

Q&A: Researcher calls for new approach to equity in autism, fragile X research

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UC Davis MIND Institute Director Leonard Abbeduto is calling for a

major shift in the way research into autism and other neurodevelopmental disabilities is conducted. He has co-authored a paper titled "Toward Equity in Research on Intellectual and Developmental Disabilities" that was the basis for a special issue of the *American Journal on Intellectual and Developmental Disabilities*.

Abbeduto, a distinguished professor in the UC Davis Department of Psychiatry and Behavioral Sciences, argues that researchers should move away from placing people into categories based solely on diagnosis. Instead, he writes, they should consider the many identities of people with disabilities, including background, support needed and more. He and lead author Sara Kover, an associate professor at the University of Washington, also state the need for more attention to issues of equity.

"Our goal in writing this piece was to encourage more dialogue about the impact of long-standing biases, such as ableism and racism," Kover explained. "It is our responsibility as a field to challenge our thinking, question assumptions, and take steps toward equitable practices—even and especially if those actions are uncomfortable."

The special issue also includes a [commentary from the National Institutes of Health](#), four commentaries from individuals with diverse viewpoints and a [response from Abbeduto and Kover](#).

"The accompanying commentaries are so powerful. We knew our writing would be an imperfect offering, and each commentary identifies gaps and raises important ideas," Kover said.

In this Q&A, Abbeduto shares why he and Kover are calling for this new approach, what alternatives exist, and why he's hopeful that progress is being made toward increased equity in research and care.

What was your main goal in putting this special issue

together?

We're questioning the value of the current approach to all our clinical decisions and research paradigms. Everything is based on diagnostic categories: intellectual disability, autism, fragile X syndrome and more. Relying on these categories hides the fact that things can vary from person to person. It also identifies the person in terms of their "label," rather than recognizing that their [life experiences](#) and outcomes may be determined by many other factors. One example we cite is that in the U.S., race may be a more important determinant of the course of many people's lives than whether they meet the diagnostic criteria for a condition.

Identifying people by these categories continues to place the onus on the individual. It's 'you have autism, so you need assistance' in a sort of paternalistic way. Our hope is that we can acknowledge that we all need levels of support. If we can cater the support more to [individual differences](#) along multiple dimensions, that would be more effective and equitable.

What are some of the challenges to changing this reliance on categories?

Everything is built around these categories. If you don't get the diagnosis, you can't get interventions. This has created systemic barriers that lead to bias, discrimination and inequities. The way we measure interventions is also created according to the dominant culture, leaving out people from underrepresented groups. They're less likely to take part in research, be adequately assessed or get needed support.

We first proposed a similar shift back in 2014, but people argued that children wouldn't get treatment without the categories. But the truth is, if

you have a system that isn't equitable, it doesn't make sense to keep reinforcing it.

What alternative research approaches do you recommend?

I'm interested in a more dimensional approach, based perhaps on what support people need. For example, we could ask whether someone could benefit from specialized help with reading, independent of whether they have an [intellectual disability](#) or fall into the category of autism or fragile X syndrome.

Other approaches include the neurodiversity perspective, which asserts that differences are not deficits and those that focus more on social factors such as income level, race and ethnicity.

What changes have you made in your own research in line with this new approach?

The MIND Institute is building a network of partnerships with self-advocates, families and community organizations to improve equity in research, which has been eye-opening. We are meeting with people who communicate in different ways and have very different abilities, and it's been so valuable to learn how to create a space that everyone can participate in. This has already informed our research agenda and created partnerships that I hope will endure.

Personally, my research has moved away from comparing people with fragile X syndrome to people in some other category. I'm focused on understanding what are the experiences, skills and family factors that allow people with fragile X syndrome to be either more or less independent as they transition to adulthood. We're getting away from the

tendency to always compare and look for weaknesses and instead working to understand people's lives so we can provide different levels of support as a society.

What other changes are needed in this field of research to achieve this goal?

We need to continue to diversify our workforce of clinicians and researchers. We need people who have lived experiences around equity. The systemic barriers in society are reflected in our institutions of research, [health systems](#) and more in the U.S., and the lack of trust that marginalized groups have in terms of academic research is a big challenge, too. And it all goes back to the fact that you need a diagnosis to get services. At some point, if you don't question the system and try to change it, you're going to keep contributing to the problem.

Putting together this special issue was very energizing, and the commentaries that accompanied our article makes me quite optimistic. People have been thinking about these issues for a long time. There won't be one right answer for how to change things.

More information: Sara T. Kover et al, Toward Equity in Research on Intellectual and Developmental Disabilities, *American Journal on Intellectual and Developmental Disabilities* (2023). [DOI: 10.1352/1944-7558-128.5.350](#)

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