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"It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer?

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Abstract

There has been a recent shift from person-first to identity-first language to describe autism. In this study, Australian adults who reported having a diagnosis of autism ($N = 198$) rated and ranked autism-terms for preference and offensiveness, and explained their choice in free-text. 'Autistic', 'Person on the Autism Spectrum', and 'Autistic Person' were rated most preferred and least offensive overall. Ranked-means showed 'person on the autism spectrum' was the most preferred term overall. Six qualitative themes reflected (1) autism as core to, or (2) part of one's identity, (3) 'spectrum' reflecting diversity, (4) the rejection of stigmatising and (5) medicalised language, and (6) pragmatics. These findings highlight the importance of inclusive dialogue regarding individual language preference.

Keywords Autism · Terminology · Autism identity · Label preference · Person-first · Identity-first

The increased discussion around what language or terms should be used when referring to people who are diagnosed with an autism spectrum disorder (ASD; henceforth "autism") demonstrates how language and terminology reflect differing worldviews (Galasiński 2018) and stakeholder perspectives (Vivanti 2020). Although professionals or researchers may use labels to communicate succinctly, members of the autism community may prefer, or even feel offended by different terms. This debate has mostly revolved around the use of person-first or identity-first language (Vivanti 2020). As individuals diagnosed with autism are traditionally a marginalised and vulnerable group, it is incumbent upon professionals, and society broadly, to understand their perspective on the language and terms used to describe them. Such dialogue can aid in forming constructive alliances and reduce stigmatisation (Dunn and Andrews 2015).

Descriptions and terms for autism have changed significantly throughout the years, partly reflecting changes in commonly used diagnostic criteria. For example, in the current version of the Diagnostic and Statistical Manual (*DSM-5*; American Psychiatric Association 2013), Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified were incorporated into a single category (i.e., ASD). This change led to widespread discussion about the implications for diagnosis and service provision (Young and Rodi 2014). Moreover, some individuals previously diagnosed with Asperger's Disorder were upset by the 'loss' of the label, which they considered part of their identity (Kenny et al. 2016; Smith and Jones 2020). Furthermore, some individuals feared stigmatisation due to the change (Linton et al. 2014), with some evidence that this stigmatisation occurs (Katz et al. 2019).

Moving away from the medical model of disability which identified patients 'as' their diagnosis (e.g., 'a paraplegic', 'an autistic'), the social model of disability presents disability as a "neutral characteristic or attribute, not a medical problem requiring a cure" (Dunn and Andrews 2015, p. 258). Rather than focusing on individual impairments, this model emphasises societal barriers that inhibit inclusion (e.g., physical obstacles to access, prejudice, discrimination; Dunn and Andrews 2015). Proponents of this model

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have argued that person-first language (e.g., 'person with a disability', 'person with autism') is preferable because it focuses on the identity and humanity of the individual rather than their disability (Wright 1983), thereby reducing devaluation of the individual or promotion of stereotypes (La Forge 1991). Person-first language has been recommended by the American Psychological Association (2012) and is commonly applied in research and clinical environments (e.g., Crocker and Smith 2019).

Nonetheless, the person-first approach has been critiqued for accentuating disability and perpetuating stigma. For example, it has been argued that person-first language inadvertently signals that having a disability is something 'bad' that should be separated from the individual (Andrews et al. 2019; La Forge 1991). Others have noted that person-first language is used inconsistently, primarily to describe individuals with a disability and not those without (e.g., 'person with autism' but not 'person with typical development'), thus person-first language ultimately emphasises the disability and not the person (Gernsbacher 2017).

More recently, minority or diversity models of disability present disability as neutral or even positive (Dunn and Andrews 2015). Thus, disability is integral to identity and culture, as well as connection to a broader "disability" community (e.g., autism community, deaf community; Andrews et al. 2019; Bagatell 2010; Lane 2005). Within the neurodiversity movement deficits are reframed as differences, which are subsequently reframed as strengths (Kapp et al. 2013). The movement advocates identity-first language (e.g., autistic person; Sinclair 1999), thereby deliberately 'reclaiming' the disability or diagnostic label as integral to their identity (Kenny et al. 2016). Identity-first language is recommended by some autism bodies (e.g., *Autistica*; Sterry 2019) and academic journals (e.g., Autism in Adulthood 2019). However, within the broader autism community there is no consensus about the use of identity-first language. As Robison (2019) suggests, "language that is appropriate to one person is offensive to another" (p. 1006).

One of the few empirical studies that has investigated attitudes towards autism terminology suggested that there is wide disagreement regarding preferred language use in the United Kingdom (UK) amongst individuals who have been diagnosed with autism or who identify as being autistic, parents, professionals, family, and friends (Kenny et al. 2016). Participants were asked to endorse commonly used terms to describe people diagnosed with autism. Although this study is widely used to support identity-first language preferences within the autism community, the findings are actually much more equivocal. The study identified differences in language preference based on the population group (e.g., professionals endorsed person-first terms more than other groups) and type of question asked (e.g., terms individuals use to describe themselves versus terms

to communicate with others about autism). Most importantly, however, approximately 60% of individuals diagnosed with autism preferred the terms 'autism', 'autistic', and 'on the autism spectrum'. However, when asked to endorse one term only, individuals diagnosed with autism most frequently chose 'autistic' and 'on the autism spectrum' (20% and 19%, respectively). Thus, there appears to be limited agreement within the UK, and within the UK autism community itself, about when and why to use specific autism terms and, contrary to a common misconception, 'autistic' was not overwhelmingly preferred over other terms.

