

Chapter 26: University through the eyes of autistic students and staff

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Dedication

This chapter is dedicated to Jo Krupa for her amazing proofreading talents and reference checking. As a neurodiverse academic, I rely on Jo's support with this aspect of my writing as well as lots of other things. Thank you, Jo.

Introduction

Work-related experiences of autistic university employees and freelance researchers receive scant research attention. This chapter seeks to slightly reduce the size of a very large hole into which this area of enquiry seems to have fallen by including information from a small scale survey of autistic lecturers and researchers involved with The Participatory Autism Research Collective (PARC). Research which aims to identify barriers to higher education participation identified by autistic students is a little more prolific and examples are discussed here. Striking overlaps between the narratives of autistic people working and studying at university emerge and conclusions are drawn from the available evidence about common approaches which could benefit autistic employees and learners alike. These shelter largely under the universal design (UD) umbrella and are generally obvious and uncomplicated. UD can potentially benefit everyone because the approach involves planning for diversity rather than being surprised that the mythical norm is imaginary. The ethos of UD is congruent with the anticipatory anti-discriminatory duty of The Equality Act (2010). A model that has acquired the acronym REAL is discussed as a way to conceptualize good autism practice within a UD paradigm with the potential to benefit everyone. The approach is informed by a commitment to equality as a social justice concern. REAL stands for: reliable, empathic, anticipatory and logical.

The emergence and purpose of PARC as a vehicle for autistic scholars to collaborate is discussed. Although the collective's reach is far greater now, PARC originated from The Critical Autism and Disability Research Group (CADS) at London South Bank University (LSBU). Participants regularly echo the contentions of autistic contributors to this paper that they are seldom remunerated justly for their contribution to autism research. CADS operates within the Centre for Social Justice and Global Responsibility at LSBU and paid autistic co-researchers are always central to our autism research. This policy decision is a point of principle informed by a social justice ethos, the principle being 'nothing about us without us' (Charlton, 1998, p1). Further pertinent detail about PARC follows in the next section.

PARC background

PARC⁴⁹ originated (unfunded) in 2015 when Dr Damian Milton and I were working together at London South Bank University (LSBU) on the two-year Cygnet Mentoring Project, funded by Research Autism, which looked closely at effective mentoring and mentor training aimed at autistic adults (Milton *et al*, 2017; Sims *et al*, 2016). Our aim with PARC was to create a structure that would provide opportunities for autistic researchers to work together and influence autism research. PARC participants write together, apply for research funding together and conduct seminars and conferences which showcase autistic expertise. In addition to the prolific contribution of Dr Damian Milton⁵⁰, further examples of publications by PARC members include: Arnold *et al*, 2018; Chown *et al*, 2015; 2017; 2018; Loomes, 2017; 2018; Ridout, 2017; Ridout & Edmondson, 2017; Woods, 2017; Woods *et al*, 2018; Woods & Waltz, 2019. Common to each is insider perspective and a strengths-based approach which problematises deficit model thinking about autism in particular and neurodiversity more generally.

PARC meetings now take place across the UK and international collaborations are forming in Europe, America and Australia. Many PARC members do not have secure paid employment commensurate with their academic qualifications. Often, they work to further the collective in their own time, unremunerated. This is not a comfortable situation. Although PARC has highlighted the concern, nobody has yet systematically gathered evidence about how many autistic scholars are actually being paid properly for their contribution to research. Autistic university employees and researchers face myriad barriers to full participation (Chown *et al*, 2015; Martin, 2017), so it is little wonder that autistic voices are either almost silenced within the research arena or effectively giving their expertise for free.

49 <https://participatoryautismresearch.wordpress.com/>

50 <https://damianmiltonsociol.wixsite.com/dmilton-autism/publications>

PARC participants are generally extremely positive about the opportunities the collective provides. The following comments from PARC participants are typical:

'It gives me life. I feel incredibly isolated and disconnected from the university which has system that I find inaccessible in many ways. PARC events and the networks of autistic researchers and allies that maintain communication across Twitter give me a (albeit distant) sense of camaraderie and belonging, as well as provide a great source of inspiration and knowledge.'

'PARC events are accessible (financially and expectation wise) and a great way to share differing viewpoints. The only thing is getting the confidence to go and finding such networks exist in the first place.'

The danger of over-promising and under-delivering was illustrated by an autistic academic who felt disappointed that PARC was not resourced to provide more practical assistance. Given the complete reliance on volunteers and lack of infrastructure or funding, PARC cannot provide any sort of bespoke service as it operates solely on good will and peer support. With funding and administrative backup, PARC could do so much more.

Since its inception at LSBU, as a result of the energy and commitment of autistic academics, PARC has gained traction in other universities in and beyond the UK (Milton *et al*, 2019). Seminars, researcher development events and conferences were increasing in frequency pre Covid, and plans are afoot to pick up once the pandemic crisis has eased. As most autistic people are not in lucrative employment (Barnham & Martin, 2017), events are always free, and this is made possible by the support of the universities hosting them. Many autistic scholars involved with PARC are self-funding doctoral candidates who cannot afford huge conference fees.

Further development of PARC is planned, particularly around influencing autism researchers about the apparently thorny issue of paying properly for autistic expertise. So far, no magic money tree has appeared to assist in this endeavor. In an ideal world, articulating the principle of fair pay when bidding for research funding would impress the funders, and even one day become the norm.

Universal design

Jorgenson *et al* (2013), Milton *et al* (2016) and others reflect on the origins and practices of UD and Universal Design for Learning (UDL). Milton *et al*'s paper focused specifically on the requirements of autistic people but reinforces the point that good autism practice is good practice for all. Put simply, UD and UDL involve planning based on the assumption that people are not identical and therefore will

have a range of access requirements relating to environments, systems, interactions and everything else. Not making assumptions that everyone thinks, feels, learns and moves in the same way is a good starting point which is broader than a disability equity concern. Ramps and automatic doors for example, help anyone moving anything on wheels. Heteronormativity and gender normativity are not the default positions in UD, so gender neutral toilets reinforce belonging and ‘they’ is a helpful default pronoun. Intersectionality is understood as ordinary, so plans with a specific autism badge on them are less useful than those more sensitive to individuality. One PARC contributor who also has a physical impairment discussed either experiencing multiple oppression or acceptance of their embodiment as just ordinary. Understanding and appreciating the value to society of diversity, and utilizing UD to enable full participation of everyone, is the gold standard. Disability is, however, frequently problematized when other diversity strands under the Equality Act (2010) are celebrated (Martin & Fraser, 2012). UD de-problematizes difference by proactively planning for inclusion and is congruent with the anticipatory duty articulated in the Equality Act (2010). The following comment shared by the line manager of a PARC member is indicative of an unhelpful lack of understanding of UD and equality principles: ‘He is an academic, he has to learn how to navigate the admin systems.’ Later in this chapter the REAL model is proposed as a way of conceptualizing good autism practice underscored by UD thinking, with benefits beyond creating conditions for the effective and equitable participation of autistic people.

