

Est.
1841YORK
ST JOHN
UNIVERSITY

Vincent, Jonathan, Potts, Megan, Fletcher, Daniel, Hodges, Simon, Howells, Jenny, Mitchell, Alex, Mallon, Brett and Ledger, Thomas (2016) 'I think autism is like running on Windows while everyone else is a Mac': using a participatory action research approach with students on the autistic spectrum to rearticulate autism and the lived experience of university. *Educational Action Research*, 25 (2). pp. 300-315.

Downloaded from: <http://ray.yorks.ac.uk/id/eprint/1821/>

The version presented here may differ from the published version or version of record. If you intend to cite from the work you are advised to consult the publisher's version:
<http://dx.doi.org/10.1080/09650792.2016.1153978>

Research at York St John (RaY) is an institutional repository. It supports the principles of open access by making the research outputs of the University available in digital form. Copyright of the items stored in RaY reside with the authors and/or other copyright owners. Users may access full text items free of charge, and may download a copy for private study or non-commercial research. For further reuse terms, see licence terms governing individual outputs. [Institutional Repository Policy Statement](#)

RaY

Research at the University of York St John

For more information please contact RaY at ray@yorks.ac.uk



“I think autism is like running on Windows while everyone else is a Mac”: Using a participatory action research approach with students on the autistic spectrum to rearticulate autism and the lived experience of university.

Journal:	<i>Educational Action Research</i>
Manuscript ID	REAC-2015-0054.R1
Manuscript Type:	Accounts of Action research and development Studies
Keywords:	Autism, Participatory action research, Higher education, Data analysis, Critical autobiography

SCHOLARONE™
Manuscripts

1
2
3 ***"I think autism is like running on Windows while everyone else is a Mac": Using a***
4 ***participatory action research approach with students on the autistic spectrum to***
5 ***rearticulate autism and the lived experience of university.***
6

7
8 This co-authored article outlines the research process and key findings from the Stratus
9 Writers Project, a participatory action research project with a group of seven students on
10 the autistic spectrum at a university in the north east of England. The project explores their
11 experiences of university through critical autobiographies and offers unique insider
12 perspectives into some of the key issues, challenges and successes. Building on a
13 participatory action research approach, the data was collected by the participants
14 themselves; however, this study departs from traditional research in that the participants
15 also analysed the data themselves, thus offering rich and potentially overlooked theoretical
16 knowledge. The paper concludes by demonstrating the strength of participatory action
17 research approaches by identifying the impact that our project and its findings have had so
18 far.

19 **Keywords:** autism; participatory action research; higher education; data analysis; critical
20 autobiography
21

22
23 **Introduction**

24 According to the Equality Challenge Unit (2013), the proportion of disabled students in the UK
25 who declared a social communication or autistic spectrum condition to their university more
26 than doubled between 2007/08 and 2011/12. In order to fully support these students, both
27 staff and peers in higher education institutions must develop understanding about autism and
28 how it affects those who identify with the diagnosis. However, much of the current literature is
29 authored by staff, parents or other stakeholders, rather than the individuals with the diagnosis
30 themselves. This co-authored article specifically seeks to address the paucity of participatory
31 studies and is actively engaged in what Madriaga and Goodley (2010) call 'socially just
32 pedagogies', where the voices of the individuals are foregrounded in the discourse surrounding
33 theory and practice. It outlines the findings from the Stratus Writers Project, a participatory
34 action research project, facilitated at one university in Yorkshire, England over 2013-2014.
35 Through critical autobiographical narratives (Griffiths 1994) written by six current
36 undergraduate students and one recent graduate on the autistic spectrum, insider perspectives
37 of the diagnostic label and experiences of university are analysed in order to identify some of
38 the key issues, challenges and implications for higher education.
39

40
41 **Rearticulating autism**

42 Autism is a developmental condition, which, according to the National Autism Society, UK
43 (2014), affects how an individual communicates and relates to others, processes information,
44 and makes 'sense of the world'. Over three decades ago Wing and Gould (1979) framed it as a
45 multi-dimensional condition - or spectrum - to capture the lack of clear boundaries and to
46 highlight the diversity among individuals, all of whom display one or more features of autistic
47 behaviour. However, the terminology used to describe autism and the purposes with which it is
48 employed by professionals, laypeople and the media have been contested by some autistic
49 people and their families (Kenny et al, 2015).

50 Waltz (2005) suggests that since the time of its formal identification (Kanner, 1943) the
51 discourse around autism has been dominated by deficit-based interpretations, with particular
52 foci on epidemiology, assessment and diagnosis. According to this view it has been portrayed as
53 a 'neurological abnormality' (Frith 2003:1) resulting in a 'triad of impairments' in social
54 interaction, social communication and imaginative thought (Wing 1996). This is exemplified, to
55 some extent, by the most recent diagnostic descriptors (DSM V) outlined by the American
56 Psychiatric Association (2013:1), which describes the symptomatic characteristics of autistic
57 spectrum disorders (which now includes Asperger's syndrome) in the following terms:
58
59
60

1
2
3 People with ASD tend to have communication deficits, such as responding inappropriately in
4 conversations, misreading nonverbal interactions, or having difficulty building friendships
5 appropriate to their age. In addition, people with ASD may be overly dependent on routines,
6 highly sensitive to changes in their environment, or intensely focused on inappropriate items.
7

8 It is argued that words such as 'impairment', 'deficit' and 'inappropriate' have taken on a
9 pejorative and judgmental tone (Milton and Bracher 2013) and signals a contentious agenda
10 toward 'normalisation', which many autistic advocates oppose (Kitchin 2000). Building on the
11 social model of disability (Oliver, 1996), there is a resistance to the characterisation of autism as
12 a personal tragedy that 'strikes each victim differently' (Cuninghame, 1988) and requires
13 treatment in order to 'cure'. This position can be summed up in the words of one of the
14 respondents from Beardon and Edmonds' (2007:332) emancipatory study, 'I don't have a
15 problem: I'm me. It's society that has no idea about acceptance, compassion or freedom to
16 choose how I want to live'.
17

