

Health and Healthcare Access among Adults with Autism Spectrum Disorder and Intellectual Disability 2015 - 2016

Henan Li, PhD

Overview

Adults with autism spectrum disorder (ASD) face many disparities in health and health care.¹⁻² Documenting and understanding these disparities helps individuals, families, physicians, and other stakeholders improve the health and health care of those individuals.



Objective

To describe the demographic characteristics, general and mental health, and healthcare access of adults with ASD and intellectual disability (ID)



Sample

Adults age 18 and older with ASD and ID who receive state developmental disabilities services (n=2,390)



Dataset

National Core Indicators (NCI) survey, 2015-2016 cycle, conducted in 35 states and the District of Columbia³



Key Findings

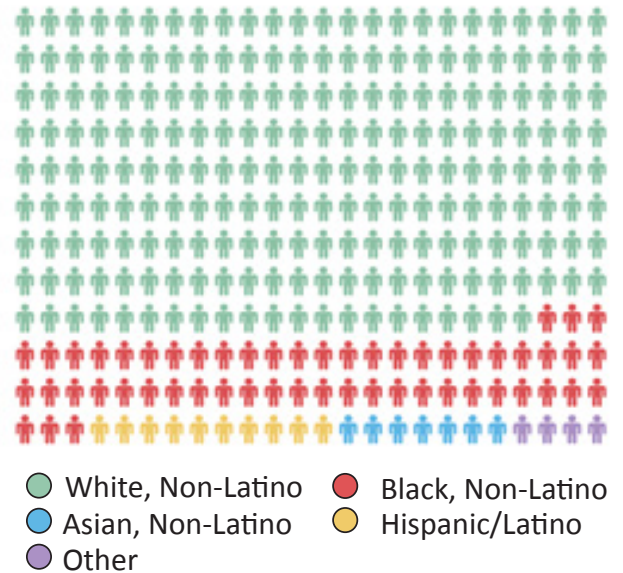
- Adults with ASD and ID reported poorer general health than the general adult population of the United States.
 - About 29% of adults with ASD and ID reported at least one chronic health condition such as diabetes, hypertension or high cholesterol.
 - More than half of the respondents reported at least one diagnosis of mental illness/psychiatric condition (anxiety disorders, mood disorders, schizophrenia etc.). Among those, three out of five took medication to treat those conditions.
- Most respondents had access to primary care doctors, annual health exams, dental care, and vision care. However, access to different types of preventive health screenings were uneven.

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Demographic Characteristics

Adults with ASD and ID averaged 34 years of age at the time of the survey. The majority were male (70%), white (74%), non-Hispanic (96%), who use English as their primary language (95%). In comparison, the composition of the U.S. population in 2015 was 49% male, 77% white, 82% non-Hispanic, and 79% used English as a primary language at home.⁴ (Figure 1)

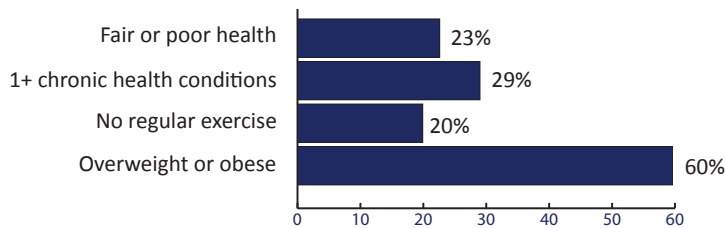
Figure 1. Race/Ethnicity of Respondents with ASD and ID



General Health

More than one in five adults with ASD and ID (23%) reported fair or poor health in general. In comparison, only about one in ten U.S. adults (10%) reported fair or poor health in 2015.⁵ About 29% of adults with ASD and ID reported at least one chronic health condition such as hypertension, high cholesterol, or diabetes. About one in five (20%) did not exercise or do physical activity regularly. About 60% were overweight or obese. (Figure 2)

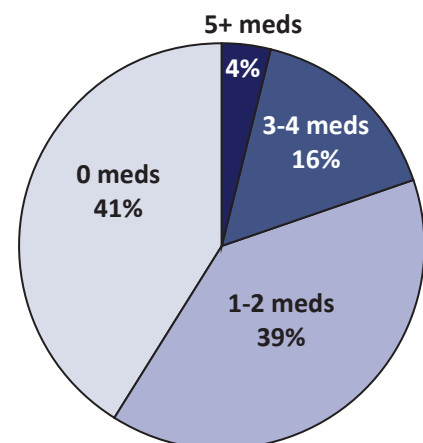
Figure 2. General Health of Adults with ASD and ID



Mental Health

About three out of five adults with ASD and ID (59%) reported taking medications to treat mental illnesses or psychiatric conditions (Figure 3). Among them, about one third (34% among medication takers, 16% overall) took at least three medications. Among those who took medications, 24% have no diagnoses on file. About 43% of respondents took medications to treat behavior problems, which is more than double the rate for other NCI participants (20%).

