Autism Identity and the "Lost Generation": Structural Validation of the Autism Spectrum Identity Scale and Comparison of Diagnosed and Self-Diagnosed Adults on the Autism Spectrum

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Abstract

Background: A population segment of autistic adults are underidentified due, in part, to historic changes in criteria for diagnosing autism and diagnostic biases related to gender, socioeconomic status, and other individual characteristics such as intellectual functioning. Some of these individuals, described as the "lost generation," may choose to self-diagnose. Although little is known about this population, it is possible that they share similar self-conceptualizations or internalized stigma as their diagnosed counterparts. This study reports on the structural validity of the Autism Spectrum Identity Scale (ASIS) with individuals diagnosed and self-diagnosed with autism and compares the demographic characteristics, stigma, self-concept, and quality of life of these two groups.

Methods: Over 1000 adults diagnosed ($n = 893$) or self-diagnosed ($n = 245$) with autism were recruited through organizations serving the autism community to participate in a nationally distributed online survey that included demographic questions and measures for stigma, self-concept, quality of life, and well-being. The diagnosed data set was randomly split with exploratory factor analysis performed on a training data set. Split-half cross-validation was used to predict the factor structure of the holdout data set. Then, the full diagnosed data set structure was used to determine the generalizability of the factor structure to the self-diagnosed data set. The diagnosed and self-diagnosed were also compared for differences in gender, age, employment status, diagnostic term preference, and factors of self-concept (autism identity and self-esteem), stigma, and quality of life.

Results: Factor analysis of diagnosed participants yielded a four-factor structure, consistent with previous research, with strong split-sample cross-validation and good internal consistency. Factor predictions of the self-diagnosed data set from the diagnosed data set ranged from 0.97 to 1.00 with similar internal consistency. Self-diagnosed participants were more likely to be older, women, or employed and less likely to be students or prefer the term "autism" than those with an autism diagnosis. The groups were remarkably similar in reported stigma, self-esteem, quality of life, and in ASIS factors; both groups reported lower quality of life than the general population.

Conclusions: The ASIS demonstrated the same internal structure with both the diagnosed and self-diagnosed samples. The profile of self-diagnosed participants matches the profile hypothesized for the "lost generation" and others at risk of being underidentified for autism. Both populations appear to be similarly struggling with employment, stigma, and quality of life. Future research should examine whether self-diagnosed individuals meet criteria for autism or could benefit from interventions, programs, or services serving autism communities.

Keywords: autism, identity, stigma, self-concept, quality of life, well-being, employment

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Lay Summary

Why was this study done?

Recent research has suggested that some individuals, such as women, older individuals, and people with higher intelligence, may not be given the diagnosis of autism even when they should receive one. These individuals, called the ''lost generation,'' might also not receive treatments or services that they would be qualified for if they had an autism diagnosis.

Some adults without an autism diagnosis believe they are on the autism spectrum. Little is known about these self-diagnosed individuals. If the self-diagnosed are autistic, it is possible that they are like diagnosed adults in their reports of autism identity, stigma, and quality of life. It is also important to know if measures developed for the autism population are valid for use with the self-diagnosed population. This study reports the structural validity of the Autism Spectrum Identity Scale (ASIS) and examines whether the ASIS is structurally valid for the self-diagnosed population. This study also examines whether these two groups are similar in demographic characteristics (such as age and gender), autism identity, stigma, and quality of life.

What did the researchers do?

I invited over 1000 adults (893 diagnosed adults and 245 self-diagnosed adults) across the United States to take an online survey. The survey measured their responses to questions on the participants' attitudes and experiences with stigma, self-concept, and quality of life. I validated the structure of the ASIS with the diagnosed and self-diagnosed participants in the study. I compared the responses of the diagnosed with the self-diagnosed participants for self-concept, stigma, and quality of life. I also examined whether self-diagnosed participants were more likely to be unidentified due to being women or an older age, or whether they were more likely to be employed.

What were the results of the study?

The ASIS structure was valid for the self-diagnosed participants. The self-diagnosed participants were more likely to be older, women, or employed than those with a diagnosis. They were less likely to be students or prefer the term ''autism.'' The groups were very similar in their reports of stigma, self-esteem, quality of life, and autism identity.

The characteristics of the self-diagnosed participants match the suggested profile for the ''lost generation'' of autistic individuals who were not diagnosed with autism. Both groups appear to struggle with employment, stigma, and quality of life.

What are the potential weaknesses in the study?

This study examined characteristics of the self-diagnosed participants but cannot determine if these individuals have autism. These individuals would need to be assessed and diagnosed by a qualified professional to determine if they have autism. The participants in this study could read and understand a survey and report on their experiences and attitudes.

How will these findings help autistic adults in the future?

This study increases our understanding of self-diagnosed people. Self-diagnosed people are an under-researched group. This group may meet criteria for a diagnosis of autism or be in need of services and programs that address issues with employment, stigma, and quality of life.

