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Schools Struggle to Educate the Severely Disabled

By **SHARON OTTERMAN**

Donovan Forde was dozing when the teacher came around to his end of the table. Pale winter light filtered in through the grated classroom window, and the warm room filled softly with jazz. It fell to his teacher's aide to wake him up from his mid-morning nap.

She shined a small flashlight back and forth in his eyes like a dockworker signaling a ship, and called his name. Then she put her hand on his cheek, steering his head forward as he focused his eyes.

The teacher, Ricardo Torres, placed a red apple against Donovan's closed left hand, and then held it near his nose so he could smell it. "Donovan, the fruit holds the seeds of the plant," he said.

Then Mr. Torres held a plastic container of apple seeds to Donovan's ear, shaking it, and placed Donovan's hand inside so he could feel them. "And these are the seeds," Mr. Torres said.

He watched Donovan's eyes and face for a sign he had understood, a smile, nod, a noise. Donovan gently pulled his hand away. No one knew if he had grasped it.

At a time when his peers are enrolled in college or earning money at jobs, Donovan, a handsome 20-year-old with a sliver of a mustache, is still in public school, being taught the most basic of facts. His vocabulary for this science unit, which lasted about two weeks, was three words: seeds, fruit and juice.

And yet, because of his cognitive disabilities brought on by a traumatic brain injury at nearly 6 months old, it is almost impossible to know what he comprehends and retains. After 15 years in the New York City school system, he is less reserved and more social, but otherwise has shown almost no progress, his mother said.

Once predominately isolated in institutions, severely disabled students have been guaranteed a free, appropriate public education like all children since the passage of federal legislation in 1975. In the years since, school districts across the country have struggled to find a balance between instruction in functional skills and academics while providing basic custodial care.

Donovan is part of a fraction of a fraction, classified as having “multiple disabilities,” a broad category under the federal [Individuals With Disabilities Education Act](#) that refers to children who have at least two disabilities and severe educational needs.

There are 132,000 such students in the United States, out of more than 6.5 million now receiving some kind of special education service at an estimated cost of \$74 billion a year.

Students with multiple disabilities, like Donovan and his schoolmates, can have a wide range of diagnoses, including cerebral palsy, rare genetic disorders and problems that stem from conditions in utero or at birth, some of which have no name.

For many of these students, the post-school future holds day residential programs, nursing facilities or group homes, not college or jobs. The concepts of educational reform and standardized assessment have little meaning for them; they are among the most costly to educate and the least understood.

Donovan recognizes familiar voices, and can mimic their intonations. He communicates some needs; at lunch, he pulls off his bib to show when he is finished. When happy, he sings fragmented notes, his scratchy voice rising in triplets and quads.

But he cannot walk, does not speak and cannot feed himself or see much beyond shapes and shadows. On standardized assessments, he has trouble with tasks most children master in infancy, like opening and closing his eyes on command. Occupied much of the time by his own inner world, he does not respond consistently to his own name.

One year before he is to leave the school system, educating Donovan remains a search for ways

to reach him.

A Question of Goals

Donovan's mother, Michelle Forde, likes his special education high school, Public School 79, the Horan School, in East Harlem, where she feels he is welcome and cared for. But she wishes his teachers would spend more time working on his practical challenges, like his self-abusive habit of hitting himself in the face so hard that he has to wear thick white cotton mitts most of the time, even when he sleeps.

Instead of having him work on basic academic goals, like identifying shapes and coins, she wishes he had physical therapy more than 30 minutes, twice a week, because it is generally the only time during the day he is taken out of his wheelchair, except when an aide takes him to the bathroom to change him.

Rebecca Bravo, the principal of P.S. 79 and the mother of a 38-year-old severely disabled daughter, says that those things are important, but she also has broader aims. For example, Donovan will never be able to prepare breakfast, but he should be allowed to help stir a pot in cooking class, even if an aide must move his hand. He might not be able to call 911, but if he learns about firefighters in social studies, he might be able to recognize a siren when he hears one.

Ms. Bravo does not want to go back to the days when students like Donovan were given only art and music instruction, along with a narrow focus on practical skills.

"For too long, that's where we kept them, in art and music, and we didn't give them some of the other things they needed," she said.

P.S. 79, following city and state mandates, has been moving toward more academic instruction for years. This year, her last before retirement, Ms. Bravo decided to add a twist.

Not only would she teach her severely disabled students adapted versions of science, social studies, English and math, but they would also switch classes almost every 50 minutes instead of remaining with the same teacher. The different environments would be stimulating, she reasoned, and give them a high school experience more like that of their general education peers.

