

Coping with Autism

BY JASMINE RAINEY
COLORADO STATE UNIVERSITY

ABC's and numbers decorate the walls of a classroom. Like any other kindergarten class, the teacher instructs the students on their colors, numbers and alphabet. Most students would rather play with toys than complete their work. One student practices writing her name while another one transforms his toy robots into cars as a reward for completing his work.

However, the students in this class have been learning their colors, numbers and letters for five months, and some have still failed to master them. The teacher leads the girl's hand in writing her name, which they've practiced over the last three months. The boy playing with robots can finally count from one to five after weeks of going over the numbers; for him this is a major achievement. If all of the children can recite the letters of the alphabet by the end of the school year, it will be a great accomplishment for these students - these autistic students.

Autism is a pervasive developmental disorder that affects one in every 150 American children and four times as many boys than girls, according to the Autism Society of America website. Autism is an umbrella term that may involve social, behavioral, communication and/or cognitive problems.

Jeanne Ellis Ormrod's "Educational Psychology: Developing Learners," fifth edition, defines autisms as being characterized by "impaired social interaction and communication, repetitive behaviors, restricted interests and a strong need for a predictable environment" as well as "an underlying condition that maybe an undersensitivity or an oversensitivity to sensory stimulation."

In addition to autism, the autism spectrum disorder includes Asperger's syndrome, marked by deficiencies in social interaction, preference for sameness of environment and difficulties with transition, but unlike autism a person still has regular linguistic and cognitive development; and pervasive developmental disorder-not otherwise specified, PDD-NOS—have some characteristics of autism but aren't easily defined as being autistic, according to ASA.

In 1911, the term "autism" was first coined

by Swiss psychologist Eugen Bleuler, but the term applied to patients with schizophrenia. In the 1940s, Dr. Leo Kanner described autism for the first time based on a study of 11 children who had withdrawn from human contact. Researchers in the 1960s found identifiable characteristics of autism and treatments.

Autism cannot be cured and the causes are still largely unknown although researchers believe it's caused by abnormalities in the brain.

"Autism is such an unusual thing because the spectrum is so wide," Dorothy Galvin, a special education kindergarten teacher in Denver, said. Galvin said there's "not a one size fits all" technique for autistic children.

Even if five autistic students have behavioral problems, the learning techniques and coping strategies used would be different for each student. Like people without autism, autistic people illustrate that each individual is unique.

Sarah Hyman, a senior psychology major at Colorado State University and a regular volunteer in special education classrooms, said, that of all of the autistic children she's worked with, no two have been completely similar in their behavior, learning and coping styles.

The needs and routine that most autistic students demand can be very taxing on the parents and teachers of such children. Yet, parents and teachers interact to give autistic children the fullest lives possible and teach them strategies that may help them cope with their individual challenges.

In this article, coping strategies are skills that allow autistic students to better manage situations that they find stressful and techniques teachers provide parents with to help them to manage their child's autism more effectively. Coping strategies may also include strategies that parents have found effective based on their own experimentation.

Each expert source interviewed said that autism is so diverse that efficient and effective coping strategies usually vary on a case-by-case basis. Yet, one strategy is shared among special education teachers: routine and repetition.

"Autistic children like their routines," Galvin said. "They want structure and consistency."

Galvin said she was absent from class one day and it disconcerted her students. They didn't know the new substitute teacher and couldn't necessarily cope with the unfamiliar situation, she said. The paraprofessionals alleviated some of the children's distress, but Galvin can't necessarily prepare the students for when she's absent, she said.

Despite her students' need for routine, Galvin tries to slowly change their daily schedule.

"We might do calendar, shapes, numbers and letters," Galvin said. "We'll start in this sequence for a while, then switch the sequence. We'll switch up the days we do certain things."

Galvin does this in an attempt to eliminate the "rigidity" that her students possess because "life isn't full of schedules," she said.

She works in a coordinated effort with the parents of her students to loosen their need for routine.

"It'd be a blessing for the parents (if the rigidity were lost)," Galvin said. "(The parents) try to mix things up at home. It's a team effort."

Galvin also uses overlearning or repetition to teach her students. She said that they'll sing a song about colors three times each day.

"I didn't do that for a week, and one student forgot all his colors," she said. "After a while it gets kind of monotonous and I don't like it when I start dreaming about the songs (due to the repetition), but I like seeing them grow in their academics. Repetition is very important for that."

Positive reinforcement is also used to make sure a behavior continues. Galvin uses a chart to motivate her students to learn.

Each chart has four stars attached to it and the words "I'm working for _____." The children have personal charts and a picture of what they want to play with is placed in the blank. The stars represent assignments that must be completed before they can have free-time. Once all four stars are removed, the students can play for a few minutes with whatever they were working for.

