

# Not hearing, not engaging, and not happening: Elusive Inclusive Higher Education,

Gibson, S

<https://pearl.plymouth.ac.uk/handle/10026.1/21664>

---

The Journal of Inclusive Practice in Further and Higher Education

---

*All content in PEARL is protected by copyright law. Author manuscripts are made available in accordance with publisher policies. Please cite only the published version using the details provided on the item record or document. In the absence of an open licence (e.g. Creative Commons), permissions for further reuse of content should be sought from the publisher or author.*

ISSN: 2398-5976

# The Journal of Inclusive Practice in Further and Higher Education

Issue 15.1

Summer 2023



## **Editorial.**

### **Marissa Hill**

Chair of the NADP Publications, Research & Ethics Standing Committee, NADP Director and Head of Disabled Student Support at Sheffield Hallam University.

Dear Colleagues,

As a relatively new member of the NADP board, I have been honoured to be invited to be an editor of a publication that I have contributed to and appreciated during my career. Our first article is the NADP-commissioned research into the staff-student ratios, as our membership has faced increasing pressure to deliver excellent and student-centred services whilst under considerable time and money restrictions. Hannah Borkin has done an excellent job of conducting and presenting this research. As well as identifying the average ratio, she has captured the feelings and experiences of our membership with empathy and understanding of difference in size and scale of organisations and has outlined recommendations for ways forward. Considering this research, the time that has been given to share knowledge, learning, and experience through the journal is greatly appreciated. I hope you will enjoy these contributions as much as I have and consider sharing in future editions.

Our second excellent article from Helen Young is based on a study that explored the inclusiveness of an eight-hour, open-book, take-home assessment format for students with specific learning difficulties. Two Specialist Study Skills Tutors were interviewed and found that the format reduced memory-related pressure and administrative burdens and provided greater flexibility and inclusivity. The take-home element was helpful for some students, but the home environment posed potential distractions. The study also identified that SpLD students perceived fairness in terms of exam time compared to non-disabled peers, a key theme for future research.

The next paper explores inclusive practices in higher education for disabled students across the UK. The national research project, conducted in collaboration with the University of Plymouth, the University of Wolverhampton, and Disabled Students UK, reveals that disabled students continue to face exclusionary practices. The paper recommends that policy makers and practitioners' partner with disabled students to create more inclusive environments at all levels very much following the 'nothing about us without us' principle.

The following article discusses the barriers that disabled academics face in advancing their careers in academia, due to systemic ableism and workplace

injustices. The research highlights the importance of implementing REAL systems and peer support to create enabling environments. However, institutional ableism in attitudes, culture, and infrastructure often creates disabling obstacles. This violates equalities legislation and human rights, resulting in a loss of potential. The authors suggest that lessons learned from the pandemic could aid in promoting inclusive academic employment.

Again considering employability, this case study explores the experiences of an autistic PhD graduate seeking employment. The lack of autism-specific support during her transition out of university is discussed, highlighting a gap in research on autism and employment. The author suggests more consideration should be given to support for autistic individuals transitioning out of educational institutions. A diagram is presented with key features for effective support, and mentoring is suggested as an important avenue for future research.

We finish this edition of the journal with a book review of "Visual Thinking," from the animal behaviourist Temple Grandin who argues that our education system and society are biased towards verbal thinkers, while visual thinkers are often overlooked. Our reviewer highlights this book as a valuable resource for disability practitioners, particularly in neurodiversity. It's accessible and thought-provoking, with personal stories, history, and science to spark discussion.

I would like to thank all the contributors for their patience, dedication, and contribution to the journal. I would also like to thank my colleagues who have supported peer reviewing, proofreading and publishing this edition of the journal, particularly the publications committee, and the NADP administration team, and especially Lynn Wilson. The dedication and support of all of you have made this publication possible despite challenging times and I am very grateful to them. Please do consider contributing to the journal, the experience and depth of knowledge in our sector are valued and appreciated and sharing this make our sector stronger.

Best wishes,

Marissa Hill

## Contents

Editorial. Marissa Hill .....	2
The experiences of staff working within Disability Services in Higher Education Hannah Borkin .....	5
Pilot Research Project: 'Exploring SpLD specialists' views on whether, and to what extent, an eight-hour, open book academic assessment format, trialled by departments at a Russell Group University, is inclusive for SpLD students' needs. Helen Young .....	35
Not hearing, not engaging, not happening: Elusive Inclusive HE, it is time to reconsider sector practices in partnership with disabled student expertise. Suanne Gibson .....	48
Human Rights: The Right to Work in Academia. Professor Nicola Martin and Dr David Birchall .....	75
The post-doctoral black hole. The importance of <i>Transitioning Out</i> support for autistic students. Barbara Sandland .....	102
A review of 'Visual Thinking: The Hidden Gifts of People Who Think in Pictures, Patterns, and Abstractions', Temple Grandin (Rider Books, 2022) Reviewed by Roddy Slorach .....	115
Editorial Board .....	117

## **The experiences of staff working within Disability Services in Higher Education**

### **Hannah Borkin**

Hannah Borkin

#### **Abstract**

The current challenges faced by disability advisers are significant and serve to legitimise many of the concerns shared regarding the future of disability services. It is undoubtedly concerning that the current ratio has now risen to on average, one disability adviser to 583 disabled students. For 22% of respondents to the survey, one disability adviser is reportedly supporting over 750 students, which is more likely to occur in providers with over 15,000 enrolled students. These particular respondents reported feeling tired and constantly overwhelmed.

This unequal ratio also comes against a backdrop of rising numbers of disabled students, with many disabled students presenting with increasingly complex and/or multiple conditions. Respondents also noted a rise in numbers of students sharing mental health conditions after the COVID-19 pandemic.

While support from fellow team members and managers is present and highly valued, many feel this is undermined to an extent by the systemic factors at play within a provider as a whole. While senior leadership buy-in is pivotal for driving disabled students up the agenda, in many cases disability is felt not to be a priority in light of competing equality, diversity and inclusion (EDI) priorities. There is also a degree of resistance from internal and external stakeholders to progress and embed inclusive practice.

Moving to an inclusive approach is felt to be a goal that would help disability advisers gate keep their time (to an extent) on more specialist provision, but many providers are not there yet. Respondents reported dealing with 'micro-cultures', wherein there was inconsistency between courses, schools and whole departments depending on the willingness of individual staff members to embed and adopt inclusive approaches. This was compounded by a perceived lack of understanding around competency standards and learning outcomes, leading to academic staff taking a view on what is and what is not 'reasonable', particularly in relation to flexibility in assessment.

While UDL serves as a strategic and operational tool for ensuring that disability equality is front and centre, awareness of its principles are low and only certain members of staff across any one provider have so far adopted it. Literature also suggests that training around UDL is lacking. This ultimately means that there continues to be a reliance on the implementation of reasonable adjustments at an individual level, which inevitably takes up valuable time and resource.

Staff working in disability services are highly specialised staff, and are committed to extensive Continuing Professional Development (CPD) to keep up with the ever-changing landscape of disability support. With this expertise in mind, it was a concern that a large number of respondents reported a perceived downgrading of their roles, wherein their professionalism felt increasingly overlooked and unsupported. Many also felt that the academic staff voice carried more weight than their own.

Respondents vowed to continue to provide the best possible quality support for disabled students, for as long as it continued to make a difference to their outcomes and experiences in HE. However, their capacity to manage their workload is diminishing, and a number of issues at provider level are leading staff in disability services to consider the ultimate cost to their professional lifespan and wellbeing. They are overwhelmingly determined to do their job well, but require improved institutional support and professional recognition to do so.

The 1999 Higher Education Funding Councils for England and Wales (HEFCE) guidance on base-level provision for disabled students in HE institutions outlined the minimum level of support that each higher education provider should provide. While many of these provisions are fortunately now in place, systemic issues and a lack of resource and support for staff working in disability services are ultimately limiting their improvement and expansion.

## **Introduction**

### **The context**

NADP commissioned a review of the disabled student support landscape in UK higher education (HE) to inform and update the 1999 Higher Education Funding Councils for England and Wales (HEFCE) guidance on base-level provision for disabled students in HE institutions. In particular, the review had an objective to provide an update on the current staff: disabled student ratio, with anecdotal evidence suggesting ratios of up to 750 disabled students to one disability adviser existing in some higher education providers (HEPs).

In response to this brief, a researcher conducted an academic search of existing literature and related guidelines, which helped to inform the development of an online survey centred on experiences of disability advisers working to support disabled applicants and students in accessing their study. Information gathered from the two phases of the project were intended to present an overall picture of the disabled student support landscape in HE, to highlight the common challenges faced by disability advisers and to provide recommendations for improvements.

## **Methodology**

### **Academic search**

The search for existing literature and related guidelines was conducted using EBSCO and Open Access journals, as well as targeting grey literature to find current examples of good practice in supporting disabled students in HE. The latter included a search of provider websites and disability-specific organisations' websites, as well as blogposts.

Advanced Boolean search terms related to: (i) higher education (ii) disability (iii) disabled students (iv) equality, diversity and inclusion (v) access (vi) support; and (vii) reasonable adjustments were used to find publications related to the overarching theme of disabled student support. As the review was aimed at discussing up-to-date examples, documents published in the last five to ten years were prioritised.

Themes stemming from the academic search were used to inform the design of the survey.

### **Online survey**

The survey opened on Wednesday 12 April 2023 and was completed by 103 respondents across 67 HEPs, which included one further education college and one NHS Student Employer. The sample represented around 6.5% of the total NADP membership, although the survey was promoted and open to all disability advisers in HE. One of the primary aims of the survey was to create a clearer picture of the current landscape of disability support in HE, and to provide an update on the current ratio of disability advisers to disabled student numbers. Quantitative and qualitative analysis was undertaken to uncover key and recurring themes, as well as any positive or negative correlations between responses.

The survey asked questions related to the following themes:

1. Prioritisation of support for disabled students
2. Perceptions of the role
3. Training and staff development
4. Collaboration with internal and external stakeholders
5. Implementation of reasonable adjustments
6. The future of Disability Services

In addition, the survey captured data on disability advisers' working conditions within their current role, such as HEP, job title, contract type, full- or part-time hours etc. The online survey was kept completely anonymous.

**The survey was open for just over three weeks, and closed on Friday 5 May 2023.**



## Limitations

The survey's focus on perceptions and experiences presents diverse insights but also has limitations. While acknowledging that information shared by respondents is not necessarily representative of the wider staff population, it presents an accurate account of the views expressed (both positive and negative) by disability advisers at varying levels of seniority. With the exception of questions related to working conditions, all of the questions within the survey were voluntary.

## Survey sample

Overall, a total of 103 members of staff working in disability services responded to the survey. There was a diverse spread of respondents across 67 individual HEPs, Table 1 provides a summary of those providers by size. Note that two providers were not included in the table as their enrolment data was not available on HESA (HESA: UK, 2020/21).

Size	Label	Number	% of sample
0-4999	Small	9	9%
5,000-14,999	Medium	8	8%
15,000-19,999	Large	18	17%
20,000 or more	Over 20,000	30	29%

Table 1 – Summary of HEPs represented in the sample, by size

A range of staff working in disability services with a core remit to support disabled students responded to the survey, with nearly half of the sample working as a 'disability adviser'. A further 18% of respondents were Head/Director/Assistant Head/Team Leader of a disability service. Table 2 highlights the breakdown of responses grouped by role/position. A full list of role titles is provided in the appendix, highlighting the range of titles used to describe the same or similar role.

Role/Position	Number	% of sample
Adviser	47	46%
Head/Director/Assistant Head/Team Leader	19	18%
Manager	19	18%
Senior Adviser/Specialist	9	9%
Coordinator/Assistant	6	6%
Officer	2	2%
Administrative	1	<1%

Table 2 – Summary of respondents' role/position at their HEP

Respondents were also asked about their working conditions, i.e. contract type and working hours. A substantial proportion of respondents were on permanent or open-ended contracts (95%), while just under 5% were on fixed-term contracts. Furthermore, over three quarters were in full-time positions (79%), while under a quarter of respondents were working part-time (20%).

Just under 15% of respondents stated that they were in receipt of Access to Work or other similar workplace funding.

## Summary of findings

### Academic search

The work of disability advisers is challenging and often complex, though in the majority of cases disability support services are regarded highly by students and perceived to deliver 'excellent and knowledgeable service.' (Gander, 2018). An article by Kendall (2016) solidified this, with all of the participants from a small scale qualitative study exploring disabled student experiences (n=13) agreeing that the support service was a 'positive resource', speaking highly of its efficiency. There is a widespread recognition that things have changed for the better since the publication of HEFCE's guidance on base-level provision for disabled students in higher education (1999), stimulated by updated legislation, reduced stigma around disclosure and the furthering of inclusive and accessible design.

Though it is not without its challenges, and Kendall acknowledged that in spite of legal duties in accordance with the Equality Act 2010, local interpretation of the legislation meant that disabled students continued to experience barriers in accessing their study. A reliance on individual reasonable adjustments has also persisted, as opposed to progressing and embedding inclusive practice and removing said barriers to learning for disabled students (Disabled Students' Commission (DSC), 2021). Moreover, a study by Beck (2022) highlighted the inconsistency in which adjustments were 'being implemented by course teams or individual tutors', leading to variance and disparity in support.

This creates an ongoing tension for disability advisers, who have frequently expressed frustration at the slow progress made in regard to inclusive practice (Omissi, 2020). A lack of confidence, commitment to and understanding of inclusive practice within a complex, social environment continues to be a contributing factor as to why a large number of disabled students experience delays or resistance from academic staff to anticipate or implement reasonable adjustments at an individual level (Beck, 2022).

One way to improve and facilitate buy-in to inclusive practice would be through increased training and awareness, which for many academic staff is difficult to commit to in the face of high workload and stress (Omissi, 2020). IES' 2011 report, '*Models of support for students with disabilities*' also stated that 'a major lever for inclusion' was the UK's Professional Standards Framework (UKPSF) (HEA, 2011). The updated UKPSF (Advance HE, 2023) clearly states the requirement of evidence around effective and inclusive practice for each of its four descriptors.

Omissi (2020) went on to suggest that although disability advisers believed that inclusive learning would be a positive development for the majority of disabled students, other cohorts of disabled students with more complex support requirements would continue to benefit from an individualised approach. It is a fervent hope and the future goal of many,

that a focus on inclusive practice would allow disability advisers to devote more time to the latter. As illustrated by the Disabled Students' Sector Leadership Group's (DSSLG) report (2017), the benefit and potential impact that inclusive practice can exert over individual reasonable adjustments is significant.

Universal Design for Learning (UDL) is one such framework with inclusive practice at the heart. This would enable all learners to articulate their knowledge and demonstrate their learning (McConlogue, 2020), as well as reducing the need for reliance on specialist provision provided by disability services, to an extent. Martin (2020) argued that 'UDL diminishes the necessity for ontologically risky disclosure procedures because the infrastructure is effectively better for everyone, which means that reasonable adjustments are therefore required less frequently by individuals.' Unfortunately, training is again lacking, and in 2019 Martin and colleagues concluded that UDL rarely featured on compulsory staff development topics.

UDL should also be a collaborative effort that is driven by the responsibility of all stakeholders across a HEP and not be the sole responsibility of disability services to deliver (Wray, 2018). Nonetheless, examples of a lack of collaboration abound. In many cases, this leads to inappropriate provision for disabled students, noted in Manley and De Graft-Johnson's study (2013), wherein both disabled students and practitioners of architecture suggested that closer working could have led to more expeditious decision making and 'effective tailoring to individual needs and the requirements of the course.' Clearly, there is room for improvement in regard to the infrastructure that supports the principles of UDL (Martin, 2020) and increased collaborative working to ensure it can be a success.

The COVID-19 pandemic presented both challenge and opportunity to disability services in equal measure. The Disabled Student Survey (GDI Hub and Snowdon Trust, 2021) identified similar experiences for disabled students, with some benefiting from remote learning, and others not. It has long been acknowledged that disabled students are not a single, homogenous group and so it was recommended by the DSC in their annual report that HEPs take a tailored approach to adjustments as far as possible, to account for differences in experiences by impairment type (2021). Taken together with the fact that HEPs were making every effort to remain in contact with all of their vulnerable students during the pandemic (Wilson et al., 2020), this inevitably increased and intensified demand on disability services.

Nonetheless, the report identified that COVID-19 was a catalyst for fast and effective progress, with many more people throughout the sector considering inclusion (Wilson et al., 2020). Disabled Students' UK's report 'Going Back is Not a Choice' (2022) highlighted five lessons from the pandemic for universities to become more accessible going forward, including that disabled students should be prioritised through leadership and through a coherent approach across the whole provider. This is further enshrined in the DSC's 'Disabled Student Commitment' (2023), which is a call to the sector and sector bodies to make the step change that is required to create a more inclusive environment for disabled

students. The sector must harness these recommendations to make create a more effective working environment for disability advisers in higher education, and ultimately to make consideration of disabled students' needs through inclusive practice a priority for all.

## Survey findings

### Disability adviser: disabled student ratio

The increasingly specialised expertise of staff based within disability services, together with improved levels and standards of service since the publication of the HEFCE's guidance (1999), has undoubtedly contributed to the sector's overall ability to support growing numbers of disabled students.

Despite positive improvements, however, disabled student numbers have continued to rise year-on-year; in many cases, caseload numbers outstrip resource within disability services. HESA student enrolment numbers by personal characteristics show that in 2017/18 there were 311,100 students with a known disability, rising to 451,580 students with a known disability in 2021/22.

A rising number of disabled students are also presenting with multiple disabilities and/or complex requirements. The COVID-19 pandemic was further noted by respondents as having had a direct effect on the 'high number of students presenting with serious mental health challenges.'

### The current ratio

At the time of the 1999 guidance, it was recommended that there should be a ratio of one disability adviser to 200 disabled students, arguing that such staffing would allow for a more proactive approach to planning and providing high-quality services.

This ratio has clearly not been sustained. On average, it was reported that **one disability adviser is now supporting up to 583 disabled students**<sup>12</sup>. In some HEPs it is significantly more unequal; nearly a quarter of all respondents (22%) stated that one disability adviser supports over 750 disabled students.

Out of 93 responses to this question, only eight respondents (representing eight individual providers) reported a ratio of one disability adviser to 200 or fewer students. It is worth noting that with the exception of two (including one NHS Student Employer provider where enrolment numbers were unknown), each of these providers had fewer than 15,000 enrolled students overall (HESA: UK, 2021/22).

---

<sup>1</sup> A total of 93 respondents (out of 103 overall) provided an accurate ratio that could be used within the report.

<sup>2</sup> Respondents were asked to include the number of FTE staff with a core remit to support disabled students.

Contrastingly, all 23 respondents (representing 13 individual providers) who reported a ratio of one disability adviser to more than 750 students had more than 15,000 students enrolled at their provider (HESA: UK, 2021/22). A substantial proportion of this group (74%) had more than 20,000 students enrolled at their provider.

### **The landscape of disabled student support**

The survey invited respondents to provide information on whether disability services was separate from or integrated with other student support services in their provider. Over half of respondents (59.2%) stated that disability services was integrated with other support services, while just under 40% stated that it was separate. Respondents working in smaller to medium-sized providers (under 15,000 enrolled students) were more likely to be co-located with other support services, with 80% of respondents in this group stating that their disability services was integrated.

Below is a summary of the 63 open responses outlining the other support services offered within integrated departments, with mental health and wellbeing most frequently mentioned:

- Mental health and wellbeing
- Counselling and CBT
- Equality, diversity and inclusion
- Chaplaincy
- Finance and money advice
- Complaints and appeals
- Visas and international student advice
- Careers
- Staff wellbeing
- Disabled Students' Allowance (DSA) and other funding advice
- Access Centres for diagnostic assessment
- Sexual violence and harassment
- Accommodation

A couple of respondents also stated that Dyslexia and Specific Learning Difficulties (SpLD) services were a distinct strand to the disability service.

While in the majority of cases the integration of disability services with mental health and wellbeing led to improved collaboration and streamlining of systems designed to better support disabled students with a diagnosed mental health condition, the following respondents suggested that a focus on wellbeing led to inefficiencies, a lack of clarity on roles and relationships, and a dilution of responsibility for disability professionals:

*“The professionalisation of the school wellbeing role has led to increasing distance between disability professionals and academics/decision makers.”*

*“Increasing amount of wellbeing initiatives across the sector can make it less clear how to direct students and sometimes involve staff who have no real disability/mental health knowledge.”*

*“Institutions pigeonholing disability serviced under the wellbeing umbrella which is not where we should be – we need to be working closely with academic development functions and policy and quality teams and with departments and faculties.”*

**Prioritisation of disabled student support**

In light of the significant increase in demand on disability services, respondents were asked to reflect on the extent to which support was prioritised for disabled students at provider level. At a minimum, it was a concern that a large number of qualitative comments indicated a widely held perception that providers did not have good awareness or understanding of their legal obligations under the Equality Act 2010.

*“I am exhausted by the lack of understanding our institution has regarding their responsibilities both legally and morally.”*

*“Academic and professional staff not understanding the legal framework within which the University has legal duties to support disabled students.”*

Figure 1 demonstrates in further detail respondents’ agreement with the statement ‘my HEP prioritises support for disabled students’ alongside ‘my HEP provides an inclusive culture for all students’, with both following similar trajectories.

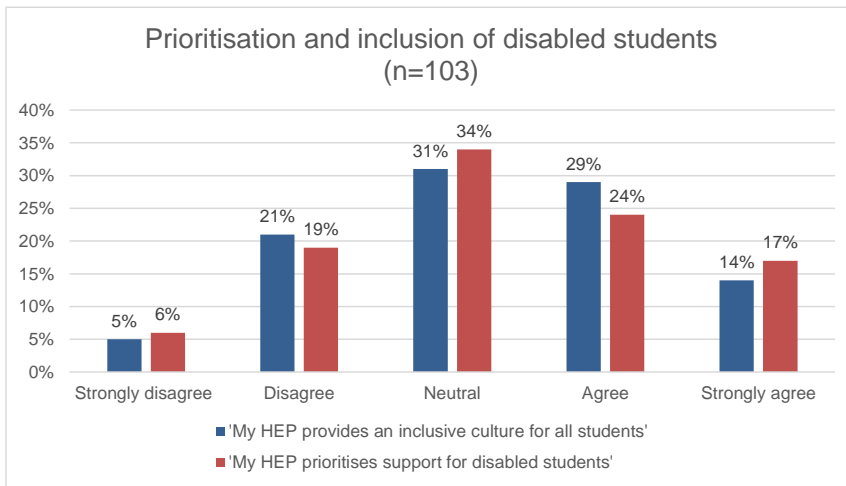


Figure 1 – Agreement ratings regarding prioritisation and inclusion of students

While 41% of respondents agreed or strongly agreed that their provider prioritised disability inclusion, qualitative responses highlighted that in some cases, disability was perceived as a lesser-considered protected characteristic in comparison to other equality, diversity and inclusion (EDI) priorities. In the same vein, a large number of respondents described a lack of strategic support and inaction from senior leadership teams, particularly when faced with 'competing requests and needs from other teams'.

*"Disability equality seems to be given a lack of priority, compared to some other issues, such as mental health and the Black, Asian and minority ethnic / white student awarding gap."*

*"We are not seen as a priority area to SMT."*

*"We require senior support from the University, and seeing us as a priority and not just a tick box/nice to have. This includes a wider understanding of what we do, and the challenges we face."*

*"It's hard to express how much we have to do and how much we want to do to create a service that is good, but we feel very unsupported in that by SMT."*

*"We feel like the neglected part of the Welfare directorate."*

Figure 2 highlights the frequency at which respondents reported working with senior leadership, adding weight to the qualitative comments on this topic and the persistent challenges respondents experienced in 'moving disabled students up the agenda'. Strikingly, roughly half of respondents (49%) reported never (rated 1 or 2) working with senior leadership, compared to just over a quarter (26%) who worked with them often (rated 4 or 5).

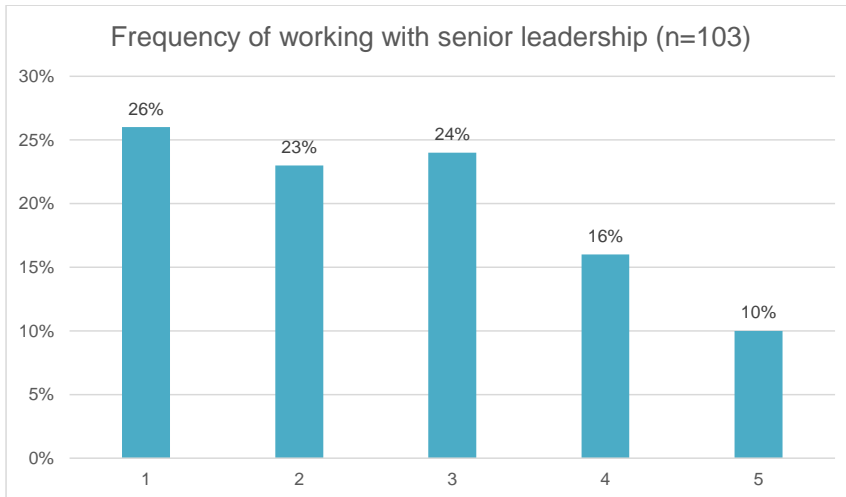


Figure 2 – Rating on how frequently respondents worked with senior leadership. Note the scale ranges from 1, ‘never’, to 5, ‘often’.

