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Abstract

The opposing positions of the social model of disability and the biomedical framework of impairment have created tensions regarding what constitutes ‘normality’. In this article, we drew upon focus group data of parents, professionals, and people with autism, to explore how the dilemmatic tensions of normality and abnormality and of disability and ability were managed. Our findings illustrated how the boundaries of normality in relation to autism are blurred, as well as how the autistic identity is fluid. The members of the focus group invoked their epistemic rights to assert their positions and delicately considered the limitations of the rhetoric of cure. Our findings have implications for professionals working with families of children with autism, specifically as they aim to maintain a balance between providing sufficient support and not being intrusive, and we show how a medical sociology can facilitate an understanding of autism as a social category.

Key words: Autism, disability, discourse, epistemic rights, normality

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Introduction

Autism is typically considered a life-long condition characterised by social and communication difficulties, as well as rigid thinking. Criteria for diagnosis continuously evolve, with recent changes made to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association 2013). While such changes have been instrumental in describing autism as a spectrum and diagnostic criteria published in diagnostic manuals are believed to be essential in determining its presence, there is no definitive test for autism and thus diagnosis is open to interpretation. The changing diagnostic criteria have however had an impact on what counts as autism; and while the prevalence of autism is not entirely known, there have been concerns of an epidemic. Arguably, these concerns have a sociological and cultural dimension as opposed to a true increase in prevalence (Eyal *et al.* 2008). Alternatively, some argue that the increase in prevalence may be due to the evolving diagnostic criteria and greater public awareness (Frith 1989). Nonetheless, in many nations, there have been international consequences because of the increased numbers of those diagnosed with autism (Bailey 2008).

Historically, much of the research surrounding autism has been focused on identifying aetiologies and generating therapeutic interventions (Nadesan 2005), with the characterization of autism often positioned in deficit-based perspectives (Broderick and Ne'eman 2008) and studied through positivistic methodologies (Glynne-Owen, 2010). As such, much of the research focused on autism has not drawn upon qualitative methodologies (Biklen *et al.* 2005). However, in more recent years, there has been a growing number of qualitative research studies focused on autism, as well as an emergent focus on identity construction in illness discourses (e.g., Sarangi 2007). Indeed, there is an expanding body of research that draws upon conversation analysis to examine the talk of people with autism (see, for instance, Dobbinson *et al.* 1998; Stribling *et al.* 2006; Wiklund 2012). Yet to date,

far less research has applied a discursive approach to the study of talk surrounding what counts as autism (for exceptions see, for example, Lester and Paulus 2012).

In this article, we report findings from a discourse analysis (DA) of the talk of stakeholders interested in autism. Our emergent research question was: what are the discursive resources that focus group members used to construct and negotiate the autistic identity? With personal commitments to considering how disabilities can be understood in relation to everyday discursive practices, we took up a DA perspective underpinned by social constructionism, which is a particularly useful approach for studying mental health conditions as psychiatric categories are produced through language (Harper 1995). Further, we recognized that a DA orientation allows us to offer counter-perspectives to the notion of autism as a static construct, as we explicitly point to how the meaning of autism is negotiated. In this study, we thus attended to how members went about making sense of what counts as ‘autism’, noting the ways in which epistemic rights were invoked when constructing an autistic identity.

Relevant Literature

Notably, the majority of the descriptions of autism are situated within a medical perspective. From such a medical perspective, people with autism are frequently constructed as isolated, disengaged from the world, and shackled by their abnormalities (Osteen 2008). These types of constructions have led to a view of people with autism as being “broken” and in need of “fixing” (Osteen 2008: 6), as well as “imprisoned” within their own bodies (Maurice 1993: 32). A critical problem with a medical perspective is that it casts individuals in a ‘sick’ role, positioning those with autism as requiring help until a cure is secured and implying dependency for the ‘mentally ill’ person who presumably cannot be cured (Wolfensberger 1972). Such a perspective results in mental illness being associated with a

deficit-based language use (O'Reilly, Taylor and Vostanis 2009) and individualistic views of disability.

While the medical view of mental illness remains pervasive, often those practicing in the field of health have adopted a more biopsychosocial viewpoint to account for some of the difficulties associated with medical ideology. This perspective is one that recognises the interplay between biological, social, and psychological factors in the context of illness (Stantrock 2007). However, many scholars still consider mental illness in terms of causation tied to the body. Thus, there has been a coexistence of ideas as opposed to a genuine integration, with the biomedical aspect of the model remaining dominant (Pilgram 2002).

