'Here I come again': the cost of success for higher education students diagnosed with autism

MacLeod, Andrea; Allan, Julie; Lewis, Ann; Robertson, Christopher

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'Here I come again': The cost of success for higher education students diagnosed with autism.

Corresponding author: Dr Andrea MacLeod

School of Education,   University of   Birmingham, B15 2TT

Co-authors: Professor Julie Allan, Professor Ann Lewis, Christopher Robertson

Abstract

This qualitative study used Interpretative Phenomenological Analysis to consult with sixteen autistic UK higher education (HE) students about their experiences of success. An in-depth participatory approach encouraged participants to become co-analysts of their data.

Participants offered counter-narratives to deficit-based interpretations of autism, giving accounts of making themselves 'extra-visible' as autistic in order to assert their rights. The autism diagnosis was perceived both as an aid to self-understanding and a cause of additional barriers. In raising awareness of their own needs, participants contributed to broader understandings of autism within their academic communities, inadvertently becoming educators and role models. The research highlights the extra effort required by autistic students to thrive within higher education and the barriers imposed by current requirements to both pursue formal diagnosis, and to disclose it in order to receive adjustments. The research was novel in its approach and in its focus on success, revealing original findings in relation to the challenges and barriers faced by high-achieving autistic students, and the implications for a more inclusive higher education curriculum and environment are considered.

Introduction

The number of disabled students entering higher education within the UK and elsewhere, whilst still disproportionately low, is growing fast. Within this number, those students disclosing social and communication difficulties such as autism/Asperger syndrome have increased dramatically in recent years, surpassing those students

declaring physical/mobility difficulties in 2015/16 (Higher Education Statistics Agency, 2017). The category of autism describes a continuum of common difficulties in social communication and flexibility of thought (APA, 2013) but these are represented within individuals in vastly different ways (Happé, Ronald and Plomin, 2006). Autistic adults[1] have been a neglected group within disability research generally, (Pellicano, Dinsmore and Charman, 2013; Parsons, 2015). They have rarely been consulted as stakeholders or offered an active role within research. Autistic researchers have rightly taken issue with this stance and the limitations imposed by it (Milton, 2014; McWade, Milton and Beresford, 2015).

Given the poor outcomes associated even with the most intellectually gifted (Billsted, Gillberg and Gillberg, 2011) and reports from autistic adults that autism should be regarded as a different "way of being" (Sinclair, 1993, page unknown), there is a pressing need to take account of 'insider' perspectives. Academic education offers important opportunities in this context. It teaches the language of academia, enabling autistic people to communicate with the dominant autism communities in a way that they understand and cannot ignore. Autistic students in higher education have by definition achieved a success valued by our society and have important narratives of success to share. This paper reports on a research study involving sixteen UK higher education students diagnosed with autism, exploring how they made sense of their achievements in the context of the autism label.

Disabled students within higher education

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[1] Boundaries between sub-categories of the autism spectrum, such as between Asperger syndrome (AS) and high functioning autism (HFA), are recognised as problematic (see Wing, Gould and Gillberg, 2011 for a fuller consideration of the issues). Within this paper, , I refer to 'autistic adults' in recognition of the fact that this tends to be the preferred term for those thus diagnosed (Kenny et al., 2015).

Improving educational opportunities and achievements is key to improving outcomes for any young person. In recent years, the emerging widening participation agenda in the UK and elsewhere has led to changes in policy aimed at addressing the needs of non-traditional students (Adams and Brown, 2006). This focus has included disabled students, although arguably they have been given lower priority than other disadvantaged groups. However, since it was not until 2001 that disability discrimination against higher education students became illegal in the UK, there remains the potential for greater discrimination within higher education than other sectors (Hopkins, 2011). Moreover, the current UK higher education landscape, with greatly increased student numbers and modularisation of the curriculum has altered the student experience, arguably to the detriment of more vulnerable students (Tinklin, Riddell and Wilson, 2005).

