Which terms should be used to describe autism? Perspectives from the UK autism community

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Abstract

Recent public discussions suggest that there is much disagreement about the way autism is and should be described. This study sought to elicit the views and preferences of UK autism community members – autistic people, parents and their broader support network – about the terms they use to describe autism. In all, 3470 UK residents responded to an online survey on their preferred ways of describing autism and their rationale for such preferences. The results clearly show that people use many terms to describe autism. The most highly endorsed terms were 'autism' and 'on the autism spectrum', and to a lesser extent, 'autism spectrum disorder', for which there was consensus across community groups. The groups disagreed, however, on the use of several terms. The term 'autistic' was endorsed by a large percentage of autistic adults, family members/friends and parents but by considerably fewer professionals; 'person with autism' was endorsed by almost half of professionals but by fewer autistic adults and parents. Qualitative analysis of an open-ended question revealed the reasons underlying respondents' preferences. These findings demonstrate that there is no single way of describing autism that is universally accepted and preferred by the UK's autism community and that some disagreements appear deeply entrenched.

Keywords

autism, terminology, disability, neurodiversity, quality of life

Members of the autism community – autistic people, their family and friends and broader support networks – often disagree over how to describe autism, as the many discussions in print and on online forums attest (Brown, 2011a, 2011b; Durbin-Westby, 2009; Snow, 2006). Tensions surrounding the language of autism are attributable, in part, to the very different ways that autism touches people's lives; some experience it personally, others through their children and others still might only encounter autism in some aspects of their lives – at school, at work, in the community or through friends and family. They are also partly due to debates and disagreements within the scientific community regarding how best to conceptualise autism and partly a consequence of the growing prominence of disability rights and neurodiversity movements. Whatever the cause, the language that we use has the power both to reflect and to shape people's perceptions of autism. In this study, we elicited the views and preferences of members of the UK's autism community to understand the terms they use to describe autism and their rationale for doing so.

The scientific and medical community's understanding of what autism *is* has changed dramatically throughout the last century. The term, 'autism', initially coined by a Swiss psychiatrist to describe a subset of symptoms in schizophrenia (Bleuler, 1911), was first used by Kanner in his report of 11 children with what appeared to be a distinct childhood psychiatric syndrome, 'infantile autism' (Kanner, 1943). Although once hailed as an emotional disorder stemming from parental rejection (Bettleheim,

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1967; Kanner, 1949), amassing research evidence establishing the validity of the condition led to its inclusion in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III; APA, 1987), formally recognising it as a medical condition. Since this time, the behaviourally defined diagnostic criteria have undergone radical changes, with the recent changes to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5; APA, 2013) being no exception. In particular, the removal of Asperger's syndrome as a separate category, subsumed under a single diagnosis of 'autism spectrum disorder', caused a furore among researchers, clinicians, autistic people and parents alike (Kite et al., 2013; Linton et al., 2014; Volkmar and Reichow, 2013). These changes highlight that what we know and understand about autism is constantly in flux and should affect the way autism is perceived, understood and referred to in broader society.

Differences in people's social and ideological beliefs about autism also impact on the language they use to describe the condition. These beliefs have shifted in recent years, in part due to the efforts of the broader disability rights movement. This movement was born out of frustration with considering disability as a medical condition – a condition in need of being 'fixed', cured or even prevented (Barnes et al., 1999; Charlton, 1998). Proponents of disability rights argued that embedding disability within a medical model perpetuates a perception that people with disabilities are subject to unfortunate circumstances, must depend on others for help and should forgo some autonomy in selecting their own life course, which they argue can be deeply dehumanising and can evoke unwanted pity (e.g. Oliver, 1990; Shapiro, 1993; Williams, 1996). Instead, they emphasise a more socially inclusive view of disability, one that asserts that the extent to which a person is disabled is not entirely due to their own 'condition' but is, in part, created by the way in which a society responds (or fails to respond) to people's particular needs or requirements (Baker, 2011; Oliver, 1990).

Advocacy groups influenced by this movement have sought to realign public perceptions of disability within this sociocultural framework. They encourage people to communicate about disability using language that promotes autonomy and creates more positive identities for those being described. Initial efforts along these lines led to a campaign for the use of *person-first language* – that is, language that refers to people first as individuals and then to their disability only if necessary (Bailey, 1991; Blaska, 1993). Terms such as 'disabled person' and 'the disabled' were held to give undue prominence to the disability and to equate a person completely with their disability.

Not all disability communities have agreed with this effort, however, with some, including especially the Deaf and blind communities, explicitly rejecting the use of person-first language (Ladd, 2003; Lane, 2000). Although

members of these communities acknowledge that the underlying sentiments are laudable, they nevertheless argue such language functions to belittle the experience of those who live with the disability and precludes the possibility of pride in a person's identity (Vaughan, 1993, 1997). They further suggest that person-first language violates the common principle that positive pronouns should precede nouns. One would never say, for example, 'people who are beautiful' or 'people with intelligence'. Violating this general principle in the specific case of disability not only makes the language cumbersome but also casts disability in a negative light, as a 'marred identity' (Goffman, 1963). The language prescribed for describing disability in general may therefore not fit with the needs and preferences of specific communities, or distinct groups within communities (Vaughan, 1993; Zola, 1993).

Some members of the autism community have similar reservations about the use of person-first language. One autism activist, Jim Sinclair (1999), for example, objects to such language on the basis that an autistic person can never, and should never attempt to, be separated from their autism. Sinclair instead defends what is known as *disability-first* or *identity-first* language (e.g. deaf person, autistic person) (see also Dekker, 2011), which adheres to the general principle of placing positive pronouns in front of nouns and thus does not imply that autism is intrinsically negative (Brown, 2011b; Halmari, 2011).

This disability-first language aligns with those autism community members who perceive their diagnosis (or their child's diagnosis) to be an accepted aspect of their identity (Davidson and Henderson, 2010; Hurlburt and Chalmers, 2002) and marks their inclusion in a community (Bagatell, 2010). These views can be consistent with the notion of 'neurodiversity' (Singer, 1999), in which autism is considered one (neurological) form within a diversity of human minds (Nicolaidis, 2012; Robertson, 2010). The neurodiversity movement eschews negative language such as 'disorder', 'deficit' and 'impairment', instead preferring descriptions of autism as a way of being. Some researchers (e.g. Baron-Cohen, 2000) also acknowledge the potentially disparaging nature of the term disorder and have called for the term to be replaced with the putatively less-negative term, 'condition'. The very limited research on neurodiversity has shown that the more people report to be aligned to notions of neurodiversity, the greater preference they show for disability-first language, although this preference was not associated with a concomitant reduction in the acknowledgement of 'deficits' in autism (Kapp et al., 2012).

Not everyone in the autism community champions the notion of neurodiversity, of course. Many community members and advocacy organisations emphasise the profound challenges they or their children face and thus advocate ways to 'treat' the condition, with some pursuing a 'cure' or ways to prevent it (Humphrey and Lewis, 2008;

though see Bovell, 2006; Moore, 2010) – pursuits that can be considered reproachable by the neurodiversity community (Broderick and Ne'eman, 2008; Chamak, 2008; Milton, 2012). The effects of these different perceptions of autism can be directly observed in the use of narratives and metaphors of autism, which can include aligning autistic people with 'aliens from a different world', or references to being 'locked inside' (see Broderick and Ne'eman, 2008; Waltz, 2012). Some parent groups are troubled by these claims, being especially concerned that the neurodiversity proponents, many of whom are articulate autistic adults, cannot – and should not be permitted to – speak for the experiences of their more severely disabled autistic children (see Bagatell, 2010). Autistic activists themselves have occasionally responded by acknowledging the difficulty and also by suggesting that autistic adults remain better suited to advocate for more disabled autistic people as a result of their shared autistic experience (e.g. Broderick and Ne'eman, 2008).

It is clear that there are deep differences in the preferences people hold regarding the terms they use to describe autism and how to understand the relationship between that language and the identity of autistic people. At present, however, little is known as to how members of the UK autism community approach these questions beyond the explicit contributions of a few activists, scientists and social commentators. This study therefore aimed to understand better the views and preferences of the UK's autism community – including those on the spectrum, their parents, friends and family and the professionals who work with them – and to determine potential differences, if any, between and within community groups.

To address this aim, we conducted a large-scale online survey to elicit both quantitative and open-ended responses with members of the autism community on their preferred terms to describe autism and their rationale for such preferences. We expected that, in particular, there would be differences between groups within the autism community regarding preferences for person-first/disability-first language in particular and that people's preferences would relate to their underlying beliefs about the nature of autism.