There are however several perspectives that have provided alternatives. For example, there are a range of models challenging biomedical dominance, including the political model, the minority model, and the social model of disability. The social model of disability has been particularly influential and advocates that disabilities are constructed by and within society (Oliver 1996). Thomas (2004) pointed to the importance of distinguishing between impairment and disability, with disability positioned as relevant only when restrictions of activity are imposed by society on the individual with impairments. This orientation is reinforced by opinions within some members of the autistic community who argue that autism is not necessarily a disability, as both advantages and disadvantages are part of the condition. Such views challenge and critique conventional views of normalcy, and point to how concepts such as normalcy, abnormality, and disability were acquired historically and legitimised through the 'discourses of scientific rationalism' (Ramanathan 2010: 3).

Previous research has also shown how parents of children with autism use the construct of autism in their talk to explain away 'abnormal' behaviours and even position autism as a gift (Lester and Paulus 2012), highlighting how normality is not conceived of as an either/or category. Rather, it is a form of evaluation that involves measurements based on

socially-constructed averages and patterns of distribution (Sarangi 2001). Yet, it is the unification of a mental health category (e.g., autism), which sets the stage for a comparative framework that serves to reify the differences between normality and abnormality (Bilic and Georgaca 2007). Further, the public stories told about autism have produced “competing” and contested “truth claims” regarding what counts as a pathological identity and what might simply be a gifted difference (Avery 1999: 119). Thus, what comes to be ‘known’ or ‘counted’ as autism is up for negotiation, frequently being made evident in talk.

Methodology

We utilised a DA approach as developed by Potter and Wetherell (1987). DA is characterised as a commitment to studying talk and text in social practice, with a focus on language and rhetorical organisation (Potter 1997). We drew upon the concepts of interpretive repertoires and subject positions, giving particular attention to ideological dilemmas (Billig *et al.* 1988). More specifically, with interpretative repertoires described as “what everyone knows about a topic” and arising as people navigate competing arguments and ideological dilemmas (Reynolds and Wetherell 2003: 495), we viewed a focus on interpretive repertoires as analytically fruitful to a study exploring the negotiation of what counts as an autistic identity. Further, where relevant, we drew upon some of the basic principles of conversation analysis in terms of identifying the social actions in the talk (Sacks 1992).

Setting and Sample

Following approval from the University of Leicester Ethics Committee, focus groups were conducted with stakeholders. Participants were recruited from England from Paediatrics, General Practice, Psychiatry, Psychology, Mental Health Services, and autism charities. In total, 13 participants consented to participate, and typically represented more than one role (e.g., child psychiatrist and parent of a child with autism). Five of the

participants had at least one child diagnosed with autism, two had siblings diagnosed with autism, and one participant was diagnosed with autism. Two of the authors acted as moderators of the groups, facilitating the discussion and frequently contributing to the conversation. Table 1 provides details of the purposively collected sample.

INSERT TABLE 1 HERE

Data Collection

Three focus groups were conducted with the same group of participants across a six-month period to promote depth and meaning for analysis. Each focus group lasted approximately two hours and was audio-recorded in accordance with the preference of the participants. Each group had different foci, with the general aim of exploring: 1) diagnosis, 2) parental information needs, and 3) research needs surrounding autism.

Data Analysis

Data were transcribed using the Jefferson system (Jefferson 2004), as this aligned closely with the analytical approach of DA (see Appendix A for the transcription symbols). In our analysis, we attended to the micro-features of the talk (in relation to the larger discourses or interpretative repertoires surrounding autism) to explore how the autistic identity was constructed and dilemmas were managed.

Findings

1) Negotiating Boundaries between ‘Normal’ and ‘Autistic’

In everyday talk, much discourse is organized around dilemmas and involves arguing around them (Billig *et al.* 1988). Within the interpretive repertoire of normality and difference, a dilemma was identified regarding the exact nature of what constitutes a person with autism and where the boundary lies between ‘normal’ and ‘autistic’. The dilemma in this sense was that by assuming an autism identity this becomes synonymous with abnormal, but to deny autism means a denial of a fundamental characteristic of self. This is compounded

further by the dilemmatic tension that diagnostic criteria, lay perceptions, and cultural notions of autism contribute to the diversity of presentations of the condition.

Extract 1 illustrates well the ways in which parents of children with autism negotiated the lay perceptions often associated with autism.

Extract 1

- 1 Lou: Yeah the dif[ferent t[ypes of autism
- 2 Joy: [Yeah
- 3 Mandy: [Yeah
- 4 Lou: >Not that everyone's got a Rainman or <Einstein
- 5 Pete: That's right
- 6 Lou: Cuz that's people's per↑ceptions
- 7 Joanne: Either [Rain
- 8 Joy: [Ye[ah
- 9 Pete: [It is

(Focus group one)

The issue of different types of autism is acknowledged by Lou, as she directly made this claim (line 1). She negotiated the dilemmatic tension of the boundary of an autistic identity by positioning the lay perception of the condition as synonymous with figures such as “*Rainman or Einstein*” (line 4), which are arguably more desirable constructions. Drawing upon cultural repertoires of intelligence, Lou demonstrated that autism is commonly understood as a condition that can have intellectual advantages. This was further emphasized by drawing upon the representation of autism from the film *Rainman*, which provides a view of autism as involving social isolation, perseverative behaviours, and extraordinary human capacities. Lou oriented to the idea that not all children with autism can be understood in this way, locating this misconception within the layperson's perception of a child with autism as

having special abilities (lines 4 and 6). Thus ideologically such diagnosed children are both conceived of as abnormal and yet privileged, which in many cases is inappropriate.