18 However, this is not to suggest that the role of medical practitioners, psychologists or
19 scientific researchers must necessarily be viewed as problematic. It is also recognised by many
20 autistic individuals, parents and advocates that the dramatic increase in research (Pellicano et
21 al, 2014), better clarification of diagnostic descriptions and greater awareness among
22 practitioners have been positive for better understanding individuals' specific needs, catalysing
23 policy reform, and providing welcome access to local funding, professional support and
24 educational opportunities (Searing et al, 2015). Thus, it is clear that whilst research into autism
25 is viewed as important to autistic people and their families there remains contention around
26 how this is conducted and the overarching message it communicates. This present study builds
27 on this position and makes use of a neurodiversity model of autism, where the condition is
28 presented in terms of difference rather than deficit (Williams, 1996; Robertson, 2009; Kapp et
29 al, 2012; Milton, 2014). Within this framework it is recognised that an autistic person, like any
30 individual, is endowed with a blend of cognitive strengths and difficulties across a range of core
31 domains, including those outlined above. A neurodiversity model assumes that individuals'
32 strengths and difficulties are contextual and tend to be the result of the interaction between an
33 ableist society and individual differences or impairments (Robertson 2009; Milton, 2014).
34

35 **Socially just pedagogies in higher education**

36 Madriaga and Goodley (2010) identify the need for socially just pedagogies in higher
37 education for students on the autism spectrum. These are described as ways of learning that
38 open up spaces of resistance and conditions for social justice and go beyond minimum 'base
39 level' practice towards creative, participatory and inclusive approaches. In order to interrogate
40 higher education according to this ideal, it is important to understand the context from the
41 perspective of the autistic students themselves. Although there are still only a small number of
42 studies that take an explicitly emancipatory approach, those that do tend to highlight a number
43 of consistent areas of concern for university students.
44

45 Primarily, evidence suggests a significant lack of understanding regarding autism in
46 higher education. Although universities tend to be places where 'no one cares if you're a bit
47 strange' some students report that their behaviour is often misunderstood as odd or even
48 disruptive by peers and staff (Beardon and Edmonds, 2007:155). To this end, students describe
49 expending copious amounts of energy and time in trying to appear 'normal' by managing their
50 behaviours, reactions and character traits so as to 'fit in' at university (Hastwell et al. 2012;
51 Knott and Taylor, 2014). Studies also relate challenges for autistic university students with
52 social communication, specifically around the requirement to understand and respond to subtle
53 communicative interactions.
54

55 If I see someone being socially successful, or if I commit a social faux-pas which 'nobody else
56 would have done', I get depressed and behave awkwardly. I beat myself up excessively, self-
57 deprecate, lose all self- confidence and get depressed

(Hastwell et al. 2012:59).
58
59
60

1
2
3
4 It is clear that the enormous pressure placed on some students on the autism spectrum to
5 conform can become challenging, leading to social exclusion, mental health issues and a
6 significant loss of wellbeing (Martin 2008).

7 Much of the student voice literature also cites examples of unfriendly social and sensory
8 environments in higher education as a source of stress and anxiety; these can include over-
9 crowded Open Days and Freshers' Fairs, bright and noisy teaching rooms or a lack of quiet
10 spaces in the institution (Van Hees et al, 2014; Bogdashina 2003). Students on the autism
11 spectrum also report finding many aspects of the university curriculum challenging, including
12 group work which requires interaction with peers, class presentations where body language
13 and eye contact are part of the success criteria and making sense of assignment briefs which are
14 not explicit (Knott and Taylor, 2014; Martin 2008). According to Bogdashina (2006) the
15 combination of students' different learning needs and institutional inflexibility can make what
16 are considered the 'nuts and bolts' of university life very stressful.

17 However, by viewing autism through a neurodiversity lens, there is also opportunity to
18 engage with students' differing dispositions, capabilities and interests rather than focussing
19 solely on what they find difficult. The study by Van Hees et al (2014:1684) identifies a range of
20 autistic students' strengths including,
21

22 their different way of processing information [which] also gives rise to some exceptional skills
23 and talents, such as a strong memory, focus precision and an eye for detail, dedication, the ability
24 of putting one's mind to a subject, analytical skills, remarkable powers of observation etc.
25

26 From this perspective it is clear that in higher education, just as in any other context, autistic
27 students' strengths and differences are contextual and in order to create socially just
28 pedagogies it is imperative to engage with the insider perspectives of those who experience it
29 first-hand. To this end the Stratus Writers Project sought to foreground the students'
30 experiences in the discourse and open up a creative space in which different aspects of
31 university life could be explored and critiqued.
32

33 **Methods**

34 The Stratus Writers Project was comprised of an academic facilitator and 7 student co-
35 researchers, all with a formal diagnosis of an autism spectrum condition. It adopted a
36 participatory action research (PAR) approach, which falls within the broader family of action
37 research and has its foundation in Lewin's systematic enquiry through democratic participation
38 (Adelman 2006). The approach seeks to emphasise the construction of expertise and validity
39 through the life stories of those who experience oppression, rather than by the professional
40 researcher or 'expert' and resonates strongly with Carr and Kemmis' (2003) Habermasian
41 theory of action research which stresses the ideological impetus towards promoting social
42 justice and resisting domination. This agentic approach to knowledge production fits appositely
43 within the social model of disability in leading to the 'systematic demystification of the
44 structures and processes which create disability and the establishment of a workable "dialogue"
45 between the research community and disabled people in order to facilitate the latter's
46 empowerment' (Barnes 1992:122). PAR is, of necessity, participatory and invites collaboration
47 from all participants as active and equal stakeholders in the research process. It seeks to create
48 'ideal speech situations' in which communication between individuals is free, open and
49 unconstrained by considerations of power and status (Somekh and Zeichner 2009:8). Following
50 this emphasis, decisions in terms of the research direction, methods and outcomes were taken
51 through discussions which sought to involve all the members of the project.
52
53

54 **Ethics**

55 PAR research produces a range of specific ethical issues in relation to the manner in which
56 power is negotiated, how personal experiences are shared and how the needs and expectations
57 of those involved are expressed and realised through the research process (Manzo and
58
59
60

1
2
3 Brightbill 2007). For the Stratus Writers Project, the process of establishing ethical principles
4 that reflected the nature of the project whilst complying with institutional ethics standards was
5 complex and the issues often subtle. Ethical approval from our institutional review board was
6 obtained on two occasions; initially prior to the project [REF ET/11/04/13/JV] and later as it
7 progressed and changed in relation to the group's revised direction [REF ET/01/05/14/JV].
8 However, significant concerns were raised by the institution's review board in relation to the
9 students who being classified as 'disabled subjects' could thus be considered a 'vulnerable
10 group'. It is clear that safeguarding 'vulnerable' individuals against risk is important, however,
11 this must happen in a communicative space that does not automatically adopt a medicalised
12 view of disability or perpetuate a system where certain groups remain invisible and voiceless
13 within higher education. To maximise the autonomy and wellbeing of participants, all plans and
14 decisions were verbally negotiated by those involved and were later provided in written form
15 by email to ensure that they had time to process and make informed decisions regarding
16 consent.

