

Original Research Article

Words matter: Language preferences in a sample of autistic adults

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Abstract

The terminology used to describe individuals with disabilities is a subject of ongoing debate. The use of person-first language (PFL), such as "person with autism," is often considered the standard by professionals and organizations. However, some communities of individuals with disabilities, such as the deaf and blind, prefer the use of identity-first language (IFL), such as "autistic person." According to published and unpublished research, preferences for IFL and PFL vary across groups. The current study evaluated autistic individuals' language preferences (IFL vs. PFL), relative to diagnosis method, cooccurring disabilities, and rating on a self-report autism measure with a sample of 247 autistic individuals. Results found no consistent trends in language preference, indicating best practice may be to alter language use based on individual preferences when interacting with autistic individuals.

Keywords

Adults, autism spectrum disorders, education services, communication and language

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Words matter: language preferences in a sample of autistic adults

The use of identity-first language (IFL; autistic person) versus person-first language (PFL; person with autism) is a debated topic in psychology and related fields (Bur-y et al., 2020). While PFL is often taught and encouraged as the default for disabled individuals, several communities, such as those who are deaf and/or blind, have stated preference for IFL (Centers for Disease Control and Prevention, 2022; U.S. Department of Education, 2022). Unpublished and published research suggests that preference for IFL and PFL varies across groups (Bury et al., 2020; Kenny et al., 2016; Vivanti, 2020). Given these discrepancies, it may be best practice to ask and use a person's preferred language when referring to disability, rather than defaulting to PFL or IFL. This may be particularly important when providing therapeutic care, as building the therapeutic relationship and providing dignity to those with whom professionals interact and provide services are considered critical to ethical and successful service provision.

Proponents of PFL state that PFL places the person before the disability (Wright, 1983). In the medical model

of disability, PFL is preferable because it focuses on the person rather than the disability. In contrast, the social model of disability emphasizes societal barriers rather than the individual deficits of a disability (Bury et al., 2020). The social model of disability views disability as a neutral or positive characteristic of a person, not an illness. This model of disability suggests that PFL perpetuates the stigma associated with disability.

Previous survey research on language preferences

Kenny et al. (2016) surveyed 3,470 U.K. residents about autism terminology. They found that different groups (people with autism spectrum disorder [ASD], parents,

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professionals, family/friends) had different language preferences. Participants were asked to choose from the following terms: ASD, autism spectrum condition (ASC), High-functioning autism, Asperger's syndrome, ASPIE, autistic, has autism/Asperger's, person with autism/Asperger's, autistic person, and on the autism spectrum. More autistic adults chose the terms autistic (20%) and on the autism spectrum (19%) than other terms. Parents were divided in their language preferences of autism/Asperger's (20%), ASC (19%), and on the autism spectrum (19%). Professionals (26%) and family and friends (28%) preferred the term on the autism spectrum than other terms.

Bury et al. (2020) utilized a sample of 198 autistic 17-18-year-old teenagers in Australia. Using Likert-type scales, the researchers queried language preferences and offensive terms used when referring to autism. Researchers used a weighted mean rank Friedman test to rank six terms. Participants ranked the following terms (ordered from highest preference to least): person on the autism spectrum, autistic person, autistic, person with autism, person with ASC, and person with ASD. Autistic received the greatest number of participants ranking it as the most preferred, though the weighted mean rank placed persons on the autism spectrum and autistic persons above it. The total percentages of participants selecting the term as their first preference are: autistic (37.9%), person on the autism spectrum (25.2%), autistic person (11.1%), person with ASD (11.1%), person with ASC (9.6%), and person with autism (5.1%).

Lei et al. (2021) surveyed 803 e-learners' responses from comments in two online courses in autism education. Self-advocates, professionals, and family and friends reported a preference for IFL. Professionals reported a preference for PFL. All three groups discussed that ASD includes a wide range of individual differences. In addition, all three groups identified three main themes around the terminology of ASD. Parents and professionals described how it is important to teach children how to self-disclose and take advantage of the resources available to them. All three groups communicated there is a need to identify unique strengths and needs across different contexts and stakeholders. The final theme was that autism is a core piece of an autistic person's identity, which may lead to a preference for IFL. Lei et al. (2021) also provided percentages of language preference for ASD stakeholders. This included 32 self-advocates, 250 friends and family, and 443 professionals. These participants were asked their preference between the following: person with autism, on the autism spectrum, autistic and ASD. In the group of selfadvocates 54% preferred autistic, in the group of family and friends 34.8% preferred autistic, and in the group of professionals 15.6% preferred autistic.

Taboas et al. (2022) surveyed 728 U.S. autism stakeholders on language preferences when referring to autism.

