

NEWS

Specialty clinics offer complete care for adults with autism

BY JESSICA WRIGHT

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Logan Madsen is an artist with Miller syndrome, a rare genetic condition marked by limb deformities (he has eight fingers and eight toes), hearing impairment, breathing difficulties and painful joint problems. He also has autism and severe depression.

Madsen, 37, had been seeing a psychiatrist for the depression since he was 13 years old, but wasn't diagnosed with autism until he was in his mid-20s. His various doctors often failed to take into account his spectrum of conditions. One of them prescribed Percocet (a combination of acetaminophen and oxycodone) for pain in his spine, not considering the addiction risk. At one point, he was taking up to eight Percocet pills a day — a dangerous dose.

Finally, in 2007, Madsen discovered the Neurobehavior **Healthy Outcomes Medical Excellence (HOME)** program at the University of Utah in Salt Lake City, where he lives. The program coordinates all aspects of medical care, from annual physicals to weekly psychiatric checkups, for children and adults with neurobehavioral conditions. About half of the participants enrolled in the program have autism, including 549 adults.

“Especially in adults with autism, there’s a lot of medical problems and a lot of psychiatric problems,” says **Kyle Jones**, director of primary care at the program. “So being able to work in close proximity and integrate the care for the individual and the caregiver helps so much. It’s huge.”

The program is one of a few attempting to fill gaps in healthcare for adults with autism. In another approach, researchers have developed an **online tool kit** designed to improve the relationship between adults with autism and their primary care providers.

Studies show that adults with autism are more likely than those in the general population to have health conditions, such as type 2 diabetes or heart disease, that **could be managed** with good

preventive healthcare. And primary care doctors **admit to being ill-equipped** to address the needs of people with autism.

“I didn’t get any training on autism,” says **Christina Nicolaidis**, a primary care doctor and associate professor at Oregon Health & Science University who is working on ways to improve primary care for adults with autism. “I struggled patient by patient, figuring out what works for each one.”

Consolidated care:

Neurobehavior HOME started in 2000 after its founders received a federal grant, along with money from Utah’s Medicaid program, to blend medical and psychiatric care for people with developmental disabilities. The funding provides a set amount of money each month for each individual, allowing the doctors to use it at their discretion. “If the typical insurance won’t cover eye glasses, but we know that helping someone see is going to help their behavior, we can pay for that,” says Jones. “We can get creative.”

The program provides each individual with a case manager who helps to schedule her appointments. In one visit to the clinic, an adult can see a general practitioner, psychiatrist and dietitian and get assistance with insurance claims.

Jones, a family physician, spends a full hour with each person. This allows him to uncover medical issues that people with autism may not readily communicate. He has learned, for example, that constipation is common in adults with autism, particularly those who take antipsychotic drugs. Severe constipation often manifests as behavioral problems, he has found.

Adults who are unable to communicate their discomfort may attack themselves or others, or run away. “When our patients come in presenting in that way, to us it’s constipation until proven otherwise,” he says.

Because the program specializes in adults with developmental difficulties, it also provides an easy transition out of pediatric care, which is often difficult for people with autism to navigate. A study looking at the insurance records of more than 16,000 young adults with autism, aged 16 to 23, found that their use of healthcare services outside of the emergency room declined notably with age¹.

Spreading the word:

Jones says hospitals from other states would like to replicate the Neurobehavior HOME program but lack the funding. Mount Sinai Medical Center in Miami, Florida, opened a clinic for adults with autism in January, using funds from a private donor. Its Adult Autism Clinic employs primary care doctors, a neurologist, a cardiologist and a gastroenterologist, all of whom are specially trained to

work with people on the spectrum. The waiting room has relaxation aids, such as noise-canceling headphones.

“We try to reduce the anxiety, as well as the difficulties in trying to care for patients with autism,” says **Elizabeth Kury-Perez**, the clinic director.

An alternative to such integrated centers might be to systematically train primary care doctors to work with adults on the spectrum. But that solution is impractical, Nicolaidis says. Most doctors are unlikely to undergo specialized training for the few individuals they see with the condition.

Even if doctors were willing to put in the time, the training is unlikely to be sufficient, given how diverse autism is. “I can’t tell them to do x, y, z for every autistic patient, because autism is so heterogeneous,” Nicolaidis says.

As the next-best solution, Nicolaidis and her colleagues have developed a healthcare tool kit for adults with autism and their primary care providers. This online resource offers health, legal and ethical information, as well as other helpful materials, for adults with autism. It includes worksheets designed to help them schedule doctor’s appointments, for example, or prepare for a wait prior to an appointment.

It also features an online questionnaire that adults with autism or their caregivers can fill out before their visit to help doctors tailor treatments. For example, a person can indicate whether it bothers him if a doctor stands too close.

Nicolaidis and her team tested the tool in 259 adults and 51 primary care providers. They found that for those with autism, overall satisfaction with healthcare improved one month after providing the tool kit to their doctors². A study of 14 clinics, half of which have access to the tool kit, and 3 large healthcare providers is underway. The goal is to integrate the tool kit into primary care.

Before the Neurobehavior HOME program, Madsen says he spent a significant portion of each medical visit trying to bring doctors up to speed on his different conditions. His sister Heather, who also has autism and Miller syndrome and participates in Neurobehavior HOME, had the same experience. “We had to educate every doctor that we went to; we had to be doctors to all the doctors,” Madsen says.

Finding doctors who could monitor his medical needs was a turning point for Madsen. His current psychiatrist, for example, has found a combination of medications that can safely manage his pain and depression. He still struggles with anxiety, he says, but his weekly visits give him the reassurance he needs to stay stable.

REFERENCES:

1. Nathenson R.A. and B. Zablotzky *Psychiatr. Serv.* Epub ahead of print (2017) [PubMed](#)
2. Nicolaidis C. *et al. J. Gen. Intern. Med.* **31**, 1180-1189 (2016) [PubMed](#)