Nonetheless, the overwhelming majority of respondents were aware of written policies designed to support disabled students (91%). Over half of respondents (56%) also noted that there was a dedicated strategy in place within their provider to support disabled students, with others sharing that a draft action plan was in progress. Roughly half of respondents (47%) further noted that there was a committee or working group responsible for overseeing the monitoring and development of written policies and gaps in disabled student support, and that disability services played a key role in driving this.

*“As part of my role, I am working on improving monitoring. We have a new focus group of students where policy changes and interventions can be shared and fed back on.”*

*“Disability Services has a Disabled Student Panel which often comments on the impact of policy.”*

In particular, respondents noted that the improved communication of support for disabled students had led to good levels of awareness. This is highlighted in Figure 3, demonstrating that nearly half of respondents (44%) agreed or strongly agreed that disabled students were aware of the support available to them. However, the following comment illustrates that communication of support at provider level was sometimes not as visible.

*“There is a disconnect between the quality and communication of support from Disability Services, and that given by the wider university. Disability Services has worked hard to improve communications and ensure these are timely and accessible, but we have no control over central Comms. Central monitoring*



*continues to be an issue as this requires support and championing at a higher level, which is currently absent.”*

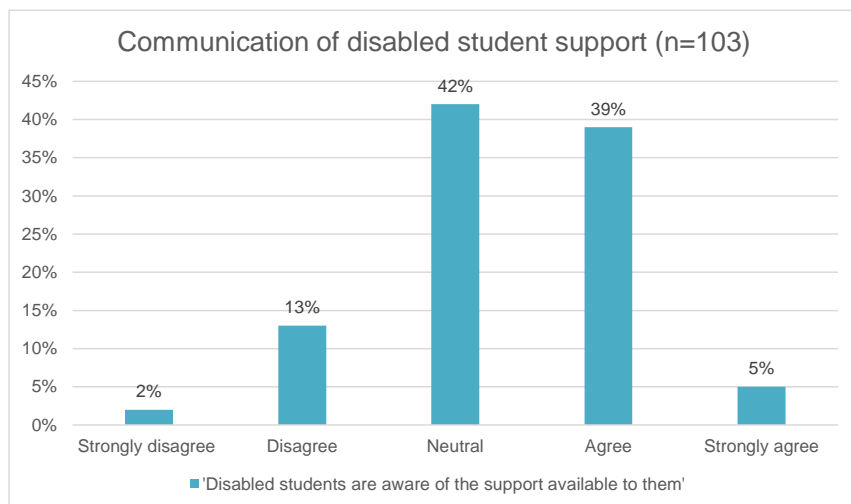


Figure 3 – Agreement ratings regarding communication and awareness of available support

### Support for disability advisers

Given what is known about the average workload of disability advisers, it is important that they are in receipt of holistic support to help manage and maintain their professional development and overall wellbeing. Most notably, 66% of respondents stated that they felt highly supported<sup>3</sup> (rated 4 and 5 respectively) by their team members and were buoyed by their passion for the role.

*“I have a great team – they are dedicated, experienced and highly supportive of me and I enjoy managing them.”*

*I have the most amazing team who are disability specialists, hugely professional, knowledgeable, generous, caring, supportive, and committed in their roles. I could not do my job without their support.”*

While just over half of respondents (51%) stated that they felt highly supported by their manager (rated 4 and 5 respectively), it was a more mixed picture in regard to the level of support offered at provider level. Overall, 30% stated that they did not feel supported by their provider at all (rated 1 and 2 respectively), which was highlighted in the following

<sup>3</sup> Note that the scale ranges from 1, ‘not supported at all’ to 5, ‘highly supported’, in response to the question ‘to what extent do you feel supported in the role?’

comments suggesting that a caring and supportive environment within a team was often undermined by broader, systemic issues.

*“My manager is personally supportive, but has no capacity to reduce our workload and limited influence when wider issues arise.”*

*“It is hard for staff to give full consideration to their development needs and aspirations when days are spent ‘firefighting’ amidst increasing student numbers.”*

Furthermore, given that we know around 15% of respondents were in receipt of Access to Work or other workplace funding, it was surprising that a third of this group (33%) were not aware of any written policies to support disabled staff at their provider. Overall, the awareness of policies designed to support disabled staff among the total sample was low, 19% of respondents were not aware of any such policies.

Respondents noted a number of other avenues from which they received support for their professional development and pastoral care. In particular, respondents relied on support stemming from participation in staff networks, membership of organisations such as NADP and Amoshe, clinical and role supervision, as well as working in collaboration with staff and allies across a provider.

*“Being part of NADP has been a valuable source of knowledge and support!”*

Notably, a couple of respondents shared that they were also receiving support from sources such as coaching, Employee Assistance and private counselling to support any emotions arising from undertaking the role as well as to ‘address a number of concerns associated with the role’.

### **Continuing Professional Development**

Disability advisers demonstrated an unwavering commitment to Continuing Professional Development (CPD) in order to keep up with the ever-changing nature of the role and knowledge of the disability support landscape. Respondents reported regularly undertaking the following CPD activities:

- Attending or presenting at webinars, conferences, network meetings
- Participating in relevant committees and working groups
- Training on particular areas of specialism, including autism, mental health and SLpD
- Training on topics related to supporting disabled students, such as mental health, trauma support and suicide awareness and prevention, as well as training on wider EDI issues
- Undertaking further study (i.e. Masters, Doctorate) in a subject directly related to their role
- Conducting independent research on good practice and effective interventions
- Reading and distilling research publications, sector guidance and reports

- Pursuing Fellowship and/or Professional Accreditation
- Attending line-management and/or leadership training

In total, 28% of respondents were Accredited or Senior Accredited members of NADP, with a further 19% currently or intending to seek accreditation in the next academic year. Furthermore, just over a third of respondents stated that they specialised in one or more areas of disability (34%), such as autism, attention deficit hyperactivity disorder (ADHD) and SpLD.

Figure 4 highlights the frequency at which respondents attended disability-relevant training during the current academic year (2022/23). Over half of respondents had attended multiple disability-relevant training sessions. Only 12% of respondents had not attended any training.

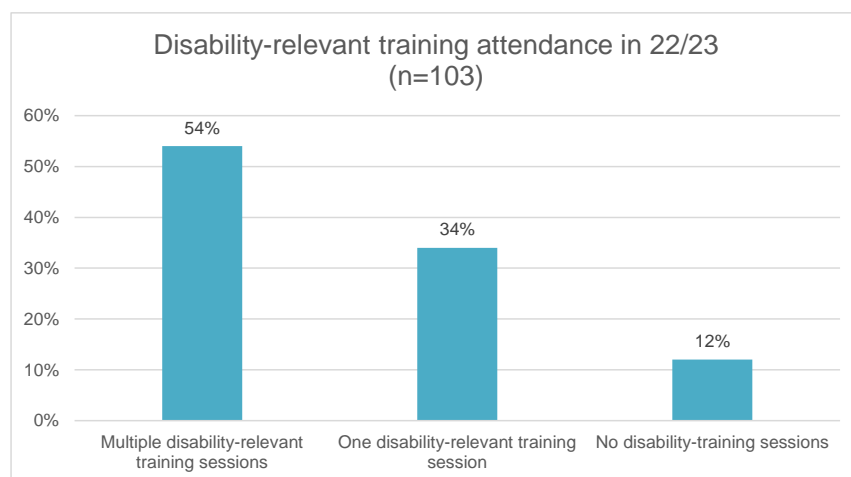


Figure 4 - Frequency of disability-relevant training attendance in 22/23

However, despite being faced with an ongoing requirement to keep abreast of sector developments, over a third of respondents (34%) either disagreed or strongly disagreed that attending disability-relevant training fitted into their current workload. Several respondents shared that they found it difficult to engage in CPD, particularly if it distracted from other priorities, and thus were often required to undertake CPD in their 'own time or at the expense of other work'.

*"The majority of disability related training was undertaken in my own time due to limited capacity and time within my current role. I am very conscious this is a similar position for other staff across the team."*

*"It is difficult to envisage or justify taking time out of the work day to focus on CPD."*

In an ideal world, respondents mentioned that they would like more time to deepen their knowledge around disability theory and the different models of disability, i.e. the 'academic' side of the role, instead of spending the majority of time actively providing student-facing support. Other knowledge gaps mentioned by respondents included understanding how to better support disabled postgraduate and international students, as well as effective data management and monitoring.

### Implementation of reasonable adjustments

Figure 5 demonstrates that respondents' knowledge and understanding of a range of reasonable adjustments was very strong. Over half of respondents stated that they felt 'extremely confident' (55%) about this topic, and no respondents offered a rating of 1 or 2.

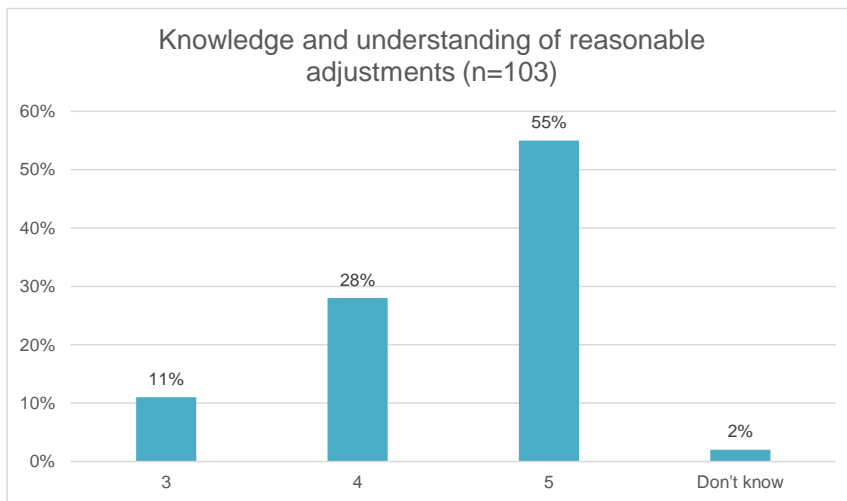


Figure 5 – Rating on how confident respondents felt in their understanding of a range of reasonable adjustments. Note the scale ranges from 1, 'not confident at all', to 5, 'extremely confident'

Despite high levels of knowledge and expertise, respondents nonetheless reported encountering an array of challenges in regard to the effective implementation of reasonable adjustments. Too often, respondents mentioned battling against 'micro-cultures' within their provider, wherein local interpretation of responsibility created inconsistency between courses, schools and even departments. Progress with putting in place reasonable adjustments often depended on the level of willingness from individual members of staff.

*"Where we are facing challenges is micro-cultures, in particular schools and courses which don't always input recommended adjustments from the Disability Inclusion team."*

*“The main issue is the difference in what the different teams believe is reasonable and appropriate.”*

*“The weight/power that one individual staff member sometimes has influences the decisions that are made at a school level.”*

This meant that, in some cases, disability advisers had a tendency to view and treat particular staff as ‘allies’, rather than striving to progress and deepen an understanding of reasonable adjustments across the whole provider.

*“Certain colleagues in the HEI are allies and are essential in implementing the support that I recommend. I could not do my job without them. But this is down to individuals, rather than this being embedded in business as usual.”*

*“We’re often advising the people most likely to want to change practice, rather than those are resistant and cannot see the point, or who do not believe in making adjustments.”*

*“There are some fantastic academic and support colleagues who understand the advice and recommendations provided and work hard to implement them and support students. It’s just a shame that this is the exception rather than the rule.”*

Finally, while 82% of respondents felt as if they had a consistent understanding of what constituted ‘reasonable’ when recommending a reasonable adjustment, a further 12% did not. A small number commented on the fact that the line between what was reasonable and what was not reasonable was becoming increasingly blurred, particularly if other staff member’s perception of ‘reasonable’ differed to their own.

*“We experience frequent pushback from academics who still believe that they are the arbiters of what is considered ‘reasonable.’”*

### **Working with academic staff**

Close collaboration with academic staff was recognised by the majority of respondents as crucial to effectively implementing individual reasonable adjustments for disabled students. Figure 6 demonstrates the frequency at which respondents worked with academic staff in their day-to-day role, with over two-thirds of respondents reportedly working with them often (rated 4 or 5). It should be noted that (with the exception of two providers) respondents who selected 1 or 2 (i.e. ‘never’) were all based in providers with more than 15,000 enrolled students, thus potentially increasing the distance between themselves and academic staff.

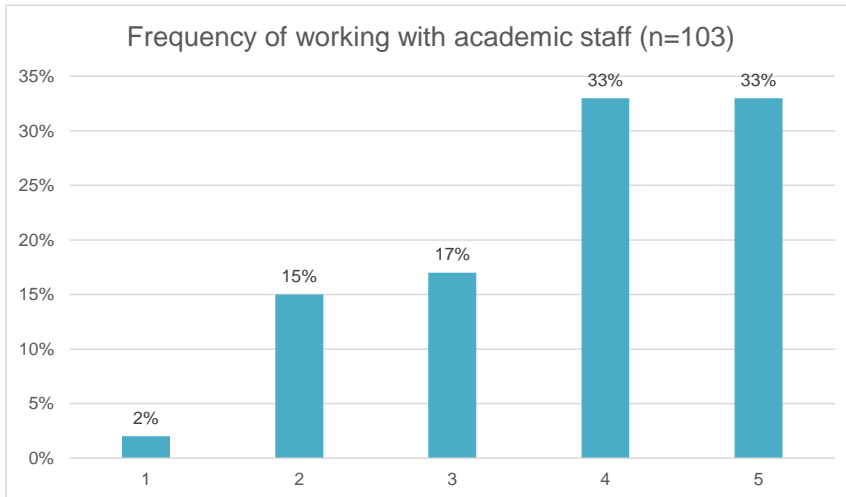


Figure 6 – Rating on how frequently respondents worked with academic staff. Note the scale ranges from 1, 'never', to 5, 'often'.

Unfortunately, respondents raised a number of persistent barriers experienced when working with academic staff that often resulted in inappropriate or delayed provision, or in some cases no provision at all. Firstly, a large number of respondents were cognisant of academic staff's similarly high workloads and that stretched capacity limited their ability to implement reasonable adjustments in a timely manner.

*"It can be difficult to convince already overworked academic staff why they should do more."*

*"They generally all want to support students, but have concerns about the time and resources required to do this effectively, so we have to be realistic in terms of managing expectations."*

*"Academic staff are under overwhelming resource pressure which can hinder partnership working if support feels to them like additional work."*

A lack of capacity extended to academic staff (including visiting lecturers) working in zero-hour or fixed-term contracts, presenting a further challenge for disability advisers. Some respondents suggested that these staff were not in a position to develop an in-depth understanding of disabled students' requirements nor commit to inclusive practice due to being time-bound in the role.

*"Some academics have no continuity or job security making it more difficult for us all to engage in collaboration, develop mutual understanding and develop in our respective roles."*

*“Academic staff are already working beyond the remit of their contracts or are bound by temporary, part-time contracts meaning that they have precious little time to dedicate to adapting their teaching.”*

Finally, many respondents stated that the implementation of reasonable adjustments was often hindered by academic staff’s perceived resistance in relation to competency standards and academic integrity. In a number of cases, this filtered through to inflexibility in assessment. In particular, a lack of awareness and understanding of competency standards in the areas of teaching, learning and assessment sometimes led to academic staff believing disabled students were offered ‘unfair advantages’.

*“Defaulting to departmental preferences (i.e. it needs to be assessed by exam) rather than considering whether something is a core competency or not, and being resistant to investigating this which involves a lot more work and involvement from our team.”*

*“There is a lack of knowledge and experience of alternative forms of assessments.”*

*“We have some professional courses that have a restriction on adjustments due to needing to meet certain professional requirements.”*

*“We need clear guidance from these professional bodies about what adjustments would be deemed reasonable by the professional body.”*

While it is clear that there need to be increased opportunities for staff based in disability services, as well as academic staff, to work with Professional, Statutory and Regulatory Bodies (PSRBs) on inclusive practice, these opportunities were limited. Figures 7 demonstrates the frequency at which respondents worked with PSRBs in their day-to-day role, and Figure 8 demonstrates respondents’ confidence working with these groups. In both charts, there is room for improvement.

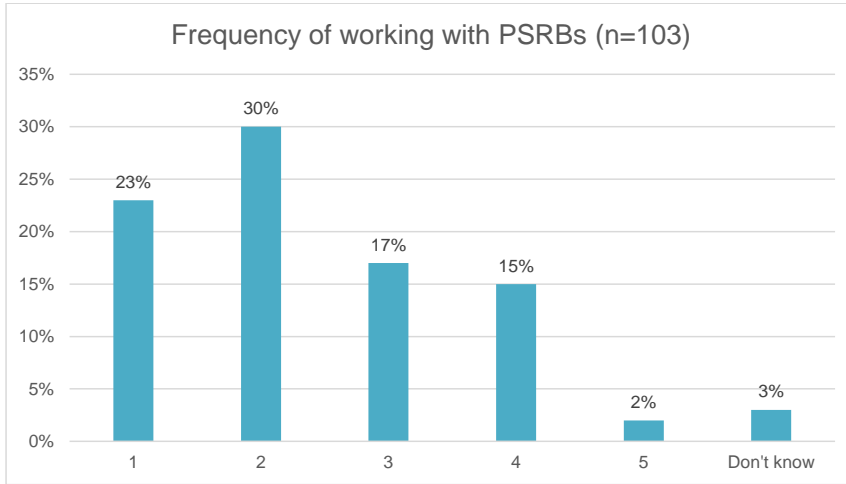


Figure 7 – Rating on how frequently respondents worked and collaborated with PSRBs. Note the scale ranges from 1, 'never', to 5, 'often'.

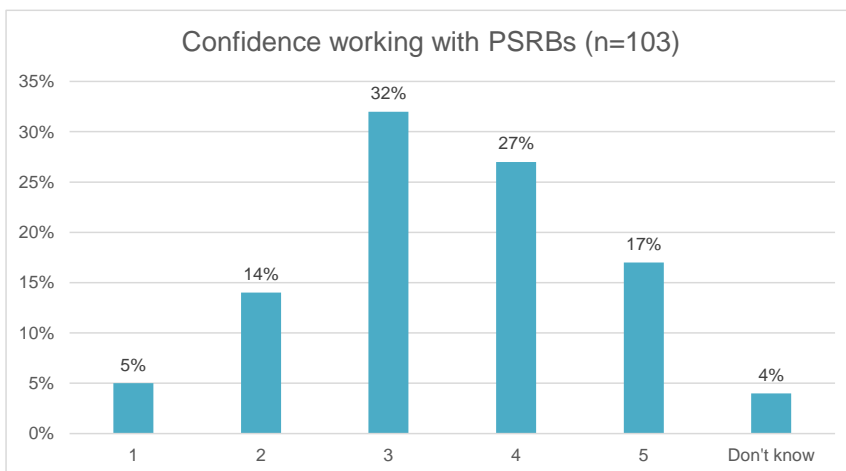


Figure 8 – Rating on how confident respondents felt guiding and advising PSRBs. Note the scale ranges from 1, 'not confident at all', to 5, 'very confident'.

Despite challenges, respondents shared a number of positive examples in regard to effective collaboration with academic staff. Overwhelmingly, respondents noted that actively reducing the distance between themselves and academic staff created a better overall understanding of inclusive practice and reasonable adjustments. In many cases, this included designing and delivering training to academic staff or basing disability advisers directly within academic departments.



*“Attending academic team meetings. The more staff know and trust me, the easier it is for them to approach me with small questions and the more receptive they are to receiving advice and guidance.”*

*“We are rolling out a project currently to embed disability advisers within departments within the aim to provide more contextualised adjustments and to work to promote understanding and embedding of inclusive practice.”*

*“I recently provided academic colleagues with training on competence standards in relation to assessment practices that has inspired real change in some faculties.”*

*“We are fortunate to have an established network of experiences ‘Disability Leads’ and ‘Disability Coordinators’ in each college and department. This helps us communicate and discuss recommendations of good practice and reasonable adjustments with relevant people at a more local level across the institution.”*

Interestingly, a couple of respondents also mentioned that their disability service has shifted to the ‘mainstreaming of the most common adjustments’, alongside ‘personal assessments’ wherein students can self-select their own reasonable adjustments from a pre-populated list. One respondent felt that it was possible this could support a move away from the idea that ‘disability advisers are essential gate keepers of reasonable adjustments at the individual student level’ and towards a more inclusive model overall, thus saving academic staff time.

### **Moving towards inclusive practice**

Moving towards inclusive practice no doubt requires a collaborative approach across a provider, with internal and external stakeholders all working together with disability services to best serve the interests of disabled students. It is clear that collaborative working is still met with resistance, Figure 9 outlines the extent to which respondents believed they had a collaborative approach at their provider. Over a third of respondents provided a neutral score of 3.

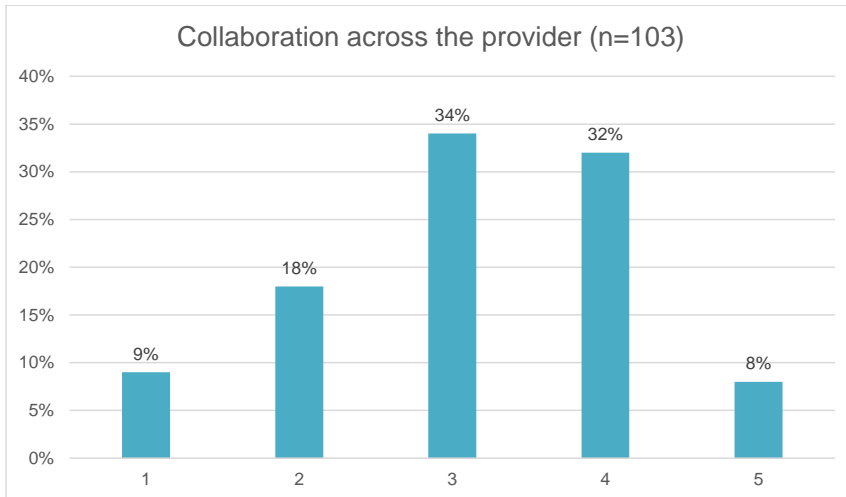


Figure 9 – Rating on the extent to which respondents believed there was a collaborative approach across the HEP to supporting disabled students. Note the scale ranges from 1, 'not collaborative at all', to 5, 'extremely collaborative'

Qualitative comments suggested that while working towards inclusive practice was the 'end goal', it was certainly not business as usual; a large number of respondents stated that much of the capacity within disability services was still consumed by implementing reasonable adjustments at an individual level rather than progressing inclusive practice.

*"It has been said for a long time, but inclusive education has to be the way forward in order to address the rise in caseloads."*

*"The more of our time that is taken on individual reasonable adjustments, the less time we have to consider inclusive practice."*

*"The university primarily functions on an individual level, with a very limited capacity for structural change or a cohesive inclusive strategy."*

Furthermore, some stated that the message of 'inclusion is everyone's responsibility' had not permeated through, and that there continued to be resistance across the provider, coupled with an overreliance on the medical model of disability.

*"People are reluctant to let go of adjustments and replace with inclusion."*

*"Inclusive practice is getting more traction, but changing attitudes towards this are slow."*

*“In order for students to access reasonable adjustments, they are still required to obtain medical evidence of a disability or medical condition. It sometimes feels that students are required to have a label to access support.”*

A couple of respondents also commented on the fact that policies and initiatives put in place during the COVID-19 pandemic and that supported inclusive practice had since been withdrawn.

*“The pandemic has led to increased expectations regarding possible adjustments, particularly related to online learning and alternative forms of assessment. However, there is pressure in some areas to revert back to pre-pandemic norms.”*

*“Some aspects of inclusive practice, such as recording classes, were bought in during the pandemic, but have since been withdrawn. There seems to be a lack of understanding of the benefits of, or buy-in to, wholesale inclusive practices.”*

### **Universal Design for Learning**

While a large number of respondents felt excited by the possibilities and opportunities brought about by an inclusive education strategy, it was surprising that uptake of Universal Design for Learning (UDL) and embedding its principles was so slow.

Awareness of UDL was also lacking, with just over half of respondents stating that they were very aware of its principles (rated 4 or 5). Over 20% of respondents were not aware of the principles at all (rated 1 or 2)<sup>4</sup>. Respondents were also asked whether, to their knowledge, their provider had adopted and embedded the principles of UDL. Of note, only 9% stated that their provider had both adopted and embedded the principles. A further 23% stated that they had adopted them, but not yet embedded them.

While for some providers, UDL was now considered ‘as standard’ within some processes related to teaching, learning and assessment, a large number of respondents commented on its inconsistent application across a provider. Similar to the implementation of reasonable adjustments, in some cases the willingness to embed UDL was partly dependent on willingness from individual members of staff.