Introduction

NOT ALL INDIVIDUALS on the autism spectrum receive an autism diagnosis. Some, such as females and individuals without an intellectual disability, are less likely to be diagnosed with autism in childhood.[1,2] Individuals in these groups may engage in compensatory behaviors that mask autistic characteristics, known as camouflaging, placing them at increased risk of being underidentified for autism.[3]

Recorded autism prevalence has increased over the last 20 years from 1 in 150 to the current rate of 1 in 59[4] children due,

in part, to the expansion of the diagnostic criteria, increased public and professional awareness, and increased access to professionals who provide diagnostic services.[5] Lai and Baron-Cohen, however, propose that a proportion of individuals (aka the ''lost generation'') who were children before this expansion of diagnostic criteria, awareness, and access were not identified during childhood and remain undiagnosed.[1] These individuals likely had early childhood characteristics more akin to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) criteria for Asperger's syndrome or pervasive developmental

disorder—not otherwise specified (PDD-NOS)[6] rather than the more classic autism features. These adults are likely older on average than adults who have an autism diagnosis.

Some individuals may also be underidentified for an autism diagnosis due, in part at least, to socioeconomic disparities or minority status.[4] According to the surveillance study by the Center for Disease Control's Autism and Developmental Disabilities Monitoring (ADDM) Network, these individuals were more likely to be diagnosed at a later age, if at all.[4]

Females are also likely to go undiagnosed.[1] While a male-to-female gender ratio of 4:1[7] is commonly cited, debate exists on whether this ratio reflects a gender bias in identification. A meta-analytic examination of odds ratios investigating the gender ratio of autistic participants in peer-reviewed literature found the male-to-female ratio to be 3:1.[8] Other studies that examine nonreferred samples (e.g., examination of the general population) have found gender ratios of 3:1 and 2:1.[9–11] Several studies have found that the male-to-female ratio for an autism diagnosis decreases with age.[12,13]

As these individuals grow older and become aware of their differences in social interactions and other characteristics, some may desire clinical assessment to determine if an autism diagnosis is appropriate. However, access to qualified professionals who provide autism diagnostic services for adults is scarce because (1) there are few professionals who provide this service, and (2) many adults may not have the resources needed to afford the assessment services.[14] Others may avoid seeking a diagnosis due to previous negative experiences with health care, social anxiety during appointments, fear of being disbelieved, concern about stigma associated with a formal diagnosis, and other barriers.[15] Given these barriers, some adults may choose to ''self-diagnose.'' Little is currently known about this self-diagnosed group of individuals.

Stigma, autism identity, and the self-diagnosed

Autism is defined by sets of behavior that violate the social expectations of others, including differences in social interaction and communication. Stigma is created when an individual or group is defined by characteristics considered to be socially undesirable.[16] Management of a stigmatized identity decreases performance (e.g., cognitive, academic, employment) and increases depression, anxiety, and maladaptive behavior following devaluating social cues for many stigmatized groups.[17,18] In previous research, I validated the Stigma Scale (SS)[19] and the Adult ADHD (attention-deficit/hyperactivity disorder) Quality of Life Scale (AAQOL)[20] with autistic adults; autistic adults reported higher levels of stigma than adults with mental health issues and lower quality of life than typical controls (but similar to those with ADHD).[21] However, some attitudes may mitigate the effects of stigma. For example, in autism, a positive autism identity is associated with increased self-esteem, quality of life, and psychological health.[21–24]

Autism identity is complex and, in previous research, I developed the Autism Spectrum Identity Scale (ASIS) to measure variation in how diagnosed and self-diagnosed adults identify with the autism spectrum. The ASIS measures autism identity along four dimensions: positive difference, changeability, context dependent, and spectrum abilities (see Table 1 for description).[21,22] The ASIS demonstrates con-

vergent and discriminant validity with self-esteem, stigma, and quality of life.[21] However, the structural validity of the ASIS has not yet been reported in the peer-reviewed literature. Scale validation is an ongoing multistep process that assesses different aspects of scale validity (e.g., construct validity, structural validity), reliability (e.g., scale reliability, test/retest reliability), and generalizability (e.g., cross-sample validity), across multiple stages of scale development and use.[25] As part of this process, it is critical to evaluate the structural validity and generalizability of a measure by investigating the latent dimensions of the scale through both exploratory factor analysis (EFA) and cross-validation procedures.[26]

This study examines the structural validity and generalizability of the ASIS with both people diagnosed with autism and self-diagnosed participants. This study also examines whether self-diagnosed participants correspond with or differ from their diagnosed peers in autism identity, stigma, self-esteem, quality of life, and demographic characteristics. Based on the theorized characteristics of the ''lost generation,'' I hypothesized that those who self-diagnose will be more likely to be older, women, and employed. Since social stigma is lower for Asperger's syndrome than for autism[27] and because self-diagnosed adults are able to choose their diagnostic category, I hypothesized that self-diagnosed individuals will prefer the less stigmatizing term of ''Aspergers'' and will be less likely to choose the term ''autism.''

