

# Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data

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## Abstract

Using online survey data from a large sample of adults with autism spectrum disorder and legal guardians, we first report outcomes across a variety of contexts for participants with a wide range of functioning, and second, summarize these stakeholders' priorities for future research. The sample included  $n=255$  self-reporting adults with autism spectrum disorder aged 18–71 years ( $M=38.5$  years, standard deviation = 13.1 years) and  $n=143$  adults with autism spectrum disorder aged 18–58 years ( $M=25.0$  years, standard deviation = 8.2 years) whose information was provided by legal guardians. Although the self-reporting subsample had much higher rates of employment, marriage/partnership, and independent living than are typically seen in autism spectrum disorder 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 autism spectrum disorder. 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 autism spectrum disorder and their families.

## Keywords

adults, autism spectrum disorder, Interactive Autism Network, outcome, patient-centered outcome research

Given the increase over time in the prevalence of childhood diagnoses of autism spectrum disorder (ASD), the number of identified adults is rising. This is both an anticipated and ongoing phenomenon, yet the fields of autism research and service provision have little capacity to meet adult needs at this point. Over the past 2 decades, a small but distinguished group of researchers has reported on adult outcomes and their predictors in this population (e.g. Howlin et al., 2000; Taylor and Seltzer, 2011), most using data from relatively small but well-characterized samples followed longitudinally over time. Due in part to increased support from several funding and governance agencies, including the US Department of Health and Human Services "Interagency Autism Coordinating Committee" (IACC), which has listed the future of adults with ASD as one of seven strategic areas of focus and funding, the

broader field is now turning greater attention to adult issues in autism research.

Given their unique firsthand experience, adults with ASD and their families are de facto experts on the needs, problems, and priorities of adults with ASD. The autism

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research community has a valuable opportunity to incorporate their perspectives into decision-making around research initiatives, funding, and public health campaigns that will maximize impact on the next several age cohorts of adults with ASD. Using survey data from a large ( $n=398$ ) North American sample of adults with ASD or legal representatives (usually parents/caregivers) of the same, the first goal of this article is to describe the lives of both “high-functioning” and less-able adults with ASD in terms of education, employment, living situation, financial support, adaptive skills, strengths and special interests, physical and mental health, and treatment and service use. The second aim is to summarize these stakeholders’ priorities for future research.

### Adult outcomes in ASD

Historically, outcomes in adults with ASD have been operationalized in terms of functional language, independent living, employment, and friendship/social engagement. Consensus among most reports is that the majority of adults with ASD have “poor” outcomes in these areas: with the exception of attainment of functional language in 70%–80% of most samples, reports indicate generally low levels of vocational and social engagement even in relation to overall cognitive, language, and adaptive skills of many adult participants (see Henninger and Taylor, 2013; Howlin and Moss, 2012; Levy and Perry, 2011). For example, national survey data indicated that young adults with ASD had the highest rates of “no participation” (i.e. in education or employment) compared to those in other disability categories sampled, and that only about half the ASD group had held some form of paid employment within 6 years of high school graduation (Shattuck et al., 2012). However, adult outcome findings differ based on rating systems used, historical time period of data collection and other contextual factors, and demographics of samples (e.g. IQ, age). Some recent literature suggests that by taking into account person–environment fit, outcomes may be more positive than they appear to be from objective markers of acceptability (Billstedt et al., 2011).

This study is unique in the context of previous literature for several reasons related to our self-reporting subsample. Most of these adults (73%) were diagnosed later in adolescence or adulthood and thus likely represent more mildly affected adults. Because most existing ASD outcome studies have focused on adults diagnosed as children, this work presents a novel view of adult outcomes in high-functioning individuals with later diagnoses who would not have received early autism-focused services and who may be underrepresented in research due to minimal clinical contact. Another novelty is that 64% of the self-reporting subsample was female, representing the largest proportion of adult women ( $n=164$ ) in an ASD outcome report. Thus, this study is unique in that we are able to provide statistics

about daily life across a variety of contexts, using a large sample that encompasses a wide age range (18–71 years old), range of functioning, and gender diversity. Finally, this adult outcome report is crucial in relation to the second aim of this article, insofar as understanding the circumstances of this sample allows us to better understand these specific participants’ priorities for ASD research (e.g. as compared with a more male-weighted sample diagnosed in early childhood).

