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At Nation's Oldest Institution for the Disabled, 13 Lives in Limbo

By Clare Ansberry

WALTHAM, Mass.—Michael Martin is 51 years old, but because of brain damage he lives his days like a very young and anxious child, prone to violent outbursts. He is learning to fold towels.

Just 13 residents remain at Fernald Development Center in Waltham, Mass., the oldest state-run institution in the country for people with developmental disabilities. WSJ's Clare Ansberry reports. Photo: M. Scott Brauer.

Yet his abilities tower over a longtime neighbor, Teresa Kacinski, who can't walk, talk, see, feed herself or change positions. With help, she can strike a key on a toy piano.

They are among the 13 remaining residents of the Fernald Developmental Center, the oldest state-run institution in the U.S. for people with developmental and intellectual disabilities. Fernald once housed thousands of men, women and children who have since joined the slow exodus from large public institutions that advocates of those with disabilities initiated decades ago.

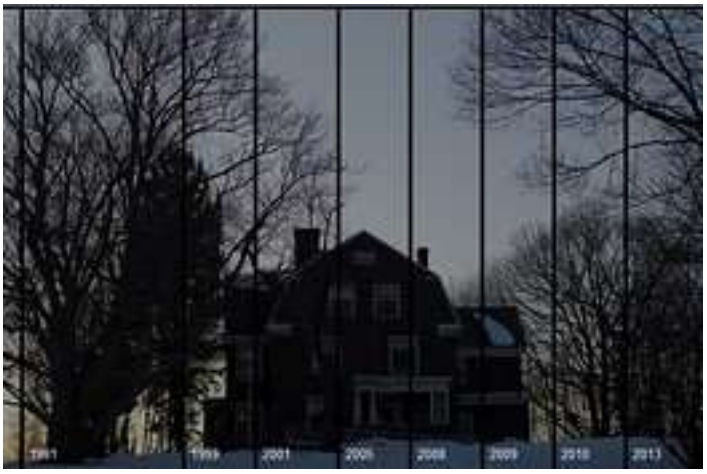
Massachusetts wants to move the last residents from Fernald and sell the 186-acre property. But their families want them to stay, saying Fernald's experienced caregivers and familiar surroundings are irreplaceable. The matter has gone to court.

A Community at a Crossroads

M. Scott Brauer for The Wall Street Journal

Resident Michael Martin, 51, drank ginger ale during a break from work at an activities center at Fernald Developmental Center in Waltham, Mass. Some of the residents perform simple tasks for pay. Mr. Martin shreds documents.

Timeline: Treatment for People With Disabilities in the U.S.



About 30,000 people remain in 160 state-operated facilities in the U.S., including many who face similar dislocations. Like those at Fernald, they tend to be older, with complex physical and psychological needs. Many require one-on-one care.

Families say uprooting people with such limited coping skills is too traumatic. State authorities say smaller settings are better than larger public facilities; they cite thousands of successful transfers.

What is different about Fernald is that its residents have legal rights others don't. In a class-action suit, they were awarded in 1993 a guaranteed level of care, regardless of cost, to compensate for decades of abuse and neglect.

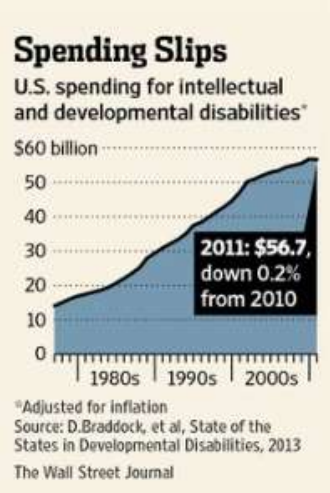
Those costs, indeed, are high. It costs $10.9 million a year to keep Fernald open for 13 people, state officials said. The per-resident cost at Fernald is about four times the national average of $220,119 spent at other state-supported institutions, according to a 2013 report by the University of Colorado. About a third of the cost to run Fernald pays to run a utility plant built to power buildings that are now mostly unused.

The dispute puts Massachusetts in the uncomfortable position of uprooting some of its weakest residents in a messy court fight.

"It's a horrible dilemma," said Michael's mother, Linda Martin. Her son functions on a level of someone between the ages of two and six. He is capable of hurting someone or himself, without apparent provocation, said Mrs. Martin, who carries M&M candies to placate him during visits.

"People like my son will never be productive. Most people see them as just kind of there, taking up space. But they are someone's brother, sister, child, aunt or uncle. They are still human beings. It's not the life I would have liked for my 50-year-old son, but he's happy where he is."

State authorities say they have a responsibility to the 34,000 other people who rely on them for care. "We really are obligated to try to manage our resources in the most efficient way we possibly can," said Elin Howe, commissioner of the state's Department of Developmental Services.



