'They're told all the time they're different': how educators understand development of sense of self for autistic pupils

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Published version

HODGE, Nick, RICE, Emma J. and REIDY, Lisa (2019). 'They're told all the time they're different': how educators understand development of sense of self for autistic pupils. Disability and Society.

'They're told all the time they're different': how educators understand development of sense of self for autistic pupils

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This is the final post reviewer feedback version of the article that was accepted for publication by Disability & Society on March 9th 2018.

Abstract

School is a site of critical importance in the development of self yet little is known about the ways in which school affects how autistic pupils come to describe and evaluate themselves. Educators are centrally positioned to support autistic pupils with development of an empowered sense of self. This article reports on a study which captured how staff in four English schools understood development of sense of self for autistic pupils. We found that educators perceived autistic pupils as being affected by both a particular biology and their social encounters with others. Our participants identified the school environment as a significant influencer on sense of self development but seemed uncertain how to make this more enabling. We suggest that one response could be to develop a framework of activism engagement in schools that might enable autistic pupils to work collectively with other autistic people towards a positive sense of self.

Points of Interest:

- stigmatisation and social rejection can make autistic people feel they are alien and unworthy
- school has powerful affects on how autistic pupils think and feel about themselves but we know very little about what educators (people who work in schools) know about this

- we asked educators about how they think school affects how autistic pupils view themselves
- the educators perceived autistic pupils' views of themselves as being affected both by autism and how other people relate to them
- the pressure of trying to make the self appear 'normal' can be overwhelming for some autistic pupils but these educators seemed unsure how best to support them
- we suggest that it might help some autistic pupils to view themselves more positively if educators enable them to have more contact with other autistic people
- we provide suggestions on how this could happen but we need to know what autistic people think about these

Introduction

The high levels of anxiety and depression experienced by autistic people and the effects of these on well-being are of international concern (Mazzone et al. 2013; Nah et al. 2017; Van Steensel, Bögels and Perrin 2011). This may result in part from the pressures put upon autistic young people when they have to manage inflexible social, physical and economical environments (Danker, Strnadová and Cumming 2016; Humphrey and Lewis 2008). For example, autistic young people may feel overwhelmed by sensory environments (Kern et al. 2006; Howe and Stagg 2016) and experience social isolation through exclusion from peer groups and/or bullying (Hebron and Humphrey 2014; Hodge and Runswick-Cole 2013). Autistic people find themselves framed as disordered, abnormal and/ or different through the pathologising language and practices of diagnosis (McGuire, 2016, 2017; Shyman 2016); a process which can result in a reduction of the self, by others, to a diagnostic category rather than being recognised, permitted and valued as a person (Hodge 2016; Shakespeare 2006). In England, as in many other counties within the Global North, educators are under continual

pressure to meet Government attainment targets whilst managing reducing budgets. One effect of this is that autistic pupils can then be positioned as a resource burden and potential threat to overall school performance (Ambitious about Autism 2014; Ball 2013; Hodge 2016; Paget et al. 2018). Post school, autistic pupils also anticipate an uncertain future, with limited opportunities for work and independence (Hedley et al. 2017). The relentless need to negotiate the disabling barriers within educational environments places additional demands on disabled learners that deplete physical and emotional resources and erode the capacity for resilience (Hannam-Swain 2018). Growing up, disabled people, consciously and unconsciously, internalise the messages contained within oppressive attitudes and practices that are prevalent and insidious within society and may come to think of themselves as 'the problem' rather than locating the barriers that limit and constrain them within societal structures and systems (Mason 1990; Morris 1991; Reeve 2004). This can then result in the perception of the self as pathologised, alien and unworthy (Hodge and Rutten 2017; Reeve 2000). The pressures on the developing self for autistic children and young people are, therefore, myriad and well documented.

The self, and a sense of that self, has been constructed in a variety of ways across historical periods through philosophical, scientific and psychological disciplines (Harter, 2012). Within sense of self and autism research literature, sense of self is predominantly defined within psychological disciplines (Farley, Lopez and Saunders 2010; Hobson 1990; Jackson, Skirrow and Hare 2012; Lee and Hobson 1998). These construct sense of self as developmental and formed through life experience (Hart and Damon 1988; Epstein 1973; Guardo 1968). The descriptive self-concept, which answers the question of 'who am I', is argued to be built upon embodied (physical), interpersonal (social) and internal representations of the self (memories and beliefs) (Hart and Damon 1988; Hobson 1990;

Neisser 1988; Rice forthcoming; Zahavi 2010). Alongside this descriptive self-concept, it is claimed that self-esteem acts as an evaluator of the self (Bosacki 2000; Harter 2012; Jordan and Powell 1995). Through this affective component, personal worth is assessed, resulting in either a positive or negatively valenced sense of self. It is suggested that this is an evaluation heavily influenced by interpersonal relationships and the appraisal we sense from others (Harter 2012, 2015). How we define sense of self here, therefore, incorporates both how people might describe themselves and the value that they attribute to who and how they are as a person. Whilst we acknowledge the varying constructions and definitions of sense of self, we actively sought not to present a 'set' definition to the educators in our study. Instead, we wanted to take an inductive approach, allowing the meanings that educators make of this seemingly nebulous concept to come to the fore.