### Research priorities in adults with ASD and their families

Patient-centered outcomes research has been effecting change among the medical community as a method of better understanding patients’ experiences and needs and in turn helping them to make informed health care decisions (Barry and Edgman-Levitan, 2012). It has been linked to patient satisfaction and superior health outcomes (Greene and Hibbard, 2012). A recent study by Pellicano et al. (2014) successfully engaged stakeholders in ASD research by directly ascertaining their views on autism research priorities in general, and specifically those forwarded by funding mandates in the United Kingdom. They found that in contrast with UK funding patterns, individuals with ASD, families of children and adults with ASD, ASD service providers, and researchers largely agreed that future priorities for autism research should lie in practical areas that make a difference in daily life. In particular, affected adults and families prioritized research that would identify effective public services and evidence-based interventions and develop programs for life skills enhancement. Compared to researchers, these personal stakeholders also put high priority on building understanding of the place of people with ASD in society and studying comorbidity risk. This study replicates and extends the survey portion of the Pellicano et al. findings from an adult perspective, with a larger sample of self-reporting adults rating expanded content that allows us to pinpoint more specific priorities in “practical areas of life.”

### Methods

In this study, we analyzed data from four subsamples (detailed below; see also Table 1).

#### *Initial data collection: participants and measures*

Data from the first two subsamples 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. Individuals with ASD who were previously registered with IAN and whose birthdates

**Table 1.** Key to the 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

SR: self-reporting; ASD: autism spectrum disorder; SR2: follow-up self-reporting subsample; IAN: Interactive Autism Network; LR: legally represented; LR2: follow-up legally authorized representative ratings about adult wards with ASD.

placed them at age 18 years or older during the data collection received an emailed invitation to complete the survey, as did previously IAN-registered parents/guardians of adults aged 18 years and older. Eligible IAN registrants also could find a link to the open surveys if they were searching the IAN website.

**Initial self-reporting subsample (SR).** Self-report data were collected from 255 adults with ASD aged 18–71 years ( $M=38.5$  years, standard deviation ( $SD$ )=13.1 years; 64% female; 86% Caucasian, 6% multiple races; 5% Hispanic). Respondents appeared to comprise a relatively mild and later-diagnosed group: 65% received Asperger's Syndrome as their initial ASD dx and 73% were diagnosed with ASD after the age of 18 years (only 11% of this subsample received their first ASD diagnosis in the toddler-to-preschool years). A doctoral-level professional or a team of professionals reportedly made the initial diagnosis for 88% of the SR sample.

**Initial legally represented subsample (LR).** Reports from legally authorized representatives were obtained for an additional 143 adults with ASD aged 18–58 years ( $M=25.0$  years,  $SD=8.2$  years; 22% female; 87% Caucasian, 3% African American; 6% multiple races; 10% Hispanic). Among the LR group, 70% received "autism/Autistic Disorder" as their first ASD diagnosis and 70% reported a current diagnosis consistent with their first diagnosis. Initial ASD diagnoses were made in ages 1–5 years for 60% and before 18 years for 90%. Almost all LR participants (95%) received their first ASD diagnosis from a doctoral-level professional or a team, and 100% reported an ASD diagnosis from professionals of the same level of credentialing at some point in life. Although we have no measured IQ data on which to compare the subsamples, the LR group is thought to represent generally less cognitively able adults in comparison to the SR group, by virtue of the former group requiring legal guardianship beyond the age of 18 years. See Table 2 for

**Table 2.** Estimated intellectual and social functioning of the legally represented 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

ASD: autism spectrum disorder.

Based on ratings from legally authorized representatives of  $n=141$  adults with ASD in response to the following items: *A person with ASD may have varied levels of ability across many areas of functioning. Still, it is helpful for researchers to have an overall assessment of functioning level. If you are willing, please indicate your average impression of [name]'s overall level of [intellectual/social] functioning by choosing from the list below to fill in the blank.*

*[Name] functions [intellectually/socially] at the level of a typical \_\_\_\_\_.*

1. Infant (younger than 12 months old)
2. Toddler (1–3 years old)
3. Pre-school or kindergarten child (4–5 years old)
4. Early elementary school child (6–8 years old)
5. Late elementary school child (9–11 years old)
6. Middle school child (12–14 years old)
7. High school child (15–18 years old)
8. Young adult (19–25 years old)
9. Mature adult (26 years and older)

guardians' ratings of the estimated intellectual and social functioning of the LR group (comparison data in the SR group were not collected).

