

# Slowly, But Surely

## May Center Treats Autism With Patience

BY GEORGE O'BRIEN

'Joe' is a 10-year-old with autism.

Like all those who have this developmental disability, Joe (that's a pseudonym) has exhibited a number of unusual behavioral patterns and has problems with communication and social interaction.

He doesn't speak much, and when he does talk he is usually repeating what others say or recalling lines from favorite movies like *The Lion King*. This is called echolalia. Meanwhile, he still eats one type of food only — saltine crackers — and one brand of cracker. He's also prone to hitting, kicking, or biting those around him, and still prefers to do most things by himself.

But Joe is getting better — much better.

Indeed, he is expanding his diet to other types of food, and the frequency of his violent acts is down considerably — from about 200 or 300 a day when he arrived at school last fall to perhaps a half-dozen a day. And he's talking more and saying things at more appropriate times, not merely shouting things out when he feels an urge.

Joe's progress is typical of the work that goes on at the May Center for Child Development in West Springfield. Opened last fall on the second floor of the former Immaculate Conception School building, the May Center — one of several facilities operated by the Norwood-based May Institute — is a place where children ages 3 to 12 who cannot learn in a traditional school setting for one reason or another come for specialized education and treatment.

Using a process known as applied behavior analysis (ABA), staff members facilitate the development of language, positive skills development, and social behavior through intervention — the use of positive reinforcement, repetition, and



Dr. Shannon Kay claps with one of the students at the May Center, an exercise in helping the students master the skill of imitation.

prompting, said Dr. Shannon Kay, the center's director and a board-certified behavioral specialist.

Progress with children who have autism, pervasive development disorder (PDD), and other developmental disabilities is measured in increments — usually very small increments, said Kay, who put emphasis on the word *small*. In the case of Joe, it took several weeks to get him to even put some type of food other than saltine crackers on the tip of his tongue.

"Joe is in many ways a work in progress, but that's what you need to focus on — the fact that we're seeing progress," she said. "Every day, he moves forward ... that's what motivates us."

There are many other success stories being written at the center, which currently has nine students and is in the process of preparing classroom space to accommodate up to 20.

*The Healthcare News* looks this month at the May Center and how its staff goes about creating a better quality of life for people like Joe.

dren in Western Mass. with autism and other developmental disabilities, and that some of these individuals need a highly structured environment and specialists in behavior analysis, the May Institute opened its center in West Springfield last year, said Alan Harchik, Ph.D., BCBA, senior vice president at the May Institute.

The institute had been providing consultative services to area school systems who have students with autism and related disabilities, and still does, said Harchik, but it created the center to take its services in Western Mass. to a higher level. May operates similar schools for children and adolescents in Arlington, Braintree, and Chatham, Mass., as well as in Freeport, Maine. It also has a school for youths with brain injuries in Brockton, Mass.

### On a Roll

As she talked with *The Healthcare News* in her office, Kay often had to raise her volume level to be heard over the rumbling of a shopping cart as it was pushed over the hardwood floors of the century-old Immaculate Conception School.

The cart, one of those that is disguised as a race car and therefore popular with young children, was donated to the center by Big Y. It has become the reward of choice for many of the students, who earn trips up and down the hall as they record discernable progress toward a goal — be it the elimination of a behavioral problem, the addition of new words or phrases, or even a willingness to experiment with new foods. Other rewards include time with toys, books, or video games, and even a hug.

"Here, we focus on getting children to learn how to learn," said Kay, adding that for many individuals this is a stern challenge, not only for them, but also for their parents and those trying to educate them.

Noting that there are many chil-

"Inclusion in a traditional, public school setting works for some children, but it doesn't work for all of them," Harchik said of the decision to create the Western Mass. facility, the only one of its kind in the area. "We opened the school in response to an increase in the demand for such services."

Kay, who came to the school after studying psychology at UMass and working in the field of "school psychology" — the study of how people learn — said the May Center is unique because of its personal, one-on-one approach and its use of ABA.

She told *The Healthcare News* that students attend the school for six hours a day, year-round — at a cost of about \$60,000 per student, with that burden absorbed by the child's school district. The facility is staffed with trained instructors and teachers who, in addition to their degrees in psychology and experience in behavior analysis, possess large quantities of patience. That's because the students take baby steps in their progress on issues ranging from the learning of shapes and col-

ors to toilet training.

Kay said that most students will be at the school for about three years before being integrated into a traditional school setting, and that the degree of progress that can be achieved with a particular individual — and the likelihood of re-integration — is usually a function of how early they can begin specialized education.

She said the cause of autism, a neurological disorder that affects the development of the brain, is not known. What is known is that it typically appears in the first three years of life, and is four times more likely to occur in boys than girls.