School has long been recognised as a critical site of development for the self (Harter 2012; Sylva 1994). It is surprising, therefore, and of concern, that we currently know very little about how staff in schools conceptualise and respond to the notion of self in relation to autistic pupils and the challenges to identity formation and self-esteem that they encounter. 'Autistic self' is a term found within the research literature that is used to represent what is claimed to be an essentially and fundamentally different type of self from the non-autistic self (Lombardo and Baron-Cohen 2010; Coleman-Fountain 2017). We are troubled by this concept as we feel to apply a division, between autistic and non-autistic people, threatens to nullify the rich and complex variety of ways of being human. As Goodley (2016, 152) states, 'One's humanity becomes known in terms of an essentialist understanding of personhood that risks knowing that person solely in terms of a neurological label'. However, we also recognise that for some autistic people the autistic self is a critical component of their identity (Woods et al. 2018).We resist, therefore, claiming or disavowing the notion of the autistic

self. Rather we engage with the idea of the autistic self as a cultural artefact which carries a range of meanings (Runswick-Cole, Mallett and Timimi 2016). How the user conceives of, and relates to, the notion of the autistic self is critical as it shapes how autistic people are then engaged with. The construction of the autistic self is, therefore, a vital concept and the lack of attention paid to it within research is of concern. Thus, we offer here an overdue and much needed contribution to education literature and practice through an investigation of what educators, in four English schools, of varied designation, understand by the concept of self in relation to autistic pupils. We also provide an illustration of what we claim is a Critical Autism Studies inquiry, offering an early contribution to the debate on what such an inquiry might look like and what might constitute the essential characteristics of its form (Woods et al. 2018).

Critical Autism Studies

Orsini and Davidson (2013, 12) identify three elements that are essential components of any study that is conducted within the emergent paradigm of Critical Autism Studies (CAS). Researchers must demonstrate:

(1) Careful attention to the ways in which power relations shape the field of autism.

(2) Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy and popular culture.

(3) Commitment to develop new analytical frameworks using inclusive and nonreductive methodological and theoretical approaches to study the nature and culture of autism.

We sought, therefore, to identify examples of how power operates within the structure, systems and practices of schools. We wanted to know: who decides for autistic pupils how the self can be constructed, which performances of self are rewarded or disavowed, and to

what extent educators feel autistic pupils are enabled to exercise agency within these processes. We sought to highlight the particular cultural constructs of autism that prove to be reductive and disabling for autistic pupils. Correspondingly, we also searched for manifestations of ways of knowing autism within schools that educators identified as more enabling and empowering, in the sense of supporting autistic pupils with feeling known, legitimate, accepted and valued. It was also important to us to capture the breadth of expression and the infinite possibilities of being for autistic people. Woods et al. (2018) add an emancipatory dimension to the definition of CAS, calling for the inclusion of paid autistic researchers within CAS inquiries. This particular study does not meet that requirement. We regret now that we did not create opportunities for autistic people to inform the design of and/or execution of the inquiry. We are, however, working to maximise the involvement of autistic people in the critique and development of the framework of activism engagement that we propose later in this paper. One of the authors is also currently engaged in a participatory inquiry with autistic pupils to capture how they feel school impacts on their sense of self. This will complement the findings of the study with educators that we are reporting on here.

The Research Context

We began our inquiry with a review of the research literature to identify the current discourses around the construction of self in relation to autism within which educators operate, and to establish what these reveal about how self for autistic people is constructed epistemologically, ontologically and axioliogically. We identified relevant literature through utilising search terms that included ‘self-identity and autism’, ‘self-concept and autism’, and ‘self-esteem and autism’ across all of the major educational and scientific information databases.

The review revealed that the majority of previous research was conducted within the quantitative paradigm and positioned autistic people as the to- be-explored 'other' with a focus on identifying and accounting for abnormal sense of self development (e.g. Farley, Lopez and Saunders 2010; Jackson, Skirrow and Hare 2012; Lee and Hobson 1998). The majority of research studies into the self are located within the disciplines of psychology and neuroscience with very few studies emerging from education. The general pattern of findings presents autistic people as demonstrating an intact physical self-awareness, in the sense of them identifying themselves as distinct beings, but as differing from non-autistic people through 'abnormal' development of the psychological and social self. For example, in some constructions of the self it is argued that development of the self for autistic people is less influenced by social relationships than for their non-autistic counterparts (Jackson, Skirrow and Hare 2012; Lee and Hobson 1998). In contrast to the majority of studies on atypical development, there is also a limited number of more humanist informed inquiries that focus on the experience of the self; for example, agency within the development and acknowledgement of the self and negotiating 'coming out' as autistic (Baines 2012; Davidson and Henderson 2010; Humphrey and Lewis 2008).

