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Faces of autism giving kids a life

By: [MARILYN H. KARFELD](#) Senior Staff Reporter

An 8-year-old boy bounces down the hallway, covered head to toe in a stretchy, royal blue stocking. A weary 11-year-old swings back and forth in a hammock hung from a doorway. An active 9-year-old dons a weighted green vest.

Far from being punitive restraints, these and other sensory stimuli are aids that the 26 boys and 1 girl attending Bellefaire JCB's Monarch School for Children with Autism often request. They help the kids pay attention while they're having lessons; as rewards for completing a task, the stimuli provide the pressure and sensation they crave.

Monarch School, for children ages kindergarten to 22, opened in 2000 with a language-based educational program. That's because language and communication are the biggest deficits in children with autism, explains Susan Ratner, Bellefaire's assistant director for special projects.

At Monarch, teachers work at "giving autistic children a language, either spoken or written, so they can reach their fullest potential," says Debra Mandell, Monarch's director.

The Monarch way

Ryan Strozniak is learning the concepts of under, in, and behind. Most children spontaneously learn the meaning of these relationship phrases in the course of acquiring language. But Ryan, 8, like other children with autism, has trouble processing language.

To teach the concepts, speech pathologist Kristi Lambert uses visual cues: photos of Ryan standing in a basket or under a basket or next to a basket. As Ryan selects the proper photo to illustrate each specific prepositional phrase, he attaches a velcro-backed sticker to a chart that reads, "I am working for computer time."

Photos, drawings and 3-D models abound at Monarch. Kids with autism have good visual processing; auditory skills do not work as well. Through pictures, gestures and written words, teachers try to break through the wall of autism.

Each child follows an individual schedule, illustrated with pictures. There's a photo of the teacher posted at the entrance to each classroom, which matches the photo on the schedule. Teachers and students use visual icons to communicate instructions, feelings, desires and needs.

At lunch, children select a picture of a specific item they want to eat. The teacher reinforces the word by verbally repeating the choice. The theory is that eventually the child will use the spoken word.

While most schools for autistic children employ visual aids to facilitate learning, Monarch emphasizes the method much more than other programs, says Dr. Howard Shane, a Harvard Medical School

professor and part of a team of Boston professionals that collaborates with the Monarch staff.

"Some children eventually learn to compensate for the visual process," says Shane. "Others will always need the visual assist."

Visuals are an adjunct and a substitute for language, Ratner says. But they are not everything. "If a kid (who doesn't talk) can point to a (picture) of a glass of water, that's wonderful. That helps parents. But that does not a life make."

"Giving kids and their families a life" is a phrase echoed by many Monarch staff members. The school focuses not just on teaching a child a specific task or lesson, but also on translating that to the larger goal, an improved quality of life.

Concepts for the real world

At Monarch, all teaching is concept-based, rather than skill-based. This means children can use what they've learned in the real world.

For instance, an autistic child in speech therapy can answer questions of "What is it?" or "Who is that?" 80% of the time. But outside the classroom, if you ask that child to identify, say, a chair, he can't, Mandell says.

So Monarch teaches the concept of chair, that it encompasses rocking chairs, restaurant chairs, and overstuffed recliners. "You have to teach the category," says Mandell. "Taking the skill out into the real world."

Many parents of children with autism say that if the schedule or the activities are not the same every day, their kids have a meltdown. To train the students to tolerate change, teachers at Monarch try to build flexibility into their lessons. For instance, during a math lesson, a teacher will ask a child to add four numbers and then have him compute with three.

Matt Elias, 15, arrived at Monarch three years ago, violent and aggressive. He pulled out much of teacher Traci Milinkovich's hair, enough to fill two quart-size baggies. Matt hadn't been to school in three years and had home tutors, says Mandell. But all of them quit because of his outbursts.

Initially at Monarch, all Matt wanted to do was go home. He talked about "doing damage" all the time. He would willfully vomit in inappropriate places. For six months, he did everything he could to get thrown out of school.

