

Autism spectrum disorder caregiver healthcare resource utilization and economic burden: results from the 2024 US National Health and Wellness Survey

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Background

- Autism spectrum disorder (ASD) is a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave.¹
- In the United States (U.S.), 1 in 36 children and 1 in 45 adults have ASD.^{2,3}
- Millions of Americans are caregivers with many caring for individuals with neurological or developmental conditions.⁴

Objectives

The study aimed to describe the sociodemographic profile and economic burden experienced by caregivers to those with autism spectrum disorder (ASD).

Methods



Data from the 2024 US National Health and Wellness Survey, a cross-sectional, nationally representative, general population survey, were used.



Participants are adults (aged ≥18 years), recruited using general population panels; using a quota sampling technique.



Participants self-reported being caregivers to adults with ASD (CA) or caregivers to children with ASD (CC). Caregiver characteristics and healthcare resource utilization (HCRU) were evaluated.



The economic burden of HCRU will be estimated using the most recent data from the Medical Expenditure Panel Survey and inflated to 2024 medical care costs using data from the Federal Reserve Bank of St. Louis.^{5,6}

Results

- Sample sizes were n=1,254 CA and n=1,908 CC.
- 63.7% of CA were male whereas 51.4% of CC were female. Many were non-Hispanic White (CA: 62.4%; CC 58.0%).
- The majority were insured (CA: 85.7%; CC: 86.6%); household income ≥\$75,000 was significantly higher among CA (CA: 61.7%; CC: 48.9%).
- Significantly more CA (81.6%) were employed (full-time or part-time) than CC (67.2%; p<0.001).

- CA were significantly more likely to be currently using technology to monitor or manage the health and safety of the care recipient compared to CC (59.2% versus 35.5%; p<0.001).
- On average, CA had more HCP visits (9.1±22.5 vs. 8.0±16.3), ER visits (2.1±4.5 vs. 1.5±4.4), and hospitalizations (2.3±5.5 vs. 1.3±2.8) in the past 6 months compared to CC.
- CA had more economic burden accrued from HCP visits (\$3,560± \$8,693 vs. \$3,083±\$6,312), ER visits (\$3,310±\$7,229 vs.\$2,427±\$6,947), and hospitalizations (\$37,798±\$91,151 vs. \$21,753±\$46,867) compared to CC.