The individual model of disability, as defined below, has long been the dominant paradigm within health, social and education services (Fisher and Goodley 2007; Shyman 2016). Many interventions designed for autistic children are aimed at "normalising" the self through a reduction in the behaviours through which autism is revealed (Broderick 2010; Shyman 2016). Within this paradigm, the potential for an empowered and celebratory self appears not even to be anticipated for autistic people. In addition, the impact of the school environment, attitudes and practices, on the development and experience of autistic pupils, remains significantly under researched (Osborne and Reed 2011). This is regrettable, for the school

environment does have an impact on the formation and conduct of the self for autistic pupils. For example, environments that are experienced as overwhelming for the senses lead autistic pupils to avoid spaces where their peers socialise. Additionally, some reactions of non-autistic peers to the sensory experiences of autistic pupils can exacerbate feelings of negative difference and feeling lesser (Williams, Gleeson and Jones 2017). This can lead to masking by autistic pupils, who suppress any visible responses which mark them out as 'different' as they seek to gain social capital through ‘passing’ as non-autistic (Baldwin and Costley 2016; Carrington and Graham 2001; Williams, Gleeson and Jones 2017). The experience of being perceived and positioned as undesirably 'different' can result in disabled bodies ‘dys-appearing’ (Leder 1990, 69). This term captures how the ‘taken-for-grantedness’ (Toombs, 1995, 9) of the body is lost as autistic pupils become hyperaware of every sign of impairment that communicates difference (Frank 1998; Martin 1994; Toombs 1995). The effort required by autistic pupils to regulate and control themselves, putting on a ‘façade’ of ‘being normal’, is experienced as ‘exhausting’ (Pellicano, Dinsmore and Charman 2014, 763). Additionally, there is the regulation of the self that autistic children and young people experience from external interventions. These usually subject children and young people to ‘explicit training’ of the self which is held to be disordered and the source of social isolation, anxiety and depression (Shyman 2016; Williams White, Keonig and Scahill 2007). Therefore, whilst educators might be expected to be well placed to support autistic pupils in recognising that the disabling barriers they encounter are often located in the system, rather than themselves, current approaches within educational support focus instead on locating and addressing the ‘problem’ within the autistic pupils themselves (Osborne and Reed 2011). Educators can play a substantial role in countering the negative effects on the development of the self through building resilience, communicating value and developing a positive sense of self in pupils that will enhance well-being (Roffey 2015). It is disappointing, therefore, that to date there

has been very little research into how staff in schools conceptualise and understand ‘sense of self’ in relation to autism and to what extent they feel equipped to support autistic pupils with responding to the assaults upon the self that are experienced within school.

Research Design

Qualitative research that is available, into how autistic pupils make sense of themselves within the school setting, has focused largely on mainstream secondary schooling (Williams, Gleeson and Jones 2017). Our research, however, included educators from a range of provision, both specialist and mainstream (i.e. typical, non-special school) primary and secondary. The research team included four academics from Sheffield Hallam University and four school practitioners. School staff assumed the role of co-researchers on this project, collaborating with academics in developing research questions and the interview schedule, coordinating the focus groups and interpreting data. The intent of the inquiry was to provide empirical qualitative data on the following concerns:

(1) how educators understand the concept ‘sense of self’ and the meanings this has for them in relation to autism

(2) what they identify as the ways in which school impacts on the development of a sense of self in autistic pupils

(3) how schools support and nurture a developing sense of self for autistic pupils.

A submission for ethical approval was reviewed and agreed by Sheffield Hallam University Research Ethics Committee.

Participants

Four schools participated in the study. These schools were selected to reflect variance in the ages of pupils and type of educational provision. Schools involved included: one mainstream

primary (7-11 years) with an integrated resource[1] ; a mainstream (non-special) secondary (11-16 years) with autistic pupils on a full mainstream timetable; one special primary (4-11 years) and one special secondary (11-19 years).[2] One member of staff from each school acted as a co-researcher. In this role they helped to recruit staff from the school for a one-hour focus group that was then facilitated by the school researcher and their partner university researcher. The number of focus group participants per school and the nature of their role are detailed in table 1 below:

Table 1:

Focus Group Participant Composition by Job Role and School Type

Job Role	Mainstream Secondary	Mainstream Primary Integrated Resource	Special Primary	Special Secondary	Total per role
Special Educational Needs Co-ordinator/Support Officer	3	1			4
Senior Leadership Team		1	1		2
Safeguarding Team				2	2
Speech and Language Team			1		1
Integrated Resource Lead		1			1
Class Teacher	1		3	2	6
Teaching assistant/ support staff	1	2		6	7
Total per school	5	5	5	10	

[1] In England an integrated resource is a name given for a unit within a mainstream (non-special/ 'regular') school that provides a base for children with special educational needs and disabilities. Pupils can then access mainstream provision outside of the base but the time allocated for this varies per pupil

[2] Special schools cater for pupils with special educational needs through a high specialist staff to student ratio and specialist curricula and resources, supporting those autistic pupils for whom mainstream provision continues to remain inaccessible (Bowen and Ellis 2015).

