. Affordable housing is not just about a building. It is about the resident's quality of life and the need for a purpose.

"You're not going to thrive in life without the right kind of housing," says Mimi Rogers, former CEO of One Step Beyond, a nonprofit organization that provides programs responsive to providing emotional support, education, employment, and access to community resources and activities. "Housing is intricately related to all that we do."

Matt Hearn, a high-functioning adult with autism, is eager to move into Big Wave: "Trust is difficult for me after being misunderstood for so many years. I want a community that is less judgmental and understands what I am going through because they have experienced it themselves. That would definitely help with my social anxiety—to have friends with similar experiences and common interests."

Hearn describes feeling like he is constantly walking on eggshells because he feels misunderstood. As an introvert his "social capital,"

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