

'Fresh start' begins for a life with autism

Ralph Savarese's book, "Reasonable People: A Memoir of Autism & Adoption," depicts obstacles facing his son.

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Grinnell, Ia. - I reached the elegant 1896 home of Ralph Savarese early and circled the block past Grinnell College, wondering why I was anxious about going in.

I'd done thousands of interviews over the years with arrogant doctors and lawyers, media-weary celebrities and politicians, threatening convicts and crack addicts on the street.

Savarese is a creative-writing professor at the college, but the atmosphere would be thick with expectations. He is sensitive to how others speak to his son and how they generalize about his disability.

Son DJ, 15, would be coming home shortly from his second day of the new school year. He has autism.

DJ is the centerpiece of Savarese's powerful new book, "Reasonable People: A Memoir of Autism & Adoption." Its premise appeared made for Disney. Savarese chronicled how he and wife Emily adopted a 6-year-old boy with autism so severe that he wore diapers and responded little to communication.

The story was far from Disney.

Savarese laid out in raw detail the nine-year struggle to help a boy communicate and function, to go to school and have friends, to trust the world again after his abuse in foster care.

Along the way, Savarese railed against injustice to disabled people, against even the professionally recognized categorization of autism on a scale of "low functioning" to "high functioning," and the notion that the greatest goal is to "cure" autism. He sees it as a gift.

"We give up on all sorts of people," he said in a National Public Radio interview.

He wrote an essay for the Los Angeles Times urging Americans to adopt the half-million special-needs children instead of traveling overseas to find kids.

He recoiled at the word "normal," preferring "neurotypical."

I wondered whether I would use the wrong words.

But perhaps the real anxiety was talking with a young boy who is both astounding and puzzling, a boy who had just come to life over 442 pages, a boy with keen insight and

unpredictable meltdowns.

By the time I walked in, Savarese was, in his words, highly revved himself. He began talking nonstop about his journey with DJ, the greatest experience of his life.

Progress chronicled, but anger, too

At its simplest, the story is of a boy raised by an abusive mother whose five children were taken by the state of Florida. Savarese's wife, Emily, worked with disabled children, including DJ. The couple didn't have children and immediately bonded with him.

Their quest to adopt DJ fills nearly the first third of the book, between commentary on the failed foster care system, philosophical arguments over personal and social responsibility, and examination of the controversy over the ability of a child with severe autism to communicate.

In the last two-thirds of the book we see DJ come to life after painstaking months and years of learning words through pictures, then using facilitated communication to converse by pointing to words and letters on a keyboard.

It was painful and challenging. Savarese doesn't sugarcoat anything, including his own cranky thoughts.

He rails against his own rich father for his failings, his sister for her self-centered ways, society for its cruelty to the disabled and even himself for the anger toward those who had done the young boy wrong.

"The editor asked me to be more sentimental in the book," Savarese said. "But I didn't want to be the designated do-gooder. I'm not that good. It's too easy to then say a few will do good while the rest are on holiday."

DJ was literally thrown away by society, like many with autism. Those with the developmental disorder characterized by difficulty with language, emotions and compulsiveness were labeled a "black hole," with little understanding of what goes in and an inability to let anything out.

In DJ, the Savareses saw a life in the balance, another kid who would be tossed away.

After several visits to the DJ who was in foster care, the Savareses got a call from the hospital. DJ had been beaten by another foster child in the home, a 13-year-old boy.

At the hospital, DJ made a hand sign to Savarese, one he had learned in prior visits, that meant "more, more." He was pleading for tickling.

Savarese had to search for a spot without bruises.

"How could we walk away from that?" he said.

Symbols, a partner aid communication

DJ enters the room wearing his backpack, his mother at his side. When the family moved to Grinnell in 2001, she gave up her career to work at DJ's side so he could attend regular school classrooms.

She taught DJ facilitated communication. The child points to pictures, symbols or letters to communicate, using a partner for support. That often involves holding a hand or touching the child as he points.

The method became controversial in the 1990s. Some research surmised it was a hoax - that the partner was guiding the child's hand to letters.

Savarese said that more in-depth research in the last few years has proved the method is authentic. Some with autism are even independently typing now in college.

Experts are unsure how it works.

"It doesn't make sense to you and me, but touch helps them focus," said Christi Kasa-Henderickson, who worked with DJ while at the University of Northern Iowa. She now teaches special education at the University of Colorado.

