

## RESEARCH ARTICLE

# Associations between co-occurring conditions and age of autism diagnosis: Implications for mental health training and adult autism research

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## Abstract

Adult autism studies are increasingly comprised of later-diagnosed adults, yet little is known about how these adults compare to those diagnosed earlier in life. The present study examines medical and psychiatric conditions endorsed by autistic adults and documents differences between those diagnosed with ASD in childhood versus adulthood, as well as across age groups and sex at birth. 4657 legally independent adults (ages 18–85,  $M = 33.4$  years) with professional ASD diagnoses who completed a medical questionnaire were drawn from the Simons Powering Autism Research Knowledge (SPARK) study. Chi square analyses,  $t$ -tests, and logistic regressions were used to compare medical and psychiatric conditions between age groups, sex at birth and adults diagnosed in childhood (before age 21) versus adulthood (at or after 21 years). Overall number of conditions endorsed as being diagnosed by a professional was high, with an average of 1.69 ( $SD = 2.01$ ) medical or developmental and 2.98 ( $SD = 2.29$ ) psychiatric conditions reported across the sample. Females were more likely to endorse psychiatric conditions ( $OR = 1.68$ ). Adult-diagnosed adults were more likely to endorse psychiatric conditions ( $OR = 2.71$ ) and reported more lifetime psychiatric diagnoses ( $M = 3.15$ ,  $SD = 2.23$ ) than their childhood-diagnosed counterparts ( $M = 2.81$ ,  $SD = 2.33$ ). These findings underscore the need for research to better understand and treat co-occurring psychiatric conditions in autistic adults and report and consider the age of diagnosis in adult autism samples. Moreover, results suggest it is imperative that mental health professionals receive autism training to promote accurate differential diagnosis and equitable access to mental health care for autistic adults with co-occurring psychiatric conditions.

## Lay Summary

In a large sample of independent autistic adults, those diagnosed with ASD after 21 years of age indicated having more psychiatric diagnoses than those diagnosed before 21 years of age. This highlights the importance of considering age of ASD diagnosis in research and underscores a need for autism training in the broader mental health field.

## KEYWORDS

adults, aging/ASD in adults, clinical psychology, co-morbid conditions

## INTRODUCTION

There is an increasing body of literature aimed at understanding autism in adulthood. Initially, adult autism research was largely focused on symptom changes and “outcomes” of childhood-diagnosed individuals from a few cohorts around the world (Anderson et al., 2014; Gillespie-Lynch et al., 2012; Howlin et al., 2004; Seltzer et al., 2003, 2004). More recently, many samples are comprised largely of individuals diagnosed with autism as adults (Huang et al., 2020). In part, this may be attributable to the use of online surveys, which may make it easier for people to participate even if they do not live near or have easy access to universities where in-person research is being conducted (Rubenstein & Furnier, 2021). This may also be attributed to the increase in adult diagnosis of autism due to expansion of diagnostic criteria to consider individuals of all ages (Lai & Baron-Cohen, 2015). While it is expected that those receiving an autism diagnosis later in life might have higher IQs, less is known about how they compare on other characteristics. Of particular interest are characteristics such as mental and physical health, as these may influence delays in diagnosis and quality of life.

When evaluating mental health outcomes, high rates of psychiatric conditions are generally reported in autistic adults. Depression, anxiety and obsessive-compulsive disorder (OCD) are commonly reported at alarmingly high rates in autistic adults (e.g., Hofvander et al., 2009; Howlin & Magiati, 2017; Nahar et al., 2019; Rydén & Bejerot, 2008). In a sample of 146 adult referrals for autism spectrum disorder (ASD), rates of psychiatric diagnoses were near 60%; the 100 adults receiving ASD diagnoses showed similar rates of co-occurring conditions as the 46 adults in the non-ASD group (Happé et al., 2016). Another study of 859 individuals referred for an autism diagnosis showed the 474 adults who received an ASD diagnosis were significantly more likely to have a clinical diagnosis of OCD compared to a non-ASD group (Russell et al., 2016). When compared to the general population of the United Kingdom, Russell et al. (2016) noted that autistic adults diagnosed in adulthood were more likely to be diagnosed with a phobia, generalized anxiety disorder, OCD, or a depressive episode.

Comparatively less work examines rates of psychiatric conditions in those diagnosed early in life compared to those diagnosed later in life. In a large study of a Danish cohort registry, individuals diagnosed in later childhood (11–15 years of age) were also more frequently diagnosed with other co-occurring psychiatric conditions, such as affective or anxiety disorders, than children diagnosed younger (Rødgaard et al., 2021). Similarly, a large study of 14-year-old children indicated that those receiving a later ASD diagnosis had more depressive symptoms and self-harm behaviors (Hosozawa et al., 2021). These studies suggest that there could be similar differences observed in adults. Similar trends were observed in a

study comparing 79 child-diagnosed and adult-diagnosed (18+) autistic adults—depression was more commonly reported in those diagnosed during adulthood (Marriage et al., 2009). However, similar rates of anxiety disorders were observed between groups (Marriage et al., 2009). While these results suggest differences in rates of psychiatric comorbidities between childhood- and adult-diagnosed adults, the small sample size limits interpretation and generalizability. More recently, Huang et al. (2021) reported that lifetime depression and not having OCD diagnosis also predicted older ASD diagnosis in a sample of 657 Australian adults, though their analyses did not distinguish specifically between child- versus adult-diagnosed individuals. Differences in sample ascertainment across studies make it difficult to compare across samples.

To address the limitation of small samples and variable ascertainment, we turn to the Simons Powering Autism Research Knowledge (SPARK; Feliciano et al., 2018) database. SPARK has been very successful, enrolling more than 100,000 individuals with ASD diagnoses to date (Simons Foundation, 2021). Although we are cautious to avoid suggesting this is a representative sample, given its focus on advancing genetic causes of autism, which some autistic adults do not support, its size makes SPARK a useful resource for exploring other research questions as well. For example, the availability of dependent and independent adult samples enrolled through SPARK provides an opportunity to investigate questions of sample differences in a very large sample ascertained similarly. Within the large independent adult sample, we can also begin to explore differences between individuals diagnosed in childhood and those diagnosed as adults.