17
18 A further ethical issue centred on confidentiality and anonymity. The institution's
19 review board had concerns regarding the use of students' real names in authoring
20 autobiographical texts and questioned whether this might potentially compromise their safety
21 and future wellbeing. It was argued, however, that removing the option altogether for
22 participants to use their real names significantly compromised their right to a legitimate
23 expression in relation to reclaiming their experience of university. As Manzo and Brightbill
24 (2007:36) point out, the desire to preserve anonymity is often 'in tension with [the] desire to
25 facilitate marginal peoples' voices in their own community and in broader political processes'. A
26 via media was reached so that pseudonyms have been attributed to students' remarks about
27 their university experiences, however, where authorised, real names have been used to denote
28 their roles in the research process and authorship.

30 ***'Autie-biographies'?***

31 According to Kindon et al. (2007) one of the most important features of PAR is its 'hands-on'
32 nature that enables participants to share their knowledge using symbols, language and art
33 forms that are most meaningful to them. Thus, PAR afforded our group the flexibility of
34 identifying creative ways to rearticulate 'insider' interpretations of autism and their lived
35 experiences of university. It was agreed by the group that the primary method of data collection
36 would be narrative. Attard (2012) notes that narrative writing holds great potential for
37 individuals to analyse their lived experiences, as the process encourages one to reflect deeply
38 on aspects that might have otherwise gone unnoticed. Some of the students were aware of other
39 personal narratives written by individuals with autism (Jackson 2002) and felt comfortable
40 with it as a form of data collection as, unlike an interview or focus group, they could take their
41 time to consider exactly what they wanted to say and how they might express it most
42 accurately. However, as the project developed it was clear that the writing was moving far
43 beyond personal narrative and closer to what Griffiths (1994) calls critical autobiography
44 where individual experience is mixed with theory and reflection about politically situated
45 realities. For Rose (2005), the mere existence of autistic narrative and autobiography (what she
46 terms 'autiebiography') radically questions the diagnostic criteria for autistic conditions (DSM-
47 V) and resists the de-humanising medicalisation of this symptomatic approach to autism.

48 The students in Stratus Writers Project were themselves instrumental in defining the nine
49 areas that they wished to 'rearticulate' in their writing. These included:

- 50
51
- 52 • what being diagnosed as on the Autistic Spectrum means to you;
 - 53 • period before coming to university;
 - 54 • first week of university;
 - 55 • practical issues at university;
 - 56 • socialising;
 - 57 • emotional needs;
- 58
59
60

- academic successes and challenges;
- living abroad as part of an exchange programme;
- life after university

In order to ensure that the project was manageable, students opted to write about those areas that resonated most strongly with their own experience and most chose between two to four areas. Although each piece of writing varied in length (the longest being 1815 and the shortest 469 words) in total the group produced nearly 16,000 words of primary data based on their insider perspectives. Table 1 outlines the topics that students opted to write about and their levels of participation at each stage of the process.

Table 1

Group member	Topics covered	Individual analysis	Visual mapping exercise	Verification of themes
Jonathan		✓	✓	✓
Alex	Diagnosis; Before university; Academic;	✓	✓	✓
Megan	Socialising; Academic	✓		✓
Simon	Life after university	✓		✓
Daniel	Diagnosis; Before university; First week of university	✓	✓	✓
Jenny	Living abroad as part of an exchange programme	✓	✓	✓
Brett	Diagnosis; First week of university; Practical concerns; Socialising			✓
Thomas	Diagnosis; Before university; First week of university; Emotional concerns			✓

Taking the next step in participatory research: data analysis

Following a PAR approach, the seven students were all encouraged to analyse the data alongside the 'neurotypical' academic facilitator. Consent was granted for each to analyse others' writing and so in this sense each 'voice' was questioning itself in relation to the other 'voices' involved (Winter 2002). In all, five students participated in this stage of the project, offering new and insightful interpretations of their own experiences of higher education and identifying their shared successes and challenges. Unfortunately not all participants were able to analyse the data; in the cases of both Brett and Thomas this can be explained by their need to balance their involvement in the project against other commitments, particularly completing their final year degree programmes. Whilst this is considered one of the limitations of the study, in ethical terms, individuals' personal circumstances must be taken into consideration and given priority over any research outcomes.

Involving individuals to reflect a full range of neurodiversity in data analysis and generation of theory has traditionally been viewed as problematic (Stalker 1998), not least among individuals on the autistic spectrum who apparently lack the ability to understand the thoughts and feelings of others or see the world from someone else's perspective (Baron-Cohen et al 1985). There is, however, a growing initiative to more fully include participants in the whole research process with the emphasis on implementing change rather than 'pure interpretation' (Winter and Munn-Giddings 2001:235). Moreover, Nind (2011) contends that any political commitment to the Disability Movement's clarion call of 'nothing about us without us' must necessarily also include data analysis and she offers various examples of how this can be done with individuals or groups. Thus, the inclusion of students in the analysis of the data in the Stratus Writers Project challenges the 'deficits' outlined above and reinforces the view that autistic students themselves 'carry revealing wisdom about the history, structure, consequences and the fracture points in unjust social arrangements' (Cammarota and Fine 2008:6) and that

both their life stories *and* their analyses offer valuable and hitherto relatively unexamined dimensions of the discourse.

