

Objectives

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:

- Report adult outcomes across a variety of contexts for participants with a wide range of functioning.
- 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; 22% 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=102 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 gather participants' priority ratings about specific treatments.

Table 1. Description of four subsamples

Abbreviation	Description	Raters	Sample Size	Year(s) Collected	Content
SR	Initial Self-Reporting Subsample	Adults with ASD	n=255	2008-2012	Initial IAN Survey: Descriptive outcome data; Specific practical research priorities
SR2	Follow-up Self-reporting Subsample	Adults with ASD	n=102 out of original 255	2014	Follow-up Survey: Broad research priorities from Pellicano et al., 2014; research priorities around treatment
LR	Initial Legally-Represented Subsample	Legal representatives (guardians) of adults with ASD	n=143	2008-2012	Initial IAN Survey: Descriptive outcome data; Specific practical research priorities
LR2	Follow-up Legally-Represented Subsample	Legal representatives (guardians) of adults with ASD	n=60 out of original 143	2014	Follow-up Survey: Broad research priorities from Pellicano et al., 2014; research priorities around treatment

Table 2. Reported level of functioning of LR subsample

Estimated developmental age	Intellectual Functioning	Social Functioning
Infant to preschooler	30%	35%
Elementary schooler	32%	34%
Middle to high schooler	27%	28%
Young to mature adult	11%	3%

Note. Based on ratings from legally-authorized representatives of n=141 adults with ASD

Reference

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, DOI: 10.1177/1362361314529627

Results – Characterization

Table 3. EDUCATION, VOCATION, and LIVING SITUATION

Education		Vocation		Living Situation			
SR	LR	SR	LR	SR	LR		
Less than High School	4%	Hold paid employment	47%	22%	Live with others	47%	53%
Special Education certificate	4%						
High school graduate/GED	10%	1-9	6%	52%	Spouse/partner	47%	2%
Trade/voc school	6%	10-19	16%	17%	Children	32%	1%
Some college (no degree)	23%	20-29	14%	13%	Housemates of choice	9%	1%
Associate's degree	8%	30-29	13%	13%	Housemates not freely chosen	4%	18%
Bachelor's degree	26%	40+	50%	5%	Parents	35%	77%
Master's degree	15%				Siblings	12%	44%
Ph.D./professional	3%	Of those who work, current work situation (check all that apply):	86%	17%	Other relatives	4%	7%
Other	1%	Regular employment without support	15%	52%	Paid caregivers	–	13%
		(e.g. job coach, special help at work)	5%	5%	Other	6%	3%
		Sheltered workshop or enclave employment	4%	48%			
		Day program with voc activities	5%	13%			
		Internship/Work study	–	–			
		Other	16%	4%			

Table 4. PHYSICAL and MENTAL HEALTH COMORBIDITIES

	SR (n=225)	LR (n=123)
Physical Health		
Sleep problems	79% ¹	61% ¹
Allergies	68% ²	57% ²
Gastrointestinal issues	64% ³	60% ³
Skin conditions	40% ⁴	38% ⁴
Asthma	31% ⁵	24% ⁵
Seizures	16% ⁶	32% ⁶
Diabetes	9% ⁷	5% ⁷
One physical comorbidity	11%	20%
Two or more physical comorbidities	88%	74%
Mental/Behavioral		
Anxiety (various disorders)	76% ¹	50% ¹
Depression	75% ²	36% ²
Attention Deficit Hyperactivity Disorder	40% ³	50% ³
Obsessive Compulsive Disorder	27% ⁴	33% ⁴
Bipolar Disorder	18% ⁵	10% ⁵
Oppositional Defiant Disorder	8% ⁶	14% ⁶
Schizophrenia	1% ⁷	2% ⁷
One mental/behavioral comorbidity	29%	28%
Two or more mental/behavioral comorbidities	57%	45%

Note. Percentages reflect proportion of subsample endorsing diagnosis of each condition.

