

'Go slowly and with your eyes open'

Experts urge early diagnosis, education, family support in successful autism treatment

By Adar Kaplan
Journal Inquirer

Ben Wytas can say the word "lollipop."
His teacher at Andover Elementary School, Ann Walsh, knows that, she says, because Ben said it twice on demand that morning.

To see if Ben can say it again, Walsh sits Ben down, unwraps a lollipop, and shows him a picture of a lollipop with the word "lollipop" written on it.

"La, la, la, Ben," Walsh says in a sing-song voice, "can you say la, la, la, lollipop?"

When Ben reaches for the candy, Walsh pulls it away and puts Ben's hands back at his side.

First of two parts

"No reaching," Walsh says. "Ben, you know how to say la, la, la. You can have the lollipop. I just want to hear you say la, la, la — lollipop."

Ben watches her mouth, touching Walsh's lips to see how she forms the sound. Walsh praises him and touches Ben's shoulders. "Good eye contact, Ben. Good looking," she says.

Ben seems like he's about to make a sound but doesn't. He's concentrating hard, but today, Walsh says, her student's effort — and desire — for the lollipop are overcome by exhaustion.

After several tries, Ben cries and swipes at Walsh's face. His eyes start to close, and he lays his head on the table.

"Okay, Ben," Walsh finally says, "that's enough."

The ordeal 8-year-old Ben went through for the lollipop is something he, his family, and teachers go through each day. It's part of the daily struggles that many autistic children face: Ben doesn't speak though he is physically able to.

What causes autism is unclear. But the latest research indicates that it's a biologically based genetic disorder that affects the way the brain works, according to Tolland-based child psychologist Michael Powers, who specializes in helping autistic children. In turn, the disorder has an impact on a person's social, interaction, and communication skills.

One in 500 people is autistic, according to 1997 statistics from the Center for Disease Control. Autism is four times more prevalent in boys than girls, according to the Bethesda, Md.-based Autism Society of America, and it knows no racial, ethnic, or social boundaries.

Autism also has no cure, although with



John Spivey / Journal Inquirer

Ben's father opens a bottle of dressing so Ben can pour it on his salad.

intense therapy and education, symptoms can ease or sometimes disappear as a child grows. But the majority of people who have autism will exhibit some signs of the disorder their entire lives, the Autism Society of America says.

It was a change in Ben's communication skills that Lynn and Mike Wytas of Andover first noticed when he was 2 years old.

Ben was developing normally, Lynn Wytas says, and capable of doing anything his peers could. He could say 40 or 50 words, which, she says, was on target for his age.

Then her son "lost his words," she says. Ben stopped being receptive to people and began playing "inappropriately," his mother adds.

Inappropriate play occurs when a child becomes fixated on a toy or object for a purpose other than the one for which it was intended. For example, Lynn Wytas says, when Ben played with blocks, he would line them up and look at them, or stack books instead of trying to read them. Instead of rolling toy cars across the floor, she says, Ben would just spin the wheels.

The Wytases eventually learned that Ben showed signs of autism. However, there is a range of symptoms that autistic people display — and in any degree of severity.

Time essential for diagnosis

Some autistic people can't stand being touched. Ben, on the other hand, tolerates affection, his mother says. Some can speak and others can't; some are retarded or mute, but some aren't. Some have steady jobs and advanced degrees; others need assistance daily. And, doctors say, it's unknown why some autistic people have certain abilities and some don't.

The variations can make autism tough to diagnose, but evolving criteria can help doctors pinpoint it, Powers says. Autism is shown in the presence or absence of certain behaviors — communication, play, and social interaction.

At the Center for Children with Special Needs in Tolland, Powers and other autism specialists diagnose children by conducting psychological evaluations based on children's play, communication, and behavior. The doctors then pool their observations to make a diagnosis.

Powers says time is essential in diagnosing autism.

"There's a good body of research that demonstrates that we have better long-term outcomes if you get kids early on and intervene with them," he explains.

Determining the right time for a diagnosis can be tricky. An early diagnosis is better, Powers says, but it's important for parents of autistic children to find clinicians who have experience making early diagnoses.

It also can be difficult to diagnose a child if other problems, such as retardation, accompany autism.

When doctors diagnose a child early, Powers says, it means education can start sooner, and there are likely to be fewer bad habits and behaviors to undo. The child's family can start learning how to deal with autism as well, he says.

"If you start with a family when a child is young," Powers says, "you can create a plan for the whole family and follow it through, and help them adapt and work with the child as effectively as possible."