“It is varied. Some departments adopted and embedded UDL principles a long time ago, others are not there on either count.”

“In some areas/departments with good members of staff it is being adopted and progressing well. In others it is not being adopted/embedded and we encounter a lot of resistance.”

“Some departments and academics have embraced UDL, but not institutionally.”

---

<sup>4</sup> Note that the scale ranges from 1, ‘not aware at all to 5, ‘very aware, in response to the question ‘how are aware are you of the principles of Universal Design for Learning?’ (n=102)

Respondents also expressed concern that ongoing challenges related to a lack of resource and capacity within disability services, as well as a lack of senior leadership buy-in and collaboration across the provider, would continue to slow progress made with embedding the principles of UDL.

“This needs senior leadership buy-in and support for projects such as UDL which require years of staffing to conduct and implement.”

“Overall, I am positive about the direction of travel in terms of developing understanding of inclusive practice and UDL – the key issue is having the resource to do it properly and with the required impact.”

### **The future of disability services** **Concern about the future**

When asked to what extent respondents felt positive about the direction of travel for disability services, as well as their service’s ability to effectively support disabled students in future, results were somewhat mixed. As demonstrated in Figure 9, while around a third of respondents felt positive about the direction of travel (rated 4), a similar proportion provided a more neutral score.

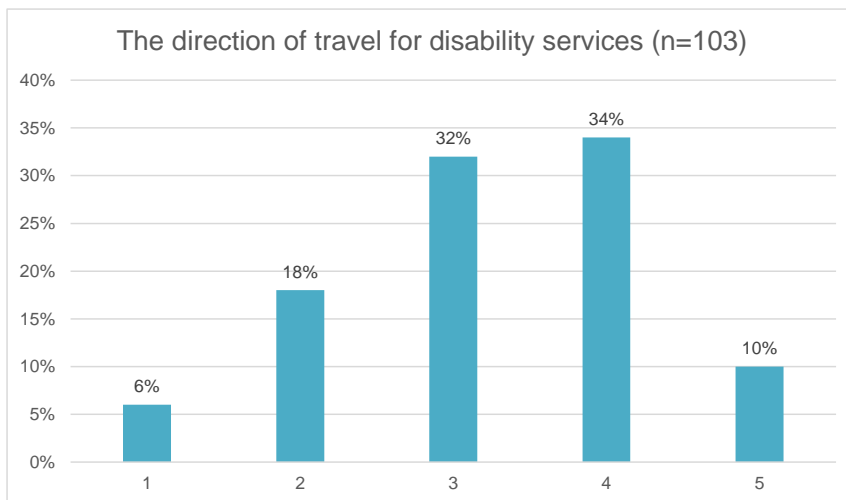


Figure 10 – Rating on how positive respondents felt about the direction of travel for disability services. Note the scale ranges from 1, ‘not positive at all’, to 5, ‘extremely positive’

Operational challenges most frequently mentioned as limiting the ability of disability services to be proactive instead of reactive included: a lack of resource within disability services and across a provider more widely; an ever increasing number of disabled students, including disabled students with more complex support requirements and/or

multiple diagnoses registering for support; deterioration of working conditions and promotion opportunities for disability advisers; outdated administrative systems and processes; and a lack of buy-in and investment on behalf of senior leadership. This is seen in the following comments.

*“Demand on our service is ever increasing (including that our student cases are becoming more and more complex, requiring more time and longer spent working on cases.”*

*“Squeezed resources and lack of staff means that we no longer have time to carry out developmental, proactive and strategic projects – we are often very reactive.”*

Taken together, respondents reported that these challenges further contributed to high workload levels that often felt ‘beyond capacity’. On occasion, this was causing some disability advisers to consider their future role, which could ultimately lead to the ‘potential loss of a wealth of experience and expertise from disability support’. This was particularly pertinent for staff working in providers with a reported ratio of one disability adviser to more than 750 disabled students, with the following comments shared by those particular respondents:

*“The workload is relentless, and I’m also responsible for my team’s workload and wellbeing.”*

*“I am very tired. My caseload is very large.”*

*“The volume and complexity of work has increased hugely in the past few years and I am constantly overwhelmed. I often feel I am not doing enough to support my students and colleagues, and that is really demoralising.”*

For a couple of respondents, while they were determined to stay in the role, their professional lifespan and ultimate cost to their wellbeing was still under consideration.

*“I love my job and remain committed to supporting disabled students, I do fear there is an emotional shelf life for those involved in supporting disabled students.”*

*“I wouldn’t want to do any other work, as I fundamentally believe in the work we do. But it comes at a cost in terms of wellbeing because of the workload and pressures of the role.”*

Moreover, a large number of respondents mentioned that the proposed changes to DSA assessments could have a direct impact on the future of the service. While no formal decision had been published at the time of administering the survey, disability advisers lacked both guidance and reassurance on the intent and implementation of changes outlined in the proposals, and how to manage them.

Finally, respondents expressed concern over the shifting perception and treatment of staff within disability services, which in some instances led to the 'de-professionalisation and downgrading of disability support roles.' Another respondent mentioned that there was a 'push to make us all generalists' within their provider. These comments serve as a reminder of the perceived precariousness of staff based in disability services, wherein the professionalism and centrality of their professional roles often felt overlooked.

*"I love my job but I'd like to be taken more seriously as an educational professional, not just learning support."*

Adding to this, one respondent described their disability service as having 'all the accountability and none of the authority'. Owing to a lack of perceived strategic support at a leadership level, several respondents felt fearful about the safety of disabled students, particularly in the wake of the Abrahart case regarding the death of a disabled student at the University of Bristol.

*"I worry constantly about the safety of students, especially when workloads are so high."*

*"Possibility of 'missing something' and being held accountable later due to lack of time."*

## **Positive progress**

It was clear that disability advisers, despite being faced with a persistently high caseload, were resolute in continuing to support disabled students to the best of their ability. This was reflected in the fact that 83% of all respondents reported often feeling 'determined to do their job well'<sup>5</sup> (rated 4 and 5 respectively). Overwhelmingly, respondents shared that they felt hopeful about the future of their role for as long as it resulted in making a difference to disabled students, albeit with some caveats.

*"It is always positive to see small adjustments make a large difference to students' ability to achieve their academic potential. The range of students I meet and the huge amount of talent and abilities they possess, leaves me awestruck."*

*"Working with and meeting so many students – they are please to meet and work with, and it's always very rewarding when we can help ensure they are getting all of the support they deserve (and need)."*

Despite aforementioned concerns around dilution of responsibilities, some respondents also noticed that their expertise was increasingly valued, and that the professionalism and specialist knowledge that exists within disability services was recognised as 'critical' to a

---

<sup>5</sup> Note that the scale ranges from 1, 'never' to 5, 'often, in response to the question 'how frequently do you feel determined to do your job well?'.  
29

provider's progress in disability equality. Recent sector publications and guidance, such as the Disabled Student Commitment (Disabled Students' Commission, 2023), also helped to give weight to embedding inclusive practice and maintaining disability awareness across a provider.

*"I think we're finally getting noticed, and senior leadership are slowly beginning to realise how critical we are to the university's accountability under the Equality Act. Our expertise is beginning to be understood and called upon in some areas."*

*"We are becoming a critical part of the institution in relation to learning and teaching principles relating to UDL and wider EDI work. There is wider recognition of the professional skills within the disability team."*

Partnership working and collaboration with staff – especially academic staff – across a provider was also on the rise, helping to ensure disabled students received high quality and consistent provision.

*"I am working collaboratively with colleagues outside of Disability Services to create a more flexible and inclusive environment in HE."*

*"We are starting to work more collaboratively which puts students and staff at the heart of the process rather than it being driven by the process itself."*

## **Conclusion and recommendations**

This report provides an overview of what has changed for staff working in disability services since the publication of the HEFCE guidance (1999). In particular, the survey findings identified where there are commonalities in experiences, and highlighted issues that were reported by a large number of staff. Ultimately, since the ratio of staff supporting disabled students has risen year-on-year to a current average of one disability adviser to 583 students, it is perhaps not unsurprising that the concerns shared were significant, and cannot be ignored.

At the time of the HEFCE guidance, it set out the minimum level of support that each HEP should provide. While many of these provisions are fortunately now in place, pressures on HEPs and a lack of resource and support for staff working in disability services are ultimately limiting their improvement and expansion.

The following recommendations derived from this research are designed to address the issues identified, and to promote and improve a supported environment for staff working in disability services.

- Senior leadership should recognise disability as a priority protected characteristic, and in the same vein recognise disability services as a priority department. A commitment to improving the experiences of disabled students (through the participation in initiatives such as the Disabled Student Commitment) should be

coupled with a commitment to improved support and professional recognition of staff working in disability services. The professionalism and expertise that exists within disability services should be acknowledged at both a systematic and cultural level.

- While HEPs should acknowledge the benefits of co-located disability services with other support services such as wellbeing, they should be cognisant of the risk that this poses to the perceived generalisation and downgrading of specialist roles.
- Greater attention should be given to staff development and awareness raising of disability inclusion across the whole HEP. This should be mandatory for, at a minimum, all professional services staff and academic staff working directly with disabled students.
- HEPs should increase opportunities to build engagement between PSRBs, academic staff and staff working in disability services. This should include targeted training for academic staff on competency standards and reasonable adjustments.
- Written policies and procedures in regard to examinations and assessments for disabled students should be clearly communicated, with HEPs considering to what extent anticipatory reasonable adjustments and flexibility can be built in as standard.
- HEPs should seek to progress inclusive practice and more specifically, adopt and embed UDL. This should be accompanied by the rolling out of widespread training and awareness raising to ensure staff across the HEP are aware of its principles. Consideration should also be given to the resource of academic staff, particularly those working in fixed-term roles, to be able to deliver this.
- Formalise open and frequent conversations between staff working in disability services and line managers to regularly monitor their wellbeing, including a focus on working hours to avoid overworking where possible. In the same vein, HEPs should recognise the emotional toll on staff working in disability services and consider the support available.
- Ensure staff working in disability services have the capacity to attend and engage in CPD without the need to do this in their own time. More specifically, increase CPD opportunities focussed on supporting particular cohorts of disabled students, including postgraduate and international students.
- HEPs should seek to improve and upgrade administrative systems designed to collect, monitor and analyse data on disabled students. Ensure staff working in disability services can anticipate (and accommodate) the growing number of disabled students registering for support.

## References

- , S. (2022). Evaluating the use of reasonable adjustment plans for students with a specific learning difficulty. *British Journal of Special Education* – Volume 49 – Number 3. DOI:10.1111/1467- 8578.12412



- Disabled Students' Commission (2020). Three Months to Make a Difference. Advance HE [online at <https://www.advance-he.ac.uk/knowledge-hub/three-months-make-difference>].
- Disabled Students' Commission (2021). Annual Report 2020-2021: Enhancing the disabled student experience [online at [www.advance-he.ac.uk/knowledge-hub/disabled-studentscommission-annual-report-2020-2021-enhancing-disabled-student](http://www.advance-he.ac.uk/knowledge-hub/disabled-studentscommission-annual-report-2020-2021-enhancing-disabled-student)]
- Disabled Student Sector Leadership Group (2017). Inclusive Teaching and Learning in Higher Education as a route to Excellence [online at [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/587221/Inclusive\\_Teaching\\_and\\_Learning\\_in\\_Higher\\_Education\\_as\\_a\\_route\\_to-excellence.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/587221/Inclusive_Teaching_and_Learning_in_Higher_Education_as_a_route_to-excellence.pdf)]
- Disabled Students UK (2022). Going back is not a choice. [Online at [disabledstudents.co.uk/not-a-choice/](http://disabledstudents.co.uk/not-a-choice/)]
- Gander, M. (2018). Professional services: supporting student success, Perspectives: Policy and Practice in Higher Education, 22:3, 69-70, DOI: 10.1080/13603108.2018.1467996
- Global Disability Innovation Hub, Snowdon Trust (2021). Disabled Students Survey [online at [disabilityinnovation.com/news/disabled-students-survey-1](http://disabilityinnovation.com/news/disabled-students-survey-1)]
- HESA. (2022). Higher Education Student Statistics: UK, 2020/21 . HESA. [online at <https://www.hesa.ac.uk/data-and-analysis/students/whos-in-he>]
- Kendall, L. (2016) Higher education and disability: Exploring student experiences, Cogent Education, 3:1, 1256142, DOI: 10.1080/2331186X.2016.1256142
- Manley, S. and De Graft-Johnson, A. (2013) Towards inclusion: rethinking architectural education. Construction Management and Economics, 2013 Vol. 31, No. 8, 914–927, doi: 10.1080/01446193.2013.797093
- Martin, N., M. Wray, A. James, E. A. Draffan, J. Krupa and P. Turner (2019), Implementing Inclusive Teaching and Learning in UK Higher Education: Utilising Universal Design for Learning (UDL) as a Route to Excellence (London: Society for Research into Higher Education).
- Martin, N (2020) A practical response to ableism in leadership in UK higher education. In N. Brown & J. Leigh (Eds.), Ableism in Academia: Theorising experiences of disabilities and chronic illnesses in higher education (pp. 76–102). UCL Press. <https://doi.org/10.2307/j.ctv13xprjr.11>
- McConlogue, T. (2020). Assessment and Feedback in Higher Education: A Guide for Teachers [online at <https://www.uclpress.co.uk/products/111601>]
- Omissi, C. (2020) 'From reasonable adjustments to inclusive practice: has the increased emphasis on inclusive learning reduced the need for reasonable adjustments for

disabled students in UK HEIs?' Journal of Inclusive Practice in Further and Higher Education, 12 (1), 5–25.

Pickard, B. (2021) How is disability portrayed through Welsh universities' Disability Service web pages? A Critical Disability Studies perspective, Volume 14, Issue 1, Spring 2021, doi: 10.3167/latiss.2021.140102

Williams, M., Pollard, E., Takala, H. & Houghton, A. M. (2019) Review of Support for Disabled Students in Higher Education in England. Brighton: Institute for Employment Studies Brighton [online at <https://www.employment-studies.co.uk/system/files/resources/files/535.pdf>]

Wray, M. (2018), 'Re-visioning support for disabled students in HE', WONKE, 25 June, [online at <https://wonkhe.com/blogs/re-visioning-support-for-disabled-students-in-he/>]

## Appendix

### *Breakdown of roles included in the sample*

Disability Adviser	33
Senior Disability Adviser	5
Disability Services Manager	5
Accessibility Adviser	3
Disability Practitioner	2
Head of Disabled Student Support	1
Senior Inclusive Support Advisor	1
Health & Wellbeing Adviser	1
Assistant Disability Adviser	1
Head of Disability Advisory Service	1
Assistant Head of Student Wellbeing Service	1
Head of Student Support	1
Assistive Technology & Alternative Formats Officer	1
Interim Head of the Disability Advisory Service	1
Deputy Head of Disability Service	1
Accessibility service Manager	1
Director, Disability and Learning Support Service	1
Head of Disability Services	1
Disability & dyslexia coordinator	1
Head of Student Life responsible for Disability Service	1
Administrative Assistant (Disability Service)	1
Head of The Disability Service	1
Disability Adviser and Assistive Technology Adviser	1
Inclusion Coordinator	1
Disability Adviser/ Study Skills Tutor	1
Pre-diagnosis Support Adviser	1

Disability Advisory Team Manager	1
Senior Wellbeing Services Manager	1
Disability and Dyslexia Assistant	1
Head of Additional Support and Disability Advice Centre	1
Disability and Dyslexia Support Manager	1
Head of Disability and Access Support	1
Disability and Inclusion Manager	1
Head of Disability Support & Inclusion	1
Disability and Neurodiversity Adviser	1
Head of Student Disability and Inclusion	1
Disability and SpLD Adviser	1
Head of Student Services	1
Disability and Welfare Manager	1
Head of the Accessibility & Disability Resource Centre	1
Disability Coordinator	1
Head, AccessAbility Centre	1
Disability Coordinator / 1.1 study skills tutor	1
Inclusion and Disability Support Manager	1
Disability Inclusion Advisor	1
Inclusion Services Manager	1
Disability Officer	1
Learner Support Assistant	1
Project Manager Disability Inclusion	1
Assistant Director, Disability Service	1
Senior Adviser for autistic students	1
Accessibility and Wellbeing Manager	1
Disability Service Team Leader	1
Senior Inclusive Support Manager	1
Specialist University Tutor	1
Specialist Disability Practitioner	1
Student Inclusion Manager	1
Academic Support Manager	1
Disability Support Adviser	1
Disability Support Services Manager	1

## **Pilot Research Project: ‘Exploring SpLD specialists’ views on whether, and to what extent, an eight-hour, open book academic assessment format, trialled by departments at a Russell Group University, is inclusive for SpLD students’ needs.**

**Helen Young**

University of Oxford

### **Abstract**

This article is a write up of a research pilot, undertaken as part of a Professional Doctorate in Education, which explored the perceptions of two Specialist Study Skills Tutors’ on the inclusiveness of an eight-hour, open book, take home assessment format trialled at a Russell Group university. Qualitative interviews were used to explore Tutors’ views on the advantages and disadvantages of the assessment format for students with specific learning difficulties (SpLDs). Interviews were transcribed and analysed utilising Reflexive Thematic Analysis (RTA) to identify common emergent themes and help clarify focus and parameters of longer-term future research.

Both tutors perceived the eight-hour, open book format of benefit in ameliorating pressures on memory for many SpLD students, reducing administrative burdens on students and staff and offering enhanced flexibility and inclusivity for a broad range of students. The take-home element was deemed beneficial for some SpLD students, offering option to move around, use voice recognition or text-to-speech software, providing greater time to plan, produce and proofread work, and where the home environment helped reduce anxiety. Conversely, however, it was observed that the home environment may also pose a barrier for others, for example if the pressure and formality of shorter, closed-book exams within a formal setting was of support with motivation or where the home environment proved a source of increased distraction.

Students’ perceptions of fairness were another key theme of the interviews, with both Tutors observing many SpLD students seemed to consider and define fairness in relation to how much time they had in exams compared to their non-disabled peers, regardless of the amount of time available. This question of fairness and how it is construed is an area identified as a focus for future research.

### **Introduction**

Higher education institutions (HEIs) within the UK have experienced an increase in diverse student populations over the past decade (Ross et al. 2018; Scott and Marchetti, 2021), including a rapid rise in the number of students disclosing a disability (Williams et al., 2019; Hubble and Bolton, 2021; DSUK, 2022). This increase has equally been witnessed within the disability services I manage at a Russell Group university. Such demographic shifts have necessitated greater consideration by universities of how best to support a wider range of learning abilities and needs.

Principles of Universal Design for Learning (UDL) have become increasingly adopted as a means of fostering inclusion for all students within the classroom (Martin et al. 2019; Nieminen, 2022) and many researchers advocate for equal application of UDL within the design, delivery and evaluation of assessment (McArthur, 2018; Hanesworth et al. 2018; Martin et al., (2019); CAST (2022)). However, there is little evidence of widespread adoption of inclusive assessment practices in universities (Hockings, 2010; Hill, 2021).

It is the question of what constitutes inclusive assessment for students, and particularly disabled students, within HE that is intended to be the focus of my future research. A main aim of the pilot was, therefore, to help clarify and inform the parameters of longer-term research, enabling opportunity to explore and apply appropriate theoretical approaches, questions, methodologies and research methods.

The pilot adopted an interpretivist approach, seeking to explore two Specialist Study Skills Tutors' perceptions and observations of inclusiveness of an eight-hour, open book academic examination format, trialled between 2020 and 2022 by certain departments at a Russell Group university (referred to hereafter as 'the University').

The Specialist Tutors interviewed (referred to hereafter as 'Tutors') are practitioners in the field of specific learning difficulty (SpLD) support, who provide study skills support, including revision and assessment strategies, for students with SpLDs at the University and elsewhere. Pilot interviews, therefore, focussed on whether, and to what extent, Tutors perceived the eight-hour open book format to be supportive of SpLD students' needs, based on their observations and discussions with those they support.

Semi-structured qualitative interviews took place individually with Tutors online, were video recorded and transcribed using software and manual editing. Reflexive Thematic Analysis (RTA), proposed by Braun and Clarke (2021, no page) to be an immersive and 'theoretically flexible' means of identifying, developing, analysing and interpreting common themes within qualitative research', was then applied. An inductive approach was applied to identify key emergent themes, which were coded as 'perceptions of fairness', 'administrative burdens', 'purpose of assessment and real-world authenticity' and 'advantages' and 'disadvantages' of the eight-hour, open book format.

Constructivist assumptions underpinned the research, asserting that knowledge and truth are subjective, socially constructed concepts (Alharahsheh & Pius, 2020), never completely distinct from a researcher's own values and beliefs (Ryan, 2018). It is acknowledged that my own subjectivity, as well as the subjective values and experiences of the Tutors interviewed, will have influenced the research and interpretations of meaning.

## **Methods and Methodology**

### **Establishing Research Methodology**

When considering an appropriate methodological approach for the pilot, the longer-term research interests and aims were considered. The future intent is to explore a range of views and experiences regarding inclusivity of assessment formats for disabled students. An interpretivist approach was deemed to align well with this objective, which, as Alharahsheh and Pius (2020, p.39) assert 'enable(s) researchers to gain further depth through seeking experiences and perceptions of a particular social context'.

Interpretivism was favoured over alternative paradigms, such as positivism, which Park et al (2020, p.1) propose more commonly has application in 'identifying causal relationships through quantitative approaches' and 'where empirically based findings from large sample sizes are favoured'. Conversely, Hammersley (2013, p.23) contends, it would be 'misguided' to solely equate positivism with qualitative approaches, noting that 'qualitative data are equally well embraced within empiricism' (p.24). However, on balance, an interpretivist paradigm was anticipated to align more appropriately with the pilot's aims, which were not concerned with causality and uniformity of data, but rather sought to explore and interpret meanings from observations and experiences.

The approach was inductive, with the intention of allowing interview data to determine the themes and focus of research and 'penetrate as far as possible into the participants' lived experience' with 'no research hypotheses ...formulated before starting' (Sibeoni et al. 2020, no page).

Conducted from a constructivist ontological standpoint, the pilot assumes that 'people actively and agentially seek out, select and construct their own views, worlds and learning' Cohen et al. (2018, p. 23). Critical reflection was applied throughout the pilot, to consider how, and to what extent, my beliefs, opinions, biases and knowledge constructs as a researcher could have influenced the research process and informed my interpretations of meaning within the findings. Similarly, acknowledgement and reflection were given to the ways in which participants' observations and understandings may have informed their epistemological and ontological positions.

## **Establishing Research Method**

### **Semi Structured Interviews**

Informed by the interpretivist approach adopted, and in recognition of wordcount and timescale limits for the pilot, a pragmatic decision was taken to utilise qualitative, semi-structured, open-ended interview questions (see [Appendix 1](#)) as a means of seeking 'deeper understandings of the human experience' (Bearman (2019, no page)). This format was favoured over alternative methods, such as unstructured interviews, quantitative questionnaires or large-scale focus groups, as the research was approached without conscious, pre-conceived expectations of what views Tutors might hold on the research topic. The semi-structured format was therefore hoped to offer flexibility and opportunities for follow-up, elaboration and clarification of points of interest or further discussion during interviews, which would arguably not have been facilitated to the same extent with closed-ended or purely quantitative methods (Cohen et al. 2018).

Conversely, unstructured interviews were ruled out as, whilst these may have facilitated greater in-depth phenomenological explorations of experiences and perceptions, semi-structured questions were deemed to better support the aim of clarifying future research parameters, providing a balance of flexibility to follow-up on emerging lines of discussion, whilst ensuring key questions and themes linked to future research scope were addressed.

Methods involving large numbers of participants were also avoided, favouring single, thirty-minute, one-to-one interviews with two Tutors, in recognition of the time required to sufficiently write up and analyse data.

## Identifying Research Participants

The initial intention when considering the pilot scope, was to interview disabled students to explore their direct experiences of eight-hour, open book assessments. Indeed, it is noted that the lack of disabled student voice within this research is arguably a limitation of the study. Conducting the pilot reinforced my desire to prioritise direct student discussions in future and so supports the pilot's aim of informing future research scope.

This is not to detract in any way from the value of Tutors' contributions, whose insights were immensely useful and relevant. Additionally, it is posited that interviewing two Specialist Tutors for the pilot, rather than two disabled students, had the benefit of enabling exploration and discussion of Tutors' observations across a diverse breadth of student experiences, which interviewing two disabled students about their individual experiences would, arguably, not have provided to the same extent.

The timeframe for the pilot, and particularly the time of year it was undertaken (December 2022 and January 2023), was also a consideration when identifying research participants. The University has shorter terms than many HEIs, which posed logistical and practical challenges. From mid-December, many students left for the Christmas vacation and were not proactively checking university emails outside of term. For others, they were focussed on submitting assignments and preparing for exams in January (another feature of some courses at the University considered in the pilot).