At the same time, the sector is being called upon to be more inclusive, both in its strategies and its processes (Madriaga and Goodley, 2010). However, as relative latecomers in terms of legislative imperatives, institutions have tended to respond to individual needs, rather than adapt their processes to become more inclusive, and in this way have been more closely aligned to an individualised model of disability that overlooks structural and cultural barriers. Given the evidence that students may seek to adopt a more positive identity in joining higher education, and thus attempt to conceal disabilities (Goode, 2007), non-disclosure can become an additional barrier with this approach (Barer, 2007; Richardson, 2009),

A number of studies have investigated directly the experiences of disabled students entering higher education, examining both student perspectives and the institutional implications arising from the findings. A recurring theme in student accounts has been their experience of bearing personal responsibility for educating tutors about their

disabilities, thus being forced into disclosure and becoming 'extra-visible' (Goode, 2007; Vickerman and Blundell, 2010). Disabled students have found themselves the pioneers of disability awareness, in addition to their academic pressures (Hopkins, 2011; Simmeborn Fleischer, 2012).

Methodology

For the current study, participants were self-selecting, recruited through Student Support departments at five higher education institutions. Student Support Services acted as initial gatekeepers, sending information out to all students who had disclosed autism via email so that participants remained unknown to the researcher until they volunteered to participate. Ethical approval was sought and gained formally via our University's committee. The negotiation of consent was treated as an ongoing process, rather than one event (Authors, 2004)). Participants had multiple opportunities to raise questions or concerns - or indeed to withdraw - as a relationship of trust and familiarity with the researcher developed.

Sixteen participants, ten males and six females, from five universities, went on to give consent and participate in the research. The profile of participants was fairly typical: primarily undergraduate students (n=13) under the age of twenty-five (n=14), who had reached higher education through a standard secondary school pathway (n=14). The male: female ratio of 10:6 reflected a higher proportion of females than the reported male: female ratio of 4-5:1 (Lai et al., 2015) and the sample is unusual in this respect.

The majority of participants opted for face-to-face interviews, with ten choosing this format outright and a further two specifying that they would have preferred face-to-face, but their circumstances precluded it. This is perhaps a surprising finding, given the

literature that suggests autistic individuals may find online communication preferable to direct contact (Jones, Zahl and Huws, 2001).

The participatory methodology was designed to be as accessible as possible for the autistic participants, with the intention of equalising the balance of power between disabled participants and non-disabled researcher as far as possible (Oliver, 1992) and moving beyond a "tokenistic level" towards more active engagement (Bourke, 2017, 232). The intention was to avoid making generalised presumptions but rather to engage with individual preferences. Three options for interview participation were offered: face-to-face; telephone; or synchronous ('real-time') online-interview, so that participants had a choice of format that hopefully included their preferred means of interaction. A synchronous online chat system was used, rather than (asynchronous) email, so that all formats used real time and in that sense, offered a similar interview dynamic. For face-to-face and telephone formats, interviews were digitally audio-recorded and transcribed. The software (MSN Messenger ©) saved a copy of the online chat automatically.

This study employed Interpretative Phenomenological Analysis (IPA), an idiographic approach which aims, through a detailed exploration of the specific, to identify universals that are novel and bring new knowledge and understandings to the field (Smith, Flowers and Larkin, 2009). It offers a combined hermeneutics of empathy with a hermeneutics of questioning, whereby the researcher attempts to both understand the 'insider' perspective and illuminate it from an external position, through making connections with the extant literature. This approachseems appropriate in exploring the experience of individuals labelled with autism, whereby sense-making may require accommodating (or rejecting) an externally-imposed identity or aspect thereof.

