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Independent living is goal for families affected by autism

The Autism Puzzle: A New Jersey Angle

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The Middletown Arts Center on Church Street has decorated a tree with blue lights as part of the Autism Speaks Light It Up Blue campaign.
JENNIFER PEYTON

A blend of housing and support services could mean happiness and security for people with autism, both while their parents are alive and long after they die, according to experts.

Most families cannot hit that target without climbing a long waiting list for financial assistance from the state Division of Developmental Disabilities. For many young adults with developmental disabilities like autism, the route to independent housing begins in their childhood homes, said Liz Shea, who oversees the division.

“The vast majority of people aging out of the school system, like the vast majority of people aging out of the school system in general, live with their families or are still largely dependent on their families in many ways,” she said.

Individuals must obtain the Medicaid Community Care Waiver to access division funded housing. Right now, 3,789 names line the priority section of the list, which is reserved for people whose parents are 55 or older and those with special circumstances. Emergencies can boost an individual to the top of that list, according to the state. But the division offers other types of assistance to those who lie in wait, spokesperson Pam Ronan said.

“Please note, too, that families often register their loved one very early on the list, since they are concerned for their loved one’s future,” she said. “Because of this concern, many of the individuals on the waiting list are already receiving some type of service [or services] and are not in need of anything additional.”

When somebody successfully scales the waiting list, they must use 75 percent of their federal disability benefits to cover room and board, according to the state.

That price tag opens a world of housing opportunities to people with autism, depending on their preferences and capabilities, experts said.

The Arc of Monmouth is one vendor that provides housing and support services to people with developmental disabilities. The organization offers everything from group homes and supervised apartments to the backing necessary for independent living, said Dawn Delaney, director of residential services.

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Nearly 100 people with disabilities live in settings run by Delaney’s department, she said. They include group homes of various sizes, smaller apartments, units where less support is provided, and even strings of consecutive apartments that are attached by adjoining doors.

“We’ve structured them so that they can have their own apartment, but they can kind of seamlessly go back and forth and visit each other,” she said.

Another 22 people take part in the Arc’s independent-living program, which places clients in dwellings of their choice with fewer supports, said Sarah Logan, director of individual and family supports. Some of those people receive Section 8 housing choice vouchers, while others move into pads paid for by parents in personally selected areas, she said.

No matter the environment, the key to independence for young adults with disabilities is the level of service that they receive in their homes, Logan said.

“It’s more than just a building,” she added. “Who’s going to support that individual? That’s the most important piece.”

People with autism may benefit from a few hours of services per week or regular assistance at the hands of two or three aides. Delaney said staff members help with shopping, cooking, budgeting, nurturing friendships in the community and any other obstacle that could appear.

“Our support really is catered to the person and what they actually need, and we also take their preferences into consideration,” she said. “So, if they said they wanted to learn, we would try to help them to learn and be more independent.”

Changes are coming down the pike for housing at the state division. Logan is hopeful that reforms will loosen restrictions on funding to better carry those dreams.

But for anybody to thrive in an independent setting, they must be prepared to tackle most of life’s daily tasks, she said. .

Mai Cleary, president of Impact Oasis, has one solution for that. She runs the organization’s TRAIL Center, a 7-acre farm stocked with chickens, goats and a pony at a park in Middletown.

There, four adults with developmental disabilities temporarily reside in a historic farmhouse. Nine other commuter students also partake in the program, which is a transitional step designed to teach a variety of work and life skills, she said.

“The whole thing is meant to create a therapeutic life that includes meaningful work, a peaceful residence and teaching healthy habits,” Cleary said. “In the long run, it will take such a stress off society because these guys will be healthy, they won’t need Medicaid, and they’ll be working and feeling like they’re contributing.”

The TRAIL Center came about due to a public-private partnership between Impact Oasis, Middletown, Monmouth County and the state, she said. Private organizations have also donated time and resources to the project, she said.

Lynn Becker, whose 31-year-old son with a developmental disability still lives at home, knows the financial burden faced by parents. Ample state funding for residential and support services is a must, she said.

Money that is currently used for self-directed services cannot be put toward housing, according to the state. Becker said the resources should come with fewer strings attached.

“It’s only for these approved day programs, so it becomes kind of what welfare is,” she said.

Becker, who sits on the Mayor’s Council on Special Needs in [Manalapan](#), is rallying to lift other constraints put in place by the state. She wants assisted-living facilities for people with disabilities to open in New Jersey, but division funding does not support such housing even with a Medicaid waiver, she said.

Other parents agree that state money should be spent to advance the life that would best suit each individual. Carol Myron, whose 21-year-old son Jeremy is set to graduate high school in June, is unsure of what will come next.

“Nobody — the government and the states — should say what is right or wrong, whether it be in a group home, an assisted living facility, a co-op, a farm or whatever,” Carol said. “They should live as they want.”

Despite her concerns about limitations, waiting lists and settling, the single mom is optimistic that New Jersey’s system of residential and support services for people with autism will meet the demand.

“It has to work,” Carol said. “There are just too many children and adults who are going to need a place.”