Methods

A semi-structured discussion schedule was devised to be used across the focus groups. This supported us with making sure that we covered the aspects that we had agreed were important whilst also leaving space to be surprised (Newby, 2014). We wanted to conduct the focus groups within a state of wonder in which we did not assume the meanings that the term sense of self would have for participants and remained alert to unexpected revelations (Van Manen 2016; Titchkosky 2011). The different constructions of the self and the challenges reported by autistic people that emerged from our review of the literature, and our own experiences as practitioners and autism researchers, informed the schedule of discussion. The broad areas of focus were:

- what 'sense of self' meant to these educators and how they conceptualised this notion in relation to autistic pupils
- what they perceived to be the factors that impact upon sense of self for autistic pupils
- what they did to support and nurture a developing sense of self for autistic pupils.

A guide was developed of seven questions related to the areas of focus that were to be asked of each group. For example, the first question related to conceptualisations of the self: What does the concept of a sense of self mean to you in relation to pupils with autism? The second addressed the factors that were understood to affect sense of self: What issues do you feel pupils with autism have in relation to development of a sense of self? Are these different to pupils without autism?

Each focus group interview was then transcribed in full in preparation for the analysis stage of the research process.

Analysis

Within the analysis, initial codes were generated from transcribed data by each research partnership, formed of the educator co-researcher and an academic lead. Following an inductive, data-driven approach, each research partnership reviewed their transcripts to identify the units of meaning that conveyed an important message of interest to them about the topic (Braun and Clarke 2006). We did not define 'important' beyond anything that the research partnerships thought had something significant to convey about how educators understood sense of self in relation to autistic pupils and how they negotiated this within their practice. As we immersed ourselves in the data, within a CAS sensibility, it became apparent that we could not 'read' the transcripts without categorising statements into representations of models of disability. When collating initial codes into basic themes, these models of disability (see below) emerged as thematic organisers (Attride-Stirling 2001). These proved useful in capturing and conveying the critical meanings that educators make of development of sense of self for autistic pupils and what these reveal about the role of the nature and culture of school in constructing a sense of self. Within the process of the analysis, the writing of this paper also played a critical role. Van Manen (2014, 20) states that '(t)o write is to reflect; to write is to research.' As we write, we remain in conversation with our data and new meanings continue to reveal themselves within the hesitancies of our text. In this way, the act of writing has become a vital part of the iterative process through which the meanings of the participants are revealed.

Models of Disability

The essence and nature of disability are fiercely contested. However, our experience of working for and with school staff and other practitioners is that many of them are unfamiliar with theorisations of disability and so only conceive of disability as located within bodies in

need of correction, rather than residing in societal structures and systems (Shakespeare, Lezzonl and Groce 2009; Vaz et al. 2015). It is important to us that the concepts that inform our analysis and argument within this paper are accessible to those readers who are working in schools and other services; therefore, we rehearse here some of the key concepts that inform the development of the two most discussed theories of disability: the individual (medical) model of disability and the social model of disability.

It is the individual model that dominates practice within health, social care and education (Barnes 1990; Beresford, Nettle and Perring 2010; Goodley 2011; Oliver 1990). This model locates the 'problem' of disability within the individual: the impaired body is conceived of as abnormal, disordered and in need of repair in order to appear and function as 'normally' as possible (Goodley 1997; Shyman 2016). In this model, experiences, such as exclusion from social spaces, rejection by employers, isolation and dependence, are held to be the inevitable results of impaired bodies. The onus for adaptation and change is then placed upon these impaired bodies rather than on the environments that impede and exclude them. In the context of schools therefore, any difficulties that pupils experience with access to buildings or activities, progress with learning, issues with behaviour or the making of friendships and belonging are considered to be the natural outcomes of conditions such as autism and beyond, therefore, the realm of educator influence. Educators are then relieved from the responsibility of reflecting on and developing their own practice to identify and address the organisational and attitudinal barriers that impede learning.

In the 1970s disabled people's organisations and disabled academics worked together to reject this individual model and produce a radical reconceptualisation of disability: the social model of disability (Oliver 1990). In this model, responsibility for disability moved away

from the individual with a particular impairment and onto the physical, social, cultural and economic systems and structures that diminish, marginalise and exclude all disabled people. In this model, disability is not located within the disabled person. Instead, it is to be found in the acts of oppression inflicted upon them (Barnes 1991; Goodley 2014; Oliver 1990; Shakespeare 2006). More recently, the social model of disability has been the subject of a number of critiques. One of the most significant of these has been the argument that the model does not allow space for discussion on the physical effects of impairment and what it means for people to live with impaired bodies (Reeve 2004; Thomas 2004). Certainly, it is important to develop knowledge and understanding of impairment effects so that organisations such as schools can adapt their environments and practices to accommodate those. However, there is then a danger that educators will continue to attribute lack of attainment or reduced pupil well-being to the inevitable outcome of living with an impaired body rather than reflecting on the role of the school within this process. One advantage of working within the social model of disability is that this compels educators to search for the reasons why a pupil with an impairment is not learning within school culture and the current practices of teaching and educational support, rather than within the child. In addition to models of disability, we also used Ableism within this inquiry as a theoretical construct to support us in accessing, and placing within context, educators' understandings of the self in relation to autism.

Ableism

Campbell (2001, 44) defines ableism as:

> a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the

perfect species-typical and therefore essential and fully human.

Disability is then cast as a diminished state of being human.