Extract 2 further highlights the ways in which the ‘bounds’ of what counts as ‘normal’ versus ‘abnormal’ was navigated.

Extract 2

- 1 Pete: I think th::e (0.4) there is (.) one key difficulties here (.) which is (.) that need
 2 t’ be addressed and that’s the generalisation (0.4) issue, the fact that (.) um (.)
 3 different individuals ↑a::re (.) affected t’ different degrees in different realms
 4 different spheres at particular times (0.2) different times different >different
 5 different different< (0.4) an’ that’s (.) gonna be a key problem t’ settin’ up any
 6 (0.4) set (.) >sort of< (.) u::m material (.02) t’ be accessed by peo↓ple

(Focus group one)

Differentiating ‘normal’ from ‘abnormal’ in the context of autism is particularly complex, but forms the basis of the diagnostic process. The diagnostic boundaries for autism appear to be constantly under review, which reflects the contention regarding the nature of this condition. The presumed differences between individuals with autism and individuals without are located within blurred boundaries, creating difficulties for defining and even constructing the autistic identity. In Extract 2, this tension was considered by Pete who repetitively emphasises the point that each individual with autism is “*different*” (lines 4-5). This repertoire of difference was positioned as particularly important due to the impact that this has in practice “*settin’ up any...sort of...material*” (lines 5-6), that is, providing individuals with autism the needed support. Ultimately, despite the degree of difference amongst people with autism, Pete voiced a dilemma in constituting this boundary between ‘normal’ and ‘abnormal’, alongside this requirement for accessing material or information associated with the ‘abnormality’.

Extract 3 highlights the tensions negotiated related to differences between individuals with autism, with these differences positioned as problematic.

Extract 3

- 1 Ben: Is it important to recogni::se that erm (0.4) that it's a massive umbrella (0.2)
2 that's the problem we have
3 Pete: I'm sure [it is
4 Ben: [it's a massive umbrella an'
5 Joanne: Yeah
6 Ben: An' what (.) the thing is you're actually accounting (.) va::: stly different
7 individual::s
8 Joanne: Uhum
9 Ben: and trying t' categorise them as one group when actually they can be quite
10 different

(Focus group two)

In Extract 3, the boundary between normality and abnormality and the boundaries within these very boundaries is illustrated by Ben's categorization of autism as "*a massive umbrella*" (line 4). This presumed diversity was situated as a "*problem*" (line 2), as it positions the autistic identity as fluid, making the dichotomy of normality and abnormality unstable. What counts as 'abnormal' is open to question in this case, as categorisation is not a simple task. The "*problem*" was argued to be related to categorising children with autism "*as one group*" (line 9), which was positioned as impossible as they are "*different*" (line 10). Ben, who is both a psychiatrist and parent of a child with autism, positioned the problem as one that is pertinent to his role as a psychiatrist, using the personal pronoun "*we*" to refer to his professional activities (line 2).

The nature of autism, therefore, creates a complexity for defining the condition, particularly as the discourses of difference are negotiated between the participants. With no definitive and singular understanding of autism, negotiating the boundaries between what counts as ‘normal’ and ‘abnormal’ becomes difficult, as the socially constructed nature results in the identity being fluid.

2) Disability versus Ability

Within this interpretive repertoire of disability, a dilemma is documented regarding the ways in which autism is constructed as an ability or disability, and whether this abnormality/normality requires a cure or societal change. Thus, if autism is accepted as a disability, then there is an expectation for desirability of a cure (as sick people seek treatments). If, however, autism is accepted not to be a disability then fitting into a social world that is not evolved sufficiently to manage the ‘impairments’ becomes problematic as the accountability for not fitting in is removed. In other words, normal individuals need to conform to the boundaries constructed by society. This connects with the rhetoric of biomedical models versus social models of disability, as well as the notion that professionals are charged with ‘curing’ the ‘abnormal’ individual, not the ‘normal’ one.

Extract 4 highlights how three of the parents of children with autism negotiated the dilemma of constructing autism as a disability.

