

# Home Is Where The Heart Is

**The Savarese family thought they were autism experts — and then they adopted DJ.**

## **WEB-EXCLUSIVE COMMENTARY**

**By Eve Conant**

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May 4, 2007 - We're told to pick our battles if we want to make a difference in the world. Activist and writer Ralph James Savarese thought he and his wife, Emily, had done just that. For her it meant working with a Florida center for disabled and autistic children. For him it meant writing and teaching college students about responsibility and social obligation. But in the late '90s they found themselves forgoing these larger causes for the smaller one staring them right in the face: an abused, autistic toddler named DJ.

The American Psychiatric Association describes autism as a disorder of impaired communication and social skills (including the delay or total lack of spoken language) and restricted or repetitive behavior such as flapping of the hands. But that view, argues Savarese in "Reasonable People: a Memoir of Autism and Adoption," robs people with autism of their humanity and in return offers little hope. "To many experts, the non-speaking autist resembles the old version of a black hole: swallowing everything, emitting nothing; forever hidden, never to be revealed." Are we giving up too early on those with classic autism, he asks? Or could it be that an autist's inner world, dynamic and profoundly human, can be made accessible if society is willing to make a reasonable effort to help it bloom?

The couple is first acquainted with the blond, curly-haired DJ when he is 3 years old and foundering in foster care. Emily works with DJ, whom she meets at her center, even though he's been written off as profoundly retarded. She also tries, and fails, to get DJ's alcoholic mother back on her feet. When DJ is severely beaten at his foster home, a caseworker begs the Savareses to provide emergency shelter. What follows is both a real-life love story and an urgent manifesto for the rights of people with neurological differences. Savarese is honest about both his own fears and how DJ is capable of plunging even the most dedicated and high-minded adult into despair. But three years and countless bureaucratic hurdles later, the Savarese family finally extracts DJ from foster care and formally adopts him.

Their aims are lofty. First, DJ's is an "open adoption," meaning that visits from his older sister or other family members are encouraged. Second, Savarese and his wife are proponents of a controversial educational method called "inclusion." With the help of on-site personal aides, they manage to include DJ in regular classrooms in Florida and then Iowa. They tirelessly urge others to open their hearts and minds to the "creative potential" of DJ's disease, even though he might flap his arms, use his head as a battering ram and scream uncontrollably. Through the much-maligned keyboard technique of "facilitated communication," they help DJ make his first forays into language. At first the parents do much of the typing themselves; within a few years they are offering DJ only minimal support at the wrist. He has much to share, including a heartbreaking, garbled tale of abandonment and sexual abuse.

Savarese is a thorough chronicler of both DJ's progress and the current thinking on autism. At times his writing can be overly academic, but not when it comes to detailing DJ's life and the ease with which disabled children are often written off. In foster care DJ was denied glasses--the doctor thought he was too severely disabled for improved vision to make a difference. So he has difficulty with tasks requiring hand-eye coordination--he does puzzles entirely by touch--until his adoptive parents figured out the problem. At first the simplest word in sign language took months to perfect. Yet by the end of Savarese's moving memoir, DJ is in sixth grade and getting all "A's" at a regular school. "DJ's autism remains--in all of its sometimes marvelous, sometimes aggravating, splendor," writes Savarese. "He hasn't been cured." Nor has he conquered many troubling habits, such as poking people in the eyes. But the sixth-grader writes the memoir's last chapter himself, with only minimal assistance. There are typos and DJ's language is often inscrutable. But his words are evidence of qualities once thought impossible for the boy: a sense of self and a concern for others. "They think well-respected, tested-as-normal kids are the OK-to-teach ones," writes DJ. "They forget these lost kids." Perhaps this book will help others remember they are more than worth the effort.