The limited prior research suggests that it is important to acknowledge and understand *why* the same terminology may be perceived very differently depending on the person and context (Robison 2019). Moreover, it is essential that language use respects the dignity and preferences of adults who have been diagnosed with autism. As discussed above, much of the current discourse advocating identity-first language preferences amongst people diagnosed with autism is based on a single study from the UK (i.e., Kenny et al. 2016), even though these findings were equivocal. Yet the UK has embraced identity-first language more broadly than other countries (Rottenstein 2014 in Dunn and Andrews 2015) and therefore may not be representative of the autism population globally. Thus, it is important to examine terminology preference in different cultures and countries.

Current Study

This current study investigated which autism terms Australian adults diagnosed with autism prefer, which they find most offensive, and why. In order to identify consensus and potentially problematic terms participants rated and rank-ordered the terms for both preference and offensiveness. In the present study we considered 'Preference' and 'Offensiveness' to be distinct constructs as opposed to opposite ends of a continuum. This allowed us to examine how offensive each term was to the individual, irrespective of how it was ranked in terms of preference. Extending previous studies, participants were also asked open-ended questions to describe the reasoning behind their choices. Given that previous research identified identify-first terms as preferred amongst individuals diagnosed with autism (Kenny et al. 2016), and the visibility of the neurodiversity movement within Australia (den Houting 2019), we predicted that participants would rate and rank identity-first terms more favourably than person-first terms. We also considered the influence of demographic variables (i.e., autism traits, gender, age and diagnosis age) that have not previously been explored.

Methods

Participants

Participants were from a convenience sample including 198[1] individuals aged 18–71 years ($M = 34.89$, $SD = 12.34$) who indicated having a formal diagnosis of autism (see Table 1 for demographics). Participants were, on average, diagnosed in adulthood (Diagnosis age: $M = 27.36$, $SD = 16.23$ years), with the majority reporting a diagnosis of Asperger's Disorder or ASD. Participants generally had at least some postsecondary education, and 51% indicated that they were employed. A relatively high proportion of women participated in this study relative to diagnostic rates (Loomes et al. 2017), which is common in online studies (e.g., Arnold et al. 2019; Kenny et al. 2016).

Procedure

Participants were recruited as part of a broader study of autism identity and disclosure, approved by the La Trobe University Human Research Ethics Committee, that ran from February to August 2019. Researchers contacted universities, autism bodies, community groups, and employers throughout Australia and asked them to share study information within their network via email, social media and on their websites. Participants accessed the study information and questionnaire online (Qualtrics 2017). Those who reported being under 18 years-old, not an Australian citizen or permanent resident, or not having a formal diagnosis of autism were exited from the study. Participants received a $10 voucher as compensation for their time.

Measures

Abridged Version of the Autism-Spectrum Quotient (AQ-Short) (Hoekstra et al. 2011)

The AQ-Short is a 28-item measure designed to assess autism trait severity. Participants responded to statements on a 4-Point Likert-scale (1 = definitely agree, 4 = definitely disagree; range 28–112), with higher scores indicating higher autism traits. A cut-off point > 65 provides sensitivity and specificity to a clinical diagnosis of 0.97 and 0.82, respectively. Cronbach's alpha in the current sample indicated internal reliability was high, $\alpha = 0.85$.

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[1] A total of 363 responses were collected. However, 165 were excluded after being identified as spam (Dupuis et al. 2019), repeat responses, and under-age responses (See Supplementary Materials 1 for details of exclusion and analysis).

Table 1 Demographic data

Assigned gender	N	%
Male	62	31.3
Female	133	67.2
Intersex/indeterminate/unknown	3	1.5
Gender identity		
Male	58	29.3
Female	111	56.1
Trans male/trans man	1	.5
Trans female/trans woman	0	0
Genderqueer/gender non-conformist	20	10.1
Different identity[a]	8	4.0
Reported autism diagnosis		
Autism spectrum disorder	93	47.0
Asperger's disorder	97	49.0
PDD-NOS	1	.5
Other	7	3.5
Autism	(4)	
Autistic disorder	(1)	
ASD with ADHD	(1)	
PDD-NOS and ID	(1)	
Diagnostician(s)		
Doctor/general practitioner	31	15.7
Psychologist	138	69.7
Psychiatrist	52	26.3
Speech pathologist	17	8.6
Don't know	12	6.1
Highest education level		
Primary school	1	.5
High school	28	14.1
Vocational or trade school	39	19.7
Some university	43	21.7
Bachelor	48	24.2
Postgraduate	39	19.7
Employed		
Yes	101	51.0
No	58	29.3
Student	39	19.7

[a]Non-binary $n = 5$; Unsure $n = 1$; No identity $n = 1$; Gender neutral $n = 1$