A semi-structured interview tool was developed, encompassing some set questions but also allowing space for the course of the interview to follow individual responses. Flanagan's (1954) Critical Incident Technique (CIT) was adapted to give a framework for triggering memories that were specific and factual, but also allow space for reflection and more in-depth description of context. To enable participants to prepare for the interview, a prompt sheet was sent out in advance. This opportunity for advance preparation has proved effective with autistic participants in other IPA studies (Huws and Jones, 2008; Griffith et al., 2012). Participants were asked to think of four 'critical incidents'(reframed as 'significant events') and provided with some broad examples of what these might be. In this way, individuals were given a common frame of reference, had the opportunity to predict what would be expected of them during the interview and to prepare their initial responses.

The interview process was divided into two phases. Following the first interview, the first author undertook an initial analysis of the data and annotated the transcript. Participants were then sent a copy of their annotated interview transcript and a personalised email preparing them for the follow-up interview, the purpose of which was to discuss emerging themes with participants. The intention was both to validate the analysis and to explore areas of disagreement or misinterpretation. Following the second interview, the same process of analysis and annotation took place, and an annotated transcript was once again sent to the participant for cross-checking.

In summary, in order to participate fully in the research, participants were required to provide consent; prepare topics for interview; commit time for two interviews; comment on annotated transcripts; and evaluate their experience of the process. The research approach therefore required a significant commitment of time and effort from its participants.

Results

Three superordinate themes emerged from the data, based on the original research focus upon experiences of success: 'The autistic experience'; 'Elements of success' and 'Identity and autism'. Following Smith's (2011) review of high quality IPA studies using large samples, codes identified by fewer than 50% of the participants were discounted.

Here the focus will be on four sub-themes,, selected from the larger study due to their relevance to the focus of this paper. The sub-themes are titled with illustrative quotes from participants in order to foreground their voices. '*I really wanted to go to university to sort of get away and start anew'*: considers the ways in which higher education was deemed important to participants. *Weebles[2] wobble but they don't fall down'* represents the different ways in which success was articulated as arising from challenges presented or the determination of individuals. Within '*Having the diagnosis put this barrier there as they looked at the label instead of me'*, participants considered the 'label' of autism and its implications, and in *'And that's what drives you forward. It's like "I will show you"'* participants discussed perceived aspects of the autism diagnosis as contributing to their achievements.

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[2] **Weebles** is a trademark for several lines of children's roly-poly toys originating in Hasbro's Playskool division on July 23, 1971. Tipping an egg-shaped Weeble causes a weight located at the bottom-center to be lifted off the ground. Once released, gravitational force brings the Weeble back into an upright position. Weebles have been designed to have a variety of shapes, including some designed to look like people and animals, among others.

The popular catchphrase, "Weebles wobble, but they don't fall down", was used in advertising during their rise in popularity in the 1970s and during successive relaunches in the early 21st century.

https://en.wikipedia.org/wiki/Weeble [Accessed 18th April 2017]

Table 1 illustrates how many participants touched upon each sub-theme in their responses. In most cases, these were discussed by the majority of respondents. The exception to this is the sub-theme '*I really wanted to go to university to sort of get away and start anew*' which was raised by only seven participants, but nevertheless deemed worthy of inclusion due to its direct relevance to the focus of this paper:

Table 1: Representation of quotes by participants

THEME	Number of Participants
"I really wanted to go to university to sort of get away and start anew"	7
"Weebles wobble but they don't fall down"	14
"Having the diagnosis put this barrier there as they looked at the label instead of me"	11
"And that's what drives you forward. It's like "I will show you"	13

'*I really wanted to go to university to sort of get away and start anew' (7/16)*'

Participants described their efforts to reach university, articulating a strong sense of purpose towards the end goal. Ben described a great sense of achievement in overcoming difficulties at school:

[interviewer] In what ways was it significant to you, getting into med. school?

It was a turning point like, after everything in education, all those difficult times, I'd made it.

Hannah articulated the transition to university as an opportunity for re-invention:

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[interviewer] It is doubly amazing that you got the results that you did then. And by the sound of things it was important for you to get into [name of institution]?

I really wanted to go to university to sort of get away and start anew. I only needed 'BBB' to get into [*name of institution*], and I was happy I exceeded this.

