Autistic people's perspectives on functioning labels and associated reasons, and community connectedness

Note

This study uses identity-first language (IFL). Previous literature has shown a preference for IFL among a majority of autistic people (e.g., Keating et al., 2023; Kenny et al., 2016), with being autistic viewed as intrinsic to the individual's life (Williams, 1996) and inextricable from one's identity (Sainsbury, 2000).

Introduction

Within the field of autism studies, the language used to describe and refer to autistic people has received growing attention within academic and autistic communities, notably the dialogue and research on the acceptability of person-first language (PFL; person with autism) versus identity-first language (IFL; autistic person) (e.g., Botha et al., 2021; Vivanti et al., 2020). One key aspect of this dialogue is how acceptable it is to use functioning labels (i.e., high functioning and low functioning), and how specific functioning labels are. Functioning labels categorise autistic people as either high- or low-functioning. As Alvares et al. (2020) state, functioning has increasingly been associated with the profile of autistic people as with strengths or weaknesses in language, higher (e.g., savantism) or lower IQ (e.g., intellectual disability), and better or worse long-term outcomes (high- and low-functioning, respectively). The literature to date suggests moving away from using functioning labels to describe the different needs autistic people have (e.g., Alvares et al., 2020; Bottema-Beutel et al., 2021). Some studies have investigated language preferences, including functioning

labels (Alvares et al., 2020; Keating et al., 2022; Kenny et al., 2016; Monk et al., 2022). However, there remains scope to develop a fuller understanding of autistic peoples' preferences, for example, by considering influential factors. In this light, further investigation of the acceptability of functioning labels is required.

Language preferences

Language is a complex phenomenon that changes according to preferences across time, similar to a paradigm shift (Kuhn, 1962), as terminology preferences are not siloed or independent of society. One notable example is the charity Scope, which was founded as the National Spastics Society on 9 October 1951 (Smith & Smith, 2019). The former name reflected the term for a person who has cerebral palsy, which was previously acceptable. As this terminology became commonly used in a derogatory way, it led to a change in the way people were described. In a similar manner, previously derogatory terminology may be reclaimed (Botha et al., 2021; Brueggemann, 2013), for example, 'queer' has been increasingly reclaimed by the LGBTQIA+ community since the 1980s (Worthen, 2023).

The terminology that people choose may reflect their overall approach and attitudes towards people with disabilities, including autistic people (Dwyer, 2022). As social beings, people use and develop the use of language, which has resulted in the derogatory use of words and phrases. As a consequence, the connotations of relevant terms and language referring to autistic people are likely to alter as shifts in views on language and the acceptability of terms change. There remains no solution to reach a universal consensus

within this debate (Bury et al., 2022; Keating et al., 2022), and will likely never be concluded due to shifts that may occur in the future, adding to the difficulty and intensity of the discussion (Dwyer, 2022).

Dwyer (2022) suggests that functioning labels are an important line of inquiry within the broader dialogue on how to refer to autistic people. Geelhand et al. (2023) claim that functioning labels are about what is the acceptable 'autism'; this is a finding echoed in Botha and Cage's (2022) mixed methods study exploring autism researchers' understandings of autistic people. Functioning labels can be perceived by autistic people as harmful, divisive, reductive and inaccurate (Keating et al., 2022). Keating et al. (2022) also identified their autistic participants believe their functioning varies across time, environment and situations. Using functioning labels may result in those classified as 'high-functioning' not accessing the necessary support, and autistic people determined as 'low-functioning' being infantilized and ignored (Keating et al., 2022), furthering arguments that functioning labels are problematic (e.g., Bottema-Beutel et al., 2021; Kenny et al., 2016; Pukki et al., 2022; Williams, 2019).

One key aspect of current dialogue surrounding language related to functioning labels is discussions about the term 'Profound Autism'. Lord et al. (2022) published their proposal for a new term they call 'Profound Autism', which is meant to refer to an autistic person with high 'severity' autism, intellectual disability, being non-speaking, and requiring consistent, extensive long-term support or care. In addition, Waizbard-Bartov et al. (2023, p 690) present individuals they see as having 'Profound Autism' as

‘a subgroup of individuals’ requiring ‘extensive long-term care’. However, Happé (2011) noted how autism subgroupings may have a similar prognosis and have clinical instability, suggesting there may be challenges faced in devising subgroups of autism based on functioning.

