

National Autism Indicators Report: High rates of mental health conditions and persistent disparities in care

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Mental health is an important part of whole-person health and wellbeing and is a key component of community health. But it is an often-



overlooked part of health care. A recent report from the A.J. Drexel Autism Institute at Drexel University highlights the importance of mental health care in autistic children and adults. The report, the latest in the National Autism Indicators Report series, found high rates of mental health conditions in autistic children and adults and persistent disparities in mental health and health care by race and ethnicity.

National estimates, based on parental reporting, suggest that three-quarters of autistic children have at least one co-occurring mental health condition, including behavior or conduct problems, ADHD, anxiety and depression. And nearly half have at least two. This is much greater than other children with special health care needs, where half have at least one mental health condition and about one-quarter have two or more.

This report is a follow-up to a previous National Autism Indicator Report on health and health care, which found autistic children had high rates of many mental health conditions, were more likely to see a mental health care provider than their peers and use psychotropic medication. And while nearly all autistic children had health insurance, fewer than half of parents reported it covered all the services they needed for mental health. Even in comprehensive care approaches, mental health care is often not addressed.

"The findings of the previous report raised some important questions and led us to further examine the role of mental health and mental health care in <u>autistic people</u>," said Jessica Rast, research associate in the Autism Institute and lead author of the report.

Researchers found that what children are diagnosed with varies by race and ethnicity. Anxiety is more common in white, non-Hispanic autistic children (51%) than in children of another race or ethnicity. Nearly half of white and Black autistic children had ADHD, while only about a third of children of another race or Hispanic children had the condition. And



all conditions are less common in Hispanic children, who are less likely to have any mental health condition than non-Hispanic children. Differences in diagnostic practices are often attributed to clinician bias, structural barriers and the historical context of racism in the health and mental health care systems, explained Rast.

Treatment or counseling was more difficult for autistic children to get than their peers, with one-fifth of parents of autistic children reporting it was very difficult or impossible to access needed services. Twelve percent of parents of autistic children reported their child needed mental health care that they did not receive in the past year.

The report also examined the relationship between mental health and community engagement in autistic youth. Youth who need mental health care but did not receive it were the least likely to participate in sports, volunteer work or paid work. Autistic youth who received all the mental health care they needed were the most likely to participate in those activities, even more so than youth who did not need any mental health care.

"Increased rates of involvement in autistic youth who get all the mental health care they report needing may suggest that quality mental health care helps autistic youth maximize community involvement by working with their provider on developmentally appropriate goals," said Tamara Garfield, a doctoral student in Drexel's Dornsife School of Public Health and co-author on the report.

Without proper care and management in primary care, mental health conditions can be cared for in acute settings when they escalate to a crisis situation. For <u>autistic children</u> in 2017, three of the most common reasons for hospital admission were related to mental health, including mood disorders (16%); disruptive, impulse-control, and conduct disorders (4%); and schizophrenia and other psychotic disorders (2%).



Mood disorders were also the most common diagnosis in autistic adults ages 18 and up (17%), followed by schizophrenia (9%).

"A big shortcoming of U.S. policy and practice related to mental health is the lack of a crisis care system. People in crisis have limited options when they need immediate mental health care," said Rast. "They can go to the emergency room where providers likely have no training in accommodating autistic people, or they can call 911 where police and other emergency responders have limited training in responding to mental health crises. Neither of these options afford the quality of care people need during a mental health crisis."

While there are no national estimates of mental health conditions in autistic adults, this report used two insurance-specific sources of information to present findings. About one-quarter of adults enrolled in Medicaid, a public health insurance program that covers children and adults with disabilities and those below an income threshold, had anxiety, bipolar, ADHD or depression identified in their medical records—a much larger percentage than adults without autism. Similarly, about one-quarter of autistic adults enrolled in Kaiser Permanente Northern California (KPNC), a private insurer covering people in Northern California, have anxiety or depression in their medical record, more than peers without autism.

"We need to ensure access to mental health services for individuals across the autism spectrum—when, how, and where those services are needed. Data from this report provides important information for structuring policy and practice to make these needed services readily available to autistic individuals across the lifespan," said Lindsay Shea, DrPH, director of the Policy and Analytics Center and leader of the Life Course Outcomes Research Program at the Autism Institute, an associate professor and co-author of the report.



There are many areas of care that can be optimized to meet the needs of the autistic community. Access to mental health care—from insurance coverage, availability of providers and telehealth, to how individuals are introduced to the specialty—is incredibly important, added Rast.

"This problem is even worse in racialized communities, where historic disinvestment, mistrust in the medical system and treatment relevance make care less effective," said Rast. "Further, the mental health workforce is disproportionately white. Care from same-race providers may add cultural competence to care that is lacking in much mental health care."

However, the success of current mental health practices for autistic patients is sometimes unknown. Many practices that are proven effective in research studies with the general population have not been studied in autistic people. More research is needed to determine the most effective practices for mental health care in autistic patients.

All of these changes would also positively impact mental health in the U.S. in general. Addressing the needs of populations often requires changes to policies that impact access to care, provider training and resources for everyone.

More information: Report: <u>drexel.edu/autismoutcomes/publ ...</u> s/NAIR-mentalhealth/

Provided by Drexel University

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