Method

We developed an online survey to gauge people's views and preferences on terms used to describe autism. The survey began with a series of background items, including participants' connection with autism, their age, gender, ethnicity and residency in the United Kingdom. These items were followed by four key questions on the phrases used to describe autism. Specifically, we asked participants (a) to identify, by selecting from a list, which terms they prefer to use when communicating about autism; (b) to identify which terms they would use to describe themselves or the person with autism that they live/work with/

know; (c) to rate their preference for a series of terms used to describe autism on a 5-point scale (1 = *strongly dislike*; 2 = *dislike*; 3 = *neither like nor dislike*; 4 = *like*; 5 = *strongly like*) and (d) to specify, by selecting from a list, which *one* term they would use to describe autism. The specific terms (see Figures 1 to 3) used were identified through consultation with autism community members, including two parents, three autistic adults and two professionals. The survey was then piloted with autism community members recruited by a national charity, who provided additional feedback regarding length and clarity of the questions. Finally, in an open question, participants were given an opportunity to provide reasons for their like (or dislike) of specific terminology.

We used a convenience sample method – snowball sampling – that relied on referral from an initial group of participants (through the National Autistic Society's mailing list) to generate additional participants, through other parent advocacy groups, practitioner and researcher networks and via social media (Twitter, Facebook) and online fora in the United Kingdom.

In all, 4622 people responded to the survey. Participants who (a) did not specify any connection with autism (n = 19), (b) did not complete all four key questions on describing autism (n = 453), (c) were under 18 years or preferred not to state their age (n = 284) and (d) were not resident in the United Kingdom or preferred not to state their place of residence (n = 396) were excluded from the dataset prior to analysis. Subsequent analysis was therefore based on complete responses from 3470 participants.

Participants were initially asked about their connection with autism. Given that people have multiple roles (e.g. a parent of a child with autism, who is also a professional working in the field), they were able to select all that applied to them.[1] Of these participants, 502 categorised themselves as autistic, 1666 as a parent or carer of a child with autism, 614 as a parent or carer of an adult with autism, 967 as a professional working in autism or a related field, 58 as a researcher, 85 as a student, 141 as a volunteer and 380 as a family member (son/daughter/sibling/grandparent) or friend to a person with autism.[2] For ease of interpretation, analysis focused on respondents who could be divided into four key groups: autistic adults (n = 502); parents of people with autism (n = 2207); professionals, including researchers, students and volunteers (n = 1109); and family members and friends (n = 380). Note that in the few cases where respondents identified themselves as belonging to several similar categories that were subsequently combined (e.g. parent of a child with autism *and* parent of an adult with autism), they were only included once.

Background information on participants can be found in Table 1. The majority of respondents were female. Almost all respondents categorised themselves as of White ethnic background and, of the four devolved authorities of the
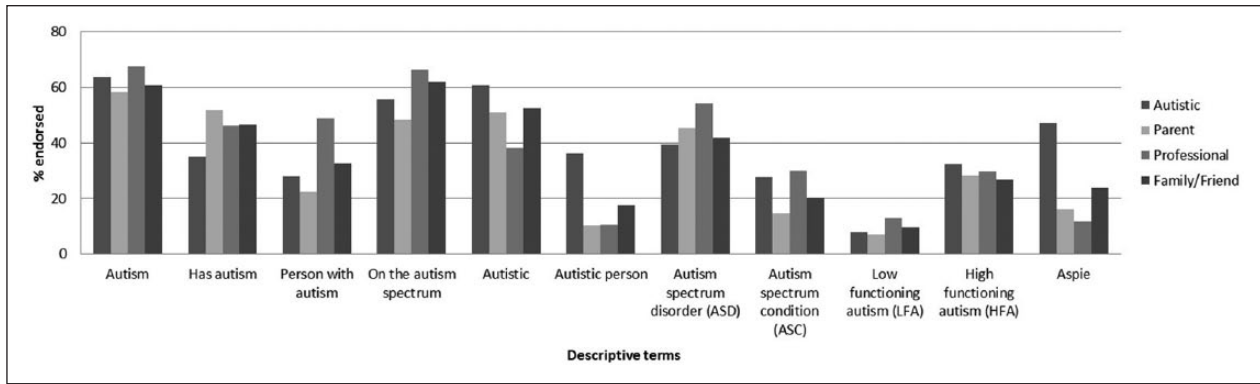
Figure 1. Graph showing the percentage of participants within each stakeholder group endorsing each of the terms to communicate about autism.
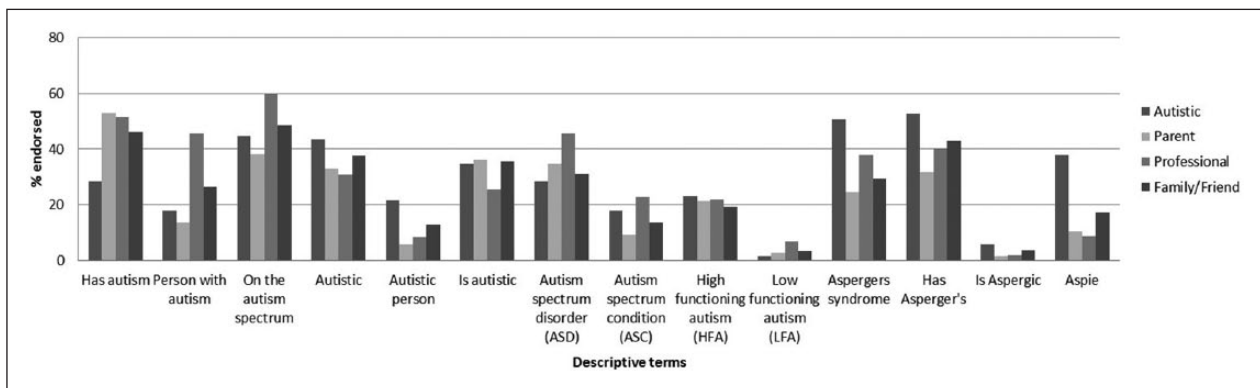

Figure 2. Graph showing the percentage of participants within each stakeholder group endorsing each of the terms used to describe themselves, their child or those they work with.
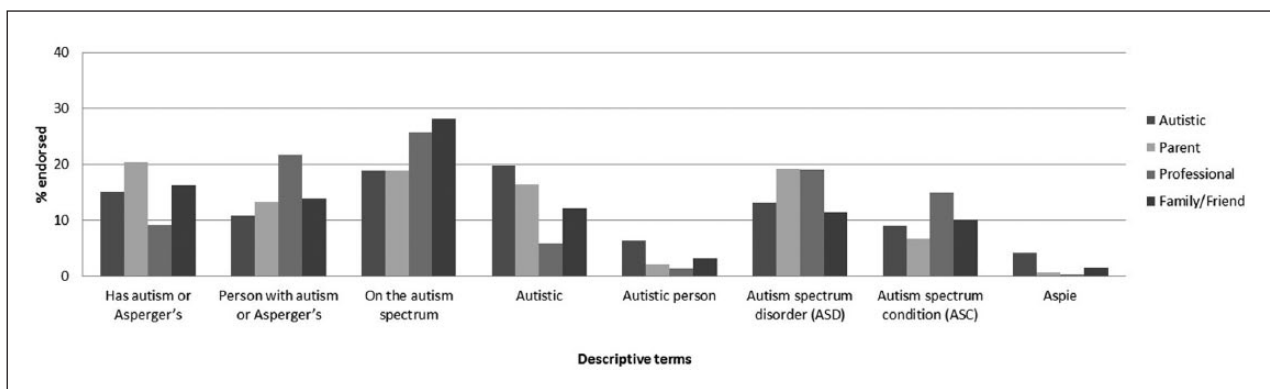

Figure 3. Graph showing the percentage of participants within each stakeholder group endorsing *one* of the following terms to communicate about autism.

United Kingdom, most respondents resided in England (see Table 1). The field(s) in which professionals worked encompassed a range of areas, including the charity/voluntary sector (n=274), education (n=519), health care (n=353), social care (n=219), research (n=44) and service commissioning (n=23)[3].

The survey took approximately 10–15 min to complete and was hosted by SurveyMonkey between December 2013 and February 2014. All data were collected by the UK's National Autistic Society and anonymised prior to the current analysis. Ethical approval for the analysis of the secondary, anonymised data was granted by the

Table 1. Background information for respondents to the online survey for each of the four key stakeholder groups.