The distinct SR and LR surveys were developed by IAN staff, with input from adults with ASD and their families. They included questions related to education, jobs, housing, financial support, adaptive behavior skills, strengths and special interests, physical and mental health, treatment and service use, as well as questions on demographics, diagnosis, and past participation in research. Note that most of the adaptive behavior/daily functioning questions were asked only of the LR group. Response scales varied by question

type. To view the original surveys, including all questions and response options, see [http://www.iancommunity.org/cs/ian\\_research\\_questions/adults\\_with\\_asd\\_questionnaire](http://www.iancommunity.org/cs/ian_research_questions/adults_with_asd_questionnaire) and [http://www.iancommunity.org/cs/ian\\_research\\_questions/adults\\_with\\_asd\\_lar\\_questionnaire](http://www.iancommunity.org/cs/ian_research_questions/adults_with_asd_lar_questionnaire)

### *Follow-up data collection: participants and measures*

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. 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) and to gather participants’ priority ratings about specific treatments. Note that because the follow-up survey was anonymous, we were unable to link participants’ responses on the initial IAN Adult Survey to their responses on this follow-up survey.

*Follow-up self-reporting subsample (SR2).* Out of the original SR subsample,  $n=102$  self-reporting adults with ASD aged 22–67 years ( $M=45.2$  years,  $SD=13.5$  years; 57% female) responded to our follow-up survey in 2014.

*Follow-up legally represented subsample (LR2).* Out of the original LR subsample, legally authorized representatives of 60 adults with ASD aged 21–51 years ( $M=29.5$  years,  $SD=8.1$  years; 27% female) responded to the 2014 survey.

Details about the diagnostic and educational characteristics of SR2 and LR2 respondents and relationships to LR2 reporters are available from the authors. Participants were asked to rate the importance of the 13 topics associated with autism research funding in the United Kingdom (which are highly consistent with North American autism research funding platforms) derived from Pellicano et al. (2014); for the full list of topics, see the middle column of Table 6. This was intended to be a direct replication of the survey portion of that work, with three modifications: (1) topic wording was revised from question format (e.g. “To what extent is autism caused by genetic factors?”) to simple phrases (“The role of genetic factors in causing autism”) to reduce verbal load on respondents along a greater range of ability levels (see the middle column of Table 6 for these reworded topic phrases); (2) the topic “Why do autistic people appear to be more at risk from some medical conditions than non-autistic people?” was simplified and separated into the following two items: “Physical health in people with ASD” and “Mental and emotional health in people with ASD” in order to ascertain which of these comorbidities was a more pressing concern for respondents; and (3) whereas Pellicano et al. (2014) randomized the presented order of these topics, we were unable to do so in our survey platform. We used the same response scale as Pellicano et al.: 1 = not important at all,

2 = of little importance, 3 = moderately important, 4 = important, and 5 = very important. Finally, the follow-up 2014 survey separately assessed stakeholders’ priorities for future study of treatments, interventions, and community supports. These items were based on the original IAN Adult Survey list of possible treatments that participants were receiving, with several additional entries from current common intervention practices and supports.

## **Results**

### *Descriptive data on adult outcomes from initial IAN Adult Survey*

*Education and vocation.* See Table 3 for details of the educational attainment and current vocational activities of the subsamples. A total of 42% of the SR subsample had a bachelor’s degree or higher. About half the subsample (47%) held paid employment; of those who were employed, half worked full-time. The majority of working SR respondents (72%) wanted more hours but could not get them. Most of this high-functioning sample who did work endorsed holding regular jobs without support, although at least 19% participated in some form of supported employment and 16% reported “other” work situations.

Of the participants reported on by legal guardians (LR), 75% had achieved a high school degree or less (see Table 3); 22% held paid employment, although half of those worked only 1–9 h/week and nearly all had a special placement or work supports. Of the 32 employed, 43% desired more hours.

Of the 99 LR and 116 SR participants who answered follow-up questions about not working, 41% of the SR subsample and 22% of the LR subsample wanted to but could not find work; 36% of both groups did not wish to work. Among both SR and LR participants, 60% found the workplace too challenging; 47% of the SR subsample and 20% of the LR subsample had faced discrimination in the workplace. A number of participants felt that work would interfere with federal or state benefits (29% SR subsample; 16% LR subsample).

*Residential settings and financial support.* A total of 20% of SR respondents lived alone, compared to 7% of LR respondents. Of the rest, about half (47%) of the SR group lived with a spouse or partner, and the majority of the LR subsample lived with parents. See Table 3 for additional details on living situations.