What's also known — and noted with a good deal of anxiety — is that the number of diagnosed cases of autism and similar disorders has dramatically increased over the past decade. Kay said she's not sure if this statistic is attributable to better methods of diagnosing the affliction or the fact that it is becoming more common. What is clear, she said, is there is a growing need for specialized facilities like the May Center.

## Pattern of Success

Kay told *The Healthcare News* that the essence of ABA is determining why an individual behaves in a certain way or develops a particular pattern, and then using repetition and positive reinforcement to achieve change. Determining why isn't always easy when it comes to individuals with autism, but there are some common threads, she explained.

Children with autism will behave a certain way — often an undesirable or violent way — to gain attention, get what they want, or avoid doing something they don't want to do, she explained. All children behave in such ways, she noted quickly, but those with autism take it to extremes, and very often their

behavior is an expression of frustration related to an inability to communicate.

"If you had masking tape over your mouth and weren't able to talk for a year, you'd probably want to hit people, too," she said. "If you can't tell people how you're feeling, what's bothering you, or simply what's on your mind, it can get very frustrating."

It is for this reason that teachers at the May Center focus on developing communication skills, said Kay, adding that with progress in this vital area, it is often much easier to then address other behavioral patterns and "rituals," as she called them.

And children with autism have many such behaviors. Kay said obsessive/compulsive behaviors are common, and that one student at the school would become upset if language cards were not arranged neatly or if the books on a shelf were not perfectly straight. Another child would put inedible objects in her mouth — at the rate of 50 times an hour — while another would arrange potato chips in concentric circles before eating them.

Altering such behavior can often be a painstakingly slow process, she said, because doing so takes the child out of a comfort zone. The goal, then, is to create a new, wider comfort zone — and this is where reinforcement and rewards, often in the form of rides in the shopping cart, come in.

Using some of Joe's behavioral patterns, or rituals, as examples, Kay said teachers at the school will isolate a particular pattern of behavior and dissect it. They begin, again, by analyzing why such behavior prevails, and then set about creating a strategy for mitigating it. Often, the primary tactic is imitation — a teacher will exhibit a desired behavior, encourage the student to

do likewise, and then recognize and reward the student when he or she behaves properly.

This is much harder than it sounds because children with autism do not actually know how to imitate, so they have to be taught that skill. In Joe's case, for example, a staff member would repeat a simple task roughly 400 or 500 times before he could successfully imitate it. Some students require 2,000 to 3,000 repetitions before they pick something up.

With Joe, the staff at May has had a lot of work to do on the broad subject of food. He would become anxious if any type of food was put in front of him except saltines. Meanwhile, he would avoid any saltine that was broken or even slightly chipped. In fact, if he came upon a broken cracker, he would promptly discard the entire sleeve.

At the public elementary school he attended before coming to May, he would often go through four or five boxes of saltines looking for a sleeve with no broken crackers. Joe was also averse to eating with anyone else because these individuals would have food other than saltines and he simply didn't want to see anything else in front of him.

Kay told *The Healthcare News* that there has been progress in all areas. Joe has actually taken a bite of chicken, and he can now tolerate being in the presence of a broken saltine, and has actually put a non-perfect cracker to his lips. And because of this, he can now eat with other people.

"None of this may sound like much to many people, but we're thrilled with how far he's come," said Kay. "He'll actually sit at a table with other foods, which is huge."

This progress has been achieved through imitation and positive reinforcement of desired behavior, she

said, adding that when Joe would sit in the company of a broken cracker for a determined length of time without getting agitated, he would be rewarded with a token; 10 tokens can buy a ride in the grocery cart.

This same approach was used to address Joe's habit of biting or kicking his classmates, said Kay. His teacher would start by rewarding him for going a certain period without an aggressive action toward another. The initial threshold was several seconds, she said, and was consistently lengthened. Now, Joe isn't rewarded unless he goes a full seven minutes without an aggressive act. The broad goal is to reinforce good behavior while simultaneously discouraging aggression.

"We make sure that he never gets what he's looking for after he's been aggressive," said Kay. "We get the message across that nothing good happens when he's aggressive."

Joe's story is similar to that of others at the center, said Kay, noting that there are degrees of autism and each child's case — and learning pace — is different.

The key, she stressed, is for parents to get help for their children with developmental disorders as soon as possible.

Assessing Joe's future, Kay said that while there will certainly be limits on what he can accomplish, she is confident that he can someday hold a job and live a somewhat normal life.

He should eventually expand his diet well beyond saltines, and, if all goes well, he will not pick up new rituals to replace the ones he has discarded.

But with autism, it is very hard to predict the future, she said, noting that the present tense is challenging enough. For students and staff alike, progress comes in small bites — literally and figuratively. ♦