Table 1: Demographic Characteristics

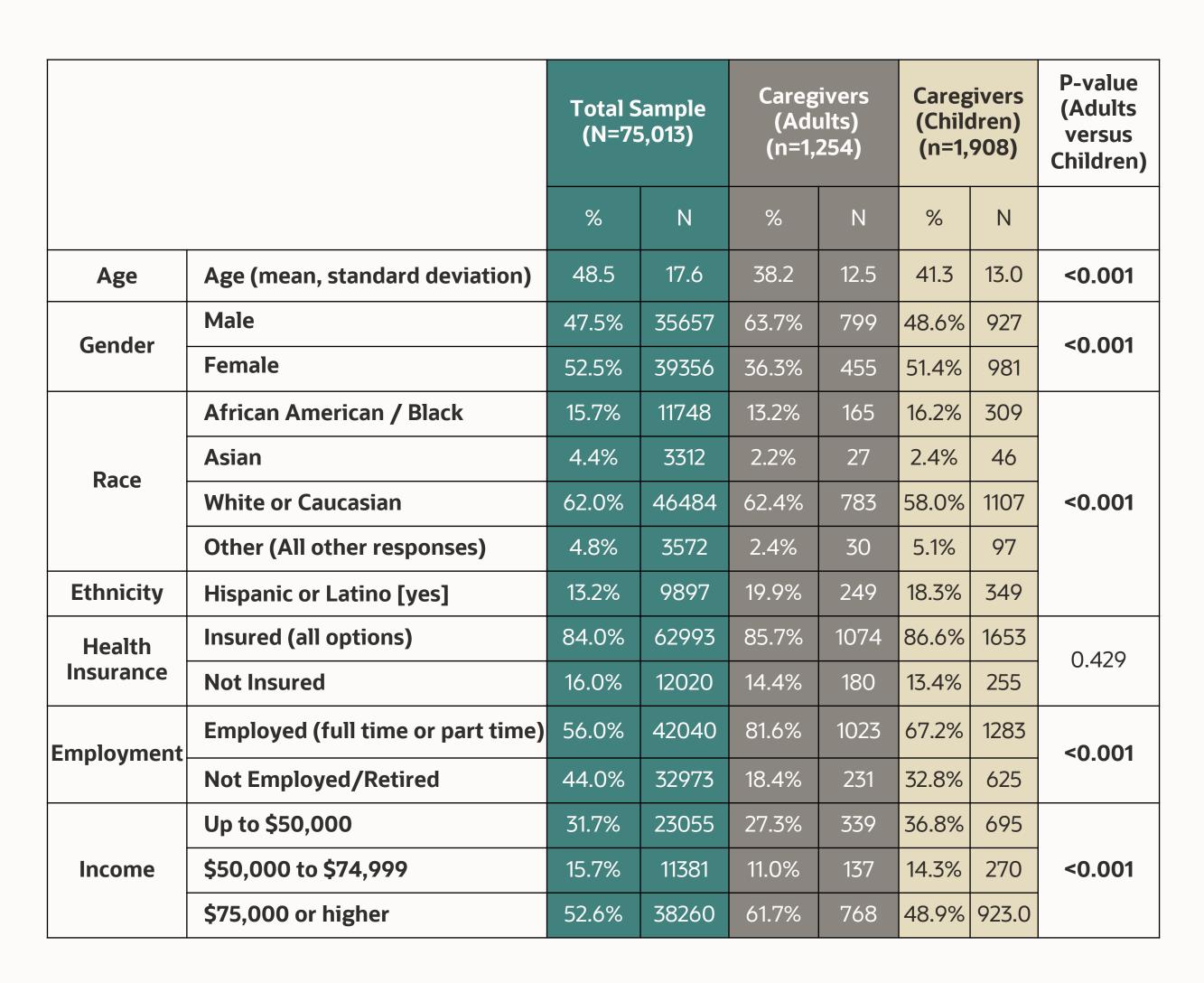