Eighty-seven percent of autistic adults preferred IFL while most professionals preferred PFL. Their research included a large U.S. sample; however, the survey did not utilize any measures of autism or ask the participants about the source of diagnosis. Taken together, this research shows differences in language preference between autistic individuals and stakeholders, indicating a need for additional research on differences in preferences across groups within the autistic community, as well as a need for individualized language use when discussing disability. Table 1 summarizes the findings reported in these articles.

Keating et al. (2023) completed the first cross-cultural investigation of autism-related language preferences, and it aimed to identify the most favored language used to describe autistic individuals. The study found that there was high agreement across countries for the terms autism, autistic person, is autistic, neurological/brain difference, differences, challenges, difficulties, neurotypical people, and neurotypicals. However, the study also found great variability in language preferences within the autistic community, suggesting that it is important to ask autistic individuals about their language preferences. Keating et al. (2023) found that there was a majority preference for IFL, with the most popular terms for self-identifying being autistic person, neurodivergent person, and autistic. In contrast, there was a considerably lower endorsement of PFL, such as a person with autism. Autistic participants argued that autism is an integral part of who they are, and therefore, language should be identity-first. However, the study also found that the term *autistic* as a noun can be dehumanizing, and while it has been reclaimed by the community it may not be appropriate for nonautistic people to use. Therefore, they recommended that nonautistic people avoid using autistic as a noun and only use it as an adjective.

Dwyer et al. (2022) emphasized the importance of promoting diversity, equity, and inclusion in healthcare, particularly in relation to autism and disability. They highlighted the negative impact of disparaging language and assumptions on the well-being of autistic individuals. The authors called for a shift towards more respectful and inclusive terminology, such as using "disability" instead of "disorder" and considering the preferences of autistic individuals regarding IFL or PFL. Cultural humility and empathy were encouraged, along with a willingness to learn from autistic individuals to promote their overall well-being. In their paper, Dwyer et al. (2022) did not present new data, however, stated that IFL should be used.

Given the differences found across previous studies in language preference, it may be beneficial to evaluate variables that may contribute to language preference in the autistic community. There may be potential differences in language preference based on when and how a person received an autism diagnosis, as well as the level of autistic traits. The current study aims to build on past research to examine these additional factors.

(continued)

 Table 1. Language preference literature review.

Autisity Aut			Kenny et al. (2016)	(2016)			Bur	Bury et al. (2020)	020)		Lei	Lei et al. (2021)		Taboas et al. (2022)
Autistic Family Multipliates Friends Autistic Family Multipliates Friends Autistic Family Multipliates Autistic							Autistic i	ndividual	s N=198					
15%* 15%* 15%* 20%* 10%* 25.7% 12.6% 35.9% 10.2% 26.9% 10%* 25.7% 12.6% 35.9% 10.2% 26.9% 10%* 25.7% 12.6% 35.9% 10.2% 26.9% 10.9%* 20.9%* 10.9%* 25.7% 12.6% 35.9% 10.2% 26.9% 10.2% 25.9% 10.2% 20.9%* 20.9		Autistic individuals $N = 502$	Parents N=2,207	Family/ friends N=380	Professionals N=1,109			Ranking			Autistic individuals $N = 37$	Family/ friends N=250	Professionals N=443	Autistic individuals $N = 298$
sm/Asperger's is9%* is9%* in0%* in0%* in0%* in0% in0% in0% in0% in0% in0% in0% in0%						1	2			9				
sm/Asperger's 35%* 50%* 45%* 45%* 17,6% 81,0% 7,6% 10,6% 28,3% 54,0% 34,8% with hyberger's 18% 50%* 45%* 45%* 45%* 14,9% 10,4%	ASPIE	* %57	15%*	20%*	10%*	25.2% 1	2.6% 35	.9% 19			n/a	n/a	n/a	%0.4
35%* 50%* 45%* n/a n/a<	Autistic	61%	51%	52%	38%					% 28.3%	94.0%	34.8%	15.6%	64.1%
28%	Has autism/Asperger's	35%*	× %05	*%54	42%×	n/a					5.4%	13.2%	3.4%	13.1%
n/a n/a <td>Person with autism/Asperger's</td> <td>28%</td> <td>22%</td> <td>30%*</td> <td>%67</td> <td></td> <td>6.2% 27</td> <td>.8% 27.</td> <td>3% 14.6</td> <td></td> <td>18.9%</td> <td>9.6%</td> <td>20.3%</td> <td>n/a</td>	Person with autism/Asperger's	28%	22%	30%*	%67		6.2% 27	.8% 27.	3% 14.6		18.9%	9.6%	20.3%	n/a
n/a n/a <td>Person with autism</td> <td>n/a</td> <td>n/a</td> <td>n/a</td> <td>n/a</td> <td>n/a</td> <td></td> <td></td> <td></td> <td></td> <td>n/a</td> <td>n/a</td> <td>n/a</td> <td>1.0%</td>	Person with autism	n/a	n/a	n/a	n/a	n/a					n/a	n/a	n/a	1.0%
35%* 10%* 10%* 15%* 11.1% 36.4% 8.6% 9.6% 5.1% 6.1% n/a	Person with Asperger's	n/a	n/a	n/a	n/a	n/a					n/a	n/a	n/a	2.0%
er 40%* 50%* 60%* 65%* n/a n/a n/a n/a n/a n/a n/a 176 n/a 13.6% 13.6% er 40%* 55%* n/a	Autistic person	35%*	10%*	10%*	15%*						n/a	n/a	n/a	1.7%
er 40%* 45%* 40%* 55%* n/a n/a n/a n/a n/a n/a n/a 17.6 % 17.6 % 17.6 % 17.6 % 17.6 % 17.6 % 17.6 % 17.6 % 17.6 % 17.6 % 17.6 % 18.6 % 18.6 % 19.6 %	On the autism spectrum	55%*	* %05	×%09	65%*	n/a					8.1%	13.6%	20.5%	7.4%
60%* 60%* 65%* n/a n/a n/a n/a n/a n/a n/a 8% 8% 8% 25%* 15%* 20%* 30%* n/a	Autism spectrum disorder	* %0ħ	42%×	×%04	55%*	n/a					8.1%	17.6%	16.5%	n/a
25%* 15%* 20%* 30%* n/a n/a n/a n/a n/a n/a 2.7% 3.2% 3.2% 10%* 10%* 10%* 10%* n/a	Autism	* %09	* %09	*%09	*%59	n/a					5.4%	%8	7.7%	n/a
10%* 10%* 15%* 10%* n/a n/a n/a n/a n/a n/a n/a n/a 35%* 25%* 30%* n/a n/a n/a n/a n/a n/a 16.2% 6.4%	Autism spectrum condition	25%*	15%*	20%*	30%*	n/a					2.7%	3.2%	2.9%	n/a
35%* 25%* 25%* 30%* n/a n/a n/a n/a n/a 16.2% 6.4%	Low functioning autism	10%*	10%*	15%*	10%*	n/a					n/a	n/a	n/a	%0
	High functioning autism	35%*	25%*	25%*	30%*	n/a					16.2%	6.4%	2.9%	%0.4

