



'Priority' waiting list to provide housing for thousands with developmental disabilities

Published: Sunday, April 17, 2011, 7:30 AM Updated: Sunday, April 17, 2011, 10:59 AM



By **Dan Goldberg/The Star-Ledger**

TOMS RIVER — Mike Festa is beaten down and losing hope that his son will be all right when he is gone.

It's evident in the folder overstuffed with hundreds of documents that he keeps in the basement of his Toms River home, in his voice when he dials Trenton searching for answers, in his sigh as he describes the thousands of hours spent in a decade-long fight to find a suitable home for his 35-year-old autistic son, Michael.

Michael is sweet and sociable but subject to seizures and incapable of living on his own. He lives with his parents, who are his around-the-clock caretakers, but who also know they need to find a home that will provide for their son when they no longer can.

"How much time do I have?" asked Festa, who is 61. "I don't know. My wife and I can pass any time. If we do, Michael becomes an emergency ward of the state, and then they put him anywhere."

And not necessarily a place suited to his delicate emotional needs — a thought that terrifies Mike and Joy Festa.

New Jersey considers Michael a priority for housing and services because his parents are older than 55. Yet he is but one of 4,879 "priorities" on an 8,000-person waiting list for people with developmental disabilities.



[Enlarge](#)

John O'Boyle / The Star-Ledger

Joy Festa plays with her 35-year old son Michael's hair as he watches online videos inside their Manchester home. Michael is autistic and has been on a housing waiting list for years. (John O'Boyle/The Star-Ledger)

Michael Festa, a 35-year old autistic man, waits for housing
[gallery \(5 photos\)](#)

The Department of Human Services, facing a severe housing shortage and an unrelenting budget crunch, was able to remove 229 names from the waiting list this fiscal year.

It wasn't supposed to be like this.

In 2005, amid much pride and anticipation, the state created the Special Needs Housing Trust Fund, signed into law by Sen. Richard Codey when he was acting governor. It was expected to provide 10,000 new affordable housing opportunities for people with developmental disabilities and mental illness by dedicating \$200 million to create new homes.

But six years later, \$168 million has been spent to provide housing to 1,500 people with special needs, according to state officials. That's 84 percent of the money to achieve 15 percent of the goal. The state Department of Community Affairs expects only another 500 units to be created with the remaining money.

That means thousands of people like Michael are growing old with their parents, while hundreds more, not fortunate enough to have caring or capable families, are warehoused in county hospitals or housed in shelters.

When the money is gone, infrastructure for special-needs housing will become nearly impossible to fund, said Ed Murphy, executive director of the Supportive Housing Coalition for New Jersey, which works to provide homes for those with special needs.

PLANNED STIPEND

The state is not walking away from the problem. As reported last month in *The Star-Ledger*, Human Services is readying a proposal that would provide an annual stipend of at least \$10,000 to families taking care of adult children with developmental disabilities. The money could be used to pay for part-time aides, summer camps or vehicles with wheelchair access, but it does not address the need for supervised care when parents die.

"The lack of decent, affordable housing is what keeps parents up at night," said Phillip Lubitz, advocacy director for the New Jersey chapter of the National Alliance on Mental Illness. "The question I hear over and over again is, 'What is going to happen to my son or daughter after I am gone?'"

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State officials and activists agree the trust failed to create the 10,000 beds it promised for a number of reasons, including well-intentioned hyperbole that initially overestimated the number of beds that \$200 million could create.

"I think it was unrealistic from the start," said Alison Recca-Ryan, director of the New Jersey Corp. for Supportive Housing, which tries to help communities create permanent housing for the homeless.

The economy also played a role. The law allowed the special-needs trust to fund up to 80 percent of construction costs for housing, but the hope was that other money — such as the balanced housing fund — would contribute more than 20 percent. The economy dried up those other funds faster than anticipated, leaving the special-needs trust to foot a larger percentage of each housing start.

The situation is further complicated by the Olmstead decision, a U.S. Supreme Court ruling that says federal law protects the right of disabled people to live in "the most integrated setting" safely possible.

Last year, in response to a lawsuit brought by the nonprofit advocacy group Disability Rights New Jersey, which alleges the state is violating the law by not reducing its 8,000-person waiting list, the state told a federal judge it was too broke to comply with Olmstead.

U.S. District Court Judge Anne Thompson ruled a trial would be needed to determine whether the state is justified in postponing a plan to move people out of state-run developmental centers because it can't afford to pay for them. No date has been set.

The state continues to face legal pressure to find supervised housing for disabled people because of two other pending cases. Disability Rights is suing the state for failing to move people with developmental disabilities who want to live in community housing from state institutions. The state is in the midst of complying with a 2009 settlement, stemming from another lawsuit brought by Disability Rights, that requires New Jersey to spend \$5 million a year to move medically stable patients from public psychiatric hospitals until 2014.

Lori Grifa, commissioner of the Community Affairs Department, which manages the trust fund, said she is optimistic the state will find a solution and be able to continue to build housing for those with special needs.

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"We're not in crisis mode," she said. "I've already begun looking at other places. Because of our concern about exhausting the fund, we have gotten very creative."

8,000 people with developmental disabilities are waiting for housing

New Jersey's Special Needs Housing Trust Fund was supposed to fund housing projects for people with developmental disabilities. There are now 4,879 "priorities" on an 8,000-person waiting list for people with developmental disabilities. The Department of Human Services, facing a severe housing shortage and an unrelenting budget crunch, was able to remove 229 names from the waiting list this fiscal year. Video by John O'Boyle

Grifa mentioned looking to municipal and federal governments for other pools of money, but she acknowledged that once the trust fund is gone, a reliable source will have disappeared.