The day starts at 8 a.m. The first hour is spent in the cafeteria, eating breakfast and waiting for children to arrive on dozens of buses from throughout the city.

Painted with colorful murals, the hallways bustle with activity. Upstairs are special classes for students with emotional disturbance, autism or learning disabilities. Some 170 adults — aides, therapists, teachers and administrators — work with 319 students. In 2009, the cost per student was \$58,877, more than triple the citywide average of \$17,696.

It is a Tuesday in late February, and Donovan's first class is adaptive physical education. A line of teacher's aides wheels and walks the students to a classroom that has primary-colored mats along one wall, as well as a few balls, cones and a floor-based basketball net.

"We are in GYM," the teacher, Kenneth Toron, announces in a circus performer voice, slurring his words somewhat because his left side is partially paralyzed from a stroke. As a visual clue, he holds up a simple line drawing of a basketball and a net known as a Mayer-Johnson symbol. "We are going to EXERCISE."

Mr. Toron sets up a few cones on the floor and starts up a music playlist on the classroom computer. "Surfin' U.S.A." by the **Beach Boys** is first up. The more advanced students begin walking, some hesitantly, others easily, around the cones.

Some students in Donovan's classes are able to speak, master vocabulary, socialize and walk, and others appear to attend to even less than he does, engaging in near-constant self-stimulating behaviors, like repetitive jaw chomping, collapsing to the floor during class or reciting many times an hour descending notes that resemble a sad bird call. Ms. Bravo believes in mixing students with multiple disabilities of varying severity so they can learn from one another.

Donovan remains in his wheelchair, moving his head slightly back and forth to the music, his legs crossed at the knees.

A soft ball covered with yellow tape dangles from a rope in front of his wheelchair. A few times during the class, Mr. Toron walks over and gives the ball a tap into Donovan's line of vision. Donovan swipes the ball weakly out of his way with his ungloved right hand, nodding his head in time to the music. Anissia Mack, Donovan's one-to-one aide, stands nearby; she occasionally

jangles the ball.

Aides lift another student, Darius Jenkins, 15, out of his wheelchair and place him on an inclined plane, where he lies quivering and drooling slightly for most of the class. He is given a squeeze ball to hold several times, but each time, he drops it.

Donovan looks as though he is resting, but when Michael Jackson's "Beat It" comes on, he smiles and raises his chin. From the back of his throat, he sings a few rough, wordless refrains that loosely follow the beat.

Next, it is off to science. Mr. Torres, a first-year teacher, uses all of his creativity to adapt the lessons, writing his own books, using symbols, pictures and words. He circulates around the room, asking students to identify the vocabulary.

"Which is the fruit?" he asks an intense young student named Isatou, presenting her with a set of two electronic buttons, one marked with a fruit picture, the other with a seed.

Sitting on her own, she presses the correct image, evoking the words "fruit, las frutas" from the button. "Good job," Mr. Torres said.

Working with the apple and the seeds, Ms. Mack, who is in charge of most of Donovan's repetition and drilling, marks his responses on a worksheet. "As far as what he's retaining, I couldn't tell you," Ms. Mack said later. She has worked with him for two years, assigned to him because he is prone to seizures, and said the main change she had noticed was that he seemed calmer. "But I do think he appreciates getting an education," she said.

'Something's Happened'

Donovan was born healthy, except for clubbed feet. An operation to correct them had been scheduled when, on Aug. 15, 1990, Ms. Forde left Donovan, nearly 6 months old, with his father while she went to work cleaning offices at night.

She felt uneasy all evening, and when she returned to her parents' house at 1 a.m., her father told her, "Something's happened to the baby."

Ms. Forde, then 18, found Donovan unconscious in the hospital, his head in a bandage. His

father had been on the street and returned home to get a baby bottle, he told her, leaving Donovan in the arms of a female friend. An under-age driver in a stolen car hit them as they stood near Avenue I and East 23rd Street in Brooklyn.

The friend's leg was broken, and Donovan landed on his head on the pavement so hard that his heart stopped. A bystander gave him mouth-to-mouth, reviving him before the ambulance came.

For six weeks Donovan remained in a coma, the swelling in his head damaging his optic nerves before a shunt was placed to drain the fluid. After a few months at a rehabilitation center upstate, he came home, forever changed.

His habit of hitting himself started when he was about 5, the same age when he began attending public school, leaving a Helen Keller early intervention program for the blind. Ms. Forde struggled to care for him while getting her bachelor's degree and working; she and his father split, and despite various attempts, she received no settlement for the accident.

