Characterizing the daily life, needs, and priorities of adults with ASD from Interactive Autism Network data


1Vanderbilt University Medical Center, Department of Psychiatry; 2Kennedy Krieger Institute, Department of Medical Informatics; 3Vanderbilt University, Department of Pediatrics; Vanderbilt Kennedy Center; 4College of Health Professions, Towson University; 5Johns Hopkins Bloomberg School of Public Health; 6Johns Hopkins School of Medicine

Using online survey data from a large sample of adults with autism spectrum disorder (ASD) and legal representatives of other adults with ASD, we aimed to:

1) Report adult outcomes across a variety of contexts for participants with a wide range of functioning.
2) Summarize these stakeholders’ priorities for future research.

Methods

- Participants included n=255 self-reporting adults with ASD (“SR”) aged 18-71 years (M=38.5; SD=13.1; 64% female; 86% Caucasian), and n=143 adults with ASD aged 18-58 years (M=25.0; SD=8.2; 23% female; 87% Caucasian) whose information was provided by legal representatives (“LR”).
- Most of the SR subsample (73%) was diagnosed later in adolescence or adulthood and thus likely represent more mildly affected adults.
- Data from these first two subsamples (SR and LR) were obtained between the years 2008 and 2012 from an elective online survey created and hosted by the Interactive Autism Network (IAN), an internet registry for North American individuals with ASD and their families.
- In 2014, the original participants who responded to the IAN Adult Survey were invited by email to answer several additional questions in an anonymous online survey. Respondents included n=302 of the SR group (“SR2”) and n=60 of the LR group (“LR2”). The purpose of this second wave of data collection was to replicate additional details on “research priorities” from a report in the current literature (Pellicano et al., 2014 – reference below) and to gathering participants’ priority ratings about specific treatments.

Results

Table 1. Description of four subsamples

Table 2. Reported level of functioning of LR subsample

Results – Research Priorities

Table 3. EDUCATION, VOCATION, and LIVING SITUATION

Table 4. PHYSICAL and MENTAL HEALTH COMORBIDITIES

Table 5. PRIORITIES FOR TREATMENT RESEARCH

Table 6. PRIORITIES FOR GENERAL ASD RESEARCH

Discussion

- Although the self-reporting subsample had much higher rates of employment, marriage/partnership, and independent living than are typically seen in ASD outcome studies, they remained underemployed and had strikingly high rates of comorbid disorders.
- Data on both descriptive outcomes and rated priorities converged with stakeholders’ reported research priorities across ASD, including: vitamins/supplements (except “Other”) within the respective domains (Physical, Mental/Behavioral) to a varying extent.
- More than 90% of SR and LR reported no treatments or interventions.
- Although the self-reporting subsample had much higher rates of employment, marriage/partnership, and independent living than are typically seen in ASD outcome studies, they remained underemployed and had strikingly high rates of comorbid disorders.
- Stakeholders also placed priority on improving public services, health care access, and above all, public acceptance of adults with ASD.
- Findings must be interpreted in light of the self-reporting subsample’s significant proportion of females and of later-diagnosed individuals.
- This study underscores the need for lifespan research, initiatives will benefit from incorporating information from the unique perspectives of adults with ASD and their families.

This work was supported by Autism Speaks; the Simons Foundation; the National Institutes of Health (grant numbers T32-MH18921; K01-MH103500-01A1; K01-MH092958); Vanderbilt Institute for Clinical and Translational Research (UL1TR000445 from NCATS/NIH). We acknowledge IAN Research participants for the generous contribution of their time and efforts.


Note: Means (standard deviations) are shown within group based on priority ratings from 1=Not important at all to 5=Very important.

* Physical and Mental Health were combined into one item (“medical conditions”) for the Pellicano et al. sample.

Note 2. Bold = category of treatment, Regular = specific treatment.

Table 5. PRIORITIES FOR TREATMENT RESEARCH

Table 6. PRIORITIES FOR GENERAL ASD RESEARCH

Discussion

- Although the self-reporting subsample had much higher rates of employment, marriage/partnership, and independent living than are typically seen in ASD outcome studies, they remained underemployed and had strikingly high rates of comorbid disorders.
- Data on both descriptive outcomes and rated priorities converged across subsamples to indicate the need for more adult research on life skills, treatments, co-occurring conditions, and vocational and educational opportunities.
- Stakeholders also placed priority on improving public services, health care access, and above all, public acceptance of adults with ASD.
- Findings must be interpreted in light of the self-reporting subsample’s significant proportion of females and of later-diagnosed individuals.
- This study underscores the need for lifespan research, initiatives will benefit from incorporating information from the unique perspectives of adults with ASD and their families.

This work was supported by Autism Speaks; the Simons Foundation; the National Institutes of Health (grant numbers T32-MH18921; K01-MH103500-01A1; K01-MH092958); Vanderbilt Institute for Clinical and Translational Research (UL1TR000445 from NCATS/NIH). We acknowledge IAN Research participants for the generous contribution of their time and efforts.