It is acknowledged that better advanced planning and preparation on my part would likely have mitigated some of these issues and this, alongside more realistic recognition of competing work and wider commitments, will be factored into future research planning (another example of the pilot informing future practices).

## Ethics

Prior to conducting interviews, participants were sent an information and consent letter, to sign and return, laying out the aims of the pilot and details on the format and anticipated time commitment for interviews. Tutors had option to withdraw from the research at any point. Consent was sought to record (audio and video) interviews within Zoom, for the purpose of supporting write up and analysis, but participants could opt-out if preferred, which it was highlighted, would not prohibit their involvement in the project. (Helpfully, both Tutors confirmed they were happy to be recorded).

Throughout the pilot, I reflected upon my positionality and biases as a researcher. It is acknowledged that one way for educational institutions to try and reflect and support the diverse needs of students, is commonly by applying individual accommodations and reasonable adjustments to assessments (Nieminen, 2022), which can take substantial time and work for disability practitioners. Over 6500 disabled students are registered with the service I work within and, during trials of the eight-hour open book assessments, it was my perception that the pressures on Disability Advisers to discuss, recommend and administer individual reasonable adjustments, reduced significantly. This has influenced my positionality and views of this assessment format as beneficial in reducing administrative pressures, for staff and students, within the wider context of rising disabled student numbers (Williams et al., 2019; Hubble and Bolton, 2021; DSUK, 2022).

Another reflection was that I have worked closely with the Tutors interviewed for over ten years. Discussions on inclusive assessment have arisen in this time and it was anticipated that Tutors would likely be aware of my own views on the topic. I also considered whether the contractual employment dynamic might influence how comfortable Tutors felt to express their true opinions. In an attempt to mitigate these concerns as best as possible, efforts were taken to ensure that the semi-structured question design included a balance of neutrally worded questions to explore both perceived positives and negatives of the assessment format.

It is also my perception that the established professional relationships formed with the Tutors over the past ten years, will have supported and encouraged open and honest discussions without fear of views being dismissed or criticised, which I perceive a benefit.

### **Process for Analysing Research**

#### **An Inductive Approach**

Researchers can adopt inductive or deductive approaches to analysis (Braun and Clarke [2006](#), [2012](#); Kiger and Varpio, 2020). An inductive analytic approach, seeks to derive themes arising from the research data (Varpio et al. [2019](#)), allowing for flexibility to identify additional themes not always directly aligned with questions posed, and not necessarily reflective of the researcher's own beliefs and interests on the subject (Braun and Clarke [2006](#)).

In contrast, a deductive approach is based upon pre-existing theories, hypotheses, or other researcher-led aims to identify themes of interest (Braun and Clarke [2012](#); Varpio et al. [2019](#)). Therefore, an inductive approach tends to provide a more extensive analysis of wider data, whereas a deductive approach may benefit focussing on a specific aspect of the data or a particular finding to examine, in the context of a pre-existing theory (Braun and Clarke [2006](#)).

Whilst either method might feasibly have application in qualitative research, an inductive approach to research and analysis was anticipated to best align with the aims of identifying and clarifying future research parameters and also supported the objective of exploring Tutors' perceptions of fairness and inclusivity of assessment methods.

### **Reflexive Thematic Analysis**

Thematic Analysis (TA) is an inductive, 'bottom-up approach to coding' (Varpio et al. 2019, p.992), most commonly applied to qualitative interviews or transcripts (Caulfield, 2022). Initially writing on TA in 2006, Braun and Clarke (2006, p.77) propose it as 'a theoretically flexible approach to analysing qualitative data' but have since expanded their thinking to promote Reflexive Thematic Analysis (RTA) (Braun and Clarke, 2019). Campbell et al. (2021, p. 2010) define RTA as 'an interpretive method firmly situated within a qualitative paradigm... (with) broad applicability within a range of ... research designs', further highlighting that the approach recognises the subjectivity of the researcher, which is viewed as valuable, rather than problematic, to the process.

RTA was adopted in the analysis of the pilot and, in transcribing the recorded interviews and reading and reflecting upon the content from discussions, I reflexively immersed myself in the data in an effort to identify commonalities and wider emerging themes.



## **Findings/Discussion**

As intended, the semi-structured format proved a valuable way of exploring Tutors' perceptions of the advantages and disadvantages of assessment formats in detail, whilst enabling broader, unstructured exploration of additional themes arising in discussions.

### **Emergent Themes**

Stemming from my interpretations of the interview data, the following key themes were identified:

#### **Perceptions of Fairness**

##### **Student Perceptions**

Departments trialling extended, open book exams, highlighted to students that the questions and format were identical to previous three-hour closed book formats (other than students had more time and access to notes and textbooks). This meant everyone, including SpLD students, who may previously, commonly have received 25% extra time, now had over 150% extra time in the new format, to use flexibly for writing, rest or planning as required. Departments anticipated this should be inclusive for the majority of students.

However, across both interviews, Tutors referenced that students' perceptions on fairness seemed based on how much time they had in exams in comparison to their non-disabled peers. Tutors reported many students' strong feelings that they should be afforded additional arrangements to non-disabled peers, regardless of the length of time available to complete an exam. In the first interview, referencing a week-long take home paper, the Tutor noted that one SpLD student vehemently perceived that non-disabled students would work consistently across the week and was angry, believing it to be inherently unfair not to receive further additional time to others. Similar observations were noted with students sitting the eight-hour, open book format of assessment.

Duncan and Purcell (2019) highlight a concept of 'Maximum Potential Thesis', which proposes all students have an upper skills and knowledge threshold, after which exam performance does not improve with provision of additional time. Whilst there is general consensus in SpLD research that the exam performance of SpLD students improves with additional time (Pearson et al. 2006; Gregg and Nelson, 2012; Duncan and Purcell, 2019) there remains inefficient consensus as to whether or not extra time benefits all students or just SpLD students (Duncan and Purcell, 2019).

##### **Academic Staff Perceptions**

Tutors noted some students mentioned they perceived questions in eight-hour, open book assessments to be more difficult than in closed book assessments, speculating whether some academics might perceive the open book nature to be easier or less academically robust. This theme of Academic's perceptions of fairness has, as a result of this pilot, been identified as a focus for future research, with the intention of interviewing academics for the wider dissertation.

Within the Reflexive TA of the interviews, 'Academic Staff Perception' was initially coded within a theme of 'Assessment Design' but on further reflection was identified as a theme in itself.

### **Reduction of Administrative Burden**

#### **For Disability and Assessment Staff Teams**

Tutors perceived, as had I, that the eight-hour, open book format significantly reduced the need for individual discussions and administration of bespoke reasonable adjustments for the majority of disabled students, compared to the time and workload historic three-hour, closed book papers necessitated, which was recognised as time consuming and administratively burdensome for staff.

#### **For Students**

Equally, the pilot recognised the additional administrative burdens that historical three-hour papers can place on disabled students. At the University, the processes to access individual reasonable accommodations and support, remain largely rooted within a medical model approach, requiring disabled students to register and evidence disability before exam adjustments can be considered (Weis and Beauchemin, 2020). It is acknowledged that additional administrative and organisational pressures involved in completing registration paperwork and managing appointments may be especially difficult for SpLD and other disabled students.

#### **Purpose of Assessment and Real-World Authenticity**

Interpreted as support for extended open book exams, Tutors queried whether alternative short, closed book papers were representative of real-world requirements in employment, asserting there are few professions which would require retention of extensive information in memory, without option to consult other resources. This feeds into wider questions of the purpose of assessment. Sambell et al. (2013) assert that assessment must have relevance to the wider future contexts in which students will operate (whether in the social world, employment market or in terms of individual self-fulfilment) and McArthur (2018, p.184), similarly emphasises the importance of authentic assessment as 'a means to capture link(s) to activities with a clear alignment in the social and economic world'.

There may be many reasons, for example, disability, language or cultural, that students may be disadvantaged by an assessment format and both Tutors reflected that the eight-hour open book format seemed more inclusive in this regard and highlighted the need for the design and delivery of assessment to ensure flexibility and responsiveness that effectively reflects all students' needs and abilities.

#### **Advantages of the eight-hour, open book format**

Reduction of pressures on memory and support with planning and information processing

Both Tutors advocated clear benefits of the eight-hour, open book format for SpLD students, highlighting especially the reduction on memory load. One Tutor noted particular benefits to students on Psychology, Law and English courses, where access to textbooks and notes in exams, reduced the requirement to retain and recall quotes, dates, names and statutes. However, it was also noted that even in open-book assessments,

many SpLD students would likely experience additional challenges in organising notes and identifying relevant references quickly.

Additionally, both Tutors believed the majority of SpLD students would take longer to process information and produce work under highly time-pressured exams, attributing this as a benefit of the eight-hour window.

#### Flexibility (of time and environment)

Both Tutors perceived greater flexibility within the longer, open book format, which they proposed enabled students to incorporate rest, writing or planning time as needed. Most of the open book papers were possible (and necessitated during the COVID pandemic) to sit at home. Both Tutors further noted the benefits and flexibility of the home environment for some SpLD students, providing options to move around, access speech to text software more readily or read work aloud to support processing.

#### **Disadvantages of the eight-hour, open book format**

##### Environment

Conversely, it was noted that the home environment could also pose a barrier for some SpLD students who reported the pressure and formality of shorter, closed book exams within a formal university setting supported with motivation. Similarly, Tutors observed the home environment posed additional distractions for some students and exacerbated attention challenges.

#### **Challenges in transition to a different format**

One Tutor suggested that students would need time and support during transition to any new assessment modes. The pandemic necessitated rapid shifts in assessment processes and formats, which may have exacerbated students' anxieties about a new mode of assessment. The question of how best institutions can support students in transition to new formats of assessment is another area, arising from the pilot, which I intend to explore in future research.

#### **Fairness**

Tutors observed students' main concerns were around perceptions of fairness. When initially coding research findings, this was included under the theme 'Disadvantages' but on further reflection was identified to be a fundamental theme in its own right (see above 'Perceptions of Fairness').

#### **Conclusion**

The pilot successfully supported the aims of informing longer-term research parameters and facilitating opportunities to develop understanding of theoretical foundations, methodologies and methods. Conducting the pilot also provided experience of designing, analysing and writing up qualitative research and, whilst the sample size and scope of the research was limited, it has been a valuable process to inform future research. Emergent themes from the pilot, which are intended as a focus for future research, include greater exploration of disabled students' and academic staff members' views on inclusiveness of

academic assessment modes and further exploration of how institutions might best support students in the transition to new formats of assessment. Perceptions of what constitutes fairness and how this might be defined will also be considered in greater depth.

## References

- Alharahsheh, H. and Pius, A. (2020), 'Global Academic Journal of Humanities and Social Sciences, 2020'; 2(3) 39-43. Available online at [https://gajrc.com/media/articles/GAJHSS\\_23\\_39-43\\_VMGJbOK.pdf](https://gajrc.com/media/articles/GAJHSS_23_39-43_VMGJbOK.pdf). DOI: 10.36348/gajhss.2020.v02i03.001. (Accessed 14/1/23).
- Bearman, M. (2019), 'Focus on Methodology: Eliciting rich data: A practical approach to writing semi-structured interview schedules', *Focus on Health Professional Education: A Multi-Professional Journal*, VOL. 20, No. 3, 2019. Accessed here: <https://search.informit.org/doi/epdf/10.3316/informit.002757698372666>. Accessed on 3/1/23.
- Braun, V and Clarke, V. (2006), 'Using thematic analysis in psychology', *Qualitative Research in Psychology*, 3:2, 77-101. Accessed here: <https://www.tandfonline.com/doi/pdf/10.1191/1478088706qp063oa> DOI: 10.1191/1478088706qp063oa.
- Braun, V and Clarke, V., (2012), 'Thematic Analysis'. In book: *APA handbook of research methods in psychology, Vol. 2: Research designs: Quantitative, qualitative, neuropsychological, and biological (pp.57-71)*. First Chapter: 'Thematic analysis'. American Psychological Association. Editors: H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, K. J. Sher.
- Braun, V and Clarke, V., (2019), 'Can I use TA? Should I use TA? Should I *not* use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches'. *Couns Psychother Res.* 2021; 21: 37– 47. Accessed here: <https://onlinelibrary.wiley.com/doi/10.1002/capr.12360> (Accessed 8/1/23).
- CAST (2020). 'UDL Tips for Assessment', Wakefield, MA: Author. Retrieved from <https://www.cast.org/products-services/resources/2020/udl-tips-assessments>. Accessed 17/1/22
- Campbell, K. A., Orr, E., Durepos, P., Nguyen, L., Li, L., Whitmore, C., Gehrke, P., Graham, L., & Jack, S. M. (2021). 'Reflexive Thematic Analysis for Applied Qualitative Health Research'. *The Qualitative Report*, 26(6), 2010-2028. <https://doi.org/10.46743/2160-3715/2021.5010>
- Caulfield, J. (2022), 'How to Do Thematic Analysis – Guide and Examples', Scribbr. Accessed here: <https://www.scribbr.co.uk/research-methods/thematic-analysis-explained/#:~:text=Published%20on%205%20May%202022,meaning%20that%20come%20up%20repeatedly>. Accessed on 13/1/23.
- Cohen, L., Manion, L. and Morrison K. (2018), 'Research Methods in Education', 8<sup>th</sup> Ed. Routledge London and New York.

- DSUK (2022), “‘Going Back is Not a Choice” - New report from Disabled Students UK shows 85% of disabled students would benefit from continuation of online learning options - Disabled Students UK’. Available from: <https://disabledstudents.co.uk/going-back-is-not-a-choice-new-report-from-disabled-students-uk-shows-85-of-disabled-students-would-benefit-from-continuation-of-online-learning-options/>. (Accessed 6/1/23).
- Duncan, H. and Purcell, C. (2019), Consensus or contradiction? A review of the current research into the impact of granting extra time in exams to students with specific learning difficulties (SpLD). Accessed here: <https://www.tandfonline.com/doi/full/10.1080/0309877X.2019.1578341>, Accessed on 6/1/23.
- Gregg, N., and Nelson, J.M. (2012). ‘Meta-Analysis on the Effectiveness of Extra Time as a Test Accommodation for Transitioning Adolescents with Learning Disabilities: More Questions than Answers’. *Journal of Learning Disabilities* 45 (2): 128–138. Accessed here: <https://pubmed.ncbi.nlm.nih.gov/20375295/> Accessed on 14/1/23. DOI:10.1177/0022219409355484.
- Hammersley, M (2013), ‘What is Qualitative Research’, Bloomsbury Academic.
- Hanesworth, P., Bracken, S., and Elkington, S. (2019), ‘A Typology for a Social Justice Approach to Assessment: Learning from Universal Design and Culturally Sustaining Pedagogy’. *Teaching in Higher Education* DOI: <https://doi.org/10.1080/13562517.2018.1465405>
- Hill, M (2021), ‘Exploring the challenges of inclusive practice at Sheffield Hallam University’. *Journal of Inclusive Practice in Further and Higher Education (JIPHE)*, (Issue 13.1). (pp. 50 – 72). Accessed here: <https://nadp-uk.org/wp-content/uploads/2021/08/JIPFHE-Issue-13.1-Hill-Inclusive-Practice-at-SHU.docx>. Accessed 28/6/22.
- Hockings, C (2010), ‘Inclusive learning and teaching in higher education: a synthesis of research’. Evidence Net. Accessed here: [https://www.plymouth.ac.uk/uploads/production/document/path/2/2735/Inclusive\\_teaching\\_and\\_learning\\_in\\_HEsynthesis\\_.pdf](https://www.plymouth.ac.uk/uploads/production/document/path/2/2735/Inclusive_teaching_and_learning_in_HEsynthesis_.pdf). Accessed 26/10/22.
- Hubble, S. and Bolton, P. (2021), ‘Support for disabled students in higher education in England’. House of Commons Library. Briefing Paper (Number 8716, 22 February 2021), (p.5). Accessed: <https://commonslibrary.parliament.uk/research-briefings/cbp-8716/>. (Accessed on: 19/10/22).
- Kiger, M. and Varpio, L. (2020), ‘Thematic analysis of qualitative data: AMEE Guide No. 131’. Accessed here: <https://www.tandfonline.com/doi/full/10.1080/0142159X.2020.1755030>. Accessed on 13/1/23.
- Martin, N., Wray, M., James, A., Draffan, E. A., Kruppa, J. and Turner, P. (2019), ‘Implementing Inclusive Teaching and Learning in UK Higher Education – Utilising Universal Design for Learning (UDL) as a Route to Excellence’. SRHE. Accessed here:

<https://openresearch.lsbu.ac.uk/download/97cc3ce39fb4b9c06d631188fac19ac43c3fe317915210dad4d54e5f7d1a5309/817348/Nicola-Martin-SRHE-Research-Report.pdf>. Accessed 8/1/23).

McArthur, J. (2018), '*Assessment for Social Justice: Perspectives and Practices within Higher Education*'. 1<sup>st</sup> Ed. Bloomsbury Academic.

Nieminen, J. H., (2022), '*Assessment for Inclusion: rethinking inclusive assessment in higher education*'. Teaching in Higher Education.

DOI: <https://doi.org/10.1080/13562517.2021.2021395>. (Accessed 5/1/23).

Park, Y.S., Konge, L. and Artino, A., (2020) 'The Positivism Paradigm of Research'. *Academic Medicine* 95(5):p 690-694, May 2020. DOI:

10.1097/ACM.0000000000003093. Accessed here:

[https://journals.lww.com/academicmedicine/fulltext/2020/05000/the\\_positivism\\_paradigm\\_of\\_research.16.aspx](https://journals.lww.com/academicmedicine/fulltext/2020/05000/the_positivism_paradigm_of_research.16.aspx). Accessed on 5/1/23.

Pearson, R., Siegel, L., Lesaux, N. K. (2006), 'The Effects of Timed and Untimed Testing Conditions on the Reading Comprehension Performance of Adults with Reading Disabilities', *Reading and Writing, Springer Journal, February 2006, 19(1):21-48*. Accessed 17/1/23. DOI:[10.1007/s11145-005-4714-5](https://doi.org/10.1007/s11145-005-4714-5).

Ross, F., Tatam J.C., Hughes, A., Beacock, O.P., McDuff, N. (2018) "*The Great Unspoken Shame of UK Higher Education: Addressing Inequalities of Attainment*".

Accessed here: <https://eprints.kingston.ac.uk/id/eprint/40707/1/Ross-F-40707-VoR.pdf>. Accessed on: 23/11/22

Sambell, K, McDowell, L & Montgomery, C (2013), '*Assessment for Learning in Higher Education*'. London and New York, Routledge.

Scott, S and Marchetti, C (2021), 'A Review of the Biennial AHEAD Surveys: Trends and Changes in the Demographics and Work of Disability Resource Professionals', *Journal of Postsecondary Education and Disability, 34(2)*, 107-126 107. Accessed: <https://files.eric.ed.gov/fulltext/EJ1319174.pdf>, accessed 1/12/22.

Sibeoni, J., Verneuil, L., Manolios, E. *et al.* (2020) 'A specific method for qualitative medical research: the IPSE (Inductive Process to analyze the Structure of lived Experience) approach. *BMC Medical Research Methodology* 20, 216 (2020).

Accessed here:

<https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-020-01099-4> DOI: [doi.org/10.1186/s12874-020-01099-4](https://doi.org/10.1186/s12874-020-01099-4)

Varpio, L., Young, M., Uijtdehaage, S., Paradis, E. (2019). 'Articulating the distinctions between theory, theoretical framework, and conceptual framework'. *Journal of Academic Medicine* 95(7):p 989-994, July 2020. Accessed here:

[https://journals.lww.com/academicmedicine/Fulltext/2020/07000/The\\_Distinctions\\_Between\\_Theory\\_Theoretical.21.aspx](https://journals.lww.com/academicmedicine/Fulltext/2020/07000/The_Distinctions_Between_Theory_Theoretical.21.aspx). Accessed on 10/1/23.

DOI: 10.1097/ACM.0000000000003075.

Weis, R and Beauchemin, E. L. (2020). *Are Separate Room Test Accommodations Effective for College Students with Disabilities?* Assessment & Evaluation in Higher Education. DOI: [10.1080/02602938.2019.1702922](https://doi.org/10.1080/02602938.2019.1702922).

Williams, M., Pollard, E., Takala, H., Houghton, A. (2019) *Review of support for disabled students in higher education in England; Report to the Office for Students by the Institute for Employment Studies and Researching Equity, Access and Participation*. Institute for Employment Studies. (P.7). Accessed: <https://www.officeforstudents.org.uk/media/a8152716-870b-47f2-8045-fc30e8e599e5/review-of-support-for-disabled-students-in-higher-education-in-england.pdf> (Accessed, 20/10/22).

## Appendix 1 – Semi-Structured Interview Questions

**Pilot Research Title: ‘Exploring SpLD specialists’ views on an eight hour, open book academic assessment format, delivered by specific departments at a Russell Group University’.**

Introduction:

Thank you so much for taking the time to speak with me today.

I have a number of semi-structured interview questions, but really I would just be grateful to hear your thoughts and observations, based on your work with disabled students, and particularly those with specific learning difficulties, of an 8-hour open book assessment format, trialled by a number of departments at the University in the past two years and offered to students, regardless of a disability.

You were approached to take part in this research due to your extensive experience as a disability practitioner across a range of specialist roles working directly and closely with SpLD students at the University.

Q1. Please could you tell me about your roles and experiences of working with SpLD students?

Q2. Have you worked with students who have sat the 8 hour open book format of paper at the University?

Q3. For each student do you know if this was the first time they had sat an 8 hr paper?

Q4. Do you know if they had previously sat other forms of assessment, such as closed book exams over a shorter time frame, either here or at a previous place of study?

If yes, what were the formats?

Do you know if the students received individual reasonable adjustments for other assessment formats and what the adjustments were?

Did students have to provide evidence of their spld in order to access adjustments in other formats of assessment?

Q5. How did students report they found the 8 hour open book format of exam?

Did students report the 8 hour format was of more or less support than other formats of assessment and why?

Q6. What did students feel were the benefits?

Q7. What did they feel were the negatives?

Q8. In your experience as a disability practitioner, what do you feel are the benefits of an 8 hour open book assessment?

Q9. What do you feel are the negatives?

Q5. Prior to introducing the 8 hour open book assessments, the Faculties trialling this format of assessment had historically implemented 3 hour, closed book, timed examinations. In those instances, it was common for disabled students to receive individual reasonable adjustments, for example extra writing time or rest time, to support the impact of their disability in exams. In the case of the 8 hour open book format, the suggestion and hope from the Faculty is that this is designed to provide a more inclusive window to offer flexibility to the widest range of students, to pace their exams and convey their knowledge effectively without need for individual adjustments.

What are your thoughts on this?

How fair and reasonable do you feel an 8 hour, open book paper is for disabled students?

Is there anything in your view that would make it fairer?

Could you elaborate on why?

Is there anything else you would like to share about your experience or observations of spld student assessment that hasn't been shared?

Thank you for your time.



**Not hearing, not engaging, not happening: Elusive Inclusive HE, it is time to reconsider sector practices in partnership with disabled student expertise.**

**Dr Suanne Gibson, Dr Zeta Williams-Brown, Jen Shute, and Mette Westander.**

Dr Suanne Gibson, University of Plymouth

Dr Zeta Williams-Brown, University of Wolverhampton.

Jen Shute, University of Plymouth

Mette Westander, Disabled Students UK and Research Associate University of Plymouth

**Abstract**

This paper focuses on inclusive higher education in the United Kingdom. It details international literature, research studies and national reports, including findings from the authors' study, 'Working with disabled students to address unequal outcomes in UK HE during the pandemic' where we critically explored inclusive practice in Higher Education (HE) and disabled students' learning experiences. Our national study was carried out as a collaboration between the University of Plymouth, University of Wolverhampton, and Disabled Students UK (DSUK). Data collection took place in 2021 with an extensive literature-based investigation alongside the dissemination of a questionnaire to DSUK members resulting in 14 responses from across a variety of UG and PG programmes. This research took place whilst DSUK were completing a complementary national study asking disabled students about their experiences of Higher Education during lockdown periods, they received more than 300 responses. Alongside these studies, the Disabled Students' Commission (DSC) (2021/2022) were compiling their annual report. Findings from our research corroborate the aforementioned investigations, contributing evidence that disabled students across undergraduate and postgraduate courses continue to experience perceived discriminatory and exclusionary practices (DSUK, 2020; NADP, 2020; NMHP, 2020). Findings from our research project 'Working with disabled students to address unequal outcomes in UK HE during the pandemic', will be explored in this paper and they suggest too many disabled students studying in HE today, experience integration, which results in frustration, course transfers and failure, as opposed to the progressive and transformational learning that is associated with successful inclusion. The paper concludes by proposing HE policy makers and practitioners 'partner-up' with disabled students to

reconsider what is understood, envisaged, implemented, experienced and evaluated as inclusive HE. Furthermore, that this collaboration and partnership is led by disabled students and takes place at both macro eg- Government, OfS and DSC) and micro levels (lecture theatre, online learning).