At home, she tried to stimulate him by constantly playing music, especially R&B. She thinks that when he sings, he remembers nursery rhymes he had heard as a baby, his intermittent "ba ba" a remnant of "Baa Baa Black Sheep."

"He only knows sitting up and making noises, because he was only 5 months old," she said of his current skills. But though he seemed frozen in infancy in some ways, his bad habits worsened. At elementary school in Coney Island, Donovan twice knocked out one of his teeth, arriving home with them in a bag. At home, he began reaching into his diaper and spreading around the mess.

Pregnant with her second child, and unable to afford private care, Ms. Forde made the wrenching decision nine years ago to move him to the nursing facility at Coler-Goldwater Memorial Hospital on Roosevelt Island, where he would get 24-hour attention and [Medicaid](#) would foot the bill. He still lives there today, sleeping in a high-walled bed in a room he shares with three other severely disabled youths.

A Plan, but Little Progress

Donovan's individual education plan paints a picture of what he is expected to learn at P.S. 79.

By November, it says, he will identify directional concepts like top and bottom, left and right with 100 percent accuracy. He will identify four United States coins and common shapes with 100 percent accuracy. He will communicate a message, a desire or need, using an electronic button or tactile icon, five times a day. The problem is that after 15 years of education, he has not learned how to do most of those things reliably.

“Donovan has not yet demonstrated consistent functional communication to indicate purposeful needs,” his plan states.

“I don’t think he can identify shapes,” his mother said, calling the plan unrealistic. “He’s not identifying anything; he just is thinking, ‘O.K., you have something in front of me — what do you want me to do?’ ” Because they need intensive interventions, students like Donovan do not fit neatly into the paradigm for special education that has prevailed in the United States for more than a decade: inclusion. Congress ranks each state for its success in moving special education children into general education classrooms, addressing a core concern in the field — that too many children are not getting access to the regular curriculum.

But whether Donovan is best served in an academic-focused classroom is an uncomfortable question for many educators, because few better options are available, and inclusion “indicates a level of hope for parents, and the absence of hope is deadly,” said David Rose, the founder of **CAST**, a national organization that works to expand learning opportunities for students with disabilities.

“It’s an awkward period,” Mr. Rose said, in talking about the education of children with the most severe cognitive disabilities. “Because we know what we are doing is not right, and we often don’t talk about things when we don’t know what we are doing about them yet.”

Following federal **No Child Left Behind** guidelines, New York State standards, even for assessments of the kind Donovan takes, are framed around academic skills. Schools choose the test subjects from a state list that includes items like number awareness, basic geometry and distinguishing living from nonliving things.

Of the 1 percent of students statewide who take such assessments, about 90 percent score at a proficient or advanced level, limiting their usefulness as an accountability standard, said Rebecca H. Cort, the state deputy commissioner for special education. “It’s a problem,” she

said.

But despite her son's lack of academic progress, Ms. Forde is not dissatisfied. She is grateful that her son goes to school like a regular student, and says that he seems happy most of the time. "The only goal I had for him was when he was in the hospital after the accident, when the nurse told me he wasn't going to live," she said. "He's here, and he's 20 years old. So he surpassed his goal. He's alive."

A Resonant Connection

There are glimmers that greater communication and interaction with other people, a momentous goal for a student like Donovan, are possible.

One day in late March, Donovan sat alone in the cafeteria before dismissal, moving his head from side to side as if discerning rhythms from the busy room around him. He smiled as if he were remembering a secret. "Who is that, [Ray Charles](#)?" said Roosevelt Adams, gesturing across the room at Donovan. "Or [Stevie Wonder](#)?"

A tall, rangy man with 26 years on the job as a teacher's aide at P.S. 79 (or, as he prefers to be known, an educational assistant), Mr. Adams holds in his mind a kind of Rosetta stone to Donovan's physical language. "That's his happy mood," he said.

Donovan's communications are hard to measure on assessments, and there is no glossary of them posted for teachers to see. So not everyone knows that a head butt, according to Mr. Adams, is how Donovan says no when he gets angry. Or that when Donovan does not want something, he turns his head. When he wants something, "he lets you give it to him," Mr. Adams said, adding that when his head is down, "that's his low."

Mr. Adams was Donovan's one-to-one aide for four years before Ms. Mack took over two years ago. It is an intimate position to be in; from nearly the moment Donovan gets off the bus to the moment he leaves, the aide feeds him, quizzes him, reads to him, changes him (if the aide is the same gender) and wakes him up when he is dozing.