Extract 4

- | | | |
|---|--------|--|
| 1 | Pete: | <But it also leads into what was ↑just ↑said> an’ that’s >↑you know< (0.4) |
| 2 | | ↑autism itself I’m a great believer that ↑autism <u>itself</u> actually <u>isn’t</u> a |
| 3 | | disability in <u>any</u> way at a::ll (.) in fact there are many areas where I would |
| 4 | | argue that my autism >is a s↑trength< (.) um |
| 5 | Joy: | >Its other people’s ignorance< isn’t it? |
| 6 | Mandy: | >There is that< |

In Extract 4, Pete managed this dilemma against his perspective that it is not a disability, positioning it as “*a strength*” (line 4). Narrating from a personal perspective, Pete, who identified as being diagnosed with autism, oriented to the medical idea that autism is considered to be a disability and contradicted this by directly arguing that “↑*autism itself actually isn't a disability in any way at a::ll (.)*” (lines 2-3). This is especially prominent given that Pete had a stake and interest in the way he was positioned within the group (Potter 1996), with a direct consequence for his own subject positioning within it. Within this context, Pete had the task of managing the tension of having an autistic identity, “*my autism*” (line 4), against any potential ‘abnormal’ subject positions that the group may have imposed upon him.

The idea that autism is not a disability is a contentious stance to make (Nauert 2011), as historically autism has been located within a deficit framework. Pete, therefore, framed this perspective as a personal belief stating, “*I'm a great believer*”, and further upgraded this to a higher status using the word “*great*” (line 2). It can be particularly difficult to challenge personal claims, as challenging someone's personal experiences can be taken up as a face-threatening act (Goffman 1967). Within interactions, individuals have the option of positioning their identity or taking up subject positions offered by others (Davies and Harré 2001). In this case, if Pete took up autism as an abnormal/disabling condition, it risks him being positioned as abnormal/disabled in some way. This was something avoided by Joy's uptake of Pete's position, as she casted the negativity associated with autism as a disability onto “*other people's ignorance*” (line 5). The disabling aspects of autism, then, were seemingly located within society versus the individual who is identified as having autism.

In Extract 5, Pete further complicated the construction of autism, as he drew upon language commonly associated with its diagnosis.

Extract 5

- 1 Pete: So you have <the triad of impairments> (.) ↑why are they impairments?
2 They're only impairments if you put peo- give them (.) there is a no::rm
3 <outside of which we fall> (0.6) so I have an impairment (0.4) in >my
4 language and communication< but actually in my view .hh the impairment
5 isn't with me it's with you because I use language properly and correctly
- (Focus group two)

Here Pete took up the technical discourse of autism with “*the triad of impairments*” (line 1). The general diagnostic language in itself builds a version of autism as being constituted by impairments rather than as “*a strength*” (Extract 4). This produces a rhetorical dichotomy between normality and abnormality, bringing with it the assumption that autism is defined by impairments. Notably, the medical diagnosis influences what society perceives to be normal and provides the boundaries for treatment (Jutel 2009). It is this inherent assumption that created the ideological dilemma for Pete. He resisted this assumption and proffered that autism is constituted only by these impairments “*if you put peo- give them*”, arguing that impairments are defined by a social “*norm*” that those with autism fall “*outside of*” (lines 2-3).

Here Pete produced a distinction between two groups: those with and without autism, using the pronoun “*we*” to include himself in the first category (line 3). This distinction worked to position Pete as having an autistic identity, with the implication that he has a stake in how the autistic identity is constructed. Further, he repositioned the presumed impairments associated with him and other individuals with autism as not being inherent to people with autism, but located with others, stating: “*the impairment isn't with me it's with you*” (lines 4-5). He further resisted the autistic identity as being a deficit by claiming that he uses “*language properly and correctly*” (line 5).

While in Extracts 4 and 5 Pete negotiated autism as not being a disability or impairment, in Extract 6, however, Joanne actively disagreed with Pete.

Extract 6

- 1 Joanne: Well I'm sorry Pete >I kinda disagree< because (0.6) wouldn't you say that
2 (0.4) <some of th::e> the like from the <tr~~i~~age> of autism (0.2) >the
3 symptoms< (.) ↑a::re a symptom of the condition which is autism
4 Pete: ↑Right
5 Joanne: So it is a disability
6 Pete: No I don[']t see it (.) well
7 Joanne: [WELL I CAN ONLY look at it from my da::ughter's point o-
8 view (.) ↑she (.) <↑she can't handle noise> an' >stuff like that<

(Focus group two)

Disagreements by their nature are face-threatening (Goffman 1967). In her negotiation of autism as a disability, Joanne performed 'doing being cautious' by stating, "*I kinda disagree*" (line 1), with this social action functioning to soften the face-threatening action of disagreement. This was a particularly delicate endeavour given Pete's epistemic rights; although a person's epistemic status is not unchallengeable (Heritage 2012). Joanne moved to validate her perspective of autism being a disability with "*so it is a disability*" (line 5), invoking her own epistemic rights (and epistemic authority) as a parent by citing her "*daughter's point of view*" (lines 7-8). Interestingly, this validation of her perspective occurred as an interruption as Pete made an attempt to reassert his position with, "*No I don't see it (.) well*" (line 6), which was structured as a mitigated construction with a brief pause and "well".