Methods

This study is part of a larger project investigating the role of identity on postsecondary outcomes for adults on the autism spectrum. Additional methods are reported in detail in McDonald.[21,22] The University of Wisconsin Education and Social/Behavioral Science Institutional Review Board approved the procedures of this study.

Recruitment for survey

I contacted ∼9000 organizations and individuals in each of the 50 U.S. states with a request to distribute an email flyer for a national online study. Those contacted included various autism and self-advocacy societies and support groups, organizations and providers serving the autism community, government agencies, and the disability service offices of colleges and universities. As an incentive for participation, the flyer advertised a chance to win a $100 VISA card. Data collection occurred over 9 months and included a second recruitment email to each organization.

Participants

Inclusion criteria for this study required participants to (1) be older than 18 years; (2) have no legal guardian; (3) to have, or identify with, an autism spectrum diagnosis, and (4) to be able complete multiple choice and open-ended questions on a survey regarding their characteristics, attitudes, and experiences. The final analysis included a total of 1139 people who responded to the survey, met these criteria, and completed at least 50% of the ASIS. Table 2 summarizes the characteristics of this sample. Among those who listed taking medications for other conditions, no other condition was indicated by more than 2% of the participants. See McDonald[21] for a

TABLE 1. SCALE DESCRIPTIONS FROM ORIGINAL VALIDATION STUDIES

Scale	Scale description	Factors	Means (SD)	α
ASIS[21,22]	The 22-item scale measures variation in autism identity with a five-point Likert scale across four domains: positive difference (vs. challenging disability), context dependent (vs. context general), spectrum abilities (vs. nonautism—specific abilities), and changeability (vs. static traits). Higher scores in positive difference, changeability, and spectrum abilities represent a more positive autism identity.	Positive difference Context dependent Spectrum abilities Changeability		0.88 0.89 0.82 0.66
SS[19]	The 28-item scale measures internalized and experienced stigma for adults with mental health problems using a five-point Likert scale. Higher scores represent higher levels of stigma. For the current study, the SS was adapted by replacing ''mental health problems'' with ''Asperger's/autism.''	Overall Discrimination Disclosure Positive aspects	62.6 (15.4) 29.1 (9.5) 24.7 (8.0) 8.8 (2.8)	0.87 0.87 0.85 0.64
AAQOL[20]	The 29-item scale measures quality of life for adults with ADHD using a five-point Likert scale. Higher scores represent better quality of life. The original study reports on both individuals with ADHD and with non-ADHD controls who demonstrate significant differences in total and factor scores. No adaptations were made to the AAQOL for this study.	ADHD Overall Life productivity Life outlook Psychological health Relationships Non-ADHD control Overall Life productivity Life outlook Relationships	 59.9 (17.4) 61.8 (21.6) 60.7 (17.7) 53.9 (22.7) 61.8 (20.2) 79.0 (12.2) 85.3 (21.6) 72.1 (15.9) 75.5 (18.2) 77.6 (15.9)	 0.93 0.88 0.79 0.83 0.75
RSE[33]	The 10-item scale measures self-regard. A five-point Likert scale was used. Higher scores represent greater self-regard. No adaptations were made to the RSE for this study.			0.77–0.88

AAQOL, Adult ADHD Quality of Life Scale; ADHD, attention-deficit/hyperactivity disorder; ASIS, Autism Spectrum Identity Scale; RSE, Rosenberg Self-Esteem Scale; SS, Stigma Scale.

flow chart of participant inclusion and a table summarizing additional sample characteristics.

Materials

The survey included demographic questions measuring age, gender, date of diagnosis (if applicable), education level, current education and employment status, geographic location, living arrangements, in a romantic relationship/married, income level, current medications, and how they heard about the study.

Table 1 summarizes the study measures. The survey included measures of autism identity, stigma, quality of life, and self-concept.

Procedures

Participants followed a URL link to the online survey. After meeting criteria and providing informed consent, participants then chose their preferred term: ''Autism,'' ''Asperger,'' or ''No Preference'' and received a survey using the corresponding term. Those who chose ''No Preference'' received the survey using autism as the reference term. After completing the demographics and the partially counterbalanced measures, providing optional comments, and, opting in or out of the incentive lottery, participants had

the opportunity to save and print study contact information before exiting the survey.

Data analyses

I conducted statistical analyses with R version 3.3.3 (Psych package, factanal function), and in SPSS version 26. I deleted missing data pairwise for EFA and cross-validation analyses and listwise for all analyses in the group comparison section below. Data analyses consisted of a multistep process described below.