In a recent study, Fombonne et al. (2020) described psychiatric and medical characteristics of the dependent adult sample. To date, while some studies have used the SPARK independent adult sample, no comprehensive characterization of the overall sample has been published. The present study aims to characterize the SPARK independent adult sample, with specific attention to the differences between childhood-diagnosed and later-diagnosed self-reporting adults. Characterization of this sample will help to inform future studies using subsets of the SPARK cohort (i.e., allow comparative representativeness of subgroups from SPARK), and comparisons of childhood and later-diagnosed adults will inform future interpretation of autism research more broadly.

## METHODS

### SPARK cohort

The SPARK initiative aims to recruit and retain a large sample of autistic individuals and their family members

to advance understanding of the genetic basis of ASD and provide a repository of participants for future research contact (Feliciano et al., 2018). To participate, independent adults must be 18 years of the age or older, be legally independent (i.e., not have a conservator or guardian), have a professional diagnosis of ASD, reside in the United States and be able to read and understand English. All participants are also given the option to contribute a saliva sample for genetic analysis (as well as the option to receive individual genetic results, should a primary genetic cause of ASD be identified). The saliva sample is optional.

Online consent was obtained at the start of each survey. All procedures were approved by the Western Institutional Review Board (WIRB). After consenting to participate, SPARK participants are asked to complete online questionnaires. Demographic, psychiatric and medical conditions were derived from endorsements on background and medical history questionnaires administered as part of this battery via the online Simons Foundation Autism Research Initiative (SFARI) portal.

## Sample selection

SPARK v5.0 was downloaded from SFARI base on December 3, 2020 and included 7323 independent adults. Of these, 4657 (64%) who had completed medical questionnaires were selected for analysis. A subset of these (3136, 67%) also had completed background questionnaires. Among the 4657 adults, 2826 were female and 2210 received an ASD diagnosis at 21 years or older.

## Measures

### Background questionnaire

The background questionnaire collected demographic information regarding the participant (e.g., gender, race and ethnicity, education, income, living situation, and employment). Participants were also asked to answer questions about their educational history and any services and supports received during school or currently.

### Medical questionnaire

The medical questionnaire lists medical, developmental, psychiatric and behavioral conditions with the instruction "Please select all conditions that you have been diagnosed with by a professional." Throughout this paper, the term "endorsed" is used to reflect that conditions were selected from a list by participants as having been diagnosed by a professional (i.e., rather than the term "self-reported" which may be erroneously interpreted as suggesting that participants were asked to freely recall diagnoses or that

conditions were self-identified, rather than professionally diagnosed).

## Statistical analyses

*T*-tests and chi-square analyses were conducted to examine the relationship between age group and sex at birth, age of ASD diagnosis, medical conditions, and psychiatric conditions. Age groups were selected to be comparable to those used by Fombonne et al. (2020) to allow side-by-side comparison of the SPARK dependent and independent samples. Age of ASD diagnosis was divided into childhood-diagnosed (before 21 years [ $<21$ ]) and adult-diagnosed (at or after 21 years [ $21+$ ]), which is also consistent with age of ASD diagnosis groupings used by Fombonne et al. (2020). Multiple logistic regressions were conducted to examine sex differences in medical and psychiatric conditions, controlling for age at completion of questionnaires and intellectual disability. Multiple logistic regressions were also conducted to examine the relationship between age of ASD diagnosis and medical and psychiatric conditions, controlling for age at completion of questionnaires, intellectual disability, and sex at birth.

The independent adult sample included a large number of middle-aged and older adults (i.e., 40+ year olds;  $n = 1209$ ; 57% female; 80% diagnosed with ASD at 21+), warranting comparison beyond Fombonne's age group of 40+, which had only included 70 adults. Thus, participants were divided into 40–49, 50–59, and 60+ and analyses were repeated and reported separately within this subgroup to provide further insights into older autistic adults.

## RESULTS

### Registration data

Participant characteristics for the 4657 are provided in Table 1. Overall, there were more females than males (1.41:1 female:male). Age groups differed significantly with regards to sex at birth ( $\chi^2[5] = 23.69$ ,  $p < 0.001$ ). Only the youngest (18–19 years) age group had nearly equal numbers of males and females, whereas there was a higher percentage of females in all other age groups. Just over half (52.5%) of all participants were diagnosed in childhood. The proportion of individuals diagnosed in adulthood was higher in older age groups, ranging from 13.2% in the 20–24 year old group to 80.1% in the 40+ year olds ( $\chi^2[20] = 1478.95$ ,  $p < 0.001$ ). A higher proportion of males (58.2%) than females (48.4%) were diagnosed in childhood ( $\chi^2[1] = 42.72$ ,  $p < 0.001$ ).

One third of the participants (33.2%) endorsed receiving some special education services (data was missing for approximately 33%), ranging from 50.1% in the 18–

**TABLE 1** Participant characteristics by age group

	All		By age group												<i>p</i> -value
			18–19		20–24		25–29		30–34		35–39		40+		
	(N = 4657)		(N = 353)		(N = 863)		(N = 874)		(N = 744)		(N = 614)		(N = 1209)		
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	
Male sex	1929	41.4	178	50.4	355	41.1	365	41.8	285	38.3	222	36.2	524	43.3	<0.001
Female sex	2728	58.6	175	49.6	508	58.9	509	58.2	459	61.7	392	63.8	685	56.7	
Age at diagnosis															<0.001
<3	246	5.3	28	8.0	57	6.6	62	7.1	32	4.3	24	3.9	43	3.6	
3–6	539	11.6	83	23.5	150	17.4	133	15.2	67	9.0	41	6.7	65	5.4	
6–12	703	15.1	102	28.9	224	26.0	148	16.9	107	14.4	54	8.8	68	5.6	
12–20	951	20.4	139	39.4	318	36.8	230	26.3	137	18.4	66	10.7	61	5.0	
21 and over	2210	47.5	0	0.0	114	13.2	298	34.1	400	53.8	429	69.9	969	80.1	
Special education <sup>a</sup>															
No	1588	34.1	51	14.4	159	18.4	229	26.2	266	35.8	257	41.9	626	51.8	
Yes	1546	33.2	177	50.1	391	45.3	372	42.6	252	33.9	165	26.9	189	15.6	

<sup>a</sup>%s reflect proportion of the overall group; this item was not answered for 1523 participants.