Preference and Offensiveness

Participants were asked "Please indicate your preference for the following terms used to describe autism" and responded using a 7-point Likert-scale (1 = strongly dislike, 7 = strongly like) to each item. They were also asked "How offensive do you find the following terms used to describe autism" (1 = not at all offensive, 7 = strongly offensive), to each item. Scores were averaged across participants for each term, with a possible mean score range of 1–7, with higher

Table 2 Correlations between age, diagnosis age, preference for (bottom diagonal) and offensiveness of (bolded, top diagonal) terms

	1	2	3	4	5	6	7	8	9
1. AQ-short	–	**.22****	**.25****	**.05**	**.04**	**− .13**	**− .08**	**.12**	**.09**
2. Age	.22**	–	**.87****	**− .11**	**− .12**	**− .04**	**− .01**	**.04**	**− .04**
3. Diagnosis age	.25**	.87***	–	**− .09**	**− .15***	**− .18***	**− .15[1]**	**.08**	**− .03**
4. Person with autism	− .09	.08	.004	–	**.64****	**.05**	**.11**	**.66****	**.67****
5. Person on the autism spectrum	− .02	.15*	.11	.53***	–	**.13**	**.09**	**.47****	**.51****
6. Autistic	.22**	.03	.13	− .25***	− .28***	–	**.77****	**− .04**	**− .07**
7. Autistic person	.20**	.01	.13	− .19**	− .22**	.79***	–	**− .10**	**− .09**
8. Person with ASD	− .09	− .04	− .08	.50***	.47***	− .31***	− .33***	–	**.73****
9. Person with ASC	− .03	.07	.05	.38***	.40***	− .19**	− .24**	.54***	–

$*p < .05$, $**p < .01$, $***p < .001$, $^1p = .039$, 95% CI .02; − .28

scores indicating greater preference or offensiveness for each individual term, respectively. Terms were those most commonly used in research and practice settings, and included four person-first terms; person with autism, person on the autism spectrum, person with autism spectrum disorder (person with ASD), and person with autism spectrum condition (person with ASC); and two identity-first terms; autistic, autistic person. Asperger's disorder was not included in the current study to reflect the *DSM-5* diagnostic criteria.

Term Rankings

Participants were asked to rank the six terms for preference ("Could you please rank these autism labels from the label you like the most [1] to the least [6]?") and offensiveness ("Could you please rank these autism labels from the label you find the most [1] to the least [6] offensive?"). Using a vertical rank order item, participants clicked and dragged terms into the order that reflected preference and offensiveness from 1 (first position or most preferred/offensive) to 6 (sixth position or least preferred/offensive), with lower scores indicating greater preference or offensiveness of an item. Following each ranking question, a follow up free text question asked participants to explain their choices ("You chose _____ as your most preferred/offensive label, why do you prefer/dislike this label?"). Participants were then asked to indicate with free text any term not listed that they might prefer. Free text entries were unlimited with regards to the number of characters entered.

Data Cleaning and Analysis Strategy

Data were missing for one item for one participant on the AQ-short, which was imputed with the mean of adjacent variables. Mean scores on the AQ-Short were comparable to previous samples ($M = 85.44$, SD = 11.21; Range 49–108; Hoekstra et al. 2011). Eight participants scored under the clinical cut-off (> 65) for autism on the AQ-Short

(scores = 49, 51, 54, 59, 60, 61, 62, 64); however, consistent with previous research (Kenny et al. 2016), and given that all participants indicated having received a formal diagnosis of ASD, a decision was made to include these participants in the study. Exclusion of these participants did not significantly affect the overall findings (see Supplementary Materials 2). Four individuals did not rank offensiveness, which cannot be imputed. The AQ-short and term ratings were not normally distributed, consequently all continuous measures were analysed with 1000 bootstrap samples and bias corrected and accelerated 95% confidence intervals (BCa 95% CI) to account for skewness (Field 2018). All analyses were conducted in SPSS Version 24 (IBM Corp. 2016). First, the simple relationships between key demographic data and term preferences and offensiveness were investigated with correlations, and one-way ANOVAs were used to investigate gender differences. Second, repeated-measure ANOVAs were used to investigate the predicted difference in term ratings, with Bonferroni pairwise comparison testing differences in mean term ratings. Third, participant rankings of terms were analysed using Friedman Tests to identify any clearly preferred or offensive term, with Wilcoxon signed-rank tests to investigate any significant differences between weighted means. Finally, thematic analysis was used to explore why participants chose their most preferred and offensive terms.

Results

Correlations and Gender Differences

Correlations Among Variables

Correlations were applied to explore patterns of response between demographic variables and autism terms (Table 2). Autism traits shared a weak but significant positive relationship with preference for *Autistic* and *Autistic Person,* as well as age and age of diagnosis. Age of diagnosis was weakly

Table 3 One-way ANOVA assessing gender differences on autism traits, age, diagnosis age, and term preference and offensives