Family is important

The plan that Powers creates depends on each child's abilities, but all of them include giving families a level of confidence to help them live with, help, and learn from the autistic child.

"When kids with autism are young," he explains, "the best place for them is with their families — not pushed away from the rest of society."

Powers adds that there are some proposals for community-based residences for adults with autism, an idea he supports.

"Folks with disabilities are best when they're part of a community. That way, if a problem comes up, you have more people to fall back on," Powers says.

Part of Powers' plan for helping the Wytases is to teach Ben the skills he needs by breaking them into small steps. A rigorous evaluation of Ben's progress through data analysis allows his parents to identify when they need to adapt teaching strategies, Powers says.

There are several strategies for teaching autistic children to communicate.

Diane Twachtman-Cullen, a speech-language pathologist who specializes in treating people with autism, helps teachers and parents set up natural situations in which they teach a child to speak. Twachtman-Cullen treats people at her office in the Higganum section of Haddam.

For example, she says, she'll devise a scenario called a joint activity routine, in which an autistic person must request or deny something. If a child doesn't talk, she may use sign language, pictures, or objects.

Her emphasis, Twachtman-Cullen says, is not just on saying a word but on giving a child a way to communicate in the context of a situation.

"I give information to parents about ways to draw out communication, but comprehension has to come first," she says.

"If you start with a family when a child is young, you can create a plan for the whole family and follow it through, and help them adapt and work with the child as effectively as possible."

Michael Powers
Child psychologist

The challenge, she says, is that autistic people have trouble applying a set of behaviors to a situation once it's altered. So while a child may master how to request a snack, he won't know how to ask for a toy.

Exercises can be difficult

Parents and teachers also can organize "discreet trials" — like the one with the lollipop — to teach.

Three times a day every weekday, and on Saturdays for two hours, Ben performs trials with aides from Walsh's class or an aide who helps him at home.

During the trials, Ben must point to pictures of objects or actions when his teacher prompts him. When he first started his trials, Walsh says, Ben had a choice of two objects or actions; now he's up to three. For Ben, his parents say, 70 or 80 percent correct is success.

But as the trial with the lollipop shows, the exercises aren't easy.

Walsh says Ben has motor planning problems, which occur when the brain's message to the body is blocked. That means not being able to point to a picture of a lollipop or say a word, though he may know what it is.

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Program aims to help students 'move beyond goals, objectives'

By Adar Kaplan
Journal Inquirer

The Eastern Connecticut Regional Education Service Center runs two tuition-based classes for autistic children in public schools; one at Andover Elementary School and another at Woodstock Middle School.

The goal of the classes is to implement an individual education program for each student, according to Paul Mullen, director of EastConn's special education program.

The program is developed by the teacher and specialists for the class, and it depends on daily communication with the child's parents, Mullen says.

Though personalized, Mullen says the program focuses on several skills: cognitive, behavioral, social, emotional,

motor, and self-help.

In the Andover class, there are six students, and there are eight students in Woodstock, Mullen says. Each class has a teacher, an occupational therapist, a physical therapist, a speech pathologist, and instructional assistants.

Mullen says the cost for each child usually is about \$31,000 but could go as high as \$37,000 for a child who requires individual instruction. The students' home districts pick up the cost.

"The class provides an environment for students to move beyond goals and objectives," Mullen says, especially because the classes are located in public schools where the autistic students aren't isolated.

For more information, contact Mullen at (860) 455-0707, or log onto the EastConn Web site at www.eastconn.org.



Battling autism

Doctors, families struggle against brain disorder /4

Ben Wytas, an autistic boy in Andover, makes his way through a play tunnel at his home.

John Spivak / Journal Inquirer

Education and 'a huge dose of love' key in working with autistic

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The trials can be tough on Ben and his teachers.

"After a while, it's hard on him," Walsh says. "It's hard on us. But you have to give everything a good shot."

"Everything" includes dietary and pharmaceutical treatments.

Ben is on a gluten-free diet. Gluten, which is in many foods, turns to glucose, or sugar. Sugar can excite any child, but for a child with autism, the glucose can make him less attentive, Lynn Wytas says.

Ben also is on what Lynn Wytas calls the "Secretin trail."

Secretin is a hormone commonly used during gastrointestinal tests; people with autism often have inefficient digestive systems. Some families have found that people with autism have spoken when Secretin was administered.

Since Secretin has no known side effects, the Wytases are willing to try it. But the

federal Food and Drug Administration hasn't approved Secretin therapy for use for autism, making it hard to find.

