

NEWS

# Community Newsletter: Ableism in autism research

BY CHELSEY B. COOMBS

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

This week, we focus on conversations around a paper from **Monique Botha**, an autistic postdoctoral research fellow in psychology at the University of Stirling in Scotland. The emotional report offers an **autoethnographic account of Botha's experiences**, going beyond conversations about participatory research to explore how autistic researchers are themselves treated.

NEW PAPER (as promised):

"Academic, Activist, or Advocate? Angry, Entangled, and Emerging: A Critical Reflection on Autism Knowledge Production" <https://t.co/oaML7Dzn7m>

Welcome to what is probably a reasonably long thread ????? 1/

— Monique Botha #TransRights (@DrMBotha) **September 28, 2021**

"To be involved in autism research when you are autistic, is to constantly experience the aggression of a field which has yet to come to terms with its own ableism," Botha wrote.

The article highlights papers from 1974 to 2018 that dehumanize autistic people, some of which derogatorily compare them to animals.

"In general, it seems that neither apes nor children with autism have — at least not to the same

extent as typically developing human children — the motivation or capacity to share things psychologically with others. This means that they both have very limited skills for creating things culturally with other persons,” one quoted paper from 2005 reads.

How researchers have traditionally studied autism is inherently ableist, Botha argues, going on to describe what it feels like when a non-autistic researcher tells an autistic researcher that they cannot be impartial. *Spectrum* wrote last year about how Botha and other autistic scientists are **reshaping autism research**.

It turns out, that it is a bar we can never reach - we will never be seen to be objective, by the nature of us being autistic, and it is designed like that because then we don't have avenues to challenge the status quo - and when you do its as easy as screaming "objectivity" 19/

— Monique Botha #TransRights (@DrMBotha) **September 28, 2021**

You do not get to treat autistic people how we have been treated by science, and then claim we are less objective, less logical, or less rational for feeling any form of an emotional response to the denial of our own humanity - the audacity is astounding 22/

— Monique Botha #TransRights (@DrMBotha) **September 28, 2021**

Botha ends the article with a call to action for autism researchers: “Please, engage with your own values, interrogate them, unpick them, doubt yourself, acknowledge your fallibility, acknowledge your mistakes, apologize, and engage with autism reflexively.”

**Clare Harrop**, research assistant professor at the University of North Carolina in Chapel Hill, tweeted that “it is one of the most powerful articles I suspect I will read this year.”

Read this paper by **@DrMBotha**

It will make you feel uncomfortable. It should. Take those feelings and channel them into more humanizing work.

It is one of the most powerful articles I suspect I will read this year.

<https://t.co/488BvNXtoP>

— Clare Harrop (@ClareHarropPhD) **September 28, 2021**

**Kristen Bottema-Beutel**, associate professor of teaching, curriculum and society at Boston College in Massachusetts, highlighted the need for non-autistic autism researchers to read and reflect on the paper.

A must read for anyone in proximity to autism research. Non-autistic autism researchers especially need to spend some time reflecting on this and engaging with ways to change our field. <https://t.co/RuUw3S5zp5>

— Kristen Bottema-Beutel (@KristenBott) **September 28, 2021**

**Hannah Belcher**, research associate at King's College London in the United Kingdom, tweeted that the paper is “everything you've ever wanted to read as an autistic autism researcher.”

Everything you've ever wanted to read as an autistic autism researcher  
[#AutisticsInAcademia https://t.co/w46Hni04cl](https://t.co/w46Hni04cl) [pic.twitter.com/enEAcCnkL1](https://pic.twitter.com/enEAcCnkL1)

— Dr Hannah Belcher (@DrHannahBelcher) **September 28, 2021**

**Sarah O'Brien**, an autistic research and policy officer at the U.K.'s national autism research charity Autistica, tweeted about the difficulty of “having to push through dehumanising descriptors of people just like you.”

Monique absolutely nails the insider/ outsider tension, ‘wearing many hats’ while having to push through dehumanising descriptors of people just like you.

It's thanks to Monique and researchers in the same position that change is happening.  
<https://t.co/pORTavt8QP>

— sarah o'brien (@Sarahmarieob) **September 28, 2021**

Botha tweeted about the social media response to the article, saying it was “sad that it’s resonated so much.”

I just wanted to say a heartfelt thank you to everyone for the exceptionally kind comments & response to this paper, which has been terrifying to publish - I am thrilled to hear that it has meant so much to people & also sad that its resonated so much, we shouldn't feel like this  
<https://t.co/4OZ3EQtTMm>

— Monique Botha #TransRights (@DrMBotha) **September 29, 2021**

Elsewhere on Twitter, **Andrew Whitehouse**, professor of autism research at the Telethon Kids Institute in Western Australia, posted a statement responding to criticism about his team’s new study in *JAMA Pediatrics*, which delivered findings on a “**preemptive**” **behavioral therapy** for autism given to babies. *Spectrum* **covered the paper** last week.

[pic.twitter.com/ZxG0rBlawI](https://pic.twitter.com/ZxG0rBlawI)

— Andrew Whitehouse (@AJOWhitehouse) **September 25, 2021**

“Autism cannot be ‘prevented,’ and this is not an aim that the study authors believe in,” Whitehouse wrote. “The babies remain neurodivergent, but they are not showing the same degree of developmental barriers that lead them to meet the ‘deficit-focused’ DSM-V diagnostic criteria of autism.”

Lastly, don’t forget to watch our **28 September webinar**, featuring **Jeremy Veenstra-VanderWeele**, professor of psychiatry at Columbia University, who spoke about goals for developing new drugs for autism — and the barriers researchers may encounter.

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](mailto:chelsey@spectrumnews.org). See you next week!

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