**Key words:** disabled students, inclusion, higher education, collaboration, partnership, widening participation

## Introduction

In the UK, widening participation, inclusive policy plus practice have been a focus and ideological driver in Higher Education (HE) for many years. This has led to increased efforts in supporting disabled students to access HE, to develop a sense of belonging whilst attending HE, experience inclusive practice, achieve in their studies, to progress and be fulfilled in life (Gibson, *et al.*, 2016; Koutsouris, Mountford-Zimdars and Dingwall, 2021). The Covid-19 pandemic led to unprecedented changes in practice and pedagogy that included moving teaching and assessment online. These changes were welcomed and led to questions as to why, although having been requested for many years by disabled students, they had not been possible before the pandemic (Borkin, 2022). This paper critically considers widening participation and inclusive practice in HE. It evidences difficulties disabled students experienced before the pandemic, and how the pandemic exacerbated disparities between disabled and non-disabled students (Disabled Students UK, 2020). The work refers to disabled students, rather than students with disabilities to visually represent and emphasise how society and institutions like the university, lead to experiences of disablement for these students (Gibson, 2020). The findings contribute to evidence that disabled students continue to experience perceived discrimination and exclusionary practices, resulting in their not being fully represented at HE nor achieving on a par with other students (DSUK, 2020; NADP, 2020; NMHP, 2020; Peruzzo, Rapper and Westander, 2023). This has a knock-on impact upon wider society and arguably the economy in terms of graduate numbers and disabled student future recruitment. The paper highlights the need to rethink and revise inclusive policy, practice and its evaluation in

partnership with disabled students. **We conclude the leading roles in this work needs to be with our disabled student body.**

## **Widening participation and Inclusion**

Widening participation has been a dominant discourse in education policy for over twenty-five years (Gibson, *et al.*, 2016) intrinsically linked in UK policy since New Labour introduced it in the party's manifesto (1997). This has led to increased efforts to engage and include disabled students amongst others prior to and during their HE experiences. The key aims of effective Inclusion and WP being that students develop a sense of belonging, experience inclusive practice, and achieve in their studies (Koutsouris, Mountford-Zimdars and Dingwall, 2021). Internationally, the term refers to policy and practice applied to 'non-traditional' or minority student groups, including disabled people (ARC, 2013). Its original and continued core aim has been to provide more equitable access to Higher Education (HE) and improve retention (Gibson, 2016; Lewis and Johnston, 2002). ARC (2013, p.ii) defined 'under-represented groups as ...*not a homogenous group. They may have a range of identities, diverse social characteristics and come from a variety of backgrounds [...].* These groups include people from lower socio-economic locations, Global Majority groups, disabled people, first in the family to attend HE, mature students, and care leavers. Conceptualisation of these groupings are termed 'intersections', i.e. they represent intersections of our world, groups in society who have experienced various forms of exclusion and oppression. It is debated within and between these intersections whether all should be linked to inclusion (Liasidou, 2014). However, commonality across all is the experience and impact of injustice and the continued need for systemic alongside cultural change to achieve equality for every person (Gibson, 2016).

Widening participation practices are commonly positioned as social justice responses to ingrained cultures and perspectives, which have prevented under-represented groups from their human right to an equal education (Gibson, 2020; Madriaga et al 2011). For instance, *The Future of Higher Education* (2003) White paper states, "Education must be a force for opportunity and social justice, not for the entrenchment of privilege" (Jary and Jones, 2004, p.1). Actions have included national directives, statutory policy, the introduction of government bodies and funding mechanisms to support access to HE, including- the Equality Act (2010), the Disabled Student Allowance (1993), the introduction of the Social

Mobility and Child Poverty commission (2010), the Higher Funding Council for England (1992-2018) and the Aim Higher programme (2004-2011).

Widening participation is currently delivered through activities and strategies organised and applied within individual HEIs, work and policy development undertaken by the Office for Fair Access (OFFA) and Office for Students (OfS), which also approve and monitor access agreements and disseminate best practice. OfS (2020a) have recently pushed HEIs to show more explicitly where they are working with and responding to student voice in revising their provision and practices. Furthermore, the work of the Higher Education Funding Council for England (HEFCE), provide activity funds and administer the National Collaborative Outreach Programme (Hubble and Bolton, 2021)- both contributing to WP across the sector. Widening participation's impact includes the growth of further education or equivalent colleges (FHEs), increased registration numbers of under-represented groups in HE, including disabled people and an increase in colleges gaining university status (Moore, Sanders, and Higham 2013).

Whilst the number of students with a declared disability in HE has increased significantly, by 46% since 2018, (HESA, 2022a; HESA, 2022b) and now make up almost 20% of home students (DSUK, 2020, 2022; HESA, 2022b), it is also evidenced there continues to be silencing, misrepresentation, and failures in supporting them (Gibson and Kendall, 2010; Gibson, 2015; Gibson and Cook-Sather, 2020). Recent 2019/2020 statistics also show a significant growth in numbers of students reporting mental health conditions since 2014/15 (Bolton and Hubble, 2021). This has been positioned as a significant positive development, as referred to in the *Success as a Knowledge Economy: Teaching Excellence, Social Mobility and Student Choice* White paper (Department for Business, Innovation and Skills, 2016, p.7): *We have gone from a higher education system that serves only a narrow band of people, to a broader, more diverse and more open system that is closer than ever before to fulfilling Lord Robbins' guiding principle that higher education 'should be available to all who are qualified by ability and attainment to pursue it*

On that basis, it could be argued widening participation is working, however the reality of students' experiences and progression is more complex and nuanced than the simple fact of an increase in numbers. For example, the statistics may not mean an increase of disabled students entering HE but indicate more disabled students deciding to declare their disability. Importantly, even with this increase of declaration, disabled students remain underrepresented in HE (Bolton and Hubble, 2021; OfS, 2020a, 2020b). Furthermore, Hamilton (2019) stated that whilst anti-discrimination legislation, including the SENDA act (2001) and Equality Act (2010) promoted a progressive shift from a deficit model of understanding disability to a social justice and rights-based perspective, 'misguided assumptions of ability and disability' have led to the shallow and tokenistic use of the term 'inclusion'. Gibson (2020, 2022) amongst others (Shaw 2021) has sourced a key failing of WP

and meaningful inclusive practice being the lack of participation and contribution of disabled people- i.e. they are a key and core group who should be central to devising and leading the necessary change. Hamilton (2019) stated there are two contrasting agendas surrounding widening participation. One a social justice agenda, which aims for inclusion and the other, more prominent, an 'ableist capitalist agenda' which focuses on providing an educated workforce to meet the needs of the economy. In addition, Shaw (2021) highlighted tensions between the Government's accountability agenda in HE and its 'inclusive practice ideals'.

### **Evidence of continued discriminatory and exclusionary practice**

It is well documented that disabled people face inequalities in many aspects of life, including education (DSC, 2021; ONS 2020) and employment (Policy Connect, 2020). Research has found that regardless of widening participation, disabled students continue to experience ineffective forms of provision, under-representation, and marginalisation. As noted, due partly to ineffective forms of consultation and engagement caused by factors such as hegemony, traditional ideology, unconscious bias and stigma (Beauchamp-Pryor, 2012; Gibson, 2012; Gibson, 2015; Madriaga, 2007; Vickerman and Blundell, 2010). Disabled students continue to be among those most at risk of withdrawing from HE studies and have lower degree outcomes than their peers (OfS, 2020b, Shaw, 2021). The Office for Students (OfS) stated in June 2020 (Office for Students, 2020b, p.2) *Before the pandemic, there were already clear attainment and outcome gaps between disabled and non-disabled students; students reporting a disability have lower degree results overall and lower rates of employment after graduation than non-disabled students.* In December 2018, the OfS had set five targets to achieve equality of opportunity in higher education. One of these targets to eliminate the degree outcomes gap between disabled and non-disabled students by 2024/2025. The gap in 2020 was 2.8% (Policy Connect, 2020).

The pandemic has intensified existing inequalities including life expectancy, income, employment, relationships, education, and progression (DSUK 2020; Meleo-Erwin et al. 2021; Runswick-Cole 2021; Pring 2021). Disabled people have been harder hit by the effects of the pandemic (Disabled Students UK, 2020). Including, being more likely to experience financial hardship, less likely to access a computer and reliable internet, needing to shield, restrictions in health and social care, being unable to access regular medication or receive hospital care, experiencing food insecurity and requiring additional mental health support (Disabled Students UK, 2020). Several reports have highlighted disabled students' negative experiences, including the Disabled Students Commission

(2021) who surveyed 473 disabled students studying undergraduate and postgraduate courses. In total, 80% of respondents reported the pandemic had a negative impact on their mental health and wellbeing. Almost half felt that universities had been 'ineffective' in considering disabled students' needs. It is imperative that examples of perceived discrimination and exclusionary practice are evidenced and critically reviewed if successful inclusion policy, practice and outcomes are to evolve. This paper now moves on to evidencing examples of exclusion from a study carried out by the authors during the Covid-19 pandemic and in summarising its findings we overlap with other studies to consider the need for the HE sector to rethink, rebuild and reposition its work on inclusive provision with disabled students being partners and leaders in those processes.

## **Methodology**

Our study: 'Working with disabled students to address unequal outcomes in UK HE during the pandemic', was a collaboration between - the University of Plymouth, University of Wolverhampton, and Disabled Students UK. It began in 2020, the first year of the Covid-19 pandemic seeking to investigate students' perspectives and experiences of Higher Education during lockdown periods. We aimed for a sample of disabled students through disseminating a questionnaire via DSUK's networks and applied an interpretivist approach when analysing the data. We aimed for an in-depth understanding of each participant's position (Basit, 2010). Data collection started early in 2021 and whilst we had a small response rate, a total of 14 disabled students completed the survey, the range of degrees and detailed responses provided much rich material to work with. We found that participants held commonalities of perspective even when studying differing courses and/or having different disabilities. We concluded our findings needed to be published to complement the other national work taking place, providing further evidence of disabled students experiences during the Covid-19 pandemic. Demographic information for participants can be found in the below tables. This information includes responses from the participants. The table in Appendix 1 shows the range of disabled students, undergraduate and postgraduate courses studied, ethnicity and gender.

By applying an interpretivist approach, the work focused on each participant's position, acknowledging that their perspective and actions alter over time and are dependent on their situational circumstances (Cohen *et al.*, 2011). The questionnaire included open and closed questions and emphasis was placed on detailing qualitative responses to evidence

differing perspectives and experiences. Questionnaires typically require participants to respond to categories decided by the researcher. This questionnaire included open ended questions to ensure that participants were able to tell us their perspectives, experiences and focus on what mattered to them. In doing so, the findings evidence experiences that the participants chose to focus on in their responses to the questionnaire. Open question responses were analysed using thematic analysis and closed question responses were calculated as percentages. It was not the case that all participants completed every question in the questionnaire. Percentages were worked out based on how many students stated they agreed with the closed question out of the sample size of participants. In considering validity of the research, participants were all disabled students studying in HE, they were from a range of universities and courses with a range of disability and the study's analysis was peer-reviewed.

In qualitative research, the relationship between researchers and participants is key. *...ethical practice implies that the relationship we establish with participants should respect human dignity and integrity, and should be one in which people feel safe, comfortable and among friends* (Simon, 2009, in, Moriña, 2021, p.1560). It was important in the planning of the questionnaire that this data collection was inclusive for all participants. We went through several iterations as we discussed differing structures, formats and the way questions were worded to ensure the content was accessible. We also detailed ways participants could gain additional support to complete the questionnaire, including contact details for members of the project team. It was also important that participants felt free to express their perspectives and experiences without concern of their identities being revealed in dissemination of the research. Questions were asked about the participants course, disability, ethnicity, gender, and sexuality. All other forms of identification were omitted from the questionnaire. For instance, participants were not asked to name their setting. This means that the study is unable to state how many universities students attended, but it provided participants with the reassurance that the team did not know where they studied. As detailed by Moriña (2021, p.1560) research needs to *respect a basic set of ethical principles* as well as ensure high quality and rigour. The front page of the questionnaire detailed information about the study, including its aims and objectives. Details on the study and information on confidentiality, anonymity of participants, right to withdraw and voluntary completion were provided online before participants completed the

questionnaire. Participants were asked to proceed to data collection if they consented to taking part.

## Findings

Our findings explore the responses provided, building a picture of participants' commonalities of perspective and experiences on the inclusivity of their particular HE experiences and practice, presenting examples of the struggles many faced during the pandemic. They have been collated into three main themes as follows:

- Failures in inclusive practice that lead to a reduced sense of belonging
- Examples of perceived discrimination
- Accessibility difficulties

### Failures in inclusive practice that lead to a reduced sense of belonging

Fewer than 21% of the disabled students in this study felt that they were accepted and/or belonged to their university. Statements from the questionnaire are evidenced in the below table:

Statement	Number of participants who agreed with this statement
I've felt a sense of belonging on my course	14%
This university welcomes disabled students	21%
People have been accepting of my disability/disabilities	21%

Eight students provided additional qualitative comments on how they believe universities treat disabled students. Four students commented on their universities lack of understanding disabled people:



*"I feel that there is a distinct lack of understanding and easements in place at my university for disabled students which would be considered unlawful within the workplace" (studying BA Hons Fashion and Costume).*

*"useless bunch...lack of understanding" (studying Law, participant 5).*

*"There has always been discrimination towards disabled people in society. Although Covid has impacted upon many, you would think and hope it would bring more understanding and aid in disseminating discrimination. It has not. People haven't changed. The same unpleasant views and actions remain" (studying Law, participant 14).*

*Just seems to be lack of awareness about disabled students, and the difficulties that they go through" (studying English).*

Four students focused on failures in supporting disabled students:

*"The disability service has been very inaccessible. I have not heard any more since I had my appointment with them" and "We don't have the option for synchronous learning. This would benefit me a lot but the university doesn't care for the disabled students" (studying a Doctorate in Clinical Psychology).*

*"The university effectively abandoned PhD students during the pandemic. They made no effort to get back to numerous emails about my worries about travel restrictions and have been silent on disability related issues" (studying PhD Health Security).*

*"Support was appalling pre pandemic, it's only been exacerbated" (studying Counselling).*

*"They're very medical model. I have a formal diagnosis and have disclosed disabilities, but I only get support if I formally request it" (studying Doctorate in Education).*

Whilst this is a small sample of participants, our findings correlate with DSUK's larger National report of that same year (2021) and feed into recommendations for better inclusive HE practice, as cited by Disabled Student's commission report (2022). For instance, Disabled Students UK's recent national report entitled 'Going back is not a choice' surveyed

326 respondents from 69 HE providers across the UK (DSUK, 2020). They found that 23.1% of disabled students received the support they needed over the pandemic, with many saying they felt 'left behind', 'alienated', and 'forgotten'. Individual accounts include the work of Nolan (2021) who describes being 'silent and unseen' as a disabled person of colour. This work provides further evidence of disabled students experiencing non-inclusive education at university.

Inclusive education is ...*a transformatory process for all participants. [Where] social justice, acceptance and promotion of diversity inform its practices* (Gibson, 2015, p,2). However, the pandemic has drawn further attention to underlying systemic barriers, which continue to constrain inclusive practice, with several reports evidencing disabled students being overlooked during this time (Zhang *et al.*, 2020; NADP, 2020; Snowdon Trust, 2021, NMHP, 2020). Additionally, some of the changes that were made because of the pandemic, were changes that have been requested by disabled students for many years. These included moving teaching and assessment online, lecturers being recorded and captioned, easement in administration required for extensions and submission evidence. These changes happened quickly in response to the pandemic but led to questions as to why they were not possible before the pandemic for disabled students (Borkin, 2022). Disabled Students UK (2020) stated:

*The fact that disabled students were long denied these same accommodations when they needed them, highlights the stark difference in the sacrifices we are willing to make for disabled and non-disabled students (especially as universities continue to deny disabled students accommodations during the pandemic).*

It is clear from these findings that meaningful and effective inclusion is not a priority in universities, too many disabled students are still experiencing perceived discrimination and exclusion in their learning and University experience.

### **Examples of perceived discrimination**

Many disabled students identified experiences of perceived discrimination in HE that have led to exclusionary practice. Statements from the questionnaire are evidenced below:

Statement	Number of students who agreed with the statement
-----------	--------------------------------------------------

I've experienced discrimination or negative bias	43%
I've experienced ableism	57%
My tutors/lecturers have employed inclusive practices	14%
My tutors/lecturers/support staff have enabled me to learn in a way that works for me	14%

Eight disabled students provided examples of the exclusion they faced studying in HE during the pandemic. Three students focused on the lack of support offered to them by their universities:

*"I am pre-diagnosis for all of my conditions. My university's policy does not allow me to receive any significant support from the disability support team without a diagnosis (I've been waiting for ADHD diagnosis for well over a year). The university takes a very reactive and individualised approach to disability, seeing it as individuals with challenges or deficits they need to be helped with, rather than systems or structures that should be made accommodating" (studying Computer Science/Robotics PhD).*

*"Hopeless. I have a variety of needs that the university has not attended to and for which I have been consulting a lawyer about" (studying Law, participant 5).*

*"I have been treated like my heightened risk is my problem to sort out" (studying Counselling).*

Five students focused on lack of adjustment offered by their universities to support their disability:

*"My university are refusing to allow blended learning because "they don't have to". The university as a whole is telling everyone they will have to attend in person teaching from 2<sup>nd</sup> semester. The university is elitist and ableist .. they don't put recording online either" (studying a Doctorate in Clinical Psychology).*

*"I tried to access subtitles for lectures, which involved me emailing multiple lecturers myself. Some started using subtitles, other said they were unable to and one professor suggested that subtitles didn't promote 'active learning' and suggested I watch the lecturers with a course mate...Before remembering we were in the midst of a pandemic and I couldn't" (studying Human and Social Sciences).*

*"Initially SFE refused to let me have a reassessment despite the fact I had changed courses and universities. This meant I was entitled to one (change of circumstances-p.6 of the DSA2 form refers). It wasn't until I raised an official complaint with SFE that they permitted me a reassessment. I have ordered my equipment but do not know if it will arrive in time" (studying law, participant 14).*

*"Because I took a medical leave of absence due to my disability in early 2020 I'm not eligible for the fee free extension all PhDs are supposed to receive. In essence I'm being punished for being disabled" (studying PhD Health Security).*

*"...Uni disability centre refused to gain us access to captioning software, directing us to DSA- but DSA won't fund things it expects universities to cover under their duty to provide reasonable adjustments. Equality reps, SU Liberation Officer etc were all involved but no one took real action to resolve it until May 2021. The move to online learning and socialising could've revolutionised my ability to partake in uni life, but everyone kept using the inaccessible platform- this was true academically as well as for the social events, they all used platforms with no subtitles!" (studying BSc Chemistry). ...".*

The Equality Act (2010) states reasonable adjustments should be made anticipatorily. However, it is clear from these findings that students were not provided such anticipatory necessary reasonable adjustments. This is comparable with findings from the Disabled Students Commission (2020) who found that reasonable adjustments that were put in place were not always adjusted to accommodate the pandemic. The Snowdon Trust (2021), along with evidence from findings of this study show that this has led to students' chasing universities to implement reasonable adjustments. The Office for Students (OfS) in its Coronavirus Briefing Note (2020b) placed emphasis on students being responsible to chase necessary accommodations. However, Disabled Students UK (2020) stated that the OfS should be enforcing the law and in not doing this they are failing disabled students.

These findings show that complexity in needs is not being taken account by these universities to ensure adjustments are suitable for each disabled student. Hughes and colleagues (2016, p.488) stated *while universities are bound by institutional requirements for 'reasonable accommodations' emanating from the Disability Discrimination Act, support levels-and quality- vary between institutions greatly, as well as across different physical, psychological and emotional illnesses or conditions.* Gorard and colleagues (2019) emphasised the need to see the complexity in disability in terms of contextualised admissions and support. Students with differing disabilities have differing experiences and require tailored support. It can be purported that inclusion is still integration, which is really focused on placement of disabled students into HE and not equally focused on ensuring disabled students are included whilst studying in HE. This is exemplified by the below examples of accessibility difficulties.

### **Accessibility difficulties**

Only 14% of disabled students felt requests for reasonable adjustments had been dealt with effectively and none agreed that staff had prioritised their access arrangements. Half of the students (50%) had been able to apply for a coursework extension without evidence. Many students emphasised that adjustments put in place because of the pandemic were not accessible for all students. Most of the accessibility statements had around half the students agreeing on its effectiveness. Examples are provided in the below table:

Statements	Number of students who agreed with this statement
I have had the necessary accessibility equipment to study from home	43%
Asynchronous/recorded online sessions work well for me	43%
Learning materials were provided in a format that's accessible to me	14%

Four students commented on their overall accessibility difficulties:

*"Poor and almost non-existent throughout" (studying BA Hons Fashion and Costume)*

*“Absolutely no accessibility whatsoever. My health has been put at risk because of the university and the course” (studying a Doctorate in Clinical Psychology).*

*“Hopeless. No inclusiveness at all” (studying Law). Still bad as the university is not making adjustments (studying Law, participant 5).*

*“Support has been poor in the past. The ongoing pandemic has exacerbated it. Access to remote learning has been removed too”...“Virtual learning environments are not accessible to screen reader users. Can’t get any answers to how in person support is supposed to work” (studying Counselling).*

Whereas three students focused on accessibility difficulties in moving back to face-to-face from online learning:

*“Massive change from online learning to in person. I struggle with change, so it’s been difficult” (studying English).*

*“Moving from online to face to face was done too quickly for comfort, it would have been better to continue making courses available online” (studying PhD)*

*“There is now a massive “get back to normal” attitude which doesn’t account for shielding students. Whenever an event is online everyone apologises and says ‘of course we wish we could all be face to face’, which I find exclusive because face to face was never accessible for me anyway” (studying BSc Chemistry).*

These findings evidence the frustration students have experienced whilst trying to access reasonable adjustments during the pandemic. This is comparable with HEPI’s report (2020) based on two roundtable evidence sessions and over 500 responses to their survey. HEPI found that disabled students have experienced inconsistency and frustration with 25% of their respondents rating the accessibility of their course as 1/5 or 2/5. There have been significant and varied difficulties experienced by disabled students in moving learning from face-to-face to online and from online to face-to face learning. Evidence has been published on the difficulties some disabled students faced in accessing specialist

equipment, such as adapted furniture when learning went online (DSUK, 2020; OfS, 2020a, 2020b) and access to specific technology required for this learning (DSC, 2021; NADP, 2020). Individual accounts of difficulty are evidenced in a variety of publications that show the difficulty students with specific disability had with moving learning online. For instance, students with sensory impairments (NADP, 2020; NMHP, 2020; Snowdon Trust, 2020), autism (NMHP, 2020; Snowdon Trust, 2021), specific learning differences (NMHP, 2020, Snowdon Trust, 2020), and students who experience mental ill-health (NMHP, 2020).

There were significant changes made because of the pandemic to provide learning for all learners (DSUK, 2020). Some of these changes had been called for by disabled students for many years. Yet, these findings contribute towards evidence provided in the above reports that one approach does not work for all disabled students. These findings show that some disabled students struggled with the move to online learning, and others struggled with the move back to face-to-face learning; some wanted to see the continuation of online learning, where others wanted to return to campus.

It is therefore essential that universities provide learning support that is accessible to all learners in a variety of ways, using a hybrid approach so that disabled students' individual reasonable adjustments can be applied.

There is also connection in this work to the discourse on Universal Design for Learning (Martin, Wray, James, Draffan, Krupa and Turner 2019), in particular that educators and systems must prioritise a position on student engagement and representation. We would assert Higher Education also take note of that model, its emergent evidence plus examples of best practice (Kilpatrick, J.R., Ehrlich, S. and Bartlett, M., 2021.)

The strength of these findings is compounded by the commonality of the DSUK (2019-2021) national research study, Policy Connect and the Higher Education Commission's report, Arriving at Thriving (2020) and the Disabled Students commission report (2022). With reference to DSUK (2022, p.4) six key lessons for the sector emerged including:

- *Universal measures such as online delivery can have a disproportionate positive effect on disabled students- One size does not fit all - access must be individualised*
- *Staff must be resourced and hold inclusive education knowledge*
- *Flexibility and compassion are valid approaches to education provision*
- *The administrative burden effectively blocks access for disabled students*

- *The sector must take responsibility through effective forms of leadership*
- *Listen to disabled students*

With similar results, Policy Connect with Higher Education Commission concluded (2020, p6-8); *Many disabled students are not fully able to access teaching and learning [...] Disabled students face heavy bureaucratic and financial burdens [...] Awareness and accessibility are needed to facilitate better social inclusion [...] Information and advice are key to successful transitions [...] training for staff is needed and reviews of inclusive provision need to be carried out with disabled students.* DSC's (2022) research further reinforced these points including student frustration with admin burden, inaccessible online learning platforms and argued the sector needed to pick up four key themes, 4 Cs, in their future considerations and planning for inclusive design (DSC, 2022, p.27): *Communication: consult and communicate with disabled students as often and inclusively as possible. Consistency: a consistent approach across departments and between HEPs is required. Choice: anticipatory reasonable adjustments and a more flexible approach to teaching, learning and assessment. Certainty: during a period of rapid change and uncertainty..*

The similarities with our study's findings are evident. In furthering the overall work in this field, we argue the following must be priority areas for current and future HEI policy and practice :

- to prioritise 'knowing' our students,
- to 'understand' and value our students' individual and collective positions,
- to know our students' story and position that knowledge as powerful, ie they are the expert
- to moving institutional practices, professional knowledge and system wide culture, beyond a pejorative/ableist position on 'disability'

What our study adds to the wider field of work is the position that disabled students need to be seen and engaged with as leaders at the table of policy development, inclusive pedagogy development, application and evaluation.



