

A photograph of a man and a woman sitting at a table, looking at each other. The woman, on the left, has curly hair and is wearing a white shirt. The man, on the right, is wearing a blue long-sleeved shirt. They are both looking at each other with serious expressions. The table is covered with a white cloth, and there is a small plate of food on the left. In the background, there is a window with white curtains featuring a floral pattern.

# THE KIDS AREN'T ALRIGHT

What happens to developmentally disabled New Yorkers  
once their parents are gone?

BY DAN GOLDBERG • PHOTOGRAPHY BY SASHA MASLOV



**G**ermaine Scott wakes each morning at 5:30 to feed and dress her son Greg.

She brushes his teeth, moisturizes his skin when it's dry, sits him on the toilet when she senses she should. She reads him for the 8 o'clock bus that will take him to his day program.

When Greg returns to their two-bedroom East Harlem home, his mother cuts carrots into chunks and pulls grapes from the vine for him. She cooks him dinner. On weekends, she takes him for walks, since he likes to move around, and to church, where he sometimes sways to the music.

Greg, who is 34, has Sotos syndrome, a rare genetic disorder characterized by large hands, feet and facial features and, in his case, severe developmental disabilities. He can't speak, bathe or be left alone.

Germaine Scott hardly looks her 71 years but admits to feeling it — whatever that feeling is that tells her, and other parents like her, that it's time to plan for life beyond their own.

What should be their golden years are consumed by worry over what will happen to their developmentally disabled adult children, incapable of living on their own, after they die.

There aren't enough spaces in New York's residential facilities for developmentally disabled adults to accommodate all the aging parents looking to secure future homes for their children. Often, no placement is found until after a death or other emergency. And that placement may be hundreds of miles away, worsening the trauma for adults who have rarely, if ever, been away from their parents.

"He is my joy, and there is nothing I wouldn't do for Greg," Germaine Scott said. "And if I had my druthers, I would outlive Greg so that I could see him safely laid to rest. But life isn't like that."

**THE SHORTAGE OF RESIDENTIAL** placements is a growing problem nationwide, as parents like Germaine Scott find the demand far outpaces the supply. Turnover in residential facilities is scarce because people with developmental disabilities now live longer than ever before, thanks to better medical care and understanding of the diseases that impair cognitive

ability.

Compounding the problem are baby boomers nearing retirement age who won't be able to care for their developmentally disabled children much longer. In New York, about a quarter of parents of such children are now over 60, according to research from the University of Colorado. Meanwhile, diagnoses — especially of autism spectrum disorder — have surged in recent decades, intensifying the demand.

New York's Office for Persons With Developmental Disabilities determines who is placed in the state's residential facilities by dividing the thousands seeking placement into three tiers: priority one, two and three.

The state's priority-one cases are emergencies — where a caregiver has died, or somebody has become homeless or is being abused. They also include so-called special populations — those leaving state institutions, being released from prison or aging out of residential schools for students with severe disabilities.

Priority-two cases are those that require emergency prevention — with caregivers' health failing, or risks of neglect or abuse — while in priority-three cases, neither the disabled adults nor their caregivers' health or well-being are in danger. Greg Scott is considered priority three.

The limited number of beds means priority-two cases are rarely placed, and even years spent on what the state once called a "waiting list" may not move them closer to placements.

"The term 'list' is, I think, misleading, because it's not as though you are waiting in a queue," said Wendy McCarthy, an association manager with the Developmental Disability Association of Western New York. "In fact, the name changed to a registry, so people would understand you're not taking a number in a line."

More than 130,000 New Yorkers with developmental disabilities receive services from the state, and about 40,000 receive residential support, according to the OPWDD. The agency says another 11,000 people have expressed interest in residential support, and it is working with 1,386 people of priority-two or priority-three status to find placements.

A report the OPWDD released in February estimated that there would be



1,711 priority-one cases in the coming fiscal year, and that 1,723 beds would become available. "The analysis of supply and demand shows that OPWDD has the existing resources needed to meet the anticipated residential needs of individuals identified as priority one," it concluded.

But this isn't manufacturing widgets. The agency's estimates are rough projections based on historical trends, and with so little room for error, many advocates are worried.

Even if the state meets the demand for priority-one placements, that only manages a crisis. It does nothing to prevent one.

As Steve Kroll, the executive director of the advocacy group NYSARC, put it: "If you haven't suffered yet, you are on the priority-two list."

**JOAN K. WAS 81 WITH EMPHYSEMA,** back pain, a heart-valve problem and an 88-year-old husband who had recently suffered a stroke. She knew she could no longer care for their developmentally delayed son Mikey, who is 57 years old, 5 feet 7 inches tall and 230 pounds and suffers from a seizure disorder.

Mikey, whose family asked that their last name be withheld because they have business before the state, had never lived away from his parents in their Yorkville home. Joan wanted to help her emotionally fragile son settle into a new home to ease the transition, her daughter Lori said.

There was a bed open at the ARC's Oneida-Lewis chapter in nearby Clinton, and Mikey had a couple of friends there. But Mikey was priority two. The state wouldn't sign off.

Joan begged OPWDD officials to bend the rules before there was an emergency. Everyone she spoke with was professional, sympathetic and consistent: There was nothing they could do. There were hundreds of families just like hers, they told her.

"Unfortunately, I'll have to be four feet under before he gets placed," Lori recalled her mother telling her one afternoon around Christmas.