In total, 36% of SR participants and 87% of LR participants received federal or state benefits, such as Supplemental Security Income or Medicaid (see supplemental Figure 1 for details, available online). Of these, 60% of the LR group and 26% of the SR group received more than half to full financial support from their families, with 35% LR (24% SR) receiving one-half or less of their

**Table 3.** Education, vocation, and living situation among the SR and LR subsamples.

Education	Vocation		Living situation	
	SR (%)	LR (%)	SR (%)	LR (%)
Less than high school	4	26	47	22
Special education certificate	4	28	47	22
High school graduate/GED	10	21	6	52
Trade/vocational school	6	1	16	17
Some college (no degree)	23	10	14	13
Associate's degree	8	1	13	13
Bachelor's degree	26	1	50	5
Master's degree	15	–	–	–
PhD/professional	3	–	–	–
Other	1	12	–	–
	100% of n = 254	100% of n = 143		
			Of those who work, current work situation (check all that apply)	
			Regular employment without support	86
			Supported employment (e.g. job coach; special help at work)	17
			Sheltered workshop or enclave employment	15
			Day program with vocational activities	52
			Internship/work study	4
			Other	48
				13
				–
				4
			Of those who live with others (check all that apply)	
			Live with others	80
			Spouse/partner	93
			Children	47
			Housemates of choice	32
			Housemates not freely chosen	9
			Parents	4
			Siblings	18
			Other relatives	77
			Paid caregivers	12
			Other	44
				7
				13
				–
				6
				3

SR: self-reporting; LR: legally represented; GED: General Educational Development.

financial support from their families, and 5% LR (vs 50% SR) receiving no family financial support.

**Daily functioning.** Among the LR subsample, the vast majority (79%) had spoken language. Among those who were able to speak, half (54%) exhibited mainly pragmatic difficulties with language, while one-quarter (26%) experienced ongoing difficulty communicating wants and needs. Of the  $n=43$  who responded to follow-up questions on atypical language use, 40% used sign language, 26% high-tech assistive device (e.g. voice output system), 40% low-tech assistive device (e.g. Picture Exchange Communication System), and 95% reportedly used gestures.

The majority of LR fed (93%), dressed (87%), toileted (86%), showered/bathed (65%), and tied their own shoes (54%) without assistance. See supplemental Figure 2 for details on participation in household chores such as shopping, cooking, and laundry. Approximately one-fifth of LR participants (21%) participated in managing finances with assistance, while three-quarters of the subsample were unable to do so.

Most adults in the LR group showed affection (77%) and an interest in social interactions outside the family (62%). Approximately 25%–35% exhibited self-injury, aggression, destructiveness, and/or wandered off (see supplemental Figure 3 for details).

**Abilities and special interests.** When asked about strengths and skills that participants attributed in part to ASD, approximately 70%–80% of the SR group endorsed ability for intense focus, honesty, creativity, good memory, and sense of justice. The most common strengths in the LR group were good memory (69%), intense focus (60%), and honesty (47%). The majority (80% or more) of both subsamples had special interests. SR participants were able to incorporate special interests in their jobs (34%), education (56%), and relationships (49%, compared to 23% of LR participants), although they sometimes got in the way of success at work, school, or relationships for approximately half (45%) of both subsamples; 23% of SR participants and 15% of LR participants had got into more significant trouble as a result (i.e. addictive behavior or law-breaking).

**Co-occurring health conditions and treatments.** Three-quarters of the SR sample reported anxiety (76%) and/or depression (75%) diagnoses, with attention deficit hyperactivity disorder (ADHD) endorsed by 40%. The LR sample reported somewhat lower but still elevated rates of psychological comorbidity (see Table 4). Rates of commonly co-occurring physical health problems were similar across groups, and most often involved sleep, allergies, gastrointestinal (GI) issues, skin conditions, and asthma (see Table 4). The majority of both subsamples were taking medication for ASD or co-occurring conditions (see Table 5). Rates of service usage were mixed, with

individual psychotherapy emerging as highly prevalent in the SR group (48%); approximately one-third of the LR group participated in more traditional ASD therapies such as social skills training and speech/language therapy (see Table 5). We lacked data to control for how accessible each of the service types was to these adults.

### Research priorities of adults with ASD and their families

We assessed stakeholders' priority endorsement of three different sets of research topics. First, 15 specific areas for research were queried for importance in the original IAN Adult Survey. As these areas were very practical in nature, they coincidentally extend the Pellicano et al. (2014) findings, in which UK stakeholders indicated that more research was needed in "areas that make a difference to people's day-to-day lives." In our 2014 follow-up data collection, we replicated the survey portion of Pellicano et al., which assessed stakeholder prioritization of broad options for general ASD research based on current funding patterns (thus, topics not necessarily focused on "practical" areas of life for people with ASD) and additionally asked about specific priorities for future research in interventions/supports.