Community Connectedness

Autistic people are a heterogeneous population, therefore views on language may be diverse. In this light, it is important to investigate the reasons behind current perspectives. Different preferences may exist across the population, and these preferences may differ between cultural groups. In addition, autistic people experience minority stressors (as defined by Meyer, 2003; and identified in the autistic population by Botha & Frost, 2020). Some autistic people face self-stigma due to a labelling effect (Becker, 2018). These may be influential factors involved in an autistic individual’s language preferences. Other aspects could include but are not limited to ethnicity or race; age; and community connectedness.

There seems to be scope to explore the prospective connection between language and community connectedness. There is an important link that has been found in many seminal works more broadly (see Bakhtin, 1981, 1984; Bourdieu, 1977, 1991; Hall, 1997); how someone identifies, and the words used regarding them, impacts identity. For example, Stets & Serpe (2016, p. 35) state “language permits using the standpoint of others with whom we are implicated in social relationships and interactions to see ourselves as objects”. For D/deaf people, those who identify as culturally

Deaf tend to be different from those who do not (Carter & Mireles, 2016). For example, those who identify as culturally Deaf are more likely to use sign language, have strong connections to other D/deaf people, and are more included in the Deaf community (Carter & Mireles, 2016). As for autistic people, the reclamation of identity for those within the autistic community may lead to framing disability as a culture or a key part of their community (Parsloe, 2015), for example, a community centred around shared language and experiences. This suggests that the products of the social interactions one has influence how people identify (Stets & Serpe, 2016).

Community connectedness can be defined as a 'cognitive or affective construct' of community affiliation (Frost & Meyer, 2012, p 37). Both Dwyer (2022) and Kenny et al. (2016) have suggested that membership in communities that use certain approaches to people with disabilities or autistic people would alter preferences. Previous studies have found that autistic people may experience an improved level of well-being with a higher community connectedness (Botha, 2020; Cage et al., 2022). Furthermore, within consultative interview data collection used to inform the current study, community connectedness seemed to be associated with the language preference differences between the respondents. Given how heterogeneous the autistic population is, the diversity of lived experiences in the population may impact views of functioning labels. Part of this diversity may include the level of contact and community connection with other autistic people.

In this light, this study investigates autistic community connectedness (ACC). ACC is defined by three key components: belongingness was regarding similarity between the experiences of each other; social connectedness was referring to specific friendship with other autistic people; and political connectedness was in regard to similar political or social equality goals held within the autistic community. The advancement of the concept of ACC includes the development of a measurement tool. This tool was constructed from interview data by Botha et al. (2022). Botha's (2020) work into community connectedness resulted in the ACC measurement tool that was validated on 133 autistic people. The understanding of ACC is founded upon participants in Botha et al. (2022), describing the benefits of autistic community connectedness, through contact with other autistic people. They stated that a greater sense of ACC increased their self-esteem, alongside a feeling of community that they did not obtain elsewhere. In addition, the participants in Botha et al. (2020) commented that a lack of connectedness is linked to less importance of their autistic identity and the potential of internalised stigma. Research since the construction of this measurement tool has investigated autistic community solidarity and well-being, notably Cage et al. (2022) who found an improved level of well-being. Cooper et al. (2023) found that young autistic people indicating greater solidarity had higher psychological well-being.

The aim of the current study was to a) identify language preferences and reasons behind their predilection among autistic adults, and b) examine whether these preferences were related to ACC. Within the academic

literature to date, much of the discussion has not considered the impact of other influential factors such as autistic community connectedness on the use of functioning labels.

This study builds on the dialogue about IFL and PFL. It is believed that autistic people with more community connectedness would be more likely to use IFL and these individuals would not find functioning labels acceptable. It has been argued that some individuals may not understand the rationale against the use of PFL (Dwyer, 2022). Therefore, a non-directional hypothesis is proposed: perspectives on language (separately PFL or IFL, and for or against functioning labels) will differ by degree of ACC, which includes a similar effect on uncertain preferences. This study sought to explore the reasons for the acceptability of functioning labels. Specifically, this study inquired into levels of agreement on the reasons for and against functioning labels and what terms are acceptable about being autistic.

Methods

Respondents and Procedure

Five hundred and sixteen autistic respondents completed the survey. There was 19% non-completion of the survey (of a total 637 respondents) resulting in their data being removed. Respondents were only excluded when they were not autistic. The mean age was 36.13 (range 12-87). Respondents were a mix of gender identities; 93 were male, 259 were female, 121 were non-binary, 21 stated other preferred terms for their

identity[1]. All other respondents preferred not to say. The majority of respondents were White (426; 83%), 32 were Mixed or multiple ethnic groups (6%), 14 were Asian or Asian British (3%), 12 were Black, Black British, Caribbean or African (2%), 7 were Arab (1%), 6 were Hispanic (1%), 5 were Ashkenazi Jewish (0.9%), 8 responded as 'other' ethnic group (most respondents specified an answer) (2%). Forty-eight percent were based in the UK, 22% lived in the USA, and all other respondents lived around the world, including Antigua and Barbuda, El Salvador, and Singapore (6 respondents did not answer this question). 383 were diagnosed and 133 were self-identifying. Specific data on socioeconomic status or educational attainment were not collected at this time.