Indeed, the argument about whether autism is a disability has implications for the diagnostic process and ongoing treatments, as it creates a tension between whether the

individual with autism needs to be fixed, cured, or left alone. Joanne's remark implied that autism is a condition that requires access to appropriate support. In recognising that autism is a disability, there is an impetus to seek treatments, which are evidence-based and require research. Thus there is clearly a dilemmatic aspect to this, as economic resources, entitlements to services, and help with behaviours or abnormalities are intrinsically tied to the diagnosis and particular labels being applied. If autism is not classified in such a way and is resisted, then there is a risk of failing to obtain the appropriate social and economic support; however, if accepted then there is a risk of exclusion and/or societal judgement and stigma.

In Extract 7, three of the participating parents further negotiated what counts as autism in relation to "research", as well as the often evoked rhetoric surrounding autism.

Extract 7

- 1 Lou: Because you get so much stuff peddled ↓that
- 2 Joy: ↓Yeah
- 3 Lou: You know we want prop↑er (.) good (0.4) proper research produced or
- 4 resea::rch that's ↑done (0.6) an' that can b::e (.) generalised to populations
- 5 not (0.2) >some little sub group here< o::r some (.) resea[rch institution
- 6 biased (0.4) [and I think parents stay =
- 7 Joy: [Yeah
- 8 Pete: [Well w- w- I I
- 9 think that
- 10 Lou: =vulnerable to a lot of these therapies (.) an' (.) people
- 11 Joy: >especially first on<
- 12 Lou: Yeah an[d trainin' things as things >think that medicine is safe< =
- 13 Pete [I I
- 14 Lou: = (.) that >will save their child< and recover them or fix them or whatever

In Extract 7, Lou illustrated the importance of “*good (0.4) proper resea::rch*” (line 3), which can inform families. She oriented to families with children with autism as “*vulnerable*” (line 10), with this vulnerability positioned in terms of families being misguided by believing that their child can be “*saved*”, “*fixed*”, or may “*recover*” (line 14). Recovery is a powerful construct, typically connected to hope, and is a notion that many parents draw upon (Broderick 2009). The use of the word “*vulnerable*” has associated discourses of exploitation, which is quite significant in this context. Historically, people with disabilities have often been oppressed (Oliver 1996), and looked upon as objects to pity (Siebers 2008). This rhetoric of a ‘cure’ potentially risks exploitation of families both financially and emotionally, which is bound up in the belief that “*medicine is safe*” (line 12). By framing autism in terms of “*medicine*” and “*cure*”, Lou oriented to how autism is generally positioned as an illness and implicitly critiques such a positioning.

In Extract 8, this rhetoric of cure was continued by Pete, as he positioned himself as not needing it.

Extract 8

- 1 Pete: ↑I'm sure there isn't a c:ure for autism >an' if there was< then I don't wan- it
2 anyway (.) I'm quite happy t' be autistic
3 (*Lines omitted*)
4 Mandy: I found that an interestin' comment ↑actually that (0.2) that you you said
5 you're happy with (0.2) your autism
6 Pete: Well I wouldn't want to be like you lot
7 Mandy: No
8 Pete: You've got to be ↑jokin' heh [heh heh heh heh heh
9 Ben: [heh heh heh h[eh heh heh

(Focus group two)

Here, Pete claimed that “*I’m quite happy t’ be autistic*” (line 2). This ‘happiness’ suggested a state of contentment, which normatively is considered to be contrary to feelings associated with being diagnosed with any form of disability. This claim was strengthened by Pete’s certainty that no cure exists for the condition, which Pete claimed he would not want “*anyway*” (line 2). Notably, Pete positioned this desire to remain identified as autistic in contrast with being like others, claiming: “*I wouldn’t want to be like you lot*” (line 6). This statement was treated with some delicacy (Jefferson 1984), being marked by laughter (lines 8-9). Nonetheless, the colloquial, “*you’ve got to be jokin’ heh heh*” marked with laughter (line 8), functioned to invite laughter from the co-participants and warranted a similar response from the recipients (Jefferson 1979).

3) Negotiating the Severity of Autism

Within the dilemma of what constitutes an autistic identity, there is a secondary dilemma regarding the severity of autism, creating a dilemma within a dilemma. Building upon the repertoire of difference, the participants negotiated levels of functioning that an individual with autism might achieve and considered the consequences of varied levels, which is illustrated well in Extract 9.