	M (SD)			F (df)	p
	Male	Female	Non-binary		
n	58	111	29		
AQ-short	84.12 (10.39)[a]	85.26 (11.71)[a]	88.76 (10.28)[a]	1.71 (2, 195)	.184
Age	36.11 (14.22)[a]	35.70 (11.59)[a]	29.33 (9.73)[b]	3.73[*] (2, 128.28)	**.027**
Diagnosis age	25.02 (18.92)[a,b]	29.89 (14.74)[a]	22.31 (14.10)[b]	3.41[*] (2, 120.17)	**.036**
Preference					
Person with autism	4.21 (1.82)[a]	3.61 (2.00)[a]	2.62 (1.92)[b]	6.52 (2, 195)	**.002**
Person on the autism spectrum	4.81 (1.93)[a]	4.55 (1.96)[a]	3.48 (2.52)[b]	3.67[*] (2, 79.59)	**.030**
Autistic	3.95 (2.16)[a]	4.59 (2.31)[a]	5.69 (2.14)[b]	5.85 (2, 195)	**.003**
Autistic person	3.97 (1.78)[a]	4.48 (2.19)[a,b]	5.24 (2.13)[b]	3.88[*] (2, 101.37)	**.024**
Person with ASD	3.69 (1.86)[a]	3.35 (2.02)[a]	2.79 (2.26)[a]	1.93 (2, 195)	.148
Person with ASC	3.74 (1.93)[a]	3.30 (1.94)[a]	2.83 (1.85)[a]	2.31 (2, 195)	.102
Offensiveness					
Person with autism	2.78 (1.84)[a]	3.06 (2.09)[a]	3.93 (2.45)[a]	2.79[*] (2, 83.06)	.067
Person on the autism spectrum	2.19 (1.53)[a]	2.38 (1.85)[a]	3.10 (2.26)[b]	2.24[*] (2, 75.63)	.114
Autistic	2.98 (2.12)[a]	2.41 (2.02)[a,b]	2.00 (2.02)[b]	2.58 (2, 195)	.078
Autistic person	3.05 (2.06)[a]	2.43 (1.96)[a,b]	1.90 (1.86)[b]	3.73[*] (2, 117.95)	**.027**
Person with ASD	2.88 (1.87)[a]	3.41 (2.28)[a]	3.76 (2.28)[a]	1.94[*] (2, 98.84)	.150
Person with ASC	2.76 (1.72)[a]	3.10 (2.08)[a]	3.28 (2.17)[a]	0.82 (2, 195)	.442

[*]Brown-Forsyth F and Games-Howell post-hoc analyses (Tukey post-hoc analysis otherwise)

Bold = p < .05

[a,b]Results of post-hoc analysis. Means in each row sharing the same superscripts do not differ significantly with BCa 95% CIs crossing zero

but significantly negatively associated with the offensiveness of *Person on the Autism Spectrum* and *Autistic*. Preference for person-first terms was negatively associated with preference for identity-first terms, suggesting a split in the sample. For offensiveness, there were significant positive relationships between the person-first terms only.

Gender Differences

A one-way ANOVA was used to explore differences between birth sex, with non-binary sex removed due to insufficient cell size, showed no significant differences across all variables (see Supplementary Material 3). To investigate differences in gender identity, a one-way ANOVA (Table 3) was run, with non-binary identities combined into one group to increase statistical power. There was no significant gender difference on the AQ. Non-binary participants were significantly younger than both males, BCa 95% CI [1.85, 11.65], and females [2.12, 10.89], and were diagnosed significantly earlier than females [1.98, 13.58]. There were no significant differences between males and females on their preferences for any of the six terms. However, non-binary participants rated *Autistic* higher than males [0.73, 2.69] and females [0.23, 1.92], and *Autistic Person* higher than males [0.32, 2.17]. Non-binary participants also rated *Person with Autism* significantly lower than both males [0.74, 2.44] and

females [0.20, 1.79], and *Person on the Autism Spectrum* significantly lower than males [0.78, 2.32] and females [0.06, 2.05]. For the offensiveness of terms there was only a significant difference for *Autistic Person*, where non-binary participants rated it as less offensive than males [0.22, 2.00].

Differences in Term Preference and Offensiveness Ratings

Mean preference and offensiveness ratings across the entire sample are summarised in Table 4. Four of the terms had preference ratings above the scale mid-point, suggesting that on average, these terms were rated favourably. A repeated-measures ANOVA indicated that there were significant differences in term preferences, Greenhouse–Geisser $F(2.35, 463.27) = 17.00$, $p < 0.001$, $\eta_p^2 = 0.08$ (see Supplementary Material 3 for full analysis). Although *Autistic* had the highest mean rating, pairwise comparisons with Bonferroni correction showed no significant differences amongst *Autistic*, *Person on the Autism Spectrum*, or *Autistic Person* however, these terms were rated significantly higher than *Person with Autism*, $ps < 0.003$, $ds = 0.25–0.42$; *Person with ASD*, $ps < 0.001$, $ds = 0.32–0.52$; and *Person with ASC*, $ps < 0.001$, $ds = 0.34–0.51$. There were no significant differences

Table 4 Means and standard deviations of preference and offensiveness ratings in order of most to least preferred and offensive, with Bonferroni pairwise comparison

Preference			Offensive		
#	Item	M (SD)	#	Item	M (SD)
1	Autistic	4.56 (2.30)[a]	1	Person with ASD	3.31 (2.18)[a]
2	Person on the autism spectrum	4.47 (2.07)[a]	2	Person with autism	3.11 (2.09)[a,b]
3	Autistic person	4.44 (2.09)[a]	3	Person with ASC	3.03 (1.99)[a,b]
4	Person with autism	3.64 (1.99)[b]	4	Autistic person	2.54 (2.00)[b,c]
5	Person with ASD	3.37 (2.02)[b]	5	Autistic	2.52 (2.07)[b,c]
6	Person with ASC	3.36 (1.94)[b]	6	Person on the autism spectrum	2.43 (1.82)[c]