Charlie Lakin, director of the U.S. Education Department's National Institute on Disability and Rehabilitation Research, said states should close large facilities like Fernald. "To keep these places open," he said, "you have to work to put people in them. When does the cycle end? It's sometimes sad, but it does have to end."

States are proud of closing big institutions, he said, and rightfully so. But, he added, "it doesn't mean they should be proud of what happened to everyone in the process."

Ideally, the remaining residents would move into group homes—mostly privately run nonprofits. But given their age and severe disorders, many people aren't suitable for most homes. There also aren't enough spaces. Nationwide, about 115,000 people with intellectual or developmental disabilities are on waiting lists for group homes, according to the Research and Training Center on Community Living at the University of Minnesota.

The city of Waltham wants to buy the property. Mayor Jeannette McCarthy said she favored letting residents stay on a corner of the property, if the state continued to provide services. "Thirteen is a manageable number," she said.

These last residents of Fernald live in four single-story cottages. The modest rooms are adorned with family photos and Special Olympics medals.

Several workers have spent four decades at Fernald, notable in a field with annual turnover rates averaging 55%, said the American Network of Community Options and Resources.

Families say uprooting people with limited coping skills is traumatic. Officials favor smaller settings.

Michael Martin, who can be abusive with unfamiliar people and in unfamiliar surroundings, has had the same roommate for 20 years and the same caregiver, Jean Marville, for 30. When Michael becomes agitated, Mr. Marville looks him in the eye and talks in a gentle voice to defuse his anxiety. "They are my family," said Mr. Marville, of Michael and the three men who share Cottage 21.

Their neighbor, Teresa Kacinski, was born with a tiny head and abnormally small brain due to a rare condition called microcephaly. Doctors said Teresa needed medical care that couldn't be provided at home. "It is still hard for me to talk and think about that," said her mother, Maureen.

Teresa is 47 years old and weighs 60 pounds. She sleeps in a white crib-like bed adorned with delicately painted flowers. During her waking hours, she sits in a wheelchair or on a mat. Music seems to make her happy. She responds to men's voices and her father's whistle.

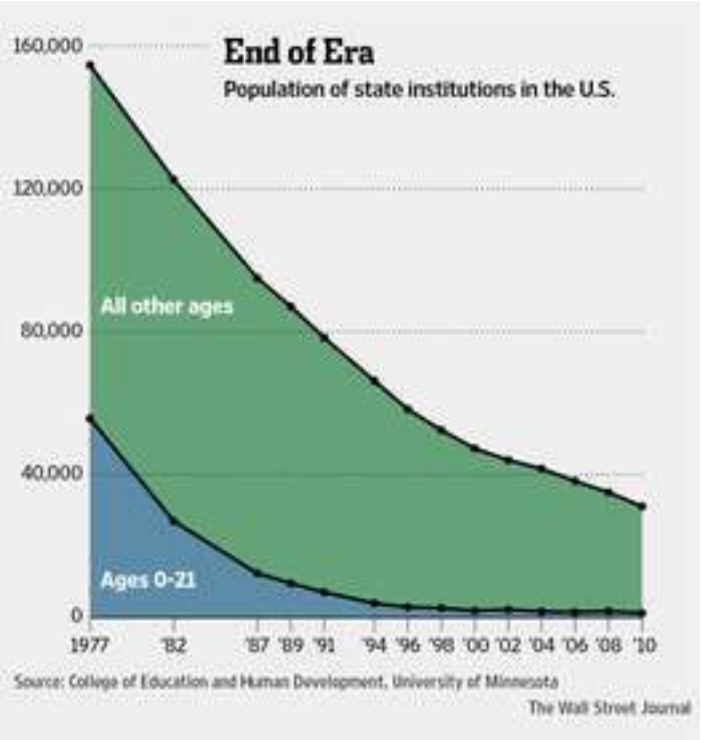
Her mother visits Cottage 23 once a week. She finds consolation watching the staff care for Teresa: One woman has been with Teresa since she arrived after her first birthday. She knows the sound Teresa makes when she swallows and can take another spoonful of food.

Two years ago, Teresa was taken to the hospital and doctors didn't expect her to live. Another longtime staff member spent the night at her bedside, feeding her a cup of tea, one drop at a time.

Built in 1888 as a school for children with disabilities, Fernald added a farm, laundry, bakery and greenhouse. Doctors and nurses lived on the grounds. But, like other institutions, it grew overcrowded and understaffed. Children lived in massive dorms, showered in groups and were left in playrooms with no toys.

Families could visit only on the first Sunday of the month. "Every time we left, Margaret would cry because she wanted to come home with us," said Dorothy Rouleau, whose sister arrived here on March 24, 1948.

Margaret was 19 at the time. She had intellectual disabilities, severe scoliosis and couldn't walk. In those days, Margaret was wheeled outside for visits, said Ms. Rouleau, who recalled Fernald as a frightening place.