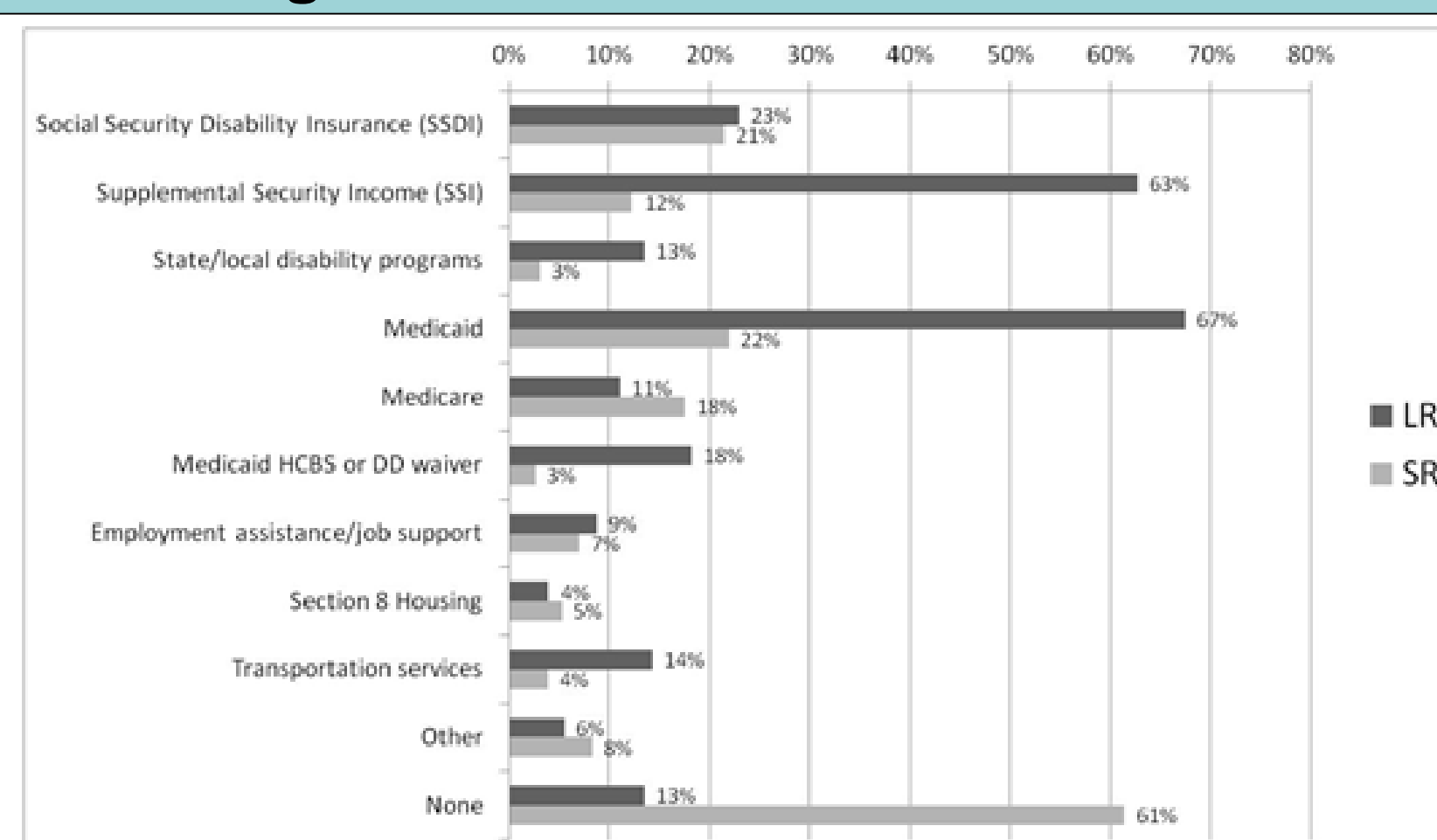
Superscripts reflect ranked prevalence of those conditions (except "Other") within the respective domains (Physical, Mental/Behavioral) within each subsample.