Figure 3. Number of Medications Adults with ASD and ID are Currently Taking for Mental Health Conditions



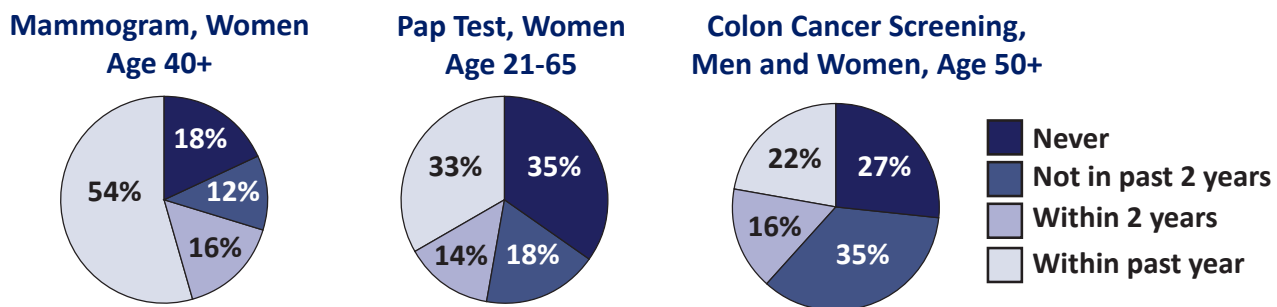
24% of respondents who reported taking medications have no diagnoses on file.

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Health Care Access

The majority of adults with ASD and ID had a primary care doctor (98%), had an annual physical exam within the past year (89%), had a dental visit within the past year (83%), had a vision exam within the past two years (76.9%), and had flu vaccinations within the past year (69%). Among women age 40 and above, 70% had a mammogram within the past 2 years, whereas 18% never had one. Among women ages 21 to 65, a combined 47% had a Pap test within the past 2 years, while 35% never had one. Among adults with ASD and ID ages 50 and above of both sexes, 27% had never received a colon cancer screening. (Figure 4)

Figure 4. Preventive Screening Access among Adults with ASD and ID



Policy Implications

- This report highlights the need for adults with ASD and ID who receive services from state developmental disability agencies to have better access to preventive health services, and access to timely and accurate psychiatric diagnoses, and appropriate treatments.
- Progress has been made in increasing health care access. The next step is to further improve the quality of care provided.
- Both obesity rates and physical activity levels were high, which suggests that regular physical activity by itself may be inadequate. In order to reduce obesity, targeted health promotion policies and practices that focus on nutrition, healthy lifestyle, and diet among adults with ASD and ID need to be developed and implemented.
- Further studies of the health outcomes and health care access among adults with ASD and ID are needed. A uniform and standardized approach to understanding the health of adults with ASD and ID in the United States should be adopted to enable comparison to other populations.

Limitations

- The NCI is not a nationally representative survey of all adults with ASD and ID. Findings in this brief may not be generalizable to other US adults with ASD and ID.
- ASD and ID diagnoses were based on state developmental disabilities service records, which were not clinically verified.

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Data Source

Data for this brief came from the National Core Indicators (NCI) 2015-16. NCI is a collaborative effort of the National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute. Adults with intellectual disability or developmental disability were eligible to participate in the NCI if they received at least one service in addition to case management from a state developmental disability agency. In fiscal year 2015-16, 35 states and District of Columbia participated in NCI.³

References

1. Bishop-Fitzpatrick L, Kind AJ. A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 1-12. 2017;47(11): 3380-3391.
2. Chiri G, Warfield, ME. Unmet need and problems accessing core health care services for children with autism spectrum disorder. *Maternal and Child Health Journal*. 2012;16(5): 1081-1091.
3. Human Services Research Institute. National Core Indicators. <https://www.nationalcoreindicators.org/>. 2017. Accessed January 9, 2018.
4. U.S. Census Bureau. 2011-2015 American Community Survey 5-Year Estimates. https://factfinder.census.gov/bkmk/table/1.0/en/ACS/15_5YR/DP05. 2017. Accessed January 9, 2018.
5. Centers for Disease Control and Prevention. National Center for Health Statistics Health, United States, 2016. <https://www.cdc.gov/nchs/hus/index.htm>. 2017. Accessed January 9, 2018.

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lurie.brandeis.edu

The Lurie Institute for Disability Policy
The Heller School for Social Policy and Management
Brandeis University
415 South Street MS 035
Waltham, MA 02453
781-736-8415
lurie@brandeis.edu