"One boy is motivated to play with robots," she said. "So he'll get his work done to play with them."

Stars are removed from the chart instead of added because it's often difficult for autistic students to comprehend abstract concepts. For example, Galvin's students would have a difficult time imagining four stars that they need to obtain on an empty chart. By removing stars, they can concretely "see" that they have two stars left that must be removed, Galvin said.

Galvin's methods have helped her students improve.

"A couple of parents were in tears and said they can't believe how much (their children) are learning and speaking," she said. "One of the rewards you have as a teacher is knowing you helped improve a child somehow."

Working as a Denver Public Schools special education paraprofessional for three years, Geneva Lawrence said that the special education classes she has worked in taught students different skills that emphasized independence.

At one school, Lawrence said there were different centers and each paraprofessional and teacher would teach a different subject for 15-25 minutes with the autistic students. The "Self-Help Centers" taught the students how to dress themselves, about hygiene and how to brush their teeth, helping them to be self-sufficient to a certain extent. Other centers focused on working independently, math, reading and writing skills.

Every Friday the children went on an excursion that allowed them to practice "how to behave in social situations," Lawrence said.

"Fifty percent of the students had a lot of behavior problems and didn't know how to react in certain situations," she said.

Some students would throw food at people when they went to restaurants, Lawrence said. "We'd make them clean up the food instead of the waiters, and that showed them that it's not OK (to throw food), and they'd have to take responsibility for their behavior. We'd show them the appropriate behavior and they learned through repetition. We'd keep taking them to restaurants so they'd learn," she said.

Lawrence also said the parents of the students said the trips to restaurants, zoos and other places helped them have an easier time when taking their children out.

When some students seemed frustrated, Lawrence would tell them to try the "blow out the candle" technique of taking in a deep breath and letting it out or "smell the flower," pretending to inhale a scented flower.

"I didn't think it would work, but it really calms them down," she said of the relaxation techniques.

Other students have specific items that calm them, she said. Or Lawrence would have the students look in her eyes. "They

don't like to look at you directly in your eyes," she said. The lack of eye contact is a characteristic of many autistic students' weakened social development. Often times, Lawrence makes the students look her in the eyes and the autistic students will begin to focus only on her eyes, which ultimately calms them down since they're concentrating.

Other coping strategies included touching their hands, heads, using a trampoline or anything that applies pressure to the child. Pressure can be soothing to autistic children who are oversensitive to sensory stimulation, particularly touch.

Although Lawrence has been bit, hit, kicked, scratched, spat on and had her hair pulled on by autistic students, she said she won't be deterred.

"I'm really not afraid of them," Lawrence said. "How they act is just a way to communicate - a way to let people know there are things they don't like."

For Lawrence, any abuse she may endure is worth it when her students learn.

"When they have a breakthrough while teaching them a single letter, it's like...wow, even though it took three months to learn it," Lawrence said, laughing. "It's just the thrill of seeing their faces light up like 'Oh, I got it!'"

Item number one in Ellen Notbohm's book "Ten Things Your Student with Autism Wishes You Knew" is that "behavior is communication." Notbohm writes (in the voice of an autistic student) "All behavior occurs for a reason. It tells you, even when my words can't, how I perceive what is happening around me. Negative behavior interferes with my learning process. But merely interrupting these behaviors is not enough; teach me to exchange these behaviors with proper alternatives so that real learning can flow."

Lawrence said that her students are all really good, and she tries to observe them first as much as she can. If they're interested in something, then she tries to incorporate it into what's she's teaching them.

The coping strategies that Dave Miles, a special education teacher and part-time interventionist for DPS, uses depend on what student he's dealing with.

One 12-year-old boy was extremely angry and also had temper problems, Miles said, and he didn't know what all the triggers for the boy were. For that student, Miles said he had to earn the student's respect, which was difficult because in most classrooms the students automatically give the teacher respect.

As time went on, Miles learned that if the 12-year-old was having a difficult time with his work or spending too much time on a task, he would start to lose control. Miles learned that for autistic students who have trouble focusing, shortening the time spent on a task helps them learn more efficiently.

For the 12-year-old student, Miles gave him time updates.

"I'd say 'you have 30 minutes' to keep him aware that it's going to be coming to an end," he said. "If he was struggling, I'd let him know it was coming to an end."

Miles also developed a timeout card for the boy to use when he couldn't deal with his surroundings.

Wherever they were, Miles and the boy would establish a "safe spot," a place where the student could retreat when he was losing control. The boy also had a folder and would slip his timeout card into his folder to let Miles know where he would be.

The timeout card proved useful for the boy's parents.