Still, Mike Wytas says, he found a way to get Secretin through a contact on the Internet, along with an out-of-state doctor willing to administer the doses.

Ben has been receiving the doses about every six weeks, and Lynn Wytas says she's noticed that Ben has been calmer and is trying to vocalize.

But Powers says that federally funded studies have shown that the drug doesn't overcome autism. A study published this month in the *New England Journal of Medicine* reached the same conclusion, Powers says.

'A huge dose of love'

Perhaps the most important concept Powers teaches parents, he says, is how to be advocates for their child and be "good consumers of information."

There's a huge body of information — and

misinformation — about the disorder, and Powers helps parents learn how to review it carefully. That includes being cautious, he says, and learning to "go slowly and with your eyes open."

With that advice, open minds, and loving hearts, Ben's parents say they hope Ben will communicate someday — even if it means using selection books with drawings and photographs of activities for Ben to tell them what he wants.

Lynn and Mike Wytas explain things to Ben by using concise sentences and visual aids. They also reprimand Ben firmly and gently when necessary.

There are frustrating days with Ben, Lynn Wytas says, but it's still important to set attainable goals — without lowering expectations.

And she adds that her family keeps two never-fail strategies in mind: "education and a huge dose of love."

Lynn Wytas recalls a day when that

philosophy paid off.

When Ben was 6, she says, he was making no formed sounds, but his parents would tell him they love him every night.

One morning, Lynn Wytas says, Ben went into her room.

"He said, 'I love you' — but without the 'v,'" Lynn Wytas says. "You almost denied you heard it."

The Wytases praised Ben for speaking, and later that day he said, "soda." When he saw the children's character, Barney, on television, Ben said, "Barney." Ben spoke again that night, saying "I love you" to his parents before bed.

Since then, Lynn Wytas says, she hasn't heard another word from her son.

When she asked doctors what triggered Ben to speak, they said they don't know, but that it's possible that for a short time, his speech wasn't blocked.

"Speech and language were just working together that day," Lynn Wytas says.

'Not enough' resources for autism

Parents, experts cite lack of service providers available to help treat disorder

By Adar Kaplan
Journal Inquirer

"No matter what's wrong with him, I'm going to fix it."

That's what Suffield resident Diane Piccolo says she found herself saying about her son, Nicholas, after a doctor suspected he was autistic.

That was about two years ago. She had taken Nicholas, now 4 years old, to a doctor who specializes in diagnosing children with special needs. The doctor saw signs of autism, Piccolo says, but because Nicholas was so young, the doctor advised her to closely watch Nicholas' development for more indications of the disorder.

Second of two parts

Those signs came: Nicholas didn't talk or make eye contact. He displayed obsessive behavior — constantly opening and closing doors — and his motor skills developed slower than normal for his age.

Piccolo took Nicholas back to the doctor, who confirmed autism, a biologically based genetic disorder that affects the way the brain works, and, in turn, has an impact on a person's social, interaction, and communication skills.

Piccolo says she learned that autism can't be fixed, but autistic children and their families can learn to communicate.

"And if I can't fix it," she remembers promising herself, "I will make him the best functioning child I can."

A series of uphill battles

One of the first things Piccolo found out was that it's essential to start educating an autistic child as early as possible. But, she says, providing the proper care and education for Nicholas was a series of uphill battles.

"It's so difficult because there aren't enough specialists in Connecticut," she says.

Piccolo called the Bethesda, Md.-based Autism Society of America, which has 240 chapters and 24,000 members nationwide, for a referral. The Connecticut chapter referred her to Michael Powers, a psychologist with the Center for Children with Special Needs in Tolland. He specializes in helping autistic children and their families.

She made an appointment with Powers last spring. The next available appointment was June 2000.

With a year before her son could see Powers, Piccolo says, she needed to do something.

Her next step was to call Birth-to-Three, a state and federally funded entitlement program for children under the age of 3 who have developmental disabilities or delays. Birth-to-Three coordinates a team of people who develop a personalized plan for a child based on his needs.

The plan provides services ranging from family counseling to social work services and is periodically reviewed and updated as the needs of the child and his family change.

Services from Birth-to-Three, like speech therapy, helped Nicholas, his mother says. But the hours and days that aides could help him were limited.

"I took what I could get — and I couldn't get any more than what they could give me," Piccolo says.

Too few specialists

On Nicholas' third birthday, the Birth-to-Three services ended.