More people are using facilitated communication today at the same time that the diagnosis of autism is at an all-time high - 1 in 150 children, an increase that also remains a mystery, she said.

The publisher sent a representative to Iowa to check on the authenticity of DJ's communication.

"I understand," Savarese said. "We live in a culture of hoaxes."

DJ was no hoax. He sat at his mother's side on the sofa. She gripped one end of a pencil and DJ held the other and began to answer questions.

I asked how he liked the book.

"Yes. Plotting to write my own book," he said, a computer voice transmitting his typing.

I asked what he would write about.

"Young kids deserve a regular education."

He was saying that kids with autism should learn alongside the "neurotypical." He is a straight-A student now in a regular ninth-grade classroom. His method of communication has allowed others to see an autistic mind at work.

"Yes, I kill my autism by typing," DJ said.

Between typing, DJ obsessively touched my pen as I wrote, before his parents called him back to task. He squealed and rose to pace the room, flapping his arms, before gently being told to focus.

Then he typed: "My mean self is here."

From dissecting past to looking forward

The task of teaching language to a child with autism is difficult, to say the least. There are frequent outbursts from anxiety. The Savarese family called it "poking," and at times it was violent.

As DJ came to language, he also was faced with communicating his past.

He was sexually abused in foster care by an older foster child. He suffered severe insecurity about losing his adoptive parents.

At points in the book, the pressure is almost unbearable. Savarese and his wife are at odds, and DJ encounters anxious moments by wildly thrashing at his parents.

The parents wrestled with approaches, moving from traditional psychotherapy, which talks out the past trauma, to urging DJ to be positive and forward-looking. He had become stuck in his own hurt.

But they also saw a young man develop with a keen sensitivity to others and poetic expressions.

When Savarese's young nephew dies of cancer, DJ faces his grieving aunt by going to his typing machine immediately.

"Do you have reasonable people to help you with your hurt?"

His aunt still has the slip of paper emitted from the typing machine and carries it with her.

Savarese used the word to snap his son out of his compulsive behaviors - "Be reasonable." But it also took on larger meanings, a political urging to society for reasonable behavior toward those who are different.

DJ wants to help other kids now, as a "political freedom fighter," while waging his private battles.

"Yes, hoping to get free of anxiety but not there yet," he said.

He is asked again about his writing, his poetry on the Web site www.reasonable-people.com .

"Yes, love to get free of the terrifying anxiety. Hear real self," he said.

Using language to erase anxiety

Savarese constructed a large building in his backyard to hold an indoor trampoline. Jumping with others has become the physical play that connects DJ to his parents and to friends.

He jumps high and around the trampoline with his father. Then he has a meltdown, squealing loudly. Savarese pins him down.

"You've got to be positive," he tells him gently. "You can do it. This is what we've been working on. You've got to deal with nervousness in a positive way."

DJ's anxiety has many colors. He was anxious about the book, saying he resents "these very hurtful conversations being easy reading for everyone." He is anxious about his place in the world, growing older and struggling with independence.

When asked what he loves about his parents, he says: "Yes, treated with respect for first time in my life. Yes, lose them and I lose everything."

His parents assure him that they will always be there for him. They have encouraged him to type independently, and Savarese even saw him doing it once.

They constantly encourage him to use his gifts. He has already signed with a New York literary agent. He wants to change the world's view of the capabilities of people with autism.

"I hesitate," DJ says. "Frees (a word for "neurotypical") don't hear much of my plotting hopeful responsible respectful thoughts."

But after his successful inclusion in the Grinnell schools, buoyed by students eager to be his friend and helpful teachers' aides and the nationwide publicity he has received from this book, the "frees" now hear his thoughts.

He is a boy who can't talk but communicates like few do.

There is no need to be nervous. Savarese wrote that language can help erase the anxiety caused by differences in people.

Language unlocked his son.

The last words in the book are DJ's, a letter to teachers at a specialized school in Florida before he was adopted, before he came to life.

"Quite pleased that you are respecting and reading this tested-as-smart, growing up better boy's resentment. I live in constant fear that respect will be taken away, and I will have to return to easy years of doing nothing.... Fear wakes easy lessons, and I get mad. I want you to know that easy effort estimates kids as retarded when they're smart.... Reasonable people should each see what they can do to free people who really can understand."

And then he concludes:

"Until I freed myself through writing, people thought I had no mind. Freeing kids who are estimated as retarded is my hope for the future. Years of fresh start have begun!

Your respectful student,

DJ Savarese