# Differences in Self-Reported Outcomes of Health & Well-Being Among Adults Diagnosed with Autism Spectrum Disorder as Children Compared to as Adults

Meredith Nicholson; Christopher Smith, PhD; Alison Marvin, PhD; Briella Baer, MHS; Kiely Law, MD, MPH

## Background/Introduction

Existing research regarding the well-being of adults with autism has uncovered struggles with executive functioning and social isolation (Balfe & Tantam, 2010; Bishop-Fitzpatrick et al., 2016; Schmidt et al., 2015). Additionally, an increased awareness of autism spectrum disorder (ASD) has led to new adult diagnoses; this has particularly been the case for adults with histories of mental illness and lifelong struggles with feeling different from others (Geurts & Jansen, 2012; James et al., 2006; Lewis, 2016; Schalkwyk, 2015).

## Objective

The researchers aimed to determine the association between subject age of ASD diagnosis and their health and well-being.

## Methods

Our sample consisted of independent adult participants in the Interactive Autism Network (IAN), a large, validated and verified, internet-mediated research registry. All adults resided in the U.S. and had already received a professional diagnosis of ASD (but not of intellectual disability), and each one completed our "Independent Adult with ASD" questionnaire.

Respondents (n=308) were grouped into two categories: adults diagnosed before reaching the age of 18 and adults diagnosed at 18 years of age or older.

$X^2$ tests were performed using STATA 13 by age of diagnosis (dichotomous variable with 0 = diagnosis before 18 years old and 1 = diagnosis after 18 years old).

### Table 1. Demographics

| Variables | All | First Diagnosis Before Age of 18 | First Diagnosis After Age of 18 | p-value |
|---|---|---|---|---|
| | (n=308) | (n=100) | (n=208) | |
| **Age in Years** | | | | |
| Median (IQR) | 38 (28–50) | 29 (23–40) | 43 (32–53) | <.001*** |
| Range | 18–75 | 18–72 | 20–75 | |
| **Sex Assigned at Birth** | | | | |
| Male, n (%) | 107 (34.7%) | 48 (48.0%) | 59 (28.4%) | <.001*** |
| Female, n (%) | 199 (64.4%) | 51 (51.0%) | 148 (71.1%) | |
| Unk/NR, n (%) | 2 (0.6%) | 1 (1%) | 1 (0.5%) | |
| **Race** | | | | |
| White, n (%) | 279 (90.6 ) | 85 (85.0%) | 175 (84.1%) | <.001*** |
| Non-White, n (%) | 27 (8.8%) | 15 (15.0%) | 31 (14.9%) | |
| Not Reported, n (%) | 2 (0.65%) | 0 (0.0%) | 2 (0.1%) | |
| **Ethnicity** | | | | |
| Hispanic, n (%) | 15 (4.9%) | 5 (5.0%) | 10 (4.8%) | NSD |
| Non-Hispanic, n (%) | 293 (95.1%) | 95 (95.0%) | 198 (95.2%) | |
| **Highest Education Completed** | | | | |
| Less Than High School, n (%) | 10 (3.1%) | 6 (6.0%) | 4 (1.92%) | <.001*** |
| High School, n (%) | 32 (9.8%) | 22 (22.0%) | 10 (4.8%) | |
| Some Post-High School, n (%) | 118 (38.3%) | 42 (42.0%) | 76 (36.5%) | |
| Bachelor's Degree or Higher, n (%) | 144 (46.8%) | 28 (28.0%) | 116 (55.8%) | |
| Other/Unk/NR, n (%) | 4 (1.2%) | 2 (2.0%) | 2 (0.7%) | |
| *Significant at <.05; **Significant at <.01; ***Significant at <.001 | | | | |

Note: Fisher Exact Test used for Sex, Race, Ethnicity and Highest Education Completed; t-test used for Age.

