

A history of autism developments



**ASSIGN
BUSTER**

In Autistic Space

Temple Grandin is a professor of animal science at Colorado State University, and consultant to the livestock industry on animal behavior. She completed her PhD in Animal Science at the University of Illinois in Urbana and invented the “ hug box”, a device to calm those on the autism spectrum. She is one of the first individuals on the autism spectrum to publicly share insights from her personal experience of autism.

Grandin was diagnosed with “ brain damage” when she was two. She could not speak until age three and struggled with severe behavioral issues through her teens. She thanked her mother who never lost faith in her and fought many battles to ensure that she got an education, and her high school science teacher, William Carlock, who built up her confidence and channeled her teenage fascination with cows into a career in animal science.

At the University, she came to see her profound emotional connection with animals as autistic, and crucial for her work. In May 1989, she moderated a round table discussion at the conference of autism professionals and educators in Chapel Hill, North Carolina. Her presentation prompted Rimland to introduce her 1986 memoir, *Emergence*, as “ the first book written by a recovered autistic individual.” By then, she was on her way to becoming the most recognized autistic people on earth.

In his 1995 book *An Anthropologist on Mars*, neurologist Oliver Sacks depicted Grandin as a mature autistic person with a complex inner life. The title of his book was inspired by Grandin when she said all her life she felt like an anthropologist observing human interactions from a distance. But by

now, Grandin wouldn't consider herself as a "recovered autistic." "Autism is part of who I am," she told Sacks, "If I could snap my fingers and be non-autistic, I would not, because then I wouldn't be me."

But Grandin's perspective did not take root among the advocacy organizations. When parent-run advocacy organizations get online in the 1990s, they continued to feature images of children on their websites, as if autistic adults didn't exist. The presentation at conferences dwelled on the usual deficits and impairments, rather than on exploring the atypical gifts that Grandin found so useful in her work.

Jim Sinclair, a young man in the audience, determined to change that. Besides being on the spectrum, Sinclair was born with the physical characteristics of both genders. His parents had raised him as female on the advice of their doctor, but he had never felt female. He was speaking in echolalia until he was twelve. The complex rules of the social world seemed incomprehensible to him when he was a teenager. By the time he was in graduate school, his efforts to pass as non-autistic fell apart.

When Sinclair saw *Portrait of an Autistic Young Man*, he had a profound sense of recognition. He could see what the experts in the film could not see: that Joseph was trying to communicate through his behavior. He wanted to connect with other autistic people, so he subscribed to a quarterly publication called the MAAP (for "more able autistic people") and submitted poems and letters to the editor hoping his peers would contact him.

One of Sinclair's poems attracted Gary Mesibov's attention. Mesibov, a cofounder of TEACCH, offered Sinclair a scholarship to attend the Chapel Hill

conference and write an essay about his experience. Sinclair's essay on the conference appeared in a TEACCH anthology along with contributions from Lorna Wing and Catherine Lord.

A year later, Sinclair was invited to sit on a panel in California by the Autism Society of America. He felt like a “ self-narrating zoo exhibit.” Rather than being the token autistic on a panel at a conference in Indianapolis, Sinclair conspired with other members of the MAAP list to make their presence visible throughout the proceedings. Each of them would make a point of raising their hands during the Q&A sessions, identifying themselves as autistic people, and then asked questions or make a relevant comment so that people would notice they were there.

In 1992, Sinclair launched the first autistic-run organization in history, called *Autism Network International* (ANI), with Donna Williams and Kathy Lissner. ANI would stand up for the civil rights and self-determination of people all across the spectrum. ANI organized its first Autreat at Camp Bristol Hills in Canandaigua, New York, in July 1996. The theme of the conference was “ *Celebrating Autistic Culture* .” Autreat became an annual event and provided a template for similar conferences in other countries.

A new idea was brewing in the autistic community. It turned out to be an old idea from Asperger that people with the traits of his syndrome have always been part of the human community, standing apart, making the world a

better place. In the late 1990s, Judy Singer, an autistic student of anthropology and sociology in Australia called it *neurodiversity* .

After her daughter’s diagnosis of Asperger syndrome at age nine, Singer recognized autistic traits in herself. She joined a mailing list called *Independent Living on the Autism Spectrum (InLv)*. People with dyslexia, ADHD, and other conditions were also welcome to join the list. It was in telephone conversations with Harvey Blume, a list member and writer in the New York Times, that Singer came up with the term *neurodiversity* .

In 2004, two teenagers named Alex Plank and Dan Grover launched Wrong Planet, one of the first autistic spaces in the internet. They were both digital natives with Asperger syndrome. The community grew slowly and steadily at first, and then it went viral with Plank’s interview with Bram Cohen, the autistic creator of BitTorrent.

In December 2007, a series of billboards appeared on street corners in Manhattan. One ad read, “ We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the beginning.” These ads were sponsored by the Child Study Center (CSC) of New York University to alert the public to the “ silent public health epidemic” of childhood mental illness. Then from out of nowhere, an organization called the *Autistic Self-Advocacy Network (ASAN)* along with outraged parents and prominent disability rights groups launched a storm of

e-mails and blogs in NYU's direction objecting to the demeaning wording of the ads. This is the first time in history that autistics were challenging the mainstream media without the help of a parent-run organization.

The architect of the protest was a nineteen-year-old cofounder of the ASAN named Ari Ne'eman. Ne'eman was diagnosed with Asperger syndrome when he was twelve years old. On December 6, the day after the CSC's ad campaign, Ne'eman called the CSC expressing his concerns and left phone messages, but got no reply. Two days later, ASAN blasted out an action alert. The next day when the major media outlets were running stories on the controversy, the CSC agreed to pull the ads.

In 2010, President Obama nominated Ne'eman to the National Council on Disability (NCS). In recent years, the ASAN had played a significant role in formulating the federal disability policy.

For parents like Craig and Shannon Rosa, the neurodiversity movement has offered ways of fighting for a better future for their children that don't depend on hopes of recovery. One of the most important lessons they had learned on their journey with Leo is patience. They have to accept that he is unfolding at his own pace. Shannon and her circle of friends launched a website called *Thinking Person's Guide to Autism* for parents just starting out on the journey so that they don't have to go through the ordeal that the Rosas did.