Jim Michaud / Journal Inquirer

Diane Piccolo takes Nicholas for a bike ride last summer.

"And then," Piccolo says, "I was scrambling to find help after that."

Piccolo says Birth-to-Three was willing to contact the Calvary School in Suffield, which Nicholas now attends, and familiarize teachers there with his curriculum.

There are not a great number of professionals who are true specialists in autism in Connecticut. There are some professionals who are working in the field of autism, but there are not enough to accommodate the numbers of people seeking service.

Diane Twachtman-Cullen
Communications disorders specialist

It took her more than a year to find a therapist to work with Nicholas at home, she says.

Meanwhile, Piccolo continues to work with Nicholas herself. She helps him exercise to stimulate his muscles, talks to him to get him to make sounds, and insists on eye contact before every activity. She also corresponds with Nicholas' teachers with a notebook to mark his daily activities and progress, since Nicholas can't tell her himself.

But, Piccolo says, "These are the most crucial times. I just don't feel like I have

medical guidance. We're at the mercy of the doctors' schedules."

According to Powers, the problem arises at the professional level.

Too few universities offer courses specializing in autism, leaving students of special education with a void in their studies. That leaves the conferences and conventions that Powers attends packed with specialists craving the latest information, he says.

One way to solve the problem, Powers says, is for more universities to develop specialized courses about autism.

Diane Twachtman-Cullen, a speech-language pathologist and communications disorders specialist who works with autistic people, also acknowledges the problem of long waiting lists. Her office is in the Higganum section of Haddam.

"There is not a great number of professionals who are true specialists in autism in Connecticut," she says. "There are some excellent professionals who are working in the field of autism, but there are not enough to accommodate the numbers of people seeking service."

Connecticut better than most states

Audrey Horne, director of the Autism Society of America, is personally familiar with the lack of medical professionals to help people with autism. She has a 31-year-old autistic son.

And although professionals today have a better understanding of autism, Horne says, "We don't have enough medical professionals who really know what autism is."

Another problem, Horne says, is that there's no parity in services that are available.

"There are some sections of our country where the services are outstanding — and

some are abysmal," she says. Horne adds that Connecticut has better resources than most states.

Connecticut's weakness is that there are too few consultants to adapt existing educational programs to fit the needs of autistic students, whose numbers have been increasing, according to Roger Frant, an education consultant with the state Department of Education's bureau of special education and pupil services.

But the state has been improving its record over the past few years by having state and parent organizations train people for educational consulting. That was implemented, Frant says, because each school district is required to provide educational services for people from ages 3 to 21.

Frant says his office has published a list of state and parent groups that people can call for referrals. His office also publishes a booklet called "Focus on Autism," a guide to workshops and other activities for professionals, people with autism, and their families.

Suggestions and a caution

Twachtman-Cullen and Horne say that families aren't helpless while they wait. They offer several suggestions.

For example, Twachtman-Cullen says to keep in mind that "what is good for a typical child is also good for a child with autism."

Activities Piccolo did with her son were on the right track, Twachtman-Cullen says. Creating repetitious tasks and situations also are important, she says.

In addition, Horne says, parents should brush up on their knowledge of disability law and find a lawyer who specializes in it.

Although parents can be great advocates for their children, according to Horne, they often don't know the intricacies of the legal system and may need guidance if their child's needs require it.

Moreover, the government "has a responsibility to our children, as it does to any other, to see that they have an equal chance," Horne says. And sometimes, she says, the government must be reminded of that obligation.

Horne adds this caution: Parents should be wary of medical professionals who say they can cure an autistic child. With the help of true professionals, educational intervention can modify autistic behaviors, Horne says, but there is no cure.

Powers says little public awareness is another reason for the scarcity of help for people with autism.

The Autism Society of America provides information to increase people's knowledge of the disorder. The group also promotes advocacy, education, and research, and is organizing a panel of professionals to produce a list of resources, Horne says.

In addition, the group supports increased funding for the Center for Disease Control, which is studying the rise in diagnoses of autism and its related disorders.

And, she adds, word of mouth is powerful: It can lead families to explore new sources of help.

Horne says that while the lack of public awareness can be frustrating, it's important to be patient with service providers. Families of people with autism shouldn't assume that educators who don't provide services are shirking responsibility, she says.

"Districts can be responsive," she says. But, like people, Horne adds, "Sometimes schools aren't trying to get out of something — they just don't know."

To contact the Autism Society of America, call 1-800-3-AUTISM.

Where there's a will ...
Woman wages battle on autism for her son /5