### Table 2: Have You Ever Been Diagnosed or Treated by a Professional for Any of the Following Conditions?

| Condition | All (n=308) | First Diagnosis Before Age of 18 (n=100) | First Diagnosis After Age of 18 (n=208) | p-value |
|---|---|---|---|---|
| ADHD/ADD, n (%) | 135 (43.8%) | 49 (49.0%) | 86 (41.4%) | 0.124 |
| Anxiety, n (%) | 232 (75.3%) | 66 (66.0%) | 166 (79.8%) | 0.023* |
| Obsessive-Compulsive Disorder (OCD), n (%) | 80 (25.9%) | 28 (28.0%) | 52 (25.0%) | 0.557 |
| Depression/Major Depressive Disorder, n (%) | 227 (73.7%) | 58 (58.0%) | 169 (81.25%) | <0.001*** |
| Bipolar Disorder/Manic Depressive Disorder, n (%) | 55 (17.9%) | 16 (16.0%) | 39 (18.75%) | 0.597 |
| High Cholesterol, n (%) | 71 (23.1%) | 18 (18.0%) | 53 (25.6%) | 0.184 |
| High Blood Pressure, n (%) | 57 (18.5%) | 18 (18.0%) | 39 (18.75%) | 0.972 |
| *Significant at <.05; **Significant at <.01; ***Significant at <.001 | | | | |

## Variables

- History of attention deficit hyperactivity disorder (ADHD), attention deficit disorder (ADD), anxiety, obsessive-compulsive disorder (OCD), depression, bipolar depression, high cholesterol or blood pressure
- Whether respondent was currently employed
- Personal comfort interacting with healthcare providers

## Results

- Findings that people diagnosed with ASD as adults were more likely to be diagnosed with anxiety and depression were statistically significant. These findings may reflect a lengthy period of social isolation or misdiagnosis.
- There was no statistically significant difference in the percentage of individuals currently participating in paid work activities.

  [First Dx <18 = 49 (49%); First Dx 18+ = 188 (57%) p-value: 0.31.]
- There was no statistically significant difference in comfort in dealing with healthcare providers, with approximately two-thirds of both those diagnosed as children and those diagnosed as adults being comfortable (i) asking questions; (ii) telling their healthcare professionals if they did not understand something; and (iii) telling the truth.

## Recommendations

- Given the quantity of findings that were not statistically significant by age of diagnosis, services for adults with ASD must be more accessible to those newly diagnosed.
- Ensure that services for adults with ASD are fully equipped to provide for overlapping disabilities, given high rates of co-morbidities irrespective of age of diagnosis.
- Increase the number of professionals capable of diagnosing ASD in adults and insurance coverage for diagnostic services.
- More research is needed to identify barriers to later diagnosis and whether there are gaps in access to needed services and support for this population.

## Conclusion

This research serves to amplify the voices of adults with ASD, and it distinguishes adults diagnosed with ASD as children from those diagnosed later in life. In the face of massive proposed cuts, our research highlights the complexities of the lives of adults with ASD and numerous comorbidities persisting from childhood. The limitations of our data include whether our sample size is generalizable to the ASD population and reliance on self-reporting, with its accompanying uncertainties. Nonetheless, our research demonstrates that in order to ensure this population's health and well-being, we must recognize the full extent of overlapping disparities throughout the lifespan.

## Acknowledgments

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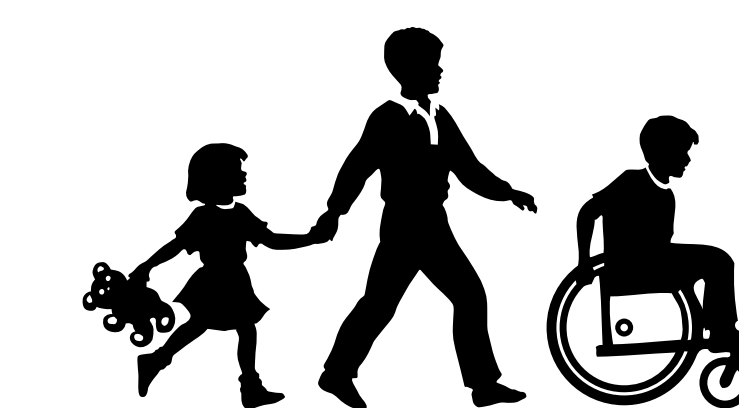
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