Table 1. Continued.

Autistic individuals Parents Family Family	-		Kenny et al. (2016)	(2016)			Bury et	Bury et al. (2020)			Lei et al. (2021)	1)	Taboas et al. (2022)
Autistic individuals N=502 Parents friends individuals (N=2,207) Parents friends (N=1,109) Professionals (N=3)						A	utistic indiv	riduals N:	= 198				
n with autism spectrum n/a n/a		Autistic individuals $N = 502$	Parents N=2.207	Family/ friends N=380	Professionals N=1.109		Ra	nking		Autistic individuals $N = 37$			Autistic individuals $N=298$
n with autism spectrum n/a n/a n/a n/a n/a n/a n/a n/						1	е.	4	5 6				
n with autism spectrum disorder n/a n/a n/a 11.1% 12.1% 16.7% 16.7% 19.7% 28.8% n/a	Person with autism spectrum condition	n/a	n/a	n/a	n/a	9.6% 15.	2% 8.1%	19.7%	22.7% 24.7		n/a	n/a	n/a
5.4% 19.6% 2.3% n/a	Person with autism spectrum disorder	n/a	n/a	n/a	n/a	11.1% 12.	1% 12.2%	16.7%	19.7% 28.8		n/a	n/a	2.7%
13.5% 19.6% 30.0% n/a n/a n/a n/a n/a n/a n/a n/a n/a	Other	5.4%	19.6%	2.3%	n/a			n/a			n/a	n/a	n/a
	No preference indicated	13.5%	19.6%	30.0%	n/a	n/a n	/a n/a				n/a	n/a	n/a

*indicates an estimate taken from a graph. Note. Bury et al. (2020) provided percentages based on how descriptors were ranked in order of preference.

Autism diagnosis

Several barriers exist to obtaining a diagnosis of ASD (Lewis, 2016). Some of these barriers are financial cost, access to qualified professionals, stigma, and that the diagnostic characteristics of ASD were developed from populations that were largely cis-gender, white, and male (Lewis, 2016). Due to these barriers, self-diagnosis is widely accepted in the autistic community (Lewis, 2016).