EFA and cross-validation of the ASIS items for diagnosed individuals. I randomly split the data file approximately in half, with 450 cases in the training data set and 443 cases in the holdout data set. Initially, I carried out all EFA procedures on the training data set only and used the holdout data set for cross-validation. EFA is hypothesis-free and is the ideal analysis for understanding the latent structure within a set of variables.[28,29] I utilized principal axis factor analysis with promax rotation with the Bayesian information criterion (BIC) to determine the best factor solution. Following selection of the appropriate number of factors, I used the factor structure of the training data set in the cross-validation analyses following procedures described by Revelle[30] to predict the factor structure of the holdout data set. Cross-validation

TABLE 2. NUMBER AND PERCENT OF PARTICIPANT
DEMOGRAPHIC CHARACTERISTICS

	Diagnosed		Self-diagnosed	
Characteristic	n	%	n	%
Highest education level				
Elementary, middle, or junior	27	3	5	3
High school	118	14	23	14
Some college	223	38	58	36
2-year college degree	40	5	5	3
4-year college degree	329	38	66	41
Graduate or professional degree	24	3	3	2
Medication use[a]				
Anxiety	344	39	57	23
Depression	289	32	50	20
ADHD	246	16	18	7
Bipolar	48	5	8	3
OCD	67	8	10	4
Other	156	18	23	9
Age of diagnosis				
Birth to 5	108	12		
6–10 years	91	10		
10–13 years[b]	66	7.3		
14–17 years	92	10.0		
18–present	585	58.6		
I don't know	90	1.9		
	Mean	SD	Mean	SD
Age	32	12.65	37	13.02

[a]Percentages do not sum to 100% because some participants reported more than one condition.
[b]Age overlap due to typographical error in survey.
OCD, Obsessive Compulsive Disorder.

demonstrates generalizability of factor solutions and is considered a best practice following EFA.[31] After cross-validation, I rejoined the two halves of the data set and calculated Cronbach's alpha to determine the internal consistency of each factor.

Cross-validation for self-diagnosed individuals. I used the four-factor model loadings of the diagnosed group to predict a four-factor structure for the self-diagnosed group. To avoid errors associated with small samples,[29] I used the maximum likelihood function to test the four-factor structure.[32]

Group comparisons. I calculated summary statistics of means, standard deviations, and internal reliability for the ASIS factors, the overall scores and factors of the SS and AAQOL and for the Rosenberg Self-Esteem Scale (RSE).[33] I performed chi-square analyses for the diagnostic category comparisons of gender, diagnostic term preference, employment, and education status. Independent samples t-tests examined differences for age, ASIS factors, and overall SS, AAQOL, and RSE scores. I performed a hierarchical binary logistic regression to examine employment status (excluding participants with concurrent student status) as a function of age for the diagnosed and self-diagnosed participants. I coded employed status ''0'' and unemployed status ''1.''

I entered age in step one and diagnostic category in step two. I used the Hosmer/Lemeshow test to determine goodness of fit for models containing the age variable.

Results

First-half sample factor analysis for diagnosed participants

Initially, I performed the principal axis factor analysis with promax rotation on the two-, three-, four-, and five-factor models, which yielded corresponding BIC values of −258.98, −397.39, −548.54, and −544.87, respectively. All items demonstrated loadings greater than 0.4. I considered cross loadings high if a second loading was over 0.3. Factors loaded cleanly with no cross-loading exceeding 0.3. The standardized root mean square residual (SRMR) was 0.03, the root mean square error of approximation (RMSEA) index was 0.003 (0.003–0.064), and the Tucker/Lewis Index was 0.92.

The four-factor model with promax rotation explained 50% of the variance in the correlation matrix with positive difference, context dependent, spectrum abilities, and changeability accounting for 17%, 16%, 11%, and 6% of the variability, respectively. Table 3 presents the results of the four-factor analysis on the training and holdout data sets, including the factor loadings, item means, and standard deviations.

Cross-validation of factors

Each factor from the training data set predicted a corresponding principal axis factor with promax rotation in the holdout data set with prediction values ranging from 0.99 to 1.00 (Supplementary Table S1). For the holdout data set, the SRMR was 0.03, the RMSEA index was 0.004 (0.004–0.068), and the Tucker/Lewis Index was 0.912 for the four-factor model.

Scale structure for self-diagnosed participants

Each factor from the four-factor model predicted a corresponding factor in the self-diagnosed population data with prediction values ranging from 0.98 to 1.00 (Supplementary Table S2). Factors loaded cleanly with no cross-loading exceeding 0.3. The RMSR was 0.04 and the RMSEA index was 0.003 (0.003–0.069), the Tucker/Lewis Index was 0.901 for the four-factor model. Table 4 presents the results of the four-factor analysis on the diagnosed and self-diagnosed samples, including the factor loadings, item means, and standard deviations.

Group comparisons

Table 5 shows the factor and overall means, standard deviations, and internal reliability for the ASIS, AAQOL, SS, and RSE. Self-diagnosed participants reported higher context-dependent scores, $t(1137) = -3.38$, $p = 0.001$, and higher positive aspects scores, $t(1090) = -4.28$, $p < 0.001$. There were no other significant differences between factor and overall scale scores.

Chi-square analyses were significant for gender, term preference, student status, employment, and employment status excluding students (Table 6). Self-diagnosed participants were more likely to be women or employed, and less likely to choose the term ''autism'' or have student or not in employment, education, or training status.