Extract 9

- | | | |
|---|---------|---|
| 1 | Lou: | I think because you are lookin’ at autism you are looking at the <u>whole</u> range |
| 2 | | so >a ↑fou::r year ol::d, with learnin’ <u>difficulties</u> < is goin’ t’ be very |
| 3 | | <u>different</u> to an <u>eleven</u> year old .hhh er::m (0.2) on the sort of more higher |
| 4 | | <u>functionin’</u> end of the spectrum and the |
| 5 | Joanne: | cuz you get a diagnosis <u>but</u> (0.4) <u>life</u> goes ↑on |
| 6 | Rani: | Yea::h |

(Focus group three)

The severity of autism has commonly been considered as being on a spectrum, which is something that Lou described in Extract 9 (line 4). By contrasting two hypothetical children, Lou illustrated that some children can fall at the “*higher functionin’ end of the spectrum*” (lines 3-4). This implied that children with autism can be located at an objective point along a spectrum. This biomedical orientation to the condition positioned these individuals as being located along a range, with some children being constructed as closer to ‘normal’ and others further away. Certain autism labels, particularly Asperger’s, have commonly been constructed as more desirable or higher functioning than others (Osteen 2008). As such, the more ‘severe’ the level of functioning, the more difficult it becomes to construct a ‘normal’ identity.

In most organisations that work with children with autism, families are required to provide a convincing argument in order to mobilise services. In order to access resources, parents often need to provide evidence that their child requires help. A dilemma is thus invoked, whereby parents have a stake in persuading professionals that their child’s problems are severe enough to deserve services, while at the same time minimising the difficulties to achieve as close to a ‘desirable’ normal family life as possible. This dilemma is highlighted in Extract 10.

Extract 10

- 1 Pete: Services are not good at children
- 2 Joy: Yeah
- 3 Pete: it disappears at transitions and then it completely falls off the maps when it
- 4 gets t’ adults
- 5 Mandy: Yeah
- 6 Pete: if you are functionin’ above a certain level

(Focus group one)

This dilemma was something that Pete oriented to by arguing that children who function at a higher level have more difficulty accessing services while they are children, with services disappearing by adulthood. Pete claimed that “*services are not good at children*” (line 1), noting that “*it disappears at transitions*” (line 3), and arguing that “*it completely falls off the maps when it gets t’ adults*” (lines 3-4). This created a dilemma of being ‘normal’, as the closer to ‘normal’ (higher functioning) the individual is the more likely s/he is to become invisible to services, which may be conceived as required to function in a society that is ‘ignorant’ of the condition. Yet, autism is a chronic condition, suggesting that an individual with autism will likely always need some level of support.

4) Negotiating authority and epistemic rights

Participants within the focus group managed being seen as an authority to speak within the focus group, as well as speaking as individuals who provide and require support. Many of the members sit on charity boards or take phone calls from distressed parents, thus affording them some level of expertise. Yet, they also have individuals with autism in their lives that require support and services. Knowledge, in general, is normatively and culturally linked to the categories of persons in varied ways. Particular categories of persons are oriented to as being entitled to know specific sorts of knowledge, with their reports on these particular things often being viewed as more credible (Potter 1996). Throughout the data, the focus group members shifted between varied categories, working up their epistemic rights and epistemic authority.

This created dilemmatic tensions in terms of three key questions. First, who has the right to determine what constitutes autism and what constitutes normality? Second, who has the right to help and inform parents about autism? Third, what counts as credible evidence? Within the context of the focus groups, most of the participating members had multiple subject positions and therefore could take up particular identities to authenticate the points

they made and yet this can create tensions as epistemic authority is negotiated and rights to knowledge constructed. Notably, speakers drew upon particular subject positions to demonstrate the authority of their claims and made reference to their own rights to speak on the issue, which is illustrated well in Extract 11 and 12.

Extract 11

- 1 Pete: I I I think it's very difficult (0.6) <to explain> (.) ↓autism autism spectrum
2 con↓ditions (.) without addressing the triad and the sensory issues
- 3 Joanne: B[y all means
- 4 Joy: [Oh[yes
- 5 Joanne: [pe[ople do that don't they
- 6 Pete: [I under[stand what you're sayin'
- 7 Joy: [they'r[e not >quite ready sometimes<
- 8 Pete: [I'm not sure >I mean< (0.2) I mean >I speak as
9 somebody with autism now< (0.2) that's a very woolly concept (.) let's jus'
10 chat about it as an overa::ll and then we'll start looking at the deta↓ils

(Focus group one)

Extract 12

- 1 Joanne: And if I can speak as a parent and someone who <provides support as well>
2 erm (0.6) I've been listenin' t' this and I find it <exciting> as well if I was
3 a parent (0.2) who had just had a diagnosis erm (0.2) rather than have >an'
4 I've heard these stories< (0.4) rather than have a pa::ediatrician or someone
5 from CAMHS give me a bibliography on a bit of pap↑er (0.4) and say ↑here
6 go and find these ↑books (0.4) if they said to me (0.6) this is a website
7 I think that would be absolutely ideal

(Focus group two)

Both Pete and Joanne invoked particular categories that entitled them to an expertise to talk about autism, with their position being more likely to be accepted as valid. Further, the subjective nature of their narratives made it difficult to challenge their claims and expertise.