TREATMENTS and INTERVENTIONS

Current use of treatments and interventions by SR (n=225) and LR (n=123):

- Medication: SR = 61%; LR = 72%
- Complementary and alternative medicine, including vitamins/supplements and special diets: SR = 30%; LR = 20%
- Behavioral therapy: SR were twice as likely as LR to use Individual psychotherapy (SR=48%; LR=24%); LR were six times more likely to use Life Skills Training (SR=6%; LR=36%); LR were three times more likely to use Social Skills Training (SR=9%; LR=28%); and Support Groups almost exclusively used by SR (SR=15%; LR=2%).
- School-based therapies were mainly used by LR: Speech language therapy, 28%; Occupational therapy = 15%
- Community supports were mainly used by SR, including: self-help books (36%), spiritual practice (29%), and online communities (18%).
- 9% of SR and 14% of LR reported no treatments or interventions.

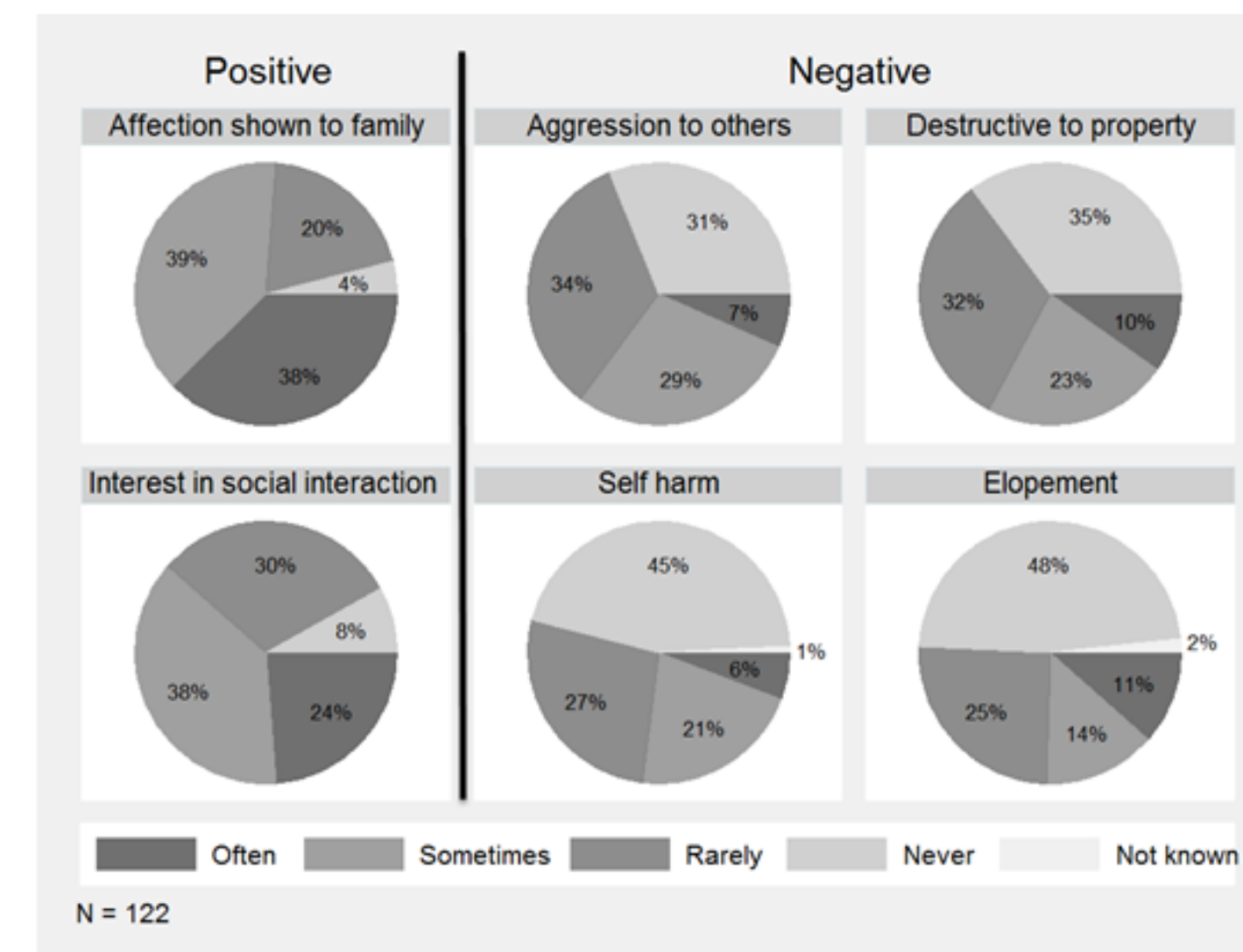
Figure 1. FINANCIAL SUPPORT



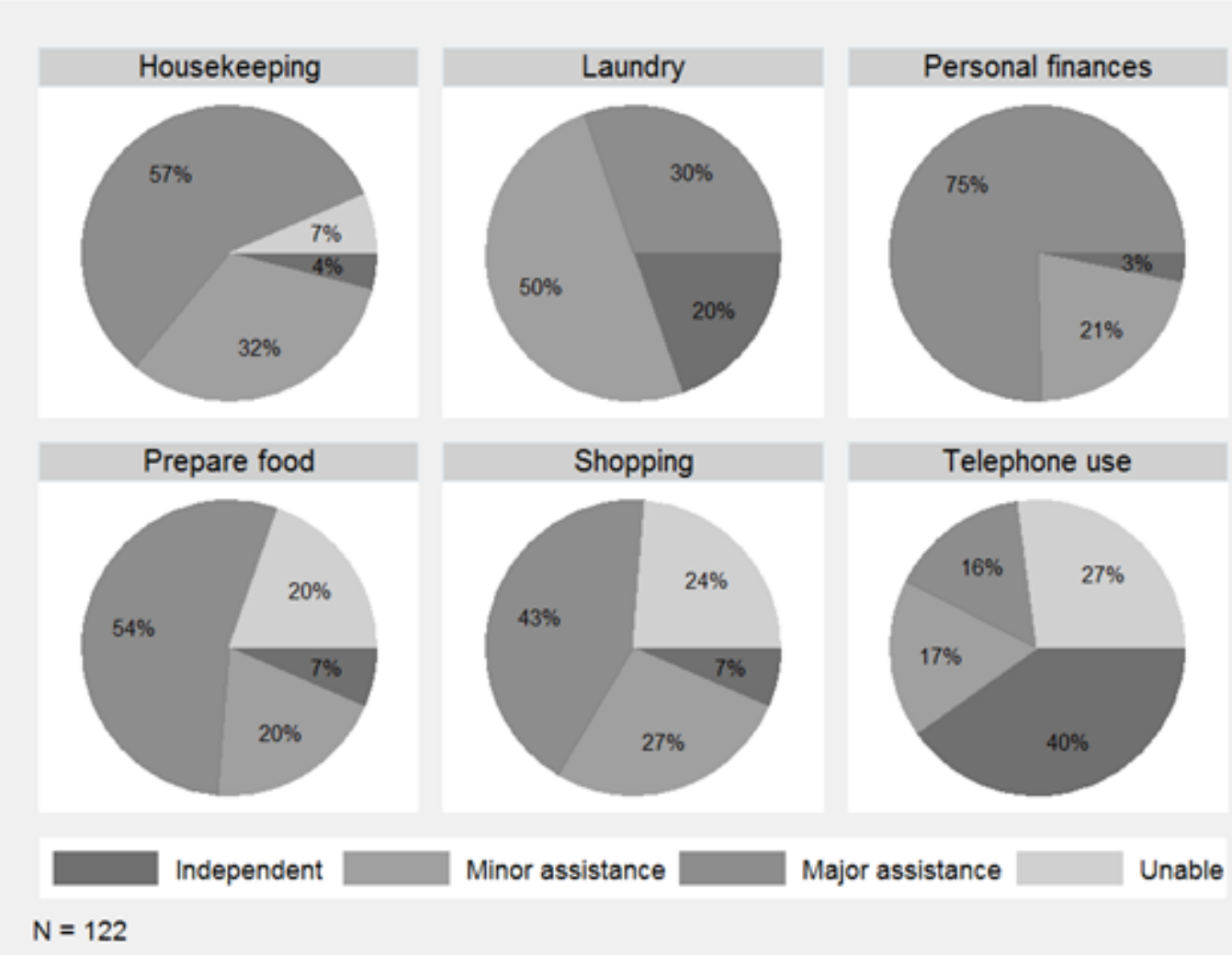
Note. HCBS=Home and Community Based Services program; DD=Developmental Disability. As participants were able to select as many options as were relevant, percentages do not total to 100% within the legally-represented (LR, n=143) and self-reporting (SR, n=254) subsamples.