Higher education in these narratives was more than a 'next step'. It was a hugely significant goal, in some cases promising much more than an academic opportunity. Through the university experience, participants hoped to achieve a positive new start, and from these accounts, it would seem that they were often successful in doing so. The higher education experience seemed to have a very direct influence upon personal development, as with Thomas:

But what I really feel I'm getting from it, it's the qualification but it's not just the experience of it. It's the experience of all the work that I've done, all the field work and the write-ups and the people I've met, the people on my course, friends I've made and the time that I've been there - I've developed more as a person as well.

Thomas was 'getting' an entire holistic experience which was developing him as a person. He was the active player in this, 'getting' benefits from the university rather than having them conferred, and he emphasised his social as well as academic development. Higher education in these accounts was hugely important as a catalyst for personal transformation.

'Weebles wobble but they don't fall down' (14/16)

The potential of self was of primary importance here. Participants shared a determination to strive to the limits of personal ability, take control of aspects of self that may act as a barrier to progress, and to do this in spite, or even because, of barriers associated with autism. For example, in Debbie's description of the need to push herself to learn:

> I think pushing myself and learning from repeated experiences, it has helped me develop life skills but each time I revisit anything it still causes the same amount of stress as the first time I did it.

Debbie gives an account of effort that was constant and iterative, almost like 'groundhog day' in the pressure, and also willingness, to face old challenges which incurred the same feelings of stress, never lessening with repetition.

Participants spoke a great deal about their determination to succeed in particular goals, whether this was in order to achieve academic success or to participate more fully in the adult social world. Rob regarded his determination as a core and lifelong character trait:

> I think that's one of my character traits, stubbornness and determination...My mum relates it to one of my childhood toys. I used to collect weebles when I was a kid, and the advert used to be 'weebles wobble but they don't fall down.'
>
> *[interviewer] You're a weeble.*
>
> Yeah and that kind of determination and stubborn streak in me, I kind of keep going, no matter what's in front of me. I think that's partly related to the autism.

Using his mother's analogy, Rob described this characteristic as central to himself - it is within the physical nature of a weeble that it cannot be knocked over, and likewise, Rob's determination to carry on in the face of challenges seemed a fundamental aspect of himself. Likewise, Christian seemed ready to embrace failure and be philosophical about the experience:

> You cannot achieve success if you are scared of failure. If you're not afraid to fail your chances of succeeding increase mentally but you're never going to get there unless you risk it all away. I risk failure and was proud of what I do. Sometimes 50% of the fun can actually be failing. Learning from your mistakes. Waking up the next morning and saying 'ok here I come again'.

In many of these accounts, there was a theme of repetition. A weeble is a small toy that is perpetually in motion, always on the verge of, but never actually, falling over. Others cited the need 'not to stop' but to keep repeatedly striving, even if the hundredth attempt is every bit as stressful as the first. The experience of failure becomes an important aspect of the learning - even, in Christian's case, a positive aspect.

Participants described successes that had arisen from a conscious determination to achieve valued goals, and in doing so, be willing to risk failure - to prove to self and others that they possessed the potential for success. Linked to this was the desire to demonstrate that barriers could be overcome. Narratives of success were often framed within the context of obstacles to be surmounted, which they made sense of either as personal (internal) barriers, or (external) barriers associated with their autism diagnosis.

For Aimee, the hurdles to be overcome were the - -low - expectations that others had of her:

Well, I remember every single little meeting – you know when they have these meetings about how they think you're going to do in the future? – I remember every single time it was like 'she's doing better than we expected' and I was like 'well what did you expect?'

