

Bringing Jodi back

Intensive therapy offers hope for autistic girl



DANIELLE P. RICHARDS/STAFF PHOTOGRAPHER

Jodi DiPiazza working with teacher Shannon Campbell at Alpine Learning Group. Therapy helps her pay attention to the world around her.

By **KATHLEEN CARROLL**
STAFF WRITER

Bee-bee-bee-beep! Bee-bee-bee-beep!

Jodi is sitting at a small desk directly opposite her teacher, who has set a kitchen timer for two minutes. The 4-year-old girl with eager green eyes and long brown curls hears the teacher call her name, so she stops fidgeting with her shirt, sits up and folds her hands in her lap.

If she can stay focused for these next two minutes – no touching her face, no gazing off into the dis-

tance – she'll earn a sticker. Three stickers and she'll get to play with her favorite princess dolls – for two minutes.

Jodi will spend this time studying photos of a classmate's family. Her teacher has asked her to identify each person's gender.

"Alright. Ready, we're going to look at pictures really fast," her teacher says.

"Here we go. Where's the girl? Point to the girl. Good! Touch the man. You're a smart girl, and I love how you're sitting."

Bee-bee-bee-beep! Bee-bee-bee-beep!

The timer goes off and the teacher exclaims, "Jodi! Guess what? You followed your rules.

What do you get?" "A sticker," the child says in a voice filled with enthusiasm, but so quiet it's nearly impossible to hear.

Her teacher sets the timer again – for another two minutes.

Jodi DiPiazza is autistic. For 11½ months a year, six hours a day, instructors at the

Alpine Learning Group in Paramus try to teach her to pay attention to the world around her so she can fit in and function in it – and not be a prisoner of her own mind. This behavior doesn't come naturally to Jodi, who lacks the curiosity or inclination to tune in to her surroundings all by herself.

In effect, the school is trying to retrain her young brain while it is still developing. Every moment is a precious opportunity to make a difference.

To do this, it uses an intensive, one-on-one therapy called Applied

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In autism's grip

Six-part special report

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4-year-old in desperate fight

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Behavior Analysis – or ABA – which teaches small, specific skills one at a time and reinforces them through frequent rewards until they become part of the child's routine. ABA is the most sought-after autism therapy in New Jersey, and the Alpine Learning Group is one of the top ABA schools in the country.

The teachers in Jodi's preschool class keep up a manic pace of drills – there can be up to 40 in a single day – to take advantage of the bouncing energy of their young students. While Jodi concentrates on her activity, her three classmates work with their own teachers in different corners of the room. They practice greeting each other, keeping eye contact and using pronouns.

There are beepers to time just about every exercise. Repetitive tasks. Constant small rewards. With every correct answer, students earn tickles and hugs and the tokens, like stickers or pennies, that eventually lead to free playtime or a sweet treat.

Jodi knows that she'll also be rewarded for every two minutes she keeps her attention focused. Periodically, the sound of the kitchen timers fills the room.

Bee-bee-bee-beep! Bee-bee-bee-beep!

It's time for a new lesson, Jodi's teacher says. Time to practice how to pretend.

Jodi has already mastered a catalog of appropriate "pretend" responses: When her teacher tells her to "pretend to be an airplane" she makes motor noises with her arms outstretched. She hops and says "ribbit" when she's told to "pretend to be a frog." And she makes "woo-woo" sounds like a siren for a fireman.

"I'm going to pretend to be a snake," her teacher says.

"I'm going to, to be a snake," Jodi repeats. She speaks in a lilting staccato, echoing her teacher's tone. Each syllable is a small bubble that pops just a little too soon.

Jodi gets down on the floor and looks up at her teacher, Nicole Scrivanich.

"Nicole, be a snake with me!"

"OK," says Nicole. "Ready on your belly! What do snakes do?"