U.S. District Court Judge Joseph Tauro was assigned a class-action suit in 1973 that was filed on behalf of residents of state institutions. He then began an overhaul of the facilities. "It was like the windows were open," Ms. Rouleau said.

Judge Tauro closed the case 20 years later, he said, satisfied the institutions were second to none. He awarded Fernald residents a lifetime of equal or better service. "Before, they were treated like cattle," he said in a recent interview. His ruling is the foundation of legal challenges to Fernald transfers.

Now 84 years old, Margaret is Fernald's oldest resident. She has a heart condition and diabetes, is blind in one eye, deaf in one ear and can't use her left hand. Getting out of bed requires a worker to operate a lift and another to guide Margaret into her wheelchair. The night staff turns her every two hours to prevent bedsores. A picture of Jesus hangs on the wall.

Only Margaret and one other Fernald resident can converse. "I go to workshop," she said, referring to her job. She earns a small paycheck assembling medical kits—putting bottles filled with bleach and water, adhesive bandages and cotton balls in bags. She looks forward to payday to buy greeting cards for her sisters, nieces and nephews. At Christmas, she was one of the three kings in a live nativity scene, dressed in robe and crown.

Ms. Rouleau worries about Margaret leaving caretakers she has known for decades, she said: They know red is her favorite color, spaghetti her favorite food, and that ginger ale gives her a lift.

Transferring to a recommended facility in Wrentham, Mass., would be a 3-hour round trip for Margaret's sister, Ms. Rouleau, who is 72. "I won't be able to see her hardly," she said.

Others with profound disabilities have successfully moved from Fernald. Kathryn Bunker had lived there 52 years before moving into a newly built group home. Her sister Joanne Shaughnessy didn't want to move Kathryn but worried the best spots would be filled if she waited. Now, she said, she is glad: "I feel it is a safe and comfortable place for her."

Moving 80-year-old Theresa Salamone to a group home "was the best decision of my life," said Salvatore Salamone, her brother. "Once I saw her bedroom and house I fell in love with it."

None of the 13 remaining Fernald residents are slated to move to a group home, although Ms. Howe, the state commissioner, said they have the option. The homes aren't subject to the same federal care standards for on-site services that parents and siblings say are needed.

The state proposed transferring them to two remaining state-owned facilities—one with close to 200 residents and the other housing more than 300. Families of Fernald residents say they

are a throwback to the old model of large institutions. The state said it would provide equal or better services at these facilities or in group homes.

The movement from full-service institutions to group homes sprang from the belief by academics, advocates and families that people can live better in smaller, neighborhood settings.

The irony, Fernald family members said, is that Fernald, once described as a "disgrace" by Judge Tauro, has shrunk to a tightknit group, small enough to accommodate outings to local shops and restaurants.

"We'd like to preserve our community," said Diane Booher, whose identical twin brothers, Randy and Ronnie, have lived at Fernald for 55 years. Born prematurely, they are blind and have severe intellectual disabilities.

Dressed in matching yellow monogrammed sweaters, the 60-year-old brothers eat lunch together. Their food is served puréed. Ronnie can feed himself. Randy needs help.

As boys here, they slept in rows of beds in large dormitories. At night, Ronnie would find Randy and sleep alongside him for comfort. They now share a room with single beds. Photos show them turn from children to men. During the week, an instructor holds them as they float in the therapeutic pool.

The brothers know their sister's voice. Randy will lift his head when he hears her. Ronnie, who can say a few words, utters "ice cream," associating Ms. Booher's voice with the treats she brings.

Randy communicates solely by behavior. On a walk with his sister, he stopped on the road and lay down when he was tired. Usually, he is harder to read. Pacing, rocking or holding his hands over his ears, might mean he is uncomfortable, frustrated, pained, tired, hungry or anxious. A caregiver will guide him to the bathroom or a favorite toy. When Randy reclines on the couch and puts his feet up, his diaper is usually wet.

The state proposed moving the brothers to a second-floor apartment. The living space is much smaller, Ms. Booher said, and crowded spaces make her brothers anxious. They have trouble with stairs.

On Sunday mornings, residents gather for Mass at the white-steepled Chapel of the Holy Innocents. The service includes simple readings and songs. Spontaneous clapping and yells are little noticed. Marilyn Davidson, 69 years old, assists as altar server. She has intellectual disabilities, is bi-polar and suffers from chronic schizophrenia. Before coming to Fernald, she spent 30 years at the Metropolitan State Hospital, often in solitary confinement.

Dressed in a royal blue vestment, she sat on the altar and brought vessels of water and wine to the priest on recent Sunday, an achievement her family called remarkable.

The chapel's priest said that because of a shortage of priests in the Boston Archdiocese, the final scheduled Mass is Sunday.

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