Aimee was very precise in her memory of 'every single little meeting' and her repetition of 'every single time' emphasises the impact of the responses she received from adults in authority, whose expectations were consistently out of step with her actual progress. Success for her was the confounding of those low expectations. Elliot described re-sitting an exam with adjustments in place for him, and moving from a fail grade to an 'A' grade:

Obviously a sense of achievement that I felt that I had a grade that was obviously a lot more representative of my ability…because since 'D' was a result of a particular difficulty not as a result of not being able to do it...Well, if I had got the 'D' and then hadn't been given the opportunity to do it again and have it explained then obviously I think I would have felt a bit hard done by…But, em very happy that I obviously got the support and had the chance to try it again.

In this case, the hurdle to be overcome was a lack of understanding from his teachers. Success stemmed directly from appropriate adjustments being put in place, and in Elliot's case, the difference this made was extreme. In his comment that he would have 'felt a bit hard done by' if he had not had this support and second opportunity, there was a strong message. Although understated, it was rendered emphatic by repetition of the word 'obviously'. Where for Elliot, this account was presented as an experience of success and self-affirmation (in his understanding that the barrier was connected with

autism and not his abilities per se), for others without this second chance, it would have become an experience of failure, leaving him with a sense of injustice and potentially limiting his educational opportunities. Debbie described the support she received post-diagnosis as making the difference between passing and failing her GCSEs:

> After getting the diagnosis mom...explained all of my stresses and managed to get me a room on my own with a key to go to the toilet if I needed to, as the toilet is also a big issue for me...after doing my GCSEs in a [private] room I then passed them which proved it was the environment rather than my learning skills.

These relatively small adjustments validated Debbie's experience of having the potential to achieve, but having been unable to do so before her support needs were recognised. Accounts revealed firmly-held beliefs in the potential of the self, and the necessity to hold onto those beliefs in the face of negative experiences.

'Having the diagnosis put this barrier there as they looked at the label instead of me' (11/16)

Participants talked of the ways in which autism, either through the 'label' or through the associated difficulties, had acted as a barrier for them. Debbie talked of the diagnosis itself as a barrier:

> I feel that having the diagnosis put this barrier there as they looked at the label instead of me and this is why I don't tell many people that I have a disability…"

Debbie's own identity had been replaced by the label of autism, and so she preferred to hide the label.

Autism is often regarded as a continuum, with 'atypical' (autistic) meeting 'typical' (non-autistic) at a certain, but non-specified point on the continuum. Participants considered these typical/autistic boundaries in relation to themselves. Ben articulated his sense of himself as an autistic person changing according to mood or circumstance:

> On a good day it's just barely there, just something in the background but on a bad day when you're sat on your own (or reading Facebook and seeing what life is life for everyone else) it is tempting to imagine how things might have been different.

In this example, Facebook seemed to compound the problem rather than alleviate it. This may seem surprising, since social media has been held up as offering great potential for autistic users. However, as it is a social medium that often mirrors real social groupings, it can also, as here, serve to remind users of a social world from which they feel excluded.

Hannah considered her social success in achieving, through considerable effort and courage, what a 'normal' [her words] person would manage with relative ease:

> It's the autism that made it a success, really. Normal people without autism or anxiety issues just do these things. It's a success 'cause I managed to do it despite the autism making it difficult.

In contrast, Josh considered how the same trait could be viewed as autistic or typical, depending on who was doing the viewing:

> Would somebody classed as normal do the same thing, do you know? You've got to be so careful of creating difference where there isn't any difference as such...Is my anxiety AS or is my anxiety what a normal person would have.

Getting anxious over my driving test for example. Plenty of people get anxious over a driving test.

In his caution about 'creating difference where there isn't any difference as such', Josh articulated a key dilemma. Participants described awareness of difference, both in their approach to the world and the response of others to them. However, they were still very much in-the-world, and these differences were not all-encompassing. Josh's words caution that the label can in fact have a de-humanising effect; the dominance of 'difference' over commonality in the 'autism identity'. Sandy, who was unsure if he agreed with his autism diagnosis, reflected on the complexity of defining associated characteristics within himself:

It's at least very difficult and probably impossible to say – 'well it's not' or 'yes it is'. Regardless of what you say it's going to be part of you because it's intimately linked. Or not intimately linked but I don't know what the difference is. And nor do they...after a while people start saying everything is to do with it. And then what's the point of saying it?

