

Doylestown couple works to create housing for autistic adults



Jim Richardson and his wife, Nancy Carey-Richardson, have founded Neuro Diverse Living. CONTRIBUTED

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For young adults, getting a first apartment or other new digs is a major step toward independence.

For young adults who are on the autism spectrum, the move away from their family home isn't so easy. Some, in fact, can't thrive without support. They may need help with everyday activities including cooking and personal hygiene, as well as with finding friends and social

opportunities due to their inability to communicate easily.

Jim and Nancy Richardson, of Doylestown Township, support their autistic son, Michael, 27, but they're concerned about his future when they won't be able to care for him, as well as the millions of other autistic adults across the state and country who will also need care in the years to come.

In Pennsylvania, the latest census in 2014 showed a 334% rise in adults with autism since 2005 and then predicted it would rise to over 36,000 adults with au-

tism living in the commonwealth by 2020.

"This dramatic growth is expected to continue as more children transition to adulthood and more adults are diagnosed. Most of these individuals will require services across the lifespan," according to the state Department of Public Welfare report.

The Richardsons have formed a new nonprofit, Neuro-Diverse Living, to help establish community living arrange-

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Spectrum

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ments for autistic adults so they can live more independently but have support and socialization when they need and want it.

Autism or autism spectrum disorder (ASD) is defined by the nonprofit Autism Speaks as "a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech and nonverbal communication."

There are many subtypes that researchers believe are influenced by a combination of genetics and environmental factors.

"Each person with autism has a distinct set of strengths and challenges," Autism Speaks said. Some are highly intelligent while others have learning disabilities, but almost all lack communication skills and have sensory issues. Researchers are trying to find the causes and potential therapies for the condition.

Growing need for housing for those on autism spectrum

The Autism Housing Network reports that there are more than 7.37 million adults with autism or other intellectual/developmental disabilities in the United States with 83% not receiving government support. And it says that 39% of these adults "no longer see friends after high school."

The Richardsons have been married for 23 years. The couple met when they both worked for a major computer company. Nancy's first marriage had failed after Michael was born prematurely and was diagnosed with autism. Jim also has grown two children from a previous marriage. The family moved to Doylestown from South Jersey specifically because they heard that the Central Bucks School District had a good education program for autistic children.

In their old school district, Michael had been put in a class for disabled children. One had a severe physical handicap but could learn easily. Michael could not. He now has the reading and comprehension of a third- to fourth-grader, his mother said. But his main issue is the inability to socialize easily with others.

"Autism was not a known diagnosis," Nancy said, looking back to when Michael was a toddler whom she could see was having difficulties with communication. "We couldn't find anybody who knew anything about it."

The couple said they went to "a flurry of doctors" at major medical institutions in Philadelphia and elsewhere, trying to find out how to deal with Michael's condition and get him the best education possible. Then they learned that Central Bucks was one of the top two school districts in Pennsylvania at that time for educating the autistic.

"We came here. Immediately we knew it was the right choice," Nancy said. And they were happy that Our Lady of Mount Carmel Church allowed Michael to participate in religious instruction and make his First Holy Communion, something that he hadn't been permitted to do at a church in South Jersey.

"They've done a wonderful job with him," Jim said. "It was the right decision."

But once he graduated out of the school system at age 21, the couple have encountered the issue of what Michael can do for the rest of his life and where he will be able to live as they age. He tried working at a major home improvement store, but that didn't work out.

"If you don't have the opportunity to get your kid into a job, where they can be active and busy and productive and contribute, what do you do," Nancy asked.

They sent him to a summer camp in Haverford for a couple of years where he learned how to dress, cook, clean and get himself from point A to point B, she pointed out. That made them realize he could live on his own with some support.

The Richardsons don't want to see their son or others placed in group homes that aren't high quality and they



Adults with autism and special needs learn how to bake, in this photo provided by Autism Speaks. FRANK ROCCO / AUTISM SPEAKS

said that the waiting lists for well-run residences can extend to 15 to 20 years because most of the adults who move into these homes are young and have long lives ahead of them.

Creating a solution

So, Jim said, they decided in 2018, "if we can't find what we want, we would create it." In 2019, they filed to form their nonprofit organization.

The nonprofit, with 501C3 tax designation, is called Neuro Diverse Living and it's "designed to provide adults living with autism or other IDD's (intellectual and developmental disabilities) with independent housing alternatives based on their support needs," the couple say in a prospectus.

They recently held an online forum with an autism expert and more than 160 people joined in, with about 80 said they would be interested in such housing for a family member.

The couple said they've identified three sites so far in Bucks and Lehigh counties that would be good for housing for either a single group home, or an intentional co-housing community where high-functioning autistic adults and others who want to help could look out for one another in separate homes situated close together.

The biggest challenge, they said, most likely will be getting municipal officials to approve the required zoning variances to allow non-related persons to live together.

The pandemic has made the issue more taxing.

Like others with autism or sensory problems, Michael cannot tolerate wearing a mask.

"I don't want him making other people uncomfortable taking his mask off," she said, so he has been more isolated at home than before the pandemic began. And their plans to develop the housing also had to take a back seat to the COVID crisis.

"It was a hard year; it took the wind out of our sails," Jim said.