For Levi (2005, 1) ‘Ableism describes prejudicial attitudes and discriminatory behaviors towards persons with a disability’ that ‘promote unequal treatment of people because of apparent or assumed physical, mental, or behavioral differences’ (Terry 1996, 4-5). Hehir (2002) illustrates how ableism reveals itself in education through the examples of how the ability to walk is privileged above rolling, the act of speaking above signing and the reading of print above braille.

We examined the data to find examples of ableism in practice within schools. We wanted to know through which school structures, systems and processes educators perceive the self becoming felt as diminished by autistic pupils; whether, and if so how, these practices are resisted by pupils and/ or educators and whether more enabling and empowering ways of engagement with autism are able to emerge. Application of this analytical framework led to the emergence of the themes to be discussed here: understanding autism; resistance; and regulation of the self.

Understanding Autism

Orsini and Davidson (2013, 7) argue that we need to reflect on what sense we make ‘of the multiple and sometimes deeply contradictory depictions of autism’. However, many practitioners are not aware of other ways of knowing disability and autism to support such a reflection. As a result, the dominant individual model discourse that constructs autism as an undesirable pathology is generally left undisturbed (Nadesan 2005; Runswick-Cole 2016; Vaz et al. 2015). McGuire (2016, 7) identifies this as ‘the common, taken-for-granted

understanding of autism as, simply, a naturally occurring unnatural (pathological) biological disorder'. Certainly, some of these educators understood autism to be biological in nature. One participant described it as a form of illness but one so serious that you cannot get better from it:

'They're not a pupil that's got a cold and they're going to get better, they're a person that's got autism, it's going to be there' (Focus Group Participant (FGP) mainstream secondary).

The participants reported that some pupils also came to understand autism as a biological 'truth' that has determined their being. Identities can become constructed around medicalised diagnostic labels (Hughes 2009; Ortega 2013). These participants identified this process as potentially enabling and/or disabling for pupils dependent upon whether pupils actively claimed and celebrated being an autistic person or internalised the dominant cultural messages of autism as a regrettable disorder. Participants perceived that for some pupils, identification with the diagnostic category can become all-consuming and then every experience becomes framed by them, and others, as essentially different; the impairment category comes to define every aspect of their being (Shakespeare 2006):

'(They) believe everything is to do with the Asperger's rather than actually everybody feels upset sometimes' (FGP integrated resource junior school).

Whilst some participants challenged the attribution of personhood to a particular impairment category, for others, every behaviour was a manifestation of autism. Ableism was revealed through how the changes of interests and hobbies as autistic pupils matured, something that might be considered typical for non-autistic pupils, were pathologised and represented as impairment effects:

‘And what they were passionate about yesterday, tomorrow they might not give a damn about, you just don't know. It should be called contrary-ism, never mind autism’ (FGP mainstream secondary).

Awareness that others perceive of them as primarily an embodiment of a specific impairment category can result in autistic children and young people constructing their identity through a ‘reductionist, biologized discourse….’ (Brownlow and O'Dell 2013, 103) in which being autistic means essentially different from non-autistic. This was evidenced in our study through participants, reporting that some autistic pupils conceived of themselves as having a distinct and different neurology:

‘Also, some children will say, "You know I'm different don't you?... My brain is wired differently"' (FGP special secondary).

Whilst they did not articulate it within the construct of models of disability, we suggest that some educators could be said to be rejecting what we would term as an individual model, essentialist conceptualisation of a disordered self in favour of a social model of disability perspective, with a focus on the contribution discourse and social relationships can make to how autism is understood and experienced. Participants then conceived of the self as being developed through interaction with others rather than as a definite and uncontested biological reality:

‘It's learnt through social interaction, they're told all the time they're different or they can't do this or they're going to a SEN (Special Educational Needs) school rather than a mainstream, so it's learnt and then they see themselves as being different’ (FGP special secondary).

Early and iterative othering has long lasting and disabling effects on formation of the self (Brownlow 2010; Coleman-Fountain 2017; Russell 2016; Taylor, Hume and Welsh 2010). Autistic children and young people may come to conceive of themselves as being an essentially different, disordered and lesser self (Coleman-Fountain 2017; Cooper, Smith and Russell 2017; McCauley et al. 2017). Notions of other like this were left largely unchallenged by the participants who tended to accept the concept of the 'autistic self' within an individual model binary of autistic and non-autistic beings. Participant talk represented this division through the use of terms such as ‘us’ (to mean non-autistic people) and ‘them’ (autistic people) and through reference to non-autistic people as ‘normal’ and ‘neurotypical’. Whilst our framework of analysis positions the participants generally working within the individual model of disability that does not mean that they accepted such precepts whole heartedly. The participants were concerned, for example, that being othered from the 'norm' was experienced by some autistic pupils as a painful and disabling process. The participants challenged ableist practices of segregation which they felt could result in low self-esteem for some pupils as they become placed outside of normal:

‘If they've been in a mainstream primary they get separated straightaway and told they are very different and they are special, and they need different, and it's true but I think it also probably gives them that sense of self of themselves that "I have to be removed from everyone else"’ (FGP special secondary).