	Autistic (n = 502)	Parent (n = 2207)	Professional (n = 1109)	Family/friend (n = 380)
Age range (years)				
19–25	103	32	75	40
26–35	115	310	227	71
36–45	125	985	312	94
46–55	114	670	323	83
56–65	42	172	157	63
66+	3	38	15	29
Gender				
Male	177	188	149	47
Female	288	1999	952	325
Other	25	4	2	5
Prefer not to say	12	16	6	3
Place of residence				
England	429	1826	886	319
Wales	20	84	40	14
Scotland	45	245	157	46
Northern Ireland	8	52	26	1
Ethnicity				
White background	450	2079	1051	360
Black background	3	20	8	2
Asian background	7	30	11	1
Mixed background	15	22	11	3
Prefer not to say	27	56	28	14

Research Ethics Committee at the UCL Institute of Education, University College London (REC645).

Results

Quantitative results

Figure 1 shows the percentage of individuals within each group endorsing each of the terms they use when communicating about autism. Examination of the figure clearly shows that people use many terms to describe autism. The most highly endorsed terms were 'autism' and 'on the autism spectrum', and to a lesser extent, 'autism spectrum disorder (ASD)' for which there was general agreement across groups. Community members disagreed, however, on the use of several terms. The term 'autistic' was endorsed by a large percentage of autistic adults (61%), family members/friends (52%) and parents (51%) but by considerably fewer professionals (38%). In contrast, 'person with autism' was endorsed by almost half (49%) of professionals but only by 28% and 22% of autistic adults and parents, respectively. Also, while a significant proportion of autistic adults stated that they used the terms 'autistic person' and 'Aspie', only a minority of other participants agreed. Very few respondents stated that they used the term 'low-functioning autism'.

Similarly, people reported using a variety of terms to describe themselves or the person with autism who they live with, work with or know in some other capacity (see Figure 2). The term 'on the autism spectrum' was endorsed by significant numbers of autistic adults (45%), parents (38%), family members/friends (48%) and especially professionals (60%). Also, there was agreement across groups about the use of certain terms: more than 30% of participants across all groups stated that they used the terms 'autistic', 'has Asperger's and 'is autistic', while very few participants reported using 'is Aspergic' and 'low-functioning autism'. More professionals reported using person-first terms ('person with autism', 'has autism' and 'has Asperger's') than other (disability-first) terms. Yet, there were inconsistencies within some of the other groups. On one hand, few parents (14%) reported using person-first language ('person with autism') to describe their children but considerably more stated that they used the terms 'has Asperger's' (32%) and 'has autism' (53%). On the other hand, less than one-third of autistic adults reported using 'person with autism' (18%) or 'has autism' (28%) but, surprisingly, more than half of the group (53%) used 'has Asperger's'. Few participants used the terms 'is Aspergic' or 'low-functioning autism'.

Table 2 shows the mode responses for participants' ratings of each term, for each group separately. The majority of terms were given a mode response of 3 (*neither like nor dislike*) or higher, indicating either an ambivalence or preference for these terms. Autistic adults reported a strong preference for the terms 'Aspie' and 'Asperger syndrome'

Table 2. Participants' mode ratings for each term describing autism according to stakeholder group (1 = *strongly dislike*; 2 = *dislike*; 3 = *neither like nor dislike*; 4 = *like*; 5 = *strongly like*).

	Autistic (n = 502)	Parent (n = 2207)	Professional (n = 1109)	Family/friend (n = 380)
ASD	3	3	4	3
ASC	3	3	3	3
High-functioning autism	3	3	3	3
Asperger's syndrome	5	4	4	4
Aspie	5	2	2	1
Autistic	4	3	3	3
Has autism/Asperger's	4	4	4	4
Person with autism/Asperger's	4	4	4	4
Autistic person	4	3	2	3
On the autism spectrum	4	4	4	4

ASD: autism spectrum disorder; ASC: autism spectrum condition.

(mode scores of 5: *strongly like*), while parents, professionals and family/friends reported a moderate preference for the terms 'Asperger syndrome', 'has autism/Asperger's', 'person with autism/Asperger's' and 'on the autism spectrum' (mode scores of 4: *like*). The exceptions to this pattern were the term 'Aspie', which parents, professionals and family/friends reported disliking, and 'autistic person', which professionals reported disliking. The terms that produced the most disagreement among stakeholders were the terms 'Aspie' and 'autistic person', both of which were rated highly by autistic adults but less favourably by other participant groups.

When participants were asked to choose which one term they would use to communicate about autism, the results revealed little consensus between *and* within groups (see Figure 3). More autistic adults chose the terms 'autistic' (20%) and 'on the autism spectrum' (19%) than other terms. Parents were divided in their selection of terms, with a similar percentage of parents selecting the terms, 'has autism/Asperger's' (20%), 'autism spectrum disorder' (19%) and 'on the autism spectrum' (19%) as their preferred terms. More than a quarter of professionals (26%) and family and friends (28%) preferred the term 'on the autism spectrum' than other terms. Again, areas of disagreement among respondents revolved around the use of person-first language. A greater percentage of autistic adults (20%) and parents (16%) stated they would use 'autistic' than professionals (6%) or family members/friends (12%) while more professionals reported choosing 'person with autism/Asperger's' (22%) than autistic adults (11%), parents (13%) and family members/friends (14%). Few participants stated that they would choose to use the term 'Aspie' or 'autistic person'.

We also examined participants' responses to all three questions based on those who categorised themselves as belonging to one stakeholder group only (n = 2762). The pattern of results for each question was remarkably similar to the analysis of responses for the entire data set (i.e. including participants who reported belonging to more

than one group). These results are available from the authors upon request.

Qualitative results

A substantial number of participants provided their views and perspectives on the issue of describing autism, including responses from 233 autistic adults, 758 family members and 340 professionals. Given the different patterns of responses between groups described above, the qualitative responses were analysed, using thematic analysis (Braun and Clarke, 2006), for each group separately. We adopted an inductive approach, providing descriptive overviews of the key features of the semantic content of data within an essentialist framework. Two of the authors (L.K. and E.P.) independently familiarised themselves with the data and met regularly to discuss preliminary themes and codes. Each author independently coded the transcripts by identifying quotations they felt were representative and placed them in a spreadsheet under the headings of the preliminary codes. The authors then met several times to review the results, resolve discrepancies and decide how the codes could be collapsed into themes and subthemes.

Autistic adults. We identified five themes from adults' responses (see Table 3). The first theme related to the importance of viewing autism as intrinsic to the person rather than something that could be separated from them. They also eschewed the notion of autism as a disorder, preferring to view it as a different way of seeing the world. People were further conflicted over whether autism itself is disabling. Some autistic adults described their autism as a disability, while others emphasised the role that society plays in creating or perpetuating that disability, including its lack of awareness and accommodations for autistic people and their families. Others still noted the need (albeit reluctantly) to describe autism as a disability because such a description enabled access to services.

Table 3. Themes identified from autistic adults' responses to an open question in the online survey (n = 233).

