

NEWS

Community Newsletter: How much do therapists know about autism, reactions to a rogue stem cell trial

BY CHELSEY B. COOMBS

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Hello, and welcome to the Community Newsletter! I'm your host, **Chelsey B. Coombs**, *Spectrum*'s engagement editor.

What do psychotherapists who treat adults **know about autism**? A thread about a study in *Autism* offered some insight this week.

A blind spot in mental healthcare? A study by a participatory autism research group provides insight into psychotherapists' knowledge and expertise when treating autistic adults.

<https://t.co/xMO1eNFvMS>

— Autism Journal (@journalautism) **December 8, 2021**

Autistic adults are often dissatisfied with their therapists' lack of knowledge about the condition, previous research shows, and this gap is the **most commonly reported barrier** to accessing treatment. For the new work, 498 psychotherapists in Germany rated their education about autism and their competency at diagnosing and treating autistic people versus those with other conditions, such as attention deficit hyperactivity disorder, bipolar disorder or depression.

The therapists rated their knowledge and skills lower for autism than for all of the other conditions.

On average, they answered only 8 out of 14 general-knowledge questions correctly, and many had outdated views, the researchers found. For instance, 43 percent said they believed vaccines cause autism, an idea that has long been thoroughly debunked.

Of those who said they were reluctant to treat autistic people, the majority, 70 percent, said it was because they did not know enough about the condition, and 55 percent said they would refer an autistic person to a colleague with special or additional training.

Formal and continuing education for psychotherapists should include more information about autism, the researchers suggest.

Ty B. Aller, a staff member at the Mental Health and Developmental Disabilities National Training Center, tweeted that these findings underscore why the center was created in the first place.

Great article worth a read. Findings are a bit frightening, but not surprising. It's why we helped create [@MHDDcenter](#)! Lot of work to be done. <https://t.co/Y03smN1yY>

— Ty B. Aller, PhD, LMFT (he/him) (@Allertalk) **December 3, 2021**

Sara Luterman, caregiving reporter at *The 19th*, contributing editor at *Radiolab* and a member of *Spectrum's* advisory board, tweeted that she has been turned away from therapists because of her autism diagnosis.

I have been turned away by prospective therapists because my autism diagnosis is “too complicated” for them. This kind of research is so, so important. Autistic adults need better access to mental health care, and mental health professionals need more education. <https://t.co/J2x2vFkOIA>

— Sara Luterman (@slooterman) **December 7, 2021**

Spectrum's story on the missteps of a stem cell trial that was described in *Frontiers in Pediatrics* in October drew strong responses online. A team in Austria **injected four autistic children** with stem cells previously extracted from the children's bone marrow. The trial did not undergo an ethical review; it wasn't approved by an institutional review board; and the researchers did not disclose

their ties to a clinic that sells the unproven therapy or the fact that the parents of the study participants paid to have their children participate in the trial.

Noah Sasson, professor and program head of psychology at the University of Texas at Dallas, asked why the journal published the study in the first place.

Just awful. No IRB approval, COIs galore, harmful and invasive, no scientific justification.

Why publish this **@FrontPediatrics?** <https://t.co/zr9ouoAbEU>

— Noah Sasson (@Noahsasson) **December 12, 2021**

Kevin Mitchell, associate professor of genetics and neuroscience at Trinity College Dublin in Ireland, wrote a thread about what he called the “most unethical, unjustifiable clinical ‘research’ I’ve seen with respect to autism.”

Jesus, this is some of the most unethical, unjustifiable clinical "research" I've seen with respect to autism... <https://t.co/VKmtEGyNDo>

— Kevin Mitchell (@WiringTheBrain) **December 11, 2021**

Mitchell added, “What possible justification could there be for doing something so invasive and dangerous, and from a scientific perspective, so fucking random?”

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— Kevin Mitchell (@WiringTheBrain) **December 11, 2021**

Dorothy Bishop, professor of developmental neuropsychology at the University of Oxford in the

United Kingdom, replied to Mitchell, saying that she was glad that the researchers did not get away with the “shocking” research.

This is shocking, but I'm very glad that the 'researchers' have not got away with it. I was astounded to find 10 yr ago that you could get IRB approval in the US for 'studies' that required participants to pay for treatment. <https://t.co/KpgSmCEDRr>

— Dorothy Bishop (@deevybee) **December 11, 2021**

That's it for this week's Community Newsletter! If you have any suggestions for interesting social posts you saw in the autism research sphere, feel free to send an email to me at chelsey@spectrumnews.org.