"It's an everyday conversation for us," said Kevin Martone, deputy director of Human Services. "Most would agree we don't have enough funds to meet the demand."

If something were to happen to Mike and Joy Festa, the state would find a place for their son, but perhaps not an appropriate one.

"The frustration is indescribable," Mike Festa said. "I don't think he'll ever get placed — not in my lifetime."

CAUGHT IN LIMBO

Steven H. is what can happen when parents are gone.

Steven was the same age as Michael when his mother, who had taken care of him all his life, died. Unsure where to turn, Steven, whose last name is being withheld because of patient-confidentiality concerns, walked into the emergency room at Bergen Regional Medical Center, where he had been treated before.

"I didn't want to go to a shelter because shelters are really bad," he said.

Diagnosed with schizoaffective disorder and prone to bouts of depression, Steven, a New Milford resident, was given a bed on unit 12B in the behavioral health wing.

That was two years ago. Now 37, Steven spent 26 months in the hospital — even though doctors said he didn't belong there — before he was able to find an appropriate home.

Bergen Regional has about 60 patients like Steven — people who have been medically cleared to leave but who have no place to go. Essex County Hospital has another 40, said Lucia Guarini, the hospital's director.

It costs \$400 to \$500 per day to care for each of those patients, said Tom Rosamilia, vice president of behavioral health services at Bergen Regional — and taxpayers foot the bill.

"There is no question it is much less expensive for the state to keep someone in independent living than it is to keep them in a hospital," Rosamilia said. "Hospitals are for when you are acutely ill. You can't move toward recovery if you are living in an isolated hospital environment."

It costs \$250,000 a year to keep a patient in a state psychiatric hospital or institution known as developmental centers, according to the state Department of Human Services. On average, the special-needs trust spent \$100,000 for each new housing unit.

Replenishing the trust is an investment that saves money in the long term, said Assemblyman John McKeon (D-Essex), one of the fund's original sponsors.

"That's my argument," McKeon said. "This is money we can't afford not to spend."

But it is also money the state does not have.

And though funds are running low, the need has not abated. In fact, the economy — in addition to depleting state coffers — has forced more people to reach out for assistance.

In addition to the more than 8,000 people with developmental disabilities on the waiting list, the special-needs trust is also geared toward the state's homeless population, which totals more than 12,000.

People like Patricia M., who wanders Newark's streets by day and sleeps in the city's homeless shelters at night.

"It's been a horrible experience," said Patricia, who spoke on condition that her last name not be printed. "I don't know anyone who likes bouncing from place to place, the constant worry. I wouldn't wish it on my worst enemy."

Patricia, like Steven, was diagnosed with schizoaffective disorder. She had stayed at a boarding house in Belleville, but when she could no longer pay, she and her few possessions were put in a van and dropped in front of her son's house.

Families join forces to improve housing for the disabled

Twelve years ago, five New Jersey families decided to jump the state's infamously long waiting list for permanent housing for disabled adults and created a housing facility of their own. The move was unheard-of but today the state is considering a shift in policy that could make setting up independent housing more common. (Video by Adya Beasley / The Star-Ledger)

She banged on the door, she said, but no one answered.

"I knew he was home," she said.

Patricia is being aided by the Mental Health Association of Essex County, which is trying to find low-cost housing for her. The association relies on homes built with funds from the special-needs trust to create beds and opportunities for people like her.

"I can't wait to have my own place," Patricia said. "There's always something to do when you have your own place."

SOLUTIONS

Susan Meyer is 36 and lives with her mother, Mary, in Ramsey. She has Asperger's syndrome, a condition that makes it hard for her to process social cues. She works two days a week but cannot live on her own unless she can find a low-cost housing opportunity in a setting that can provide some social services.

Being able to leave the nest and being forced to cook and clean for herself would provide a measure of self-confidence and liberation that Susan said she has rarely experienced.

"Sometimes I wonder, 'Am I worth anything?' " Meyer said. "If I could live on my own, I'd know I was worth something."

That is why Codey said he is trying so hard to find some way, any way to recapitalize the fund. He said there are a number of options he is considering, including a state referendum.

"We want to live up to the commitment we made in 2005," said the Essex County Democrat, who pledged to finish the job and meet the goal of 10,000 housing opportunities. "We have 8,000 to go."

Codey is lauded for his role in creating the fund, which has helped open dozens of homes like the Rose House in Hanover Township. The 12-bed home cost \$1.9 million to build and received \$800,000 from the trust. Mark Kramer, the home's executive director, said he received more applicants than he could handle and had to tell people to stop sending referrals.

Latisha Davis, who manages the Pointe, which opened in January in Morristown thanks to \$612,000 from the special needs trust, had a similar experience.

"I have a file cabinet drawer full of referrals," she said. "They keep coming in every day. They are hoping we'll have other special-needs housing ... somewhere."

The requests come from agencies and advocates, from pleading parents and desperate siblings, who compete against one another for the few new beds that become available each year.

"Those beds are like gold," said Rosamilia of Bergen Regional.

They are precious and expensive, but McKeon argued that finding a proper home for these many thousands of individuals should be a primary responsibility of government.

"This continues to be something worthy of our support," McKeon said. "We have to ask ourselves, as a society, what will our priorities be?"

Staff writer Susan K. Livio contributed to this report.

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