Results – Characterization (cont.)

Figures 2 & 3. (MAL)ADAPTIVE BEHAVIORS AMONG LEGALLY-REPRESENTED ADULTS



Note. The response "Often" is anchored in the 3 o'clock position on the face of the pie, and the other options proceed clockwise from there.



Note. The response "Independent" is anchored in the 3 o'clock position on the face of the pie, and the other options proceed clockwise from there.

Results – Research Priorities

Table 5. PRIORITIES FOR TREATMENT RESEARCH

Research Priority:	SR (n=100)	Research Priority:	LR (n=60)
Life-skills training	4.22(1.0)	Life-skills training	4.54(0.8)
Social skills training	4.16(1.1)	Behavioral therapy	4.45(0.8)
Vocational skills training	4.08(1.1)	Social skills training	4.31(0.9)
Behavioral therapy	4.04(1.0)	School-based therapy	4.30(1.0)
Regular exercise	3.99(1.2)	Speech/language therapy	4.25(1.0)
School-based therapy	3.98(0.9)	Vocational skills training	4.12(1.1)
Individual psychotherapy	3.97(1.1)	Occupational therapy	4.07(1.0)
Community supports	3.90(1.0)	Community supports	4.07(0.9)
Creative/expressive therapies	3.87(1.1)	Regular exercise	4.02(0.7)
Occupational therapy	3.75(1.2)	Medication	3.93(0.9)
Speech/language therapy	3.67(1.2)	Social activity groups for ASD	3.88(1.1)
Social activity groups for ASD	3.65(1.3)	Peer-matching program	3.76(1.2)
Support groups for ASD	3.64(1.2)	Creative/expressive therapies	3.67(0.9)
Marital or family therapy	3.59(1.1)	Applied Behavior Analysis	3.64(1.1)
Peer-matching program	3.54(1.2)	CAM	3.60(1.1)
Community clubs	3.54(1.2)	Physical therapy	3.53(1.2)
Online communities	3.47(1.3)	Community clubs	3.52(1.2)
Group psychotherapy	3.37(1.2)	Individual psychotherapy	3.31(1.2)
Medication	3.35(1.1)	Support groups for ASD	3.30(1.2)
Physical therapy	3.32(1.2)	Marital or family therapy	3.14(1.1)
Spiritual practice	3.25(1.4)	Vitamins, herbs, supplements	3.12(1.0)
CAM	3.24(1.3)	Group psychotherapy	3.10(1.3)
Applied Behavior Analysis	3.10(1.3)	Special diets	2.96(0.9)
Self-help books	3.02(1.2)	Alternative medicine	2.93(1.1)
Vitamins, herbs, supplements	2.99(1.4)	Online communities	2.88(1.0)
Special diets	2.97(1.4)	Spiritual practice	2.79(1.2)
Alternative medicine	2.66(1.3)	Religious support person	2.33(1.1)
Religious support person	2.65(1.3)	Self-help books	2.07(0.8)

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

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

Results – Research Priorities (cont.)