Themes	Subtheme	Example quotes
Autism is not separate from the person		'I understand the push for "I am a person with autism" but I would never say "I am a person with brown hair". I would say, "I'm a(n) aspie/autistic" or "I'm a brunette"'.
		'Separating the person from their autism is damaging, as it reinforces opinions about autism being a 'thing' that can be removed, something that may be unpleasant and unwanted, and something that is not just another aspect of a whole, complete and perfect individual human being. Describing oneself as autistic is an extremely important and positive assertion about oneself, it means that one feels complete and whole as one is'.
		'In describing someone who's autistic as "a person with autism/person who has autism/(or worst of all) person who suffers from autism" you imply that autism is separate from a person, and behind their autism is a "normal" person'.
Disorder vs. difference	Autism is a different way of seeing the world	'Autism is not a disability, disorder or syndrome, more a different way of perceiving the world'.
		'Autism is just another way of thinking, not some sort of disease that one can catch'.
		'Never forget that autistic people are PEOPLE who are complex and not fundamentally broken in some way'.
		'It is not a disorder, I am not a disordered version of a non-autistic person'.
		'I dislike the use of the words "condition", "disorder" and "disability" because I do not consider myself to be handicapped in any way. While there are things I find difficult, like making friends and coping with change, I can learn to overcome these issues with support from family, friends and professionals'.
	It is society that disables us	'Autism is only a disability in a neurotypical world, I can communicate perfectly with other AS people'.
		'Autism is not the disability. The disability occurs where there aren't sufficient supports. Just like a person in a wheelchair wouldn't have as many problems if all places had ramps and stuff'.
		'Autism can lead to difficult experiences for the person on the spectrum, but it only becomes a disabling condition within the context of an abelist society which does not understand, cares little for or offers limited support to people with autism'.
	Disability allows access to services	'I think condition is better accepted than disability but it can undercut people's needs for support e.g., Disability Living Allowance'.
		'The word disability has to be used carefully, I often explain it in terms of level of dysfunction against norms of society and expectations. However, disability is a very real and useful term to ensure access to support services'.
Asperger's vs. autism	Asperger's is part of our identity	'Care needs to be taken with the difference between Autism and Asperger's. This survey seems to treat the two as almost interchangeable and they are not'.
		'Don't let us Aspies lose our identity'.
		'I would like to keep the term Asperger's as it is part of my identity'.
	Use of Asperger's divides the autism community	'I think the way people communicate about Asperger's leads to elitism and prejudice against autism as a whole. I know many people of extremely high intelligence living independent lives who have Autism and not Asperger's'.
		'Asperger syndrome is a form of autism. I feel this phrase belittles Asperger's. I am Asperger's and every time I read that phrase it makes me feel isolated. For Asperger's to be a form of autism implies Asperger's is not autism'.
		'Separating Asperger's from autism gives people the illusion that they must be more "normal" and can be harmful to them because of that'.

(Continued)

Table 3. (Continued)

Themes	Subtheme	Example quotes
Notion of the 'autism spectrum'	Everyone being on the spectrum trivialises difficulties we face	'I find terms involving "autism spectrum" create more problems than they solve – tend to lead to well-meaning but unhelpful comments along the lines of "it's a spectrum so we're all on there somewhere" – trivialising the very real problems it causes for those who are genuinely autistic'.
		'Saying that EVERYONE is on the spectrum makes it harder for me and the problems I encounter because of my Asperger's to be taken seriously'.
		'I hesitate a bit about the idea of "everyone being on the spectrum" because I've heard it used in ways that seem designed to downplay the need for extra support'.
	High-functioning/ low-functioning are misleading descriptors	'In my experience this focus encourages people to devalue more profoundly autistic people and overlook their gifts/abilities'.
		'I think that the term "high functioning autism" should be scrapped because it minimizes the problems someone with autism can face in daily living'.
		'High- and low-functioning imply a value judgement with unpleasant implications'.
		'It is important to avoid making assumptions of a person's potential for independence, accomplishment or happiness based on their apparent level of intellectual ability or "functioning level". Such apparent "functioning levels" are inherently subjective to the observer and have more to do with how well we "pass" than with actual ability. They are also highly contextual and vary depending on the person's current cognitive, sensory or emotional processing load. In general functioning labels should be abandoned in favour of concrete descriptions of an individual's specific access needs for particular accommodations'.
Emphasise other qualities of autism	We do not grow out of autism	'I think it is important to get across that autism is for life'.
		'We need to promote that this is a lifelong condition – we do not "grow out" of it suddenly when we become adults as many people still seem to think!'
	Autism people have talents too	'Accentuate the positive more. A child will have problems but in many cases can overcome or work around them and be successful. Ditto for adults and we can also be excellent reliable hardworking employees'.
		'Although we have difficulties we can also have incredible talents'.
		'People with autism are almost always honest, sincere, loyal and non-judgmental. They may be very creative and original, not getting trapped in "group think", and have great problem-solving skills'.
	Autism is a hidden disability	'I come across this a lot, that I don't look autistic or my needs are not as important as other people on the spectrum. Just because you cannot see it so therefore it's not there'.
		'I think it should be stressed that some autistic people are outwardly "normal" and may live independently, but one should still take their condition seriously as they may be very affected by their symptoms. We just don't show it as much to other people'.

Respondents also questioned the notion of the 'autism spectrum'. Some autistic adults were wary of the autism spectrum extending into the neurotypical population, which they felt trivialised the challenges they face. Other adults felt that the way that the spectrum is commonly conceived – ranging from 'low functioning' to 'high functioning' – is overly simplistic. They described the often-limited relationship between a person's intellectual functioning and the nature of their autism and noted the potentially damaging effects that such functioning-level descriptors can have on people's lives:

It is also often used to disregard the opinions of autistic people. Non-autistics decide for themselves that we are either

'too low functioning' to be capable of having an opinion, or 'too high functioning' for our experiences to be relevant.

Many adults were keen to emphasise other qualities of autism, counteracting commonly held beliefs that perpetuate in the media. They stressed that autism is a lifelong condition – that they do not 'grow out of it' when they become adults. They also described how it is often a hidden disability – that although many people often look outwardly 'normal', this does not mean that their needs should not be taken seriously, and that there were many strengths and positive characteristics associated with autism that need to be nurtured and appreciated.

Respondents were divided, however, on the relationship (or lack thereof) between Asperger's syndrome and autism. Some people felt that Asperger's was part of their identity and that, despite the changes to the DSM, it was important to uphold the distinction between autism and Asperger's syndrome. Others felt that such a distinction was confusing and served to undermine the notion of a united autism community. They felt instead that people should use one term only ('autism' or 'autism spectrum').

Professionals. Six themes were identified from professionals' responses, some of which overlapped with those of autistic adults (see Table 4). Unlike autistic adults, many professionals felt that person-first language (e.g. 'person with autism', 'has autism') should be used when describing autism because the person should always come first, not the condition. Nevertheless, similar to autistic adults, they were uncomfortable with the use of the terms 'disorder' and 'disability', which they felt had too many negative connotations and mistakenly suggest that it is something that 'can be cured or made better'. Despite this view, they did not want to discount the many difficulties or challenges that autistic people can face and acknowledged the need to use the language of disability when referring to the people with whom they worked in order for them to access the necessary supports and services. Some noted that people need to become more alert to the way in which society disables people on the spectrum (e.g. non-autism-friendly environments).

Professionals were also divided with regards to the distinction between Asperger's syndrome and autism. Some felt that, for many people, Asperger's is a meaningful term – it is a good way of describing a person's needs, which are often very different to those with so-called classic autism, and is part of some people's identity. Others disagreed, stating that the term was confusing, especially for families. They suggested that people tend to perceive Asperger's syndrome as a lesser form of autism, which they felt is not necessarily the case and may preclude people from accessing necessary services.

Some professionals went so far as to question the need to use such distinctions at all. They suggested that catch-all terms such as 'Asperger's' and 'autism' can generate false expectations about what a child 'looks like' and prevent professionals from focusing on individuals' unique characteristics and needs. They further emphasised the need not to generalise (including with regards to the distinction between low- and high-functioning autism) but to recognise that every person with autism is different, with a unique set of qualities, including strengths and talents. One professional noted the way that language mediates our expectations: 'I feel it is important to generate useful language that does not limit our expectations, does not narrow our view but respects the very real difficulties that differences can create'.

Many professionals also noted the importance of context when describing autism – that the way they describe autism to parents of a newly diagnosed child, for example, will be very different to how they describe autism to their colleagues working in the health system, which will vary again from how they describe autism to teenagers (with or without autism). They were aware of the need sometimes to use the words 'disorder' and 'disability', as they help people who are not aware of autism to understand the difficulties that autistic people face and also acknowledged that these same words can be perceived negatively by young children/adults who have autism and can lead to them believing (unhelpfully) that there is something wrong with them.

Family members. Several similar themes were identified from parents' and other family members' responses (see Table 5).[4] This group, however, was the most divided in its sentiments. To begin, there was disagreement with regard to the extent to which autism was considered a part of a person's identity. For some family members, autism was seen as intrinsic to, and inseparable from, their child. Others, however, stressed that their child should not be defined by their autism, in some cases preferring to view it as something that is treatable.

Like autistic adults and professionals, family members also challenged prevailing negative perceptions of autism. Many family members suggested that their son, daughter or grandchild is not 'disordered' or faulty but, rather, sees the world in a different way. They also emphasised the way that their child's disability can often be attributed to barriers in society, including a lack of inclusive attitudes and unwelcoming environments. Yet, others also stressed the need not to underestimate the impact of autism, which can require substantial supports and services, and can have serious effects on the child and their family. Consistent with this view, some family members also spoke of the need to challenge commonly held beliefs about autism, especially the 'Rain Man' stereotype, that perpetuate in the media and in communities. In so doing, they called for more efforts to enhance awareness of 'the gritty truth about autism'.

