

National Autism Indicators Report: Health and health care of individuals with autism

December 1 2020

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Health and Health Care
November 2020

drexel.edu/AutismOutcomes/NAIRhealth



Credit: Drexel University

People on the autism spectrum face barriers to comprehensive care that may cause their health and quality of life to be worse than that of their peers. While some people may be predisposed to worse health,

preventive services and comprehensive health care can go a long way in improving the trajectory of health throughout their lives.

In the recently published sixth report in the National Autism Indicators Report series, researchers from Drexel University's A.J. Drexel Autism Institute highlight a holistic picture of what health and [health care](#) look like across the life course for people on the autism spectrum.

"Health and health care are critical issues for many children and adults on the autism spectrum," said Lindsay Shea, director of the Policy and Analytics Center at the Autism Institute and interim leader of the Life Course Outcomes Research Program, an associate professor and co-author of the report. "They may experience more frequent use of services and medications. They may need more types of routine and specialty healthcare. And their overall health and [mental health care](#) tends to be more complex than people with other types of disabilities and special health care needs."

The complexity of a person's health needs depends, in part, on the number of issues they need help with and whether they have access to the types and quality of care they need. The health care journey may be less complicated if people are able to access care that is integrated across health and mental health, if they have fewer unmet needs, and if their care is coordinated when needed.

Unfortunately, the current health care system often fails to adequately address the needs of people on the spectrum. As a result, there is more frequent need for emergency health care and hospitalization. The gaps in health care for people with autism, versus those with other disabilities, are important to address.

"This is one of our most ambitious reports to date. We combined data from several national and regional sources to understand the health and

health care of people on the autism spectrum of all ages," said Jessica Rast, a research associate in the Autism Institute and lead author of the report. "We need to understand health and health care needs across the life course so that recommendations can be made about how to improve health and health care at critical points across a person's life."

Children and adults with ASD have a lot of health concerns and complex health care needs

Researchers found when parents were asked about whether their child had certain [health conditions](#), children with ASD had higher rates of every single condition except for asthma, compared to other children with special health care needs. Conditions included learning disability, behavior or conduct problems, attention deficit hyperactivity disorder (ADHD), speech or language disorder and anxiety.

Similarly, in another set of data, adults with ASD had higher rates of many conditions than a random sample of other adults. Adults with ASD were two to three times as likely to have depression or anxiety, compared to adults without ASD and were also far more likely to have hypertension, epilepsy, ADHD, bipolar disorder or schizophrenia.

When it comes to paying for the health care, almost half (46%) of parents of children with ASD reported that their child's insurance did not always cover the services they needed. One-fifth of parents of children with ASD reported avoiding changing jobs because of concerns about maintaining health insurance for their child—five times the rate of parents of children with no special health care needs.

Because of the complexity of care, parents either sought help or felt they needed more help with coordinating health care. Of parents whose child with ASD had more than one health care appointment in the past 12

months, 28% reported someone helped coordinate or arrange care among different providers, similar to parents of children with other special health care needs. Another 30% of parents of children with ASD reported they could use more help coordinating care—more than parents of other children with special health care needs.

Health and health care varied by race and ethnicity in children with ASD

Researchers discovered that certain conditions varied in prevalence by race and ethnicity in children with ASD. ADHD and anxiety were more commonly reported in white, non-Hispanic children than in children of any other race or ethnicity. Asthma and developmental delays were the most common in black, non-Hispanic children.

Health care use also varied by race and ethnicity. Hispanic children with ASD were the least likely to have regular appointments for health and dental health. Hispanic children and black, non-Hispanic children were the least likely to have a usual source of care, compared to white, non-Hispanic children and non-Hispanic children of another or multiple races. Black, non-Hispanic children with ASD were the least likely to have family-centered care, an important component of effective, comprehensive health care. And they had the lowest rates of effective care coordination.

Researchers say acknowledging these disparities is only the first step to combating them. Future research must work to reduce them. The reliance on public health insurance (Medicaid), especially among underserved and underrepresented groups, suggests that research focused in these systems should be an area of emphasis. Economic disparities are also of particular concern in this population, where costly services and insurance inadequacies are common.

"Our current health care approaches are not up to task, we need systems-wide improvement focused on holistic care," said Shea.

More research is needed to determine how to improve systems and services to increase levels of health and decrease health care burden, but researchers provided a few suggestions for moving forward.

Care coordination is a key to improving health in people with complex conditions like autism. Interdisciplinary strategies should be explored and evaluated.

"For example, the reasons that children with ASD have worse dental health than their peers could include lack of insurance coverage, a need for behavioral supports for successful office visits and daily hygiene, dietary issues linked to dental health, or lack of accommodations at the dental office," said Rast. "If these all impact dental health, they must all be included in a plan to improve dental health."

The latest report in the series, "National Autism Indicators Report: Health and Health Care," combines data from two national surveys about health, The National Survey of Children's Health (NSCH) and the Medical Expenditure Panel Survey, to examine health and health care in [children](#) on the autism spectrum; one national sample of hospital inpatient stays, The National Inpatient Sample (NIS), to examine hospital inpatient stays in all ages of people on the autism spectrum; and previously published findings from Kaiser Permanente Northern California (KPNC) patient records, which add a vital source of information on adult health and [health](#) care.

More information: [drexel.edu/autisminstitute/res ...sthash.iIX9qHKq.dpbs](https://drexel.edu/autisminstitute/res...sthash.iIX9qHKq.dpbs)

Provided by Drexel University

Citation: National Autism Indicators Report: Health and health care of individuals with autism (2020, December 1) retrieved 25 December 2023 from

<https://medicalxpress.com/news/2020-12-national-autism-indicators-health-individuals.html>

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