All results are summarized in Tables 5 and 6. As they encompass three item sets rated by five distinct samples (SR, LR, SR2, LR2, and self-reporting adults from the Pellicano et al., 2014 sample), we summarize in text only those rated among the top priorities across multiple (sub) samples. Across either "practical" or broad areas of research, these include (with means given on a scale from 1=not Important to 5=very Important) the following: *understanding and acceptance of adults with ASD* ( $M=4.59$  or higher across groups); *how to improve the life skills of people with ASD* ( $M=4.54+$  across groups); *mental and emotional health in people with ASD* ( $M=4.50+$  in the two groups given this specific option, that is, not combined into "medical conditions" as in Pellicano et al., 2014); *how public services can best meet the needs of people with ASD* ( $M=4.36+$ ); and *current treatment and health care access* (both at  $M=4.33+$  across groups). See Table 6 for details, including patterns of priority unique to specific (sub)samples. Finally, SR2 and LR2 follow-up samples largely converged in their ratings of interventions/supports to prioritize for future research (see Table 5), with *life skills training* ( $M=4.22$  or higher across groups), *social skills training* ( $M=4.16+$ ), *vocational skills training* ( $M=4.08+$ ), and *regular exercise* ( $M=3.99+$ ) most strongly endorsed across groups.

### Discussion

Despite the later-diagnosed and high-functioning nature of our self-reporting subsample, our findings were consistent with prior research in indicating that adults with ASD tend

**Table 4.** Physical and mental/behavioral health issues in the adult self-report and legally represented subsamples.

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

SR: self-reporting adults with ASD; LR: legally authorized representative ratings about adult wards with ASD.

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.

to be underemployed and to have two or more comorbid physical and/or mental health condition(s). Of note, data on descriptive outcomes and rated priorities converge in *both* our large self-reporting subsample and the generally less-able group represented by legal guardians to indicate that more adult research is needed particularly on life skills, co-occurring mental and emotional health conditions, treatments, and vocational and educational opportunities. Priority was also placed on improving public services, health care access, and above all other options, public acceptance of adults with ASD.

Our findings must be interpreted through the lens of our sample demographics, which represent both a significant strength and a limitation of this study. The SR subsample likely included many self- or spouse-identified individuals who sought a community diagnosis of ASD in adulthood; while this is not representative of many of the research samples of adults who have been carefully phenotyped since their early childhood, it does, however, represent an adult ASD population about whom little is known beyond preliminary reports of significant risk and high health care needs (Cassidy et al., 2014). In addition, these data represent a disproportionate number of women with ASD (64% of the SR subsample) compared to general ASD population gender ratios of 4 or 5 males to 1 female (due to space limitations, we will summarize gender differences in these data in a separate brief report).

**Outcomes.** Our self-reporting subsample of high-functioning, later-diagnosed adults reported much better outcomes

than those typically observed in ASD adult research. They endorsed higher rates of employment, almost half had a post-secondary degree, and many were working in areas that coincide with their special interests. The slight majority lived alone or with a spouse or partner, and half received no family financial support. This provides a glimpse into a population of adults with identified ASD who are "making it" in many ways. But even among this unique group, there are highly significant areas of concern. Many were underemployed, with only one-quarter holding full-time jobs. Half the subsample reported workplace discrimination, and the majority found it too challenging to hold a job. In addition, comorbid psychological disorders were an enormous problem, with three-quarters reporting anxiety disorders and three-quarters reporting depression diagnoses; rates of physical health conditions were similarly elevated.

Outcomes in our sample of legally represented adults with ASD were more consistent with general ASD outcome studies characterized by low rates of employment and independent living (e.g. Anderson et al., 2013). Approximately 90% of the LR subsample lived with family or paid caregivers and received state or federal financial assistance. A very small percentage (10%) held paid employment for more than 10h/week. What we cannot know from these close-ended surveys is what adults with ASD do with their time if they are not employed and do not have access to services and programming (which are extremely limited for these age groups in most geographic areas). Evidence suggests that underemployment and lack