Figure 1: Caregiver Interest in Technology

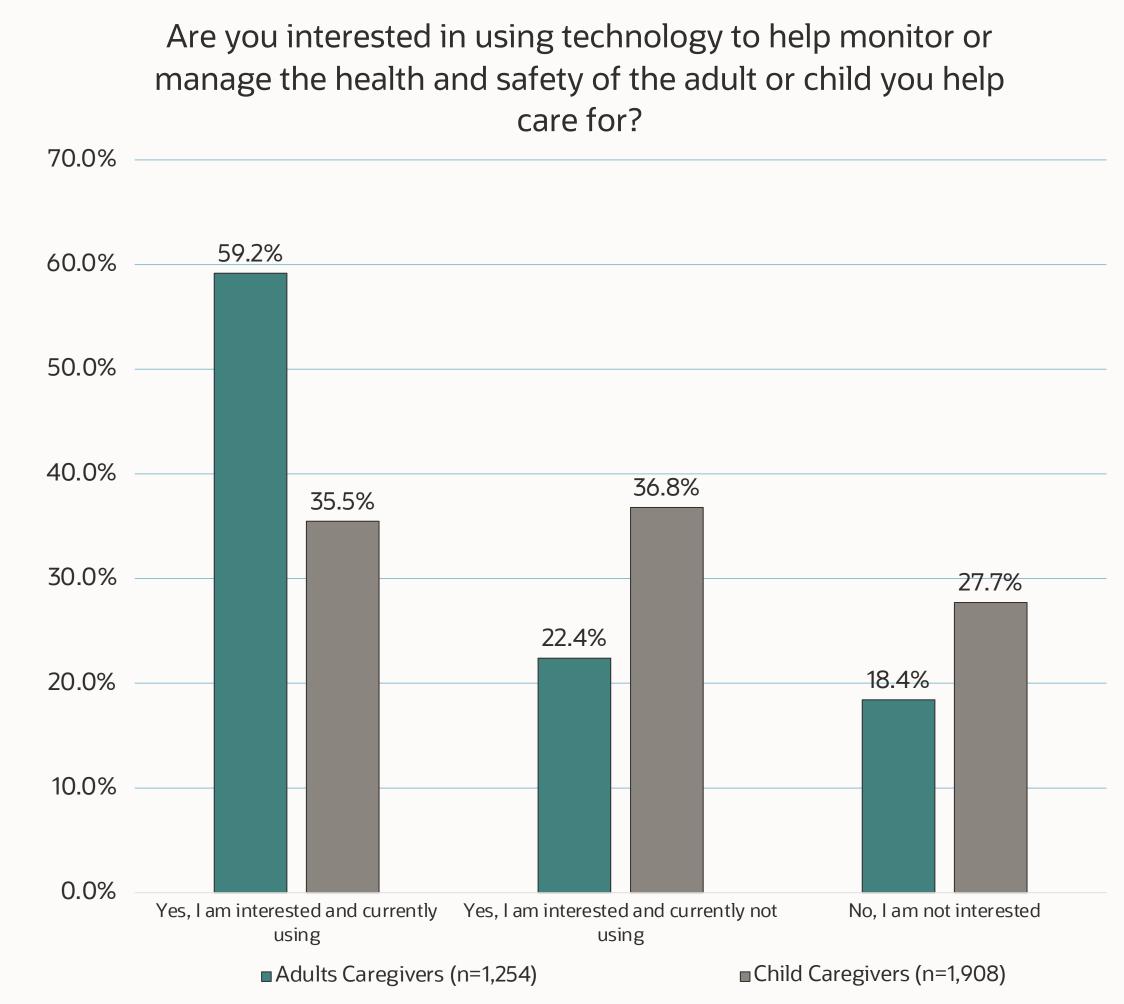
