

Boy's story sparks hope, skepticism in autism community

April 16 2009, By Jessica Meyers

The twiggy boy who greets strangers at his Cedar Hill, Texas, home with a handshake and an impish grin bears no resemblance to the toddler who shied away from contact, screamed when he had to walk down the stairs and spent hours staring at the ceiling fan.

Roman Scott's cheerfully innocuous disposition belies the whirlwind he's stirring in [autism](#) circles. He's the subject of his mother's book, which claims he overcame the disorder after her intensive 2½-year training program. "Raindrops on Roman" was released this month in conjunction with Autism Awareness Month.

On one level, Elizabeth Scott's account has stoked existing controversy among autism experts who question whether situations like Roman's are a promising development or a case of false hope. But it also reveals how limited services have forced parents into the unwitting role of therapist, caretaker and healer.

Texas is "on the bottom of the totem pole in terms of resources," said Michelle Guppy, who runs Texas Autism Advocacy, an online network intended to help parents navigate the state's bureaucracy.

Her 15-year-old autistic son waited eight years before he received services from the state. By that time, the family had gone \$60,000 into debt and had yanked him out of therapy.

"I could help one son now and that takes away college for the other and I

couldn't do that," said Guppy, who applauds the book's inspirational tone and instructive suggestions. "Who knows -- he could have been one of those recovered kids."

The Texas Health and Human Services Commission estimates that about 50,000 Texas children have a disorder related to autism.

Roman was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified at 18 months and autism at 3 years old. Both fall within the umbrella of autism spectrum disorders, with PDD-NOS considered milder. There are five types, which range from mild to severe and often involve problems with [social interaction](#), appropriate behavior, speech development and repeated compulsive actions.

The state-administered Early Childhood Intervention (ECI) program treats about 60,000 children with disabilities and developmental delays up to 3 years of age. Individual school districts take over with special education programs from age 3, but both systems have a shortage of professionals and inconsistent services.

Some children who have delayed speaking problems may only see a speech therapist twice a month, unlike in California, where regional centers offer a range of services to parents of autistic children. In Texas, parents wait up to 10 years for Medicaid programs that offer aid to people with mental disabilities.

The Texas Legislature passed a law two years ago mandating that insurance companies cover autism-related services for children between ages 3 and 5, but the coverage is often limited. Children often need therapy reinforced beyond this point, and that can cost upwards of \$50,000 a year and is generally out-of-pocket.

Unlike states such as California and Indiana, Texas has no central autism

resource center. Parents are left relying on each other to find out what's available.

That's largely what motivated Scott to write the memoir.

"If there is a story of recovery and this is it, then parents need to know about it," she said, as 7-year-old Roman alternated between building his Lego city and watching "Tom and Jerry" in the living room.

Scott, who has a master's in elementary education, said she had to try something as she watched Roman choke on his food, churn his hands in circles, throw tantrums at the sight of a camera, smack the television every morning or fight the sensation of a toothbrush.

"I needed to work all day to keep him from retreating into his own world," she said. "I ran the Boston Marathon, and that was cake compared to this."

Frustrated with only two hours a week of ECI therapy, she stopped working and dedicated herself to re-training her son. Her husband continued to work nights as a computer analyst for J.C. Penney.

She turned her sitting room into a work space with shoe-lacing activities and puzzles for fine motor skills, word charts for language development, and a spot for timeout. The "skills and drills" took at least 10 hours a day, from songs at breakfast to spelling in the bathtub at night.

Three months into the regime, Roman started talking. Then the recurring laps around the house stopped. Slowly, he started responding to the reading drills. By 4, he tested out of special education.

Roman's altered behavior did not go unnoticed.

"He has far surpassed any of the other kids I have ever seen," said Paige Garza, his preschool teacher and a neighbor who has witnessed all of Roman's stages. "Now he's a grown man in a little person's body. If I had met him today, I would never believe it."

She cited Roman's progress as her impetus for returning to school to focus on special education.

The word "cure" is considered taboo among researchers, and stories of recovery are rare. But they're not inconceivable for a disorder that affects one in 150 children in the United States. High-profile cases have inspired self-help books and made-for-TV movies. The Son-Rise Program and the Autism Treatment Center of America sprang from the apparent recovery of Raun Kaufman, an autistic child who stopped showing symptoms after his parents developed a comprehensive therapy program for him.

Actress Jenny McCarthy has garnered significant recent attention for autism recovery by claiming that a special diet helped her son cease his autistic behaviors.

Researchers warn against following these examples too closely.