Respondents were recruited via convenience sampling, using an advertisement on social media, and emails to international, national, and local relevant groups, organisations and charities. Organisations and charities and groups supporting individuals with additional support needs or an intellectual disability were also contacted with a link to the survey. It remains unknown if individuals with an intellectual disability completed the survey at this time.

This research study gained a favourable ethical opinion on 15th June 2022 by the [anonymised ethic body] at [anonymised university] ([redacted application code]). Interviews were initially conducted to gain proposed

[1] 16 identified themselves the following: 4 as agender, 3 as genderfluid, 3 as trans, 2 as auti-gender, 2 as demiguy or demiboy, 1 as quoigender, and 1 as gender-queer.

reasons for functioning labels. The survey was piloted on five autistic people prior to launch, asking for feedback of the accessibility of the survey as well as testing issues in relation to flow of the questions. Individuals piloting the survey were also asked to test each 'branch' for individual language preferences, to ensure the survey worked for all language preferences. The feedback collected was integrated into the survey used for data collection. Recruitment for the survey began in September 2022 through contacting relevant international, national and local organisations, and groups and a social media campaign. Respondents accessed the survey via a link to the information page whereby they could click a button to continue to the survey. The order of the questions was presented the same for each respondent. Respondents could stop and return to the survey. They could not skip key items. The last item in the survey was open-ended so respondents could express their thoughts about the survey and its topic. Upon completing the survey, the respondents received a thank you note for finishing the survey.

Materials

The survey was fielded over 3 months between September and December 2022. The survey options were developed during 2022, following a consultancy period interviewing autistic people. They were asked about their preferences regarding functioning labels and reasons for or against them; this informed the survey with their responses aggregated into themes (see table 1). Six reasons for and eight reasons against using functioning labels were surmised from these consultancy interviews. The

reasons that the respondents rated are provided in Table 1. The research assistant (third author) input the survey options into Qualtrics. Respondents accessed the survey online. Respondents gave consent to participate after reading an information sheet at the start of the survey by clicking a button to continue the survey.

[Insert table 1 near here]

Survey

The survey consisted of 10 questions, excluding follow-up questions for respondents answering that another (or 'other') answers are possible. These respondents were then asked to supply an answer to 'other' reasons. The survey began with demographic questions, e.g., age, gender, geographic location, ethnicity or race, diagnostic status (only non-autistic people were excluded based on their answers to this question), and community connectedness. For the latter, Botha et al. (2022) Autistic Community Connectedness measure was used (described below).

Survey Questions. Respondents were asked how they would like autistic people to be termed in the survey, which offered data on how many people find each term acceptable. The preferred term was then used when relevant throughout the remainder of the survey. In addition, this study asked all respondents what terms about autistic people were acceptable (person with autism, Aspergers, disorder, conditions, living with autism, autistic). The survey implemented a 3-point Likert scale ('Yes - this term is okay', 'No - this term is not okay', and 'I do not have an opinion on this term

or phrase'). The respondents then proceeded with the main purpose of the survey to ask about functioning labels, i.e., whether to use them, not use them, or 'do not know'. The survey used a branching approach whereby respondents were supplied only relevant questions based on their answers (e.g., reasons for functioning labels were provided to those who agreed; reasons against functioning labels were provided to those who did not agree; reasons for and against were provided for those that had no preference). Each response was rated on a 3-point Likert scale; (1 being 'Agree', 2 'Neither agree nor disagree' and 3 'disagree').

Options to supply other reasons or answers to the listed options were provided where applicable. In addition, an open-ended question surrounding general comments was offered at the end of the survey. The qualitative data will be reported separately.

Autistic Community Connectedness (ACC) (Botha et al., 2022). The ACC measurement instrument assesses to what degree each respondent felt connected to the autistic community. Respondents were asked to read nine statements and rate their agreement on a 6-point Likert scale (1 being 'strongly disagree' up to 6 described as 'strongly agree'). For example, statements included "I feel a sense of belonging to the autistic community". Total scores could range from 9 to 54. The higher the score, the more the respondent felt connected to the autistic community. The validity of the measure was tested through a Product Moment Pearson

Correlations (all items were valid <.05). Using Cronbach Alpha reliability testing, the measure is highly reliable (α=.89).