Table 4. Themes identified from professionals' responses to an open question in the online survey (n = 340).

Themes	Subtheme	Example quotes
The person should always come first		'The person should always come first e.g., person with autism. Preferably using the person's name'. 'The person with autism is a person-first and their condition second'. 'I don't like phrases which describe a person as their condition, so would always go for "person" first, because that's what we all are regardless of what conditions we have. I would never describe myself as a thyroidy, for example'. 'We need to describe the individual and ASD as separate entities with the emphasis on the individual not the disorder'.
Disorder versus difference	The language used is too deficit-focused	'I, and those I work with, object to words like disorder and disability in relation to the autistic spectrum. They imply that there is a right and a wrong way to perceive the world'. 'I particularly dislike the term "ASD", "Disorder". Whilst I realise this is a medical description I believe that it has too many negative implications i.e., Disorder = Wrong/broken etc. Within my work and everyday language I do not use "disorder" and will often challenge others if they use the term'. 'I feel uncomfortable describing autism as a disability. Whilst there can be co-morbid disabilities associated with it, because most of the students I work with have HFA, and working in a school, the word "disability" has negative connotations'.
	Autism can be disabling	'I prefer considering autism as a way of seeing the world that we can all learn from and which offers diversity rather than deficit. However, this is at odds with the current system of funding and benefits, which relies on viewing autism as a disability. This represents a conflict'. 'Calling it a condition can undermine the impact it has on an individual's ability to function within society and not acknowledge how severely limiting it can be for the person and their family'. 'I like the focus on difference in talking about people who have autism, but not to the exclusion of difficulty or disability. I feel it is very unfair to those people who have significant difficulties as a result of their autism to focus solely on difference & positive impact of these'.
	Need to understand how society disables people on the spectrum	'I think it is important to be alert to the way in which society disables people on the spectrum. The word "disorder" suggests that the difficulties are due to personal dysfunction rather than the result of social barriers'. 'Autism itself is not a disability but a different way of interpreting and interacting with the world. The disability only occurs when other people do not recognise and understand the different way of communicating and interacting. Society causes the disability not autism'. 'If we are truly an inclusive society do we need to label? We should address difficulties, change the environment and the label will not be necessary'.
Asperger's versus autism	People understand what Asperger's means	'Based on feedback from "service users and carers", I would just emphasise the importance of continuing to highlight and explain Asperger's Syndrome as this is meaningful to many people (whether diagnosed as on the Autism Spectrum or not)'. 'Asperger's needs to be kept in the language because it makes it easier for kids (and parents) to accept and understand'.
	People with Asperger's are very different from those with classic autism	'I am disturbed by the new trend of absorbing Asperger's onto the spectrum. I think many people with Asperger's like their distinct diagnosis. It looks quite different from autism'. 'I work with university students. I think that there is a strong preference in this group for the term Asperger Syndrome rather than the more general "Autism". Of course they realise that they are diagnosed as on the autistic spectrum but they see themselves in most cases as very different to those with classic autism'.

Table 4. (Continued)

Themes	Subtheme	Example quotes
	The term Asperger's is confusing	'There is often confusion with families I support with regards to the difference between high functioning autism and Asperger's Syndrome'.
		'I think that the term Asperger's syndrome is misleading and confusing. Many people perceive it as a less severe form of Autism and consequently with better outcomes for the individual. My experience is that this is not the case and can prevent people from getting the appropriate support they need. AS is part of an ASC. It is better to describe the abilities and needs of the individual while the umbrella term ASC acts as a signpost to the types of difficulties an individual may have'.
		'I find it confuses people that Asperger's is part of ASD and reduces the understanding of the severity of classic autism'.
		'Need to keep in line with medical professions as many children and parents get very confused by the different terms. Diagnostic terminology needs to be considered'.
	There are problems with labelling people	'I think the label autism prevents us from seeing the individual differences in each person. By using the label, educators use a one-size-fits-all approach, doctors don't bother to test for individual issues (sleep problems, visual problems, pain etc.) (all get put down to their autism). If feel if we took away the label and assessed each person's health, sensory perception, language processing etc., then we could treat each area for the advantage of all those with individual differences. The label stops us from understanding the individual'.
		'Would prefer not to label within the autism spectrum as each child is individual and I feel the autism spectrum says just that (i.e., not labelling as Asperger's or high functioning etc.)'.
		'Diagnosis and labelling should not provide excuse to deliberately underperform'.
Descriptions should focus on people's unique qualities	Autism can affect people in very different ways	'In describing ASC, it has to be in the context of the person, encouraging others to understand what is relevant and meaningful to that individual … what they like, don't like, how autism presents in that person'.
		'I think it's really important that we don't generalise because every person with autism is different and affected in different ways'.
		'There needs to be more about the variation of presentation of autism & especially the impact of the environment on how autistic people function'.
	We need to celebrate the strengths	'While it is clearly imperative to consider the needs that people with an ASD have, I feel that there also needs to be more of a focus on strengths and differences rather than disabilities'.
		'Any definition should include strengths as well as difficulties. The emphasis is too deficit-focused at present'.
		'Need to also concentrate descriptions on the strengths of people with autism not only the limitations. This may well help dispel myths of autism and assist in the positive view of people with autism in relation to employment etc.'
	Functioning-level descriptors are misleading	'HFA and LFA are often inadequate descriptors. I can see how they may be useful in a health/social care setting, but in my opinion they are overused. In my experience if you're viewed as high functioning then your needs are often dismissed. If you're viewed as low functioning then your strengths are often dismissed. Also, "functioning" is something that can vary between tasks and on different days according to stress levels, for example'.
		'More person-centred language – less "high functioning" or use of the words condition/disorder. "A person who may …" or "is unique" – focus on the individual and listen to how people view themselves, and how they would like to be described'.
		'Intelligence and severity of the ASD are not related'.

(Continued)

Table 4. (Continued)

Themes	Subtheme	Example quotes
Should be asking people with autism how they want to be described		'I would like to talk about the spectrum in a way that is respectful, considering the views of those who live with it'.
		'I think you should attach most weight to the views of people who have autism or Asperger's syndrome themselves'.
		'I think that the terms used should be what people on the spectrum want. This may differ from person to person'.
How you describe autism depends on who you're talking to		'As a professional working with families who have a child with autism (aged 0–5), I am happy to adapt my language to that which is most comfortable to the family'.
		'When talking to families I would be very careful not to use certain phrases or labels as I feel this takes away the individuality of each person. When dealing with professionals in other agencies, I would use certain "phrases" to start to guide expectations of the abilities of a person, but always reinforced by the individual complexities and abilities'.
		'Different terms are appropriate to different audiences/arenas'.
		'I come from health background where ASD is the label that is used. It is not one that I would necessarily feel comfortable with but it is sometimes necessary when communicating the diagnosis to certain people'.
		'What the appropriate language to use is may well vary from audience to audience'.

Family members, like autistic adults and professionals, were divided about the use of the term Asperger's syndrome. On one hand, some family members felt that the features of Asperger's are very different from those of autism, especially for their (autistic) children that need consistent and often lifelong support. On the other hand, some family members noted that the distinction could sometimes cause people to believe that Asperger's is a lesser form of autism, as if their child is essentially less disabled, which they suggested was often not the case. Other family members simply found the distinction – and the lack of agreement among professionals – confusing and unhelpful.

Many family members spoke of the need to understand the wide variation among those on the autism spectrum. They cast doubt over whether the term 'autism spectrum disorder' could convey this diversity and the manifold ways that autism can affect a person. Nevertheless, family members, especially parents, felt frustrated by the terms 'low- and high-functioning', which they felt were inadequate descriptors for their children, particularly for those who did not have an additional learning disability but still had significant needs. They felt that these descriptors were unhelpful 'short-cuts' to understanding, which could result in people, professionals in particular, not taking the time to understand the individual needs of their child. Furthermore, some family members were worried that the umbrella term of 'autism spectrum disorder' meant greater emphasis on more able individuals, to the detriment of more severely disabled children. They felt that there should be more focus on these children with more complex needs rather than 'kids that are just a bit odd'.

Family members also wished for a more nuanced description of autism – one that emphasised the positive aspects of autism, the invisibility of the condition (which would mean that their children were not mistakenly perceived as 'naughty' or 'troublemakers') as well as the potentially debilitating effects of co-occurring medical conditions (e.g. gastrointestinal problems) and psychiatric conditions (e.g. attention deficit hyperactivity disorder (ADHD), mental health problems).