"What is true for one child is not going to be true for most children for autism," said Susan Swedo, chief of pediatrics and the developmental neuropsychiatry branch at the National Institute of Mental Health. She has just begun a study on autism recovery.

While it's possible that children like Roman stop showing symptoms, it's also conceivable that they received a "squishy" or inaccurate diagnosis, she said. A behavior checklist rather than a medical test determines whether a child has an autism spectrum disorder. So if the child was having a bad day during the evaluation or has a general fear of strangers,

that can affect the results. She also noted that the previous behaviors could re-develop later in life in less structured settings, such as a junior high cafeteria.

Scott's repeated and rigorous training techniques resemble the most commonly accepted autism therapy, Applied Behavior Analysis, Swedo said. And they only could have helped in an area where so much rides on early intervention.

"The earlier you start, the more time you will have to be in therapy and won't get stuck in negative patterns," she said.

The American Academy of Pediatrics recommends autism screening as early as 18 months. The academy also encourages systematic activities for at least 25 hours a week even before a definitive diagnosis is made.

Most parents don't have this time or the financial means to focus solely on their children, said Dr. Doreen Granpeesheh, the founder of the California-based Center for Autism and Related Disorders.

"You're basically teaching a child a new communication system," she said, emphasizing that even several hours a day of structured one-on-one lessons from mom or dad can help a child under the age of 7. For the busy parent, she suggested paying a high school student to go over reasoning skills or asking a sibling to play games that require hand-eye coordination.

Granpeesheh endorses the notion that some children can recover from the disorder. She worked on the seminal 1987 autism treatment study that spanned two years and showed astounding progress in autistic children after 40 hours a week of behavioral therapy. Almost half of the children tested normally when the study ended. She has continued her own research, and completed a documentary last year that featured four

children who, like Roman, no longer show signs of autism.

Autism studies are gaining more ground as the word enters the mainstream. The National Institutes of Health will commit about \$60 million from the stimulus package toward autism research, the most funding to date. The Texas Department of Assistive and Rehabilitative Services started a pilot program last April that gives \$5 million to four Texas agencies devoted to [autism spectrum disorders](#) and behavioral therapy.

In the meantime, parents search for reassurance, advice and clarity for this perplexing condition and its myriad forms.

"We've ordered a couple of copies (of Scott's book) for the family," said Kimberly Henderson, a St. Louis resident whose 2-year-old son has developmental delays and is undergoing testing. She squeezes in lessons when she gets home from work at 6 until bedtime. "I use it as my textbook. Knowing that she has overcome this is important to me."

Roman also knows his mother has written a book about him but doesn't fully understand why. He still exhibits a few quirks. He understands comments on a more literal level than most kids and hates the texture of almost all foods, but he already has "a million girlfriends."

He has plans to be an architect, once he makes it through first grade.

AUTISM RED FLAGS, TREATMENT TIPS

'Red flags'

- Does not make eye contact or interact with other children

- Does not react to smiling and is resistant to change
- Is unusually attached to certain objects; excessively lines up toys
- Is prone to tantrums
- Does not babble, coo or make meaningful gestures (pointing, waving, grasping, etc.) by 1 year
- Engages in repetitive behaviors (hand twirling, flapping)
- Is oversensitive or undersensitive to pain
- Has fine or gross motor problems

TREATMENT TIPS FROM ELIZABETH SCOTT

1. Stop repeated behaviors: Count down to warn the child to stop a repeated habit, then replace it with a toy or activity.
2. Focusing: Have the child sit at a small table and participate in a variety of activities (shape sorter, Play-Doh, arts and crafts) for one to two minutes. Increase the time per activity over weeks. Use a timer and lots of language to keep the child talking.
3. Daily living activities: Incorporate skills into regular activities such as feeding, bathing and driving. Have a "goodie bag" of stuffed animals, squishy balls and flash cards. When the child is done with one toy, hand the child another. Interact using the toy. This will keep the child focused on something purposeful even while you are doing your daily routines.

4. Improving fine motor and gross motor skills: Have the child lace pictures, play with beads, use stamps, and do stacking and sorting. Increase gross coordination with activities such as tunnel play, rolling and throwing a ball, basketball shots, bowling and using playground apparatus.

Sources: Autism Society of America; National Institute of Child Health and Human Development

(c) 2009, The Dallas Morning News.

Visit The Dallas Morning News on the World Wide Web at

www.dallasnews.com/

Distributed by McClatchy-Tribune Information Services.

Citation: Boy's story sparks hope, skepticism in autism community (2009, April 16) retrieved 25 April 2024 from <https://medicalxpress.com/news/2009-04-boy-story-skepticism-autism.html>

<p>This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.</p>
--