**Table 5.** Treatments and professional intervention: current use and priority for future research.

	Current use: SR (n = 225)	Current use: LR (n = 123)	Priority for future study: SR2 (n = 100)	Priority for future study: LR2 (n = 60)
Medication	61% <sup>1</sup>	72% <sup>1</sup>	3.35 (1.1)	3.93 (0.9) <sup>7</sup>
Complementary and alternative medicine	30% <sup>4</sup>	20%	3.24 (1.3)	3.60 (1.1)
Vitamins, herbs, supplements	–	–	2.99 (1.4)	3.12 (1.0)
Special diets	–	–	2.97 (1.4)	2.96 (0.9)
Alternative medicine	–	–	2.66 (1.3)	2.93 (1.1)
Behavioral therapy	–	–	4.04 (1.0)	4.45 (0.8)
Individual psychotherapy	48% <sup>2</sup>	24%	3.97 (1.1) <sup>5</sup>	3.31 (1.2)
Group psychotherapy	8%	6%	3.37 (1.2)	3.10 (1.3)
Marital or family therapy	4%	2%	3.59 (1.1)	3.14 (1.1)
Applied behavior analysis	3%	12%	3.10 (1.3)	3.64 (1.1)
Support groups for ASD	15%	2%	3.64 (1.2)	3.30 (1.2)
Social skills training	9%	28% <sup>3</sup>	4.16 (1.1) <sup>2</sup>	4.31 (0.9) <sup>2</sup>
Vocational skills training	–	–	4.08 (1.1) <sup>3</sup>	4.12 (1.1) <sup>4</sup>
Life skills training	6%	36% <sup>2</sup>	4.22 (1.0) <sup>1</sup>	4.54 (0.8) <sup>1</sup>
Social activity groups for ASD	–	–	3.65 (1.3)	3.88 (1.1)
Peer-matching program	–	–	3.54 (1.2)	3.76 (1.2)
School-based therapy	–	–	3.98 (0.9)	4.30 (1.0)
Speech/language therapy	4%	28% <sup>3</sup>	3.67 (1.2)	4.25 (1.0) <sup>3</sup>
Occupational therapy	5%	15%	3.75 (1.2)	4.07 (1.0) <sup>5</sup>
Physical therapy	6%	7%	3.32 (1.2)	3.53 (1.2)
Creative/expressive therapies	–	–	3.87 (1.1)	3.67 (0.9)
Community supports	–	–	3.90 (1.0)	4.07 (0.9)
Spiritual practice	29% <sup>5</sup>	10%	3.25 (1.4)	2.79 (1.2)
Religious support person	7%	2%	2.65 (1.3)	2.33 (1.1)
Regular exercise	–	–	3.99 (1.2) <sup>4</sup>	4.02 (0.7) <sup>6</sup>
Community clubs	–	–	3.54 (1.2)	3.52 (1.2)
Self-help books	36% <sup>3</sup>	6%	3.02 (1.2)	2.07 (0.8)
Online communities	18%	0	3.47 (1.3)	2.88 (1.0)
Other	14%	9%	–	–
None	9%	14%	–	–

ASD: autism spectrum disorder; SR: initial self-reporting subsample; LR: initial legally authorized representative ratings about adult wards with ASD; SR2: follow-up self-reporting subsample; LR2: follow-up legally authorized representative ratings about adult wards with ASD.

Percentages in first two data columns reflect proportion of SR or LR subsample endorsing current use of each type of treatment. Means (standard deviations) in the second two data columns are shown within group based on priority ratings of 1 = not important at all to 5 = very important. Superscripts reflect relative priority ranking within sample (column) for all treatments except "Other."

of purposeful engagement of one's time are precursors to physical and mental health problems and behavioral decline over time in ASD, as they are in other populations (see Taylor et al., 2014; Taylor and Hodapp, 2012). Consistent both with those findings and with previous reports of comorbidity rates in ASD, the vast majority of both subsamples had one or more physical and mental health problem in addition to ASD and took medication for either ASD-related or co-occurring symptoms.

Despite these problems, it is encouraging that a large proportion of the LR subsample had pragmatic language problems alone (though approximately one-fifth of the sample had no language and an additional fifth had difficulty communicating wants and needs). The vast majority was independent in feeding, dressing, and toileting and showed affection within the family and interest in social

interactions outside the family. One-quarter to one-third exhibited maladaptive behaviors (e.g. self-injury, aggression, destructiveness, and/or elopement). The implications of this diverge, in that the somewhat low adult rates of behavioral issues provide hope for improvement to families struggling with such problems in childhood (e.g. see Table 1 of Hill et al., 2014 for comparison rates of aggressive behaviors in children with ASD, ranging from approximately 8% to 79% of samples reviewed). However, the remaining problems highlight the need for access to high-quality behavioral treatments often lacking in adulthood.

**Research priorities.** There was surprising consistency across both the milder and more severely affected subsamples in prioritizing research on life skills, mental and emotional health, and public services for adults with ASD.