The student's parents could now take him to more places and not worry about him running off to some unfamiliar, unsafe place. "Sometimes he would just run away, and he wouldn't even know where he was going," Miles said. Now, the boy and his parents could establish a safe spot at a restaurant, the zoo or wherever. He could put his time-out card in his folder,—left where his parents could find it—run to his safe spot if he became frustrated, and his parents would know where to find him.

Miles said it felt good to provide the family with a coping strategy that relieved some of their stress and worry, "but some of the things you (teach) don't always last," he said.

He stresses consistency in whatever he teaches as well as constant tweaking of his methods. If there's no consistency then the skills fade quickly, he said.

Whatever he does, Miles attempts to help his autistic students lead as close to "normal" lives as possible.

Growing up with dyslexia with his twin brother, Miles learned early on the challenges that having a disability could bring, but he also learned that having a disability didn't mean he had no future.

"Just because they're special education doesn't mean they can't succeed," Miles said of his students and special-need children in general.

Temple Grandin is autistic and did indeed prove that autistic people can be successful.

Grandin was diagnosed with autism when she was 2 ½ years old in 1949. She had very low social reactions, lacked emotion and was sensitive to loud sounds and physical contact.

“High school kids teased me,” she said. “High school students can be really mean and nasty. They called me things.” The students called her “tape recorder” since she repeated words.

From elementary school to the first year of high school, none of Grandin’s teachers excited her about school or learning. “I wasn’t really into studying,” she said.

Then, in the 10th grade, she had a science teacher who ignited a passion for science in her. He took her obsessive interests and directed them toward science projects.

“He got me interested in science,” Grandin said. “Good teachers make the most difference in the world. I can’t emphasize enough what a good teacher does.” Her 10th grade science teacher was a good teacher.

Grandin began to study more and devoted extra time in the science lab and to riding horses, the only two places where she wasn’t teased.

After graduating high school, Grandin attained her bachelor’s degree in psychology from Franklin Pierce College, her master’s degree in animal science at Arizona State University and her doctorate in animal science from the University of Illinois in 1989.

Grandin has written several best-selling novels about autism and animal behavior. In addition to being a novelist, she travels around the nation speaking about autism and cattle handling, is a successful livestock handling equipment designer, has designed numerous facilities that handle cattle in the U.S. and has written over 300 articles about facility designs, animal handling and welfare. She presently is an associate professor in the animal science department at Colorado State University.

Like many autistic people, Grandin has an intolerance of being touched due to her skin being oversensitive. She wrote in the “Journal of Child and Adolescent Psychopharmacology” that “Occupational therapists have observed that a very light touch alerts the nervous system, but deep pressure is relaxing and calming.” By arousing the nervous system, a light touch can create a wave of overwhelming stimulation. For Grandin, a light hug is extremely painful.

According to the Autism Research Insti-

tute’s website a touch that is firm enough to stimulate deep touch receptors somehow produces a calming effect instead of a painful one. The site also states that stroking autistic people’s skin with different cloth textures can desensitize their hypersensitivity to touch.

Sensory stimulation also varies for each individual. ARI’s website said sensory stimulation is similar to the idea that a cool breeze may bring relief from the heat for one person and may make another person shiver. Therefore, a hug for Grandin is painful, but it may be soothing for other autistic people.

For autistic children who become overwhelmed, angry or anxious, this coping strategy of deep pressure may relieve some of their frustration. Some autistic children wrap themselves in numerous blankets or climb between mattresses to seek out “deep pressure.” Grandin used to climb between the sofa cushions and have her sister sit on her.

While in elementary, Grandin developed and later patented what she called a “squeeze machine,” improving the initial design throughout the years. She came up with the idea for the first human squeeze machine when she had an anxiety attack at her aunt’s Arizona ranch. She jumped in the squeeze chute used to hold cows as they’re vaccinated and asked her aunt to squeeze the sides against her.

In her book, “Thinking in Pictures,” Grandin writes that after the first moments of panic, a “wave of relaxation” washed over her.

She used plywood panels to construct her squeeze machine, using the same design as the cow squeeze chute. Presently, one design has foam-padded panels and allows the user to control the pressure exerted.

This concept of using pressure to calm an autistic person can be applied in the classroom through smaller items like pillows, blankets and mats.

In Galvin’s classroom, one autistic student suffers from sensory processing disorder. According to the article “Sensory Processing Subtypes in Autism: Association with Adaptive Behavior,” published in the “Journal of Autism and Developmental Disorders” children with autism “frequently reported to exhibit behaviors associated with sensory sensitivity (e.g., covering ears to loud, unexpected sounds; restricted food preferences), sensory under-responsivity (e.g., failure to orient to name or react to pain) or sensory seeking (e.g., rocking, hand flapping, noise-making).”

When visiting the general education classroom, the noise level may become too much for Galvin’s student to process. He can be-

come very disruptive and make noises.