Finally, just like professionals, some family members noted that the way that autism is described necessarily depends on the context, underscoring the existence of many and varied ways of describing the condition.

Discussion

This study sought to understand the terms UK autism community members prefer to use to describe autism. Our findings clearly demonstrate that there is no universally accepted way to describe autism. Instead, the terms preferred by community members varied considerably across groups. The terms 'autism' and 'on the autism spectrum', and to a lesser extent, 'autism spectrum disorder (ASD)', were consistently favoured across all groups. Yet, there were notable points of disagreement between, and even within, groups, many of which appear to be largely attributable to fundamental differences in beliefs about autism – and disability more broadly.

The use of person-first language was the principal point of contention among community members. Professionals reported a clear preference for the use of person-first language (e.g. 'person with autism/Asperger's'), while

Table 5. Themes identified from family member and friends' responses to an open question in the online survey (n = 758).

Themes	Subtheme	Example quotes
Autism and identity	Autism is an intrinsic part of who they are	'Autism is who and what and why these people are. You cannot separate these concepts'.
		'My main concern is that using the word autism, or autistic or ASD implies that autism is something to be ashamed of or embarrassed by hence the attempts to distance ourselves from it with a series of endlessly reinvented euphemisms. My son is autistic. It's part of him. He's not ashamed by it and feels no need to hide the fact. Nor do I. Nor does anyone who knows and loves him. Autistic and proud you might say'.
		'We find the phrase "has autism/Asperger's" very upsetting as it implies our child's own being is in someway wrong'.
		'I say my son "is autistic" in the same way I say he "is black" not because that is all he is, but because it is a big part of his identity as a person, it has a huge bearing on the way he is perceived in society and so in my opinion, it is something that must be embraced as a positive'.
		'I think that using the language of "a person who has autism" makes it sound like an illness or disease that can be cured, which it is not. That is why I prefer the term "autistic"'.
	Autism does not define the person	'I do not like to use the phrase "disability" nor do I like to refer to my son as "autistic" – he has asthma and eczema and I don't refer to him as asthmatic or eczemic. It is a part of him, it is not the whole of him'.
		'I think of autism as a feature (not always defining). We describe it with my 9-year-old son as just an aspect of who he is, rather like having blue eyes or blond hair'.
		'I'm not a fan of the expression "he/she is autistic". I don't like labelling my child with that word, autism is just a part of him it doesn't define him'.
		'There are those who do not think autism is a lifelong disability and that individuals can be cured'.
Perceptions of autism	My son/daughter is not 'disordered' or defective, just a different way of being	'I do not like the word "disorder" it makes me think of something or someone that is chaotic, faulty or broken, not as good as, damaged. I love my girls, an adult with Asperger's Syndrome and child diagnosed with ASD, with complex care needs, learning difficulties and delayed development. They've taught me to look at the world through various different perspectives in all things'.
		'Too much emphasis on it being a disorder (i.e., wrong) at present. I tend to emphasise the positive or difference in my descriptions of my child, but do not want to give the impression that he is ill or needs fixing'.
		'It is important to ensure that people on the autism spectrum are not seen as lesser people – rather that they think and see the world differently'.
	My son/daughter is only disabled because society does not respond to his/her needs	'My son really likes people without autism to have labels too – e.g., neurotypical. It seems fairer to him and helps everyone think positively about autism as difference while helping to explain the disabling effect of operating with autism in a world set up for typical people'.
		'I have told my children that it is not the autism that is disabling, but the way the world cannot accommodate anyone who is even slightly different from what it imagines the average person to be, e.g., left handers, the deaf, the very intelligent, very tall or very short people'.
		'I believe my son is different not disabled – society disables him through ignorance and intolerance of difference'.
	Need to be careful not to downplay the impact of autism	'I am not keen on the description ASC, which feels like it downgrades the impact of autism. ASD or autistic describes something that is intrinsic and lifelong'.
		'I prefer disorder to condition because I think it conveys better the seriousness and the need for support and intervention'.
		'Please don't play down/dilute their difficulties. It's difficult to be positive towards professionals who are opting out of their responsibilities/duties to our children when we're being told it's just a different way of being in the world … !!!'

(Continued)

Table 5. (Continued)

Themes	Subtheme	Example quotes
	Need to counteract popular myths	'Autism is not a gift. People ask me if I get my son to choose lotto numbers … or if he can draw wonderful pictures. Although Rainman was a good film, it does not accurately portray all people with autism'.
		'I wish we could stop people assuming that all people with ASD have some kind of special skill or ability. The number of times I've been asked what my sons "gift" is, is ridiculous & sometimes upsetting'.
		'I think it is critical that the language we use to describe autism helps to challenge stereotypes, is a constant reminder of the unique value and potential of every individual with autism and proactively models the positive attitudes and behaviours needed to influence the sustainable change we all wish to see'.
Asperger's versus autism	Asperger's is very different from autism	'I think there should be a clear identity between autism & Asperger's as they affect the individual in different ways. I have 2 children with Autism & 1 child with Asperger's and the descriptors fit their personality. I do not like it all under the one umbrella of ASC as that plays down how big & diverse the disability is'.
		'Asperger's syndrome should be used instead of being referred to as ASD, as the high functioning Aspies are very different from those who need lots of support in life'.
	The distinction makes people think that Asperger's is less of a disability	'Descriptions of Asperger's implies that they are less disabled/suffer less when in my experience they suffer more from mental health issues and from the difficulties of having to live/wanting to live in the neurotypical world'.
		'The use of the term Asperger's can give people the wrong perception of an individual's needs and they may be judged as being less disabled than they really are therefore resulting in an under provision of services'.
		'If I tell people he has ASD they look at me with pity and he is excluded from mainstream clubs and friends; If I say he is Asperger's people nod approvingly. It would be a lot easier if everybody on the spectrum was given ASC'.
		'I dislike the way people tend to use the term Asperger's instead of autism as somehow that seems to be more acceptable since it is usually associated with higher intelligence. My son has autism NOT Asperger's yet I seem to be told all the time it must be Asperger's as he is so clever. It's like that's not so bad. IT'S NOT!'
	It's hard to understand the similarities/differences between Asperger's and autism	'Asperger's should continue to be a separately described condition from autism. We have 2 boys, one has Classic Autism with Complex, Profound and Multiple Learning Disability, the other has ADHD and Asperger's. Using ASD to describe them both is counterproductive because people don't understand the differences'.
		'I think there is confusion within the general public, and professionals, about how autism and Asperger's are related. Some believe the terms are interchangeable whilst others believe they are separate conditions'.
		'Our son has a diagnosis of ASD. It has been difficult to explain it to family members because there is such mixed information about the difference (if there is any) between Autism and Asperger's. Some information we have been given says that Asperger's is not autism and some says that it is a type of autism. Some says Asperger's is no longer used and the whole spectrum of conditions comes under ASD and some says ASD should not be used and it should be ASC. With the diagnosis of ASD we have been able to access extra support in school which a friend whose child has a diagnosis of Asperger's was not able to access. It would be great if everyone could agree!'
		'I am confused about the seeming interchangeability between Asperger's and high-functioning autism. My son is diagnosed as HFA but as he can speak well is often referred to as Asperger's although he has clear educational needs and will struggle to gain any qualifications'.