Alternatives to self-diagnosis include diagnosis by a medical provider, such as a physician, psychiatrist, or psychologist, and school-based eligibility for special education services. Recent research indicates substantial delays between initial parent concerns and diagnosis, and access to autism assessment providers may be substantial barriers to a formal autism diagnosis (Martinez et al., 2018). Martinez et al. (2018) surveyed 450 families on barriers to autism diagnosis and found the average time between first concern and diagnosis was about 19 months, with nearly a third of families waiting over 2 years for a diagnosis. Over 40% of the sample had to travel over 20 miles to find a provider, and 34% indicated they struggled to find a provider.

School-based determination of eligibility for special education services under the category of autism will include a variety of assessments, such as cognitive assessments, adaptive behavior measures, and measures of autistic symptoms, where a school-based team with family representatives will determine if the data support eligibility for special education services, such as an individualized education plan. These assessments are provided at no cost to families of school-age students (U.S. Department of Education, n.d.), making them more accessible than diagnoses by medical or clinical providers. Given the discrepancies found between the autistic community professionals, parents and families, and friends on language preference when discussing disability, it is possible preferences may also differ across autism diagnostic sources within the autistic community, especially when considering how each may contribute to a person's understanding of autism and their own strengths and needs.

Current study

Surveying the autistic community on language preference can help clarify the language debate and help professionals use inclusive language that reflects the values of the community they serve. However, there is very little research on the language preferences of autistic individuals, especially in the United States. The research that does exist often has methodological issues, such as sampling bias (Lei et al., 2021), or being conducted in another country (Bury et al., 2020; Kenny et al., 2016). Currently, no published research has examined language preferences by autism diagnostic source or included a measure of autism.

The purpose of this study is to gain information on autistic individuals' language preferences and determine if the type of diagnosis, the presence of multiple diagnoses, or rating on a self-report autism measure correlate with this preference.

Methods

Questions related to language preferences and diagnosis, demographics, and the Autism-Spectrum Quotient Test (AQ; Baron-Cohen, Wheelwright, Hill, et al., 2001; Baron-Cohen, Wheelwright, Skinner, et al., 2001) were given as part of a larger study validating the Adult Social Skills Rating Scale (ASSRS; redacted for review, 2022). The entire survey was distributed for expert review for content validity and general feedback to an autistic researcher and advocate. The ASSRS, AQ, and other measures were given to 3,000 participants. Participants were recruited using the Pollfish (2022) online survey platform. A total of 3,000 respondents were targeted, with specific inclusion criteria set for age (18-65 years) and location (the United States). Respondents were compensated with one to three dollars upon completion of the survey. The amount of compensation is determined by Pollfish, based on the participants' membership and previous activity on Pollfish.

Validity questions were utilized to assess the validity of participant responses. These questions included items such *I have flown on a plane 6 times in the last week*. Of the participants who passed the validity check (n = 2,154), 257 participants indicated they had a diagnosis of autism (self-diagnosed, school-based eligibility, or formal/medical diagnosis). These responses were pulled and analyzed for the current study.

Measures

Participants completed an anonymous survey, as described above. For the current study, participants' responses to demographic questions, autism diagnostic sources, cooccurring diagnoses, and AQ scores were utilized in analyses and reported. All items were self-reported. Participants were selected from multiple choice options for each of the demographic and diagnostic source items. For the language preference item, participants were asked Which do you prefer?, and given the following options: person-first language (she/he has autism), identity-first language (she/he is autistic), no preference, this is not relevant to me, I prefer not to say, and none of the above.

The AQ was presented as a matrix, where participants selected the most accurate option on a Likert-type scale for each item. The AQ was originally normed with 1,088 participants, including 58 autistic adults (Baron-Cohen, Wheelwright, Hill, et al., 2001; Baron-Cohen, Wheelwright, Skinner, et al., 2001). Test-retest reliability was measured with 17 participants

over two weeks, with adequate reliability (r = .7). To validate the AO, 11 participants with a score of 32+ were clinically interviewed, where it was determined seven of these participants met the criteria for a diagnosis of autism. Baron-Cohen, Wheelwright, Hill, et al. (2001) and Baron-Cohen, Wheelwright, Skinner, et al., (2001) originally suggested a cutoff score of 29 and above as being consistent with symptomology of autism; although, their more recent work has promoted scores of 26 and above (Baron-Cohen et al., 2020). Woodbury-Smith et al. (2005) gave the AQ to 100 participants between the ages of 18 and 69. Each participant was seen later for a more comprehensive diagnostic assessment. The AQ was determined to be able to differentiate between autistic and nonautistic individuals adequately. The area under the ROC curve was 0.78, representing the accuracy of the AO in the moderate range.

