

NEWS

New estimate suggests most autistic adults in England lack a formal diagnosis

BY EMMET FRAIZER

9 JUNE 2023

Anywhere from 435,700 to nearly 1.2 million people in England may be autistic but undiagnosed, according to a **study** of primary-care records — an estimate that includes more than 9 in 10 autistic people aged 50 and older.

Living for so long without a diagnosis can have consequences — **especially for mental health**, says lead investigator **William Mandy**, professor of neurodevelopmental conditions at University College London in England. “If you don’t have the label,” he says, “you’re less likely to get the adaptations and the support that you might need.”

Mandy and his colleagues examined more than 5 million medical records from 2000 to 2018 to track when people received their diagnosis. Among 602,433 people registered at a primary-care practice in 2018, 1,069 girls and women and 3,635 boys and men had an autism diagnosis. The label was more common among children and adolescents than in adults, ranging from 2.94 percent of 10- to 14-year-olds — who, the team says, likely have the best access to diagnostic services — to only 0.02 percent of people aged 70 and up.

This spread is consistent with the idea that improved autism awareness and the **evolution of autism’s diagnostic criteria** have contributed to an overall uptick in cases among younger generations, Mandy says.

When the condition first appeared in the “Diagnostic and Statistical Manual of Mental Disorders” (DSM) in 1980, it was “a very, very narrow concept of autism,” he explains, whereas today’s criteria are “more carefully written to reflect a much wider diversity of autistic presentations.”

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