Although individuals also talked of the positives of diagnosis (for example, Hannah: I think my life's improved since, because I know I'm not just making a fuss over nothing, and I have a word for the way I am) these accounts illustrate that the experience of an autism diagnosis involves, at least in part,   facing new barriers - those imposed by the presumptions of others. Individuals had to find ways of overcoming these barriers in order to achieve success, and as illustrated in the next section, it was sometimes this that defined the success.

'And that's what drives you forward. It's like "I will show you"' (13/16)

Often, successes were defined by exceeding either participants' own expectations, or those of the people around them. In Josh's case, achievement was important in order to prove wrong those authority figures who had written him off during his school years:

> Because I've got a lot of bad memories of people in education who basically said to my mum 'Josh will not achieve anything in his life'. And that's what drives you forward. It's like 'I will show you' and that's what it's all about really.

Accounts revealed a determination to achieve, and suggested an awareness of their own potential, even in the face of external barriers. For some, their differences growing up had led them to be judged and under-estimated. Worryingly, judgements sometimes came from educators who were instrumental in either affording, or withholding, opportunities. Potential to succeed was therefore very directly affected by the way in which they were perceived by the authority figures surrounding them. In other cases, participants under-estimated themselves. They nevertheless worked to the best of their abilities and in doing so, surpassed their own expectations. Hannah was surprised by her achievements, despite the fact that they had been predicted by her parents and teachers:

> ...because I really didn't expect to do that well.   You asked if anyone expected me to do so well in my 'A' levels; my mother said she wondered if I'd get an 'A'. Physics teachers had believed I could get an 'A' (I never thought I could and still don't know how I managed to!).

Participants often responded to their situation by wanting to improve understanding of

autism. Greg described a spontaneous decision to stand up in assembly and share his experience of having Asperger syndrome:

> I just felt like I wanted to speak up and say something…Next thing you know I got a letter from one of the girl's classes that everybody's signed and it said 'thank you for being so brave'…

Debbie wrote a personal account to be used for staff training and recounts her reasons for doing so:

> Having AS I wasn't able to let people know how I felt and things I found difficult, the only person I would tell is my mom, but as I get older I feel it's important to let people know as other people who have been diagnosed may feel the same and not be able to let people know

In these ways, participants were using their experiences to connect themselves not just with autistic/disabled communities, but with the community as a whole, finding ways to create positive outcomes from their challenging situations.

In summary, participant responses were very individual as would be expected, reflecting a diverse group of participants with different life experiences and perspectives. What these different narratives share is the description of needing to work hard, not just towards their goals, but also to overcome barriers – barriers which might be internally experienced or externally imposed. The depth and eloquence of these accounts suggested the expression of ideas and opinions that had been formed and contemplated over a period of time. In many cases, the research seemed to offer the opportunity for participants to voice long-held thoughts on their own situations.

Discussion: The 'cost' of success

Within the current environment of higher education, additional support is contingent on disclosure of diagnosis, but for autistic students, like others with less visible disabilities, disclosure is also a choice (Riddell, Tinklin and Wilson, 2005). Decision to disclose will be influenced by, amongst other things, the ways in which individuals identify (or not) with the diagnoses they have been given (Holt, 2012). Individuals may subscribe to different identities (eg. disabled, non-disabled) depending on time, context and, to some extent at least, personal choice.

Within this study, reflections on success revealed experiences framed by awareness of disability. There were descriptions of personal barriers, sometimes related to social anxiety but at least as often, to the assumptions and limitations imposed by others. In order to succeed, participants had been forced to resist deficit-based interpretations of autism from others. Voices of resistance were apparent throughout the accounts - articulating in very different ways participants' determination to reach their goals, with or without support. Narratives referred to negative experiences at school, and in contrast, participants often described their university experiences as positively transformative, describing not just academic, but also social success. Madriaga (2007) found that students welcomed the opportunity to re-invent themselves at university, and this often seems to have been the case in these accounts, albeit with continuing challenges.