"Slither on the floor," Jodi



DANIELLE P. RICHARDS/STAFF PHOTOGRAPHER

Jodi DiPiazza, with instructor Lauren Alexander, learning to overcome her fear of water. Jodi's parents want her therapists to test her limits.

replies.

They lay side by side on the floor and wriggle like snakes. For a moment, Jodi is a typical child doing a typically silly thing.

Jodi stopped talking soon after her first birthday.

She didn't walk until she was 16 months old, then seemed to have no common sense, no idea of danger. She'd climb up on the couch, stand there for a moment and take off walking, as if the couch would carry her across the room.

Her father was Jodi's shadow, constantly running through their house in Rochelle Park, holding out his arms to catch her.

The intense crying started when Jodi was anxious. A new outfit could set her off, especially one that was pulled on over her head. She would flap her hands, agitated and teary. When her dad sang to her, slightly off-key, she would claw at his face and scratch his lips.

Thinking back, her parents can see it clearly now, how their daughter was acting out a textbook guide to the disorder that hadn't yet been diagnosed. Her silence. Her anxiety. The way she walked on her tiptoes, ballerina-

like. The way her hands danced.

Still, Tom and Michelle DiPiazza weren't terribly worried, not yet. Jodi was just a baby. She seemed so happy. She smiled and laughed while she watched television – especially Barney, the singing purple dinosaur.

Jodi's pediatrician thought she might have a hearing problem and wrote a prescription to make sure her ears were clear. The DiPiazzas gave her the medicine for months and waited in vain for the words to return. But then Tom found a list of worrisome signs on a Web site about child development:

Not speaking. Failing to notice people. Staring at spinning objects.

Jodi. Jodi. Jodi.

They made an appointment at the Institute for Child Development at Hackensack University Medical Center. It was November 2003. The diagnosis came quickly.

Their 25-month-old daughter had autism. No cause, no cure.

"You'll have to fill your schedule," the doctors said.

What did that mean? they wondered.

The DiPiazzas followed a path familiar to many families of chil-

dren with autism: They began a panicked research effort to determine the best therapy for their daughter. It's impossible to know how far any child can progress. Some will never learn to speak; others may be able to lead ordinary adult lives. As many as half of all people with autism also have some degree of mental retardation.

New Jersey is rich in autism resources, with a growing number of public schools and top-flight private schools offering behavior therapy, speech therapy and play-based Floortime therapy. Each approach has its proponents.

But Applied Behavior Analysis has stood out as a beacon of hope for many. Its popularity grew after a 1987 study found that 40 hours a week of ABA – which is based on B.F. Skinner's theory that people's actions can be modified by altering their access to pleasurable things – helped half of a sample group of autistic children to function normally. A popular book among families of newly diagnosed children, "Let Me Hear Your Voice," is a mother's memoir of what she terms the "recovery" of her two autistic children after ABA therapy.

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Jodi's parents read the book. She soon began five hours of ABA therapy a week at home through the state's Early Intervention program.

The therapists immediately stormed Jodi's solitude — and the family home was filled with her cries. Jodi was protesting as she was pried from her interior world. Although the therapists were working to establish a trusting relationship, they also needed to withhold things from her, to force her to interact with her environment.

"I'll never forget. It was every Monday afternoon from 2 to 4. Every Sunday I would start getting sick to my stomach because I knew that the next day she would just be screaming for two hours," said Michelle.

A stubborn Jodi had met her match: The therapists cheerfully told her — and showed her — exactly what they wanted her to do.

She balked.

They told her again.

She tearfully refused.

They told her again.

And again.

And again.

And again.

Within weeks, Jodi began to respond to phrases such as "touch your head" and "tap the table" to earn her teachers' praise and gain access to her favorite toys. She couldn't speak, but she was listening.

She learned to sit at a small work table after a therapist stood behind her, preventing her from wiggling out of the seat. She learned to look at her therapist's face after the therapist placed her hands on either side of her head. The behavior was reinforced by praise like "Good sitting!" and "Nice looking!" and sweet or salty snacks.

