

OPINION, VIEWPOINT

Clinicians must put more effort into autism-specific medical care

BY SHANNON DES ROCHES ROSA

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My high-support adult autistic son's many medical appointments have become routine. Even so, I broke into sobs during a recent session. Despite years of consults and procedures, no one seems to know how to treat his debilitating headaches. Not because potentially effective treatments don't exist — they do — but because none are accessible to an autistic person with his sensory and developmental traits.

I am begging the autism research and clinical community: Please put more efforts into autism-specific medical accommodations and training so that people like my son can get the medical care they need.

The pain from my son's headaches significantly disrupts his life. It limits his ability to participate in daily activities and compromises his coping threshold. The headaches are chronic and sometimes occur several times each day. It is, ruefully, possible that he has always had these headaches, but that when he was younger and we were **interpreting his autism** through an applied behavior analysis lens, we considered his pain episodes "autistic behaviors" rather than distress. As we began learning more **about autism through autistic sources** and also — though he is still minimally speaking — as his ability to communicate improved, it became clear that our otherwise cheerful and affectionate teenager was in agony, not "acting out" because of autism.

He has since seen an armada of specialists, from ENTs to neurologists to dental surgeons and beyond. And most of those specialists — thoughtful and caring professionals all — have thrown up their hands and declared defeat or passed him on via yet another referral.

And this is specifically what I mean when I beg for better accommodations in medical care: Because of his disabilities, my son cannot comply with many of the testing or diagnostics they want to order, and he cannot tolerate standard solutions for his headaches, such as mouth guards or Botox injections. Instead, he must settle for over-the-counter painkillers, which are neither

sufficient, nor a reasonable long-term solution. He deserves effective health care solutions, and so do his autistic peers with chronic untreated conditions.

I am not alone in my frustration **over the lack of appropriate care** for patients like my son. Yes, autistic people are more likely to need accommodations for routine care such as shots or blood draws, or specialty care such as sedation for dentistry. But they are also more likely to have atypical or paradoxical reactions to medication, such as getting sleepy from stimulants or amped up on decongestants. They are less likely to be **able to communicate symptoms** in ways non-autistic people will understand, because of challenges with interpreting their own sensory and emotional signals. All of these factors, when not accommodated for or understood, can compromise care.

We need more research into systemic barriers to diagnoses and medical approaches for autistic people, and research that **incorporates autistic and neurodivergent perspectives** on how to accommodate autistic patients. Although we do have progress in oft-overlooked areas, such as the **sensory issues** that can complicate medical access, research is still **heavily restricted** in too many areas that could be promising for autistic well-being, such as cannabis. The result is that autistic people frequently **don't get the medical care they need**, with tragic and sometimes even fatal consequences.

You would think my son would have better luck with headache solutions. We have good insurance, and our local hospital is a world-class center for medical research and innovation. Yet that leads to more systemic concerns: If my son can't get the care he needs, what does that say about the autistic people who don't have our advantages? Who face language, racial, sexual or gender discrimination? Or whose reactions to pain and distress continue to be framed as "just autism?" Providing informed and accessible medical care must be a multi-pronged effort to benefit the entire community to which my son belongs — him included.

Strides are happening. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) is working on creating **better tools for health services for autistic people**, including those for whom direct communication with medical professionals can be difficult or impossible, through the Autism Patient Reported Outcomes Measures (AutPROM) Toolbox (disclosure: I am an AutPROM community partner). The Autistic Health Access Project brings **autistic people into medical schools** to talk directly with students about autistic access needs. And the Institute for Exceptional Care is targeting **health care disparities for people with intellectual and developmental disabilities**, with an emphasis on the additional service gaps for non-white and low-income people.

These are good starting points, but so much more work needs to be done before autistic people get the care they need.

As always, researchers should prioritize autistic perspectives when looking for guidance or

considering direction. Autistic people have been vocal about wanting autism research efforts rebalanced, with less funding and **emphasis on biological issues** such as causation and more work on **quality-of-life matters** such as **accessible health care**. They want **autistic role models** involved in medical education. They want **neurodiversity-friendly medical environments**, in which autistic professionals can both be themselves and be more effective with patients as a whole and autistic patients specifically.

I want these things, too. I also don't think it is a coincidence that my son has had no openly autistic members on his health care team.

We haven't given up on treating my son's pain. Neither has one of his current specialists, who is proposing a medication with a promising (though off-label) track record for treating intractable chronic pain. This option brings additional worries: My son is an atypical responder to many medications, and in the past other off-label medications have torpedoed his motor and adaptive skills, which was scary for him as well as for us. The new meds may also sedate him intolerably, and as an active guy he doesn't want that, and neither do we. But we are proceeding, with caution. As long as truly accessible medical care remains out of reach, it's all we can do.

Shannon Des Roches Rosa is senior editor at Thinking Person's Guide to Autism.

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