"We told him you're safe, we'll help, we aren't sending you home," says Mandell. "He couldn't sit in a chair or interact with an adult. He had to be reinforced for good behavior every two or three seconds.

"Now Matt converses, he studies, he goes on field trips. He likes coming here. He wasn't doing what children did before. Here's a kid whose life was saved."

Danny Ordillas, 9, is learning to read. Special education teacher Marcie Timen points to a picture of a toy in a book and asks Danny to say the word. Repeatedly babbling a variety of unrecognizable sounds,

Danny finally manages to say "toy."

As a reward for his success in the pre-kindergarten reading readiness class, he gets to play for a few minutes with a toy called Light Brite, a board with light-up pegs.

The sounds Danny makes comfort him if he's not getting a lot of hugging and holding, says Timen. "He's creating his own sensory stimulation, the vocalizations."

A group of four boys, working with a speech pathologist and two special education teachers, are singing a song, "There's something in my bag." The teacher puts an object in a sack and asks the boys, "What is it?" Or "Who is it?"

Through the game, the boys are learning how to talk to each other and to interact with their peers. Helping kids develop comprehension and expressive skills inherently improves their behavior, Mandell notes. "It's the reason most are here."

Ten-, 11-, and 12-year-olds, all of whom talk and read pretty much at grade level, go on frequent field trips, taking the rapid to Tower City, visiting the planetarium, going bowling. They go horseback riding once a week.

"They need tons of experiences," Mandell says. The field trips help the children translate the lessons learned in the classroom into daily life.

The Boston team

After Monarch School was underway, Susan Ratner approached Shane, director of the Communication Enhancement Center at Children's Hospital Boston. The school needed some expertise, and Ratner wanted to build a long-distance collaboration.

With the relationship now in its third year, two or three people from Harvard Medical School, Children's Hospital Boston, and Massachusetts General Hospital are at Monarch about one day a week. Team members talk to one another and their colleagues at Monarch almost daily.

"We know all the children," says Shane. "We know their needs, the issues, we're involved in programmatic changes, new hires."

Monarch was an exciting opportunity, says Shane, who holds a doctorate in speech and language pathology, because of its commitment to language and communication. It has five speech pathologists for the 27 children, which he calls far more than is typical. The school also has served as a laboratory for some of the Boston professionals' ideas.

"The foremost thing was having a curriculum that makes sense, one that is carried over at home," he says. "We wanted to package this and export the model to other programs. There's a sudden upswing in children with autism. Every school system in the country is overwhelmed. Families and schools are desperate for strategies so children make progress."

Above all, Shane wanted to make sure Monarch's approach was humane. The school's staff use aspects of applied behavior analysis (ABA), a repetitive, one-on-one approach that teaches social and language skills in very small steps. Each proper response is rewarded with a small snack, hug or kind word.

But unlike some practitioners of ABA, who include negative stimuli like bending a child's arms behind his back or pinching, Shane says Monarch uses only positive incentives.

"We do use ABA methods, just not exclusively," says Bellefaire executive director Adam Jacobs. "No one has the silver bullet. If someone did, we wouldn't have a problem."

Meeting Ohio's standards and beyond

Ohio has curriculum standards every teacher needs to follow. At Monarch, the staff develop language modifications to help the children meet these standards.

For instance, the state has a standard about money. While the typical child easily grasps that a quarter is more than a dime, kids with autism have to be taught to understand the concepts of more than and less than.

Most autistic children do not pass the regular grade level proficiency exams mandated by the state. Instead, they take an alternative assessment developed for youngsters with special needs.

Because the crisis of autism has reached epidemic proportions, Monarch has begun to develop templates of their teaching methods and materials that can be replicated and used by teachers across the country. But before Monarch staffers can share these ideas, they have to make sure the concepts work.

Data collection is key. For instance, to measure if a student grasps the concept of "in," teachers will keep track of the number of times a student correctly places an object in a cup rather than beside or under the cup on successive number of days.

At Monarch, teachers measure not just accuracy, but also the child's participation, Shane says. "We want to understand how independently he can accomplish the task. Did the teacher have to give verbal, gestural or physical assistance? Did the teacher point and say 'go ahead'?"