Emancipatory research principles and ethical concerns

In this section I reflect specifically on ethical considerations arising from a body of work that I authored or co-authored. I am not the only researcher in this arena by any means, but I am not well placed to critique in detail the ethical foundations of other studies because information provided about the ethical dimensions of the work is usually brief and somewhat anodyne. It is certainly very rare to see any sort of statement about paying autistic researchers.

Mindful of trying not to fall into the ‘researcher as parasite’ (Stone & Priestley, 1996, p699), I acknowledge that although I am disabled, I am not autistic and cannot therefore claim direct insider perspective. Emancipatory researchers emphasise the importance of insider perspectives, but there are arguments that the idea of insider is not necessarily impairment-specific (Barnes, 2014). Impairment-specific research runs the ethical risk of identifying labelled individuals as other, by reflecting the salient features of the othered identity while de-emphasising individuality (Madriaga *et al*, 2008). Interactions between systems and procedures

which have not been equality impact-assessed under the Equality Act (2010), and my own neurodiverse cognitive style have certainly created problems for me in the workplace. My experience may well equip me with some degree of empathy with others who do not conform to the erroneously assumed neurotypical stereotype.

Emancipatory research is characterised by involvement of, control by and usefulness to disabled people (Barnes & Sheldon, 2007; Barnes, 2014; Barton, 2005; Oliver, 1997). While CADS aspires to emancipatory methodology, currently work emanating from the research group is at best participatory because of the level of control of the process by autistic people. Autistic participants in many of the studies with which I have been involved have provided their insights without any sort of incentive beyond selflessly making things better for others. (Examples include: Atkinson *et al*, 2011; Hastwell *et al*, 2012; 2013; 2017; Beardon *et al*, 2009; Madriaga *et al*, 2008; Martin, 2000; 2005; 2006a; 2006b; 2007; 2008a; 2008b; 2008c; 2011b; 2012; Martin *et al*, 2008; Milton *et al*, 2017; Sturgess, 2018). In keeping with the emancipatory principle of usefulness, findings have been reported jargon-free, mainly in practitioner journals, in order to reach people who are able to enact useful research-informed practice improvements. While steering groups of autistic people steer the ship, and paid autistic researchers are part of the team, CADS has yet to undertake a project led by an autistic principal investigator, so falls short of the emancipatory ideal in this respect, too.

Studies cited here with which I have been involved had ethical clearance of course, but these research outputs are not without ethical dilemmas. Alongside others I have gathered vast amounts of data over the years, some of which I feel we have not scrutinised as fully as we could have. Beardon *et al* (2009), for example, have only thematically analysed in depth one theme of the vast ASPECT report (Beardon & Edmonds, 2007). The moral responsibility to ensure that data analysis is detailed and informed by disabled people requires enough time to deeply and repeatedly engage with the process. Conducting unfunded research while navigating other time pressures does not negate the moral responsibility to do justice to the very personal information provided by participants.

Limitations around questionnaires are considered in Martin (2008a). Comparison between student interview data from Hastwell *et al* (2013) and Madriaga *et al* (2008), and questionnaire responses from Martin (2008a), evidence the relative richness of working with transcripts of interviews. I have tried not to fall into the ethical trap of over-generalising from questionnaires and interpreting responses of some people with a particular label as if they relate to a larger population. PARC participants are keenly aware of the danger of assuming homogeneity by impairment label. The interpretivist paradigm (Willis *et al*, 2007) which characterises my body of work signals a move from ‘this is what I know’ to problematising the notion of knowing,

influenced by the contention that there is no such thing as shared objective truth, as 'knowing' (Cooper, 1981; Foucault, 1982; Peters, 2003).

A continuing ethical responsibility is incumbent upon researchers because once something is published it is 'out there'. Ethically, researchers need to be mindful of the potential on-going impact of work which is in the public domain (ideally being contactable to answer questions and address misconceptions and generalisations). Participant anonymity is particularly pertinent as people can change their minds over time about what they want to say. I always take great care to ensure that no research participant could be identified. I also harbour a concern that I might unknowingly cause anxiety on occasion because participants did not feel confident to let me know.

Foucault's work around power relationships is relevant to research in which the researcher, directly or indirectly, has power over the researched (Foucault, 1982; Goodley, 2010; McIntosh, 2002). Undertaking research with autistic students while being in a position to impact directly on their university experience has an ethical dimension. Research ethics is about more than filling in a form and seeking approval, and the concerns I have already raised about the exploitation of autistic researchers who are giving their expertise for free come under my personal research ethics umbrella.

Alongside Barnes and Sheldon (2007), Barnes (2014), Barton (2005), Milton *et al* (2019), Oliver (1997) and others, 'nothing about us without us' is an ethical principle in my book. The operation of respectful non-exploitative working practice is part of the equation within CADS research.

Many PARC participants are involved in HE as either doctoral students, researchers and/or lecturers. Contributors insights into a small-scale survey about their perceptions of barriers and enablers around university work in these roles inform the next section.

Insights about employment from autistic scholars

Contributors to this section completed a short questionnaire or wrote their ideas on Post-it notes at a PARC meeting. The questionnaire was emailed by an autistic academic and asked open-ended questions around a loose set of themes designed to elicit comments about barriers and enablers in higher education employment. The following observations are only based on a small snapshot of 12 individuals of all genders between their mid-30s to mid-50s, and do not claim to be representative of anyone else. Unfortunately, there is no solid evidence base on which to build firmer conclusions. Nobody who replied had a full-time, permanent academic contract. Tangible parallels between staff and student experiences were immediately apparent from the small number of responses and the tiny amount of research

focusing on staff experiences. Points from research gleaned using search terms such as autism, employment, university and autistic academics are included alongside direct quotes from questionnaire responses.