**Table 6.** Stakeholders' mean priority ratings of ASD research topics from the initial and follow-up surveys.

Initial IAN Adult Survey research priority topics ( <i>in order of SR rankings</i> )	SR (n=255)	LR (n=143)	Follow-up survey research priority topics (based on Pellicano et al., 2014; <i>in order of SR2 rankings</i> )	SR2 (n=102)	LR2 (n=60)	Pellicano et al. sample (n=122)
Understanding/acceptance of adults with ASD	4.59 (0.7) <sup>1</sup>	4.66 (0.7) <sup>1</sup>	How people with ASD think and learn	4.74 (0.5) <sup>1</sup>	4.59 (0.8) <sup>4</sup>	4.28 (0.9) <sup>4</sup>
Employment	4.44 (0.8) <sup>2</sup>	4.31 (1.0) <sup>8</sup>	How to improve the life skills of people with ASD	4.54 (0.7) <sup>2</sup>	4.80 (0.4) <sup>1</sup>	4.54 (0.8) <sup>2</sup>
Current treatments	4.33 (0.9) <sup>3</sup>	4.63 (0.6) <sup>2</sup>	Mental and emotional health in people with ASD	4.54 (0.7) <sup>2</sup>	4.50 (0.6) <sup>5</sup>	*4.05 (1.0) <sup>6</sup>
Health care access	4.33 (0.8) <sup>4</sup>	4.59 (0.7) <sup>3</sup>	How the brains of people with ASD might be different from the brains of people without ASD	4.43 (0.8) <sup>3</sup>	4.28 (0.9) <sup>8</sup>	3.87 (1.1) <sup>7</sup>
Education	4.28 (0.9) <sup>5</sup>	4.23 (0.8) <sup>10</sup>	Recognizing the signs and symptoms of ASD	4.37 (0.8) <sup>4</sup>	4.32 (1.0) <sup>7</sup>	4.28 (0.9) <sup>4</sup>
Health conditions	4.27 (0.9) <sup>6</sup>	4.47 (0.7) <sup>6</sup>	How public services can best meet the needs of people with ASD	4.36 (0.8) <sup>5</sup>	4.68 (0.6) <sup>3</sup>	4.59 (0.7) <sup>1</sup>
Financial issues	4.18 (1.0) <sup>7</sup>	4.35 (0.9) <sup>7</sup>	What the future holds for adults with ASD	4.27 (0.9) <sup>6</sup>	4.35 (0.8) <sup>6</sup>	4.43 (0.9) <sup>3</sup>
Federal/state assistance	4.05 (0.8) <sup>8</sup>	4.55 (1.0) <sup>4</sup>	The role of people with ASD in society today	4.17 (0.9) <sup>7</sup>	4.08 (1.0) <sup>10</sup>	4.15 (1.1) <sup>5</sup>
Friendship	4.04 (1.0) <sup>9</sup>	3.88 (1.0) <sup>13</sup>	How to best treat the main symptoms of ASD	4.16 (1.0) <sup>8</sup>	4.78 (0.5) <sup>2</sup>	3.77 (1.2) <sup>9</sup>
Daily life	3.94 (1.0) <sup>10</sup>	4.29 (0.9) <sup>9</sup>	Learning about different types of ASD	4.12 (0.9) <sup>9</sup>	3.88 (1.0) <sup>13</sup>	3.80 (1.1) <sup>8</sup>
Criminal justice system	3.93 (1.1) <sup>11</sup>	4.19 (1.0) <sup>11</sup>	Physical health in people with ASD	4.01 (0.9) <sup>10</sup>	4.25 (0.8) <sup>9</sup>	*4.05 (1.0) <sup>6</sup>
Living situation	3.90 (1.0) <sup>12</sup>	4.52 (0.8) <sup>5</sup>	The role of genetic factors in causing ASD	3.91 (1.0) <sup>11</sup>	4.07 (1.0) <sup>11</sup>	3.45 (1.2) <sup>10</sup>
Romantic relationships	3.78 (1.1) <sup>13</sup>	3.18 (1.3) <sup>15</sup>	The role of environmental factors in causing ASD	3.70 (1.1) <sup>12</sup>	4.05 (1.1) <sup>12</sup>	3.22 (1.3) <sup>12</sup>
Sexuality	3.60 (1.1) <sup>14</sup>	3.32 (1.2) <sup>14</sup>	Finding out how common ASD is (counting how many people have ASD)	3.49 (1.0) <sup>13</sup>	3.38 (1.0) <sup>14</sup>	3.37 (1.2) <sup>11</sup>
Transportation	3.49 (1.2) <sup>15</sup>	3.97 (1.0) <sup>12</sup>				

SR: initial self-reporting subsample; LR: initial legally authorized representative ratings about adult wards with ASD; SR2: follow-up self-reporting subsample; LR2: follow-up legally authorized representative ratings about adult wards with ASD; ASD: autism spectrum disorder. Means (standard deviations) are shown within group based on priority ratings from 1 = not important at all to 5 = very important. 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.