On the drawing board

While experts disagree over the treatments for autism, they concur that intensive early intervention offers the best hope of raising a productive adult. Such instruction is very expensive, often requiring one staff person for every student. It costs Monarch \$68,000 to \$70,000 per year to educate each child in the school, says Jacobs.

The state of Ohio requires school districts to provide an appropriate education for every child. Some school districts will agree to an autistic resident attending Monarch; this year, they pay \$62,000 for each child enrolled.

Other districts have their own special-education programs and refuse to place a child in more costly schools. Parents of autistic children sometimes hire lawyers and fight to get the school district to pay for their child to attend a desired program.

Today, all the Monarch programs are housed in a remodeled former residential cottage at Bellefaire. This September, administrators will break ground on a 22,500-square-foot, \$3.5 million autism school and residential facility on the Bellefaire campus. The school will be able to serve 56 kids; the boarding

academy will have space for 12.

Monarch's new facility will be built with \$2 million from the Jewish Community Federation of Cleveland's Centennial Initiative, \$1 million from the state of Ohio, and a \$500,000 anonymous gift. Other major donors to Monarch services include The Cleveland Foundation, the Mt. Sinai Health Care Foundation and the Elizabeth Severance Prentiss Foundation.

Plans call for eventually adding another wing for a preschool, when the necessary \$1 million is raised. The Bellefaire board of trustees also wants to offer lifespan services for those who have aged out of the Monarch school. A wing for independent living and vocational training will cost another \$1 million. When complete, the facility will total 32,500 square feet.

Family life improves

Parents whose offspring have spent time at other special-education programs say they are pleased at their children's progress at Monarch.

Dr. Ivy Boyle of Shaker Heights describes her son Alex as charismatic and terrific. At 17, he's 6 feet, 2-1/2 inches, a "gentle giant" with a very serene approach to life. He also is very handicapped.

His previous school, a publicly funded program for multi-handicapped children, was very happy with him because he was well behaved and sweet, his mother says. "But he didn't learn anything."

Alex had never completed a single goal on his Individual Evaluation Plan, a state-required document, before he came to Monarch.

"All of us were surprised he could change at all," Boyle says.

While he could talk a bit before attending Monarch, he couldn't dress or toilet himself. Button-down shirts were out of the question. If you asked him to take his shirt off, he'd just pull it apart, buttons flying.

Since coming to Monarch, all that has changed.

Boyle, who has two grown children living out of town, says Alex will now talk on the phone to his brothers. Prior to coming to Monarch, he'd just stand with the phone or smell it.

He's learned how to use a computer mouse and understands that the mouse is connected to an arrow on the computer. At home, Alexander now does chores, like taking out the trash or putting groceries away on the shelf.

His parents are beginning to plan a vocational path for him, such as assembling products in a supported workshop or delivering items in an enclosed campus setting.

Alex now wants to spend time with his family shopping or going to concerts. He's more able to tolerate outside stimuli. This year, for the first time, he attended the family's New Year's Eve party. "He was the happiest human being," Boyle says.

Alex still requires full-time care. The family employs several caregivers to provide coverage 16 hours a

day, seven days a week. Legally entitled to attend Monarch or a similar program until he's 22, Alex will one day need to live in a group residence.

Boyle hopes Bellefaire, where her son feels at home and where the director calls him "the little prince," will be able to provide it.

Derek Rusek was the first student enrolled at Monarch. Now 11, his behavior remains a challenge, and he still has tantrums at least once a week, especially over moving from one place or activity to another. But his mother, Stella Rusek of North Royalton, sees much improvement.

Within his first year at Monarch, there was a big boost in his vocabulary. With two hours of speech therapy a day, compared to the one hour a day at his previous school, his language has blossomed.

An obsessive-compulsive, Derek couldn't let go of any idea. Lights had to be on. Lights had to be off. Doors had to be open or closed.