"Don't say that," Lori had gently admonished.

Joan died of a heart attack less than two months later.

Mikey was told his mother was going to heaven, and Karen Korotzer, who runs the Clinton home, told his family

she would ensure he made his way to the bed his mother had begged for.

He spent his first night in a respite home — a welcome option for many families, meant for temporary relief — but unable to cope, he acted out and was taken to the emergency room. The next night was his first in the Clinton home, and again, he acted out and had to be taken to the emergency room.

Two nights later, overwhelmed by the separation and anxiety, he lost control.

**"If I had my druthers, I would outlive Greg so that I could see him safely laid to rest. But life isn't like that."**

His brothers headed to the Clinton home to calm his nerves. When they arrived, the police were already there, putting a handcuffed Mikey into the back of a squad car.

Mikey was taken to the emergency room, his third trip in four days. Still handcuffed, Mikey — with a childlike understanding gleaned from his favorite television show, "Cops" — stroked the police officer's hand, apologized and begged forgiveness.

"If only he had transitioned when my mom was alive, he wouldn't have had to go through any of that," Lori said.

**RESIDENTIAL CARE IS ONE OF** the nation's longest-lingering public health problems. New York's battles over where and how to house the developmentally disabled have been shaped for half a century by what happened at the Willowbrook State School on Staten Island, an institution Sen. Robert Kennedy famously called a "snake pit" in 1965. Seven years later, a young investigative reporter named Geraldo Rivera, in his first big scoop, brought in hidden cameras to document filthy, naked children, moaning amid piles of their own feces.

Those images were seared into the public consciousness, and Gov. Hugh Carey soon announced he would move to empty the institution. A subsequent court order forced the state to deinstitutionalize and move residents into smaller, community homes, and in 1978, the OPWDD was created to implement the changes.

The state has been working ever since to reduce the number of New Yorkers living in institutions. When Rivera's report aired, more than 27,000 New Yorkers lived in them. Now, fewer than 1,000 do.

As the state moved people out, it became clear there weren't enough beds in smaller facilities to meet the growing need. In 1998, Gov. George Pataki allocated \$500 million for a five-year program that aimed to build

4,900 new residential beds. That program exceeded its goal, building 5,075 beds in five years, and in 2004 was renewed to create another 1,900 residential opportunities over a decade.

That funding was discontinued in 2008, and a new emphasis was placed on providing services to parents who could keep their children at home.

Gov. Andrew Cuomo's administration has continued that approach, believing that with the right mix of supports — day programs, respite services, home care — more people could stay in their own homes and communities. The strategy: Build more supply, and reduce demand.

To that end, Cuomo has provided more funding for supportive individualized residential alternatives, which are homes capped at three people who receive some services but don't require 24-hour staff support and supervision. The state has also applied for Medicaid waivers that would make it easier for parents to care for their children at home.

The state's most recent budget allocated \$110 million for new resources to help meet the needs of people living at home with caregivers, and transitioning from schools.

That compares with \$10 million allocated toward building more residential facilities for priority-two and priority-three placements, far short of the anticipated need. Kroll said it would take at least 10 times that.

**"THERE IS A PHILOSOPHICAL SHIFT** toward people with developmental



Greg Scott with his mother Germaine in the two-bedroom apartment they share in East Harlem.

disabilities living more like other people and less segregated,” said Ann Hardiman, the executive director of the New York State Association of Community and Residential Agencies. “Families are having a hard time with it. Many families see group homes as the answer, and many of their sons and daughters probably need more secure housing.”

Two bills in the Legislature seek to address the shortage of that housing. The first, sponsored by Sen. Kemp Hannon and Assemblywoman Aileen Gunther, would instruct the state to take caregivers’ age into account in placing residents and bar it from automatically granting special populations priority-one status. The second, sponsored by Sen. Robert Ort and Assemblyman David Weprin, would use settlement money from Wall Street banks to create a \$500 million fund to build, renovate and support residential facilities.

Neither bill has moved out of

committee or is likely to pass in the near future, which means the state appears set to continue to follow the path Cuomo has laid out.

That approach, which aligns with federal thinking, comes with unquestionable upsides. It helps the state comply with the Supreme Court’s 1999 ruling that people have the right to live in the least restrictive environment. And it’s far less costly to keep people in their own homes, and often far better for them. Many parents prefer to keep their children home, provided they are offered supports like respite programs and home health aides who can help bathe or feed them.

But what happens when those parents can no longer take care of their children, regardless of what the state provides? Where will those children go?

“You want to say to the state, ‘I’ve done my part — aren’t you supposed to help take care of him?’” Germaine Scott said. “We try to tell the Legislature, the governor: He’s a citizen, too.”

She doesn’t know how much longer she’ll be able to care for Greg. Maybe five years, maybe 10.

The love is easy. It’s the life that is hard.

She still sings to him the song she sang to him as a baby — “I wish you love.” It still brings a smile to his face and coaxes a guttural grunt from his lips. That’s how they communicate, and she lights up when she hears that sound.

She takes Greg to the dentist, the doctor, the hospital. She checks to make sure his medication and dosage are correct. Once, an overworked nurse handed over the wrong medication. Scott caught the mistake.

“But when I’m not here—” She took a deep breath. “Who’s going to make sure that’s...?”

She didn’t finish the thought.