The employment of PARC participants is almost always fractional or hourly paid. Doctoral candidates often occupy a liminal space between university researcher, part-time lecturer and student. Their contribution is included here under the loose category of staff, but straddles rather uncomfortably the staff-student divide. More uncomfortable is the fact that some participants identified here as researchers are not really university staff in the traditional remunerated sense, as the university is not paying them, and neither is anyone else. Disappointingly, it is not uncommon for PARC members to leave university with a doctorate only to find themselves without a job related to their area of expertise. The following is not indicative of unbounded optimism in this regard:

*‘*IF* I make it through my PhD (which in itself will feel like an overly tremendous achievement) I do not know how I will find a place for myself in academia.’*

Common characteristics of scholars associated with PARC are a genuine in-depth interest in their area of academic expertise, an immense capacity for hard work and a desire for their employment to make use of their talents. The follow comment illustrates a typically positive but cautious attitude:

‘I hope I will be able to find a department where my needs will be taken into account and I will be supported to thrive and undertake work that, in turn, will hopefully benefit more autistic people both in its manner of engagement and co-production, and in terms of applications of findings.’

The advantages of having someone on the team who possesses these qualities hardly need to be spelled out. Despite evidence of academic excellence including peer-reviewed papers, typically, as revealed by the following comment, contributors did not assume that they would have a smooth trajectory into work commensurate with their talents and achievements:

‘While universities might “traditionally” have been institutions that could have suited autistic academic employees very well, these days are long gone. Nowadays, the ever-changing face of Higher Education means that demands are myriad and varied, lack tangibility and could pose frustrating challenges to an otherwise exceptionally competent autistic academic.’

Pre-entry considerations focused on criticism of recruitment practices. Promotees found themselves disadvantaged again either by the difficulty of negotiating

processes, which lacked transparency, or the feeling that procedures around progression were too daunting to even contemplate. Some talked with sadness about feeling that they might need to attempt to hide their autism in order to secure employment and then continue to do so in the workplace, at great personal cost. Their rationale was that this was a necessary evil in order to be able to fit in and avoid stereotyping and discrimination.

While most disabled students can access technological and other forms of assistance from the Disabled Student Allowance (DSA), and a range of in-house services, the lack of equivalent systems for employees was identified as a barrier by contributors. This concern is echoed in research which suggests that processes for assisting the transition to work of disabled students are inadequate (Barnham & Martin, 2017; Wilson & Martin, 2017).

Access to Work (AtW) (Sayce, 2015) is an imperfect employee-facing initiative which nevertheless has potential. Processes around AtW and similar initiatives were variously described as chaotic and not joined effectively with university systems. One participant suggested that they could hardly face trying to make AtW work for them because the interface between the scheme and the institution felt impenetrable, medicalised and othering, and confidentiality could not be guaranteed. This is unfortunate because AtW is designed specifically to assist disabled employees already in the workplace, as well as job seekers. The scheme offers a range of valuable resources including personal assistant-type support and training in assistive technology. Alarming, autistic scholars involved with PARC and trying to move into academic employment post doctorate have very little knowledge of AtW which suggests that nobody is telling them about it. The Equality Act (2010) applies to careers and alumni services and disabled students should have equal access to their resources post-graduation.

Autistic applicants particularly commented on the interview process, which did not routinely play to their strengths because of unspoken expectations around neurotypical approaches to communication. These included engaging in irrelevant chat, making sustained eye contact without staring, and deciphering convoluted and improbable lines of questioning. Feedback on the recruitment process for one research project commended the practice of providing straightforward written questions for the candidates, all of whom were autistic, half an hour before the interview. Doing so required minimum effort and could easily become routine, alongside things like thinking about the sensory environment and the clarity of information provided. Autistic people are best placed to advise on exactly what is required. Promotees described similar issues around processes associated with promotion. Research evidence suggests that disabled people working in supportive teams certainly think twice about going for promotion, for fear of being unable to replicate hard-won supportive working conditions in another context (Roulstone & Williams, 2014).

Administrative procedures were found to be particularly challenging by autistic academics, many of whom felt that their induction had been inadequate, lacking in practical detail or even non-existent. A PhD scholar made the following comment, which is also relevant to staff:

‘Administrative barriers are the most immediately stressful. Complex and convoluted online systems and programmes, and labyrinthine networks of people that you need to call or email to get things done or fixed... struggling and failing ... through an impossibly challenging online system that was both visually impossible to navigate and not designed in a way that would be accessible to anyone.... It left me very much with the sense that – this system is not for “people like me”. Either the university did not expect “people like me” to progress this far into education, or they simply don’t want me here.’

Another respondent expressed exasperation about, *‘a reluctance to provide explicit instructions, with the suggestion that it is up to the individual to make up their own way of doing things, which generally results in a later situation in which it is revealed that the only way to do things was their way (which they did not communicate).’*

Bureaucratic requirements were not experienced as value-free by the following contributor, who felt that the institution was not geared up to embrace difference practically and positively. Some might call this ‘(institutional) ableism’, which is exemplified by a culture in which a ‘mythical norm’ dictates the way things are done and variance is not tolerated, let alone celebrated (Campbell, 2009; Jammaers *et al*, 2013; Kattari *et al*, 2018).

‘Misunderstanding of my needs, negotiating bureaucracy and unwritten cultural expectations, jumping through hoops... there are many barriers to working in this sector.’

Assuming the ability to navigate impenetrable complexities about getting paid without road-testing the processes with people who might face disadvantage, as in the next example, suggests that systems may not have been equality impact assessed as required by The Equality Act (2010):

‘Getting actually paid for work I had done was almost impossible. I had more than one contract because I had more than one role. I never saw these contracts so could not really work out what I was being paid for and whether I was paid at all for some of the work.’