19 year old group to 15.6% in the 40+ year olds ( $\chi^2[5] = 455.8, p < 0.001$ ). A higher proportion of males (58.9%) than females (42.8%) received special education services ( $\chi^2[1] = 78.22, p < 0.001$ ). The sample varied widely in self-reported education (22.9% had a baccalaureate degree or higher, 9.3% had an associate's degree or completed trade school, 19.3% were currently in college or had completed some college, 13.4% were high school graduates or had a GED diploma, 2.5% attended some high school or did not attend high school; 32.6% did not report) and employment status (21.2% were employed full-time, 14.3% were employed part-time, 28.3% responded that they were unable to be employed or currently unemployed, 1.5% were retired, 1.4% had an unpaid student internship and 33.3% did not report).

### Age group differences in co-occurring conditions

Total number of endorsed lifetime professional diagnoses of co-occurring medical and developmental conditions ranged from 0 to 15 ( $M = 1.69, SD = 2.01$ ), with 40.5% of participants reporting two or more diagnoses. As shown in Table 2, both birth defects (4.2%) and birth or pregnancy complications (9.0%) were reported relatively infrequently, with similar rates across age groups. Intellectual disability was also relatively infrequently reported, but significantly more likely in younger age groups. Developmental delays and disorders were endorsed in 30.3% of the sample, with most individual conditions being more commonly endorsed in younger age groups. Sleep diagnoses or problems were also endorsed by 31.5% and showed the opposite age association, with older individuals significantly more likely to report sleep diagnoses or problems.

While neurological conditions did not differ by age, both growth conditions and vision or hearing conditions showed association with age at reporting. Growth conditions included obesity, which was endorsed most in the 25–29 (10.2%) and 30–34 (9.4%) year-old groups, in contrast to only 4.0%–6.6% of 18–19 and 20–24 year-olds, respectively. Deafness/hearing loss and cataracts were most common in older individuals.

Co-occurring psychiatric diagnoses are presented in Table 3. Total number of endorsed lifetime professional diagnoses ranged from 0 to 15 ( $M = 2.98, SD = 2.29$ ), with 86.8% endorsing at least one psychiatric or behavioral condition and 52.8% of participants having three or more diagnoses. Mood and anxiety disorders were the most commonly endorsed, with 58.4% endorsing any affective condition and 65.8% any anxiety disorder. Conduct Disorder, Oppositional Defiant Disorder, Intermittent Explosive Disorder, Schizophrenia, Tourette's or Tic Disorder, and Hoarding were the least frequently endorsed (all <6%). The youngest and oldest age groups were less likely to endorse most psychiatric diagnoses. Exceptions included ADHD and ODD, more commonly endorsed in younger ages, and Hoarding and "other" psychiatric disorder, endorsed more frequently in the oldest age groups.

### Sex differences in co-occurring conditions

Table 4 shows the breakdown of psychiatric conditions by sex at birth. Of the 33 medical and developmental conditions reported, 6 showed sex differences (see Supplemental Table 1). Females less commonly endorsed language delay or disorder ( $OR = 0.72, p < 0.001$ ) and more commonly endorsed premature births ( $OR = 1.53$ ,

TABLE 2 Medical conditions by age group

	All		By age group												p-value
			18–19		20–24		25–29		30–34		35–39		40+		
	(N = 4657)		(N = 353)		(N = 863)		(N = 874)		(N = 744)		(N = 614)		(N = 1209)		
	N	%	N	%	N	%	N	%	N	%	N	%	N	%	
Birth defects															
Skeletal	91	2.0	6	1.7	10	1.2	18	2.1	10	1.3	16	2.6	31	2.6	0.15
Craniofacial	23	0.5	3	0.8	1	0.1	2	0.2	3	0.4	6	1.0	8	0.7	0.14
Involving CNS (spina bifida, brain malformation)	36	0.8	1	0.3	1	0.1	7		6	0.8	6	1.0	15	1.2	0.08
Thorax (heart and lung)	57	1.2	5	1.4	5	0.6	12	1.3	7	0.9	8	1.3	20	1.7	0.35
Gastrointestinal system	29	0.6	1	0.3	3	0.3	6	0.7	3	0.4	9	1.5	7	0.6	0.09
Urogenital	15	0.3	0	0.0	2	0.2	1	0.1	2	0.3	4	0.7	6	0.5	0.32
Any of the above	197	4.2	16	4.5	21	2.4	38	4.3	27	3.6	35	5.7	60	5.0	0.03
Birth or pregnancy complications															
Premature births (delivery before 37 weeks)	334	7.2	26	7.4	59	6.8	75	8.6	61	8.2	40	6.5	73	6.0	0.25
Intraventricular hemorrhage	13	0.3	2	0.6	3	0.3	5	0.6	1	0.1	0	0.0	2	0.2	0.24
Insufficient O <sub>2</sub> at birth with NICU stay	164	3.5	13	3.7	34	3.9	38	4.3	24	3.2	24	3.9	31	2.6	0.31
Any of the above	418	9.0	33	9.3	74	8.6	95	10.9	73	9.8	54	8.8	89	7.4	0.13
Cognitive functioning															
Cognitive delays or impairment due to another medical condition or exposure (e.g., brain injury, stroke, lead poisoning, FAS, HIV, radiation, hydrocephalus, brain tumor, drug effects, etc.)	272	5.8	8	2.3	49	5.7	46	5.3	39	5.2	39	6.4	91	7.5	0.007
Intellectual disability, cognitive impairment, global developmental delay, or borderline intellectual functioning	283	6.1	26	7.4	67	7.8	67	7.7	47	6.3	33	5.4	43	3.6	<0.001
Any of the above	484	10.4	29	8.2	101	11.7	100	11.4	77	9.9	63	10.3	114	9.4	0.34
Developmental delays & disorders															
Language delay or disorder	618	13.3	51	14.4	144	16.7	151	17.3	101	13.6	66	10.7	105	8.7	<0.001
Mutism	66	1.4	1	0.3	16	1.9	15	1.7	7	0.9	9	1.5	18	1.5	0.28
Speech articulation problems	562	12.1	50	14.2	115	13.3	121	13.8	97	13.0	63	10.3	116	9.6	0.011
Learning disability (LD, learning disorder, including reading, written expression, math, or NVLD [Nonverbal learning disability])	973	20.9	69	19.5	212	24.6	205	23.5	178	23.9	131	21.3	178	14.7	<0.001
Motor delay (e.g., delay in walking) or developmental coordination disorder	306	6.6	27	7.6	71	8.2	76	8.7	42	5.6	38	6.2	52	4.3	<0.001
Any of the above	1410	30.3	107	30.3	314	36.4	317	36.3	233	31.3	175	28.5	264	21.8	<0.001

