

NEWS

Community Newsletter: Oral histories from autistic adults, how much intervention is enough

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.

First on the agenda this week, I wanted to let you know that *Spectrum* will hold a Twitter chat during the Society for Neuroscience conference from 12:30 to 1:30 p.m. EST on Wednesday, 10 November. Come chat with your fellow researchers and our reporters about conference posters, keynotes and presentations, using #SpectrumChat. We'll lead the discussion from the *Spectrum* Twitter account.

Our first tweet this week comes from **Rozanna Lilley**, a postdoctoral researcher in education at Macquarie University in Sydney, Australia. Lilley and her colleagues published a new study about **self-identity in autistic adults** who are diagnosed later in life.

<https://twitter.com/boldlygrowing/status/1451504436480643077>

Two of the researchers, who were themselves diagnosed as adults, interviewed other late-diagnosed autistic adults born in Australia before 1975. The participants spoke most often about being different from others, exploring their identities with camouflaging and self-reinvention, and dealing with trauma. Being diagnosed and identifying as autistic positively affected their sense of self, many said.

"Their vivid and nuanced accounts are, we suggest, in radical tension with research positing deficits in autistic selfhood," the researchers conclude.

Megan Freeth, senior lecturer in psychology at the University of Sheffield in the United Kingdom, tweeted praise for the article.

A wonderful, really well-written article! <https://t.co/0nml301sM2>

— ShARL (@ShefAutismRes) **October 22, 2021**

Sarah O'Brien, a research and policy officer at the U.K. national autism research charity Autistica, tweeted about why autistic researchers interviewing autistic participants was so important.

It makes a real difference when the interviews are conducted by people like you, in this study's case autistic researchers interview autistic people.

A wonderful, sensitive and important piece of research that hands the mic over to autistic people to tell their histories <https://t.co/GiJPe7LQeL>

— sarah o'brien (@Sarahmarieob) **October 22, 2021**

Our next thread this week comes from **David Trembath**, associate professor of speech pathology at Griffith University in Queensland, Australia, who tweeted about a new opinion article that offers a framework to help clinicians determine **how much intervention** an autistic child needs.

How much therapy/support is optimal for autistic children?

In the absence of clear and consistent guidelines, we proposed an evidence-based framework to help parents and practitioners make informed choices.

Free read/download until Dec 8.<https://t.co/66xlr5g7JV>

— David Trembath (@DavidTrembath) **October 19, 2021**

A number of non-pharmacological interventions are used, but the evidence for their effectiveness "is more piecemeal than systematic, and often reliant on evidence from lower quality study designs," Trembath and his colleagues write.

Clinicians need to evaluate whether the interventions they turn to are plausible and evidence-based, practical to deliver, desirable for an individual child and her family and defensible, looking at all of the available options.

We propose that recommendations should be PLAUSIBLE (a scientific rationale), PRACTICAL to deliver (taking into account all child/family/contextual considerations), DESIRABLE (to the child and family), and DEFENSIBLE (when considering all possible options).

— David Trembath (@DavidTrembath) **October 19, 2021**

Co-investigator **Andrew Whitehouse**, professor of autism research at the Telethon Kids Institute in Western Australia, tweeted that it is "One of the most thoughtful and engaging papers I've been lucky to be part of."

One of the most thoughtful and engaging papers I've been lucky to be part of.
We describe one possible evidence-based practice framework for determining the most appropriate therapy/support intensity for children on the autism spectrum.
The thread below describes more ???? <https://t.co/0w7wVp4zT9>

— Andrew Whitehouse (@AJOWhitehouse) **October 19, 2021**

Lauren Osborne, a speech pathologist in New South Wales, Australia, replied that it is an important issue, and she recalled a previous conversation with Trembath about whether continuous weekly therapy for autistic children made sense.

I am looking forward to reading this!

I remember, when I was a student and you were a CE, a conversation about how "weekly

"therapy forever" wasn't necessarily the ideal scenario for children diagnosed with autism. It's an important issue to think about/discuss.

— Lauren Osborne (she/her) (@speechieLO) **October 19, 2021**

Trembath responded with a reflection on how "our role as practitioners changes over time."

Thanks very much Lauren - I remember the conversation arising from reflections on the fact that our role as practitioners changes over time, in response to each person's goals; preferences; life stage; family and network of friends, colleagues, community; and so on.

— David Trembath (@DavidTrembath) **October 19, 2021**

You can watch our 28 October webinar featuring Zachary J. Williams, a medical and doctoral student at Vanderbilt University in Nashville, Tennessee, who spoke about **measuring alexithymia in autistic people**.

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. See you next week!