Then she started to follow directions.

"Get ball," a therapist would say. At first, Jodi would do nothing — the phrase meant nothing to her.

The therapist would repeat the direction and walk Jodi over to the ball, guide her hand to hold the ball and congratulate her for getting the ball.

"Good! Excellent! That was getting ball!"

The direction was repeated dozens, or even hundreds, of times — however long it took for

Education options

ABA

Applied Behavior Analysis — the most popular approach in New Jersey's public and private schools — has three major components: teaching skills one step at a time, giving frequent positive reinforcement, and continuously collecting data and refining lessons. Most lessons include a specific request, the child's response, and a reaction and/or reward from the therapist. Children are expected to adjust their behavior to gain a reward — such as affectionate praise or a snack — and thus learn new skills.

More information:
abainternational.org

Floortime (also called Greenspan or DIR)

In Floortime, therapists sit on the floor, at the child's level, and follow his lead in learning activities. It focuses on emotional development as the way to improve children's cognitive and speech skills. Its creator, Stanley Greenspan, described six rungs on the developmental ladder, from interest in the world at a basic level to emotional ideas and thinking at the highest levels. Adults build on the child's interests to engage him or her in ever-higher levels of activities.

More information:
floortime.org

Statewide information

For a statewide list of school programs, and what approach is used in each, contact the New Jersey Center for Outreach and Services for the Autistic Community at njcosac.org or 800-4-AUTISM (800-428-8476).

Jodi to connect the activity with the phrase. When she learned to get the ball on her own, her teacher placed toys all over the room and asked Jodi to "get" them, too.

The child who wouldn't notice whether someone else was in the room was delighting in her teachers' praise and working hard to please them.

Her parents said she seemed to be waking up from a long sleep.

"After a session of ABA, she would seem alert later in the day," said Tom. "Some days she didn't get therapy and she didn't seem very alert. It seemed to turn her brain on. The more she worked,

TEACCH

The Treatment and Education of Autistic and Related Communication Handicapped Children centers on the uneven skill development and particular interests of autistic people. It assumes that autistic children must have a reason and a means to communicate and it respects the "culture of autism" by not teaching students to act "normal." Instead, TEACCH therapists build on an autistic person's narrow abilities — such as strong visual or memorization skills — to encourage wider understanding of how the world works.

More information:
teacch.com

Other methods

Children with autism may also receive occupational or speech therapy or learn to communicate by using technology. One common example is the Picture Exchange Communication System, or PECS, in which children who cannot speak use picture cards or printed sentences to communicate their needs. More high-tech options include voice output devices, which allow autistic people to "say" what they wish by pressing a few buttons and broadcasting the appropriate words.

Unnerved, Tom and Michelle started to mix up the letters to try to alter her routine. And so Tom was relieved some time later when he saw the letters spread out in no particular order.

But his sister stood before the same arrangement with a quizzical look.

"Why are you trying to teach her *that*?" she asked.

Teach her *what*? Tom wondered.

They fetched a computer keyboard and compared it to the letters arrayed on the floor.

It was a mirror image.



These were flashes into their daughter's world. She was noticing the things around her. She did see. She did understand.

Michelle and Tom soon increased Jodi's ABA therapy to 20 hours a week. The state helped offset some of the cost — families pay on a sliding scale, based on income — but it was still expensive. Therapists may charge anywhere from \$30 to \$120 per hour, depending on their experience.

"This is the hard way," Tom said about the ABA approach. "Your child cries and you have to fight through it. It's very expensive, and it's going to take a long time."

They had been worried about ABA, which has been criticized as teaching rote, robotic responses rather than true communication. Detractors say it is too demanding, particularly for children diagnosed when they are toddlers. Some recent research has found more modest success than the original study.

Would it really help if Jodi learned "touch your head" and earned an M&M? Was it worth subjecting her to hours of tears? They had seen a posting on the Web, from a mother who said her child developed post-traumatic stress disorder after ABA therapy. Some therapists even told them to limit the sessions to only a few hours a week, to avoid pushing Jodi too much.