But even if they recognised the effects of ableism, the participants appeared to have little access to modes of resisting these disabling practices. Theirs was a more felt than articulated and critiqued sense of how ableism impacts upon development of the self. However, the participants did identify that pupils and parents/carers have established ways of resisting some of the practices of ableism.

Resistance

Participants interpreted pupils as demonstrating a number of strategies for resisting the disabling effects of being categorised as essentially different, although not all these have an enabling effect on a sense of self. Some pupils, for example, counter the negative conceptualisations of autism that they perceive as held by others through actively disavowing the identity of autistic:

‘He's like "well why am I here? I don't know why I'm at this school with all of these" and he sees himself as separate’ (FGP special primary).

Some participants perceived of these acts of resistance, to being labelled and positioned as other, as detrimental to the well-being of pupils. They were interpreted as expressions of a denial and suppression of a pupil's sense of self as an autistic person. For these participants, knowing about your diagnosis and identifying as autistic was seen as critical for pupil well-being. It was felt that this should happen as soon as ‘difference’ was confirmed through diagnosis. A child could then be supported with recognising and embracing their autistic nature:

‘The earlier they're diagnosed, given the information, the interventions are put in place, I believe the easier their life becomes because they're brought up to accept it’ (FGP mainstream secondary).

In some cases, parents were perceived of as working against this necessary process through their own resistance to the labelling of their child as autistic. Parents find themselves caught within a dilemma as they cannot support their children with claiming and celebrating an autistic identity without simultaneously moving them into a category of being that is

‘synonymous with abnormal’ and which might then result in social marginalisation and stigma (Lester, Karim and O'Reilly 2014, 142). Without a specific label around which to establish an identity as a member of a specific impairment group, the participants felt that young people come to know themselves as ‘different’ but without a structure in which to understand and embrace that (Taylor, Hume and Welsh 2010). Leaving pupils unsupported with negotiating a relationship with their autistic identity can result in anxiety and the perception of a self that is not only different but ‘wrong’ and undesirable:

‘And we also have parents who will not, even though they've been advised by school, take their child to see about a diagnosis and those are the ones that we have problems with. We've got one in Year 8 at the moment who at one point said, "What is wrong with me then? Why am I different?" and we know …We can't tell them though’ (FGP mainstream secondary).

In raising these issues participants did not challenge the nature and practice of diagnosis and the naming of pupils as autistic. Even though the effects of these were identified as having potentially damaging consequences on development of a sense of self, the practice of medical categorisation was accepted and left untroubled.

Regulation of the Self

Hannam-Swain (2018) identifies the additional labour required of disabled students as they navigate educational environments that are not designed with learners ‘like them’ in mind. Some participants reported that autistic pupils, who are self-reflective, may continually and actively check and monitor themselves to try and work out what is them, what is autism and to make sure that they are not coming across as too autistic. This results in some autistic pupils developing a hyper sense of self:

‘I think probably autistic people do have more of a sense of self because they're constantly trying to work out who they are’ (FGP mainstream secondary).

To avoid being identified as different and potentially rejected some pupils attempt to hide or disguise behaviours that might identify them as autistic (Baldwin and Costley 2016; Carrington and Graham 2001). It was felt by participants that this disciplining, regulation and containment of the self to achieve conformance with ableist norms resulted in significant costs for the individual (Campbell 2009; Hodge and Rutten 2017; Reeve 2000). The participants identified aspects of school culture and practice that led autistic pupils to expend significant emotional and spiritual effort in denying the self. This was observed as resulting in pupils suffering from anxiety and the increased perception of themselves as a failure: 'They also project a slightly different self in school because they need, to a certain extent, to conform to what school society expects for them…They try their hardest because they want to be like everybody else in the school, they want to be what we call "normal" but they can't sustain it and we see a lot of children with levels of anxiety because they can't be like everybody else' (FGP mainstream secondary).

The participants did not feel, however, that all autistic pupils engage with the act of masking. Some pupils appear to be unconcerned about fitting in or even revel in celebratory rejection of ableist norms. They do not appear to use the judgments of others to evaluate themselves: 'He actually doesn't care about anybody else: he's hot, the solution is to take his clothes off, he will take his clothes off. He doesn't give a monkey's about what everybody else thinks and feels' (FGP mainstream secondary - talking about an autistic child outside of the school).

Campbell (2009) argues that disabled children are more used to having things done to than with them. Bagatell (2007) argues that agency, having a say about who and how you are, is

critical to the construction of identity. However, our participants felt that autistic pupils experienced a lack of autonomy over identity construction and representation of the self: 'The autistic children don't necessarily make decisions and choices for themselves and their lives…they're put places…their lives are sort of lived for them in a way' (FGP integrated resource mainstream junior).

In the same way, there appeared to be few opportunities in or outside of school for autistic pupils to explore and decide upon their relationship to autism, what it means to their own sense of self and who they feel they are and want to be. Many of the support programmes and "interventions" start from the position that the manifestations of autism are aberrant and unwanted as children are trained into becoming, or at least appearing, more normal (Brownlow 2010; McGuire 2013; Shyman 2016). Within these, there are few, if any, opportunities for children and young people to challenge these precepts and to identify and define their own understandings of autism, their relationship to it and how they want to present themselves to others. Support with 'orchestrating the voices' that contest and compete for autistic identity is critical for young people: negotiating understandings of autism, that can be so polarized and fiercely contested, can fundamentally disturb and trouble young people (Bagatell 2007; Ortega 2013). We argue, therefore, that according to the data from this study the potential for enablement of agency within the construction of identity for autistic children and young people continues to be neglected and left unexplored within many of our schools.