The following description is of a situation that has gone horribly wrong:

‘I’ve had a lengthy career outside academia... However, my one month in an academic post came to a grinding halt when I was found wandering in a daze outside the office...’

I stopped ... for the sake of my mental health. Although it hasn't always been the easiest, this is the one and only time I have been unable to cope with employment.'

Research with disabled staff in higher education indicates that administrative systems that are difficult to understand and technological requirements that are hard to pick up often create extreme stress. This is particularly so if accompanied by an inadequate induction underpinned by the expectation that the new person will just work it all out for themselves (Martin, 2017). Autistic scholars trying to negotiate inadequately explained work practices described being overwhelmed and completely stressed out by tasks which were apparently supposed to be simple. Being the one who is just not grasping the plot by mysterious, magical osmosis is an othering experience with which I am also quite familiar as a neurodiverse academic. I share the view of autistic colleagues that advice which includes the expression, 'It's easy, you will just pick it up as you go along,' is both annoying and alienating. Angell-Wells (2019) suggests that anxiety around getting to grips with workplace technology is by no means limited to disabled employees. Her research identifies an aching wide gap in enquiry concerned with the affective dimensions of learning to handle intimidating and unfamiliar ICT systems.

Conferences are not routinely autism friendly. Networking demands social competences and motivations not necessarily traditionally associated with autistic dispositions. Small talk unrelated to the conference theme, for example, is often an unspoken expectation which not all autistic scholars enjoy. The following contribution illustrates that, before even getting there, paperwork and travel can pile on the stress:

'I spoke at three international conferences, all of which were incredibly terrifying and none of which were paid... I don't feel I can do that again without some practical support if the journey is to another part of the UK or abroad. I'm not sure how I will be able to get those kinds of accommodations, so I've put the ideas of conferences off for now.'

Although under-resourced and by no means perfect, PARC conferences on the other hand are led by autistic academics and organised with some understanding of the requirement for clarity and sensory sensitivity.

Environmental and sensory issues are revealed in the preceding and following quotations and exacerbated by open-plan offices, hot desking and similar practices. Equality impact assessment is relevant to environmental conditions as well as systems and all other aspects of university life.

'Physical barriers include the sensory environments being like hell... Strip lighting that makes a hideous whirring sound, supervisions in crowded areas or a broom cupboard...'

Clear communication is something contributors identified as essential. Ambiguity, miscommunication and unclear expectations in interactions with others caused obvious distress, such as in the examples provided below:

'The most prohibitive barriers related to communication... political games play out and some information is given to one, but conflicting information given to others... I find it all exhausting and confusing and has made me feel like quitting many times, even though I love my research and find the academic work itself not at all challenging.'

'Communication between colleagues is very rushed and focused on informal 'chats' between lectures rather than clear conversations with a possibility for clarification. The inability to switch between tasks to participate in these conversations is tricky.'

One contributor expressed frustration about having to tell colleagues again and again about the relatively straightforward reasonable adjustments they required in order to be effective:

'There is only so many times that I can clearly, kindly, explicitly explain my needs in relation to being autistic (sensory environment, a need for clear instructions and timeframes, etc...) and they are ignored. I am assuming that my difficulties are overlooked because I appear competent in other areas, I've explained in plain terms that I am a 'vulnerable person' to be told that my supervisor also thinks of himself as vulnerable (he has no disability).'

Woolly, ambiguous boundaries have created problems for the contributor who provided the following comment:

'Students expect an increasing amount of 'interaction' with lecturers, but often fail to grasp (or be consistently given) basic ground rules for such interaction. They do not always turn up for meetings or read feedback on their essays, and often see the 'seminars' as a chance for one-to-one conversations that could easily be conducted elsewhere. I find this clash between students' expectations (of having someone available as a 'buddy' rather than a teacher) and the realities of teaching (when they will be one of many students that the lecturer is responsible for), very distressing.'

Supportive colleagues were identified frequently by participants as a force for good. Relying on the better nature and helpfulness of co-workers was not seen as enough

in itself. Addressing institutional obstacles arising from a culture of ableism was proposed as a sustainable approach.

'I have found some people to be very understanding, whereas others were not. I love learning, thinking, writing and playing with ideas and theories. I find it depends on the people and the team – in terms of vibe but also accessibility too.'

'A thing I have learned about oppression is that even when people or organisations are nice, you can't assume that it will continue. The rug can be pulled out at any time and this makes it hard to feel safe.'

Frustratingly, the reasonable adjustments autistic colleagues need in order to thrive are usually potentially very simple, but somehow get over complicated along the way. One contributor, for example, spoke of their delight at being enabled to just get on with their job without having to travel a long distance to the campus and join in with meetings that were only tangentially relevant to their role. This adjustment cost nothing.

While the work of CADS prioritises autism research, and autistic researchers are therefore usually recruited to CADS to research autism, PARC participants clarified that they often have expertise in unrelated fields. Just as Professor Stephen Hawking did not identify his discipline as Critical Disability Studies, contributors described getting a bit tired of being expected to take an interest in disability research when their academic interests lay elsewhere. The danger of being pigeonholed as an autism researcher with only insider perspectives to contribute is reflected in the following statement:

'We can address this barrier by making space for autistic researchers to do all kinds of autism-relevant research, informed by our perspectives as autistic people but not limited to sharing personal perspectives as autistic people.'

The expectation of flag-waving irritated disabled academics in Martin's (2017) study of the experiences of disabled leaders in higher education. Although this was problematised more by those with visible impairments, the following quote illustrates that autistic people are not immune to the expectation that they will fly the flag or pave the way for others:

'It has been absolutely gruelling. I feel, at every turn, particularly as an autistic PhD candidate in a small department, that I am carving the way for people like me and it is taking a significant effort.'

Although gathered from a small number of contributors, all these comments graphically illustrate the amount of effort required to navigate academic life as an autistic researcher or lecturer. Equality impact assessment undertaken by (paid) autistic researchers could identify potential obstacles and manifestations of ableism and pose solutions which could eradicate or at least diminish them and, in doing so, create a more conducive and less chaotic environment. To this end, some helpful ideas are presented in the next section in the form of questions an autistic person might ask. Representatives from academic institutions with the power to address some of the concerns illuminated by these questions, might wish to flex their empathy muscles and attempt to answer them from an institutional perspective.