Nind (2011) contends that at times it may be necessary to make the task of analysis more accessible and cites time, space, support and practice as enabling factors. Thus to cut down the time required to analyse the text, the full script was converted into a segmented version and circulated to the whole group, although all students also had access to the text in its entirety. Written guidance on how to conduct qualitative data analysis was provided and there was opportunity to practise these skills using short extracts from Prince-Hughes' (2002) edited texts. Our analytical approach was informed by grounded theory and thematic analysis (Madriaga and Goodley 2010). This approach seemed appropriate where grounded theory, according to Bryant and Charmaz (2007), involves deriving analytic categories directly from the culture under investigation, rather than from preconceived concepts or hypotheses. Our thematic analysis involved assigning codes or thematic labels, followed by sub-codes to parts of the transcripts (see Table 2 for examples). The more detailed sub-codes were later grouped into broader coherent themes following a visual mapping exercise with some of the participants, which were then circulated to the rest of the participants for clarification and validation.

Table 2

Codes			
Understanding autism	Anxiety	No social choices	Success with friends
Otherness / difference	New = frightening	Academic pressure	Overwhelming
Lack of understanding	Transition	(In)dependence	Fear vs reality
Difficulties	Managing unknown	Uncertainty re disclosure	Optimistic
Bad previous experiences	Fear of isolation	Routines	Making friends
Coping with change	Resilience	Social discomfort	Continuous learning
Fear of change	Loneliness	Nervousness	Comfortableness
Celebrating individuality	Desire for friendship	Flexibility	Positive change
Sub-codes			
Otherness / difference	New = frightening	Optimistic about university	University support
Lack of understanding	Social discomfort / anxiety	(In)dependence	Fear vs reality
Desire for friendship / fear of loneliness	Having real social choices	Experiencing success	Fear of change
Thematic groups			
Sense of difference	Social interactions	Responding to change and independence	'Fear vs. Reality'

The process of establishing themes that reflected the experiences of all the students was challenging and resonates with Cook's (1998) sense of 'messiness' in research. A good example of this was during the validation process where there was dispute over the wording of sub-codes; terms such as 'fear of change' or 'social anxiety' were considered to have overly negative connotations and so through discussion, clarification and further validation these were altered to 'responses to change' and 'social interactions' respectively. Although the iterative process of group analysis was somewhat laborious, it allowed for greater authenticity and insight (Nind 2011; Winter 2002) and produced important interpretations that may have otherwise been missed.

Findings and discussion

The group's analysis identified four main themes: a sense of difference; social interactions; responding to change and independence; and fear vs reality. Attempts have been made to foreground the students' voices by offering verbatim extracts and demonstrating how these build towards new knowledge and practice.

Theme 1. A sense of difference

Otherness and difference

The theme of difference or otherness is prominent throughout the students' writing and was identified by almost all of those that conducted the analysis. Here the sense of difference is understood in terms of the students' self-concept of autism and what this means in relation to others.

I think autism is like running on Windows while everyone else is a Mac. This leads to information being lost in social situations. People are like the background NPC's in video games where you can press 'x' to find out what they are thinking, but my 'x' button is broken. (Chris)

I wonder if I'm an alien who's been dispatched to earth and missed my mission briefing (Nicola)

In both of these examples, the students rework the ontological realities of personhood to perceive themselves as different to others based on their experience of life as an individual on the autistic spectrum (Madriaga and Goodley 2010). Here, this experience is described in otherworldly terms and is understood to be qualitatively different to those considered 'neurotypical'. Similarly, Williams (1996) relates a conception of difference based on how she processes information and interacts with others, which she describes as mono- or multi-track processing. This representation coheres with the sense of running on alternative operating systems identified by Chris's allusion to running on Windows/Mac. Madriaga and Goodley (2010) suggest playful and strategic distinctions between 'us' and 'them' such as these can actually be used positively, to allow space for valuing the 'us' of those on the autistic spectrum while deconstructing and critiquing the 'them' of neurotypicality.

Lack of understanding

However, as with other emancipatory studies in higher education settings (Beardon et al. 2009, Hastwell et al. 2012 *inter alia*), frequently for students the label and others' perceptions of it appear to create distance, or 'othering'.

...it's not easy approaching people to tell them you find certain things difficult, or have additional needs... When I started university I had only recently been diagnosed and wasn't comfortable talking about my autism at all. (Nicola)

When I tried to hand in my CV at a fancy dress and magic shop...I added that I was also autistic and that I might need some support working in a different environment. Unfortunately, I had no reply from them at all concerning further details. (Timothy)

It is clear that the lack of understanding and sense difference experienced by the students, whether self-attributed or imposed by others, is still a barrier to feeling fully included within the university setting and beyond.

Theme 2. Social interactions

Desire for friendships / fear of loneliness

Traditional conceptions of autistic spectrum conditions, including Asperger's Syndrome, have assumed that individuals lack the desire and the skills to foster meaningful relationships with others (Waltz 2005). However, the students here contest this classical conception by outlining their clear desire to develop friendships whilst at university:

I'm not very good at socialising and meeting people for the first time but I did genuinely want to make new friends rather than spending three years at university being lonely. (Ben)

1
2
3 I want to socialise and have friends like any normal people, but every time the invitation comes, I
4 almost always go into default mode and say “no”. I’m not sure if it’s because of my Autism or if
5 I’m shy like that. (Karen)

6
7 Ben and Karen’s comments both correspond with Martin’s (2008) suggestion that students on
8 the spectrum have strong desires to make friends. However, it seems clear from the writing and
9 analysis that alongside a desire for friendship, social anxiety and fear of loneliness are perceived
10 to be significant barriers.

11
12 I was also a little bit worried about the idea of making new friends (or rather, having a distinct
13 lack of friends) (Edward)

14
15 [I] was scared about being lonely (quite strange for someone with an ASD!). (Mark)

16
17 These themes were particularly borne out in the coding of the text, where terms such as
18 ‘nervousness’, ‘loneliness’ and ‘social anxiety’ were frequently identified by the writers. The
19 anxiety and loneliness that an individual on the autistic spectrum can experience has been
20 widely recognised (Bauminger and Kasari 2000; Frith 2003). Green and Ben-Sasson (2010)
21 outline estimates of anxiety disorders for children on the autistic spectrum to be anywhere
22 between 18-87% and Gillott and Standen (2007) assert that anxiety experienced in childhood
23 often continues into adulthood.