But pushing was just what Jodi needed, they decided.

"It just became apparent, she needed strict therapies because that's where she would get her gains," said Tom. "Even while she was crying, she was interacting — which was something she had never done."

the smarter she got afterwards."

Jodi became interested in a set of colorful magnetic letters, which she moved around on the living room floor. One day, a pattern caught Michelle's eye. Shocked, she called a therapist over and they decided to make a quick test. They stuck a few letters on the front door, scattering them at random.

Jodi walked over and rearranged the letters.

BARNEY. The name of the singing purple dinosaur.

Jodi also began spelling out the alphabet, over and over, lining up the letters from A to Z.

Only thing was, no one had ever taught Jodi her ABCs.

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Michelle and Tom stopped themselves from interrupting lessons to comfort her. Michelle would walk outside into the yard so she couldn't hear Jodi's cries.

Because if Jodi wasn't forced to listen and pay attention, she would never make sense of the world. She wouldn't interact with people. She wouldn't ask for the things she wanted or be able to follow directions. Her anxiety would never ease.

She would never be happy.

Her parents would fight her for every word.

"With typical kids everything comes so natural, so easy," said Michelle. "You don't have to teach them how to say this or how to ask for that. When they see you say it, they automatically do it. I'll see a mother and child having a conversation – just anything, you know, 'Oh, Mommy, look, I dropped something.' I always wonder, do they know how special that is? Do they have any idea?"

"And they don't."



There is never a day of rest for the DiPiazas.

They have upended their professional lives to coordinate Jodi's care. Initially, Michelle took a leave of absence from her job as an assistant to the president of a cardboard box manufacturer in Fort Lee. Eventually, she was called back to work, and Tom, who works in sales for the same company, began to work from home in the afternoons.

They estimate they've spent \$40,000 to \$50,000 a year on therapists and nutritionists, toys, special food and other supplies – including a \$4,000 infrared sauna they installed in their home office to help Jodi sweat out toxic substances in her body, which some physicians feel may exacerbate autism. Costs have already surpassed the six-figure mark.

"It puts a lot of stress on everything – financially, everything," said Michelle. "We never have a few minutes to ourselves. Thank God we are who we are. I know a lot of marriages break up in times like this. We always say, 'We're Team Jodi.' We call ourselves that.

"Our one goal is to make sure that she's OK."

They admit that almost no one understands what they recognize



DANIELLE P. RICHARDS/STAFF PHOTOGRAPHER

Michelle DiPiazza at home with Jodi. "Our one goal is to make sure that she's OK," Michelle says.

as their life's work.

"They don't know it's a lifelong thing. My sisters, my brothers, they're like, 'Oh, how's Jodi? What does the doctor say?'" Michelle said.

"Yeah – it's like, 'How is she coming along? When is this going to be over?'" said Tom.

"Like she's going to get a pill or something and this is going to be gone," said Michelle.

"I guess we could hope for that," said Tom.

They laughed.

After more than a year of treatment, Jodi spoke. Out in the backyard, she sat down on a miniature porch swing, put on a safety belt and waited for a push. When none came, she took matters into her own hands.

"Swing," she said to her therapist.

The therapist pushed her back and forth. But then she stopped.

So Jodi asked again. "Swing."

She got what she wanted. And she learned: When I say "swing," I get a push.



Jodi enrolled in the Alpine Learning Group last year. It was a coup: The school has only 28 students – from preschoolers to 21-year-olds – and a waiting list of 300. Just a few precious spots open each year, when students age out or transfer to a regular public school; about 29 percent make that transition. Tuition costs \$78,200, not including transportation, and is paid by the students' local school districts.

Each student follows a curriculum developed just for him or her

and has a 6-inch black binder stuffed with performance data and progress reports. There are graphs that show which skills have been mastered and which need more practice. Teachers regularly visit families' homes and parents must sign off on every lesson and approve every reward.