In Extract 11, Pete began by making an assessment of autism by differentiating the general concept of autism with the details associated with the condition, noting “*the triad and the sensory issues*” (line 2). Assessments in the first position can serve as a resource for indexing epistemic rights (Heritage and Raymond 2005) and Pete deployed this first position by stating “>*I speak as somebody with autism now*<” (lines 8-9). By invoking his autistic identity, Pete moved to redirect the conversation of the focus group. He directed the group, setting up the agenda for what comes next “*let’s jus’ chat about it as an overa::ll and then we’ll start looking at the deta↓ils*” (lines 9-10), stopping the other members from talking about the details of autism. Pete’s subject position of having autism is a powerful construct for displaying his epistemic right to direct the conversation, and his personal and direct insight into the condition creates a situation whereby challenging or contesting that viewpoint is difficult. This was particularly pertinent given that it tends to be the case that when the speaker holds primary epistemic rights it is socially expected that these accounts will remain uncontested (Heritage and Raymond 2005). However, epistemic authority can be challenged and as we noted in Extract 6, these challenges did and can occur, albeit with some delicacy. Using first positions was a discursive strategy also employed by other members of the focus group.

It has been argued that people have an epistemic right to talk about their feelings, experiences and thoughts (Heritage 2013). Furthermore, the distribution of rights and responsibilities in terms of what participants can accountably know, how they know it, and whether they have the right to describe it is implicated in the organised practice of speaking (Heritage and Raymond 2005). This is evident in Extract 12 where Joanne positioned herself

as both a “*parent*” and “*someone who provides support as well*” (line 1). By employing two positions of epistemic authority, she was able to account for her rights to knowledge regarding the usefulness of web-based resources. Given the wealth of information available to parents globally about this condition, there are risks regarding the credibility and authenticity of that information. Additionally, the volume of information available can be overwhelming for some parents. Here, Joanne discussed this problem by evoking her expertise both personally and professionally to argue that web-based resources are more beneficial than a “*bibliography*” of books (line 5). The legitimacy of this knowledge claim is bound up within the performative nature of her account (Horton-Salway 2004), with her expertise as both parent and professional being employed as the basis for her claim.

Discussion

While the diagnosis of autism remains controversial, the evolution of the contemporary discussion of the condition has raised additional questions. In the early descriptions of autism, the condition had fairly clear boundaries (Kanner 1949), hence the lower frequency of diagnosis. Over time, there has been a growing consensus that autism should be described as a spectrum, thereby allowing for a broader range of ‘core’ symptoms that include notions of high functioning autism. As such, the biomedical discourses and changes in meaning have led to the boundaries of autism being blurred, alongside growing concerns about the increasing medicalization of society.

This has been complicated by the lack of definitive diagnostic tests, with professionals making subjective judgements regarding whether an individual requires diagnosis (Karim *et al.* 2014). While clinical practice is primarily guided by diagnostic mental health manuals, these manuals construct mental disorders against a benchmark of constructed normality, with professionals giving meaning to the disorders through ascertaining how similar or dissimilar an individual’s behaviours are to the criteria (Crowe

2000). This is particularly pertinent with the recent publication of the DSM-5. There have been significant concerns regarding the most recent manual's reliability and validity, particularly with its drive to increase the sensitivity of psychiatric diagnosis resulting in reduced specificity (Frances and Nardo 2013). This has led to a broadening of the inclusivity of diagnosis and a greater risk of over-diagnosis, with this risk also interrelated to societal resources and expectations. Consequently, concerns prevail regarding whether the "the pool of 'normality'" has shrunk "to a mere puddle" (Wykes and Callard 2010: 302).

Although a significant body of literature around autism exists, there is far less research focused on how the carers of people with autism perceive autism in the context of normality and abnormality. What is lacking in the literature are the broader explorations related to the meaning of the constructs of normality and abnormality, and ability and disability, as well as what these constructs mean for individuals with autism and their families (Broderick 2009). In this article, we focussed on how the dilemmas of normality and the autistic identity were negotiated. The constitution of the focus groups represented a range of different perspectives on the subject of autism. While most participants were either carers or siblings of individuals with autism, one member had a medical diagnosis of autism himself. Thus, despite the small number of participants, the broad range of differences within autism was well reflected.