## Conclusion

As shown findings from our study, correlate to the more expansive DSUK research (2021) and the DSC report (2021). The study provides examples of disabled students not being considered by their universities, having inappropriate reasonable adjustments, struggling to get universities to agree to appropriate provision, and/or being told that the university cannot put in place reasonable adjustments. These actions are evidence of what maybe unintentional but nonetheless unlawful practice, where statutory provision has been broken and equal rights not valued or upheld. Research has shown that inclusive practice for disabled students was not fit for purpose before the Covid-19 pandemic and, whilst changes have occurred in both policy and practice terms, they have not resulted in successful transformative inclusive education for disabled students.

It is clear from our findings and those of others (NADP, 2020; NMHP, 2020, DSC 2022) that disabled students' needs differ and therefore so too will requirements for reasonable adjustments. Borkin (2022) highlights that a 'one-size-fits-all' approach is not suitable between disabled and non-disabled students and/or in relation to disabled students differing needs. Borkin (2022, p.1) stated "...we know that disabled students are not a homogenous group and so approaches must be tailored as far as possible by impairment type and applied with an intersectional lens". Disabled students who have been diagnosed with the same disability for instance Specific Learning Difficulties, Autistic Spectrum Conditions and mental health conditions are likely to have variation in 'degree and type'. Cameron and colleagues (2019, p.214) state that *in practice, this means that two individuals who have been given the same broad diagnosis may experience very different educational challenges which differ in type, degree of difficulty, and which may depend upon the environmental barriers present in a particular context.* Regarding reasonable adjustments, Cameron and colleagues (2019, p.214) go on to say that *...what may be 'reasonable' for one student given a particular diagnosis may not be so for another given the same diagnosis.* Nolan (2022, p.151) emphasises the importance of considering intersectionality and how it can create 'a compounded burden'. As a disabled student of colour Nolan reflects on disparity in disabled student's experiences:

*We must understand that the individual-level barriers of a white male will be different than those of a Black woman, even if they have similar disabilities or chronic illnesses. The process of self-acceptance is a critical consideration, as is awareness*

*of identity-specific barriers that may lead to difficulty accepting help or accessing services.*

Considering this important point further, it is necessary for the HE sector to understand the ways in which various intersectionality combine, thus increasing the individual's exclusion and oppression. The research clearly shows that disabled students with significant cultural and financial capital will and do experience inclusion differently than disabled students from less financially secure backgrounds (Naylor and Mifsud (2020)). This plays out in the need for the latter student group to seek employment whilst studying, thus adding another demand on their time for study and self-care/health.

There also appears from our findings to be challenges across the sector in its definition and application of term 'reasonable adjustments'. This is echoed in research that has found a lack of understanding in Equality Act entitlements (Cameron, Coleman, Hervey, Rahman and Rostant 2019) and a lack of *knowledge, training and awareness of disability* (Banbury, 2020, p.966). Universities have been subject to disability equality legislation since 2001 (DfE, 2001 ) with the Equality Act (2010) imposing further obligations on HE regarding the inclusion of disabled students, i.e.: *...universities must take reasonable steps to avoid any substantial disadvantage which would otherwise be faced by disabled students as a result of a provision, criterion or practice or physical feature...*(Roberts and Hou, 2016, p.149). Perceived discriminatory and exclusionary examples evidenced in our findings and other larger-scale reports, show that students' negative experiences are not because they have asked for unreasonable adjustments. In fact, all the requests detailed in these findings, including blended learning and use of captioning, can be considered as reasonable adjustments, adjustments that universities could and should provide.

An evident issue is that these universities do not engage with their students' lived knowledge and expertise, which if utilised effectively, could change policy, procedures, training and/or reasonable adjustments/resources, as obligated by the Equality Act (2010). Inclusive practice has been aimed for in HE for many years, efforts now need to focus on listening to our disabled students, learning from their knowledgeable voices, taking their lead to ensure an end to the elusive practice of inclusive education in today's HE. As evidenced in our findings this means ensuring policy, procedures, training, and reasonable adjustments are effectively put in place to meet disabled students differing needs, furthermore, ensuring that it is disabled students who evaluate the effectiveness of

provision. We argue, this change needs to happen at both macro and micro levels and be conducted in partnership with and led by disabled students.

The pandemic exacerbated existing disparities between disabled and non-disabled students and showed that significant pedagogic and systemic change can happen, when suddenly prioritised as essential. Findings suggest we rethink inclusive practice by listening to and engaging with our disabled students, to ensure that disabled students studying today experience HE where they fully participate, feel they belong, are always included and progress successfully. One way in which this can be done is through meaningful collaboration with organisations like DSUK who (DSUK 2022a) *embody a radically different model of disabled students as experts and creators of change rather than recipients of charity*. A new model for inclusive provision in HE, emerged from this organisation after the publication and dissemination of their report *No Going Back* (DSUK 2022b). The model is entitled- *Access Insights* and entails DSUK experts working with HEIs to develop systemic reviews of their practices, and provide consultation for inclusive student services and for senior leaders with input to annual reports such as the Access Participation and Plan.

It is clear from our research that *user informed positions, practices and leadership need to be prioritised in all HEIs* and across all courses, otherwise what continues is the reproduction of integration, labelled as 'inclusion', resulting in frustration, struggle and failure for many. This has a knock-on effect in terms of our wider social wellbeing and our national economic sustainability, i.e. we all miss out. The authors of this paper align themselves with the position as poignantly taken by DSUK (2020, p.20) and argued from a position of power, *The pandemic can be used as an excuse to deny disabled students their rights, or it can be used as a springboard for creating more humane and inclusive universities. We recommend readers take lessons from this work, pushing forward in partnership for change and equality in our HE spaces with disabled students leading the way.*

## References

- ARC (2013) Literature Review of Research into Widening Participation to Higher Education, Report to HEFCE and OFFA by ARC Network.
- Basit, T. (2010), *Conducting research in educational contexts*. London: Continuum international Publishing group.

- Beauchamp-Pryor, K. (2012). From Absent to Active Voices: Securing Disability Equality Within Higher Education, *International Journal of Inclusive Education*, 16 (3): 283–295.
- Borkin, H. (2022) Disabled students needs to be prioritised, not generalised. [online] [Disabled students need to be prioritised, not generalised | Wonkhe](#) [accessed September 2022].
- Cameron, H., Coleman, B., Hervey, T., Rahman, S. and Rostant, P., (2019). Equality Law Obligations in Higher Education: reasonable adjustments under the Equality Act 2010 in assessment of students with unseen disabilities. *Legal Studies*, 39(2), pp.204-229.
- Cohen, L., Manion, L, Morrison, K. and Bell, R. (2011), *Research Methods in Education*. (7<sup>th</sup> ed.). London: Routledge.
- Department for Business, Innovation and Skills (2016) *Success as a Knowledge Economy: Teaching Excellence, Social Mobility and Student Choice*. [online] [Cm 9258 - Success as a Knowledge Economy: Teaching Excellence, Social Mobility & Student Choice \(publishing.service.gov.uk\)](#) [accessed September 2022].
- Disabled Students' Commission (2021) '*Annual Report 2020-2021: Enhancing the disabled student experience*'. [online]. [Disabled Students' Commission Annual Report 2020-2021: Enhancing the disabled student experience | Advance HE \(advance-he.ac.uk\)](#). [accessed September 2022].
- Disabled Students UK (2020) '*Impact of the pandemic on disabled students and recommended measures*'. [online]. [DSUK Report Update.pdf \(disabledstudents.co.uk\)](#). [accessed September 2022].
- Disabled Students UK, (2022), *Going back is not a choice*, DSUK publications
- Gibson, S. (2012). "Narrative Accounts of University Education: Socio-Cultural Perspectives of Students with Disabilities." *Disability and Society* 27 (3): 353–369.

- Gibson, S. (2015). When rights are not enough: What is? Moving towards new pedagogy for inclusive education within UK universities. *International Journal of Inclusive Education*, 19(8), 875–886.
- Gibson, S. (2016) Students as core: A time for change in the higher education discourse of 'widening participation' and 'inclusion', in, Brown, Z. (eds.) *Inclusive Education: Perspectives of pedagogy, policy and practice*. Routledge: Oxon.
- Gibson, S. (2020). A matter of Disablism? Re-considering Higher Education in relation to disability and social justice. Burke, P.J., Bunn, M., Lumb. M. (Eds). *An invitation to reconceptualise Widening Participation through praxis*. Centre of Excellence for Equity in Higher Education Resource. Available at: <https://www.newcastle.edu.au/ceehe/>
- Gibson, S. (2022), *Disability and identity: Engaging with matters of intersectional equality and inclusive practice in Higher Education*, invited pre-recorded talk, [National Association of Disability Practitioners \(NADP\) annual conference](#).
- Gibson, S. Baskerville, D. Berry, A. Black, A. Norris, K. Symeonidou, S. (2016) 'Diversity' 'Widening Participation' and 'Inclusion' in Higher Education: an International Study. [online]. [https://pearl.plymouth.ac.uk/bitstream/handle/10026.1/6678/Gibson\\_Diversity\\_Widening\\_Participation.pdf?sequence=3](https://pearl.plymouth.ac.uk/bitstream/handle/10026.1/6678/Gibson_Diversity_Widening_Participation.pdf?sequence=3) [accessed 29<sup>th</sup> June 2022].
- Gibson, S., Cook-Sather, A. (2020). Politicised compassion and pedagogical partnership: A discourse and practice for social justice in the inclusive academy, *International Journal for Students as Partners*, 4(1), 16-33.
- Gibson, S., and L. Kendall. (2010). Stories from School: Dyslexia and Learners' Voices on Factors Impacting on Achievement, *Support for Learning* 25(4), 187–193.
- Gillham, B. (2007) *Developing a questionnaire*. (2<sup>nd</sup> ed.). London: Continuum books.
- Gorard, S., Boliver, V., Siddiqui, N. and Banerjee, P., (2019). Which are the most suitable contextual indicators for use in widening participation to HE?. *Research Papers in Education*, 34(1), pp.99-129.

- Hamilton, L., (2019). The rhetoric of widening participation in higher education: Ending the barriers against disabled people.
- HESA. (2022a, January 25). *Higher Education Student Statistics: UK, 2020/21* . HESA. <https://www.hesa.ac.uk/news/25-01-2022/sb262-higher-education-student-statistics>
- HESA. (2022b, February 10). *Who's studying in HE?* HESA. <https://www.hesa.ac.uk/data-and-analysis/students/whos-in-he>
- HEPI (2020) New Report: the experiences of disabled students in higher education. [online] <https://www.hepi.ac.uk/2020/10/14/new-report-the-experiences-of-disabled-students-in-higher-education/>. [accessed June 2022].
- Hubble, S. and Bolton, P. (2021) Support for disabled students in higher education in England. [online]. <https://researchbriefings.files.parliament.uk/documents/CBP-8716/CBP-8716.pdf>. [accessed June 2022].
- Hughes, K., Corcoran, T. and Slee, R., (2016). Health-inclusive higher education: Listening to students with disabilities or chronic illnesses. *Higher Education Research & Development*, 35(3), pp.488-501.
- Jary, D. & Jones, R. (2004) Widening Participation an overview and commentary. [online] <http://www.c-sap.bham.ac.uk/hottopic/admin/extras/wpbriefing.pdf> [Accessed 10 June 2022].
- Kilpatrick, J.R., Ehrlich, S. and Bartlett, M., 2021. Learning from covid-19: Universal design for learning implementation prior to and during a pandemic. *Journal of Applied Instructional Design*, 10(1), p.1.
- Koutsouris, G., Mountford-Zimdars, A. and Dingwall, K., 2021. The 'ideal' higher education student: understanding the hidden curriculum to enable institutional change. *Research in Post-Compulsory Education*, 26(2), pp.131-147.
- Lewis, E. and Johnston, B. (2002) *Assessment in Universities: A Critical Review of Research*. Learning and Teaching Support Network Generic Centre, UK. [online]. <http://eprints.soton.ac.uk/id/eprint/59244>. [accessed June 2022].
- Liasidou, A. (2014). Critical Disability Studies and Socially Just Change in Higher Education, *British Journal of Special Education* 4 (2), 120–135.

- Madriaga, M. (2007). Enduring Disablism: Students with Dyslexia and Their Pathways into UK Higher Education and Beyond. *Disability and Society*, 22(4): 399–412.
- Madriaga, M. Hanson, K. Kay, H. & Walker, A (2011): Marking-out normalcy and disability in higher education, *British Journal of Sociology of Education*, 32:6, 901-920
- Martin, N, Wray, M, James, A, Draffan, EA, Krupa, J and Turner, P (2019). *Implementing Inclusive Teaching and Learning in UK Higher Education – Utilising Universal Design for Learning (UDL) as a Route to Excellence*. Society for Research into Higher Education. <https://openresearch.lsbu.ac.uk/item/8666q>
- Meleo-Erwin Z., Kollia, B., Fera J., Jahren A., Basch C. (2021) 'Online support information for students with disabilities in colleges and universities during the COVID-19 pandemic'. *Disability and Health Journal* 14 (2021) 101013.
- Moore, J., Sanders, J. and Higham, L., (2013). Literature review of research into widening participation to higher education. *Report to HEFCE and OFFA. AimHigher Research & Consultancy Network*.
- Moriña, A., 2021. When people matter: The ethics of qualitative research in the health and social sciences. *Health & Social Care in the Community*, 29(5), pp.1559-1565.
- National Association of Disability Practitioners (2020) 'Covid-19: Disabled Students in Higher Education: Student Concerns and Institutional Challenges'. [online] [COVID-19 Resource Hub \(Coronavirus\) – NADP \(nadp-uk.org\)](#). [accessed June 2021].
- National Association of Non-Medical Helper Providers (2020) 'Your DSA Support and Covid-19 – Student and Provider Survey Final Report – 12th May 2020'. Available at: [Your-DSA-support-and-Covid-19-Student-and-NMHP-Survey-Final-Report-v-4-0.pdf \(nmhproviders.co.uk\)](#). (Accessed: June 2021)
- Naylor, R. and Mifsud, N. (2020) Towards a structural inequality framework for student retention and success, *Higher Education Research & Development*, 39:2, 259-272, DOI: [10.1080/07294360.2019.1670143](https://doi.org/10.1080/07294360.2019.1670143)
- Nolan, S.L., (2022). The compounded burden of being a black and disabled student during the age of COVID-19. *Disability & Society*, 37(1), pp.148-153.
- Office for Students (OfS) (2020a), Student engagement and Consultation, <https://www.officeforstudents.org.uk/advice-and-guidance/promoting-equal-opportunities/effective-practice/student-engagement-and-consultation/advice/> (Accessed January 2023)

- Office for National Statistics (ONS) (2020) Outcomes for disabled people in the UK:2020. [online]. [Outcomes for disabled people in the UK - Office for National Statistics \(ons.gov.uk\)](#). [Accessed September 2022].
- Office for Statistics (OFS) (2020b) Disabled Students. [online] [Disabled students - Office for Students](#). [Accessed September 2022].
- Peruzzo, F., Raaper R. and Anwar-Westander M. (2023). *It's time to make English higher education institutions accessible: disabled student representatives lead the way to change*. Higher Education Policy Institute. Retrievable at <https://www.hepi.ac.uk/2023/01/18/its-time-to-make-english-higher-education-institutions-accessible-disabled-students-representatives-lead-the-way-to-change/> [Accessed 25<sup>th</sup> January 2023].
- Policy Connect (2020) '*Arriving at Thriving*'. [online]. [Arriving At Thriving: Learning from disabled students to ensure access for all | Policy Connect](#). [accessed June 2021].
- Pring J. (2021) '*Disabled women decide "enough is enough" and launch protest over pandemic deaths*'. *Disability News Service*. [online]. [Disabled women decide 'enough is enough' and launch protest over pandemic deaths – Disability News Service](#). [accessed July 2021].
- Roberts, P. and Hou, E., (2016). The best education money can buy? Disabled university students and the Equality Act 2010. *International Journal of Discrimination and the Law*, 16(2-3), pp.143-160.
- Runswick-Cole I. (2021) '*Reflections on learning disability and Covid-19 for Learning Disability Week*'. *iHuman*. [online]. [Reflections on learning disability and Covid-19 for Learning Disability Week | iHuman | The University of Sheffield](#) [accessed July 2021].
- Shaw, A., (2021). Inclusion of disabled Higher Education students: why are we not there yet?. *International Journal of Inclusive Education*, pp.1-19.
- Snowdon Trust (2021) '*Disabled Students Survey*'. *Global Disability Innovation Hub (GDI Hub)*. Available at: [Disabled Students Survey - Snowdon Trust](#). (Accessed: July 2021)



Vickerman, P., and M. Blundell. 2010. Hearing the Voices of Disabled Students in Higher Education, *Disability and Society*, 25(1), 21–32.

Zhang H., Nurius P., Sefidgar Y., Morris M., Balasubramanian S., Brown J., Dey A.K., Kuehn K., Riskin E., Xu X., Mankoff J. (2020) 'How Does COVID-19 Impact Students with Disabilities and Health Concerns?'. [online] [How Does COVID-19 impact Students with Disabilities and Health Concerns? \(arxiv.org\)](#) [accessed June 2021]

UK Government (2001) 'Special Educational Needs and Disabilities Act' (DISABILITYYA). Available at: [Special Educational Needs and Disability Act 2001 \(legislation.gov.uk\)](#) (Accessed: July 2021)

UK Government (2010) 'Equality Act'. Available at: [Equality Act 2010 \(legislation.gov.uk\)](#) (Accessed: July 2021)

### Appendix 1: Table of Participants

Participant number	Course studied	DISABILITY	Ethnicity	Gender
1	BA(Hons) Fashion and Culture	C-PTSD and limited upper-body mobility	White British	Female
2	Computer Science and Robotics PhD	ADHD Likely Ehlers-Danlos Likely POTS Potential Autism Phantosmia Delayed Sleep Phase Disorder All undiagnosed	White	Male, but possibly on the agender or demigender spectrum

3	Human and Social Sciences	Moderate ADHD (combined), dyspraxia and anxiety	Caucasian	Nonbinary/transmasc
4	Doctorate in Clinical Psychology	Rare autoimmune disease. Leaving me extremely 'clinically vulnerable' and impacts on my mobility	White Welsh	Female
5	Law	Irlen Syndrome, Dyspraxia, Chronic back pain due to a variety of back problems, asthma. So a hodge podge of problems with no easy answers.	White British	Male
6	Ancient History and archaeology	Mental Health	White/Asian	Female
7	PhD Health Security	Longstanding illness and mobility impairment	White	Female

8	Counselling	Covering multiple domains	British	Male
9	Doctorate in Education	Mental Health Condition (Bipolar) and long term health condition	White	Female
10	BSc Psychology	Mental and physical disabilities that limit quality of life	White	Female
11	English	Issues with coordination and writing	South Asian	Male
12	PhD	Limb difference	Indian	Agender
13	BSc Chemistry	Severe chronic pain  Sensory disabilities Auditory processing disorder Neurodivergent (autism)  Mental health conditions	White European	Nonbinary/gender fluid
14	Law	Epilepsy and severe migraines	White	Female

## **Human Rights: The Right to Work in Academia. Professor Nicola Martin and Dr David Birchall**

Research Centre for Social Justice and Global Responsibility

London South Bank University

Key Words: Employment. Academia. Disability. Entitlement. Barriers. Enablers.

### **Abstract:**

This article considers aspects of The United Nations (UN) Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2006), relevant internationally, and the *Equality Act 2010* which applies in England, Scotland and Wales. Focussing on work in academia, it explores insider perspective research involving disabled academics seeking to progress in academic careers. It illuminates barriers arising from systematic ableism and workplace injustices, and considers enablers which make academic work possible. Enablers include reliable, empathic, anticipatory, logical (REAL) systems, based on universal design, and peer support. Institutional failure to make employment work for disabled academics arises from ableist attitudes, culture and infrastructure which often inadvertently constructs disabling obstacles throughout the employment journey. Failing to address these issues translates into violations of human rights through non-compliance with equalities legislation, leading to wasted potential. The aim of this contribution is to support positive progress towards inclusive academic employment and the authors argue that lessons learned from the pandemic may be helpful in this regard.

### **Introduction**

Focussing on insider insights of disabled academics, the requirements of the *Equality Act 2010* and relevant United Nations (UN) conventions and international human rights law, this paper illuminates myriad barriers faced by disabled employees in academia, and considers potential enablers including functional systems and peer support. Barriers often represent ableism and poor institutional legislative compliance, and enablers are frequently straightforward to enact through reasonable adjustments or cultural change within an inclusive workplace informed by principles of Universal Design (UD).

Pertinent legislation and UN conventions are considered and contextualised within a broader picture of employment of disabled people in the UK. Insider perspective studies about academic employment of disabled people are the focus and broader research is included where relevant.

Principles of UD are discussed in relation to academic employment of disabled people, and research-informed suggestions for enacting change are included throughout for their practical value.

### **Relevant Equalities Legislation and UN Conventions**

Alongside the UN Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006), the most pertinent pieces of legislation is the *Equality Act (EA) 2010*. The *Disability Discrimination Act (DDA) 1995* in Northern Ireland fulfils a role similar to The *Equality Act 2010* which operates in Scotland, Wales and England and combines and supersedes older equalities legislation. The *EA* covers disability as one of nine protected characteristics, and is cognisant of multiple identity.

Part 2, Chapter 1, Section 6 of the *EA* defines disability as:

‘a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities’ (*Equality Act 2010*).

While this definition is medically focussed, legislative duties include addressing barriers to societal participation through reasonable adjustments, and promoting equality of opportunity (Griffiths, 2020; Robson et al, 2016). Social modelists conceptualise disability around socially-constructed disabling barriers experienced by people with impairments (Brown, 2020; Campbell, 2009; Finesilver et al, 2020; Oliver, 2009). Despite its medicalised definition of disability, the *EA*, like the CRPD (UN, 2006), is focussed on a proactive, anticipatory, stakeholder informed approach to reducing barriers.

Research evidence points to workplace failure to make anticipatory reasonable adjustments compliant with the *EA* (Ewens and Williams, 2011; Löve et al, 2018; Robson et al, 2016; Roulstone and Williams, 2014). The *EA* emphasises involving disabled people in decision making, but failure to embrace the ‘nothing about us without us’ principle (Charlton, 1998) and stereotyping around an impairment label is

evident, resulting in the frustration of being told what reasonable adjustments an employer plans rather than disabled employees being asked what they need (Bagilhole, 2010; Berghs and Dyson, 2020; Brown and Leigh, 2020; Cameron, 2010, 2011; Corlett and Williams, 2011; Ellingson, 2021).

The CRPD (UN, 2006) covers work and employment under Article 27, including reasonable accommodation and universal design. The full scope of Article 27 was recently elaborated in a General Comment by the Committee of the CRPD (UN, 2022). General Comments provide authoritative interpretation of the content and implementation of human rights treaties. The interpretation of Article 27(i) covers reasonable accommodation and universal design. The wording of 27(i) is that State Parties to the Convention must '[e]nsure that reasonable accommodation is provided to persons with disabilities in the workplace' (UN, 2006, p.20). The General Comment elaborates that '[r]easonable accommodations are those modifications, adjustments and supports that are needed to ensure the equal enjoyment or exercise of a human right or fundamental freedom... To fall within the concept of reasonable accommodation, the changes need to be negotiated with the individual. The duty to provide reasonable accommodation is applicable from the moment that a request for such accommodation is received or the need becomes apparent (UN, 2022, p.5). Reasonable accommodation is therefore defined as a reactive policy based on individual need. This is contrasted with universal design, which is defined as 'a duty built into systems and processes without regard to the needs of a particular person with disabilities' (ibid.). There exists 'an ongoing obligation to provide accessibility through universal design' rooted in the prohibition of indirect discrimination (ibid.). The ideal imagined by the CRPD Committee appears to be a starting point of universal design supplemented with additional individualized accommodations as they arise.

While the aspiration to disability equality in employment is consistent within human rights discourse, the quality of such opportunities remains variable. Equality in employment data which follows illustrates under-representation of disabled people in higher-level UK university positions. A knock-on effect is lack of senior disabled role models, which may impact negatively on aspirations (RADAR, 2010; Martin, 2020; Nash, 2009). Particularly demotivating is the reality that disabled scholars with PhDs report finding that their doctorate is not a passport to successful academic employment (Chown et al, 2015; Martin, 2021; Milton et al, 2019).