		Factor 1		Factor 2		Factor 3		Factor 4		Mean (SD)	
		First	Second	First	Second	First	Second	First	Second	First	Second
Positive difference											
18	If I were cured of Aspergers/autism, I wouldn't be me anymore.	**0.98**	**0.86**	0.04	−0.07	−0.13	−0.01	−0.09	−0.07	**3.26** (1.10)	**3.15** (1.11)
6	I like having Aspergers/autism or being autistic.	**0.84**	**0.84**	−0.15	−0.10	−0.11	−0.06	0.02	0.07	**3.45** (1.22)	**3.33** (1.28)
9	I feel Aspergers/autism has more benefits in abilities than challenges.	**0.81**	**0.86**	0.10	0.05	0.00	−0.03	−0.02	−0.03	**2.99** (1.05)	**2.91** (1.06)
12	I like the way I am different from everyone else.	**0.62**	**0.67**	0.00	0.11	0.02	0.02	0.05	−0.06	**3.59** (0.99)	**3.56** (1.01)
21	I am better off because I have Aspergers/autism.	**0.59**	**0.62**	0.19	0.14	0.08	−0.01	0.04	0.03	**2.90** (1.01)	**2.86** (1.04)
11[a]	I would be better off if I didn't have Aspergers/autism.	**0.51**	**0.48**	−0.14	−0.20	0.04	0.13	0.13	0.19	**3.36** (1.04)	**3.31** (1.16)
5[a]	Aspergers/autism only makes things harder for me.	**0.48**	**0.34**	−0.07	−0.04	0.14	0.32	−0.11	−0.08	**4.15** (1.05)	**4.13** (1.06)
Context dependent											
8	I feel like I only have Aspergers/autism around certain people, like classmates, teachers, parents, or coworkers.	0.05	0.02	**0.91**	**0.83**	0.06	0.05	−0.17	−0.10	**2.31** (1.13)	**2.30** (1.18)
20	I only "have Aspergers/autism" when people treat me like I do.	0.05	0.06	**0.89**	**0.88**	−0.05	0.03	−0.10	−0.05	**2.31** (1.12)	**2.32** (1.17)
13	I feel like I only have Aspergers/autism in certain places, like school, home, work, or somewhere new.	−0.06	−0.07	**0.72**	**0.76**	0.01	−0.01	0.02	−0.01	**2.47** (1.18)	**2.45** (1.21)
17	There are some places where I don't have Aspergers/autism.	−0.02	−0.02	**0.71**	**0.68**	−0.01	0.03	0.05	0.10	**2.74** (1.22)	**2.64** (1.22)
14	When I'm alone, I don't feel like I have Aspergers/autism.	0.11	0.14	**0.55**	**0.58**	−0.02	−0.11	0.05	−0.02	**2.09** (1.00)	**2.09** (1.07)
1	I feel like I only have Aspergers/autism in certain activities, like completing work, organizing, getting ready to go somewhere, or new activities.	−0.13	−0.02	**0.54**	**0.62**	−0.02	0.02	0.13	0.12	**2.34** (1.25)	**2.27** (1.14)
4	There are some people with whom I don't feel I have Aspergers/autism.	0.00	−0.06	**0.44**	**0.54**	0.00	0.05	−0.03	−0.04	**2.88** (1.30)	**2.72** (1.27)
Spectrum abilities											
7[a]	My good qualities have little to do with Aspergers/autism.	−0.04	−0.09	−0.06	−0.02	**0.75**	**0.74**	0.09	0.12	**3.78** (1.06)	**3.71** (1.12)
22[a]	My strengths have little to do with Aspergers/autism.	0.02	0.00	0.00	−0.09	**0.71**	**0.75**	−0.12	−0.07	**3.54** (0.96)	**3.50** (1.04)
15	Aspergers/autism means having unique abilities.	0.08	0.07	0.05	0.12	**0.70**	**0.74**	0.11	0.05	**4.06** (0.91)	**4.04** (0.96)
19[a]	I don't feel I have additional abilities from my Aspergers/autism.	−0.03	0.00	−0.12	−0.09	**0.65**	**0.66**	−0.08	−0.11	**3.33** (0.99)	**3.28** (1.06)
3	I am good at some things because I have Aspergers/autism.	0.23	0.13	0.16	0.22	**0.49**	**0.64**	0.06	0.04	**4.03** (0.86)	**4.04** (0.93)
Changeability											
2[a]	There is little I can do about my Aspergers/autism.	0.02	0.15	0.03	0.02	−0.01	−0.13	**0.71**	**0.75**	**3.48** (1.07)	**3.38** (1.08)
10	If I work hard enough, I can minimize my Aspergers/autism.	−0.13	−0.12	0.17	0.21	−0.03	0.00	**0.67**	**0.62**	**2.87** (1.20)	**2.81** (1.20)
16	If I work hard enough, I can minimize the challenges associated with Aspergers/autism.	0.06	−0.03	−0.10	−0.11	0.02	0.11	**0.45**	**0.59**	**2.89** (1.11)	**2.93** (1.14)

Bold values under Factor columns indicate the items included within each factor domain (positive difference, context dependent, spectrum abilities, changeability). Bold values under the Mean (SD) column indicate mean values.

