

Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

Sexual and Gender Minorities with Autism Spectrum Disorder May Face Challenges to Getting Needed Healthcare

A study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR).

Autism spectrum disorder (ASD) is a developmental disability that affects how people communicate and process information. Recent studies have shown that a significant number of adults with ASD identify as being lesbian, gay, bisexual, transgender, or queer (LGBTQ+). Research has also shown that both adults with ASD and adults who are LGBTQ+ may have trouble accessing needed healthcare services, and people with both identities may have particular difficulty developing good working relationships with doctors. In a recent NIDILRR-funded study, researchers looked at the healthcare experiences of adults with ASD who identified as LGBTQ+. The researchers wanted to find out if these adults reported poorer health or if they encountered more trouble accessing healthcare compared with adults with ASD who identified as straight and cisgender, meaning their gender matches the sex they were assigned at birth. They also wanted to find out what unique challenges adults with ASD who are LGBTQ+ reported facing in healthcare settings.

Researchers at the [Collaborative on Health Reform and Independent Living](#) looked at data from the National Survey on Health and Disability. Specifically, the researchers reviewed survey responses from 54 adults, ages 18-62, who self-identified as having ASD. Out of those, 19 identified as LGBTQ+ and 35 identified as straight and cisgender (identified gender matched the sex they were assigned at birth). The survey respondents answered questions about their physical and mental health, including how many days in the previous month they had experienced poor physical or mental health, whether or not they had a mental illness such as anxiety or depression, and their health behaviors, such as whether or not they smoked. The respondents then answered questions about their health insurance and whether or not their insurance covered needed prescriptions and specialists, and if the provider network was adequate to meet their healthcare needs. The respondents were also asked whether they had been unable to access needed healthcare services in the previous year, and if so, whether they had trouble finding a doctor who took their insurance, getting insurance to cover the services they needed, or if a doctor refused to serve them for other reasons besides their insurance plan. Finally, the respondents provided demographic information, including their level of education.

In addition to the survey responses, the researchers also conducted interviews with 5 individuals who identified as having ASD and being LGBTQ+. During the interviews, the participants were asked more in-depth questions about their healthcare experiences, health insurance, and any difficulties they encountered in getting needed healthcare.

When comparing the respondents who were versus those who were not LGBTQ+, the researchers found that:

- The LGBTQ+ respondents had higher rates of mental illness: 79% reported having a mental illness or psychiatric condition, compared with 34% of the straight, cisgender respondents. In particular, 21% of the LGBTQ+ respondents reported a higher rate of having post-traumatic stress disorder compared to 3% of the straight, cisgender respondents.
- The LGBTQ+ respondents reported having about twice as many days in the previous month when their physical health was not good: 11 days on average for the LGBTQ+ respondents compared to 5 days for the straight, cisgender respondents. However, the two groups reported similar numbers of poor mental health days on average.
- A much higher percentage of the LGBTQ+ respondents reported that they smoked (27%) compared with 3% of the straight, cisgender respondents.
- When asked about insurance, 16% of the LGBTQ+ respondents had privately purchased health insurance on the individual market, compared to none of the straight, cisgender respondents. Only 59% the LGBTQ+ respondents had Medicare or Medicaid compared with 76% of the straight/cisgender respondents.
- The LGBTQ+ respondents reported much higher rates of having an insurance plan with an inadequate provider network, or having doctors not accept their insurance, than the straight, cisgender respondents. The LGBTQ+ respondents also reported more frequently that they could not get needed prescriptions or specialist care. In total, 74% of the LGBTQ+ respondents reported that their insurance failed to meet at least one of their needs, compared with only 44% of the straight, cisgender respondents.
- In addition, 35% of the LGBTQ+ respondents reported that a doctor refused to serve them for reasons other than insurance, compared with only 20% of the straight/cisgender respondents.

When the researchers interviewed the adults with ASD who identified as LGBTQ+, they found that the participants reported multiple challenges to accessing needed healthcare. Three of the respondents reported being refused healthcare services, such as transgender-specific healthcare. Several participants perceived that they were treated poorly by doctors because of their ASD, their LGBTQ+ identities, or both. For example, some of the participants felt that their doctors assumed that they were not sexually active or could not have LGBTQ+ identity because of their ASD. As a result, 4 of the 5 participants reported that they did not always tell doctors about having ASD or being LGBTQ+. Finally, one of the participants described that switching from private insurance to Medicaid allowed them to receive better healthcare options.

Previous research has shown that, in general, people who attain higher levels of education have better health outcomes and lower rates of depression and smoking than that those with less education. In this study, the researchers found that the LGBTQ+

respondents had much higher rates of college completion (68%) compared with only 36% of the straight, cisgender respondents. Despite that favorable factor, participants with ASD who identified as LGBTQ+ still showed poorer health outcomes and higher rates of mental illness and smoking than their peers who were straight, cisgender. The authors noted that people with ASD who are LGBTQ+ may be at particular risk for mental illness, perhaps related to experiences of trauma stemming from stigma and discrimination. These individuals may also have more complex healthcare needs that are often going unmet, particularly if they are using private health insurance. Private health plans may have narrower provider networks, or they may have providers who are less familiar with people with ASD who have LGBTQ+ identities. These individuals may also face challenges due to common stereotypes about the sexual and gender identities of people with ASD, such as the assumption that adults with ASD are asexual or lack a clear gender identity. Healthcare providers may benefit from training on the unique experiences of people with ASD who are LGBTQ+. In addition, future research may be useful to better understand these individuals' relationships with their healthcare providers in order to identify ways to improve the quality of healthcare that they receive.

[To Learn More](#)

The [Rehabilitation Research and Training Center on Community Living](#) offers a range of research-based resources for individuals with intellectual and developmental disabilities, including ASD. The Winter 2016 issue of Impact featured [Supporting Wellness for Adults with Intellectual and Developmental Disabilities](#), with examples of those leading the way in supporting attention to life areas that are essential to everyone's well-being - healthy activity, social connections, pleasure and meaning, supportive relationships, and participation in health care.

[A Guide for Understanding, Supporting, and Affirming LGBTQI2S Children, Youth, and Families](#) (PDF), produced under a grant from the Substance Abuse and Mental Health Services Administration (SAMHSA) provides general information for service providers, educators, allies, and community members who seek to support the health and well-being of children and youth who are lesbian, gay, bisexual, transgender, questioning, intersex, and/or two-spirit (LGBTQI2S) and their families. This guide will help to promote full and affirming inclusion of diverse LGBTQI2S youth and families in all aspects of systems of care.

The [Collaborative on Health Reform and Independent Living \(CHRIL\)](#) continues to research barriers and supports to accessing health care among people across the disability spectrum. Visit chril.org for articles, reports, and presentations on their findings.

[To Learn More About this Study](#)

Hall, J.P., Batza, K., Streed, Jr., C. G., Boyd, B.A., and Kurth, N.K. (2020) [Health disparities among sexual and gender minorities with autism spectrum disorder](#). Journal

of Autism and Developmental Disabilities, 2020. This article is available from the NARIC collection under Accession Number J83020.

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