Design and Data Analysis

This study used a cross-sectional, exploratory correlational design, exploring the relationship between language preferences and community connectedness. To answer the research question to identify language preferences among autistic adults and their prospective rationale for or against functioning labels, descriptive statistics were employed. Data were analysed using linear regression conducted in SPSS (Version 28) to examine the relations between the variables and test our hypothesis.

Results

The respondents' perceived language acceptability was as follows: 80% of the respondents (n=408) preferred IFL being used for themselves, 15% had no preference, and 6% selected PFL. Descriptive statistical analysis was applied to the questions about IFL and PFL (n=503). Although the survey allowed for 'Aspies' or 'person with Aspergers' to be used, these were subsumed into IFL and PFL respectively. Next, 510 respondents answered whether functioning labels should be used. Seventy-four percent of the respondents stated that they should not be used, 13% responded that they should be used, and 13% indicated that they do not know.

The whole sample was asked what terms are acceptable regarding being autistic (the wording used their chosen preferred term). Table 2 shows near universal agreement that autistic is an acceptable term, regardless of their

individual preference, and just over three quarters thought 'autists' or 'autistics' was okay. However, half of the respondents did not like 'person with autism' and three-fifths didn't accept Aspergers. 'Living with autism was also rejected by over half of the respondents. This shows there is a strong preference for autistic as a term, with Aspergers or 'living with' names less favoured, though not universally rejected.

[insert **Table 2 near here]**

Most groups had a high number of respondents preferring IFL and not using functioning labels. Similarly, grouping autistic people based on their current location by country suggests some countries may have a preference for PFL. However, with only one respondent in certain countries, this cannot be generalised, and it is not representative of the autistic population in these countries. This is similar for views on functioning labels. For the raw data regarding these cultural factors, please see supplementary materials.

Autistic Community Connectedness

In order to understand the respondents' lives, the survey measured community connectedness (M=39.31, SD= 8.94, range: 9 - 54). The mean connectedness was of those requesting IFL (41) was substantially higher than PFL (28) and those that didn't mind (32). A similar pattern is seen for level of community connectedness for those against functioning labels. This implies that there is a difference within the sample between respondents based on language preferences.

To investigate the relationship between ACC and what is acceptable language regarding being autistic and functioning labels, linear regression was conducted. This model fits the data well (PFL-Don't mind Tolerance = .99, VIF= 1.01; Yes to use of functioning labels-Maybe Tolerance=.98, VIF = 1.02).

As can be noted in the tables, both IFL versus PFL (table 3), and for or against functioning labels (table 4) were statistically significant, as well as those that had no preference for both. These models were significant, with model 1, $F(6, 490) = 26.119$, $p < .001$, explaining 24% ($R^2 = .242$) of the variance in ACC, and model 2, $F(6, 490) = 30.417$, $p < .001$, explaining 27% ($R^2 = .271$) of the variance in ACC. The respondents' preferences, age, and gender were significant for model 1, but neither age nor ethnicity were significant in model 2. Importantly, PFL (-13) and those that had no preference (-7) scored lower ACC, as were those that preferred functioning labels (-10) and those that had no preference (-8).

It should be noted that this finding could be two-directional; for instance, autistic people who feel more connected to the autistic community are more likely to prefer IFL, and to be opposed to functioning labels, yet similarly autistic people who prefer IFL and who oppose functioning labels feel a stronger connection to the autistic community.

[insert Table 3 and 4]

To complete the regression models, categories of ethnicity were transformed into 'white' or 'non-white' due to small samples in some groups. The gender variable was transformed into dummy variables for 'male', 'female', and 'non-binary, third gender, prefer not to say and other'. Of interest is the significant results for 'female' (-3 in both models), and 'non-binary, third gender, prefer not to say and other' (-5 in model 1, and -4 in model 2), compared to males. This finding indicates that respondents identifying with these genders had less ACC. In model 1, age was significant, suggesting with every increasing year, the respondents would increase ACC by 0.07 (see table 3).

Reasons Regarding Functioning Labels

Only 132 respondents were asked about reasons for functioning labels, because they agreed or had no preference regarding their use. As seen in table 5, most respondents answering this question agreed that functioning labels help to understand autistic people's needs and to deliver care. Half of the subsample identified it helps to categorise autistic people, a third were neutral and just over a fifth disagreed, this shows that while there is a preference for identification, this is far from a homogeneous view. However, of the 119 respondents answering whether they describe themselves with functioning labels (see table 5), it remains unclear due to about a third of these respondents stating agree, disagree or neither agree nor disagree to each. Most respondents (over a third of the 120 answering) neither agreed nor disagreed that being high functioning sounds

encouraging as a reason for using functioning labels. Between 11 and 13 respondents have missing data for these questions (see table 5).