Now, life has changed for the Ruseks, who have two other sons, ages 14 and 8. Prior to Derek's attending Monarch, the family rarely went out in public. Now, the Ruseks go to movies and restaurants during the week, when it's less crowded. They go roller skating, bowling and sledding. Best of all, Derek wants to participate.

Within the last year, he's learned the concept of time. If he wants to do something on a Monday, Rusek can tell him to wait two days until Wednesday. He also has learned to read.

The family never traveled before for pleasure. Now, for a March vacation, Rusek is writing a simple story describing the car trip step by step so Derek will know what to expect.

In the long term, Rusek would like Derek to be more social, to interact with peers. While he has low intelligence, he can learn things. At present, he's doing second-grade math.

"We don't know how far he can go," she says. "I can't worry too much about the future. You start to panic."

Monarch's extraordinary artist

At 21, Seth Chwast is the oldest student at Monarch. When he turns 22 on March 30, he'll age out of state-supported education. Of all the students at Monarch, he comes closest to fitting the stereotype of the autistic savant. Around 10% of people with autism have similar special or remarkable skills.

Seth was diagnosed with autism at age 2. When he was 4, his mother Debra Chwast had his intelligence tested and was told he had a nonverbal IQ of 148, an extremely high score. But others treated him as mentally challenged.

"What Seth needed most in the world was language," says Chwast. "He had words, but no language."

After years at a special-education program not geared for children with autism, Seth, a tall, handsome young man, attends Cleveland Heights High School each afternoon. There, he's learned computer-aided design (CAD) and started an engineering program.

He has begun an internship with a local architect, spending two hours each afternoon working with CAD. He will get his high school diploma from Heights High this June.

While Chwast says the Cleveland Heights school district did all it could for Seth, he was receiving only one hour of speech therapy a month. At Monarch, where he spends his mornings, he's getting 2-1/2 hours of speech therapy daily.

Speech pathologist Christina Stancato works on problem solving with Seth as well as language, taking him into stores or on drives. He practices ordering food at restaurants and buying items at Wal-Mart. She's taught him to chat with and have lunch with people.

A year and a half ago, Seth shocked his mother by starting to paint. Chwast, who studies kabbalah five hours a week by phone with a rabbi in Israel, had enrolled her son in several community classes: one at The Cleveland Museum of Art (CMA), a ballroom dancing group, and another in modern dance.

The art took off.

On a 6-by-7-foot canvas, Seth painted an almost life-size red horse standing against a background of snow-capped mountains and white clouds. "Fantasy Horse," painted in a folk art or naïve style, is the subject of an eight-minute documentary that screened last fall at the Ohio Independent Film Festival at Cleveland Public Theatre. Chwast spent \$16,000 financing the film.

Michael Cunningham, the former CMA curator of Oriental art, said the painting could go into any contemporary gallery in any museum in the country, Chwast recalls.

"This was news to me," she says. "We were looking at data entry (as an eventual vocation) at \$6 an hour."

Chwast has hired local artists to work with Seth each morning at Monarch. Bellefaire has set up an art studio in an unused basement cafeteria, with deep window wells that let in natural light. Stancato is helping each artist communicate effectively with Seth.

A large new painting, "Blue Whale," complete with floating bubbles and red coral reef, sits on an easel at Bellefaire. It's a study for a larger seascape. While Chwast is excited about this new aspect of Seth's life, the divorcée acknowledges that she has devoted her life and her resources to her only child.

"I have to be prepared to support Seth past the grave," she says. "I want him to have meaning in his life, admiration, a peer group, a sense of accomplishment. I want him to have some place to go. If he sells a painting, that would be wonderful. So far, there's not a painting I would part with."

Parents hope that one day their autistic child will converge: that is, pass as "normal," says Chwast, a former social worker. If it doesn't happen by age 12, it's not going to happen.

"If he's not going to converge, there's silence and despair," she says. "You drop into this black hole. There is no big picture. Now, I feel there's a big picture. Seth can stay at Monarch. It's some place to get up and go to in the morning. It's his place.

"If Monarch can become that for all the families here, this will be a mitzvah."