Discussion

This paper reports on a study that involved 4 schools. Those educators who came along to the focus groups were the school staff who were most interested in, aware of and committed to

the issues that concern disabled pupils. We cannot not claim, therefore, that these findings are representative of other staff within those schools or of educators in general. Milton (2012) argues that non-autistic people experience profound difficulty empathising with the perspectives and lived experience of autistic people; the bridging of epistemic chasms between different life experiences is inevitably challenging (Hodge and Runswick-Cole 2018; MacKenzie and Scully 2008). We were surprised therefore by the extent to which the participants revealed themselves as reflecting on sense of self and evaluating empathically the school environment from what they imagined to be the standpoint of autistic pupils. These participants were remarkable for the extent to which they had adopted an inside-out approach (Williams 1996) in coming to know a pupil's sense of self by focusing on the systems of being of their autistic pupils and paying attention to the accounts of their experience, whether these were expressed through speech or behaviour (Hodge and Runswick-Cole 2018; MacKenzie and Scully 2008). We remain sceptical, however, that this is typical of the majority of staff within schools and more research is clearly required to find out whether this is so.

Without participants making reference to them, the principles of both the individual and social models of disability appear to be informing the participants' understandings of sense of self in relation to the experience of autistic pupils. Examples of the models in operation are clearly seen within participant accounts. In line with the individual model of disability, autism is, for the most part, constructed as something that is essential, definite and a maker of bodies that are biologically different and in need of change. The concept of a distinct 'autistic self', within a binary of autistic and non-autistic, was uniformly accepted and left unchallenged. Even when autistic and non-autistic pupils were felt to share many of the same

challenges of maturation, the fundamental distinction between autistic and non-autistic, as perceived by the participants, remained largely undisturbed.

The social model of disability was also present in the participants' accounts of how they feel the self is constructed by autistic pupils. The participants perceive coming to understand oneself to be different and thus positioned, metaphorically and physically, outside of the norm as a potential threat to the development of a positive sense of self. These participants suggested that this arises in part from cultural collusions that present the notion of the 'autistic self' as abnormal, disordered deficit and devalued. As Lester, Karim and O'Reilly (2014) report, ‘the majority of the descriptions of autism are situated within a medical perspective, from which people with autism are frequently constructed as isolated, disengaged from the world, and shackled by their abnormalities’ (Osteen 2008,140). Without naming them the participants appear to reconcile these competing models of disability within a conception of an 'autistic self' that is essentially different but made problematic predominantly through disabling and exclusionary practices, and behaviours, that mark out and segregate those who cannot perform within narrowly prescribed permitted ways of being. School is understood to be a site of change and development but currently it is only the autistic pupils who are expected to mutate, or at least self-regulate, into something less autistic, whilst the disabling systems and structures of education may be observed and regretted but are, for the most part, left undisturbed. As represented by these educators, the physical and social environments of school seems to play a more disabling than enabling role in the development of sense of self. Therefore, we began to wonder how this might be changed, so that those autistic pupils who might benefit from it could be supported with developing an enabling, empowered and valued understanding of themselves. One aspect of the participants' accounts that particularly stood out to us was the portrayal of the autistic

pupil's struggle with sense of self as an isolated pursuit that was mainly unsupported by peers. We feel that this could be critical to address if we are to support autistic pupils more effectively with development of a positive sense of self. We suggest that to enable this we should develop with schools a framework of activism engagement for autistic pupils.

Hughes (2009) identifies contending agenda between a disability activist rejection of the medicalised self with a refocus on exclusionary barriers and 'biological citizenship' (Rose & Novas, 2005: 439) in which people identify with, embrace and gather around their 'condition'. Levitt (2017, 736) develops the notion of disability activism into 'the active model of disability' through which the effects of disability are reduced by the individual and collective action of disabled people. Levitt illustrates the model through the use of three ways 'in which the actions of disabled people can shape their own disabilities: self-help, engaging with support groups and using assistive technology.' From our data, the establishment of a positive autistic identity, knowing, accepting and valuing who you are, was felt by some of our participants to be a critical component in the formulation of a positive and enabling sense of self. Connecting with others who also embrace an autistic identity can aid this process significantly (Coleman-Fountain 2017). However, educators, as yet, seem to be highly uncertain as to whether this is something they should or could be doing. In one of our participant schools, staff utilise video clips presented by autistic people to offer access to 'enabling role models' and to promote the concept of a positive autistic identity. Beyond this though, the internet appears to remain an underused resource in schools as a means of connecting autistic young people. This leaves many autistic young people without access to online or offline autistic communities and therefore denied the potential affirmation, empowerment and practical advice for navigating non-autistic spaces that could come from feeling belonging within a community of those who share the lived experience of