Jodi's ABA routine spills over into every facet of her home life, too. Her parents pay ABA therapists to conduct two-hour sessions in the evenings and teach her how to swim. There is an ABA session to practice sitting in church on Sundays.

An Alpine Group therapist even visited at 6 a.m. one day to snap photographs of Jodi's morning schedule – all broken down by the therapist into specific tasks – and collected them in a small book for Jodi to use as a script each day:

Jodi waking up.

Jodi going to the bathroom.

Jodi eating breakfast.

Jodi getting dressed.

Jodi brushing her teeth.

One of Jodi's Alpine teachers leads a peer modeling session – sort of a regimented play date – with Jodi and her 6-year-old cousin Gia every Monday.

A recent afternoon found Gia and Jodi drawing together at a small desk in Jodi's room. It's a little girl's dream world, crammed with bins of toys and more than 50 stuffed animals. They shared a box of crayons and took turns deciding which shapes to draw.

Jodi decided they would draw a green circle. Her teacher prompted her twice to "tell Gia" – without the reminder, she would sim-

ply say "green circle" to no one in particular.

"Gia, draw a green circle," Jodi said. The girls both grabbed green crayons and circles appeared.

Then it was Gia's turn. She opted for a red heart. Jodi panicked. Her breath heaved and she began to cry a steady, high-pitched wail. A red heart was horribly, painfully wrong.

"I want to draw a blue square," she sobbed. She started to get out of her seat and search for another crayon.

Her teacher held the red crayon in her hand and told Jodi they must draw the heart. The cries grew louder as Jodi waved her arms in protest. The teacher quickly guided Jodi's hand through the motions of drawing a heart and congratulated her. She let her drop the crayon.

But Jodi was lost in her tantrum. Her teacher stood in front of her and distracted her to calm her down.

"Clap your hands," she said.

Jodi complied. Her face was smeared with tears, but she was interested in what her teacher had to say.

More directions followed: "Touch your head." "Touch your nose."

She touched her head and her nose.

"Good," her teacher said with an enormous smile. "Now, when you're quiet, you can draw your blue square."

Jodi began to wail again and so her teacher continued with the distractions.

Where do you live?

Jodi hiccupped and cried out, *Rochelle Park.*

How old are you?

Four.

Where do you go to school?

Alpine School.

What's your dog's name?

Skippy.

Her teacher gave her one last direction:

"Jodi, stop crying. Sit quietly like a big girl."

Jodi calmed down and got her blue crayon. She drew her blue square.

Tom walked in a moment later and said, "Oh, you're so quiet!" with delight. He looked at the teacher.

"I didn't come in until she stopped crying," he said. "I know the rules."

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Later that same day – after six hours of school and her afternoon date with Gia – Jodi sat perched in a booster seat at the kitchen table, looking worried. She squinted her eyes as hard as she could and covered them with her hands.

It was Monday. It was dinner-time. Her teacher was still there.

She knew what was coming.

Corn. Or peas.

Jodi likes to eat pureed baby food and her crunchy reward snacks. Nothing else. But her parents and her teachers have decided that it's time she learn to eat regular food.

So a few evenings each week, like this Monday, she must take a few bites of peas or corn.

She started to wail as soon as a laminated card and a pile of stickers appeared. She quieted down when another card with her rules for eating was placed in front of her. She read the rules aloud in a clear voice.

When I'm eating, I will:

1) Take a bite.

2) Put my food down.

3) Chew and swallow my food.

4) Take another bite after I swallow.

She followed the directions, spearing a piece of canned corn on her child-sized fork and gracefully placing it in her mouth. Every time she put the fork down, her therapist gave her a sticker and cheered her on.

Jodi was clearly uncomfortable, but she managed. Her final reward was a plate of the snacks she likes: veggie crisps and pretzels.