Table 5. (Continued)

Themes	Subtheme	Example quotes
Variability along the autism spectrum	People without a learning disability can still face significant challenges	'Having two children one with a definite diagnosis and one who more than likely has but not been able to get diagnosed that it is definitely not the case that my son who was diagnosed with high functioning autism/ Asperger's is of normal development. I believe the high functioning aspect is quite misleading'.
		'I personally feel the term high-functioning autism can be very misleading. People tend to want to relate to high intelligence and therefore in less need of support. When their support needs can in fact be just as large as someone in the spectrum who is not high functioning'.
		'High-functioning autism implies there are few difficulties. Some people without learning difficulties (even with degrees) can also need full time care'.
		'It needs to be more clear that individuals with autism without accompanying learning disabilities may still need a substantial amount of support with day-to-day living'.
	Autism affects every person differently but 'high' and 'low' terms too simplistic	'I do not like it all under the one umbrella of ASC as that plays down how big & diverse the disability is'.
		'One thing to keep emphasising is that everyone is a unique individual, so no two people are affected the same way by their autism'.
		'We cannot sensibly expect one single word "autism" to be the only word used to describe this hugely complex condition. Autism is far too diverse and its degree of impact on those who manifest its symptoms is enormously wide'.
		'The biggest issue as I see it with descriptions of ASD is that there is not enough emphasis on the fact that it's a SPECTRUM. People have preconceived notions about what it is to have autism and when a person doesn't "fit" their idea of autism, i.e. they make eye contact or are very socially motivated, professionals particularly do not accept it'.
		'Someone like my daughter who would be classified high-functioning by her language and speech is actually viewed by the professionals who are involved in her care as more at the level of classic autism due to her extreme emotional and social difficulties. I also find the idea of language being a definer of "function" out-dated and frankly quite arrogant'.
		'The single most important thing would be to get rid of the concept of high functioning/low functioning. It is demeaning and misleading. Autism is autism but some individuals have intellectual impairments as well. Those without are not necessarily less "autistic"'.
	People on the more 'severe' end of the spectrum are often overlooked	'While it is good to celebrate autism and to find positive ways of talking about it, there is concern from parents of the most severely disabled children that their high level of need could become lost in this process. As the parent of a young man who is very significantly affected by autism, learning disability and communication "impairment" (I don't like the word but it is very hard to find another), and who will never live an independent life, I share these concerns'.
		'As a full time carer for someone who is autistic & needs full time care, can't function independently & has a lot of problems, I sometimes get angry re the whole "spectrum" thing as it makes people think my son doesn't have as much to cope with as he does & diminishes his challenges'.
		'The media is focusing too much on people with Asperger'sand mostly ignored people who cannot speak, cannot advocate for themselves'.
		'The picture shown on media and TV only shows the talent for the more able not the classic cases of autism. My son will never be employed, drive a car, have a girlfriend, live independently'.
Different qualities of autism	Need to emphasise the positive aspects of autism	'I would like to see people with autism described in positive ways that value and celebrate their gifts and contributions and inclusion as equal citizens'.

(Continued)

Table 5. (Continued)

Themes	Subtheme	Example quotes
		'I feel that more coverage should be given to the inherent strengths that can accompany autism. I have two sons with Asperger's Syndrome and as a result of this their single mindedness and focus enables them to achieve in non-team sports e.g., sailing and scuba diving. This focus enables them to achieve things in life and does not disable them!'
		'Would like more emphasis on the positive aspects of autism, such as creativity, thinking differently'.
	The co-occurring difficulties complicate autism	'Sometimes autism, ASD etc. are not the only problem the child/person have to cope with. For example my son has Asperger's Syndrome, as well as ADD and Dyslexia. With having a few problems it's sometimes hard to explain what his problems and needs are'.
		'It's hard to know whether my son's developmental difficulties (especially communication) are as a result of his autism, an accompanying learning difficulty or both'.
		'The sensory side is too underplayed. Many of the problems people with autism face in the world are to do with their sensory issues and awareness of this needs to grow'.
	People think our children are naughty because they look 'normal'	'When children on the spectrum are having a tantrum they are often looked at by older people as "just a naughty child" and the parent is seen as not a good parent. I have been subjected to so many thoughtless comments over the years. We need to raise awareness about young children on the spectrum not just being naughty as it's a hidden disability'.
		'HFA needs far more understanding as it's not so visual. In most cases labelled as naughty, mischievous, or troublemakers'.
The way we describe autism depends on the context		'Maybe it's quite useful to have a range of descriptions, from professional to more domestic'.
		'I don't think the exact wording you use really matters, so long as you communicate whatever information is appropriate to the situation'.
		'I think in many ways it's important to remember that lots of ways of describing autism are useful because people experience it in different ways. I wouldn't like to see a situation develop where people are being told the way they talk about it is wrong, it's different for each group or family'.
		'The balance is hard to strike – you need to use different language when speaking to professionals than when speaking to friends or people who understand less'.

autistic adults and parents (albeit to a lesser extent) favoured disability-first terms (e.g. 'autistic' or 'autistic person'). This pattern of results was not wholly unexpected. Person-first language was initially championed to challenge medical and moral beliefs that define people by their disabilities, instead referring to them first as individuals and then to their disability, if necessary. In so doing, it focuses on people's abilities and distinguishes the person from the disability (Blaska, 1993; Feldman et al., 2002; Foreman, 2005). Researchers, educators, clinicians, other health professionals and the broader public have long been schooled in the philosophy and the desirability of person-first language and so it is not surprising that very similar explanations for the use of such language were given by the professionals in our study.

Our data suggested that the preferred terms used to describe oneself, one's child or the person one supports might be linked to one's relative distance from autism. That is, the closer one was to directly experiencing autism hour-to-hour, day-to-day, the more likely the community member endorsed the use of disability-first (rather than person-first) terms. It is possible that immediate experience of being autistic, and therefore of the positive and/or negative effects associated with autism and the ways in which others respond to those on the spectrum, might therefore influence the language that one uses. Indeed, many of our autistic adults suggested that the use of language that separates a person's autism from their identity not only undermines the positive characteristics of autism but also perpetuates the notion that autism is an inherently 'wrong' way of being. These sentiments echo previous work (Bagatell, 2010; Davidson and Henderson, 2010; Hurlburt and Chalmers, 2002) and reflect a growing movement among disability – and autistic – activists and scholars,

which argues vehemently against the use of person-first language. Rather, they suggest that language should be 'disability first' since the 'disability', and in this case, 'autism', is an all-encompassing part of a person's identity (Brown, 2011b; Kim, 2014; Robison, 2011).

Yet having immediate experience, at least as parents and family members, did not always lead to the adoption of disability-specific terms. On one hand, some parents and family members shared the beliefs of many autistic adults that autism is a central, positive aspect of their child's identity – and their family's identity (e.g. King et al., 2006) – that should be 'celebrated' rather than 'cured'. On the other hand, some parents felt that their children's autism was fundamentally distinct from their child. These diverging opinions may be attributable at least in part to the multiple roles parents play. Parents not only act as caregivers, they also act as advocates, therapists, practitioners, and as 'warrior-heroes' waging battle against social and political forces to gain medical and educational interventions for their children (Sousa, 2011: 220; see also Langan, 2011). These sometimes-competing roles (Silverman, 2011) may well shape their beliefs and language that they use. The lack of consensus among parents might also be due, in part, to the nature of their child's autism. Previous research has demonstrated that those families whose children have 'severe' forms of autism, often with co-occurring intellectual, mental health and other difficulties, report feeling more stress in their everyday lives (Hassall et al., 2005; Ingersoll and Hambrick, 2011). We did not ask parents to report on the nature of their child's autism, but future research in this area should aim to establish whether there is indeed a link between parents' preferred terms used to describe autism and the severity of their child's condition.

Opinion was also divided about the utility of the term and (once) diagnostic category, Asperger's syndrome (at least in DSM-5), although such division was observed just as often *within*-community groups as it was between groups. The decision to remove Asperger's syndrome as a distinct category from DSM-5 (APA, 2013) was a result both of the lack of consistent evidence demonstrating meaningful differences between Asperger's syndrome and so-called high-functioning autism (for a review, see Witwer and Lecavalier, 2008) and research showing that the diagnoses children received depended largely on where (i.e. in which clinic) they were diagnosed (Lord et al., 2012). Nevertheless, concerns were raised by some (Baron-Cohen, 2009) about the potential impact this removal might have on individuals who feel this as part of their identity. This appears to have been borne out. Some of our autistic respondents believed describing themselves as 'Aspies' or having Asperger's was an important part of their identity and felt disappointed about the diagnostic category being removed from DSM-5 (APA, 2013). Some family members and autistic respondents also highlighted

the potential value of the term, Asperger's syndrome, to describe a person who may need additional support in the absence of an intellectual disability or language delay. Some parents further expressed a preference for a diagnosis of Asperger's syndrome for their child as it is perceived to carry less social stigma (see also Calzada et al., 2012). Indeed, in an Australian survey study, parents and professionals reported an increased stigma associated with the label of autism compared with Asperger's syndrome (Kite et al., 2013).

Yet, this perspective was not universal. Some of our respondents from across community groups argued strongly against the continued use of the term Asperger's syndrome. They suggested that such a clinical or linguistic distinction might hamper the quest for a united autism community, instead creating a hierarchy by making a value judgement on the differences between autism and Asperger's syndrome. These sentiments chime with those of researchers, who have suggested that the unitary label of 'autism spectrum disorder' should serve to benefit *all* individuals who require support from service delivery within education, health and care systems (Grzadzinski et al., 2013; Mahjouri and Lord, 2012). Notwithstanding, researchers and clinicians have also highlighted the heterogeneity among individuals diagnosed, arguing for greater research designed to understanding the source(s) of that heterogeneity and its implications for diagnosis, interventions and services (Lai et al., 2013).