## Equality in employment data

Potential inaccuracy around reporting is flagged by Brown (2020), Farahar and Foster (2021), Griffiths (2020), Lewis (2021), Nash (2014), Martin (2020), RADAR (2010), Roulstone and Williams (2014), Sayce (2011) and others who point to disquiet amongst disabled employees around 'disclosure' (which is itself a contested term). Bonaccio et al (2020), Olsten (2022) and others corroborate Nash's (2014) findings from a study of over 2,000 disabled employees from diverse settings that 'disclosure' is a particular issue for those with hidden impairments who effectively have the choice not to disclose.

Nash (2014) cites the anticipatory requirement to make reasonable adjustments under the *Equality Act 2010* and argues therefore against waiting for accurate figures before doing anything useful. However flawed, the tables which follow provide a snapshot which points to low levels of employment of disabled people in general.

Figures were provided by the House of Commons Library Briefing *Disabled People in Employment* (Powell, 2021). Coronavirus pandemic effects could be a factor, and the data is not sufficiently nuanced to illuminate concerns around disabled graduates unable to secure graduate level jobs.

**8.4 million** people age 16-64 reported that they were disabled in October-December 2020, **20%** of the working age population, an increase of 327,000 from 2019.

An estimated **4.4 million** were in **employment**, an increase of 25,000 from a year previously.

**52.3%** of disabled people were in employment, down from 54.1% a year previously. The non disabled employment rate was 81.1%, down from 82.2%.

**3.6 million** disabled people of working age were economically inactive, not in or seeking work, an increase of 226,000 from a year before.

Disabled people's economic inactivity rate was **42.9%**, compared to 14.9% for non disabled.

The employment rate of disabled people is **28.8 percentage points lower** than non disabled.

#### **Impact of the coronavirus pandemic**

The proportion of disabled people unemployed or economically inactive has risen from 45.9% to 47.7% in the year to October-December 2021.

Non disabled increase is from 17.8% to 18.9%.

In July-November 2020, 21.1 per thousand disabled employees were made redundant, compared to 13.0 per thousand non disabled.

Powell (2021, pp.3-4)

The Equality Challenge Unit's (ECU) 2015 report concluded that most university leaders identified as non-disabled white men between 46 and 55. As the ECU was disbanded shortly after their report was published, the figures have not been updated. Guibourg (2019) refers to systemic non-disabled white male privilege, and the ongoing absence of senior disabled role models suggesting little improvement in the HE sector since the ECU report. A participant in Martin's (2017) qualitative study, with around 100 disabled leaders in HE, reflected 'I don't look like any of our senior leadership team. I'm not an old white dude in a grey suit' (p.16).

While disabled people feeling reluctant about 'disclosure' could lead to inaccurate data, impacts upon individuals are arguably more concerning. During the pandemic, for example, employers may have been unaware of an employee's requirement to medically shield.

'Masking' was referenced in various studies and there is an extensive body of literature on the phenomenon by autistic academics (Cage et al, 2018; Goldstein Hode, 2012; Martin, 2021; Milton et al, 2019). Boucher's (2017) interview-based Australian research with 20 women managers with physical impairments reported downplaying fatigue and pain and a tendency to 'present an optimistic demeanour' (p.7). Feeling pressure to perform at work in ways which involve masking is symptomatic of ableism (Campbell, 2009; Goodley, 2014). 'Ableism' is about 'the invalidation of impaired bodies and the



constant struggle to establish credibility' (Loja et al, 2013, p.193). Reliable reporting on disability in the workplace is impossible when ableist workplace cultures make 'disclosure' feel risky and masking seem necessary.

### **Government initiatives to promote disability equality**

Independent evaluations of government initiatives to promote disability equality are sparse. The Access to Work Scheme (DWP, 2023a) is arguably the flagship initiative. It focusses mainly on bespoke reasonable adjustments for individual disabled employees and, in some cases, job seekers. People need to know about the existence of the scheme and its interface with the workplace needs to be robust in order for it to be effective: Martin's (2017) participants were not confident that this happened routinely.

Sayce's (2011 and 2015) evaluations of Access to Work concluded that the process was poorly understood by employers. This is somewhat ironic as Access to Work is government funded, so universities unable to make their systems work in tandem with the scheme have to find resources themselves. Adams et al (2018) and Mounsey and Booth (2021) provide an alternative positive narrative about the effectiveness of Access to Work, which clearly has enormous potential, especially within a joined-up entitlement-based system.

Initiatives designed to embed disability equality systemically include the Positive About Disabled People 'Two Ticks' symbol, later replaced by the Disability Confident scheme (DWP, 2014). Two ticks, developed by Jobcentre Plus in 1990, was regarded by Robson et al. (2016) and others to be somewhat toothless. Employers could gain two ticks by responding to five position statements covering aspects of disability equality at work. Hoque et al's (2014) critique found 15% of 'Two Ticks' organisations surveyed evidenced all five commitments, 38% only one and 18% none at all.

The three-level Disability Confident scheme is the latest Department of Work and Pensions initiative (DWP, 2014, updated in 2021). Its stated aim is 'to encourage employers to think differently about disability and take action to improve how they recruit, retain and develop disabled people' (DWP, 2021). Most recently, in April 2023 the Buckland Review of Autism Employment (DWP, 2023b) was announced with a focus on the employment of autistic people.

Principles of UD emphasise strategic, systemic approaches to embedding disability equality which reduce the requirement for individualised reasonable adjustments, and therefore reduce costs. UD however, while potentially improving things for everyone, cannot replace bespoke services for a small minority who may require, for example, help with physical tasks from a personal assistant (Maddison et al, 2022) or use of a service animal such as a guide dog (Lindsay and Thiyagarajah, 2022). Initiatives based on UD principles are discussed in the next section.

### **Promoting equity in academic employment via universal design (ud)**

UD is about planning and designing for diversity. This demands a strategic approach involving coherent, stakeholder-informed anticipatory action to promote inclusion (Avery et al, 2016; Jorgenson et al, 2013; Martin et al, 2019; Milton et al, 2016). The anticipatory nature of the EA's public sector duty is very clear, and echoes the expectation of the CRPD (UN, 2006) that disabled people will be actively involved in processes and decisions which impact on their lives. These principles are congruent with UD. Disabled commentators concur that UD principles, provided they translate into workable inclusive practices, minimize, but do not eliminate for everyone, the requirement for bespoke individual reasonable adjustments.

Several studies concluded that universities could usefully evaluate systems from the perspective of end users to identify aspects which could work more coherently together, processes which could be streamlined, and communications which could be more effective (e.g. Brown and Leigh, 2021; Ewens and Williams, 2011; Jorgenson et al, 2013; Martin, 2017; Milton et al, 2016; Roulstone and Williams, 2014). The ideal would be a more proactive approach in which policies, practices and procedures underwent an Equality Impact Assessment (Home Office, 2011) at the planning stage, followed by ongoing stakeholder-informed evaluation and development.

The pandemic signalled a sudden cultural shift in the workplace with the potential to accelerate UD practices such as flexible home-based working (Ahmed 2020; Brown and Ciciurkaite, 2023; Hoque and Bacon, 2022; Kruse et al, 2022; Martel et al, 2021; Wong et al, 2022). Lessons learned during this unprecedented time may or may not lead to longitudinal change; it is too early to tell. Post-lockdown policies around returning to campus could usefully be subjected to Equality Impact Assessment (Home Office, 2011)

as part of a thorough review. It is highly likely that disabled people with health vulnerabilities may be disproportionately impacted by this requirement (Shaw et al, 2020).

Various studies evidenced practices antithetic to UD at every stage of the employment journey. These included unconscious bias within recruitment, lack of role models, chaotic workplace systems and micro-aggressions, such as being told rather than asked about reasonable adjustments. (Brown, 2020; Ellingson, 2021; Robson et al, 2016). Participants commented that university services for disabled students were counterintuitively rarely available to staff in research by Draffan et al, 2017; Farahar and Foster, 2021. The interface between institutional structures and external sources of help, such Access to Work, was often impenetrable, and careless about confidentiality (RADAR, 2010; Martin, 2017). Brown's (2021) edited volume, entitled *Lived Experiences of Ableism in Academia*, illustrates that even when obvious reasonable adjustments are agreed, the process can involve unreasonable bureaucracy, as in the following example: 'I'm just scanning proof that my leg is still amputated for next year's parking pass' (Ellingson, 2021, p.17).

Ableism within recruitment and promotion can make getting to first base, as well as progressing in academic employment, problematic. Participants in several studies reported: feeling unsure about their rights around interview, not trusting recruiters to enact interview guarantees for disabled individuals who fulfil essential criteria, or providing dishonest non disability related reasons or excuses for not appointing, in order to avoid potential litigation (Brown, 2020; Farahar and Foster, 2021; Lewis, 2021; Milton et al, 2019; Mounsey and Booth, 2021). Within the autism and employment literature are examples of badly designed interviews, which do not play to autistic strengths and allow unconscious bias around communication expectations to flourish amongst panel members (Barnham and Martin, 2017; Milton, 2017).

Once in work, participants in various studies reported finding progression limited by external factors such as inaccessible leadership training. Disability Rights UK's (2013) 'Career development programme for people in employment, living with a disability or health condition', which was delivered by disabled leaders, was given as a useful example, but this was contrasted with stories about inaccessible venues and ableist assumptions. Staying put with supportive colleagues and workable systems, which were hard to replicate, and the invisibility of disabled senior role models, were frequently

described as reasons for not looking for promotion (Roulstone and Williams, 2014; Martin, 2020).

Various attempts to hold institutions to account have been instigated but none has been particularly useful. The Equality and Human Rights Commission (2018) articulated explicit monitoring requirements when the *EA* came into force, along with the process of Equality Impact Assessment, which does not occur routinely (Home Office, 2011).

UD can only work within a culture which values diversity and enacts practices which enable diverse communities to thrive. Senior leadership buy-in to cultural change informed by stakeholders, leading to efficient anticipatory co-ordinated systems and clear communication about how processes work in practice, was thought to be the gold standard (Robson et al, 2016; Martin et al, 2019).

Covid brought into sharp focus the need for creative approaches to work-based equity, and practices such as home working are increasingly possible with imaginative use of technological capabilities and a nuanced understanding of intersectional factors such as the impact of family circumstances (AbuJarour et al, 2021; Rathnayake et al, 2022).

This section has largely reported practices antithetical to UD and it is unfortunate that most of the available evidence points to things that have gone wrong. A student-facing report from The National Association of Disability Practitioners written by Martin et al (2008) perhaps over-simplified the concept of UD, but nevertheless introduced a useful acronym (REAL) which could inform the enactment of UD in the employment journey. REAL stands for: reliable, empathic, anticipatory and logical. The concept echoes suggestions from disabled employees in academia who wanted systems and people to be reliable, empathy and anticipation to be enacted in order to plan to avoid potential difficulties, and process and communications to work logically, unambiguously and in tandem with each other. Strategic planning around UD and informed by Equality Impact Assessment (Home Office, 2011) could usefully incorporate REAL thinking which, as with all UD practices, could benefit everyone.

A recurrent refrain in various studies points to the value of supportive colleagues and peer support networks. In the following section two such networks are discussed.

## Peer support networks

Supportive co-workers were identified as important by disabled employees and cited as a reason for not moving jobs in studies by Mounsey and Booth, (2021); Roulstone and Williams, (2014).

Grassroots organisations such as the Participatory Research Collective (PARC), set up by autistic academics (Milton et al, 2019), and the National Association of Disabled Staff Networks (NADSN) (Robson et al, 2016) were found to offer opportunities for peer support, skills development and collective emancipatory research. PARC revealed an expectation that unemployed or underemployed autistic scholars would give of their research expertise without adequate remuneration. This highlights the disjuncture between disabled researchers being asked to share their wisdom for free while at the same time experiencing barriers to effective employment and progression within academia (Chown et al 2017, 2018; Milton et al, 2019).

PARC started, unfunded, at LSBU in 2015 and was 'the first autistic-led venture of its kind in the UK to have a sustained impact' (Milton et al, 2019, p.8). Still unfunded, PARC now has an established national and developing international reach, offers valuable peer support to autistic scholars and contributes to insider informed research. PARC has an interactive website and runs numerous free events, including an autistic-led annual conference, seminars, networking and skills development workshops. Participants are making effective use of social media to network between events, using for example the #AutisticsInAcademia tag, created by PARC convenor Gill Loomes in 2016, and via blogs such as Beardon's (2017) '#AUTISTICSINACADEMIA #AUTISTICPRIDE. *Perspectives on Autism*'.

Universities offer support in kind, mainly by providing space for activities. The network is loosely structured and inclusive, with Dr Damian Milton as national convenor, and various regional convenors across the UK. Nobody is paid so it is difficult to imagine how the network might 'get to the next level' (whatever that means). Certainly, paid administrative support and help with applying for funding would be useful. Milton et al (2019) identified one of the main functions of PARC as 'supporting autistic individuals in their attempts to establish themselves within academic systems that may not always be considerate or accommodating' (p.82). This is important as barriers to academic employment are myriad, and the emotional labour required to sustain an academic role is arduous.

Bertilsdotter Rosqvist et al (2019), Gartsu and Stefani (2019), Goldstein Hode (2012), Harmuth et al (2018) and others argue that, to get the best from employees, institutions should be open to the idea that individuals approach work in different ways. Although 'equality' is the term used in legislation, this idea is closer to 'equity' which is about facilitating equal access through practices which are cognisant of the fact that people are not all exactly the same. Autistic people talk about 'masking' at work, to their own detriment, out of a sense that their way of being is deemed unacceptable by others (Milton and Sims, 2016).

Examples of publications by autistic scholars associated with PARC include: Arnold et al (2018); Bertilsdotter Rosqvist et al (2019); Chown et al (2015, 2017 and 2018); Chown and Leatherland (2021); Lawson (2015, 2017); Lawson and Lawson (2017); Loomes (2017); Milton et al (2017, 2019); Ridout (2017); Ridout and Edmondson (2017); Woods et al (2018). Inclusion in Research Excellence Framework (REF) submissions are not an option for many of these authors because they are disenfranchised by the lack of relevant employment contracts. For autistic students, research and lecturing jobs rarely follow doctoral completion (Gartsu and Stefani, 2019; Harmuth et al, 2018). Hiscock and Leigh (2021) emphasise the importance of disabled staff role models for students and the rarity of disabled scholars with decent contracts does not reflect well on the university sector. The well-worn phrase 'the right to work' should not mean 'the right to work for free and at great personal cost'.

Vejdemo-Johansson and Gent (2021, p.27) commented that (academic) 'Community building takes energy and conscious effort' and PARC outputs are testimony to this. Universities serious about equity could usefully translate policy into more effective practice which could support the endeavours of networks such as PARC, and NADSN, which is discussed next.

NADSN arose in response to duties placed upon the HE sector by the EA, including; involving disabled people in decision making, supporting disabled staff through individual adjustments and 'cultural and attitudinal change throughout workplaces in order to ensure that disabled employees are both enabled and more importantly, they are valued' (Robson, 2016, p.28). Monitoring and publishing equalities information is an EA expectation, and Robson et al (2016) advised that the Department for Work and Pensions Office for Disability Issues (2014) advocate direct engagement with disabled employees

for this purpose, including through staff networks. NASDN fulfils a co-ordinating function among university disabled staff networks, both for peer support and to influence sectoral change. In this regard Robson et al (2016) commented on the value of intersectionality between employees identifying with protected characteristics listed in the *EA*, but also highlighted examples (such as the one which follows) where the principle was operationalized somewhat awkwardly.

... a staff network picnic... brought together disabled, gender, BME and LGBT network members to 'get to know each other' and offer mutual support. There was considerable discomfort felt around this type of event, which lacked a clear purpose and led to some awkward situations around identity: is the white able-bodied woman there because she is a woman? Or because she is from an ethnic minority, has a hidden disability, or is a lesbian or is she transgendered? She may have chosen to declare her position within one or all of the networks but might not wish to share that aspect of her identity amongst other groups.

(Robson et al, 2016, p.31)

Getting staff networks together visibly may be interpreted as celebratory and supportive or could be seen as just another form of virtue signalling. Boucher (2017) raised concern about organisations using images of people with visible impairments to boost diversity credentials, and the following comment from Martin (2017) echoes a similar disquiet: 'I do not want my being part of a network to give the university the impression that I necessarily want to be a visible "face of disability"' (p.27). The study also highlighted the value of peer support via staff networks.

'Peer support is really important. I became disabled about 6/7 years into the job and I came to you (xxxxx) for advice because I felt vulnerable, isolated and lost and didn't know what to do. I still remember I said how I may end up in a wheelchair and you said, 'Don't worry, you'll have more energy!'

(Martin, 2017, p.28)

Networks such as NADSN, PARC, and Purple Space (Nash, 2014), described on the website as ‘the network for promoting disabled talent in business’ (Purple Space, 2021), as well as providing peer support, fulfil a lobbying role and model good practice, for example by organising accessible conferences and leadership training. Such networks influence organisational change most effectively when they are plugged in to structures which influence strategic direction, as in the following example:

‘Our disabled staff network is a sub-committee of the Diversity and Equal Opportunities Committee which is chaired by the Vice-Chancellor. It fits into the structure in a real way and this helps us to get our voices heard.’

(Martin, 2017, p.28).

### **The case for employing disabled people in academia**

Arguing the business case for recruiting, retaining and promoting the best person for the job may well have more traction with budget holders than social justice arguments. Studies by Bebbington (2009), Martin (2017), Nash (2014) and others point to the value of diverse teams and the useful qualities often displayed by disabled employees, which really ought to make universities keen to keep them, even if a few entirely reasonable and, Sayce (2011) found, usually inexpensive adjustments may be required.

In addition to rights-based arguments, there exists a compelling business case for employing disabled people because of the proven value of diverse teams, comprising all the talents (Bebbington, 2009; Bennett et al, 2003; Black, 2015; Morley, 2013).

Disabled participants in various studies tended to focus on their potential contribution to developing inclusive environments conducive to performing highly, and ensuring that the benefit of working conditions based on universal design were felt by the entire organisation (Martin, 2017; Roulstone et al 2014). Creative solution-focussed approaches were emphasised, indicative of effective leadership practices built on valuing every team member. Those who used theoretical terms in Martin’s (2017) study with disabled university leaders specifically referred to having a transformational or distributive leadership style. ‘Transformational leadership’ involves collaboration, social exchange and sharing of power, valuing and developing all team members and working together towards a shared vision (Bass, 1999). ‘Distributed leadership’, according to Bolden et al



(2008) and others, is based on productive, cooperative team dynamics, in which hierarchy is de-emphasized and sharing of ideas is nurtured.

Despite scholarship arguing for the value of diversity in leadership, and the power of transformational and distributed approaches, scant reference to disability is found in organizational and leadership diversity research by Bebbington (2009), Chen (2017), Kezar and Holcombe (2017), Lee (2021) and others. Arguably this represents a missed opportunity, as life experiences of disabled people, including navigating ableist barriers, are a fine preparation for leadership involving strategic planning, problem solving and teamwork (Campbell, 2009; Oliver, 2009; Shakespeare, 2013). Strengths associated with neurodiversity (Logan and Martin, 2011) were apparent in Martin's (2017) study, including 'big picture' thinking and finding innovative practical solutions. The following comment was typical:

I see the bigger picture while not losing sight of detail. I am strong in working with group dynamics, power relations, inequalities, diversity and inclusion. I have vision and think outside the box. I am not afraid to try new approaches but at the same time I am not too attached to my own perspectives and ideas. Instead, I prefer to work through community and cooperation, while appreciating and providing space for people's uniqueness. I work hard and am committed and invested. I am organized.

(Martin, 2017, p.19)

Enablers need to be cognisant of broader considerations beyond impairment labels and understanding individuality and intersectional factors was referenced in various studies, including Berghs and Dyson (2022) and Brown and Leigh (2020). Reliable, empathic, anticipatory and logical (REAL) approaches are built on the UD principle of respect for the contribution of each person and practices to facilitate equity should be based on the understanding that we all equal but we are not all the same.

## **Conclusions**

The right to work is not a reality, and in academia work commensurate with qualifications is a rarity for the majority of disabled people. Ableism and tokenism are common, and

often workplace reasonable adjustments require disproportionate effort by disabled employees, because institutional systems do not make life easy. COVID-19 suddenly made things that were perceived as impossible, such as increased home working, not only possible but essential. Lessons learned from the pandemic in this regard could be harnessed, with a view to developing equitable and efficient long-term practices beneficial to the organisation and its employees. Lived experience of disability in itself can equip disabled people with immense problem-solving abilities and leadership skills which could be harnessed more effectively in the workplace.

Building organisational processes around rights-based UD principles, in which belonging is central and supported by effective REAL processes, is advocated here. It is vital to listen to disabled and marginalized people, and act upon their individual and collective wisdom, in order to move forward towards the right to work being translated into the reality of equitable employment.

## References

- AbuJarour, S., Ajjan, H., Fedorowicz, J. and Owens, D. (2021) How working from home during COVID-19 affects academic productivity. *Communications of the Association for Information Systems*, 48(1), p.8.
- Ahmed, N. (2020) Can we perform like “super-cripples” during this challenging pandemic? Opportunities for disabled people working in academia. *Alter*, 14(3), p.247.
- Adams, L., Tindle, A., Downing, C. and Morrice, N. (2018) Access to Work: Qualitative research with applicants, employers and delivery staff. London: Department of Work and Pensions. Available from: <https://www.gov.uk/government/publications/access-to-work-research-review> [accessed 25-05-2023]
- Arnold, L., Milton, D., Beardon, L. and Chown, N. (2018) England and Autism. In: Volkmar, F. (Ed) *Encyclopaedia of Autism Spectrum Disorders*. New York: Springer.
- Avery, D.R., McKay, P.F. and Volpone, S.D. (2016) Blaming the building: How venue quality influences consumer bias against stigmatized leaders. *Journal of Applied*

*Psychology*, 101(8), pp.1111-1121. DOI:  
<https://psycnet.apa.org/doi/10.1037/apl0000117> [accessed 25-05-2023]

- Barnham, C. and Martin, N. (2017) Considering employment of young people with intellectual impairment and autism leaving school and college. *Autism and Intellectual Disability in Adults*. 2 (1), pp.53-59. Hove: Pavilion Press.
- Beardon, L. (2017) #AUTISTICSINACADEMIA #AUTISTICPRIDE. *Perspectives on Autism*. Available from: <https://blogs.shu.ac.uk/autism/2017/06/17/autisticsinacademia-autisticpride/> [accessed 11-05-2023]
- Bertilsdotter Rosqvist, H., Kourti, M., Jackson-Perry, D., Brownlow, C., Fletcher, K., Bendelman, D. and O'Dell, L. (2019) Doing it differently: emancipatory autism studies within a neurodiverse academic space. *Disability & Society*, 34 (7-8), pp.1082-1101. DOI: <https://doi.org/10.1080/09687599.2019.1603102>
- Bagilhole, B. (2010) Applying the lens of intersectionality to UK equal opportunities and diversity policies. *Canadian Journal of Administrative Sciences/Revue Canadienne des Sciences de l'Administration*, 27(3), pp.263-271.
- Bass, B.M. (1999) Two decades of research and development in transformational leadership. *European journal of work and organizational psychology*, 8(1), pp.9-32.
- Bebbington, D. (2009) *Diversity in Higher Education: leadership responsibilities and challenges*. London: Leadership Foundation for Higher Education.
- Bennett, N.I., Wise, C., Woods, P. and Harvey, J. (2003) *Distributed Leadership: A Review of Literature*. National College for School Leadership. Available from: <https://oro.open.ac.uk/8534/1/bennett-distributed-leadership-full.pdf> [accessed 13-05-2023]
- Berghs, M. and Dyson, S.M. (2020). Intersectionality and employment in the United Kingdom: Where are all the Black disabled people? *Disability & Society*, 37(4), pp. 543-566. <https://doi.org/10.1080/09687599.2020.1829556> [accessed 25-05-2023]

- Black, S.A. (2015) Qualities of effective leadership in higher education. *Open Journal of Leadership*, 4(02), p.54.
- Bolden, R., Petrov, G. and Gosling, J. (2008) *Developing collective leadership in higher education*. London: Leadership Foundation for Higher Education.
- Bonaccio, S., Connelly, C.E., Gellatly, I.R., Jetha, A. and Martin Ginis, K.A. (2020). The participation of people with disabilities in the workplace across the employment cycle: Employer concerns and research evidence. *Journal of Business and Psychology*, 35, pp.135-158.
- Boucher, C. (2017) The roles of power, passing, and surface acting in the workplace relationships of female leaders with disability. *Business & Society*, 56(7) pp.1004-1032.
- Brown, N. (Ed.) (2021) *Lived Experiences of Ableism in Academia: Strategies for Inclusion in Higher Education*. Bristol: Policy Press.
- Brown, N. (2020) Disclosure in academia: A sensitive issue. In: Brown, N. and Leigh, J. (Eds) *Ableism in Academia. Theorising experiences of disabilities and chronic illnesses in higher education*. London: UCL Press, pp.51-73.
- Brown, N. and Leigh, J. (Eds) (2020) *Ableism in Academia. Theorising experiences of disabilities and chronic illnesses in higher education*. London: UCL Press.
- Brown, R. & Ciciurkaite, G. (2022). Disability, Discrimination, and Mental Health during the COVID-19 Pandemic: A Stress Process Model. *Society and Mental Health*, 12(3):215686932211153 DOI:[10.1177/21568693221115347](https://doi.org/10.1177/21568693221115347) [accessed 25-05-2023]
- Business Disability Forum (2005) Disability Smart Self-Assessment <https://members.businessdisabilityforum.org.uk/about/> [Accessed 04-05-2023]
- Cage, E., Di Monaco, J. and Newell, V. (2018) Experiences of autism acceptance and mental health in autistic adults. *Journal of Autism and Developmental Disorders*, 48(2), pp.473-484.