Questions arising from staff facing research

Recruitment:

- Am I sufficiently convinced that recruitment processes are non-discriminatory so referring to my impairment in advance will not disadvantage me?
- Will the interview play to my strengths or will people make negative judgements about me based on social conventions around communication style?

Induction:

- Is this induction going to be useful to me in that it will cover information I need, clearly, consistently and without contradictions?
- Will I be able to explain what sort of support I need during the induction process and will this be acted upon effectively?
- Does the organisation understand how to make processes such as accessing Access to Work support happen with minimum fuss?
- Will my contract be clear and specific?
- Will there be a named person who can help me if there is anything I do not understand?

Administrative systems:

- Will the administrative systems I am expected to use be explained clearly and will they work effectively?
- What sort of administrative support will I receive?
- Will processes around getting paid work effectively?

Communication:

- Will communications with colleagues be clear and logical?
- Will communication systems be clear and logical?

Sensory environment:

- Will I have an appropriate space to work in that does not cause too much sensory overload?

- Will I be able to avoid hot desking?

Changing jobs/promotion:

- Will the fact that I am autistic mean that I am pigeonholed by the university as ‘an autism researcher’?

- Will I be supported to progress in the organisation?

Insights from autistic students

Studies focusing on the university experience of autistic students include work by Cain *et al* (2016); Gellbar *et al* (2014); Lucas and James (2018); Madriaga and Goodley (2010); Newbutt *et al* (2016); Siew *et al* (2017); Taylor (2005); Taylor *et al* (2010); Van Hees *et al* (2015) and others. I have been directly involved in several projects over almost 20 years. Examples include: Atkinson *et al* (2011); Beardon *et al* (2009); Chown *et al* (2018); Hastwell *et al* (2012, 2013 and 2017); Madriaga *et al* (2008); Martin (2000, 2005, 2006a, 2006b, 2007, 2008a, 2008b, 2008c, 2011b); Martin *et al* (2008); Milton *et al* (2016, 2017, 2018); Sturgess (2018).

Despite differences of emphasis arising from the phenomenology of the researchers concerned, there is a striking degree of congruence between the findings of various studies in this field. Agreement that autistic people struggle with ambiguity and lack of predictability, for example, is widespread. While I prefer to lay problem causality at the feet of the unpredictable ambiguous institution, occasionally the tone of research is somewhat deficit model and locates ‘the problem’ firmly with the autistic person. Studies sometimes problematise the way autistic students present themselves and this does not sit particularly comfortably with me. I am not a fan of the term ‘challenging behaviour’ for example, as, in keeping with many autistic researchers, I prefer to look at communicative intent and factors within the environment which elicit distress responses. My ontological perspective leads me to see the world through an overtly social model lens (Oliver, 2013). I am clearly of the view that environmental factors which disadvantage autistic people need to be identified and addressed as a matter of social justice.

In my writing, I problematise the notion of pragmatic acceptance of labelling (as a gateway to services) while flying the flag for UD and UDL and inclusive practice which benefits everyone (Milton *et al*, 2016). Inclusive practice is based on the idea that the learning environment is conducive to all learners and that diversity is a beautiful thing to be celebrated (Martin, 2011a; 2011b). Inclusion is not about bashing square pegs into round holes, it is about having a wide variety of different-shaped holes and niches into which a wide variety of differently shaped people can snuggle down and

feel comfortable and motivated. Maslow *et al* (1987) identified conditions for progress to self-actualisation a long time ago and students are not likely to be productive and reach their potential if they feel as if they do not belong. Here, 'belonging' is posed as a reductivist definition of inclusion, which embraces disability as a valuable diversity strand. Belonging implies community (Martin, 2017; Milton, 2017a).

Evidence of adverse impacts on self-esteem through social exclusion at university reminds us that what goes on in the classroom is only a small part of university life (Chown & Beavan, 2011; Chown *et al*, 2018; Hastwell *et al*, 2012; 2017). Autistic participants emphasised the need for a comfortable social environment and highlighted the difficulty around finding such a thing. Freshers' Week got several mentions because of the sensory overload of Freshers' Fair, leading to lack of access to the clubs and societies that have the potential to form the basis of a social life with like-minded people (Madriaga *et al*, 2008; Martin, 2008a; 2008b). 'Othering' (Cliff, 1983; Foucault, 1982; Richards, 2008) is an important concept when thinking about working effectively with students in a way that does not make them feel alienated and 'othered'.

Findings from the wide range of studies cited here coalesce around a series of common threads, which are most tangibly summarised into a list of questions for HE staff focusing on the student journey from pre-entry to post-exit. These questions reflect the concerns of autistic students and ideas that arose from the insider perspectives of research participants.

Pre-entry:

- How do I get clear information about courses?
- Can I come and visit and meet people who will be working with me?
- Can I visit the campus a few times to see how it feels?
- Who can help me decide?
- How do I apply for Disabled Student Allowance (DSA)?
- Who can help me apply for DSA?
- How does all the paperwork around enrolment work and who can help me with it?
- What's it like in halls of residence and can I visit before I move in and maybe stay the night?
- How do I sort out my student loan?

First few weeks:

- Can somebody meet me and show me where to go?
- How do I choose from different modules and options?

- Will it be possible to join clubs and societies?
- How do I find out about clubs and societies?
- How can I make friends?
- Where can I eat my sandwiches?
- What if the halls of residence are too noisy?
- How do I organise my time?

Assignments:

- What if I get a rubbish mark?
- How will I know if I'm doing ok?
- How can I ask my lecturer questions?
- How do I hand my work in?
- What if I'm working in a group and other people don't take it seriously?

Exams:

- What if I don't understand the question or instructions?
- What if I fail?
- What if it's noisy in the exam hall?

Placement:

- How do I find a placement?
- How do I get to my placement?
- What if it does not work out?
- How do I talk to people on placement?
- Who can help me if I get stuck?

Dissertation:

- How do I decide what to do?
- How do I plan my time?
- How do I organise all this information?

Finding a job:

- How do I know what sort of job I want?
- Who can help me decide?
- How will I manage the interview?
- What if I hate my job?
- Is there any sort of support at work?