[a]Reversed items.

		Factor 1		Factor 2		Factor 3		Factor 4		Mean (SD)	
		FDX	SDX	FDX	SDX	FDX	SDX	FDX	SDX	FDX	SDX
Positive difference (FDXα=0.87; prop of var.=0.16; NDXα=0.84; prop. of var.=0.15)											
18	If I were cured of Aspergers/autism, I wouldn't be me anymore.	**0.92**	**1.00**	−0.02	−0.09	−0.07	−0.24	−0.08	−0.03	**3.21** (1.11)	**3.13** (1.00)
6	I like having Aspergers/autism or being autistic.	**0.84**	**0.72**	−0.13	−0.18	−0.09	−0.03	0.05	−0.02	**3.39** (1.25)	**3.19** (1.13)
9	I feel Aspergers/autism has more benefits in abilities than challenges.	**0.85**	**0.76**	0.07	0.07	−0.03	−0.03	−0.03	0.06	**2.95** (1.06)	**2.85** (0.93)
12	I like the way I am different from everyone else.	**0.65**	**0.70**	0.06	0.16	0.02	−0.04	−0.01	−0.05	**3.57** (1.00)	**3.47** (1.04)
21	I am better off because I have Aspergers/autism.	**0.61**	**0.50**	0.16	0.19	0.03	0.09	0.03	0.12	**2.88** (1.02)	**3.00** (0.99)
11[a]	I would be better off if I didn't have Aspergers/autism.	**0.49**	**0.41**	−0.17	−0.18	0.09	0.15	0.17	0.04	**3.33** (1.10)	**3.29** (0.98)
5[a]	Aspergers/autism only makes things harder for me.	**0.40**	**0.43**	−0.06	−0.05	0.23	0.22	−0.10	−0.10	**3.97** (1.07)	**4.13** (1.06)
Context dependent (FDXα=0.86; prop. of var.=0.17; NDX α=0.84, prop. of var=0.17)											
8	I feel like I only have Aspergers/autism around certain people, like classmates, teachers, parents, or coworkers.	0.03	0.07	**0.87**	**0.78**	0.06	−0.03	−0.13	−0.02	**2.31** (1.15)	**2.47** (1.16)
20	I only ''have Aspergers/autism'' when people treat me like I do.	0.05	0.05	**0.89**	**0.86**	−0.01	−0.01	−0.08	−0.01	**2.31** (1.15)	**2.53** (1.10)
13	I feel like I only have Aspergers/autism in certain places, like school, home, work, or somewhere new.	−0.06	−0.14	**0.74**	**0.74**	0.00	0.04	0.01	0.14	**2.46** (1.20)	**2.65** (1.18)
17	There are some places where I don't have Aspergers/autism.	−0.02	−0.01	**0.69**	**0.78**	0.01	0.04	0.08	−0.03	**2.69** (1.22)	**2.88** (1.17)
14	When I'm alone, I don't feel like I have Aspergers/autism.	0.12	0.12	**0.56**	**0.42**	−0.06	−0.08	0.01	0.03	**2.09** (1.04)	**2.17** (1.06)
1	I feel like I only have Aspergers/autism in certain activities, like completing work, organizing, getting ready to go somewhere, or new activities.	−0.07	−0.10	**0.59**	**0.57**	0.00	0.04	0.12	0.21	**2.31** (1.20)	**2.59** (1.12)
4	There are some people with whom I don't feel I have Aspergers/autism.	−0.02	−0.06	**0.49**	**0.57**	0.03	0.16	−0.04	−0.22	**2.80** (1.29)	**3.02** (1.29)
Spectrum abilities (FDXα=0.83; proportion of var=0.12; NDXα=0.77; prop. of var.=0.10)											
7[a]	My good qualities have little to do with Aspergers/autism.	−0.07	0.05	−0.04	−0.15	**0.76**	**0.78**	0.11	−0.04	**3.75** (1.09)	**3.72** (1.03)
22[a]	My strengths have little to do with Aspergers/autism.	0.01	−0.05	−0.05	−0.10	**0.72**	**0.77**	−0.09	−0.08	**3.52** (1.00)	**3.45** (0.94)
15	Aspergers/autism means having unique abilities.	0.07	0.13	0.09	0.17	**0.73**	**0.57**	0.08	0.08	**4.05** (0.93)	**4.04** (0.85)
19[a]	I don't feel I have additional abilities from my Aspergers/autism.	−0.01	0.08	−0.10	−0.23	**0.64**	**0.47**	−0.09	−0.19	**3.30** (1.03)	**3.25** (0.98)
3	I am good at some things because I have Aspergers/autism.	0.17	0.09	0.20	0.19	**0.58**	**0.62**	0.04	0.14	**4.03** (0.89)	**4.03** (0.85)
Changeability (FDXα=0.67; proportion of var=0.06; NDX α=0.55, prop of var.=0.06)											
2[a]	There is little I can do about my Aspergers/autism.	0.10	0.20	0.03	0.06	−0.08	−0.03	**0.73**	**0.75**	**3.43** (1.08)	**3.41** (1.04)
10	If I work hard enough, I can minimize my Aspergers/autism.	−0.12	−0.10	0.20	0.05	−0.01	−0.12	**0.64**	**0.67**	**2.84** (1.20)	**2.92** (1.14)
16	If I work hard enough, I can minimize the challenges associated with Aspergers/autism.	0.01	−0.05	−0.11	−0.13	0.08	0.22	**0.52**	**0.29**	**2.91** (1.12)	**2.92** (1.06)

Bold values under factor columns indicate the items included within each factor domain (positive difference, context dependent, spectrum abilities, changeability). Bold values under the Mean (SD) column indicate mean values.