Baffling disorder called epidemic

Autism is a puzzling neurological disease. It's called a spectrum disorder because there's a broad range of developmental problems involving communicating and interacting with others. Autism also has a wide variety of symptoms.

Some children don't talk but will hug their parents and play with others. Some can't stand to be touched. Others engage in harmful, repetitive behaviors, like banging their head against a wall. Some can't tolerate subtle background noises, like the buzz in a fluorescent light.

Frequently, children with autism have below normal intelligence or mental retardation.

Autism can seemingly strike overnight. Sometimes, around age 2, a child's behavior and language skills begin to regress. He descends, as one parent of an autistic son describes it, into a deep well.

Ten years ago, one in 10,000 children was diagnosed with autism.

Now, estimates vary, but experts say roughly one in 250 people suffer from the disease, boys four times more often than girls. Scientists say the epidemic affects those of all races and all socioeconomic classes.

At Monarch School for Children with Autism, 20% of the students are Jewish.

Although no one knows why some children have autism, scientists recognize heredity as a major factor. It occurs more often in children with a sibling diagnosed with the disease. While there's no genetic test as yet, scientists have identified several chromosomal clusters that may lie behind autism.

Others suspect environmental influences, like infections or childhood immunizations. Parents of children with autism vary diets, eliminate certain foods, try homeopathic remedies, and travel to Mexico and elsewhere for alternative treatments.

Monarch Academy provides treatment, not babysitting

Monarch Boarding Academy, the only residential facility in Ohio dedicated solely to children with autism, opened this past year and is currently home to four boys, ages 7 to 12. Two of the boys speak; two do not.

In Ohio, counties scramble to pay the academy's \$350-a-day fee by pooling dollars from funds designated for mental health or mental retardation services, moving the cash from one lean pocket to another.

The academy does not provide custodial care, says Robert Schuppel, Bellefaire director of residential treatment. "It's treatment, not babysitting."

Everything the school does, the academy continues, in 30-minute structured activity sessions. Each child's individual schedule lists such activities as arts and crafts, chores, computer lab, reading and treadmill. The staff rewards desirable behavior with nutritious snacks, time with a favorite toy, or a

session in the padded sensory room. Staffers record each child's daily progress.

"We don't do punishment," says Schuppel, who toured residential facilities for autistic children up and down the East coast before opening the academy. None provided a model he could emulate.

"Fingers were being bent back" in those facilities, he says. "Spraying water. Helmets with face guards if there was spitting. Velcroing kids down."

Finally, he found a program in West Virginia that did not add anything noxious to the child's environment. At Monarch, "we will do negative reinforcement, like taking away computer time or something rewarding," Schuppel says.

At least twice a day, staff members take the children to the mall or into the community. They teach them how to ride the escalator and how to purchase something.

Brian (not his real name), 12, arrived at the academy after spending years locked in the basement. His affluent, well-educated parents feared he would hurt himself or someone else and didn't know what else to do with him.

After 30 days at Monarch Boarding Academy, Brian was sitting down and eating; he learned the word no, something his parents never said to him.

His mother visited, and with tears in her eyes, said, "I am a bad parent." But Schuppel insists that's not the case. "She didn't have staff there 24 hours a day, seven days a week. Staff here rotate kids every 30 minutes, because it's very hard to work with these kids."

John (not his real name), age 8, arrived at the academy last June with his arms strapped to his side because he hurt himself. He wore a helmet because he needed the self-stimulation that hitting his head provided.

Despite the helmet, he had developed a bleeding gash. He was starting to damage his retina. "The kid was going to die," says Adam Jacobs, Bellefaire executive director.

In the months he's been at Monarch, John has removed the helmet, graduating first to a baseball hat and then to no hat. His scalp has healed. He traded the arm straps for long-sleeved shirts, tucking his hands inside the cuffs. Now, that behavior is gone, too.

Today, he's listening to his parents and interacting with them. They are asking how to get him back home, says Jacobs. "For \$350 a day, we saved a kid's life."

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