Table 6. PRIORITIES FOR GENERAL ASD RESEARCH

Initial IAN Adult Survey Research Priority Topics (in order of SR rankings)	SR (n=255)	LR (n=143)	Follow-up Survey Research Priority Topics (based on Pellicano et al., 2014) (in order of SR2 rankings)	SR2 (n=102)	LR2 (n=60)	Pellicano et al. Sample (n=122)
Understanding/Acceptance of Adults with ASD	4.59(0.7) ¹	4.66(0.7) ²	How people with ASD think and learn	4.74(0.5) ¹	4.59(0.8) ⁴	4.28(0.9) ⁴
Employment	4.44(0.8) ²	4.31(1.0) ²	How to improve the life skills of people with ASD	4.54(0.7) ²	4.80(0.4) ¹	4.54(0.8) ²
Current treatments	4.33(0.9) ³	4.63(0.6) ²	Mental and emotional health in people with ASD	4.54(0.7) ²	4.50(0.6) ²	*4.05(1.0) ⁴
Health care access	4.33(0.8) ³	4.59(0.7) ²	How the brains of people with ASD might be different from the brains of people without ASD	4.43(0.8) ³	4.28(0.9) ⁴	3.87(1.1) ¹
Education	4.28(0.9) ³	4.23(0.8) ¹⁰	Recognizing the signs and symptoms of ASD	4.37(0.8) ³	4.32(1.0) ²	4.28(0.9) ⁴
Health conditions	4.27(0.9) ⁴	4.47(0.7) ⁴	How public services can best meet the needs of people with ASD	4.36(0.8) ³	4.68(0.6) ²	4.59(0.7) ¹
Financial issues	4.18(1.0) ⁷	4.35(0.9) ⁷	What the future holds for adults with ASD	4.27(0.9) ³	4.35(0.8) ³	4.43(0.9) ³
Federal/state assistance	4.05(0.8) ⁸	4.55(1.0) ⁴	The role of people with ASD in society today	4.17(0.9) ³	4.08(1.0) ¹⁰	4.15(1.1) ²
Friendship	4.04(1.0) ⁹	3.88(1.0) ¹³	How to best treat the main symptoms of ASD	4.16(1.0) ³	4.78(0.5) ²	3.77(1.2) ²
Daily life	3.94(1.0) ¹⁰	4.29(0.9) ⁹	Learning about different types of ASD	4.12(0.9) ³	3.88(1.0) ¹¹	3.80(1.1) ³
Criminal justice system	3.93(1.1) ¹¹	4.19(1.0) ¹¹	Physical health in people with ASD	4.01(0.9) ¹⁰	4.25(0.8) ³	*4.05(1.0) ²
Living situation	3.90(1.0) ¹²	4.52(0.8) ⁵	The role of genetic factors in causing ASD	3.91(1.0) ¹¹	4.07(1.0) ¹¹	3.45(1.2) ¹⁰
Romantic relationships	3.78(1.1) ¹³	3.18(1.3) ¹³	The role of environmental factors in causing ASD	3.70(1.1) ¹³	4.05(1.1) ¹²	3.22(1.3) ¹²
Sexuality	3.60(1.1) ¹⁴	3.32(1.2) ¹⁴	Finding out how common ASD is (counting how many people have ASD)	3.49(1.0) ¹³	3.38(1.0) ¹⁴	3.37(1.2) ¹¹
Transportation	3.49(1.2) ¹⁵	3.97(1.0) ¹⁵				

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

Note 2. Superscripts reflect relative priority ranking within sample (column).

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

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.

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