What constituted the meaning and boundaries of normality was debated by the focus group members. With their narratives positioned against a backdrop of lay misconception, the participants worked to construct where the autistic identity lies on the 'spectrum' of normality to abnormality. In turn, this was negotiated against an additional dilemma of whether autism is constructed as normal in the sense of being an 'ability' against whether autism is constructed as abnormal and therefore a 'disability'. As autism was constructed as a life-long condition by the participants, the idea of a cure was treated with scepticism. This

rhetoric was further couched within a repertoire of severity, by which participants negotiated different meanings of normality/abnormality against the benchmark of the severity of the condition. This invoked discussions of differing characteristics and ‘symptoms’, which are important for fitting in against the expectations of society. By shifting the focus to exploring language and notions of embodiment in disabilities, it is possible to examine the consequences of impairments associated with autism, which impacts one’s ability to participate in social life (Solomon 2011).

Within the data, there were some differences constructed around children with autism regarding their age, level of functioning, and social impairments, with the differences within the condition being positioned as central to the perception of normality and abnormality. The different positions held by the speakers have the potential to impact those who feel entitled to speak about the condition. With much of autism research focused on the perspectives of a small group of individuals (i.e., ‘expert’ researchers), questions can be raised regarding who should shape the meaning(s) of autism, autism-related research, clinical practice and the activity of labelling behaviour ‘normal’ versus ‘abnormal’. The task of negotiating autistic/non-autistic identities is imbued with contradictions and is far more complicated than the binary construction of normal versus abnormal (Lester and Paulus 2012).

There is therefore clearly a challenge for those considered impaired living in a society that is politically, socially and economically structured to privilege those who act and speak in normative ways (Lester and Paulus 2012). There are expectations within society that individuals will conform to the ‘norm’ and these are postulated through various channels. Health policies are language in various ways and political channels dictate what and who can or cannot be supported, positioning and constraining how patients’ voices and experiences might be countered by those in medicine (Ramanathan 2010). Additionally, cultural ideologies are influential in shaping normalcy and in recognising the needs of people

with autism. For example, an appreciation of non-Western ideas regarding disability may offer greater inclusion for people with autism than Western medical models allow (Kapp 2011).

It may be helpful for professionals to remain reflective about the varied perspectives of individuals with autism and their families. Who can claim the epistemic rights in a local or national context is essential for shaping the future of care and our understanding of the broader issues surrounding autism. Such rights need to be extended across a broad cross-section of individuals with autism and their families to fully appreciate the context.

Appendix A

Jeffersonian Transcription Conventions

The transcription conventions utilized were developed by Jefferson (2004) and adapted for use within the context of this research study.

| Symbol | Explanation |
|---------------|---|
| (.) | A full stop inside a parenthesis denotes a micro pause. |
| (0.1) | A number inside of a parenthesis denotes a timed pause. |
| [] | Square brackets denote overlapping speech. |
| > < | Arrows surrounding talk in this direction denote that the pace of the speech has quickened. |
| < > | Arrows surrounding talk in this direction denote that the pace of the speech has slowed down. |
| () | A space between parentheses denotes that the words spoken were too unclear to transcribe. |
| (()) | Double parentheses appear with a description inserted, denoting some contextual information with no symbol of representation available. |
| <u>Under</u> | An underlined word or part of a word denotes a rise in volume or emphasis. |
| ↑ | An upward arrow indicates that there is a rise in intonation. |
| ↓ | A downward arrow indicates that there is a drop in intonation. |
| CAPITALS | Capital letters denote that something was said loudly or shouted. |
| = | Equal signs represent latched speech. |
| ::: | Colons represent elongated or stretched sound. |
| ¿ | An upside down question mark represents rising intonation that is weaker than that indicated by a question mark. |
| ? | A question mark indicates strongly rising terminal intonation. |

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Table 1: Pseudonyms for participants

| | | |
|-----------------------|---|---|
| Mandy Rane | Senior Lecturer in Psychology | Brother with autism |
| Ben Holt | Consultant Child and Adolescent Psychiatrist | Son with autism |
| Andreas Alverado | Senior Learning Designer | |
| Rose Etwall | Research Design Service representative | |
| Joy Heath, | Parent/Carer council representative | Son with autism |
| Joanne Cornish | Parent/Carer Council – Ex-Chair of her local branch, National Autistic Society | Daughter with autism |
| Meena Dutta | Child and Adolescent Mental Health Service Manager | |
| Eloise (Lou) McSorley | General Practitioner | Son with autism |
| Pete Saunders | Diagnosed Asperger's Syndrome, Chair of his local branch of the National Autistic Society | Autistic himself and 2 sons with autism |
| Rani Patel-Whyte | Patient Public Involvement research lead, | Brother with Asperger's |
| Farrah Taylor | Research Design Service representative | Researcher in autism |
| Gina Murray | Research Associate from Paediatrics | Paediatric researcher |
| Veronica Stanton | Research Assistant | Researcher in autism |