(Continues)



TABLE 2 (Continued)

	All		By age group												<i>p</i> -value
			18–19		20–24		25–29		30–34		35–39		40+		
	<i>(N</i> = 4657)		<i>(N</i> = 353)		<i>(N</i> = 863)		<i>(N</i> = 874)		<i>(N</i> = 744)		<i>(N</i> = 614)		<i>(N</i> = 1209)		
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	
Sleep problems diagnosed by a professional															
Sleep disorder or problem	1238	26.6	63	17.8	189	21.9	218	24.9	210	28.2	181	29.5	377	31.2	<0.001
Neurological conditions															
Seizure disorder or epilepsy	299	6.4	16	4.5	60	7.0	71	8.1	46	6.2	44	7.2	62	5.1	0.057
Traumatic brain injury (hospitalized)	111	2.4	4	1.1	12	1.4	22	2.5	15	2.0	13	2.1	45	3.7	0.007
Brain infection such as bacterial meningitis, encephalitis	41	0.9	3	0.8	4	0.5	4	0.5	9	1.2	6	1.0	15	1.2	0.28
Lead poisoning	17	0.4	0	0.0	4	0.5	4	0.5	4	0.5	0	0.0	5	0.4	0.46
Other neurological conditions															
No	4148	89.1	320	90.7	774	89.7	787	90.0	656	88.2	536	87.3	1075	88.9	0.45
Yes	509	10.9	33	9.3	89	10.3	87	10.0	88	11.8	78	12.7	134	11.1	
Any of the above	843	18.1	48	13.6	150	17.4	166	19.0	142	19.1	125	20.4	212	17.5	0.13
Growth conditions															
Short stature	107	2.3	7	2.0	16	1.9	26	3.0	18	2.4	18	2.9	22	1.8	0.41
Difficulty gaining weight	64	1.4	2	0.6	19	2.2	12	1.4	15	2.0	4	0.7	12	1.0	0.035
Obesity	372	8.0	14	4.0	57	6.6	89	10.2	70	9.4	50	8.1	92	7.6	0.003
Small head size (microcephaly)	20	0.4	1	0.3	4	0.5	1	0.1	4	0.5	6	1.0	4	0.3	0.22
Large head size (macrocephaly)	49	1.1	2	0.6	10	1.2	13	1.5	2	0.3	8	1.3	14	1.2	0.2
Other growth conditions															
No	4558	97.9	345	97.7	845	97.9	853	97.6	728	97.8	601	97.9	1186	98.1	0.99
Yes	99	2.1	8	2.3	18	2.1	21	2.4	16	2.2	13	2.1	23	1.9	
Any of the above	551	11.8	26	7.4	97	11.2	127	14.5	101	13.6	68	11.1	132	10.9	0.005
Vision or hearing conditions															
Deafness/hearing loss	288	6.2	12	3.4	43	5.0	34	3.9	52	7.0	41	6.7	106	8.8	<0.001
Blindness	39	0.8	3	0.8	11	1.3	13	1.5	3	0.4	2	0.3	7	0.6	0.051
Cataract	82	1.8	2	0.6	8	0.9	5	0.6	8	1.1	5	0.8	54	4.5	<0.001
Strabismus	186	4.0	17	4.8	34	3.9	36	4.1	26	3.5	21	2.4	52	4.3	0.85
Any of the above	508	10.9	30	8.5	87	10.1	80	9.2	78	10.1	63	10.3	170	14.1	0.003

$p < 0.001$ ), mutism ( $OR = 2.62$ ,  $p = 0.001$ ), sleep diagnoses or problems ( $OR = 1.45$ ,  $p < 0.001$ ), short stature ( $OR = 2.18$ ,  $p = 0.001$ ), and obesity ( $OR = 1.60$ ,  $p < 0.001$ ).

Females endorsed a greater number of psychiatric and behavioral conditions, with an average of 3.03 ( $SD = 2.32$ ) diagnoses compared to an average of 2.52 ( $SD = 2.16$ ) reported by males ( $t[4319.59] = -1.76$ ,  $p < 0.001$ ). Consistent with the general population, females more commonly endorsed affective ( $OR = 1.87$ ,  $p < 0.001$ ), anxiety ( $OR = 2.34$ ,  $p < 0.001$ ) and eating ( $OR = 3.47$ ,  $p < 0.001$ ) disorders than males, even after controlling for age at reporting and intellectual

disability. Other psychiatric conditions did not show sex differences.