[a]Reversed items.

FDX, full diagnosed participant data; SDX, self-diagnosed participant data.

Table 5. Descriptive Statistics Showing the Mean (Standard Deviation) and Cronbach's Alpha of the Autism Spectrum Identity Scale Factors, Adult Attention-Deficit/Hyperactivity Disorder Quality of Life Scale and Stigma Scale Overall and Factor Scores, and the Rosenberg Self-Esteem Scale for the Diagnosed and Self-Diagnosed Groups

	Diagnosed		Self-diagnosed	
	Mean (SD)	α	Mean (SD)	α
ASIS[21,22]				
Positive difference	3.35 (0.81)	0.87	3.27 (0.72)	0.84
Changeability	3.06 (0.88)	0.67	3.08 (0.79)	0.55
Spectrum ability	3.73 (0.34)	0.83	3.70 (0.33)	0.77
Context dependent	**2.42 (0.87)**	0.86	**2.64 (0.85)**	0.84
AAQOL[20]				
Overall	58.39 (13.65)	0.92	56.90 (11.51)	0.90
Life productivity	58.44 (17.02)	0.88	56.61 (15.17)	0.86
Life outlook	55.93 (15.14)	0.82	54.99 (13.59)	0.80
Relationships	65.68 (18.31)	0.80	63.96 (16.27)	0.74
Psychological health	55.13 (17.65)	0.83	53.82 (15.78)	0.71
SS[19]				
Overall	81.32 (13.48)	0.83	81.47 (12.56)	0.83
Discrimination	39.69 (8.21)	0.79	38.54 (7.65)	0.77
Disclosure	29.05 (6.53)	0.77	29.45 (5.37)	0.79
Positive aspects	**12.56 (2.80)**	0.43	**13.48 (2.60)**	0.36
RSE[33]	32.26 (8.53)	0.91	32.72 (7.16)	0.87

Significant differences are in bold.

Table 6. Observed Frequencies and Column Percentages of Gender, Term Choice Preference, Student Status, and Employment Status by Diagnosis

	Diagnosis					
	DX n = 892		SDX n = 172		(X²)	p
Gender	n	%	n	%	7.59	0.023
Male	**325**	**36.4**	**44**	**25.6**		
Female	**514**	**57.6**	**101.7**	**66.9**		
Other	53	5.9	13	7.6		
	DX n = 893		SDX n = 246		(X²)	p
Term choice preference	n	%	n	%	10.36	0.006
Autism	**284**	**31.8**	**53**	**21.5**		
Asperger	440	49.3	124	54.5		
No term preference	169	18.9	59	24.0		
	DX n = 889		SDX n = 167		(X²)	p
Student status	n	%	n	%	13.15	<0.001
Student	**332**	**37.3**	**38**	**22.8**		
Nonstudent	**557**	**62.7**	**129**	**77.2**		
	DX n = 875		SDX n = 162		(X²)	p
Employment status	n	%	n	%	6.36	0.012
Employed	**435**	**49.7**	**98**	**60.5**		
Not employed	**440**	**50.3**	**64**	**39.5**		
	DX n = 544		SDX n = 122		(X²)	p
Employment status (excluding students)	n	%	n	%	5.12	0.024
Employed (IEET)	**291**	**53.5**	**79**	**64.8**		
Unemployed (NEET)	**253**	**46.5**	**43**	**35.2**		

Significant column differences are in bold.
DX, diagnosed sample; IEET, in employment, education, and/or training; NEET, not in employment, education, and/or training; SDX, self-diagnosed participant data.

TABLE 7. LOGISTIC REGRESSION ANALYSIS
OF EMPLOYMENT STATUS (EXCLUDING STUDENTS)

Predictor	β	SE(β)	Wald's χ^2	df	p	e^{β}
Age	0.002	0.006	0.069	1	0.793	1.002
DX category	−0.430	0.213	4.094	1	0.043	0.650
Constant	0.228	0.333	0.469	1	0.494	NA

Omnibus tests	χ^2	df	p
Wald's test	4.188	1	0.041
Hosmer and Lemeshow test	10.64	8	0.223

Cox and Snell $R^2 = 0.006$.
Nagelkerke $R^2 = 0.009$.

Table 7 shows the results of the logistic regression analysis. Age was not a significant predictor of employment status when entered alone. While diagnostic category was a significant predictor of employment status, age was not a significant predictor of employment status when added to the model.