Unlike Asperger's syndrome, the terms 'low-functioning' and 'high-functioning' autism have never appeared in any diagnostic manual. Rather, they are colloquial conventions used to refer to an individual's intellectual or verbal ability and/or level of apparent social and everyday capabilities. Very few of the respondents in this study endorsed the term 'low-functioning autism' – a term that is usually conferred to those who have limited spoken language and have additional intellectual disabilities – because it makes assumptions about a person's potential (see Tables 3 to 5). Similarly, the term 'high-functioning autism' was also felt by many to be an unhelpful and misleading descriptive shortcut because it assumes that cognitively able individuals function well ('highly') in everyday life, which is not the case for some such individuals, who struggle to find and retain employment, to live independently and to sustain friendships and intimate relationships (e.g. Howlin et al., 2004). Others also emphasise that autistic intelligence, specifically the distribution of scores on verbal and non-verbal measures, is qualitatively different from non-autistic intelligence (Dawson et al., 2007) and conventions such as functioning-level descriptors are not sufficient to accurately represent an individual's ability. As suggested by our respondents, this term may even lead to society disabling these individuals even further by creating a false impression that they do not need additional support. Some researchers have eschewed the use of functioning-level

descriptors for these very reasons (Insel, 2011; Pellicano and Stears, 2011).

Another point of agreement across groups was a preference for terms that lead people to consider autism as part of natural diversity, rather than a deficit. Following the social model of disability, many autistic adults, professionals and family members noted the potentially disabling role society plays for people with autism. They explained that a person in a wheelchair is no longer disabled if the necessary structural accommodations are made to the built environment; similarly, an autistic person should also not be disabled if the necessary accommodations are made to match their cognitive style and specific needs. Rather than using value-laden terms such as 'disability', 'deficit' or 'disorder', which imply that any difficulties experienced by autistic people are a result of them being 'broken' in some way, their preference for the term 'diversity' is illustrative of a trend towards actively de-stigmatising autism (see also Ryan and Runswick-Cole, 2009). Some respondents, however, were divided (in their own minds) on whether autism should be conceived of, and described, as a 'difference'. They felt that there was a danger in construing autism solely as a difference in that it may impede access to the requisite services and supports (Baker, 2011). These respondents saw it necessary to adopt both medical and social models of disability for strategic means, ultimately ensuring that they, their children or those they support secure access to necessary services (Russell and Norwich, 2012). This promotes the suggestion that perhaps we should move towards an integrated biopsychosocial model of disability which echoes the recommendations outlined by the World Health Organization (WHO, 2001) in their International Classification of Functioning and Disability framework (ICF), a system that identifies an individual's health, care and service-related needs as well as the effect of the physical and social environment on the disadvantages that they experience in their lives. Little use of this approach has yet been made in autism (but see Bölte et al., 2014), but experiments in this direction might well be welcomed by a wide variety of respondents to our investigation.

This issue relates to another highlighted by our respondents – the importance of context. People experience autism in many different ways – personally, professionally or as a parent, relative or friend – and therefore in a variety of contexts and situations. Professionals in particular, but also parents and autistic adults, noted the need to describe autism in different ways depending on who one is speaking to and the context in which one is speaking. For example, how a professional describes autism when speaking to the parents of a newly diagnosed child might well differ to the way that an autistic adult will describe herself to someone online. It may also be the case that people might prefer to use one descriptor themselves and have others describe them in different ways (e.g. it is possible that someone will

refer to themselves as an 'Aspie' but desire their non-autistic teachers or work colleagues to call them something else). For these reasons, some disability researchers caution against an overly narrow, rigid and formal set of guidelines regarding the use of language, especially when such guidelines might restrict progressive dialogue relative to disability and to autism more specifically (Mackelprang, 2010). Instead, they advocate the use of terminology that is context specific, although informed by investigations such as this one. For example, disability-first language can be used to discuss autistic people and the autism community. Person-first language might be used in some contexts, especially in some healthcare contexts, or when speaking to parents.

On the basis of this investigation, we believe this kind of flexibility is suitable given the wide variety of preferences among those in the autism community. The fundamental finding of this research, after all, is that there are reasonable and rational disagreements between members of the autism community as to which terms should be used to describe autism. In some cases, these appear to have stemmed from key differences in beliefs about autism. In other cases, different terms were adopted despite sharing similar beliefs (e.g. of the desire to emphasise an individual's strengths or to vary one's language according to the context). It is also plausible to suggest that both beliefs and terminology will continue to change in complex ways across time. There is likely to remain, therefore, a wide and understandable plurality of perspectives when it comes to talking about autism for years to come, not as the result of any error or false perception but as the result of divergent experiences and ranging points of view. For those working with autistic people and their families and carers, therefore, making the right judgements about choosing which words to use at which time will remain a difficult task, requiring substantial degrees of care, introspection and practical wisdom. The overriding principle for those who are unclear about appropriate terminology should therefore be to inquire of the people with whom they are working or describing for clarification (Mackelprang and Salsgiver, 2009).

Adopting a person-centred approach has important implications for researchers, clinicians and practitioners alike. Autistic people (and their families) are often excluded from the decisions that affect their lives, leaving many feeling disenfranchised as a result (see Pellicano et al., 2014a, 2014b; Pellicano and Stears, 2011). Furthermore, the words or phrases people speak or write may well impact on society's perceptions of autistic people as well as the identity of the individual themselves (Blaska, 1993; Froschl et al., 1984; Zola, 1993). As a result, it is reasonable to suggest that researchers have both an ethical duty to deploy terminology that autistic people are comfortable with and a practical interest in doing so in order to maintain their own acceptability and legitimacy within the autism community.

The most compelling imperative for researchers, clinicians and practitioners is therefore to ensure that they have a clear understanding of the needs and preferences of individuals themselves and to learn how to listen effectively to autistic people and their families (see Pellicano et al., 2014a, 2014b; Pellicano and Stears, 2011).

One final point raised particularly by autistic adults related to the use of the term 'autism spectrum' – the term most favoured by all of our community groups. Lorna Wing (1975) coined this term to highlight the heterogeneity in behavioural features those diagnosed with autism. Yet, the term 'spectrum' also refers to the continuity between the general population and the clinical population. There is increasing empirical research that autistic-like traits are present to varying degree in the whole population (see Lai et al., 2013, for discussion). The notion that everybody in the population lies somewhere on the autism spectrum was, however, unpopular among our autistic respondents. They felt that this notion trivialises the very real difficulties and differences that those who are 'truly autistic' face and make it harder for their difficulties to be taken seriously or their differences to be recognised, a sentiment that is often reported in the media (see, for example, Wallace, 2014). While empirical research on autism as a (uni)dimensional trait may be useful in facilitating scientific discovery, describing autism straightforwardly in such a way is perceived to be unhelpful to those who are clinically diagnosed.

Conclusion

This large-scale study is the first to examine the terms that UK community members use to describe autism. The results are necessarily limited by the online, self-selecting nature of our recruitment method, which may have led to an over-representation of female respondents, especially autistic females (see Gilmour et al., 2012; Kapp et al., 2012 for similar results), and more able autistic respondents who are able to communicate themselves effectively. Nevertheless, the data clearly show that there is not one preferred term to describe autism. Rather, the terms used vary according to complex multiple factors, including people's beliefs about autism and the context in which they find themselves. Being attentive to how we use language to describe people, that is, 'being aware, for example, of how different words impact on different speech partners in different situations' (Lee, 1997: 448) – in the research laboratory, in the clinic, in schools and in the community – should go some way towards improving society's understanding of autism and the well-being of those on the autism spectrum.

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Notes

1. This methodological decision was taken following piloting with community members. The fact that the same person could place himself or herself into more than one group meant that the groups were not strictly independent and not straightforward to analyse statistically. The results are therefore presented in a descriptive format.
2. A total of 253 people responded 'other' to this question and specified their connection to autism. Of these respondents, 234 could easily be reassigned to one of the four stakeholder groups on the basis of their responses and were included in subsequent analyses.
3. Participants could select more than one option for this question. The number of responses therefore exceeds the number of participants.
4. The qualitative responses of 629 parents and 129 family members/friends were highly similar and were combined in the analysis for ease of interpretation.

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