[insert Table 5 near here]

Table 6 reports data from respondents that were asked about their disagreement with using functioning labels; this was due to stating their opposition to functioning labels or not having a preference. As seen in table 6, nearly all of these respondents answered that they agree they are discriminative stereotypes. Nearly all of the 433 respondents answering the question agreed that functioning labels increase assumptions about autistic people's needs. In addition, this is amplified by over three quarters of these respondents agreeing that categorical labels are unhelpful or inconsistent. Furthermore, nearly all of these respondents agreed that functioning labels are used to selectively deny services. Most of these respondents agreed functioning labels should not be used because those that are deemed low functioning become overlooked or demoralised. Nearly all of these respondents selected that the terms cause stigma, and most respondents agreed that these terms dehumanise and dismiss autistic people. It could be therefore expected that these terms might lead to trauma or mental health issues, to which just over three quarters of respondents agreed.

[insert **Table 6 near here]**

Lastly, for those against functioning labels, the survey asked what language they would prefer to be used. In table 7, 377 respondents answered this question, of which there was a combined total of 86% agreeing to 'stating individual needs of each person' and 'both of the above'. Under a quarter of these respondents answered that only stating specific diagnoses would be preferred.

[insert Table 7 near here].

Discussion

This study has helped identify autistic people's perspectives on language preferences, including perspectives on functioning labels. Respondents reported a preference for IFL among autistic adults, and the analysis indicated a relationship between preferences and ACC. Therefore, the language that was deemed acceptable seemed to differ by ACC (separately PFL or IFL, and for or against functioning labels, including on uncertain views). An important comparison to be made is with Cage et al. (2022). The mean ACC in Cage et al. (2022) was 41.34 (SD = 10.67, range 15–60). In their study, fewer respondents preferred identity-first language (n = 136, 69.4%), more respondents had no preference (n = 46, 23.5%), and approximately 1% more preferred person-first language in their study (n = 14, 7.1%). The spread of data in their study is likely wider due to more respondents having no preference, and less preference for IFL. Comparatively, Cage et al. (2022) respondents had a similar range of ACC, but with a higher range than the current study. Due to neither Cage et al.

(2022) nor this study collecting information about co-occurring intellectual disabilities nor use of language, it cannot be known whether the distribution of ACC is different due to influences related to this factor.

This study can specifically support professionals and academics use of language that has greater acceptability for autistic people, understand the reasons for and against using functioning labels, and understand that autistic community connectedness correlates with autistic people's opinions about language.

The findings echo cultural knowledge within the autistic community, and previous recommendations and suggestions for describing autistic people within the academic literature (e.g., Bottema-Beutel et al., 2021; Monk et al., 2022). Respondents who did see merit in using functioning labels to describe autistic people also reported not necessarily using them about themselves. Community membership was found to impact the language respondents used to describe the support needs of autistic people, including the utilisation of functioning labels.

Keating et al. (2022) also found that there were heterogeneous perspectives regarding language. It is believed that this study addresses this matter well; with 47% of autistic people suggesting that using the term ASD is acceptable and 41% unacceptable, yet 97% of all respondents stating autistic person is okay. The findings from this study replicate Keating et al. (2022) that there is a dominant acceptance of IFL.

Agreement Within the Heterogeneity of Views

Most of autistic people in the sample agree that IFL is okay, however a mix of opinions were reported for medical language such as disorder and conditions. However, it has been identified that autistic people from the UK are more inclined to accept medical language than some other countries (Keating et al., 2022). Nonetheless, the level of agreement about IFL seems to align with the notion that autistic people can positively claim their disability (including as an identity) (Botha et al., 2021; Brueggemann, 2013). Moreover, most autistic respondents of the survey did not want functioning labels used, which has been identified in past research (Alvares et al., 2020; Keating et al., 2022; Kenny et al., 2016; Monk et al., 2022). It appears that the reasons are wide-ranging, potentially more so than the options provided in the survey.

The findings from this study replicate the recommendation from Monk et al. (2022) that describing specific needs is preferential to using functioning labels. The respondents of the survey in this study supplied levels of agreement to reasons for using functioning labels; the reasons with the highest agreement for those that answered the questions (for, n=121; against, n=434) were to deliver care and understand autistic people's needs. This survey further identifies that those against functioning labels wish academics and professionals to state the individuals' needs instead of using functioning labels. This would mean that those *for and against* functioning labels want language that identifies the autistic persons' needs,

with some respondents suggesting this could be achieved through functioning labels.