■ ■ ■

The next morning, the little girl who used to cry all day long, who couldn't tell anyone why she was sad, is back in her classroom. There will be more repetition. More tasks. More challenges. More rewards. More fun. And more *bee-bee-bee-beeps* of the kitchen timers telling her when she's done.

Before her diagnosis and ABA, she couldn't communicate with the world around her. When her parents plopped her in the backyard to play, she'd wave her arms in the air frantically and scream. She couldn't bear to touch the wet grass.

Her mom would tuck her in every night with the same words: "I love you more than the universe."

But Jodi couldn't say anything



DANIELLE P. RICHARDS/STAFF PHOTOGRAPHER

Jodi DiPiazza at her keyboard at home with teacher Courtney Berman. Jodi, who loves music, can tap out tunes and name the notes when the keys are hit at random.

in return.

Even a year ago, when the family vacationed at the beach in Wildwood, Jodi refused to touch dry sand. They went again this summer, and Jodi played on the beach and got covered in sand, just like a regular kid.

A year ago, too, her playtime was strictly controlled: She would pick an activity on a list of favorite games and spend a short time on it before she was given a token and told to pick the next game.

Now, she is starting to play on her own, without tokens, because she has learned to move from one activity to the next without losing focus and drifting off into her own world. Over time, she may not need constant schedules and visual reminders.

She is showing her talents.

This spring, she donned a yellow tutu and performed perfectly in her first dance recital, just another little ballerina alongside the others. She had attended the regular class but was guided by a teacher assigned just to her.

She can name the notes on the piano when her music therapist

hits them at random. The other day, she ran up to a keyboard after listening to classical music and played the basic tune.

She easily understands long sentences and can read just about anything that's put in front of her. No one taught her how.

"She can do things that no one can do, and then she can't do some of the most simple things," her father said.

She uses a laptop computer and has her own Web site, designed by her aunt, so she can link easily to her favorite games and family photos. She found a vocabulary-building Web site on her own and started using the new words:

She came home after a tantrum-filled day at school and announced "Grumpy – that means when you're in a bad mood." Up all night with croup, she declared "Frustrated – that means when you can't get what you want." She runs throughout the house saying "Gargantuan – that means really big and tall."

She doesn't cry anymore when it's time to put on a new outfit.

She seems happier, more able to navigate her world to her liking.

To her parents' amazement, she waved and greeted shoppers during a recent trip to the grocery store.

But she doesn't say much to anyone aside from "hi" because she doesn't know how to socialize. It's difficult for her to mix in with typical children. She may be able to attend a family gathering now without growing anxious and crying, but she is unable to communicate with the other children there.

At a birthday party last month, Tom and Michelle couldn't help noticing how very different she seemed from everyone else.

"She looks so autistic. You could just tell," said Michelle. "Here's all the kids playing, and there's Jodi. She did say 'hi' a couple of times to some of the kids, but that's all she would know how to say. They were playing games, and she wouldn't be able to understand that unless someone was there and explained it to her. It's just really sad. It was really upsetting."

Those moments slap them in the face: Wake up, they say to themselves. Stop dreaming of college and marriage and grandchildren. Our daughter is autistic.

Then a day later, Jodi astonishes them with a new phrase or skill and they stop thinking far into the future. The other week, when Tom picked her up from school, she ran up to him, said, "Hi, Daddy!" and jumped into his arms for a long hug.

Sitting around the supper table on a recent summer evening, Tom and Michelle marveled at how far Jodi had come.

"Jodi, tell Momma you love her," Tom said, cuddling his daughter into his chest.

She looked across the kitchen table. Michelle beamed with pride.

"Momma," she said, a series of fast-popping bubbles. "Open the door please."

She had reached for the wrong phrase. Tom smiled and tried again.

"Jodi, tell her," he said. He picked Jodi up like an airplane and piloted her into his wife's lap.

"Momma!" said Jodi, wrapping her arms around Michelle's neck and kissing her cheek.

"I love you more the universe."