

NEWS

Community Newsletter: Controversial ‘cost of autism’ paper, ‘doctors’ speak,’ double empathy explained

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.

A **new paper** in the *Journal of Autism and Developmental Disorders* caused a huge uproar on Twitter this week.

“Rising prevalence, the shift from child to adult-dominated costs, the transfer of costs from parents onto government, and the soaring total costs raise pressing policy questions and demand an urgent focus on prevention strategies,” the researchers wrote.

The first author on the paper is **Mark Blaxill**, chief financial officer of the Holland Center, a Minnesota-based day treatment program for autistic children and young adults, and editor-at-large of the site “Age of Autism,” which often publishes anti-vaccination content.

Many autism researchers took to Twitter to denounce the study.

Michelle Dawson, an autism researcher at Hôpital Rivière-des-Prairies in Montreal, Canada, wrote that the work was “baseless” and “egregious.”

"In the absence of a comprehensive plan to either raise revenue or prevent autism... the costs of autism represent a serious threat to the economic future of the U.S"?

<https://t.co/BK4HOj9AwS> published by JADD in 2021, baseless, egregious

— Michelle Dawson (@autismcrisis) **July 19, 2021**

Kristen Bottema-Beutel, associate professor at Boston College in Massachusetts, tweeted about a conflict of interest not disclosed in the “garbage article.”

For anyone interested in how COIs and academic publishing work, the article referenced below is already being promoted on the author's blog website- the same website where they solicit donations and monetize content via advertisements. <https://t.co/jEfJwJ3ScQ>
<https://t.co/XpZB4GueSH>

— Dr. Kristen Bottema-Beutel (@KristenBott) **July 19, 2021**

David Mandell, professor of psychiatry and pediatrics at the University of Pennsylvania and *Autism* editor-in-chief, replied to Dawson, “It is difficult to know where to start in dissecting how poorly done this study is. The fundamental assumptions are verifiably wrong.”

It is difficult to know where to start in dissecting how poorly done this study is. The fundamental assumptions are verifiably wrong. I'm working now to write a response.

— David Mandell (@DSMandell) **July 19, 2021**

Daniel Sohege, director of the U.K. consultancy firm Stand for All, which is “focused on human, refugee and migrants rights, tweeted, “I've heard plenty of people discuss eugenics in regards to autistic individuals before, but this is the first time I have seen it effectively advocated as a way to save money.”

Holy crap. I've heard plenty of people discuss eugenics in regards to autistic individuals before, but this is the first time I have seen it effectively advocated as a way to save money. Well, thanks for putting a price on our lives folks. Now could you kindly jog on.
<https://t.co/MG3Da0Ye7d>

— Daniel Sohege ???? (@stand_for_all) **July 21, 2021**

Spectrum plans to publish more on the response to this paper soon, so stay tuned.

Our next thread comes from **Melissa Chapple**, research assistant in sociology at the University of Warwick in Coventry, England. She and **Joanne Worsley**, research assistant at the Institute of Population Health at the University of Liverpool in England, wrote a commentary about **changing the terminology** clinicians use to reflect the preferences of the autistic community.

????New paper????- Commentary with **@joanneworsley9** critiquing the linguistic framings of autism/autistic people that have stemmed from the medical model / discussing discrepancies between the language used in healthcare settings and the autistic community <https://t.co/EEMacqoMMB>

— Melissa Chapple (@melissachapple) **July 21, 2021**

In the paper, they delve into the history of the medical model of the condition, and how it gave rise to language that divides autism into categories such as “high-functioning” and “low-functioning.” There is little evidence that “these typologies add value to our understandings of autism,” they argue, among other points. “High-functioning” labels can trivialize disability and people’s needs, they note, whereas “low-functioning” labels can make people seem as if they have reduced worth or capabilities.

Finally, I want to let you all know about a new *Spectrum* **explainer on double empathy**, a topic **we’ve covered** in the **Community Newsletter often**.

Noah Sasson, associate professor of behavioral and brain sciences at the University of Texas at Dallas, who was interviewed for the piece, tweeted that it “includes many useful links to primary source evidence.”

Great new piece by **@RachelZamzow** for **@Spectrum** on the Double Empathy Problem. Features quotes by me, **@milton_damian** and others. Includes many useful links to primary source evidence. <https://t.co/GbcoLgyimj>

— Noah Sasson (@Noahsasson) **July 22, 2021**

That's it for this week's Community Newsletter from *Spectrum*! 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!

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