In previous academic literature, descriptions of individual needs have been recommended to describe the variety of autistic people's support needs (Bottema-Beutel et al., 2021; Monk et al., 2022). Alvares et al (2020) also identified a lack of validity of functioning labels. The data from this study further strengthens these suggestions. Furthermore, describing individual support needs allows for further personalisation of support. Additionally, this can be with specific difficulties as well as strengths, in order to provide a more accurate description. This ensures that the binary issue of functioning labels is circumnavigated, and the description of needs better accommodates the fluid, dynamic nature of autistic people's 'functioning'. Additionally, it provides more clarity about support needs from other diagnoses, for example intellectual disability. The conflation of low functioning with intellectual disability occurs and is made possible with use of functioning labels, which can result in diagnostic overshadowing. It is vital that all autistic people's needs are described accurately, as unmet support needs lead to a lower quality of life (Mason et al., 2018).

Discrimination, stigma and community connectedness

Using functioning labels can result in discriminating practices and be experienced as dehumanisation of autistic people (Keating et al., 2022; De Hooge, 2019). Therefore, researchers should take care to attend to individual perspectives surrounding language and understand the

implications of utilising functioning labels. Furthermore, as Dwyer (2022) states, it is possible those who prefer PFL might not have considered the reasons against its use. This argument could be broadened to functioning labels and how the alternative achieves the goal that most respondents agreed was their reason for using them (i.e., to help understand and meet autistic people's support needs).

The stigmatisation from categorising autistic people as low functioning (Bottema-Beutel et al., 2021) may well be felt akin to labelling theory (Scheff, 1974). If an individual is deemed low functioning, they may be treated in a manner that assumes low capacity for choice and control of their life (Williams & Porter, 2017). Autistic people who are perceived to be 'low functioning' may face paternalistic attitudes in the services and settings that support them (as argued by Mulick & Butter, 2015; Knight, 2016; McDonough & Taylor, 2021). Through ability and 'functioning' being perceived as a binary, the fluid, dynamic nature of autistic people's 'functioning' is not supported (Bottema-Beutel et al., 2021; Monk et al., 2022).

Of interest is the mixed response from respondents regarding using functioning labels for themselves. It is unknown why this might be the case, but in light of stigmatisation this could be important. If these autistic people perceive the terms as acceptable, then questions rise to why they may not use this language to describe themselves. Bury et al. (2022) discovered those that found IFL more offensive had greater internalised stigma.

Therefore, it *might* be that they experience self-stigmatisation. As Botha et al. (2022) suggest, less connection with autistic people and the autistic community may include internalised stigma. Bachmann et al. (2019) found that autistic adults (n=149) do experience internalised stigma, with older respondents in their sample reporting a higher level of internalised stigma. In spite of internalised stigma as a potential influencing factor, respondents may not always use functioning labels to describe themselves, or only use them for other autistic people (e.g., 'low functioning' others). In view of this, perhaps it is a better choice to align to perspectives of each individual, i.e., disclosure of needs over functioning labels.

Functioning labels create a hierarchy of being autistic. Keating et al. (2022) express how some autistic people may wish to lessen the sense of stigmatisation and noted that some prefer terms that enable a sense of being 'superior' than other autistic people (for more information, see De Hooge (2019) regarding 'Aspie supremacy').

Furthermore, this survey has identified that community connectedness is indeed important to the acceptability of functioning labels. Referring back to the three domains of ACC (belongingness, social connectedness and political connectedness) (Botha et al., 2022), connections to other autistic people (social connectedness) and knowledge from the autistic community (political connectedness) are two possible sources of information on functioning labels. Studies exploring autistic community connectedness have suggested that closeness to the autistic community appears to

influence the perceived importance of having an autistic identity (Botha et al., 2022; Cage et al., 2022). These findings emphasise the importance of community on perceptions and beliefs, echoing studies in different contexts; for example, beliefs about smoking (Ragan, 2016); beliefs about climate change (Stevenson et al., 2019).