Participants

Participants were 247 autistic adults and were evenly represented between female (49.8%) and male (50.2%) reported gender. Participants reported age ranges of 18–24 (22.7%), 25–34 (30.8%), 35–44 (30.4%), 45–54 (8.9%), and >54 (7.3%). Participants reported belonging to the following race categories: White (68.85%), Hispanic or Latino (11.07%), Black (10.25%), Asian (4.10%), Multiracial (2.05%), and Arab (0.82%). An additional seven participants (2.87%) reported Other (unspecified) race, and three (1.21%) preferred not to respond.

Participants were asked to report how they were diagnosed with autism: doctor/psychologist, school special education eligibility, or self-diagnosis. Participants reported a diagnosis by a medical doctor or psychologist (49.80%), being found eligible at school (14.17%), and self-diagnosis of autism (36.03%). While participants' autism diagnoses were not verified, participants completed the AQ with an average score of 26.70 (SD = 7.10; range: 6-47), where scores of 26 and above indicate an individual might have autism (Baron-Cohen et al., 2020). One category of participants, those who reported being found eligible at school, were below the cutoff of 26 (M=24.6), and all groups had mean AQ scores at or below 28, indicating this sample may experience relatively low levels of autistic traits. The highest AQ scores belonged to the group that indicated a self-diagnosis of autism.

Participants were also asked about cooccurring disabilities. About 90% of the sample reported a cooccurring diagnosis of either depression, anxiety, attention-deficit hyperactivity disorder (ADHD), or a learning disability. Over 50% reported a diagnosis of depression, over two-thirds reported a diagnosis of anxiety, over 40% reported a diagnosis of ADHD, and just under 25% reported a learning disability. The exact frequencies and percentages

of these data and other demographic variables can be found in Table 2.

Data analyses

Prior to data analyses, the data file was cleaned to allow for analyses and interpretation. Specifically, participants were allowed to select all possible diagnosis types (diagnosis by doctor/psychologist, school special education eligibility, and self-diagnosis) when taking the survey. Researchers then assigned participants to only one level based on their responses. If a participant reported an autism diagnosis by a medical doctor or psychologist, they were placed in the doctor/psychologist category, regardless of other selections. If a participant reported they were eligible for services under the category of autism in school and self-diagnosis, they were placed in the school category. Participants who only reported self-diagnosis were placed in the selfdiagnosis category. The AQ items were scored according to the publisher's directions (Baron-Cohen, Wheelwright, Hill, et al., 2001; Baron-Cohen, Wheelwright, Skinner, et al., 2001), and the total score was used in analyses.

Categorical data were summarized with frequency counts and percentages across levels of each variable. Chi-square tests of association were utilized to evaluate trends in language preference across sources of autism diagnosis and cooccurrence of multiple diagnoses. Multiple diagnosis categories were created for those with no, one, two, three, or four additional diagnoses. Autism diagnosis has three levels: doctor, school, and self-diagnosis. Each of the cooccurring diagnoses had two levels: yes or no. Language preference had six levels: PFL, IFL, no preference, not applicable, none of the above, and prefer not to say. Participants could select multiple options. The category of no preference included those who selected both PFL and IFL as their language preference, selected no preference, or selected all three of these options. All other categories were single selections. Two one-way ANOVAs were conducted to evaluate potential differences in AQ across autism diagnosis method and language preference. Data met the assumptions for all analyses. Statistical analyses were conducted in Jamovi, an open-access statistical program (The Jamovi Project, 2022).

Results

Participants reported six options for language preference: PFL (34%), IFL (21.9%), no preference (35.6%), not applicable (7.3%), prefer not to say (0.8%), and none of the above (0.4%). See Table 2 for additional summaries of categorical demographic variables. Comparisons of language preference and autism diagnostic sources are below, followed by comparisons of autism diagnostic source and language preference on AQ total scores.

Table 2. Sample demographic characteristics and descriptive results.

Variable	n (Missing)	Level	Frequency	Percentage
Gender	247 (0)	Male	124	50.20
		Female	123	49.80
Age	247 (0)	18-24	56	22.67
nge	247 (0)	25-34	76	30.77
		35-44	75	30.36
		45-54	22	8.91
		>54	18	7.29
Race	244 (3)	White	168	68.85
nuce	244 (3)	Hispanic/Latino	27	11.07
		Black	25	10.25
		Asian	10	4.10
		Multiracial	5	2.05
		Arab	2	.82
		Other	7	2.87
Autism Dx source	247 (0)	Doctor	123	49.80
Autism Dx Source	247 (0)	School	35	14.17
		Self		
	245 (2)		89	36.03
Cooccurring	245 (2)	Yes	222	89.88
		Depression	140	57.14
		Anxiety	172	70.20
		ADHD	109	44.49
		Learning Disability	59	24.08
		None of the above	23	9.39
Language preference	247 (0)	PFL	84	34.01
		IFL	54	21.86
		No preference	88	35.63
		Not applicable	18	7.29
		Prefer not to say	2	.81
		None of the above	1	.40