Besides physical therapy at P.S. 79, Donovan receives an hour each of occupational and speech therapy each week, and a half-hour of vision therapy. His classroom teachers must divide their time with 11 other students with multiple disabilities. So more than anyone else at P.S. 79, the

teacher's aides may have the best shot at providing the intensive one-on-one time that many experts say it takes to make progress with a student like Donovan.

They are also among the lowest paid people in the system, earning between \$21,000 and \$36,000 a year, and requiring no specific training in special education beyond what they learn on the job.

Donovan's love for music requires no translation. He sings in fragmented high-pitched tones, or in throaty notes that blossom into rhythmic phrases. But Mr. Adams got him to achieve more.

By getting Donovan into a really happy mood, by tickling him or giving him a head rub, he found he could get him to sing "Old MacDonald" with him. And though he does not speak, Donovan managed the "Old Mac" and then — his favorite part — a loud "E-I-E-I-O."

"Singing, that's a form of talking," Mr. Adams said, adding that Donovan reminded him of his mother and brother, both of whom were blind. "He understands very well, quite as much as you and I do. If he could talk, and he could see, he could express himself a little bit better."

Without knowing it, Mr. Adams's efforts had touched on recent research in educating severely disabled children that focuses on using emotion and human connection to reach them. As higher functioning areas of their brains are underdeveloped, emotion moves them at a deeper level, lighting up the same part of their brain, the limbic system, as meaningful music, and possibly creating a bridge to greater intellectual cognition.

"We are so focused on teaching them skills, we don't focus on the emotional part of the child," said Rosanne K. Silberman, who coordinates graduate teacher preparation programs in severe disabilities and blindness at [Hunter College](#). "You want them to be happy. You want to be about working on showing this kid that he's a worthwhile human being."

Since Mr. Adams was reassigned to other students, Donovan no longer sings "Old MacDonald," aides in his class said. He also appears to have forgotten how to indicate, with a nod, which is more: one marker tapped against his arm or two, said Sharon Naftali, his former classroom teacher who works with him in a [yoga](#) class. "It wasn't practiced," she said.

But Ms. Bravo said she believed exposing Donovan to change would help him be more flexible in the face of whatever lay ahead for him, likely a residential day program where he will get less

one-on-one support than he does now. His therapies are starting to be scaled back in preparation for the transition.

“We find that very often we do a disservice to our kids when they come to depend on just one person,” she said.

A Year to Go

Donovan is the only legally blind student in his class, and when teachers take that into account, he comes alive. One Thursday afternoon, Timothy Carton, his English teacher, filled his brightly colored classroom with choruses of bird calls, the chirps of cardinals and blue jays causing Donovan to sing back. An interactive smart board narrated a simple story.

“Donovan, this is the big nest,” Mr. Carton explained in a bright tone, holding a handmade nest of twigs next to Donovan’s hand. “It’s round. It goes round and round and round. And in the middle is the bird,” he said, putting a chirping red plastic cardinal in his hand. “Can you feel the bird? Can you pick the bird up? The bird flies around, and you put the bird back in its nest.” He put his hand over Donovan’s to guide him through the motions.

But in math class, Donovan was unable, as were most of his classmates, to distinguish a dollar from a quarter, or participate in an exercise in which he was told it would cost \$1 to buy a plastic model of French fries and 25 cents for a plastic toy version of a doughnut. An aide working with him and another student could not get a clear response, and after a few minutes, stopped trying.

One morning in mid-March, there was an accomplishment. In a modified yoga class called Getting Ready to Learn, Donovan’s vision teacher slipped off both of his gloves and spent time massaging his stiff arms, which tend to stay bent at right angles. Calmed, he was able to keep them off for the rest of the day.

“If I have one issue with the Department of Education, it’s that one size doesn’t fit all,” said Barbara Levine, the vision teacher, who has worked in city special education schools for 25 years and who wants Donovan to have a music class.

“What I’m seeing is that what they are doing is a great fit for 15 to 20 percent of the kids, and the rest of them, we go well over their heads,” she said.

Ms. Bravo said her goal was to strike a balance between functional and academic instruction, focusing on what is really important: the skills that Donovan will need to help communicate to caregivers in the years ahead. Whether that actually took place, she said, will be looked at.

She is retiring this year, but will recommend that the school scale back its class-switching experiment next year, Donovan's last. Although the teachers and many of the students seemed to relish the dynamism of the curriculum, it proved too much for a single teacher to learn the individual learning styles of dozens of highly challenged students.

But Ms. Bravo is confident the school is moving in the right direction. "I believe we are a special place," she said. "Are we perfect? No. But no place is."