Limitations

Respondents were required to be able to complete the study in English and due to the nature of an online survey, they had to have access to the Internet. The majority of the respondents in the study were based in the UK and USA. Only 18% of survey respondents identified as male. Given the underdiagnosis of autistic women and individuals who are not cisgendered males (Haney, 2016), it could be expected that the study would have gained more male respondents. However, common demographics when responding to online surveys needs to be addressed. Fewer males generally respond to online surveys (Rødgaard et al., 2022; Rubenstein & Furnier, 2021). Although, it means the data may not necessarily represent autistic males. In addition, this study did not collect information about respondents' potential co-occurring intellectual disability, other co-occurring conditions, or use of oral language (following other studies that have used ACC, such as Cage et al., 2022). Therefore, it is not possible to know if autistic people with intellectual disabilities were present. Consequently, this could be a focus of future research.

Future Research

Future studies may wish specifically to identify autistic people with intellectual disabilities and investigate language preferences and ACC. It would be useful to study what could be the direction of the impact of community connectedness and whether there are other variables that may have influence on language preference. For example, it is possible to query whether self-stigmatisation led to their view.

Recommendations

The proposed best option for language choice is not to find consensus, but instead choose the optimal choice that is one in which people find the least offensive or disagreeable. The social essentialism[2] of autistic people, whereby professionals and clinicians categorise autistic people because "social essentialist perspectives shape how people navigate the social world" (Williams et al., 2022) misconstrues the diversity of autistic people's lived experiences and beliefs.

Pineo (2022) remarks that non-autistic people would not want to be autistic and as such the manifestation from their internalised ableism leads to an embodiment of their beliefs towards autistic people; in other words, their good intentions culminate in the erasure of the autistic being. It has been identified that language impacts one another, and as such it must be recommended to maintain an up-to-date understanding of its impact on the minority group to whom the words refer. Therefore, the recommendation

[2] Social essentialism is defined as "beliefs that group members are fundamentally the same" (Williams et al., 2022).

regarding current language must be to adopt the word 'autistic' (IFL) due to the respondents' near universal agreement that this term is acceptable. Similarly, most respondents suggested not using functioning labels. The proposed recommendations mirror Alvares et al. (2020), who stated that professionals, including researchers and clinicians, should move away from binary towards the variety of autistic people's cognitive profiles. This is also relevant to the current dialogue surrounding profound autism (Waizbard-Bartov et al., 2023) whereby the term is meant to differentiate between autistic people based on their functioning or support needs.

Conclusion

This study sought to understand if what was deemed acceptable language is impacted by ACC, and the reasons for the views regarding functioning labels, notably that community connectedness impacts views on language; it could be possible that how connected an autistic person is to the community may influence their views, or that their perspective make them more likely to be connected to the community (i.e., seeking out like-minded people).

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Footnotes

[1] 16 identified themselves the following: 4 as agender, 3 as genderfluid, 3 as trans, 2 as auti-gender, 2 as demiguy or demiboy, 1 as quoigender, and 1 as gender-queer.

[2] Social essentialism is defined as “beliefs that group members are fundamentally the same” (Williams et al., 2022).

Autistic people's perspectives on functioning labels and associated reasons, and community connectedness

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Purpose: Functioning labels have been used in relation to autistic people and differentiating between support needs. The main purpose of our study was to identify perspectives regarding language about being autistic. In regard to themselves and functioning. Furthermore, we investigated the influential factor of community connectedness on use of language acceptability and functioning labels.

Methods: 516 autistic respondents completed our survey. We asked about demographic characteristics, how respondents would like autistic people to be termed in the survey, and their acceptability (person with autism, Aspergers, disorder, conditions, living with autism, autistic). We also asked about respondents' Autistic Community Connectedness, acknowledging the implicit nature of language and identity (Stets & Serpe, 2016). The main focus of our survey was whether or not to use functioning labels, and the supporting rationale.

Results: 97% of respondents stated that they find the term 'autistic' acceptable. Respondents who did see merit in using functioning labels to describe autistic people also reported not necessarily using them about themselves. Community membership was found to impact the participants' language preferences to describe the support needs of autistic people, including the use of functioning labels.

Conclusion: The proposed best option for language preferences is not to find consensus but instead, opt for the optimal choice that people find the least offensive or disagreeable. This means using identity-first language and not using functioning labels.

Keywords: autism, functioning labels, identity-first language, community, language

Table 1.

Reasons for and against the use of functioning labels determined through interviews with autistic adults (n=17).

Reasons for Functioning Labels	Reasons against Functioning Labels
Functioning labels help us understand needs	Discriminative stereotypes
Deliver care	Increase assumptions about needs
Being high functioning sounds encouraging	Used to selectively deny services
I describe myself with functioning labels	Dehumanise and dismiss autistic people
Helps us categorise autistic people	Can lead to trauma/mental health issues
	Categorical labels are unhelpful/inconsistent
	Those deemed low functioning are overlooked/demoralised
	They cause stigma

Table 2.