24 25 *Social discomfort*

26 However, a number of the students independently identified the term ‘social discomfort’, to
27 suggest an uneasiness and apprehension regarding social situations as distinct from ‘social
28 anxiety’. This term is interesting as it offers an insider perspective that is relatively under-
29 represented in the literature. Chris’s description offers a clear example of social discomfort:

30
31 Understatement: I am not good with crowds or social situations. Every person in a group seems
32 to square how difficult it is to talk to them. Have you ever felt like someone was watching you
33 and you don’t know why? In some crowds whenever someone looks my way I get nervous, I think
34 why would they look at me and I go through everything I think I could have done or be doing
35 wrong. I become overly paranoid and self-conscious. I say that these crowds have a negative
36 aura. (Chris)

37
38 Moreover, social discomfort here frequently relates to a sense of pressure in unplanned social
39 settings such as pubs and clubs where social rules are perceived as flexible and challenging to
40 discern.

41
42 I have no problems with general socialising most of the time. It’s just the going out part that I
43 freak out on. The social rules in society keep changing overnight! (Karen)

44
45 The rules change according to who you’re with, where you are, why you’re talking. (Nicola)

46
47 It is clear that the enormous pressure placed on some autistic students to conform to changing
48 social norms can be immensely stressful, lead to social exclusion and a significant loss of
49 wellbeing.

50 51 *Having ‘real’ social choices at university*

52 A number of writers noted that one of the compounding issues was that the university did not
53 provide environments which offered *real* social choices for them.

54
55 The university (or at least the Student Union) didn’t appear to offer much in the way of Fresher’s
56 week activities that would be considered ‘friendly’ for students with Autism/Asperger’s.
57 (Edward)

For some of the students, sensory issues, including loud noises, intense lighting and overcrowding created significant barriers to social interactions. Much of the literature also cites examples of unfriendly social and sensory environments in higher education as a source of stress and anxiety (Bogdashina 2003, Beardon and Edmonds, 2007). Green and Ben-Sasson (2010) suggest that sensory over-responsivity is a common feature found in more than half of individuals on the autistic spectrum and is also often linked to anxiety and isolation (Jones et al 2003). Students relate how, in order to avoid the sensory discomfort that comes from these experiences, they tended to isolate themselves.

If there had been another choice for a 'Fresher's/Welcome Week', other than to get drunk, then I would have been more interested in it, so that I would have gotten out of my apartment more and met new people, however, there was not any other choice, so I simply stayed in. (Mark)

It is clear from Mark's comment that the very lack of social choice at university for students on the autistic spectrum is itself what disables them; a position which fits appositely with the social model of disability (Oliver 1996).

University support

Almost all of the literature recognises the importance of university support in creating opportunities for success for students on the autistic spectrum (Van Hees et al., 2014; Knott and Taylor, 2014; Martin 2008, Madriaga and Goodley 2010, Martin 2008) This is reflected throughout the writing both where provision could have been improved and where it was successful and made a significant impact on students' experience and success.

The mentoring service that I received helped me incredibly in coping with my first year at university...I was able to discuss anything with my mentor that was causing me difficulty. (Mark)

Furthermore, where universities offer spaces and places where students can socialise in a physical environment free from sensory over-stimulation and engage in shared interests this was seen as positive. Some noted the benefits of the social group at their university specifically for those on the autistic spectrum or those who identify with the label.

The university has made great strides in this area thanks to its part in setting up a group...where people with Autism/Asperger's can meet with like-minded (and similarly 'socially challenged') people in a quiet room or place on an evening, away from the bustle of university and city life. It is certainly a group that I have enjoyed attending and that I believe has helped to solidify my comfort with myself and the fact that I have Asperger's. (Edward)

These findings suggest that university groups of this kind can offer 'real' choices to students, help build social confidence and create environments where difference is accepted and celebrated.

Theme 3. Responding to change and independence

'New = frightening'

It is well documented in the literature that transition and change can be particularly challenging for individuals on the autistic spectrum (Ehlers and Gillberg 1994). In analysing the texts, the students identified terms including 'nervous', 'anxious', 'apprehensive', 'challenge' and 'fear' to code some of the experiences around this issue. However, the code that seemed to capture the feeling best was Nicola's 'new = frightening'. Mark's description of the summer before coming to university exemplifies this well:

I remember [as a child] feeling frightened, confused and upset and I ran straight out of the building towards home. Although this was over ten years ago now, I still have similar feelings

1
2
3 today whenever I am faced with new situations or surroundings and as a result moving from
4 home to university was an incredibly scary thought...Change in routine has never been
5 something that I have dealt with very well but going to university was an entirely new prospect; I
6 would have to start again from scratch. (Mark)

7
8 Mark's comments signal the importance of familiarity and routines in order to create stability.
9 Smith and Sharp (2013) link the disruption of routines, such that life becomes unpredictable, to
10 sensory responses which can be powerful and unpleasant triggering emotional reactions,
11 including a strong sense of discomfort, anger, overwhelming fear or even pain.

12 13 **Theme 4. 'Fear vs. Reality'**

14 15 *Better than expected*

16 However, whilst the group identified a range of challenges that concur with much that is present
17 in the literature, there was also recognition that often the experience of university was better
18 than had been feared. This is a significant and positive theme that, without downplaying the
19 challenges outlined above, questions the current 'personal tragedy' model of autism
20 (Cunningham, 1998) and highlights the sense of excitement, optimism and resilience
21 experienced by many of the students.
22

23
24 I have a fairly decent social life at university and it has been surprisingly much better than I
25 thought it might. (Ben)

26
27 ...my fears quickly subsided upon my arrival, especially with regards to my first interactions with
28 my new housemates. (Edward)

29
30 Moreover, at times the challenge of social interaction and change represented an opportunity to
31 test personal reserves and capabilities. A number of students relate how they had a desire to,
32 and at times were successful in, overcoming their social discomfort and anxiety.