being autistic (Bertilsdotter Rosqvist, Brownlow and O'Dell 2015; Coleman-Fountain 2017). Without this community, what we learn from our participants, supported by our review of the research literature, suggests that young autistic people risk developing a sense of themselves as wrongly wired and out of place; a state of being that they attribute only to the nature of their autistic self. Autistic self-advocates argue that 'individuals need to be enabled to identify with a group that is perceived as constructive and empowering' (Autism Dialogue, Twitter, March 5th 2018). Recent years have witnessed a rise in activism by some autistic people across a number of countries as they come together in community to claim more control, or at least the right to participate in, the social practices that define and regulate the autistic self (Folsom 2017; Orsini and Smith 2010). This can be seen in the reach of organisations like the Autistic Self Advocacy Network (ASAN) in the United States and the Participatory Autism Research Collective (PARC) in the United Kingdom. Currently, however, many autistic pupils remain unaware of these initiatives. Nor are staff in schools sufficiently informed to support pupils with developing a sense of self within a rights based agenda. No mention was made by participants of disability equality being taught within the curriculum; a regular omission in English schools (The Children's Society 2008). Nor did these educators refer to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN 2007): we did not detect any engagement with autistic pupils around a rights and empowerment agenda. Again, there is very little evidence generally of English schools complying with Article 8 2b of the CRPD which obligates schools to foster in all children respect for the rights of disabled people (Rieser 2017). To us, this would seem currently to be a critical omission in our schools,

Within CAS it is necessary for research to make a positive and practical difference to the lives of autistic people. Therefore, we respond to the concerns raised by our participants by

suggesting that what is required is a framework for activism engagement to provide the means and opportunities for young autistic people to connect together. Raising awareness and developing acceptance of what it means to be autistic, will also help those autistic pupils who do not demonstrate awareness of how others perceive them as they will have an informed and empowered extended community to advocate for them. Moreover, the framework could apply beyond autism or disability as it could support all young people who have been marked out as, and/or identify as, different and do not have ready access to others who might share their experience. Within the framework of activism engagement, it is hoped that autistic pupils would develop an empowering identity around the impairment category so that they come to accept, value and celebrate their autism with others who also identify as autistic. Through community, autistic pupils may well then come to recognise that the causes of the issues they face often lie outside the self.

We propose that the components of a framework of activism engagement, in relation to autism, are:

- awareness and appreciation, by all school stakeholders, of the particular challenges that autistic pupils are confronted with
- recognition, appreciation and celebration of the contributions made by autistic pupils even when these are not made in typical or expected forms
- a commitment to the identification and removal or modification of the physical, social and cultural barriers that reduce and limit the aspirations and achievements of autistic pupils
- enabling those autistic children and young people for whom it would be supportive, and who choose to do so, to connect with the autistic community in safe online and offline spaces

- inclusion across the curriculum of disability equality awareness and the rights of disabled people under the Convention on the Rights of Persons with Disabilities
- a commitment to effect change to enable the emergence of empowered autistic selves who experience being accepted for they are and valued for what they contribute.

Conclusions

In this inquiry we employed two of the most written about models of disability in partnership with Ableism to form a new framework of data analysis within the emergent paradigm of Critical Autism Studies. We wanted to know how school staff understand and respond to a sense of self in relation to autistic pupils. In keeping with the principles of CAS, we sought to reveal how power was situated and practised within the formation and maintenance of a sense of self for autistic pupils. We perceived the staff in schools to be significant gatekeepers to enablement of sense of self for autistic pupils and that their views should, therefore, be a critical focus of research.

Low self-esteem and its pursuant problems for young autistic people should be of concern to all educators, nationally and internationally. If these are conceived of as the natural outcomes of an essential, biological, disordered being, then the self, for autistic people, becomes subject to treatments and interventions that only emphasise and reinforce a sense of being that is defective and lesser. The educators who participated in this inquiry demonstrated a more nuanced understanding of the self as constructed as much through social engagement as biology. The ableist practices of the school environment were reported as being a significant contributor to the formation of a devalued and problematic sense of self but the educators seemed uncertain of how to address these. From their accounts, we suggest that one mechanism might be to develop within our schools a framework for activism engagement

with a focus on connecting pupils with the autistic community. We propose that this might support pupils with coming to appreciate that it is perhaps the system, and not themselves, that is in need of a change.

Within this particular inquiry we regret that autistic people were mot more directly involved in its design and implementation. We recognise that this will preclude our study from meeting the requirements of some definitions of research within the paradigm of Critical Autism Studies. However, we are now actively collaborating with autistic people, as well as other autism stakeholders, on critiquing, developing and actualising the proposed framework of activism engagement.

Acknowledgments: The authors would like to thank the fellow researchers who worked on the Autism and a Sense of Self Project. These include Ms. Helen Basu Chaudhuri and Dr. Jill Pluquailec from Sheffield Hallam University. We thank too the four school based researchers. Unfortunately, these need to remain unnamed to ensure compliance with the ethical conditions that governed the inquiry. We also thank Dr Katherine Runswick-Cole for reviewing an early draft of the paper and the three anonymous reviewers. We appreciate how the feedback received has helped to develop the final paper.

Declaration of Interest: No declaration of interest was reported by the authors.

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