 $\textit{Note}. \ \mathsf{ADHD} = \mathsf{attention\text{-}deficit} \ \mathsf{hyperactivity} \ \mathsf{disorder}; \ \mathsf{IFL} = \mathsf{identity\text{-}first} \ \mathsf{language}; \ \mathsf{PFL} = \mathsf{person\text{-}first} \ \mathsf{language}.$

Diagnostic source and language preference

To evaluate whether the source of autism diagnosis was associated with language preferences, a chi-square test of association was conducted. The overall model was non-significant, indicating no relationship between diagnostic source and language preference (X^2 (10) = 4.65, p = .913). No preference was selected by 40% of school respondents, 37.40% of doctor respondents, and 31.46% of self-diagnosed respondents. PFL was selected by 37.14% of school respondents, 30.08% of doctor respondents, and 38.20% of self-diagnosed respondents. IFL was selected by 17.14% of school respondents, 24.39% of doctor respondents, and 20.22% of self-diagnosed participants. See Table 3 for the model contingency table with all observed counts.

Multiple diagnoses and language preference

A large portion of participants (89.88%) who reported an autism diagnosis also reported the presence or nonpresence of the following conditions: depression (n = 140; 57.14%), anxiety (n = 172; 70.20%), ADHD (n = 109; 44.49%), and learning disabilities (n = 59; 24.08%). Participants could select as many of the four conditions as applied to them. Seventy participants (28.57%) reported one additional diagnosis, 69 (28.16%) reported two additional diagnoses, 61 (24.90%) reported three additional diagnoses, 23 (9.39%) reported four additional diagnoses, and 22 (8.98%) indicated they had no additional diagnoses. Two respondents declined to respond.

Additional chi-square tests of association were conducted to observe trends in multiple diagnosis categories and language preference. There were no statistically significant trends in the number of reported diagnoses and

Table 3. Contingency table for source of diagnosis and language preference.

				Lang	uage p	reference	e
Dx source	PFL	IFL	No preference	NA	PNS	None	Total
School	13	6	14	2	0	0	35
Doctor	37	30	46	8	1	1	123
Self	34	18	28	8	1	0	89
Total	84	54	88	18	2	1	247

Note. Total cells include total counts across rows and columns. Internal cells report observed counts. PFL = person-first language; IFL = identity-first language; NP = no preference; NA = not applicable; PNS = prefer not to say; None = none of the above.

language preference $(X^2 (20) = 22.56, p = .311)$. Those who reported no cooccurring diagnoses preferred PFL (45.45%), IFL (22.73%), or had no preference (27.27%). Those who reported one additional diagnosis preferred PFL (34.29%), IFL (20%), or had no preference (34.29%). Those who reported two additional diagnoses preferred PFL (39.13%), IFL (15.94%), or had no preference (37.68%). Those who reported three additional diagnoses preferred PFL (31.15%), IFL (31.15%), or had no preference (27.87%). Finally, those who reported four additional diagnoses preferred PFL (13.04%), IFL (21.74%), or had no preference (60.87%). See Table 4 for the contingency tables with observed counts for each of these comparisons.

Differences in AQ

Two ANOVAs were conducted to analyze differences in AQ scores across autism diagnostic source and language preference. For the diagnostic source, data met the assumptions of normality (W=0.991, p=.136) and homogeneity of variance, F(2, 244) = 1.04, p=.354. For language preference, data failed the test for normality (W=0.988, p=.043); however, AQ scores had skew within normal limits (skew=0.229). Homogeneity of variance was observed, F(5, 241) = 1.85, p=.105.

Autism Diagnostic Source. Differences were observed between autism diagnostic source on AQ total scores, F(2, 244) = 3.29, p = .039. Omega-squared indicated a small effect (0.018). Post-hoc analyses indicate a statistically significant difference in AQ total scores for those who reported self-

Table 4. Contingency tables for multiple diagnoses and language preference.

				Lang	guage	preferen	ice
Multiple diagnoses	PFL	IFL	No preference	NA	PNS	None	Total
Autism only	10	6	5	1	0	0	22
Plus one	24	14	24	6	2	0	70
Plus two	27	11	26	5	0	0	69
Plus three	19	19	17	5	0	1	61
Plus four	3	5	14	1	0	0	23
Total	83	54	87	18	2	1	245

Note. Total cells include total counts across rows and columns. Internal cells report observed counts. PFL = person-first language; IFL = identity-first language; NP = no preference; NA = not applicable; PNS = prefer not to say; None = none of the above.

diagnosis and those who met eligibility for special education services for autism in school (t=2.42, p=.043). Cohen's d indicated a small effect (0.483). Participants who reported self-diagnosis had an average AQ score of 28 (SD=7.15; range: 14–47). Participants who were found eligible in school had an average AQ score of 24.6 (SD=6.87; range: 12–42). Those who reported a diagnosis by a medical professional or psychologist had an average AQ score of 26.3 (SD=7.00; range: 6–46).