33
34 I still freak out a little when it comes to going to pubs and clubs, but I'm getting over that. I am
35 more sociable than I was before, which is what I wanted to accomplish, and I did. (Karen)

36
37 The findings from the Stratus Writers Project suggest that the students generally experienced
38 many of the same challenges at university as other autistic students who had taken part in
39 previous emancipatory studies. However, their recommendations for more inclusive practice
40 and the positive shift in the discourse reflect the development of new theory underpinned by
41 the sense of agency and ownership central to our project.
42

43 44 **Impact and conclusions**

45
46 As the name suggests action is a necessary component of any piece of action research, including
47 PAR. In the first instance, the group's writing and analyses have had an immediate impact,
48 particularly for the participants involved. As students detailed their experiences, reflected on
49 their own and others' writing and pulled together themes that reflected a collective experience,
50 they developed a greater depth of understanding about themselves and what being autistic
51 means to them. Secondly, our project and its findings add to a nascent body of literature with
52 the aim of developing theory and improving practice in higher education for students on the
53 autistic spectrum. Our findings suggest that there are still significant challenges and barriers
54 within higher education institutions, particularly in relation to the sense of difference
55 experienced or perceived, social interactions and managing change and independence.

56
57 Since completing the project we have taken opportunities to create more socially just
58 pedagogies. The findings from the project have so far been presented at four international
59 conferences and in November 2014 two members of the Stratus Writers Project co-presented a
60

paper at the CARN conference, winning a prize for their research contributions. At an institutional level the students' critical autobiographical extracts have been used at two universities as the basis of participatory workshops focussed on supporting students on the autistic spectrum. In these settings trainee teachers and members of university staff engage with the students' insider perspectives and are encouraged to enter into a 'dialogue' with them by reflecting on their own practice and considering how they might adapt this to make it more inclusive. Recommendations from staff have included working alongside students to co-design AS-friendly teaching activities, developing more inclusive assessments and considering alternative social events and induction processes.

The final sphere of action is a contribution to greater democracy and more inclusive research methodologies. It was our aim from the outset that all members of the group would be considered equal participants in the process and that their involvement would be at every level – problematising experiences; identifying meaningful research methods; collecting and making sense of the data through analysis; and disseminating the findings in a format that will affect change. In doing so, it was made clear that we were seeking to 'break the monopoly on who holds knowledge and for whom social research should be undertaken' (Kindon et al. 2007:11) and engage in the most radical modes of participation: collective action. Assessing the extent to which this was realised is perhaps the most challenging to assess, however, one of the participants gives an indication of our success when she states,

The greatest success from my point of view was having a voice. We weren't treated like research subjects but research partners in the process...right from the beginning through to presenting at conferences (Nicola).

Acknowledgements

TBC

Disclosure statement

No potential conflict of interest was reported by the authors

References

- Adelman, C. (1993) Kurt Lewin and the Origins of Action Research, *Educational Action Research*, 1(1) 7-24
- American Psychiatric Association (2013) 'Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders'[internet] <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf> <Accessed 28.03.14>
- Attard, K. (2012). The role of narrative writing in improving professional practice. *Educational Action Research*, 20(1), 161-175.
- Barnes, C. (1992) 'Qualitative research: valuable or irrelevant?' *Disability, Handicap and Society*, 7 (2): 115-124.
- Baron-Cohen, S., Leslie, A., and Frith, U. (1985). 'Does the autistic child have a "theory of mind"?' *Cognition*, 21 (1) pp37-46
- Bauminger, N., & Kasari, C. (2000). Loneliness and friendship in high-functioning children with autism. *Child development*, 71(2), 447-456.
- Beardon, L. and Edmonds, G. (2007) *ASPECT Consultancy Report. A National Report on the Needs of Adults with Asperger Syndrome*. Sheffield: Sheffield Hallam University.
- Beardon, L., Martin, N. and Woolsey, I. (2009) *What do students with Asperger syndrome or High Functioning Autism want at college and university?* Sheffield: Sheffield Hallam University.

- 1
2
3
4 Bogdashina, O. (2003) *Sensory Perceptual Issues in Autism and Asperger Syndrome. Different Sensory Experiences. Different Perceptual Worlds*. London: Jessica Kingsley
- 5
6 Bryant, A., & Charmaz, K. (Eds.). (2007). *The Sage handbook of grounded theory*. London: Sage.
- 7
8 Cammarota, J., & Fine, M. (Eds.) (2010) *Revolutionizing education: Youth participatory action research in motion*. New York: Routledge.
- 9
10 Carr, W., & Kemmis, S. (2003). *Becoming critical: education knowledge and action research*. Routledge.
- 11
12 Couser, G. (2000). 'The Empire of the "Normal": A Forum on Disability and Self-Representation: Introduction'. *American Quarterly*, 52(2): 305-310.
- 13
14 Cuninghame, K. (1988) *Autism: A World Apart* (documentary) Icarus Film Productions [Internet] <http://icarusfilms.com/fanlight/aut.html> <Accessed: 06/04/14>
- 15
16 Equality Challenge Unit (2013) 'Equality in higher education: statistical report 2013' [internet] <http://www.ecu.ac.uk/publications/equality-in-higher-education-statistical-report-2013> <Accessed 12.03.15>
- 17
18 Frith, U. (2003) *Autism: Explaining the Enigma*. (2nd Ed). Oxford: Blackwell Publishing.
- 19
20
21 Gillott, A., & Standen, P. J. (2007). Levels of anxiety and sources of stress in adults with autism. *Journal of intellectual disabilities*, 11(4), 359-370.
- 22
23 Green, S. A., & Ben-Sasson, A. (2010). Anxiety disorders and sensory over-responsivity in children with autism spectrum disorders: is there a causal relationship?. *Journal of autism and developmental disorders*, 40(12), 1495-1504.
- 24
25
26 Griffiths, M. (1994). Autobiography, feminism and the practice of action research. *Educational Action Research*, 2(1), 71-82.
- 27
28
29 Hastwell, J., Martin, N., Baron-Cohen, S., Harding, J., (2012) 'Giving Cambridge University students with Asperger syndrome a voice', *Good Autism Practice*, 13 (1) pp 56-63.
- 30
31
32 Jackson, L. (1998) *Freaks, Geeks and Asperger's Syndrome: A User's Guide to Adolescence*. London: Jessica Kingsley
- 33
34 Kanner, L. (1943). Autistic disturbances of affective contact *Nervous Child*. 2 (1) 217-50
- 35
36 Kapp, S. K., Gillespie-Lynch, K., Sherman, L. E., & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology*, 49(1), 59-67.
- 37
38
39 Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2015). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*. 1 (21) 1-21
- 40
41
42 Kindon, S., Pain, R., & Kesby, M. (Eds.). (2007). *Participatory action research approaches and methods: Connecting people, participation and place*. London: Routledge.
- 43
44
45 Kitchin, R. (2000). 'The researched opinions on research: disabled people and disability research'. *Disability & Society*, 15(1), 25-47.
- 46
47
48 Knott, F., & Taylor, A. (2014). Life at university with Asperger syndrome: a comparison of student and staff perspectives. *International Journal of Inclusive Education*, 18(4), 411-426.
- 49
50
51 MacLeod, A. G., Lewis, A., & Robertson, C. (2013). 'CHARLIE: PLEASE RESPOND!' Using a participatory methodology with individuals on the autism spectrum. *International Journal of Research & Method in Education*, 1(2), 1-14.
- 52
53
54 Madriaga, M., & Goodley, D. (2010). Moving beyond the minimum: socially just pedagogies and Asperger's syndrome in UK higher education. *International Journal of Inclusive Education*, 14(2), 115-131.
- 55
56
57 Manzo, L. and Brightbill, N. (2007) 'Towards a participatory ethics'. In Kindon, S., Pain, R. and Kesby, M. (eds.), *Participatory Action Research Approaches and Methods: Connecting People, Participation and Place*. London: Routledge.
- 58
59
60 Martin, N. (2008) *REAL services to assist students who have Asperger syndrome*. Northampton: National