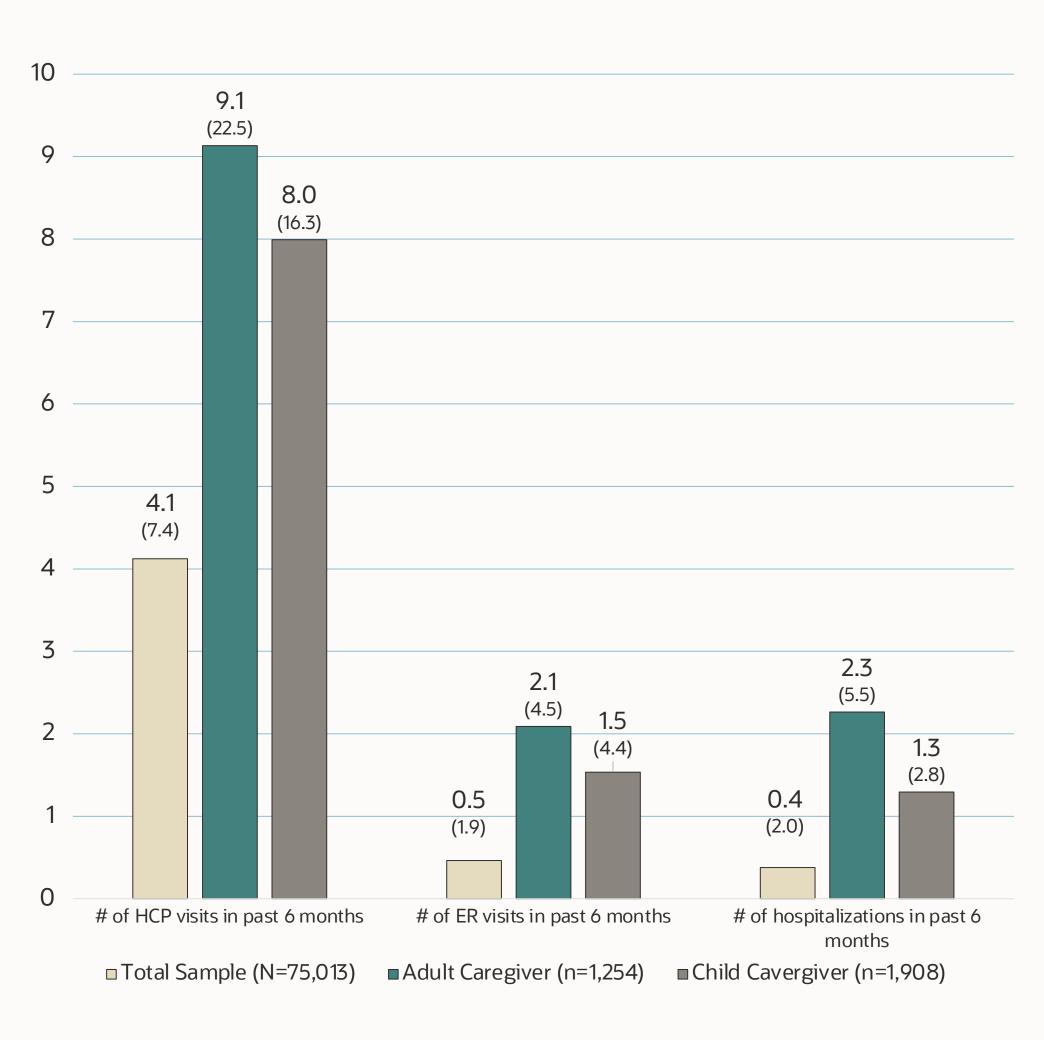
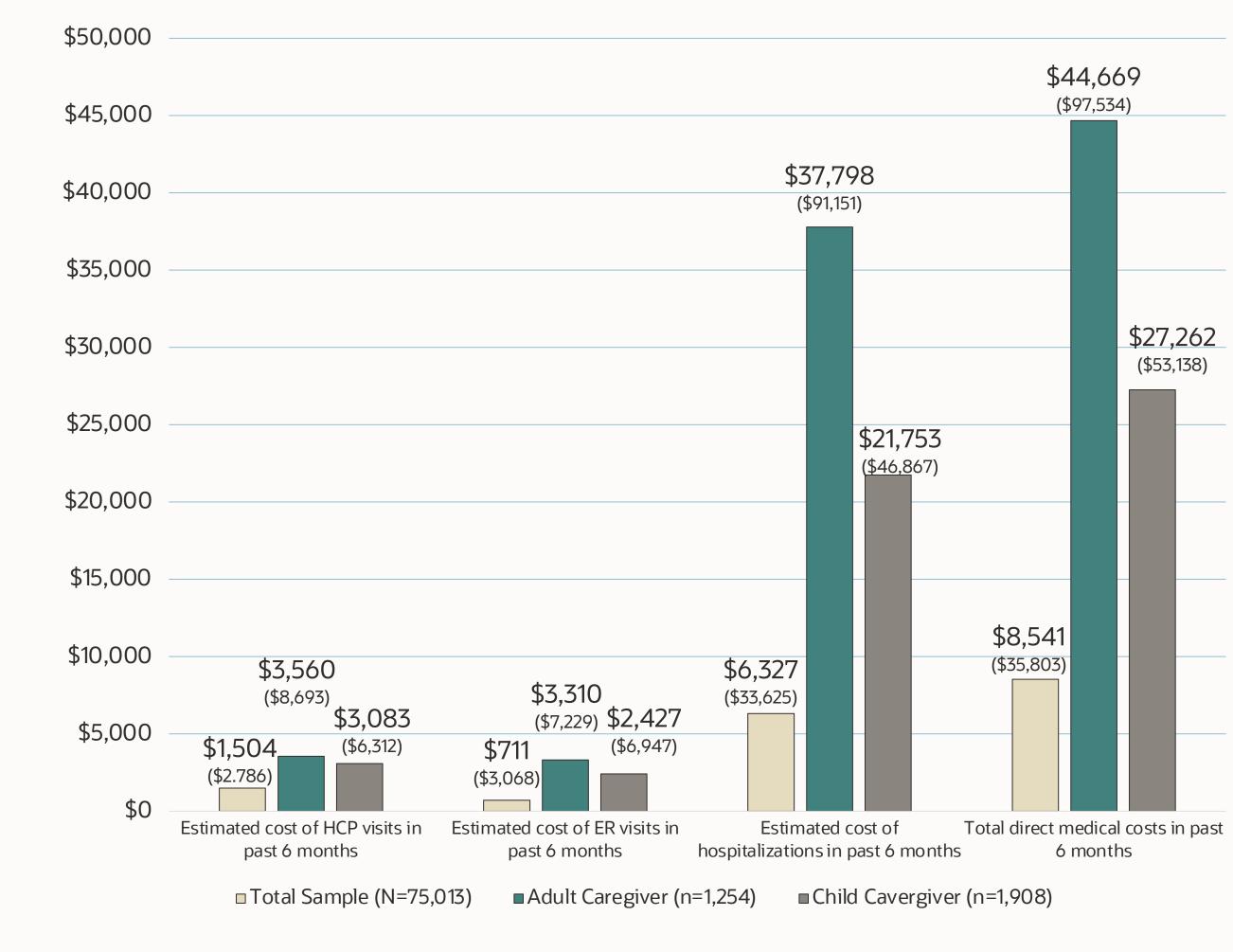