Language Preference. No differences were observed between language preferences on AQ total scores, F(5, 241) = .665, p = .650. Participants who indicated a preference for PFL had a mean score of 25.9 (SD = 7.51) on the AQ, those who indicated a preference for IFL had a mean score of 26.4 (SD = 7.57) on the AQ, and those who indicated no language preference had a mean score of 27.3 (SD = 6.94) on the AQ. AQ scores for additional preferences included "not applicable" (M = 28.3, SD = 4.38), "prefer not to say" (M = 23, SD = 2.83), and "none of the above" (AO = 25).

Discussion

This study evaluated relationships between autism diagnostic source, cooccurring diagnoses, and language preference. Data on these variables were collected from 247 participants reporting a diagnosis of autism. A large proportion of these participants (89.88%) reported cooccurring diagnoses of depression, anxiety, ADHD, and/or a learning disability. Chi-square tests of association indicated no relationships between autism diagnostic source or the presence of multiple diagnoses and language preference. Generally, participants were most likely to report no language preference (35.6%), followed by PFL (34%), then IFL (21.9%), indicating a no-size-fits-all approach should be taken regarding disability language use. Instead, individuals may utilize a mixed-language approach, alternating between language use, when speaking to a group (Shakes & Cashin, 2019). When speaking with an individual, it may be best to ask that person for their language preference and modify language use according to their preference.

This study also evaluated differences between language preference and scores on the AQ, finding no significant differences. However, differences were observed between diagnostic source and total AQ scores. Specifically, participants who reported self-diagnosis had significantly higher AQ scores than those who were found eligible in school, although this was a small effect. Of note, those who were found eligible in school had the lowest average AQ score, followed by those diagnosed by a medical professional or psychologist, with those who were self-diagnosed having the highest AQ scores. Reasons for these differences go beyond the scope of the current study; however, early intervention and access to services and supports may be at least partially responsible for these small differences in AQ

scores, given those with formal diagnoses reported lower AQ scores, and those who are self-diagnosed may have limited access to therapeutic resources due to cost relative to those with formal diagnoses.

Ultimately these findings do not completely align with other survey research in this area. While previous research has been variable in its findings, most of this work indicated autistic individuals preferred IFL when compared to nonautistic stakeholders (Bury et al., 2020; Kenny et al., 2016; Lei et al., 2021; Taboas et al., 2022). However, prior research did not compare language preference across diagnostic source, a potential source of variance in language preference, given the involvement of self-diagnosed autistic individuals in self-advocacy. Further, prior research utilized rank choice or forced choice selection for language preference, whereas the current study allowed for multiple selections of preferred language. The most frequent language preference category in the current study was no preference, indicating preferences may be fluid or less important to at least some individuals with autism. Additionally, the current study utilized a brief measure of autism symptomology, first to validate the sample, and finally as a potential source of variance in language preference. Despite these findings differing from previous work, the results continue to indicate that language preference should be highly individualized, as no consistent predictors were established for an individual preferring PFL or IFL.

The findings of this study contribute to the ongoing debate surrounding language use in relation to autism. While proponents of IFL argue that it affirms autistic identity, the current sample of autistic individuals indicated that PFL was preferred over IFL, emphasizing the importance of recognizing personhood alongside autism. It is worth noting that this study did not specifically address the arguments put forth by Dwyer et al. (2022), which emphasized the negative impact of disparaging language and advocated for a shift toward inclusive terminology, however, this article does present new data which contradicts Dwyer et al. (2022), by finding that in this data set autistic individuals are diverse in their language preferences. These contrasting viewpoints highlight the complexity of the language debate within the autistic community and emphasize the need for continued dialog and consideration of individual preferences.

Limitations and future directions

The current study has some limitations. First, these data were collected via survey from a convenience sample. While a diverse sample in regard to gender, age, and race was recruited, several categories in each variable had low participant counts, resulting in class imbalances across some comparisons. Future research on this topic should attempt to gather a larger, more representative sample. Second, all data were self-reported by participants, which may have been impacted by response biases and misreporting. Response

validity was initially checked with validity items in the survey, and mean AQ scores generally support symptoms consistent with autism; however, no further confirmation of diagnosis was attempted. Furthermore, the study's participants had an average AQ score of 26.70, which is only slightly above the recommended cutoff point for autism. This suggests that the sample may not be fully representative of autistic adults, as individuals with lower levels of autistic traits or no autism may have scored similarly. As such, caution should be exercised when generalizing the findings to the broader autistic adult population. To improve the validity of recommendations, future work could verify autism diagnosis and diagnostic source, as well as collect a sample of individuals with a wider range of levels of autistic traits.