### Co-occurring conditions differences by age of ASD diagnosis

Differences in childhood- (<21 years) and adulthood- (21+ years) diagnosed adults were observed across five reported medical or developmental conditions (see Supplemental Table 1). Those diagnosed later less commonly endorsed language delays or disorders ( $OR = 0.50$ ,  $p < 0.001$ ), speech articulation problems

**TABLE 3** Psychiatric conditions by age group

	All		By age group												<i>p</i> -value
			18–19		20–24		25–29		30–34		35–39		40+		
	(N = 4657)		(N = 353)		(N = 863)		(N = 874)		(N = 744)		(N = 614)		(N = 1209)		
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	
Mood, depression, anxiety or OCD															
Anxiety disorder (e.g., GAD) except for social anxiety	2583	55.5	177	50.1	477	55.3	491	56.2	438	56.6	378	61.6	577	47.7	<0.001
Social anxiety disorder/ social phobia	1698	36.5	94	26.6	309	35.8	318	36.4	296	38.2	261	42.5	420	34.7	<0.001
Separation anxiety	528	11.3	40	11.3	101	11.7	104	11.9	93	12	71	11.6	119	9.8	0.53
Obsessive–compulsive disorder	1127	24.2	76	21.5	218	25.3	219	25.1	198	25.6	159	25.9	257	21.3	0.046
Hoarding	239	5.1	6	1.7	38	4.4	34	3.9	43	5.6	40	6.5	78	6.5	0.001
Depression or dysthymia	2464	52.9	140	39.7	460	53.3	448	51.3	440	56.8	333	54.2	643	53.2	<0.001
Bipolar (manic-depressive) disorder	755	16.2	41	11.6	144	16.7	185	21.2	124	16	97	15.8	164	13.6	<0.001
Any anxiety disorders (first 3)	3064	65.8	209	59.2	567	65.7	591	67.6	515	69.2	442	72.0	722	59.7	<0.001
Any affective disorder (last 3)	2719	58.4	153	43.3	510	59.1	522	59.7	474	63.7	362	59.0	698	57.7	<0.001
Any emotional/affective disorder (any of the above eight disorders)	3557	76.4	241	68.3	663	76.8	687	78.6	590	79.3	483	78.7	893	73.9	<0.001
Attention and behavior disorders															
ADHD (attention deficit-hyperactivity disorder) or ADD	2049	44	174	49.3	422	48.9	432	49.4	313	42.1	264	43.0	444	36.7	<0.001
Conduct disorder	88	1.9	5	1.4	11	1.3	16	1.8	15	2.0	15	2.4	26	2.2	0.59
Oppositional defiant disorder	264	5.7	39	11.0	49	5.7	64	7.3	39	5.2	37	6.0	36	3.0	<0.001
Intermittent explosive disorder	107	2.3	7	2.0	13	1.5	20	2.3	23	3.1	16	2.6	28	2.3	0.43
Any disruptive disorder (any of the above 4)	2117	45.5	180	50.1	433	50.2	442	50.6	322	43.3	277	45.1	463	38.3	<0.001
Schizophrenia, other psychosis or schizoaffective disorder	211	4.5	12	3.4	41	4.8	42	4.8	44	5.9	31	5.0	41	3.4	0.13
Tourette's or tic disorder	191	4.1	18	5.1	47	5.4	38	4.3	25	3.4	24	3.9	39	3.2	0.13
Other psychiatric condition	527	11.3	39	11.0	99	11.5	70	8.0	75	10.1	77	12.5	167	13.8	0.002
Overall psychiatric morbidity															
Any lifetime disorder (excluding other psychiatric condition)	3895	83.6	276	78.2	738	85.5	757	86.6	634	85.2	528	86.0	962	79.6	<0.001
Any lifetime disorder	4011	86.1	290	82.2	764	88.5	769	88.0	650	87.4	542	88.3	996	82.4	<0.001
Personality disorder	576	12.4	19	5.4	85	9.8	113	12.9	108	14.5	92	15.0	159	13.2	<0.001
Eating disorder	503	10.8	33	9.3	105	12.2	90	10.3	88	11.8	71	11.6	116	9.6	0.34
Any lifetime disorder (including personality disorders and eating disorder)	4041	86.8	293	83	755	87.5	771	88.2	652	87.6	548	89.3	1011	83.6	<0.001