[#]Position highest to lowest mean score; [a,b,c]Means in each column sharing superscripts do not differ at $p < .05$ with significance values adjusted for Bonferroni multiple comparisons

Table 5 Frequency of rankings with percentage of responses to each level of ranking, and weighted mean and ranking ($n = 198$)

Term	Rank[†]	M[††]	Preference rankings					
			1	2	3	4	5	6
Person on the autism spectrum	1	2.73[a]	50 (25.2%)	25 (12.6%)	71 (35.9%)	38 (19.2%)	8 (4.0%)	6 (3.0%)
Autistic person	2	3.26[b]	22 (11.1%)	72 (36.4%)	17 (8.6%)	19 (9.6%)	56 (28.3%)	12 (6.1%)
Autistic	3	3.30[b]	75 (37.9%)	15 (7.6%)	16 (8.1%)	15 (7.6%)	21 (10.6%)	56 (28.3%)
Person with autism	4	3.58[b]	10 (5.1%)	32 (16.2%)	55 (27.8%)	54 (27.3%)	29 (14.6%)	18 (9.1%)
Person with ASC	5	4.05[c]	19 (9.6%)	30 (15.2%)	16 (8.1%)	39 (19.7%)	45 (22.7%)	49 (24.7%)
Person with ASD	6	4.08[c]	22 (11.1%)	24 (12.1%)	23 (12.2%)	33 (16.7%)	39 (19.7%)	57 (28.8%)

[†]Overall rank preferences based on Friedman test

[††]Weighted mean rank from Friedman test

[a,b,c]Means sharing superscripts do not differ at $p < .0033$ (Bonferroni correction) according to Wilcoxon signed-rank test; Preference rankings (1 = most preferred, 6 = least preferred)

between *Person with Autism*, *Person with ASD* or *Person with ASC* and these last two terms were rated below the scale mid-point.

Mean ratings for the offensiveness of each term were below the midpoint suggesting that, on average, participants did not find any of the terms highly offensive. A repeated-measures ANOVA indicated that there were significant differences between terms, Greenhouse–Geisser $F(2.34, 460.87) = 9.44$, $p < 0.001$, $\eta_p^2 = 0.05$. *Person with ASD* was rated the most offensive term; however, pairwise comparison with Bonferroni corrections showed no difference between *Person with Autism*, nor *Person with ASC*. *Person with ASD* was significantly different from, *Autistic*, *Autistic Person*, and *Person on the Autism Spectrum* (ps < 0.009, Cohen's d = 0.25–0.42). *Person on the Autism Spectrum* was rated significantly less offensive than *Person with Autism* and *Person with ASC* (ps < 0.001, ds = 0.40, 0.31, respectively); but not *Autistic Person* nor *Autistic* (ps > 0.05, ds = 0.04; 0.03, respectively). *Autistic Person* and *Autistic* were not significantly different to *Person with Autism*; nor *Person with ASC,* nor from each other (ps > 0.05, ds = 0.01–0.21).

Rankings of Preference and Offensiveness

Term rankings showed interesting patterns of preferences (Table 5). For example, although 37.9% of the sample rated *Autistic* as most preferred, 28.3% of participants rated it as the least preferred term. The second most preferred term was *Person on the Autism Spectrum* (25.2%), with the majority of participants ranking it within their top three. *Person with Autism* was ranked predominately in the third and fourth position. Terms containing a diagnostic term (condition/disorder) were ranked most frequently in the lower third.

A Friedman Test showed a significant difference in term preference, $\chi^2(5) = 75.41$, $p < 0.001$, $\eta_p^2 = 0.08$, with weighted means suggesting that *Person on the Autism Spectrum* was most preferred overall (Table 5; see Supplementary Material 3 for complete statistics). Post hoc analysis with Wilcoxon signed-rank tests were conducted with Bonferroni correction resulting in an alpha level of $p = 0.0033$. *Person on the Autism Spectrum* was ranked significantly higher than all other terms, $Zs = -3.06$ to -7.80, $ps < 0.001$–0.003, $rs = 0.21$–0.55. *Person with ASC* and *Person with ASD* were rated lowest and significantly different from *Autistic Person*,

Table 6 Frequency of offensiveness rankings with percentage of responses to each level of ranking, and weighted mean and ranking ($n = 194$)

Term	Rank[†]	M[††]	Offensiveness rankings					
			1	2	3	4	5	6
Person with ASD	1	2.96[a]	51 (26.2%)	38 (19.7%)	38 (19.6%)	20 (10.3%)	28 (14.4%)	19 (9.8%)
Person with ASC	2	3.03[a]	45 (23.1%)	48 (24.9%)	29 (14.9%)	22 (11.3%)	28 (14.4%)	22 (11.3%)
Person with autism	3	3.32[ab]	22 (11.3%)	28 (14.5%)	60 (30.9%)	50 (25.8%)	17 (8.8%)	17 (8.8%)
Autistic Person	4	3.79[bc]	15 (7.7%)	48 (24.9%)	14 (7.2%)	21 (10.8%)	78 (40.2%)	18 (9.3%)
Person on the autism spectrum	5	3.93[c]	14 (7.2%)	16 (8.3%)	34 (17.5%)	71 (36.6%)	24 (12.4%)	35 (18.0%)
Autistic	6	3.96[c]	48 (24.6%)	15 (7.8%)	19 (9.8%)	10 (5.2%)	19 (9.8%)	83 (42.8%)