Descriptive statistics regarding acceptability of language about being autistic (n=501).

Are these ways of talking about being autistic okay?	Yes - this term is okay (%)	I do not have an opinion on this term or phrase (%)	No - this term is not okay (%)
Person with autism	33.7	17.2	49.1
Aspergers	22.2	16	61.9
Autism Spectrum Disorder (ASD)	47.1	11.6	41.3
Autism Spectrum Conditions (ASC)	48.9	27.7	23.4
Living with (autism, ASD or ASC)	25	16.4	58.7
Autistic person	96.6	2.6	0.8
Autists or autistics (n=497)	77.5	11.9	10.7

Table 3.

Model 1 of the linear regression analysis on acceptability of language terms regarding themselves, using ACC as the dependent variable.

	Variable	Estimate	*SE*	95% CI		*p*
				LL	UL	
	PFL *only*	-12.893	1.635	-16.106	-9.679	<.001
	Don't mind the term used *only*	-7.415	1.039	-9.456	-5.375	<.001
Controls	Age	.070	.028	.014	.126	.014
	Female (compared to Males)	-3.388	.971	-5.297	-1.480	<.001
	Non-Binary/Third Gender, or other (compared to Males)	-4.611	1.088	-6.748	-2.475	<.001
	White compared to Non-White Ethnicity	-.268	.992	-2.217	1.682	.787
IFL	Intercept	51.667	3.383	45.019	58.315	<.001

Note. Total *N* = 497. CI = confidence interval; LL = lower limit; UL = upper limit.

Table 4.
Model 2 of the linear regression analysis on acceptability of language terms regarding functioning labels, using ACC as the dependent variable.

	Variable	Estimate	*SE*	95% CI		*p*
				LL	UL	
	For the use of functioning labels *only*	-10.274	1.082	-12.401	-8.147	<.001
	Maybe to use of functioning labels *only*	-8.086	1.096	-10.240	-5.932	<.001
Controls	Age	.053	.028	-.002	.108	.060
	Female (compared to Males)	-3.415	.950	-5.282	-1.548	<.001
	Non-Binary/Third Gender, or other (compared to Males)	-4.409	1.060	-6.492	-2.326	<.001
	White (ref Non-White)	-1.066	.970	-2.971	.840	.272
Against the use of functioning labels	Intercept	53.438	3.294	46.966	59.909	<.001

Note. Total *N* = 497. CI = confidence interval; LL = lower limit; UL = upper limit.

Table 5.
Reasoning for functioning labels according to individuals who support their use (n=121).

Why do you think people should use functioning labels?	Agree % (N)	Neither Agree nor Disagree % (N)	Disagree % (N)

Functioning labels help us understand needs	71.9 (87)	18.2 (22)	9.9 (12)
Deliver care	65.3 (79)	20.7 (25)	14.0 (17)
Being high functioning sounds encouraging (n=120)	23.3 (28)	39.2 (47)	37.5 (45)
I describe myself with functioning labels (n=119)	31.1 (37)	32.8 (39)	36.1 (43)
Helps us categorise autistic people	50.4 (61)	28.9 (35)	20.7 (25)
Specified other or selected other reasons exist	19.8 (20)	73.3 (74)	6.9 (7)

Table 6.
Reasoning against functioning labels according to individuals who do not support their use (n=434).

Why do you think people should not use functioning labels?	Agree % (N)	Neither Agree nor Disagree % (N)	Disagree % (N)
Discriminative stereotypes	91.9 (399)	5.5 (24)	2.5 (11)
Increase assumptions about needs (n=433)	90.3 (391)	8.5 (37)	1.2 (5)

Used to selectively deny services	89.6 (389)	8.5 (37)	1.8 (8)
Dehumanise and dismiss autistic people	87.1 (378)	10.1 (44)	2.8 (12)
Can lead to trauma/mental health issues	75.8 (329)	19.8 (86)	4.4 (19)
Categorical labels are unhelpful/inconsistent	83.6 (363)	12 (52)	4.4 (19)
Those deemed low functioning are overlooked/demoralised	89.2 (387)	7.8 (34)	3.0 (13)
They cause stigma	91.9 (399)	6.5 (28)	1.6 (7)
Specified other or selected other reasons exist	33.5 (114)	59.4 (202)	7.1 (24)

Table 7.
What language would autistic people prefer professionals and academics to use (n=377).

	Percent (%)	N
Stating individual needs of each person	49.6	187
Stating specific diagnoses	5	19

Both of the above	36.6	138
Other (please specify)	8.8	33