**TABLE 4** Logistic regressions for psychiatric conditions by sex at birth

	Male		Female		OR	CI
	( <i>N</i> = 1929)		( <i>N</i> = 2728)			
	<i>N</i>	%	<i>N</i>	%		
Mood, depression, anxiety or OCD						
Anxiety disorder (e.g., GAD) except for social anxiety	804	41.7	1734	63.6	<b>2.330</b>	2.064–2.630
Social anxiety disorder/social phobia	587	30.4	1111	40.7	<b>1.514</b>	1.337–1.716
Separation anxiety	135	7.0	393	14.4	<b>2.328</b>	1.891–2.865
Obsessive-compulsive disorder	412	21.4	715	26.2	<b>1.298</b>	1.128–1.493
Hoarding	73	3.8	166	6.1	<b>1.742</b>	1.310–2.317
Depression or dysthymia	847	43.9	1617	59.3	<b>1.757</b>	1.559–1.980
Bipolar (manic-depressive) disorder	259	13.4	496	18.2	<b>1.417</b>	1.201–1.671
Any anxiety disorders (first 3)	1031	53.4	2015	73.9	<b>2.335</b>	2.059–2.648
Any affective disorder (last 3)	940	48.7	1779	65.2	<b>1.865</b>	1.653–2.105
Any emotional/affective disorder (any of the above eight disorders)	1309	67.9	2248	82.4	<b>2.082</b>	1.811–2.393
Attention and behavior disorders						
ADHD (attention deficit-hyperactivity disorder) or ADD	875	45.4	1174	43.0	0.897	0.796–1.010
Conduct disorder	45	2.3	43	1.6	0.751	0.488–1.154
Oppositional defiant disorder	103	5.3	161	5.9	1.188	0.917–1.539
Intermittent explosive disorder	47	2.4	60	2.2	0.942	0.637–1.394
Any disruptive disorder (any of the above 4)	900	46.7	1217	44.6	0.909	0.807–1.024
Schizophrenia, other psychosis or schizoaffective disorder	86	4.5	125	4.6	1.092	0.821–1.452
Tourette's or tic disorder	97	5.0	94	3.4	0.696	0.519–0.933
Other psychiatric condition	196	10.2	331	12.1	1.193	0.988–1.442
Overall psychiatric morbidity						
Any lifetime disorder (excluding other psychiatric condition)	1522	78.9	2373	87.0	<b>1.673</b>	1.428–1.960
Any lifetime disorder	1583	82.1	2428	89.0	<b>1.639</b>	1.384–1.942
Personality disorder	204	10.6	372	13.6	<b>1.326</b>	1.103–1.595
Eating disorder	92	4.8	411	15.1	<b>3.467</b>	2.736–4.393
Any lifetime disorder (including personality and eating)	1595	82.7	2446	89.7	<b>1.683</b>	1.416–2.001

Note: Bolded reflects  $p < 0.005$ . OR controlling for age at reporting and intellectual disability.

(OR = 0.66,  $p < 0.001$ ), a learning disability (OR = 0.76,  $p = 0.003$ ), motor delays or developmental coordination disorder (OR = 0.57,  $p < 0.001$ ), and blindness (OR = 0.26,  $p = 0.003$ ).

Those diagnosed at or after age 21 reported more lifetime psychiatric diagnoses ( $M = 3.15$ ,  $SD = 2.23$ ) than those diagnosed before the age of 21 ( $M = 2.81$ ,  $SD = 2.33$ ;  $t[4633.18] = -5.16$ ,  $p < 0.001$ ). Age of diagnosis was also associated with several specific psychiatric conditions, even after controlling for age at reporting, sex at birth, and intellectual disability (Table 5). Those diagnosed as adults were significantly more likely to report anxiety disorders (OR = 2.20,  $p < 0.001$ ) and depression or dysthymia (OR = 1.90,  $p < 0.001$ ), than those diagnosed before 21.

### Analysis of older adults (ages 40+ years)

Within the oldest age group (i.e., 40+), comparison of 40, 50, and 60+ year olds indicated few age effects (see Supplemental Tables 2 and 4). Cataracts was the only medical diagnosis emerging as significant, reflecting more frequent endorsements by 60+ year olds (13.8%), as compared to 40–49 (1.8%) and 50–59 (5.1%) year olds ( $\chi^2[2] = 47.14$ ,  $p < 0.001$ ). Personality disorders was the only set of psychiatric diagnoses that was significantly more commonly endorsed by 60+ year olds (24.7%), as compared to 40–49 (11.5%) and 50–59 (10.5%) year olds ( $\chi^2[2] = 23.96$ ,  $p < 0.001$ ). Older females more commonly endorsed anxiety (OR = 1.76,  $p < 0.001$ ) and eating (OR = 4.17,  $p < 0.001$ ) disorders than males even after



**TABLE 5** Logistic regressions for psychiatric conditions by age of ASD diagnosis (<21 and 21+)

	<21		21+		OR	CI
	(N = 2439)		(N = 2210)			
	N	%	N	%		
Mood, depression, anxiety or OCD						
Anxiety disorder (e.g., GAD) except for social anxiety	1212	49.7	1320	59.7	1.907	1.653–2.201
Social anxiety disorder/social phobia	803	32.9	894	40.5	1.472	1.277–1.696
Separation anxiety	290	11.9	237	10.7	0.868	0.701–1.075
Obsessive–compulsive disorder	567	23.2	559	25.3	1.281	1.092–1.503
Hoarding	117	4.8	122	5.5	0.824	0.609–1.115
Depression or dysthymia	1127	46.2	1336	60.5	1.900	1.652–2.185
Bipolar (manic-depressive) disorder	391	16.0	362	16.4	1.153	0.959–1.387
Any anxiety disorders (first 3)	1459	59.8	1581	71.5	2.196	1.886–2.557
Any affective disorder (last 3)	1271	52.1	1445	65.4	1.905	1.652–2.197
Any emotional/affective disorder (any of the above eight disorders)	1731	71.0	1820	82.4	2.386	2.011–2.831
Attention and behavior disorders						
ADHD (attention deficit-hyperactivity disorder) or ADD	1119	45.9	927	41.9	1.093	0.952–1.254
Conduct disorder	50	2.1	38	1.7	0.769	0.462–1.280
Oppositional defiant disorder	180	7.4	83	3.8	0.639	0.467–0.875
Intermittent explosive disorder	57	2.3	50	2.3	0.938	0.595–1.479
Any disruptive disorder (any of the above 4)	1156	47.4	958	43.3	1.090	0.950–1.250
Schizophrenia, other psychosis or schizoaffective disorder	121	5.0	90	4.1	0.878	0.630–1.224
Tourette’s or tic disorder	116	4.8	75	3.4	0.849	0.596–1.210
Other psychiatric condition	235	9.6	292	13.2	1.299	1.049–1.607
Overall psychiatric morbidity						
Any lifetime disorder (excluding other psychiatric condition)	1960	80.4	1928	87.2	2.315	1.908–2.809
Any lifetime disorder	2023	82.9	1981	89.6	2.583	2.097–3.182
Personality disorder	248	10.2	327	14.8	1.361	1.108–1.673
Eating disorder	231	9.5	270	12.2	1.360	1.093–1.691
Any lifetime disorder (including personality and eating)	2032	83.3	2002	90.6	2.707	2.185–3.354

Note: Bolded reflects  $p < 0.005$ . OR controlling for age at reporting, intellectual disability, and sex at birth.

controlling for age at reporting and intellectual disability (see Supplemental Table 3). No significant sex differences were observed in endorsement of medical or developmental conditions (data available upon request).