But neither gives up when the going gets tough. Jim survived four back and neck fusions following a bad car accident in his 20s as well as a brain tumor in 2001 and both he and his wife continue to have successful corporate careers even as they approach retirement age and are caring for Michael.

The couple hope to get their first and second house open and running this year but do need community support and corporate sponsors to keep the program going.

Since children, including autistic children, typically outlive their parents, the Neuro Diverse Living communities "will offer families a sense of comfort, knowing that their special-needs child will have a permanent and safe place to live indefinitely," the couple state in their brochure.

Challenges to independent living for those on the autism spectrum

"Of all the challenges that go along

with creating housing for a special needs group, the township and the zoning is probably going to take the longest. It certainly isn't a lack of available property or land. It certainly isn't a lack of funding from investors, or getting grants from the state or housing tax credits, but getting the township to give you a variance for what you want to do," Jim said. "That's why we do need to get our legislators ... This is going to take a number of people getting behind it to make it happen."

"It's certainly not for a lack of need."

The couple really would like to establish a housing model where several people with autism or other intellectual disabilities, but who do not need to be institutionalized could live in a group of row homes or pods, but within a wider community where support would be available if they need it.

However, there are two key stumbling blocks.

Each municipality has its own zoning regulations for group homes, said Bucks County Planning Director Evan Stone. And federal and state regulations regarding the distribution of "consolidated waivers" to help people pay for housing for those with disabilities won't allow the homes to be grouped together.

"You cannot create multiple structures," said Mary Dunn, Bucks County deputy administrator for developmental programs because the waivers are waiving the need for intermediate institutional services. They're designed to prevent segregating the people with disabilities from the "fabric of life in the community."

Setting up a duplex or pair of twin homes to house the autistic would be fine, but creating any larger community would prevent the occupants from receiving the federal and state financial support that they may need.

The waiver program uses Medicaid funding channeled through the Pennsylvania Office of Developmental Programs to assist families in getting housing for those with developmental disabilities.

"We have seen our numbers increase substantially in the last several years," said Dunn. She now estimates more than 2,000 people have applied for services.

Donna Bell, director of the Bucks County Department of Behavioral Health and Developmental Programs, said there is a waiting list in the county for the consolidated waivers. The state has given Bucks County 681 slots but more are needed.

Jim Richardson agrees. "The demand for services far, far outweighs the capability currently available," he said.

The county does have a Life Share program where a disabled person could live with another family willing to offer them support, but Richardson said that few families with an autistic adult want to place their child in someone else's home. They don't see that as a long-term solution for someone who may need support to thrive for the rest of their lives.

And they fully expect that some on

autism spectrum may want to marry and have a home of their own.

Jeffrey Fields, director of the Bucks County Department of Housing and Community Development, said, "housing for people with disabilities is an eligible use under Community Development Block Grant (CDBG) and we regularly fund acquisition and renovation of housing used for this purpose. In any given year we have utilized CDBG funding to either make repairs to existing group homes or to assist in acquisition of property that would be used for housing people with disabilities. I don't think we have had recent applications specifically for people with autism, but such a project would be eligible."

While the county is now receiving relief funds to assist people with housing needs during the pandemic, Bell said these would not provide a long-term solution to assist families with housing for intellectually disabled or autistic adults.

Jim Richardson met Monday with officials from Woods Services, the Bucks County-based provider of educational services and care for individuals with special needs.

"Woods serves individuals who have complex behavioral challenges and medical conditions for whom typical group home community living is not a good option. As Woods looks to develop additional community housing for individuals with autism and other intellectual and developmental disabilities, it is seeking to learn from those who are who are developing creative residential models that offer individuals a safe environment in which they can thrive," said Cheryl Kaufman, senior vice president of communications and development. Woods is hosting its Run for Woods Saturday.

The Richardsons have reached out to state legislators for help but so far, no one has provided answers on a housing model of what could work and still meet federal and state guidelines for financial assistance for those families in need.

State Sen. Steven Santarsiero who represents the 10th District of Bucks County, sent information on a virtual roundtable he will host from noon to 1 p.m. May 5 on PA ABLÉ accounts, which can "give individuals with qualified disabilities a tax-free way to save for disability-related expenses, while maintaining government benefits."

Speakers for the event will include representatives from state and advocacy organizations, which provide a variety of services and the Pennsylvania Treasury- Bureau of Savings Programs oversees the PA ABLÉ program, Santarsiero's office stated.

Information from the Pennsylvania Office of Vocational Rehabilitation, Disability Rights Pennsylvania and from the Office of Developmental Programs about the Medicaid waivers will also be provided. Roundtable information is available at <https://www.senatorstevensantarsiero.com/event/pa-able/>.

Risk of homelessness in autistic adults

In their Neuro Diverse brochure, the Richardsons point out that the Centers for Disease Control report from May 2020 states that without "access to affordable housing in their community or the support to live in their own home, adults with autism are at risk of homelessness or displacement from their community."

Desiree Kamela of the Autism Housing Network said that a large percentage of autistic adults are already homeless because their lack of social skills prohibit them from nailing a job to support themselves, and to provide for their own housing.

That is the Richardsons' greatest fear for autistic and intellectually disabled adults, and the greatest worry for the families who love them.

For more information on the program or to make a tax-deductible donation or stock gift, to Neuro Diverse Living, visit <https://neurodiverseliving.org>.