

Autism and Mental Illness

Summarized by Thomas T. Thomas

We find increasing mention of the autism diagnosis coming up in our NAMI East Bay support groups for families with a relative with mental illness, and this poses questions about diagnosis, resources, and further exploration. Our June speaker was **Professor Alison Morantz** from Stanford Law School. As Director of the [Stanford Intellectual and Developmental Disabilities Law and Policy Project](#), she teaches mental health law. (Next month's Speaker Meeting will host a genetic researcher who will discuss her area as it applies to mental illness and autism.)

At our meeting, Morantz told the story of her son Micah, now age 21. He seemed normal as a baby, with no particular red flags for emotional or intellectual development. He was verbal, bright, and conversational, but there were subtle indications including a lack of social reciprocity. At age three, he was diagnosed as autistic under the criteria of the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV), which have since been updated.

"Things have changed a lot since then," she said. It is no longer "an autism" but a plurality, with many pathways leading to the condition. And doctors are still diagnosing it by symptoms rather than by biomarkers. For example, there is a condition called "fragile X"—a mutation on the X chromosome that prevents the brain from producing a protein needed for normal development—but some people with the condition develop autism while others don't. "Definitional issues are contentious," she said, "and there's a lot of variability in consistency of diagnosis."

Often people with autism appear to have intellectual disabilities. But then there is Asperger's syndrome, where people—often of high intellectual capacity, such as university physics professors—have social impairments but are not intellectually disabled. Now the current version of the manual, DSM-V TR, differentiates Asperger's from autism. But still, it's common for autism patients to have social and communication effects. In the midst of this distinction the term "profound autism" arises.

The issue has become politicized, with well-resourced advocacy groups speaking out for change. And self-advocacy—under the banner "Nothing about us without us"—has become common. But many people with autism and intellectual development issues can't communicate verbally and aren't as well equipped to navigate the political world that distributes aid dollars. People with high support needs—who used to be called "low functioning"—are usually those who can't communicate. And parents of children with autism are just getting through the day helping them.

Morantz's son at age three was verbal and not intellectually disabled, but he was very oppositional. He once said that he thought reality should bend to his will. Over the next five years, he became physically assaultive, with property destruction and feces smearing to show his defiance. He wouldn't do anything anyone asked of him, including dressing himself to go outside.

Morantz and her husband tried every approach at home. They tried the therapy recommended by Applied Behavior Analysis, with four hours of daily sessions five

days a week that mixed skill building, play, and scheduled breaks—but to no effect. Micah became a “scary seven-year-old. He said he believed adults lie and you can’t trust them. He said his sister needed to be killed.

At age eight, the family tried in-patient assessment and hospitalization. People with autism and developmental disabilities generally get services through a community-based, state-funded regional center, covered by insurance and Medicaid/Medi-Cal funding. The family tried the local center but without success. They did get a comprehensive assessment at a center in Salt Lake City.

At age 8-1/2, the boy suffered a psychotic break, went non-verbal or spoke in “word salads,” and experienced an IQ drop from about 115 to about 40 or 50. He spent years in psychiatric hospitals. He was diagnosed as possibly schizophrenic and put on five different antipsychotics, although schizophrenia in one so young is rare. He was put on Clozapine at a high dose for three years, and that seemed to help, but the improvement may have been due to his clinical program.

At Stanford Hospital, he was diagnosed with pediatric acute-onset neuropsychiatric syndrome (PANS), which is caused by a virus that penetrates the blood-brain barrier, causes inflammation, and leads to intellectual deficits. The treatment is with antibiotics, but in Micah’s case it was not effective. He was still violent and assaultive.

The Palo Alto regional center determined that Micah needed his own program. Morantz went to the head of the California Department of Developmental Services and worked out a plan where the boy would be attended by three people at all times. The family would provide these services at home—a first in California. They bought and prepared a house for this and began their around-the-clock program. Ten years later, Micah is down to only two caregivers at one time, but he is still significantly intellectually disabled.

Morantz pointed out that a conservatorship for intellectual and developmental disabilities (IDD) is different from a conservatorship for a serious mental illness (SMI). But in either case, if the parent is the trustee, a judge can remove him or her and appoint a paid conservator. Morantz and her husband instead formed a company to provide support for their son without a conservatorship—which was possible since he was not an adult who could challenge his treatment. They have a power of attorney and other measures in place that Micah signed when he was 18.

The law under MediCal also allows a waiver for a Self-Determination Program (SDP), which enables patients and their families to control the funds provided so they can live at home and in the community rather than at an institution. And since 2013, the program has been made more robust, including self-directed services so that patients—especially those with physical disabilities—have more flexibility in spending on hiring help and budgeting for needs.

Morantz has been a founding member of [Disability Voices United](#), representing self-advocates with lived experience, to effect some of these programs.

Today, although Micah is still disabled and needs care, he is out in the community, has a peer group, likes vacations and hotels, likes cooking, and earns tickets from his caregivers through good behavior to get the things he wants.

You can read more about Alison Morantz or contact her through her webpage: <https://law.stanford.edu/alison-d-morantz/>.