Comparing earlier- and later-diagnosed older adults, learning disability was the only developmental condition less commonly endorsed by later-diagnosed adults (OR = 0.558,  $p = 0.002$ ) after controlling for age at reporting, intellectual disability, and sex at birth. In contrast, later-diagnosed older adults were significantly more likely to endorse anxiety (OR = 2.02,  $p < 0.001$ ) and mood (OR = 2.21,  $p < 0.001$ ) disorders and significantly less likely to endorse conduct (OR = 0.30,  $p = 0.004$ ) or oppositional defiant (OR = 0.37,  $p = 0.005$ ) disorders than their childhood-diagnosed counterparts after

controlling for age at reporting, intellectual disability, and sex at birth (see Supplemental Table 3).

## DISCUSSION

This study evaluated psychiatric and medical conditions in a SPARK community sample of legally independent autistic adults. Results from this study highlight the importance of considering differences in self- versus caregiver-ascertained samples. Perhaps unsurprisingly, the current sample of self-reporting adults had few (6.1%) adults with intellectual disability, cognitive impairment, or borderline intellectual functioning, compared to SPARK's caregiver-report sample of adults (43.4%),

described by Fombonne et al. (2020). While difference in sex distributions (58.6% females in the independent adult sample versus 21.2% in the caregiver report sample) could also account for some differences in the samples, results point to the significance of examining age of ASD diagnosis as an important characteristic of autistic adult samples. The present sample, including 47.5% of later-diagnosed individuals, provided an opportune sample to explore differences in childhood- (diagnosed with ASD before 21 years) and later-diagnosed (received ASD diagnosis at age 21 or older) autistic adults.

First, it is notable that the proportion of adult-diagnosed individuals increased across age groups, ranging from 13% of 20–24 year olds to 80% of 40+ year olds. There was also a higher proportion of females (52%) than males (42%) who were diagnosed at 21 or later. Sex differences in medical and developmental conditions were mostly limited to the childhood-diagnosed group exhibiting more frequently reported language delays or problems. Adult-diagnosed adults were significantly more likely to endorse psychiatric diagnoses ( $OR = 2.71$ ), reflecting higher proportions of mood, anxiety, personality and eating disorders, even after controlling for sex at birth, intellectual disability, and age at time of reporting. These results are consistent with findings that adolescents diagnosed in later-childhood are more likely to be diagnosed with anxiety and mood disorders (Rødgaard et al., 2021) and associations between age of diagnosis and presence of depression in adults (Huang et al., 2021; Marriage et al., 2009). While it is unknown whether the differences in psychiatric diagnoses between childhood- and adult-diagnosed autistic adults present in the current study reflect *misdiagnosis* prior to ASD diagnosis due to overlapping symptoms or *co-occurring* conditions which could have contributed to delay in ASD diagnosis, these findings highlight a need for research to clearly characterize age of diagnosis in samples and exercise caution in generalizing findings from one group to the other. Further, lack of information regarding age of psychiatric and medical diagnoses limit interpretations.

Despite not knowing the specific timing that other psychiatric diagnoses were made, these findings also clearly demonstrate that co-occurrence is more the rule than the exception and underscore a need for more attention to understanding the impacts of psychiatric conditions on the lives of autistic adults. Consistent with other studies of autistic adults, concerning high rates of psychiatric conditions were endorsed, higher than the general population rates in the United States (Croen et al., 2015; Kohane et al., 2012). Females endorsed a significantly higher number of lifetime psychiatric diagnoses compared to males. This largely reflects more females reporting diagnoses of eating, anxiety and affective disorders compared to males, consistent with previous studies of adults on the spectrum (Croen et al., 2015) and in the general population (National Institute of Mental Health,

2021; Terlizzi & Norris, 2021; Terlizzi & Villarroel, 2020).

Considering the larger proportion of females in the later diagnosed group, future study is needed to understand how sex and co-occurrence of other psychiatric conditions impact the timing of ASD diagnosis. As many studies suggest differences in the presentation of autism in females (Lai et al., 2011; Mandy et al., 2012; Wijngaarden-Cremers et al., 2013), it is perhaps pertinent to also consider the intersection between possible male-bias in our conceptualization of autism and sex-bias in how we interpret behaviors exhibited by males and females. Alternatively, diagnostic overshadowing may contribute to delayed ASD diagnosis in individuals with co-occurring emotional dysregulation (Mazefsky et al., 2012). It is notable that females were less likely to report language delays (which could have influenced their being “missed”) but more likely to report diagnoses of selective mutism (which may reflect bias in how early communication differences are interpreted by clinicians). Diagnostic overshadowing may also work in the other direction, where those diagnosed with ASD at an earlier age are at risk for under-diagnosis of co-occurring problems (Pezzimenti et al., 2019).

In addition to understanding how other diagnoses may affect timing of ASD diagnosis, studies are needed to explore the potential impact of childhood ASD diagnosis on longer-term mental health outcomes. Hosozawa et al. (2021) suggest that earlier ASD diagnosis may lead to approaches that target person-environment fit, which could lower risk for depression and self-harm behaviors. Others have posited that experiences (e.g., low self-esteem, bullying, social rejection, awareness of limitations, etc.) could contribute to development of depression or anxiety and that diagnosis may help with self-acceptance (Lai & Baron-Cohen, 2015). Consistent with this, studies of adult-diagnosed individuals highlight diagnosis as helping individuals to move from self-criticism to self-compassion, understanding and acceptance (e.g., Harmens et al., 2022; Leedham et al., 2019).