Figure 2: Average Healthcare Resource Use in the Past 6 Months



Standard deviation are in parenthesis under mean values.

Figure 3: Average Estimated Healthcare Resource Expenditure in the Past 6 Months



Standard deviation are in parenthesis under mean values.

Conclusion

CA utilized more healthcare services and faced a higher economic burden compared to CC, suggesting CA may need additional forms of support to continue to provide adequate care. However, both CA and CC may need additional support to mitigate the financial burden due to caregiver responsibilities, as both groups faced higher HCRU and economic impact.

References

- 1. National Institute of Mental Health. Autism spectrum disorder [Internet]. National Institute of Mental Health. National Institute of Mental Health; 2024. Available from: https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd
- Maenner MJ, et al. Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020. MMWR Surveillance Summaries [Internet]. 2023 Mar 24;72(2):1–14. Available from: https://www.cdc.gov/mmwr/volumes/72/ss/ss7202a1.htm.
- 3. Dietz PM, Rose CE, McArthur D, Maenner M. National and State Estimates of Adults with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders. 2020 May 10;50(12).
- 4. Lerner D. Invisible Overtime: What employers need to know about caregivers [White paper]. Boston, MA: Tufts Medical Center, Program on Health, Work and Productivity; 2022 Jan. Available from: https://rosalynncarter.org/wp-
- content/uploads/2022/03/Invisible-Overtime-White-Paper.pdf.

 5. Federal Reserve Bank of St. Louis. Consumer Price Index for All Urban Consumers: Medical Care in the U.S. City Average. Published November 2024. Accessed January 8, 2025. https://fred.stlouisfed.org/series/CPIMEDSL
- 6. Agency for Healthcare Research and Quality. Medical Expenditure Panel Survey. Accessed January 8, 2025. https://www.meps.ahrq.gov/mepsweb/