Discussion

For this study, I report on the structural validity of the ASIS for adults diagnosed and self-diagnosed with autism. In addition, I compared the characteristics of self-diagnosed participants with diagnosed participants in terms of gender, age, student and employment status, and scores on the ASIS, SS, AAQOL, and RSE.

Validation of the ASIS with adults diagnosed and self-diagnosed with autism

The four-factor structure of the ASIS was the best fit for the training data set of the diagnosed participant data and this structure strongly predicted the structure of the holdout data set, as well as the factor structure of the self-diagnosed participant data. The clean loadings of the factors indicate the distinct structure of each of the factors. The strong structural relationships demonstrated by training-holdout cross-validation procedures indicate the reliability of the four-factor structure. Finally, the strong structural relationships between the diagnosed and self-diagnosed samples indicate that the ASIS is structurally valid for use with the self-diagnosed population.

Lost generation: individual characteristics and camouflaging

Consistent with the hypotheses in this study, self-diagnosed participants were more likely to be older, women, and employed than the diagnosed participants. It is possible these individuals are part of the underidentified "lost generation" described in the literature. It should be noted that the ADDM Network examines the prevalence of autism in children at age 8. It is currently unknown how the prevalence of autism changes for adults. For example, while the prevalence was 1 in 150 for 8-year olds in 1992, it is unknown how many undiagnosed 8-year olds went on to receive a diagnosis as a preteen, teen, or adult. Other re-

search highlights the lack of studies examining screening and diagnostic tools with individuals who have high IQs and the concern that gifted individuals may be particularly challenging to assess.[2]

The self-diagnosed were more likely to be employed, to consider experiences of being on the spectrum as contextually dependent, and to feel that being on the spectrum provided some positive aspects, such as having more empathy for others. This is consistent with the literature proposing that individuals who have greater communication and/or social skills, have higher IQ, or who engage in greater camouflaging are less likely to be diagnosed with autism.[1–3]

The self-diagnosed participants strongly resembled their diagnosed counterparts in terms of autism identity, stigma, quality of life, and self-esteem. While both groups reported strikingly similar scores in stigma and quality of life, these scores also show that both groups report higher levels of stigma than individuals with mental health conditions and much lower quality of life than the scores reported by the control group in their respective literatures.[19,20] Even without the label of the diagnosis, the self-diagnosed group has clearly experienced and internalized stigma, formed an autism identity similar to the diagnosed counterparts and, in general, were less likely to prefer the "autism" label. In addition, both groups reported much higher unemployment rates than the U.S. average unemployment of 6.2 at the time of this study,[34] indicating that both groups must contend with employment challenges.

Strengths and limitations

Strengths of this study include a large, nationwide data set, rigorous methods for scale development, and a quantitative approach to assess autism identity. In addition, this study validates the ASIS with self-diagnosed adults, an understudied group within the autism literature.

As previously reported, the respondents for this survey could comprehend complex sentences and report their own experiences and perceptions. As such, this study does not assess the identity, and other characteristics, of those who cannot provide this type of self-report. Despite being able to self-report, the participants in this study experience significant postsecondary challenges and are underserved in the community and in research.

Based on the classic autism spectrum male-to-female prevalence ratio that ranges from 4:1 to 5:1[7] and the more recently suggested prevalence ratio of 3:1,[8] a disproportionate number of women participated in this study. Women have outnumbered men in several other studies using an online survey format with autistic adults[3,24,35] and these gender proportions are likely representative of survey study methods with this population. Nevertheless, women continue to be an understudied group within the autism literature. Participants were able to self-report their autism diagnosis for this study. This limitation is potentially mitigated by allowing participants to participate without a formal diagnosis, lessening the likelihood that participants without a diagnosis would claim such a diagnosis to participate in the study. Furthermore, as previously described in greater detail, the pattern of characteristics of the diagnosed participants (e.g., employment, stigma, quality of life) is consistent with the research literature with this population.

Conclusion

The ASIS demonstrates structural validity for both adults diagnosed and self-diagnosed with autism. Furthermore, the self-diagnosed adults strongly resembled their diagnosed counterparts on autism identity, gender, age, employment, stigma, quality of life, and other factors. The high levels of stigma, low quality of life, and low employment indicate that the self-diagnosed group is experiencing challenges similar to adults with an autism diagnosis on these factors. While future research should examine the accuracy of self-diagnosis, the results of this study indicate that self-diagnosed individuals may have similar needs related to identity, stigma, quality of life, and employment as adults who have an autism diagnosis. Additional future research should examine facilitators and barriers for self-diagnosed individuals to access diagnostic and treatment services as well as community resources.

Authorship Confirmation Statement

T.A.M.M. conceived the project idea and designed the overarching and current study. T.A.M.M. identified the project theories and identified, adapted, and/or created the study measures. T.A.M.M conducted the study, collected data, and conducted the data analyses. This article has been submitted to *Autism in Adulthood*, only, and has not been published elsewhere.

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Supplementary Material

Supplementary Table S1
Supplementary Table S2

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