In addition to affording comparison of earlier- and later-diagnosed adults, the SPARK sample includes a sizable number of adults aged 40+. Notably, despite having had lived longer and the majority being later-diagnosed, 40+ year olds had somewhat lower rates of several psychiatric diagnoses relative to adults 18–39 years of age. Differences could be explained by lack of awareness or increased stigma regarding mental health, which may make older generations more reluctant to share difficulties with providers or pursue mental health supports. Lower rates of attention and behavioral disorders may reflect shifts in diagnostic practices and many diagnoses not being widely diagnosed until much more recently. Lower rates of anxiety disorders, however, are less easily explained. Further research is needed to understand the range of outcomes and achievements in older adults, as well how they have navigated the challenges they

encountered throughout their lifetimes. Such understanding could provide invaluable insights into supports for children being diagnosed more recently, particularly identifying factors that may have protected against anxiety or other co-occurring difficulties. Interestingly, Hoarding and Personality Disorders were the only specific diagnoses in which older individuals showed the highest rates across age groups. Even within those 40+, the 60+ year olds endorsed higher rates of Personality Disorders than 40–49 and 50–59 year olds. Future studies, perhaps even within the SPARK cohort, should collect timing of diagnosis of psychiatric conditions to inform whether these are difficulties that emerge later in life for autistic individuals or represent mischaracterization of autistic symptoms at an earlier time point. It is possible that these diagnoses reflect more limited knowledge and consideration of autism by professionals diagnosing and/or treating older adults.

Taken together, these findings have important implications for clinical practice and research. The high rates of co-occurring psychiatric conditions in autistic individuals have been reported previously. However, even within already elevated rates, that adults receiving ASD diagnoses in adulthood were significantly more likely ( $OR = 2.39$ ) to have an anxiety or affective disorder than their childhood-diagnosed counterparts highlights the need for mental health professionals to be well-versed in autism and differential or co-occurring diagnosis. This may reflect a need to rethink existing health systems, as differences in how individuals with neurodevelopmental disorders and those with other psychiatric disorders access and finance care often results in gaps in services (Hossain et al., 2020). This also clearly presents an urgent need for psychiatrists, psychologists, social workers and other mental health providers to be adequately prepared to support autistic people. As it stands, to the extent that it is even provided in psychology or psychiatry programs, most autism training occurs in the child and adolescent tracks and the majority of specialty autism services exist in pediatric departments. Many community mental health providers highlight a lack of knowledge and competence working with autistic adults (Maddox et al., 2020). Yet when adults are referred for care, there is clearly a need for those professionals to include autism as part of the differential diagnosis. While reason for referral may reflect a more pressing need (e.g., suicidality), understanding the referral question in the context of ASD diagnosis is critical to inform appropriate care. Although a major limitation of this sample is the lack of information regarding timing of psychiatric and medical diagnoses, these data still clearly point to a dire need to ensure that autism in adulthood is included in psychiatry, clinical and counseling psychology, social work and other mental health-focused training programs. While not all trainees need to become experts in autism, including autism as a standard facet of training programs

(as compared to a subspecialty only pursued by clinicians wanting to focus in autism) will help to promote clinician awareness and (cultural) humility when working with autistic people. This is a critical first step toward ensuring equitable access to mental health care for autistic adults.

In autism research, we must be careful to identify samples as childhood- or adult-diagnosed, as this may have implications for presentation of ASD and other co-occurring conditions. Considering influences of emotional and behavioral challenges on autism symptom measures in children (Havdahl et al., 2016; Hus et al., 2013), this calls for research to account for psychiatric co-occurrence in adult samples when interpreting autism symptom measures. Indeed, work by South et al. (2017) suggests poor discriminant validity of common autism screening tools when used with adults with high anxiety. It is likely other autism measures will also exhibit reduced specificity in psychiatric populations, calling into question their use of “autism severity” measures in the presence of conditions. Indeed, labeling difficulties as reflective of “autistic traits” when they are driven by a psychiatric condition is likely to be confusing to patients and unlikely to help advance our understanding of underlying mechanisms.

This sample has a number of limitations that limit generalizability, including more female respondents and a greater proportion of later-diagnosed individuals in the older age groups. While the large number of participants in both of these groups may be viewed as a strength that allows analyses to explore the health of autistic females and later-diagnosed individuals, the specific proportions are likely to be affected by ascertainment bias and not representative of the larger population of autistic adults. In particular, SPARK’s focus on advancing understanding of genetic causes of autism likely prevents participation of adults who do not support such research. Further, as SPARK questionnaires are administered online, participation may be limited to those with access to internet. SPARK participants are also recruited from North America and notably lacking in diversity (68.6% of the sample is White), though the self-report sample does reflect a range of education and socioeconomic levels.

## CONCLUSIONS

Adult-diagnosed adults were significantly more likely to report lifetime diagnosis of psychiatric conditions, even after controlling for age at reporting, intellectual disability, and sex at birth, compared to childhood-diagnosed adults. These findings highlight the need to include age of ASD diagnosis as a descriptive characteristic of autism samples, as well as greater attention to the presence of co-occurring psychiatric conditions in autistic adults. Such high rates in those later diagnosed suggest a critical need to include information about autism diagnosis,

differential diagnosis and treatment in psychology, psychiatry, and other training programs as a first step to promoting equitable access to mental health care.

## ETHICS STATEMENT

All procedures were approved by the Western Institutional Review Board (WIRB).

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## CONFLICT OF INTEREST

Dr. Vanessa H. Bal receives research funding from Western Psychological Services and has received honoraria and/or consulting fees from Regeneron, Janssen and Simons Foundation for unrelated work.

## DATA AVAILABILITY STATEMENT

Approved researchers can obtain the SPARK population dataset described in this study by applying at <https://base.sfari.org>.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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