1
2
3 Association of Disability Practitioners.

4 Milton, D. E. (2014). Autistic expertise: a critical reflection on the production of knowledge in autism studies.
5 *Autism*, 1(4) 1-9

6
7 Milton, D. and Bracher, M. (2013) 'Autistics speak but are they heard?' *Medical Sociology Online*, 7(2), 61-69.

8
9 National Autistic Society (2014) 'What is Asperger syndrome?' [online at [http://www.autism.org.uk/about-](http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-asperger-syndrome.aspx)
10 [autism/autism-and-asperger-syndrome -an-introduction/what-is-asperger-syndrome.aspx](http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-asperger-syndrome.aspx)].

11 Nind, M. (2011). Participatory data analysis: a step too far?. *Qualitative Research*, 11(4), 349-363.

12
13 Oliver, M. (1996) *Understanding Disability, from Theory to Practice*. Basingstoke: Macmillan

14
15 Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views
16 and priorities from the United Kingdom. *Autism*, 18(7), 756-770.

17
18 Rose, I., (2005), 'Autistic Autobiography - Introducing the Field', [internet]
19 <http://www.cwru.edu/affil/sce/Representing%20Autism.html> <Accessed: 26.02.13>

20
21 Prince-Hughes, D. (Ed.). (2002). *Aquamarine blue 5: Personal stories of college students with autism*. Ohio: Ohio
University Press.

22
23 Robertson, S. M. (2009). Neurodiversity, quality of life, and autistic adults: Shifting research and professional
24 focuses onto real-life challenges. *Disability Studies Quarterly*, 30 (1).

25
26 Searing, B. M. J., Graham, F., & Grainger, R. (2015). Support Needs of Families Living with Children with Autism
Spectrum Disorder. *Journal of autism and developmental disorders*, 45(11), 3693-3702.

27
28 Smith, R. S., & Sharp, J. (2013). Fascination and isolation: a grounded theory exploration of unusual sensory
29 experiences in adults with Asperger syndrome. *Journal of autism and developmental disorders*, 43(4), 891-910.

30
31 Somekh, B., & Zeichner, K. (2009). Action research for educational reform: Remodelling action research theories
and practices in local contexts. *Educational action research*, 17(1), 5-21.

32
33 Stalker, K. (1998) 'Some ethical and methodological issues in research with people with learning difficulties'.
34 *Disability & Society*, 13(1), 5-19.

35
36 Van Hees, V., Moyson, T., & Roeyers, H. (2014). Higher education experiences of students with autism spectrum
37 disorder: challenges, benefits and support needs. *Journal of autism and developmental disorders*, 1(45), 1673-
1688

38
39 Waltz, M. (2005). 'Reading case studies of people with autistic spectrum disorders: a cultural studies approach to
40 issues of disability representation'. *Disability and Society*. 20(4): 421-435.

41
42 Williams, D. (1996) *Autism: An Inside-Out Approach*. London: Jessica Kingsley Publishers.

43
44 Wing, L. (1996) *The Autistic Spectrum: A Guide for Parents and Professionals*. London: Constable

45
46 Wing, L., & Gould, J. (1979) 'Severe impairments of social interaction and associated abnormalities in children:
47 Epidemiology and classification'. *Journal of autism and developmental disorders*. 9(1), 11-29.

48
49 Winter. R. (2002) Truth or fiction: problems of validity and authenticity in narratives of action research,
Educational Action Research, 10:1, 143-154

50
51 Winter, R., and C. Munn-Giddings, eds. (2001) *A handbook for action research in health and social care*. London:
Routledge.

Dear reviewers,

Thank you for taking the time to read and respond to this co-authored piece. It has been a very long time in the coming and your comments have been extremely useful for developing it further and causing us to rethink certain aspects of our article. Please see my comments below in relation to your points.

I look forward to hearing from you soon.

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author

This paper describes a participatory action research project with seven university students on the autism spectrum. The participants both contributed to and analysed the data, providing a unique insider perspective to both the university experience of these students and participatory research. I congratulate the authors on designing this inclusive and empowering study.

This is a very well written and engaging article, and makes an important contribution to the field of education and social model of disability studies.

The following comments are offered to hopefully strengthen the final manuscript:

Page 1, "Background". I would like to suggest that a couple of sentences describing the "spectrum" of AS would be helpful to further set the scene for the discussion of medicalization and epidemiology that follows. Without this clarification, your introduction makes it sound like the 'neurotypical' community wants to limit access to people with AS simply because they only see the pathology. For people with AS who wish to seek out therapy/support services, the pathologising of their condition allows access to services they may wish to seek. Perhaps the broader issue is that we want our society to create conditions to allow all citizens to reach their potential, and have equal access to choices in education and opportunities for participation/employment.