Sources of help:

- How am I supposed to understand who can help me with what?
- How do I contact different services for different sources of help?
- What do I do if I need help that is not to do with my course?
- Who can I talk to if I feel worried?
- Will confidential information about me be shared?

This list of questions illustrates the sort of concerns research participants have raised but fails to reflect the fact that autistic students have a bucketful of strengths to bring to the academic party. These include application and a high level of motivation and interest (Hastwell *et al*, 2013). The flipside of seriousness and dedication is that autistic students often experience anxiety born out of perfectionism. On many occasions, I have found myself trying hard to persuade an autistic student that 75% is a very good mark. Group work anxieties often arise from the worry that other people are not pulling their weight and will bring down everyone's grade (Martin, 2008a; 2008b; Sturgess 2018). This can be easily rectified by assigning individual marks as well as credit for ensuring that every group member is included and has a clear role to play.

The need for clarity is a recurrent theme. Ambiguous information and impenetrable administration systems can cause high levels of anxiety. Instructions that are not clear can make it difficult for a student to focus on an assignment because they are worried that they might be getting it wrong. Badly written exam questions and instructions cause a great deal of stress. Reliability is something that autistic students value. Over-promising and under-delivering create confusion, so it really helps if people just do what they say they are going to do. At a systemic level, a culture of reliability is helpful. If, for example, a class must be moved to a different room, notifying all students in advance routinely via an agreed system helps everyone, not just autistic students. Having named reliable people is valued, particularly when the roles of individuals are unambiguous. Having a mentor to help with navigation between people, roles and systems is something many students found helpful.

A focus on social aspects of university life such as living in halls and making friends illustrates a common preoccupation of autistic students. Some were keen on social groups with other autistic students, but others would run a mile and would much rather just join in with people who have similar interests. As mentioned, Freshers' Week was problematic for many because of the huge sensory overload of activities like Freshers' Fair. Joining clubs and societies online was helpful. Sensory overload concerns were frequently reported by participants, so a guided tour of the campus was recommended to help students find quiet comfortable spaces.

By paying attention to student's concerns it is possible to anticipate the sort of arrangements which are likely to reduce potential difficulties. Anticipating that applying to university is a big step, and potential students and their parents will have lots of questions, has prompted some universities to arrange pre-entry events that provide clear unambiguous information and opportunities such as pre-entry summer school. Knowing that job interviews can be a barrier, the employability team could work to make alternative arrangements with potential employers, such as work trials. Every step in between could also be equality impact assessed with input from autistic people.

Commonality between autistic students and staff

Research, and common sense, tell us that the whole student journey is important from pre-entry to post-exit. Equally, disabled staff face barriers at various points in their employment, including the stage prior to securing a job in the first place (Martin, 2017). The acronym REAL encapsulates the essence of studies discussed here. REAL stands for: reliable, empathic, anticipatory and logical (Martin 2008a). Enacting the REAL principle amounts to doing what you say you are going to do **reliably**, **empathising** with the world view of the individual, **anticipating** potential difficulties and addressing them before they arise, and communicating clearly and **logically** to avoid ambiguity. REAL encompasses many features of UDL /UD so is potentially useful beyond the original aim of trying to improve the university experience of autistic people.

Limitations

All the research discussed here has limitations of course. Much of it was unfunded and therefore poorly resourced. Gender was not isolated as a consideration and many other variables and intersectionality could have been considered more fully. Factors such as Social Capital (Bourdieu, 1986) were largely ignored or not named as such. Chown *et al* (2015), for example, considered the intersection between being autistic and the first in the family to embark on higher education in relation to the doctoral journey, but this exploration did not specifically draw upon Bourdieu's work on Social Capital. Differences between studying from home and while living away, the implications of being the first in the family to go to university, campus versus city locations, gender, poverty and so on and so on, are things that could have been considered and may be the focus of future research. Poverty is not a protected characteristic under the Equality Act (2010) but the idea of being autistic and managing either to study while not having two pennies to rub together or to budget on extremely low pay deserves consideration.

Lest we forget, much of the contributing autistic expertise within the research discussed here was unpaid, which is perhaps the biggest limitation of all. I

am in the privileged position of being able to make proclamations such as ‘the CADS research group will not undertake autism research without paid autistic researchers. As an ally, I feel that it is incumbent upon me to do so, but I also acknowledge that it is not too difficult from the relative safety of my salaried leadership position. Ethical statements within autism research papers are not required to provide information about whether the team included paid autistic researchers. Perhaps this systematic limitation could usefully be rectified. CADS will certainly not be party to such an omission.

References

- Angell-Wells (2019): A hermeneutic phenomenological study of lecturers’ lived experience of ipad adoption. Unpublished EdD thesis, London South Bank University.
- Arnold, L., Milton, D., Beardon, L., and Chown, N. (2018) England and Autism. In: Volkmar, F. (Ed) *Encyclopaedia of Autism Spectrum Disorders*. New York, NY: Springer.
- Atkinson, R., Evans, S., Gandy, C., Graham, C., Hendrickx, S., Jackson, V., Martin, N. (2011) A Buddy Scheme - Supporting transition and progression for students identified with Asperger Syndrome (AS). *Journal of Inclusive Practice in Further and Higher Education* **3**(2), 109-126.
- Barnes, C. (2014) What a difference a decade makes: reflections on doing ‘emancipatory’ disability research. In: Nind, M. and Rix, J. (eds.) *Ethics and Research in Inclusive Education*, pp. 55-70. London: Routledge.
- Barnes, C. and Sheldon, A. (2007) Emancipatory disability research and special educational needs. In: Florian, L. (ed) *The Sage handbook of special education*, pp.233-246, London: Sage.
- Barnham, C. and Martin, N. (2017) Considering employment of young people with intellectual impairments and autism leaving school and college. In: Milton, D. and Martin., N. (eds.) *Autism and Intellectual Disability Volume 2*, pp. 51-53. Hove: Pavilion.
- Barton, L. (2005) Emancipatory research and disabled people: Some observations and questions. *Educational review*, **57**(3), pp.317-327.
- Beardon, L. and Edmonds, G. (2007) ASPECT consultancy report. A national report on the needs of adults with Asperger syndrome. www.shu.ac.uk/theautismcentre [accessed 01 July 2018]
- Beardon, L., Martin, N. and Woolsey, I. (2009) What do students with Asperger syndrome and high functioning autism want from college and university – in their own words. *Good Autism Practice*. **10**(2), 35-44.
- Bourdieu, P. (1986) The forms of capital. In: J. Richardson (ed.) *Handbook of Theory and Research for the Sociology of Education*, pp 241-258. New York, NY: Greenwood.
- Cain, R.Y. and Richdale, A.L. (2016) Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, **46**(1), 31-41.
- Campbell, F.K. (2009) *Contours of ableism: The production of disability and abledness*. Basingstoke: Palgrave Macmillan.
- Charlton, J. I. (1998) *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA: University of California Press.
- Chown, N. and Beavan, N. (2012) Intellectually capable but socially excluded? A review of the literature and research on students with autism in further education. *Journal of Further and Higher Education*, **36**(4), 477-493.
- Chown, N., Beardon, L., Martin, N. and Ellis, S. (2015) Examining intellectual prowess, not social difference: removing barriers from the doctoral viva for autistic candidates. *Journal of Inclusive Practice in Further and Higher Education*, **6**(1), 22-38.

- Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J. and MacGregor, D. (2017) Improving research about us, with us: a draft framework for inclusive autism research. *Disability & Society*, **32**(5), 720-734.
- Chown, N., Baker-Rogers, J., Hughes, L., Cossburn, K. N. and Byrne, P. (2018) The 'High Achievers' project: an assessment of the support for students with autism attending UK universities. *Journal of Further and Higher Education*, **42**(6), 837-854.
- Cliff, M. (1983). *Claiming an Identity, They Taught Us to Despise*. Watertown, MA: Persephone Press.
- Cooper, B. (1981). *Michel Foucault. An Introduction to the Study of his Thought. Studies in Religion and Society*. Volume 2. New York, NY: Edwin Mellen.
- The Equality Act (2010) <https://www.disabilityrightsuk.org/understanding-equality-act-information-disabled-students> [accessed 23 August 19].
- Foucault, M. (1982) The subject and power. *Critical Enquiry*. **8** (94), 777-795.
- Gelbar, N.W., Smith, I. and Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of autism and developmental disorders*, **44**(10), 2593-2601.
- Goodley, D. (2010). *Disability Studies. An interdisciplinary introduction*. London: Sage.
- Hastwell, J., Martin, N., Baron-Cohen, S. and Harding, J. (2012) Giving Cambridge University students with Asperger syndrome a voice: a qualitative, interview- based study towards developing a model of best practice. *Good Autism Practice* **13**(2), 56-64.
- Hastwell, J., Harding, J., Martin, N. and Baron-Cohen, S. (2013) *Asperger Syndrome Student Project, 2009-12: Final Project Report, June 2013*. University of Cambridge. <https://www.disability.admin.cam.ac.uk/files/asprojectreport2013.pdf> [Accessed 28 Jun 2018].
- Hastwell, J., Martin, N., Baron-Cohen, S. and Harding, J. (2017) Reflections on a university based social group for students with Asperger syndrome. *Good Autism Practice*, **18**(1) 97-105.
- Jammaers, E., Zanoni, P. and Hardonk, S. (2016). Constructing positive identities in ableist workplaces: Disabled employees' discursive practices engaging with the discourse of lower productivity. *Human relations*, **69**(6), 1365-1386.
- Jorgenson, L., Singleton, K. and Bennett, J., (2013), September. Universal Design for Learning in Higher Education. In: *Innovations in Teaching & Learning Conference Proceedings* (Vol. 5). [add online source? Available from: <https://journals.gmu.edu/index.php/ITLCP/issue/view/189> [accessed 17 Aug 2019].
- Kattari, S.K., Olzman, M. and Hanna, M.D., 2018. 'You Look Fine!' Ableist Experiences by People with Invisible Disabilities. *Affilia*, **33**(4), 477-492.
- Loomes, G. (2017). The politics of autism: navigating the contested spectrum. *Disability and Society*, **32**(5), 761-762.
- Loomes, G. (2018). Researching about us without us: exploring research participation and the politics of disability rights in the context of the Mental Capacity Act 2005. *Journal of medical ethics*, **44**(6), 424-427.
- Lucas, R. and James, A.I. (2018). An evaluation of specialist mentoring for university students with autism spectrum disorders and mental health conditions. *Journal of autism and developmental disorders*, **48**(3), 694-707.
- Madriaga, M., Goodley, D., Hodge, N. and Martin, N. (2008). Enabling transitions into higher education for students with Asperger syndrome. *York. Higher Education Academy*.
- Madriaga, M. and 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.
- Martin, N. (2000) Widening opportunities for students with Asperger's syndrome. *Widening Participation and Lifelong Learning. The Journal of the Institute for Access Studies and the European Access Network. Open University* (2) August 2000:42-48.
- Martin, N. (2005) Asperger's syndrome in the workplace. Potential difficulties and straight forward solutions. *The SKILL Journal*. 81: 30-34