The teacher of the general education classroom said he has a “calm-down box.” If the teacher sees he’s about to lose control, she’ll signal for him to get his box by looking at him and sweeping her hair back with her hand. His box contains a weighted pillow, a toy phone called a “whisper phone” and other little objects that calm him down.

Just as people without autism have diverse interests and recreational activities, people with autism also have diverse methods of relaxation. The squeeze machine works for Grandin, the pillow and phone for Galvin’s student, and singing for others.

Galvin would say the point to remember is to observe the student before he or she becomes too frustrated or overwhelmed, and give him or her time to calm down with whatever method works best for that student.

The squeeze machine as well as her other accomplishments, has give Grandin world-wide recognition.

To date, Grandin has been on “ABC’s Prime-time Live,” “Larry King Live,” “20/20” and the “Today Show.” According to Grandin’s website, Bravo cable did a half-hour show about her life, and she said that HBO is currently in the process of producing a story about her.

Grandin has autism but has proven that it’s not a disability that hinders achievement. She is a success.

In her book “Emergence: Labeled Autistic,” Grandin writes that many people believe that autism is a condition that exists for life. However, in her book she states, “To these people, it is incomprehensible that the characteristics of autism can be modified and controlled. However, I feel strongly that I am living proof that they can.”

Grandin’s books helped the parent of a son who has PDD-NOS understand some of the behaviors her son displayed.

Adelaida Nieves was always told that her son seemed different. When her son, Evan, was 6, his teacher asked her if she’d ever heard of PDD-NOS. At the time she didn’t but after years of research, she’d know as much as possible about the disorder.

Grandin’s books helped Nieves understand some of Evan’s behaviors that weren’t explained in any of the other material she had read.

Because Grandin’s book explained that autistic people often suffer from lack of sensory integration, Nieves understood she was fortunate that Evan could be very affectionate and lov-

ing constantly hugging her, but he liked to touch people's hair and at times he would hug her tightly.

She said she thinks Evan grew out of touching people's hair and wasn't as affected by a lack of sensory integration as others because of all the activities he was enrolled in. He boxed, participated in karate and played sports.

Nieves said the impact of the activities helped Evan relax and acclimate his body to touch.

When Evan would become frustrated or overwhelmed, he displayed it through self-talk and echolalia, the repetition of words.

"He'd say something like 'I'm going to the store, store, store,'" Nieves said. It took years for Evan's speech to develop, she said.

Nieves's son was in individualized education program classes throughout the majority of his primary school. She said that she and her husband taught him most of his learning and coping strategies with little or no assistance from his teachers.

"It was so impersonal," Nieves said of Evan's teachers and school system. The teachers weren't prepared to teach children with autism, she said.

Nieves gave one example of when Evan had moved to a general education classroom with only a paraprofessional to assist him.

The teacher should tell the paraprofession-

als what they'll be instructing in advance, so they can figure out how to convey it to the students to maximize the learning process, Nieves said. "The teacher barely did that for my son."

Music soothes and helps Evan learn, Nieves said. "He learned his colors through the Ninja Turtles" and the different colored masks that the turtles wore, Nieves said.

For some unknown reason, music has a positive effect on most autistic people. In Grandin's book "Thinking in Pictures," she mentions that one of the only times she feels emotions is when listening to music.

Galvin, also said that her students seem to learn better when singing.

"One little girl, stands at the board and sings all of her numbers," Galvin said. "I say whatever works."

Nieves said that finding effective strategies can be difficult.

"Being a parent, there's no manual," she said. "It's always trial and error. Mirrors would get Evan going. We learned not to do things to stimulate him in a negative way."

Miles expressed an admiration for parents like Nieves, who have special-needs children.

"My time with these kids is limited six hours a day for four days a week," he said. "I can checkout from it at the end of the day. They can't."

While some autistic children will always re-

quire constant care, the coping and learning strategies that teachers, psychologists and parents provide autistic children can help many become productive, self-sufficient adults.

For parents like Nieves, the lack of programs and help for autistic adults is disappointing. She said most of the research coming out on autism focuses on children and how to help them early. Nieves wants to eventually create ways to help autistic adults find jobs and help them to continue to grow, so they're not jobless like her son.

With the growth rate of autism rising from 22 percent in 1992 to over 1000 percent in 2008 (Fighting Autism Web site), Nieves would like to get more help for autistic adults sooner rather than later.

For other parents who have children with special-need children, Nieves said: "Never assume that you can't do anything until you try. A... doctor said, Evan would never be able to learn anything, and he was wrong. People with disabilities are people with potential."

Additional Source:

(2008) "History of Autism." Autism-Help.org <http://www.autism-help.org/autism-history.htm>