Agreed - I hope that you will see how I have attempted to neutralise the tone of this section and incorporate a neurodiversity position that accounts for differences without opposing medical and research advances.

Page 3: the series of subheadings with only small amounts of information was a little confusing to me ("Understanding of autism spectrum conditions"; "social interactions"; "Social environment and course requirements"). I suggest creating a broader subheading, perhaps "experience of university" or similar, and replacing the other subheadings with a clear sentence to open each paragraph.

This has been addressed and subsumed into 2 smaller paragraphs with an additional dimension following the aforementioned neurodiversity model.

Page 4, Ethics: for the final version of this manuscript, full ethics details such as institution, date and approval numbers should be included.

I have tried here to offer greater exposition of some of the ethical issues (there were many and in reality I could have written about the research process alone) related to the project and focus in particular on anonymity, consent and subject/co-researcher relationship.

1
2
3 You will also find the two separate ethics approval references, however, if I am honest I think
4 this seems unnecessary and incongruent with the EARJ style; I do not see this same practice
5 reflected in a single other study published in the most recent 2015 edition 23(4) or many
6 submissions before this either.
7

8 Page 4, “Autie-biographies”. This section is well described. I would have also liked to get a
9 sense of how much data was generated by each participant and in total. For example, was
10 there just one autiebiography submitted, or did participants complete multiple pieces of
11 writing?
12

13 Yes I think you are right here - see table inserted to make clearer which students participated
14 at each stage and additional information on some of the data collected.
15

16 Page 5, line 15, sentence: “Independently selected, these topics echo areas of discussion
17 around university provision and experiences outlined in the previous section.” The meaning
18 of this sentence is unclear to me.
19

20 Removed
21

22 Page 5, “Taking the next step in participatory research: data analysis”. This section is a good
23 attempt at explaining a complex process. However, I feel that more information is needed in
24 the following areas:
25

- 26 • It would be useful to have an explanation for why only 5/7 participants engaged in the
27 analysis stage.

28 See how this has been addressed with additional information regarding 2 of the students’
29 commitments that prevented them from being involved at all stages
30

- 31 • A diagram showing the process of analysis would be helpful, as there is very little
32 description apart from a mention of “grounded theory” and “thematic analysis”.
33

34 I have included a table, which I hope satisfies – it should be clear how the codes were used to
35 identify sub-codes and broader corresponding themes.
36

- 37 • Is there any literature that supports a group approach to qualitative analysis? It seems that
38 the approach here is quite unique, and so therefore would benefit from further description so
39 that future researchers can benefit from what you learnt.
40

41 Collaborative analysis is not particularly unique in my view – in much co-authored research
42 the analysis is conducted in this way. Where this study is different is that it is individuals are
43 on the autism spectrum, however, I feel that I have responded to this sufficiently in the text.
44

- 45 • Figure 1: is the academic researcher the first column? It might be useful to use a different
46 heading, and then get rid of the big black line before the participant data – symbolically, you
47 seem divided.
48

49 I agree – on reflection this did signify a barrier – I have simply removed it.
50

- 51 • Figure 2: I don’t find this particularly useful. I would have liked to know which participants
52 went on to complete this step of the analysis, and why some chose not to.
53

54 Again – another good point - removed
55

56 Page 7, Findings and discussion: The presentation of the results is engaging and interesting. It
57 would be helpful to explain to the reader at the start of this section how the results are
58 structured. For Theme 1 and 4, it appears that there are no codes/subthemes? I would suggest
59
60

1
2
3 that the full codes (or subthemes) should also be included somewhere, perhaps as a table or in
4 an appendix, so that the reader can see how the main themes were derived. This is important
5 for the transparency of the analysis process. For Theme 2 and 3, it appears that there are
6 “subthemes/codes”, but these are not labeled as such. I suggest including a descriptor to help
7 the reader follow the analysis.
8

9 **I hope that the table + the additional codes will make this clearer to the reader**

10
11 Page 11, line 5: “Particularly, it was through this process that all those involved in the project
12 were able to see how others had often shared similar experiences of university, thus
13 establishing a community of respect and solidarity.” There are certainly fantastic actions that
14 have come out of this research. However, this sentence is problematic because not all
15 participants took part in the analysis of the data. I suggest that you rework this paragraph to
16 reflect the different ways that participants engaged with the research. It was great to hear that
17 the findings have been shared at conferences and in a variety of other ways. Congratulations
18 on a wonderful project.
19

20 **Yes agreed - I have attempted to be a little more measured here and edited this significantly.**

21
22 **Reviewer: 2**

23
24 **Comments to the Author**

25
26 This paper provides an interesting and novel take on participatory research with co-
27 researchers with autism and gives a very readable and accessible account of the co-research
28 enterprise. There is also plenty here around the potential to promote socially just pedagogies.
29 I think the work would be further improved by adding the following considerations to the
30 arguments of the paper.
31

32 1. More on critical autism literature could be provided especially in relation to neurological
33 atypical activism and activism self-advocacy that is growing in the States and beyond.

34 **Whilst I think that it is important to engage with the advocacy movement generally, I do not**
35 **feel that activism in the US is particularly relevant to this study and would probably take it in**
36 **a different direction. I have opted to focus more specifically on a neurodiversity model of**
37 **autism, which I feel offers a broader view but is still pertinent to the discussion.**

38
39 2. More discussion of the interface between critical disability studies, social model and
40 pedagogy in the early parts of the paper - how do they interact? What would a social model
41 pedagogy look like?
42

43 **Again, I do not think that I have the sufficient space to really engage too much with these**
44 **theoretical issues here; in fact if anything I have simplified this discussion still further. I have,**
45 **however, attempted to be clearer regarding the ‘socially just pedagogies’ proffered by**
46 **Madriaga and Goodley (2010).**
47

48
49 3. More details on the setting up and running of this peice of co-research and the
50 methodological challenges.

51 **Agreed – see greater detail re methods / ethics as per statements above.**

52
53 4. Further explanation in the analysis section on socially just pedagogies - what does this look
54 like in practice? How can or should we theorise socially just pedagogies?
55

56 **As above**

57
58 I hope these comment are useful
59
60