- Martin, N. (2006a) Strategies which increase the likelihood of success at university of students with Asperger's syndrome. *Good Autism Practice*, **7**(2), 51-60.
- Martin, N. (2006b) At ruste studerende med Asperger's syndrome til at klare en universitetsuddannelse - god praksis for de ansatte. *Autismebladet* **2**,14-18.
- Martin, N. (2007) Personal statements. Helping transition to further education and employment. *Good Autism Practice*, **8**(2), 17-21.
- Martin, N. (2008a) REAL services to assist university students who have Asperger syndrome. *NADP Technical Briefing 10/08*
- Martin, N. (2008b) A template for improving provision for students with Asperger syndrome in further and higher education. *NADP Technical Briefing 11/08*
- Martin, N. (2008c) Empathy is a two-way street. In: Pollak, D. (Ed.) *Neurodiversity in Higher Education: Positive responses to specific learning differences*, pp.149-168. Oxford: John Wiley.
- Martin, N. (2011a) Disability Identity. Disability Pride. *Perspectives: Policy and practice in higher education*, **16**, 14-19.
- Martin, N. (2011b) Promoting inclusive practice for PhD students near completion. *Journal of Inclusive Practice in Further and Higher Education*, **3**(2), 37-52.
- Martin, N. (2012). Giving Cambridge University students with Asperger syndrome a voice: a qualitative, interview-based study towards developing a model of best practice. *Good Autism Practice*, **13**(1), 56-63.
- Martin, N. (2017). Encouraging disabled leaders in higher education: recognising hidden talents. *Leadership Foundation for Higher Education*.
- Martin, N., Beardon, L., Hodge, N., Goodley, D. and Madriaga, M. (2008) Towards an inclusive environment for university students who have Asperger syndrome (AS) *Journal of Inclusive Practice in Further and Higher Education*, **1**(1), 3-14.
- Martin, N. and Fraser (2012) The First LSE Disability Identity Conference. Sample Abstracts and Evaluation Mat Fraser and Nicola Martin. *Journal of Inclusive Practice in Further and Higher Education*, **3**(1),5-10.
- Maslow, A. and Lewis, K.J., 1987. Maslow's hierarchy of needs. *Salenger Incorporated*, **14**, p.987.
- McIntosh D (2002). An archi-texture of learning disability services: the use of Michel Foucault. *Disability and Society*. **17**(1) 65-79.
- Milton, D. (2017a) *A Mismatch of Saliency: Explorations of the Nature of Autism from Theory to Practice*. Hove: Pavilion.
- Milton, D. (2017b) Employment: a reflective review. In: Milton, D. and Martin, N. (eds.) *Autism and Intellectual Disabilities in Adults*, Vol. 2. Hove: Pavilion.
- Milton, D., Martin, M. and Melham, P. (2016) Beyond reasonable adjustment: autistic-friendly spaces and Universal Design. In Milton, D. and Martin, N. (Eds), *Autism and Intellectual Disabilities in Adults*, Vol. 1, pp.81-86. Hove: Pavilion.
- Milton, D., Sims, T., Dawkins, G., Martin, N. and Mills, R. (2017). The development and evaluation of a mentor training programme for those working with autistic adults. *Good Autism Practice*, **18**(1), 25-33.
- Milton, D., Ridout, S., Kourti, M., Loomes, G. and Martin, N. (2019). A critical reflection on the development of the Participatory Autism Research Collective (PARC). *Tizard Learning Disability Review* [Online] 24:82-89. Available at: <http://dx.doi.org/10.1108/TLDR-09-2018-0029>.
- Newbutt, N., Fabri, M., Andrews, P.C. and Pukki, H.K. (2016). Using design thinking to engage autistic students in participatory design of an online toolkit to help with transition into higher education. *Journal of Assistive Technologies*, **10**(2), 102-114.
- Oliver, M., 1997. Emancipatory research: Realistic goal or impossible dream. In: Barnes, C. and Mercer, G. (eds) *Doing disability research*, pp.15-31. Leeds: The Disability Press.
- Oliver, M., 2013. The social model of disability: Thirty years on. *Disability & society*, **28**(7), pp.1024-1026.

- Peters, M. (2003). Truth-telling as an educational practice of the self: Foucault, Parrhesia and the ethics of subjectivity. *Oxford Review of Education*, **29**(2), 207-224.
- Ridout, S. (2017). The autistic voice and creative methodologies. *Qualitative Research Journal*, **17**(1), 52-64.
- Ridout, S. and Edmondson, M. (2017). 'Cygnets Mentoring Project: combined experiences from a mentor and a mentee.' *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, **1**(5). Available at: <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR20> [accessed 23 Aug 2019].
- Richards, R. (2008). Writing the Othered Self. Auto ethnography and the problem of objectification in writing about disability and illness. *The journal of qualitative health research*, **18**(12), 1717-1728.
- Roulstone, A. and Williams, J. (2014). Being disabled, being a manager: 'glass partitions' and conditional identities in the contemporary workplace. *Disability and Society*, **29**(1), 16-29.
- Sayce, E. (2015). *Access to Work* review. <https://www.parliament.uk/accesstowork> [accessed 13 Dec 2018].
- Siew, C.T., Mazzucchelli, T.G., Rooney, R. and Girdler, S. (2017). A specialist peer mentoring program for university students on the autism spectrum: A pilot study. *PLoS ONE*, **12**(7), <https://doi.org/10.1371/journal.pone.0180854> [accessed 23 Aug 2019]
- Sims, T., Milton, D., Martin, N. and Dawkins, G. (2016) Developing a user-informed training package for a mentoring programme for people on the autism spectrum. *The Journal of Inclusive Practice in Further and Higher Education*, **7**, 49-52.
- Stone, E. and Priestley, M. (1996). Parasites, pawns and partners; disability research and the role of non-disabled researchers. *British Journal of Sociology* **47**(4), 699-716.
- Sturgess, S. (2018) *How do autistic physics undergraduate students experience working with others?* Unpublished MA dissertation, London South Bank University.
- Taylor, M.J. (2005). Teaching students with autistic spectrum disorders in HE. *Education + Training*, **47**(7), 484-495.
- Taylor, M., Baskett, M. and Wren, C. (2010). Managing the transition to university for disabled students. *Education + Training*, **52**(2), 165-175.
- Van Hees, V., Moyson, T. and Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of autism and developmental disorders*, **45**(6), 1673-1688.
- Willis, J.W., Jost, M. and Nilakanta, R., 2007. *Foundations of qualitative research: Interpretive and critical approaches*. London: Sage.
- Wilson, L. and Martin, N. (2017). Disabled Student Support for England in 2017. How did we get here and where are we going? A brief history, commentary on current context and reflection on possible future directions. *Journal of Inclusive Practice in Further and Higher Education* **9**(1), 6-22.
- Woods, R. (2017). Pathological demand avoidance: my thoughts on looping effects and commodification of autism. *Disability & society*, **32**(5), 753-758.
- Woods, R., Milton, D., Arnold, L. and Graby, S. (2018). Redefining Critical Autism Studies: a more inclusive interpretation. *Disability & society*, **33**(6), 974-979.
- Woods, R. and Waltz, M. (2019). The strength of autistic expertise and its implications for autism knowledge production: A response to Damian Milton. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, **1**(6). <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/CO2> [accessed 23 Aug 2019]