[†]Overall rank preferences based on Friedman test

[††]Weighted mean rank from Friedman test

[a,b,c]Means sharing superscripts do not differ at $p < .0033$ (Bonferroni correction) according to Wilcoxon signed-rank test; Offensiveness ranking (1 = most offensive, 6 = least offensive)

Autistic and *Person with Autism*, $Zs = -2.98$ to -3.84, $ps < 0.001–0.002$, $rs = 0.21–0.27$. There were no other significant differences.

Ratings of offensiveness somewhat mirror the preference responses, but the pattern of results is less clear (Table 6). Similar to preference, A*utistic* was most often ranked least offensive, but was also commonly ranked as most offensive, second only to *Person with ASD*. A Friedman Test showed a significant difference in term offensiveness, $\chi^2(5) = 56.25$, $p < 0.001$, $\eta_p^2 = 0.06$, with weighted means suggesting that *Person with ASD* was ranked as the most offensive term. However, there were no significant differences between rankings of *Person with ASD*, *Person with ASC*, or *Person with Autism*. *Autistic* was ranked significantly lower than *Person with ASD*, $Z = -4.12$, $p < 0.001$, $r = -0.30$, and *Person with ASC*, $Z = -3.63$, $p < 0.001$, $r = 0.26$. *Autistic Person* and *Person on the Autism Spectrum* were ranked significantly lower than the other person-first terms, $Zs = -3.79$ to -5.53, $ps < 0.001$, $rs = 0.25–0.40$. There were no other significant differences.

Thematic Analysis of Term Preference and Offensiveness

The free text responses provided insights into the participants' reasoning behind the terms they ranked as most preferred and most offensive. In total, 185 participants provided a response to explain both their preferred and offensiveness rankings, 6 participants responded to one prompt only resulting in a total of 376 statements. Thematic analysis (Braun and Clarke 2006) was conducted by RJ to code the responses for meaning. A sample (30%) of responses were independently coded by SMB. Codes were collapsed into themes, and these were discussed between the two raters and revised until consensus was reached. Through this process, six themes were generated.

Being Autistic is Core to My Identity

This theme tended to capture statements from participants who preferred identity-first terms, explaining that autism "defines who I am". Statements in this theme reflected that being autistic is core to these participants' sense of self, and not something that can be removed or separated from them (i.e., their autism is not an 'accessory'). For example, one participant explained their preference for *Autistic* by stating, "[I] am autistic, it is an integral part of me and not a [separate] part that can be taken away. [Without] it [I] would be someone else", and another stated, "autism is intertwined with who I am, my identity, you cannot separate the two, I would be a completely different person." Several participants also noted that many other attributes are not spoken about in a 'person-first' manner. Participants compared the phrase "person with autism" to phrases such as "person with tallness" or "person with bisexual".

Some participants closely linked their preference for identity first language to pride and empowerment, as illustrated in this quote:

> Because I feel that my brain being wired differently isn't a "condition" and that I will always be autistic - it is not something I will outgrow or can [be] changed. I find using the label autistic helps me to be proud of my identity and embrace my differences. I find it empowering and not as degrading

This theme was also observed in participants' reasoning for ranking person-first terms as most offensive. More specifically, they explained that they were offended by the implication that autism is something separate to them. For example, when explaining why they had ranked *Person with Autism* as their most offensive term, one participant stated, "with something implies I can be rid of it".

Having Autism is Part of My Identity

This theme reflected that for some participants, although autism was part of their identity, it was only one part and that being a person came first; autism was seen as "something I have". For example, one participant explained their preference for *Person with Autism* by stating, "because it humanises them, it names them as a person first, and autism second" and another participant stated that "opening with 'person' emphasises shared humanity with neurotypicals." Another preferred *Person with ASD*:

> Because this is how I describe myself, it's true and correct to my original di[a]gnosis, it doesn't carry stigma like the other labels and it doesn't dehumanise me by calling me an "autistic person" like that is all I am. I am still a person just with this condition.

This theme also captured reasons why some participants were offended by identity-first terms, explaining that these terms were dehumanising and depersonalising. A participant explained that they were most offended by *Autistic Person* "because autism is the first word I hear. I can tell that that is the first thing on the person's mind. To them, the fact I am I person does not come first; the fact I am autistic comes first…".