This research also revealed considerable challenges faced by young autistic students within the compulsory education system. These young people had the potential to succeed, as evidenced by their transitions into higher education. However, within their narratives, they presented more as 'lucky escapees' than products of an effective and inclusive school system. Adjustments often came later, following initial resistance from educators, and depended upon

a minority of isolated champions or serendipity, rather than a network of supportive professionals. Accounts were less critical of the higher education system, perhaps due to its ability to offer opportunities for transformation, reinvention and escape, or perhaps, as found in other studies, simply because the experience of higher education was better than school (Hopkins, 2011).

Nevertheless, within the accounts is evidence of supportive people who had pivotal roles in enabling and encouraging their achievements, and this is not insignificant. The pedagogues, peers and parents who, in countless small and often simple ways, removed barriers, opened up possibilities, and influenced the futures of participants for the better, should be viewed as examples of what is possible within our current societal structures.

Negotiating the diagnosis

All participants in this study had a formal diagnosis of autism, although not all agreed with it. Whilst some had pursued diagnosis for themselves, others had it imposed upon them in childhood, causing a traumatic period of coming to terms with its implications. Still others reacted with an ambivalence that suggested unproblematic acceptance. In short, responses and experiences were hugely different even in this fairly small sample. Diagnostic labelling is a problematic practice. Its stated intention is to support the child and ensure they receive better provision and opportunities. As Allan (1996) has suggested, "...in a climate of resource constraints, distance from the norm has become valued" (223) and this is particularly apparent in the case of autism, where specific implications for therapies and interventions are attached to a diagnosis. Other studies looking at higher education students have indicated that diagnostic labels were useful in enabling practitioners to be more aware and to ensure that adjustments were put in place (Madriaga and Goodley, 2010; Molloy and Vasil, 2002) More

often, the key difference for these participants was better self-awareness and crucially, less self-blame. Diagnosis removes, or at least reduces, the barrier of feeling personal responsibility for disabling experiences. Yet even for those who welcomed diagnosis, the tone was not celebratory, but more bittersweet, with the label bringing its own challenges. This is arguably the problem with diagnosis and how it is currently used – it is primarily a language of categorisation, rather than a force for change.

The diagnosis of autism is often imposed upon individuals without their choosing it (Shakespeare, 2006), and there needs to be recognition that to apply a label that is likely to influence that person for the rest of their life, whether or not they have chosen it themselves, is not a neutral action which carries no further responsibility. Rather, it is a radical action, carrying significant potential for damage. Within the sphere of higher education (and indeed, employment), it becomes a different type of issue. In common with similar legislature elsewhere, the UK Equality Act (2010) confers a range of rights and adjustments for disabled people, but these are entirely dependent upon individual disclosure, which is in turn dependent on the individual having some acceptance of their diagnosis and indeed, awareness of their potential rights.

It is of note that participants responded to the negative experiences in their lives by wanting to improve understanding of autism and the situation for autistic people more generally. They had often chosen to make themselves 'extra-visible' in their school careers, foregrounding their 'autistic self' in order to share their personal experiences with peers or educators. There were examples of this even in cases where the participant had described ambivalence about the part autism played within their sense of identity, as described by Debbie. She and others saw themselves as agents for change - writing, speaking and performing in order to share their experiences.