Further, while the current study contributed additional information about language preferences in the autistic community across three diagnostic sources and compared to AQ scores, additional sources of variance in language preference may be present. Additional research could identify and evaluate these variables as contributors to language preference. While the debate continues, it seems the best practice recommendation may be to utilize a heavily individualized approach.

Data availability: The data that support the findings of this study are available from the corresponding author, Jaime Flowers, upon reasonable request.

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References

- Baron-Cohen, S., Tsompanidis, A., Auyeung, B., Nørgaard-Pedersen, B., Hougaard, D. M., Abdallah, M., Cohen, A., & Pohl, A. (2020). Foetal oestrogens and autism. *Molecular Psychiatry*, 25(11), 2970–2978. https://doi.org/10.1038/s41380-019-0454-9
- Baron-Cohen, S., Wheelwright, S., Hill, J., Raste, Y., & Plumb, I. (2001). The "reading the mind in the eyes" test revised version: A study with normal adults, and adults with Asperger syndrome or high-functioning autism. *Journal of*

- Child Psychology and Psychiatry, 42, 241–251. https://doi.org/10.1111/1469-7610.00715
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Autism Developmental Disorders*, 31(1), 5–17. https://doi.org/10.1023/a:1005653411471
- Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It defines who I am" or "It's something I have": What language do [autistic] Australian adults [on the autism spectrum] prefer? *Journal of Autism and Developmental Disorders*, 53(2), 677–687. https://doi.org/10.1007/s10803-020-04425-3
- Centers for Disease Control and Prevention. (2022). *Preferred terms for select population groups & communities*. Centers for Disease Control and Prevention. https://www.cdc.gov/healthcommunication/Preferred_Terms.html
- Dwyer, P., Ryan, J. G., Williams, Z. J., & Gassner, D. L. (2022). First do no harm: Suggestions regarding respectful autism language. *Pediatrics*, *149*, https://doi.org/10.1542/peds.2020-049437N
- Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism Research*, 16(2), 406–428. https://doi.org/10.1002/aur.2864
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462. https://doi.org/10.1177/1362361315588200
- Lei, J., Jones, L., & Brosnan, M. (2021). Exploring an e-learning community's response to the language and terminology use in autism from two massive open online courses on autism education and technology use. *Autism*, 25(5), 1349–1367. https:// doi.org/1362361320987963
- Lewis, L. F. (2016). Exploring the experience of self-diagnosis of autism spectrum disorder in adults. *Archives of Psychiatric Nursing*, 30(5), 575–580. https://doi.org/https://doi.org/10.1016/j.apnu.2016.03.009
- Martinez, M., Thomas, K. C., Williams, C. S., Christian, R., Crais, E., Pretzel, R., & Hooper, S. R. (2018). Family experiences with the diagnosis of autism spectrum disorder: System barriers and facilitators of efficient diagnosis. *Journal of Autism and Developmental Disorders*, 48(7), 2368–2378. https://doi.org/10.1007/s10803-018-3493-1
- Real Consumer Insights: Pollfish Survey Tools. (2022). *Real consumer insights: Pollfish survey tools*. https://www.pollfish.com/
- Shakes, P., & Cashin, A. (2019). Identifying language for people on the autism spectrum: A scoping review. *Issues in Mental Health Nursing*, 40(4), 317–325. https://doi.org/10.1080/ 01612840.2018.1522400
- Taboas, A., Doepke, K., & Zimmerman, C. (2022). Short report: Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism*, 27(2), 565–570. https://doi.org/10.1177/13623613221130845
- The Jamovi Project. (2022). *Jamovi* (Version 2.3) [Computer Software]. https://www.jamovi.org
- U.S. Department of Health and Human Services. (2022). Person-first and destigmatizing language. National Institutes of Health. https://www.nih.gov/nih-style-guide/person-firstdestigmatizing-language

Vivanti, G. (2020). Ask the editor: What is the most appropriate way to talk about individuals with a diagnosis of autism? *Journal of Autism and Developmental Disorders*, 50(2), 691–693. https://doi.org/10.1007/s10803-019-04280-x

Woodbury-Smith, M. R., Robinson, J., Wheelwright, S., & Baron-Cohen, S. (2005). Screening adults for Asperger syndrome

using the AQ: A preliminary study of its diagnostic validity in clinical practice. *Journal of Autism and Developmental Disorders*, *35*(3), 331–335. https://doi.org/10.1007/s10803-005-3300-7

Wright, B. A. (1983). *Physical disability: A psychosocial approach* (2nd ed.). Harper & Row.