Diversity Within the Spectrum

This theme tended to develop from participants who preferred terms including the word 'spectrum'. Participants commented that they preferred a term that recognised the variation in autism, as illustrated in this quote, "Emphasis on the word 'spectrum' is a valuable component of the label, in my opinion, due to the incredibly varied and inconsistent implications a diagnosis can raise". Other participants noted that the term 'spectrum' also highlighted individuality; "we all have similar traits but we are all very individual and different". Some felt that identity-first terms did not adequately capture their experience, "nobody is the same this is the problem [with] saying autistic or autistic person", and some participants seemed to want to differentiate their identity from others on the spectrum, as described in the following quote:

> Autism is a SPECTRUM, not a cookie cutter diagnosis. I may not "look" autistic, but I am on a very large spectrum filled with a diverse group of people. I have friends on the spectrum who prefer being called autistic, but personally I feel as though societal preconceived ideas on what it means to be autistic differ greatly from how I am. I don't want to be put in a box, I'd prefer to be on a spectrum.

I Am Different Not Disordered

This theme included statements where participants rejected medicalised or disorder focused terminology, and this reasoning was apparent across a range of preferred terms. This rationale was provided to explain a preference for *Person on the Autism Spectrum*, by stating; "I don't like "diagnosed" and [I] don't like "disorder". Makes us sound diseased". Similarly, one participant justified their preference for *Person with ASC* by stating, "I prefer that it's a condition. Disorder has an air of 'faulty goods'". Those who preferred Autistic added "because it doesn't [indicate] disability/disorder/condition".

In explaining offensiveness rankings, this theme tended to emerge amongst participants who ranked person-first language as most offensive. For example, when explaining why *Person with ASD* was most offensive, a participant wrote: "I cannot speak for everyone, but I don't view my autism as a 'disorder'. This upsets me. It is just another way of seeing the world". Similarly, two participants who ranked *Person with Autism* as most offensive explained, "With autism sounds like a disease I caught" and "like it is a tragic condition. No help for them". Thus, central to this theme was the idea that an "ASD brain isn't broken" and a recommendation that we "need to drop the term disorder".

Language Can Stereotype and Stigmatise

Some participants explained that they preferred certain terms because they had observed other terms being used in an insulting or derogatory manner. This was expressed across the terms, with both positive and negative reactions to most terms. For example, one participant preferred *Person on the Autism Spectrum* because "it seems less judgmental/ derogatory than the others", whereas another participant considered this term to be most offensive because "it just sounds like someone who doesn't know autistic people much and thinks it's a bad thing, like a psychologist/psychiatrist, makes me uncomfortable". Similarly, one participant preferred *Person with ASD* because "it sounds the least offensive and isn't often used in the wrong way" whereas another participant felt that *Person with ASD* "sounds like a big, bad, scary disorder". Responses to identity-first terms indicated that these terms can also be stigmatising. For example, some participants explained that they had heard *Autistic* used as an insult and so found this term most offensive as illustrated in these quotes, "I hear people make jokes about autism and the joke usually includes calling someone 'autistic'" and "it can be used in conversation as a way to bully people". This theme indicated that each term was considered by at least one participant as offensive. Moreover, some participants considered the very act of labelling to be offensive, "[I] hate all the labels, why label us for being different?".

Pragmatic

Despite the disagreement over terms, the final theme 'pragmatic' indicated that for many, language is first and foremost a communication tool and their preference was informed by the terminology that served a specific purpose. For example, one participant stated that they preferred *Person on the Autism Spectrum* because it was "simple and most in public understand something about autism these days". Other participants preferred *Autistic* because it was "short sharp to the point" and "everyone knows what it means" and *Autistic Person* because "[it's] accurate", *Person with ASD* because "it has the most precise description in the name", and *Person with ASC* because it "sounds official". Statements within this theme also emphasised clarity over "political correctness". For example, one participant rated *Person with ASC* most offensive because it is "Too PC, might be okay in academia but who cares in real life". This pragmatism was described across the different term preferences.

Alternatives Terms

Participants were also asked to indicate if there were any other labels that that they preferred. From 163 text responses, the majority (52.5%) reiterated a preference for one of the listed terms or that there were no other terms they would prefer. A small group (13.1%) of participants advocated the return of Aspie/Asperger's ("Aspergers to be its own label again"), and another small group (5.1%) would prefer simply 'person' or their own name ("Just my name that's about it.[I'd] rather be known as a person and not what I have"). A few participants endorsed a variant of neurodiverse (5.6%, "Neurodivergent person"), or terms that highlighted strengths (3%; "Person with special abilities"). Other less common suggestions (3%) were variants of "Autie" or "Autist", and one person suggested "Spectrumite".

Discussion

The results of the current study offer insight into the diverse and nuanced perspectives underlying term preference amongst Australian adults who self-reported a diagnosis of autism. The quantitative results suggested a clear preference for the terms *Person on the Autism Spectrum*, *Autistic* and *Autistic Person* over other terms, particularly compared to person-first terms that included identifiers 'disorder' or 'condition'. Moreover, the negative correlations amongst the identity-first and person-first term preferences suggest that people who prefer person-first terms tend to perceive identity-first terms negatively, and vice versa. Term rankings highlighted these differing views. Although the largest percentage of participants ranked *Autistic* as their most

preferred option, this term was highly polarising as a large percentage of participants ranked it as their *least* preferred term, and very few participants ranked it in the middle. This pattern was mirrored when asked to rank the offensiveness of terms. The preference for *Autistic* is consistent with prior research (Kenny et al. 2016) and recommendations from an increasing number of autism-focussed journals (e.g., Autism in Adulthood 2019) and community groups (Sterry 2019). However, our findings suggest that *Autistic* may also be highly divisive, consistent with Robison's (2019) assertion that what is acceptable for some is offensive for others. Thus, as astutely noted by Vivanti, "a complete shift away from person-first language appears premature" (2020, p. 2).