Pellicano et al. stakeholders indicated that practical issues in daily life were most important for future study. The current IAN samples, when given the chance to rate both broad, scientific priorities and "practical" daily life priorities, tended to prioritize similar topics consistently across all item sets (e.g. comorbid conditions, treatments and care access, and employment/vocational skills). These topics tended to emerge as most salient compared to other daily issues like transportation or romantic, sexual, and friend relationships. That consistency is encouraging in terms of making patient-centered decisions on future adult ASD research foci. Of note, however, our sample demographics

likely influence these ratings in every aspect—for example, perhaps these various other practical topics were not more highly endorsed because a larger proportion of the SR subsample than is typical for the ASD population already experiences independence in residence, finances, and transportation, or has a romantic partner or friends. Indeed, the LR group put higher priority on living situation, federal/state assistance, and finances than did the SR subsample.

Of particular interest, understanding and acceptance of adults with ASD was the top-rated priority in *both* SR and LR subsamples and thus does not appear to be an artifact

of a milder subsample which, it may be argued, may have fewer concrete needs in daily life. Rather, the importance placed on societal understanding in both groups suggests that adults all along the spectrum are facing significant stigma and/or barriers (such as the highly endorsed workplace discrimination), despite widespread public education campaigns on prevalence and recognition of autism in children. It will be important to understand whether and how these stigma/barriers are related to generally poor outcomes observed in adults with ASD. The current finding also calls for survey and qualitative research to ascertain what “understanding and acceptance” mean to individuals with ASD and their families, as well as the study of other special population movements that have had success in changing public perception.

Understandably, scientists and self/family stakeholders may have disparate research priorities because they do not always share the same end goals. There is certainly need for—and should be “room” for—research addressing a variety of aims that improve our scientific knowledge base as well as the lives of individuals with ASD. We would argue that stakeholder involvement in research may carry unique weight in improving *current* lives, especially if that research is translated quickly into treatment development or policy change. Ideally, stakeholder interests and experimental findings should be balanced to complement each other, effectively working in tandem. Our focus on stakeholder priorities stems from the knowledge that (1) the rates of adults with identified ASD are increasing, (2) we have little to offer these adults by way of empirically validated treatments and supports (Taylor et al., 2012), and (3) stakeholders’ firsthand knowledge of daily life and needs with an ASD could provide valuable information when prioritizing the types of treatments/supports to prepare for dissemination in this stage of life. Qualitative studies seeking input from adults with ASD will be particularly important going forward (see as an example the portion of Pellicano et al., 2014, not replicated here).

### Strengths and limitations

In comparison to extant adult ASD literature, this work represents a large sample encompassing a wide age range. The data are not limited to those presenting clinically and include a greater proportion of female respondents than typically represented in ASD research. We were limited by the elective online survey context, resulting in an inability to verify diagnosis and IQ, and lack of generalizability to those with lower socioeconomic status. We do not have data about friendships and current social engagement for these participants, which is known to be another area of poor outcome for adults with ASD (Howlin et al., 2000; Orsmond et al., 2013), nor do we have data on previous diagnoses which could help us understand the experiences of later-diagnosed participants. Finally, we were not able to present all data from both the SR and LR groups, as some

questions were asked only of one subsample (e.g. adaptive functioning and maladaptive behaviors in the LR group).

### Conclusion

These findings indicate that areas of poorest adult outcome in ASD were associated with co-occurring conditions, poor vocational engagement, and low levels of adaptive behavior that limited independent living. Consistent with these outcomes, greatest stakeholder priority for future research was placed on societal understanding and acceptance; mental and emotional health; and life, social, and vocational skills training. Lifespan issues still receive the lowest funding allotment of the seven IACC strategic areas of focus by a significant margin (2% of all reported ASD funding in the United States vs 11%–22% for the other six areas; Office of Autism Research Coordination and National Institute of Mental Health on behalf of the IACC, 2012). Ideally, studies such as the current one will result in greater funding opportunities for much needed lifespan research. It is imperative that information on the current needs, problems, and priorities of adults with ASD and their families is incorporated into decision-making around research initiatives and public health campaigns that will maximize impact on the next several age cohorts of adults with ASD.

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The authors have no conflicting interests to declare.

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