Participants were active in their efforts at self-work, willing to risk failure and face personal challenges in order to reach their goals. At the same time they resisted presumptions associated with the autism label, and articulated instead the complexity of autism as an identifier, and indeed its inadequacy in representing their experience. Brownlow & Dell (2013) noted that autistic individuals currently draw strategically on discourses around disability, contingent on which may the most appropriate course of action for the current time, and suggest that rather than debating the 'true' ontology of autism, energies are better spent focusing on the common disadvantages and inequalities experienced by those so labelled. Within this study, participants likewise took pragmatic decisions about their identifications and indeed, through their activities they took ownership of 'what it means to be autistic' and sought to change this in positive ways. The philosopher Ian Hacking has talked of such narratives creating a "looping effect" (Hacking, 1999, p.34), whereby the new knowledge that is produced by autistic accounts influences interactions between autistic and non-autistic people and also influences the ways in which autistic people think about themselves. Through this looping effect, how autism is understood, defined and even classified is itself transformed.

This challenging of dominant ideas through lived experience potentially helps to bring autism studies into line with some other areas of disability studies, in which debates are influenced more equally by stakeholders who experience disability and those who do not. They contribute forcefully to discussions surrounding diagnostic labelling practices, highlighting the additional barriers, internal and external, that these processes can impose upon the individual, as well as the benefits that they could and should confer. As Broderick and Ne'eman (2008) observe, counter-narratives of autism such as these play an important role "in the process of cultural critique and resistance to ideological hegemony." (474).

Reflections on the participatory approach

In choosing to focus in-depth on the experiences of a relatively small number of participants, my findings are inevitably constrained by sample size, and caution must therefore be exercised in generalising results. It is acknowledged that IPA research cannot be used to generate nomothetic claims, although key emergent themes can be of use in moving understanding forward on a more general level (Smith, Flowers and Larkin, 2009). The participatory model demanded considerable commitment from those involved. Other studies have found that the time commitment required for participatory approaches can be problematic (Nind, 2011) and may reflect the researchers' values, rather than those of participants (Bourke, 2009). In this light, the zero dropout and subsequent willingness from participants to comment on publications would seem to offer a validation of the approach. More broadly, it indicates the huge (largely unused) potential that autistic individuals have to become a force for positive change - and ought to be a call to arms for practitioners and academics within the autism field to harness this potential and acknowledge the contribution it offers. This research focused on areas of success rather than failure and sadly, was highly novel in doing so. All of the participants within this study had experienced successes within their lives. These were not limited to academic successes; however, by entering higher education, they had each achieved one of their life aspirations, and were working towards others. They demonstrated that they were resisting limitations imposed by a deficit model of autism, or by narrow, two-dimensional definitions.

All study participants were sent a draft of this article for comment. Four offered feedback, concurring with its findings and commenting on the similarity of their experiences, especially with regard to the double-edged sword of formal disclosure: 'I often wondered if I had sold my soul to the devil'.

Conclusions

Higher education plays an increasing role in the lives of young people, as more are steered towards undergraduate and postgraduate study as the pathways most desired by employers. In the very act of disclosing disability and seeking adjustments, students are faced with further hurdles to negotiate, requiring their time and effort, and potentially causing stress – an additional challenge that non-disabled students do not face. Institutions, and the staff within them, need to take note and seek to minimise the stress caused by their own systems. The pressurised higher education environment has already been linked to an increase in students with mental health needs (Callender et al., 2011).

Participants were on the whole positive about their experiences within higher education. However, there were within this study (and echoed in the wider literature) many descriptions of social alienation; of being misunderstood by figures of authority, and of the enormous extra effort required by them in comparison to their non-autistic peers. An important finding for educators is that, in many cases, the accommodations that made the difference between success and failure for these participants were very minor: for instance, access to toilet facilities or discussion of the implied meanings of exam questions. In an educational environment that properly values individuality above conformity, many such adjustments could be available without the need for individual disclosure. Moreover, they may well benefit the many rather than the few. Higher education environments are increasingly diverse and provision needs to be flexible enough to accommodate diversity in all its forms – an inclusive approach benefits other non-traditional learners such as international, mature and part-time students (Morgan, and Houghton, 2011). Recognition of the impact that can be made by simple adjustments is of huge value not only to autistic students but to *all* students – illustrating inclusivity as an achievable aim, rather than a complicated ambition.

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