In contrast to the pattern for *Autistic,* perceptions of *Person on the Autism Spectrum*, were more consistent across the sample. Although it was ranked as the most preferred term somewhat less frequently than *Autistic*, statistical analysis revealed that *Person on the Autism Spectrum* was the most favourable term in terms of overall term preference rankings. Indeed, few people were offended by this term. We note that the popularity of *Person on the Autism Spectrum* is not entirely surprising. Although researchers and advocates often cite the 'majority' endorsement of *Autistic* in Kenny et al. (2016) as evidence for using this identity-first language, the original Kenny et al. results were much more equivocal, with a similar proportion of participants in that study preferring *Autistic* and *on the Autism Spectrum*.

An important contribution of this research is that participants were given the opportunity to explain their rankings for both preference and offensiveness. Thematic analysis of participants' explanations for their choices revealed that, regardless of their specific preferences, participants wanted to be 'humanised' and not 'medicalised'. Participants preferred terms that expressed their identity and facilitated communication and understanding with others. Many participants felt that identity-first terms, and *Autistic* in particular, were most appropriate for these purposes; and their reasoning was similar to that of Kenny et al. (2016) and some autism advocates (Sinclair 1999). Thus, participants favouring *Autistic* tended to feel that it was impossible to separate autism from their identity or how they see the world, and for some, *Autistic* provided a link to a broader community of similar individuals.

However, the current study also revealed that for some participants, particularly those endorsing person-first terms, term preferences reflected a desire for common humanity, individual uniqueness, and respect for diversity. Although some participants seemed to be reacting to the stigma they believed was attached to identity-first language, others stressed a common humanity with individuals without an autism diagnosis through person-first language. For these participants, it was important to emphasise their personhood first and identify autism as just one part of their identity.

The desire to stress both shared humanity (person-first) but also stress their uniqueness also seemed to underlie some participants' preferences for *Person on the Autism Spectrum,* as including the word 'spectrum' reflected their uniqueness from others with an autism diagnosis, and from stereotypes associated with an autism diagnosis. It is also interesting to note that *Person on the Autism Spectrum* uses the preposition 'on' rather than 'with'. This small wording shift may allow individuals to retain their autism identity but also highlight their own unique strengths and challenges within this identity. These themes were not captured by Kenny et al. (2016), which could reflect cultural differences between the UK and Australia, or the method used to collect and analyse qualitative data.

The results of the current study suggest that for many participants, their preferred terms reflect how they see themselves and choose to express their autism. Wherever possible, it is important to ask people with an autism diagnosis how they prefer to talk about autism and respect those preferences in subsequent interactions. Where preferences are unknown, it might be tempting to conclude that any term can be used (given the overall low ratings of offensiveness in the current study). However, the qualitative data suggests that certain terms can have a strong negative impact and are perceived as stigmatising. Some researchers (Dirth and Branscombe 2018; Dunn and Andrews 2015) suggest that using a mixture of person-first and identity-first language in academic writing may help to destigmatise disability terms such as 'autistic'. Destigmatising, or at least humanising individual experiences of autism, is a common theme amongst those who prefer identity-first and those who prefer person-first terms. Some terms may become less offensive over time as more people are diagnosed and experience those terms in constructive ways, such as within the neurodiversity movement. In the current study, there was some indication from the correlational analyses that participants who received a later diagnosis found identity-first terms less offensive, although it could also be that those who have lived with an autism diagnosis longer have an inclination away from identity-first terms.

One limitation of the current study is the use of online recruitment and that diagnosis was self-reported. Although the overall method was consistent with prior research (Kenny et al. 2016), and the online format allowed for a large and relatively diverse sample of adults on the autism spectrum, we were unable to confirm diagnosis. Further, online surveys may not be accessible for all individuals in the autism community, and indeed this sample was highly educated, more often employed, and diagnosed later in life. Due to this, the study was unlikely to have captured the full heterogeneity of preferences within the autism population (see also Vivanti 2020). Although the free-text responses provided some insights into language use around autism,

a more in-depth understanding could be obtained through semi-structured interviews that also includes individuals with differing levels of verbal communication. However, this approach may still not be accessible to all individuals.

Acknowledging these limitations, the current study aimed to understand which terms a broad group of Australians diagnosed with autism prefer and which terms they may find offensive. Continuing and improving the inclusiveness and respectfulness of the discourse about autism is imperative because language reflects broader assumptions and stigma about a community (Galasiński 2018). Although our findings suggest no consensus on a single preferred term, *Person on the Autism Spectrum* may be a reasonably 'safe' option when the specific audience's term preference is unclear. We also found that that terminology including the terms "disorder" or "condition" were overall unpopular amongst participants. Our recommendation would be these terms should be applied with sensitivity. Respecting people on the autism spectrum, as well as their individual preference regarding terminology and communication style, is the most important step in inclusive communication.

Compliance with Ethical Standards

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