

Federally funded studies into treatment for chronic conditions overlook efficacy in adults with autism, analysis finds

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Physical health disparity conditions in autistic adults have not been the

focus of any research funded by the U.S. National Institutes of Health (NIH) in the last four decades, an analysis of a federal database found.

Using the NIH Research Portfolio Online Reporting Tools Expenditures and Results (RePORTER) database to determine whether the NIH has funded any research related to physical [health](#) disparity conditions in [autistic adults](#), T. A. Meridian McDonald, Ph.D., faculty research instructor in the Department of Neurology at Vanderbilt University Medical Center, used 30 separate searches to discover that "autism" is often used as a key term—not the target population.

Results of the study are published today in the *Journal of Autism and Developmental Disorders*.

Autistic adults are at greater risk of nearly every major chronic health condition, including obesity, diabetes, gastrointestinal and sleep disorders, and cardiovascular and immune conditions. These conditions contribute to increased pain and mortality experienced by [autistic people](#) as well as to decreased quality of life such as lower rates of employment and social inclusion.

"We don't know if treatments designed for the general population will work for autistic people," McDonald said. "Take [cognitive behavioral therapy](#), the front-line [treatment](#) of insomnia, for example. This treatment is typically carried out in six to eight face-to-face provider-patient clinic sessions. During these sessions, the clinician provides a ton of information about how sleep works and how to do the treatment. The delivery of this information in these types of sessions may overtax many autistic people's information and social processing abilities."

It's key to understand how treatments work in different populations, accounting for social and physiological determinants of health, McDonald said. In the example of insomnia, the treatment often requires

patients to change routines and habits, and that may be a serious challenge for autistic patients, she said.

McDonald used "autism," and "adult" coupled with one of 30 health disparity condition terms in the RePORTER, a repository of NIH-funded projects that is searchable with key terms. Searches surfaced numerous studies, which, upon analysis, often used "autism" in a project as a key term rather than a study designed to evaluate the prevalence or manifestation of disease or treatment in autistic people.

Research found only four studies that look at health conditions related to autistic adults, but none of the studies examined the treatment of physical health disparity conditions in autistic adults.

"Many of these studies are focused on the prevention of multiple health conditions. A study's goals might focus on the prevention of neurological conditions, such as stroke, epilepsy and autism. This type of study is not looking at the prevention of stroke in autistic people, who may have different risk factors or need specialized treatment options," said McDonald, lead author on "Mind the NIH-Funding Gap: Structural Discrimination in Physical Health-Related Research for Cognitively Able Autistic Adults."

"We need funding to test whether interventions are effective with autistic people. If treatments are not effective, then funded research is needed to adapt or develop interventions that are effective in treating physical health disparity conditions experienced by autistic adults," she said.

Both the U.S. Congress and the Interagency Autism Coordinating Committee identified co-occurring physical health conditions as a research priority and allocated funds for autism research to the NIH. Each of the 27 institutes that comprise the NIH have latitude in how it

determines its research priorities.

The research in JADD describes several potential "nodes," or processes that contribute to the lack of studies focused on health disparities in autistic people, including designation of a "primary disease," which are often thought to be the cause of other conditions.

McDonald and colleagues note this assumption has not been tested in autism and "this designation [of primary disease] prevents researchers from testing whether co-occurring physical [health conditions](#) can be treated in [autism](#)."

Audrey Scudder, co-author and an autistic undergraduate student at Vanderbilt University and active member of both the McDonald's Spectrum for Life Lab and the Vanderbilt Autism & Neurodiversity Alliance, wants to prioritize advocacy for the autistic community as she pursues a research career.

"Many of my [family members](#), friends and other fellow community members have expressed a need for health care that is accessible and effective for autistic people," Scudder said. "Addressing health disparities would greatly improve the quality of life of many autistic adults who struggle with finding care that treats their whole personhood. This study indicates that at this point in time there isn't enough research supporting what's effective in this population of adults."

Autistic adults have been left out of the recent shift to root out disparities in research, diagnosis and treatment, McDonald said.

"Moving forward I want the NIH to change funding policies to prioritize research on physical health disparity conditions in autistic adults. At the very least, they should not be excluded from review across agencies that fund physical health research," she said.

More information: T. A. Meridian McDonald et al, Mind the NIH-Funding Gap: Structural Discrimination in Physical Health–Related Research for Cognitively Able Autistic Adults, *Journal of Autism and Developmental Disorders* (2023). [DOI: 10.1007/s10803-022-05856-w](https://doi.org/10.1007/s10803-022-05856-w)

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