- Cameron, C. (2010) *Does anybody like being disabled? A critical exploration of impairment, identity, media and everyday experience in a disabling society*. Doctoral dissertation, Queen Margaret University.
- Cameron, C. (2011) Not our problem: impairment as difference, disability as role. *The Journal of Inclusive Practice in Further and Higher Education*, 3(2) pp.10-25.
- Campbell, F. K. (2009) *Contours of ableism*. Basingstoke: Palgrave Macmillan.
- Charlton, J. I. (1998) *Nothing about us without us: Disability, oppression and empowerment*. Berkeley, CA: University of California Press.
- Chen, A. (2017) Addressing Diversity on College Campuses: Changing Expectations and Practices in Instructional Leadership. *Higher Education Studies*, 7(2), pp.17-22.
- 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), pp.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), pp.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), pp.837-854.
- Chown, N. and Leatherland, J. (2021). Can a person be 'a bit autistic'? A response to Francesca Happé and Uta Frith. *Journal of autism and developmental disorders*, 51(2), pp.749-751.
- Corlett, S. and Williams, J. (2011) The effects of discourse and local organising practices on disabled academics. *Identities and Critical Management Studies*. Stream 29. University of Northumbria. Available at:

[http://nrl.northumbria.ac.uk/8651/1/Corlett\\_and\\_Williams.pdf](http://nrl.northumbria.ac.uk/8651/1/Corlett_and_Williams.pdf) [accessed 13-05-2023]

Department for Work and Pensions Office for Disability Issues (2014) *Better Working with Disabled People: The Way Forward - The Government response to consultation findings*. Available from:  
[https://publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/assets/320870/better-working-the-way-forward.pdf](https://publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/assets/320870/better-working-the-way-forward.pdf) [accessed 13-05-2023]

Department for Work and Pensions (2021) Disability Confident Employer Scheme. Available from: <https://www.gov.uk/government/collections/disability-confident-campaign#become-a-disability-confident-employer> [accessed 28-05-2023]

Department for Work and Pensions (2023a) *Access to Work: get support if you have a disability or health condition*. Available from: <https://www.gov.uk/access-to-work> [accessed 25-05-23]

Department for Work and Pensions (2023b). The Buckland Review of Autism Employment <https://www.gov.uk/government/news/new-review-to-boost-employment-prospects-of-autistic-people> [accessed 28-05-23]

*Disability Discrimination Act (DDA) 1995*. Available at:  
<https://www.legislation.gov.uk/ukpga/1995/50/contents> [accessed 13-05-2023]

Disability Rights UK (2013) Disabled people leading career development. Available from: [www.disabilityrightsuk.org/disabled-people-leading-career-development](http://www.disabilityrightsuk.org/disabled-people-leading-career-development) [Accessed 04-05-2021]

Draffan, E.A., James, A. and Martin, N. (2017) Inclusive Teaching and Learning: What's Next? *Journal of Inclusive Practice in Further and Higher Education*, 9(1) pp.23-34.

Ellingson, L.L. (2021) A leg to stand on: irony, autoethnography and ableism in the academy. In: Brown, N. (Ed.) *Lived Experiences of Ableism in Academia: Strategies for Higher Education*. Bristol: Policy Press, pp.17-36.

*Equality Act 2010 (c. 15)* Available from: [www.legislation.gov.uk/ukpga/2010/15/contents](http://www.legislation.gov.uk/ukpga/2010/15/contents) [accessed 13-05-2023]

Equality and Human Rights Commission (2018). Available from: [Equality Act 2010 | Equality and Human Rights Commission \(equalityhumanrights.com\)](http://EqualityAct2010.EqualityandHumanRightsCommission.equalityhumanrights.com) [accessed 25-05-23]

Equality Challenge Unit (2015) *Equality in higher education: statistical report 2015 part 1: staff*. London: Equality Challenge Unit. Available from: <https://www.advance-he.ac.uk/knowledge-hub/equality-higher-education-statistical-report-2015> [Accessed 13-05-2023]

Ewens, D. and Williams, J. (2011) *Enabling equality: furthering disability equality for staff in higher education: literature review*. Equality Challenge Unit and Leadership Foundation for Higher Education. London: Equality Challenge Unit.

Farahar, C. and Foster, A. (2021) #AutisticsInAcademia. In: Brown, N. (Ed.) *Lived Experiences of Ableism in Academia: Strategies for Higher Education*. Bristol: Policy Press, pp.197-216.

Finesilver, C., Leigh, J. and Brown, N. (2020) Invisible disability, unacknowledged diversity (2020). In: Brown, N. and Leigh, J. (Eds) *Ableism in Academia. Theorising experiences of disabilities and chronic illnesses in higher education*. London: UCL Press, pp.143-160.

Gartsu, G.N. and Stefani, M. (2019) *TAPPING INTO PEOPLE WITH AUTISM SPECTRUM DISORDER: "Moving Towards an Inclusive and Neurodiverse Workspace"*. Unpublished MA thesis. Available from: <http://kth.diva-portal.org/smash/get/diva2:1328726/FULLTEXT01.pdf> [Accessed 11-05-23].

Goldstein Hode, M. (2012) *The Tyranny of Neuronormativity: Neurotypical Privilege in Communication*. University of Missouri-Columbia post-doctoral paper. Available from: [https://www.academia.edu/1539557/The Tyranny of Neuronormativity Questioning Neurotypical Privilege in Communication](https://www.academia.edu/1539557/The_Tyranny_of_Neuronormativity_Questioning_Neurotypical_Privilege_in_Communication) [Accessed 11-05-23].

- Goodley, D. (2014) *Dis/ability Studies: Theorising Disablism and Ableism*. Oxford: Routledge.
- Griffiths, E. (2020) 'But you don't look disabled': Non-visible disabilities, disclosure and being an 'insider' in disability research and 'other' in the disability movement and academia. In: Brown, N. and Leigh, J. (Eds) *Ableism in Academia. Theorising experiences of disabilities and chronic illnesses in higher education*. London: UCL Press, pp.124-142.
- Guibourg, C. (2019) Big university gender pay gap revealed. *BBC News: Business*. Available from: <https://www.bbc.co.uk/news/business-47723950> [accessed 11-05-2023].
- Harmuth, E., Silletta, E., Bailey, A., Adams, T., Beck, C. and Barbic, S.P. (2018) Barriers and facilitators to employment for adults with autism: A scoping review. *Annals of International Occupational Therapy*, 1(1), pp.31-40.
- Hiscock, J. and Leigh, J. (2021) Teaching with and supporting teachers with dyslexia in higher education. In: Brown, N. (Ed.) *Lived Experiences of Ableism in Academia: Strategies for Higher Education*. Bristol: Policy Press, pp.249-264.
- Home Office (2011) *Impact Assessment To The Equality Act 2010 (Specific Duties) Regulations 2011*. Available from: <https://www.legislation.gov.uk/ukxi/2011/2260/impacts> [Accessed 28-05-2023]
- Hoque, K., Bacon, N. and Parr, D. (2014) Employer disability practice in Britain: assessing the impact of the Positive About Disabled People 'Two Ticks' symbol. *Work, employment and society*, 28(3), pp.430-451.
- Hoque, K. and Bacon, N. (2022) Working from home and disabled people's employment outcomes. *British Journal of Industrial Relations*, 60(1), pp.32-56.
- Jorgenson, L., Singleton, K. and Bennett, J. (2013) Universal Design for Learning in Higher Education. In *Innovations in Teaching & Learning Conference Proceedings* (Vol. 5). DOI: <https://doi.org/10.13021/G84W3Z>



- Kezar, A.J. and Holcombe, E.M. (2017) *Shared leadership in higher education*. Washington, DC: American Council on Education.
- Kruse, D., Park, S.R., van der Meulen Rodgers, Y. and Schur, L. (2022) Disability and remote work during the pandemic with implications for cancer survivors. *Journal of Cancer Survivorship*, 16(1), pp.183-199.
- Lawson, W. B. (2015) *Older Adults and Autism Spectrum Conditions: An Introduction and Guide*. London: Jessica Kingsley Publishers.
- Lawson, W. B. (2017) Issues of Gender & Sexuality in Special Needs Children: Keeping Students with Autism & Learning Disability Safe at School. *Journal of Intellectual Disability-Diagnosis and Treatment*, 5(3), pp.85-89.
- Lawson, W.B. and Lawson, B.M. (2017) *Transitioning Together: One Couple's Journey of Gender and Identity Discovery*. London: Jessica Kingsley Publishers.
- Lee, C. (2021) Promoting diversity in university leadership: the argument for LGBTQ+ specific leadership programmes in higher education. *Perspectives: Policy and Practice in Higher Education*.25(3), pp.91-99. DOI: <https://doi.org/10.1080/13603108.2021.1877205>
- Lewis, C. (2021) Invisible disabilities and (re)negotiating identity: life after major traumatic injury. In: Brown, N. (Ed.) *Lived Experiences of Ableism in Academia: Strategies for Higher Education*. Bristol: Policy Press, pp.301-314.
- Lindsay, S. and Thiyagarajah, K. (2022). A scoping review of the benefits and challenges of using service dogs for finding and maintaining employment. *Journal of Occupational Rehabilitation*, 32(1), pp.27-43.
- Logan, J. and Martin, N. (2012) Unusual talent: A study of successful leadership and delegation in entrepreneurs who have dyslexia. *Inclusive Practice*, 4, pp.57-76.
- Loja, E., Costa, M.E., Hughes, B. and Menezes, I. (2013) Disability, embodiment and ableism: stories of resistance. *Disability & Society* 28(2), pp.190-203.

- Loomes, G. (2017) Autistic Terror: On “Impact”, and its Academic and Everyday Socio-Political Implications for Researched Communities. *Participatory Autism Research Collective (PARC)*, July 17. Available from: <https://participatoryautismresearch.wordpress.com/2017/07/17/autistic-terror-on-impact-and-its-academic-and-everyday-socio-political-implications-for-researched-communities/> [accessed 23-05-23].
- Löve, L., Traustadóttir, R. and Rice, J. (2018) Achieving disability equality: empowering disabled people to take the lead. *Social Inclusion* 6(1), pp.1-8.
- Maddison, J., Brooks, J., Graham, K. and Birks, Y. (2022). ‘They Exist but They Don’t Exist’: Personal Assistants Supporting Physically Disabled People in the Workplace. *Work, Employment and Society*, p.09500170221075532.
- Martel, A., Day, K., Jackson, M.A. and Kaushik, S., 2021. Beyond the pandemic: the role of the built environment in supporting people with disabilities work life. *Archnet-IJAR: International Journal of Architectural Research*. 15(1), pp.98-112. <https://doi.org/10.1108/ARCH-10-2020-0225>
- Martin, N. (2017) *Encouraging disabled leaders in higher education: recognising hidden talents*. Stimulus paper. Leadership Foundation for Higher Education. Available from: <https://www.advance-he.ac.uk/knowledge-hub/encouraging-disabled-leaders-higher-education-recognising-hidden-talents> [Accessed 11-05-2023]
- Martin, N. Beardon, L., Hedge, N., Goodley, D. & Madriaga, M. (2008) Towards an inclusive environment for university students who have Asperger syndrome (AS). *Journal of Inclusive Practice in Further and Higher Education*. Issue 1.1. pp.3-14.
- Martin, N. (2020) A practical response to ableism in leadership in UK higher education in Brown, N. and Leigh, J. (Eds) (2020) *Ableism in Academia. Theorising experiences of disabilities and chronic illnesses in higher education*. London: UCL Press pp76-103.
- Martin, N. (2021) Perspectives on UK university employment from autistic researchers and lecturers. *Disability & Society*, 36(9), pp. 1510-1531 . <https://doi.org/10.1080/09687599.2020.1802579> [accessed 27/06/23]

- Martin, N., Wray, M., James, A., Draffan, E.A., Krupa, J. and Turner, P. (2019) *Implementing Inclusive Teaching and Learning in UK Higher Education – Utilising Universal Design for Learning (UDL) as a Route to Excellence*. Project report: Society for Research into Higher Education
- Milton, D. (2017) Employment: a reflective review. In: Milton, D. and Martin, N. (Eds.) *Autism and Intellectual Disabilities in Adults, Volume 2*. Hove: Pavilion, pp.59-62.
- Milton, D. and Sims, T. (2016) How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability and Society*, 31(4) pp.520-534.
- 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*. Hove: Pavilion, pp.81-86.
- 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), pp.25-33.
- Milton, D.E.M., 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*, 24(2), pp.82-89.
- Morley, L. (2013) *Women and Higher Education Leadership*. Stimulus paper. Leadership Foundation for Higher Education.
- Mounsey, C. and Booth, S. (2021) Three cheers for Access to Work partnership: two cheers for Two Ticks and one question about a university-wide self-disclosure scheme. In: Brown, N. (Ed.) *Lived Experiences of Ableism in Academia: Strategies for Higher Education*. Bristol: Policy Press, pp.171-184.
- Nash, K. (2009) Disabled Employee Networks: a practical guide. Available from: [https://blogs.kent.ac.uk/visible/files/2018/10/Disabled\\_employee\\_networks\\_a\\_practical\\_guide\\_2009\\_by\\_Kate\\_Nash.pdf](https://blogs.kent.ac.uk/visible/files/2018/10/Disabled_employee_networks_a_practical_guide_2009_by_Kate_Nash.pdf) [accessed 27/06/23]
- Nash, K. (2014) *Secrets & Big News. Enabling People to be Themselves at Work*. Codsall: Kate Nash Associates.

- Oliver, M. (2009) *Understanding Disability, from Theory to Practice* (2nd Ed.) Basingstoke: Palgrave Macmillan.
- Olsen, J., 2022. Employers: influencing disabled people's employment through responses to reasonable adjustments. *Disability & Society*, pp.1-20.
- Powell, A. (2021) *Disabled people in employment*. House of Commons Library Briefing Paper no 7540. Available from: <https://commonslibrary.parliament.uk/research-briefings/cbp-7540/>[accessed 04-05-2023]
- Purple Space (2021) *Building disability confidence from the inside out*. Available from: [www.purplespace.org](http://www.purplespace.org) [accessed 04-05-2023]
- RADAR (2010) *Doing Seniority Differently. A study of high fliers living with ill health injury or disability*. Available at: <https://www.disabilityrightsuk.org/sites/default/files/pdf/doingseioritydifferently.pdf> [accessed 11-05-23]
- Rathnayake, N.M., Kumarasinghe, P.J. and Kumara, A.S. (2022) How Do Different Types of University Academics Perceive Work from Home Amidst COVID-19 and Beyond? *Sustainability*, 14(9), p.4868.
- Research Excellence Framework. Available from <https://www.ref.ac.uk/> [accessed 11-05-2023]
- Ridout, S. (2017) The autistic voice and creative methodologies. *Qualitative Research Journal*, 17(1), pp.52-64.
- Ridout, S. and Edmondson, M. (2017) "Cygnnet 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 11-05-2023].
- Robson, L., Patel, M. and Nicholson, J. (2016) National Association of Disabled Staff Networks (NADSN) – "Our Stories: Experiences from our Disabled Staff Networks

Commented [SSJ1]: Date

across the UK". *The Journal of Inclusive Practice in Further and Higher Education* (7) pp.28–33.

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) pp.16-29.

Sayce, L. (2011) *Getting in, staying in and getting on. Disability employment support fit for the future*. London: Department for Work and Pensions.

Sayce, E. (2015) *Access to Work review*. Available at: <https://publications.parliament.uk/pa/cm201516/cmselect/cmworpen/386/38605.htm> [accessed 13-05-2023].

Shakespeare, T. (2013) *Disability rights and wrongs revisited*. Oxford: Routledge.

Shaw, W.S., Main, C.J., Findley, P.A., Collie, A., Kristman, V.L. and Gross, D.P. (2020) Opening the workplace after COVID-19: what lessons can be learned from return-to-work research? *Journal of Occupational Rehabilitation*, 30, pp.299-302.

United Nations (2006) Convention on the Rights of Persons with Disabilities. Available from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> [Accessed 11-05-2023]

United Nations, (2022) *Committee on the Rights of Persons with Disabilities CRPD/C/GC/8: General comment No. 8 (2022) on the right of persons with disabilities to work and employment*. Available at: <https://www.ohchr.org/en/documents/general-comments-and-recommendations/crpdgc8-general-comment-no-8-2022-right-persons> [accessed 11-05-2023]

Vejdemo-Johansson, M. and Gent, I.P. (2021) Depressed academics: building a group blog community. In: Brown, N. (Ed.) *Lived Experiences of Ableism in Academia: Strategies for Higher Education*. Bristol: Policy Press, pp.265-282.

Wong, J., Ezeife, N., Kudla, A., Crown, D., Trierweiler, R., Capraro, P., Tomazin, S., Su, H., Pham, T. and Heinemann, A.W. (2022) Employment Consequences of

COVID-19 for People with Disabilities and Employers. *Journal of Occupational Rehabilitation*, 32, pp.464–472. <https://doi.org/10.1007/s10926-021-10012-9>

Woods, R., Milton, D., Arnold, L. and Graby, S. (2018) Redefining critical autism studies: A more inclusive interpretation. *Disability & Society*, 33(6), pp.974-979.

## **The post-doctoral black hole. The importance of *Transitioning Out* support for autistic students.**

**Barbara Sandland**

Barbara Sandland, University of Birmingham

### **Abstract**

This paper presents an autoethnography, of my experiences, as an autistic PhD graduate seeking employment. Finding myself, in what I term, the 'post-PhD black hole' I explore the personal implications, as a result of my autism, of finishing my time at university alongside the lack of autism specific support to enable me to progress into employment. The information that is shared is aimed at directly addressing the reported gap, (Nicholas et al, 2019) of a lack of 'autistic voice' in research relating to autism and employment. By relating my experiences to empirical research, I present an argument of a need for significantly more consideration to be given to the support available to autistic students transitioning out of an educational institution, either to further their academic career or into employment. A '*Transitioning Out*' diagram is presented to highlight the key features organisations should be addressing to ensure effective support for autistic individuals. The role of mentoring is reflected upon as a facilitator of a *transitioning out* support programme and as such it is suggested as an important future avenue of research to explore its impact.

### **Key Words**

Autism, employment, education, university,

### **Introduction**

Within this autoethnography, I explore my first-hand experiences of being autistic, negotiating the uncertain period once I completed my PhD and how this has impacted on my ability to seek and indeed find employment. Although research focusing on autistic employment, post university, is still relatively sparse, where it does exist, a focus is often given to improvements needed in the process of employment by employers, such as during interviews. While these are recognised as important, the following article focuses on the experience of being an autistic student and how these experiences impact on the process transitioning from higher education into employment. Directly addressing the reported gap, by Nicholas et al (2019) that there is a lack of 'autistic voice' in research relating to autism and employment. Through the sharing of my experiences, I argue that more focus is needed on supporting autistic students in the transition out of university and into employment. Furthermore, that the use of mentoring, during this period of transition,

for autistic students, requires further research to consider the possible positive impact it can have on the autistic student's career and personal wellbeing.

## Autism in Academia

The number of autistic students in Universities across the United Kingdom is reported to be increasing (Vinecni & Fabri, 2020; Gurbuz et al., 2019). Specifically, the number of postgraduate research (PGR) students within the UK who disclosed autism, has increased from 220 in 2016 to 525 in 2020 (HESA, 2022), more than doubling therefore, in the last four years. This is despite PGR student numbers generally, dropping by over 1,000 in the same period, for those students not disclosing a disability. Despite such a growth, autistic individuals have disappointing employment outcomes (Vincent 2020; Remington & Pellicano 2019; Nicholas et al. 2017; Bublitz et al. 2017) Allen and Coney (2018) report that only 33% of autistic graduates are in full-time employment, in comparison to 71% of their non-disabled peers.

The European Union's Bologna Process Report (2018) identified that universities have a duty to enhance a students' employability through effective career guidance. Furthermore, that students with 'disabilities' such as autism, should be provided with assistance in finding and obtaining employment (United Nations, 2006). Despite this, research suggests that a 'one size fits all' approach to careers advice often results in disabled students being disadvantaged (Williams, 2007; Allen and Coney, 2018).

## Methods

A biopsychosocial approach is taken when considering my autism and personal experiences. As such it is acknowledged that there is a biological factor to my autism, however equal importance is placed on the way I process the world (psychological factors) and how my experiences are impacted by the environment around me (social factors). Guldberg (2020) reinforces this approach by arguing that it should be viewed as a biopsychosocial-insider model in autism studies:

*“emphasises the need to understand the interrelationship between the biological, psychological and social whilst ensuring that individuals and subjective experiences are also taken into account when developing understandings of autism and autistic people”. (Guldberg, 2020, p16)*

I recognise, and indeed endorse, that autism impacts everyone differently. The experiences presented here therefore, may be comparable to some autistic student's experiences while not to others. To ensure relevance and transferability of my experiences, I will seek to draw the key concepts out and contextualise them with wider literature on the topic of autism and employment.



## Qualifications alone don't get you a job

The PhD is often viewed as the pinnacle of intellectual achievement (Bogle et al, 2011), I know I did. The ultimate achievement, that changes your title to Doctor and demonstrates to the world that you have reached a level many others have not. The trouble with viewing the PhD in this way, especially with my logical autistic brain, was that I thought, that by completing the PhD I would be opening a metaphorical magical doorway to employment and success. And quite simply, I did not. I don't want to play-down the achievements of completing a doctorate, it's hard work and something I was proud to say I had done. But when it comes to employment, having the Dr title doesn't change the process, where we all must seek out jobs and prove we are good enough to be given them.

Often when we frame employment as a difficulty, we think about following compulsory education, or maybe following an undergraduate degree. For these reasons, I often think people perceive me, now I have the all-important 'Dr' title as being intelligent enough to sort myself out! While I may be intelligent in some ways there are other ways that I am not. Dacre Pool and Sewell (2007) in their "CareerEDGE" model of employability, highlight the impact emotional intelligence has on employment success. While often emotional intelligence is assumed, especially with autism, to be a lack of awareness of one's own emotions and the emotions of others, it includes so much more. Goleman's four domains of emotional intelligence (1998), demonstrates that while self-awareness and social awareness are included within emotional intelligence, so is Self-Management which includes

*"being able to motivate oneself and persist in the face of frustration; to control impulse and delay gratification; to regulate one's mood and keep distress from swamping the ability to think; to empathize and hope"* (Goleman, 2020, p30).

The features outlined here relates to the difficulties I have experienced, despite my so-called high intelligence. My experiences will be explored more in the subsequent sections, however, at this stage It is important to acknowledge that academic qualifications do not mean the autistic individual does not need support. In my case, academia has been the 'safe' route throughout my life. Indeed, it could be argued that I never left school, having pursued a career in teaching for some time. Therefore, it is only now I have completed my PhD that the uncertainty of employment becomes an issue.

## The Post-Doctoral Black hole

As I have previously mentioned, I viewed the PhD as a magical doorway (enshrined in light) to employment. Which is why the realisation that this didn't exist is represented by a black hole. The blackness represents the lack of awareness of where I was going, how I was going to get there and the negative impact my experiences have had on my mental health, which I hope to make evident as I outline the key areas of difficulty I have experienced. Unemployment generally, has been reported to lead to adverse effects on mental health (Remington & Pellicano 2019; Howlin and Moss 2012). Through my experiences I seek to reinforce that consideration of this is even more important for autistic individuals, who are already more likely to experience mental health problems throughout their lives, than their non-autistic peers (Autistica, n.d.).

The black-hole analogy also refers to the feeling of not being unable to navigate a way out, with going back as the seemingly only option. Within the following article I seek to raise awareness of the key areas of difficulty I have experienced following completion of my PhD:

- Uncertainty
- Loss of role identity
- Loss of focus
- Social isolation
- Inaccessible support systems

Within each section I will also provide suggestions of how institutions can begin to support others in my position, I hope, even in a small way, to help other autistic graduates to navigate their way out the other side of any post education black-hole they may find themselves in.

## Uncertainty

In simplistic terms I hate uncertainty, up until now I hadn't given it much thought as to why, I just knew that uncertainty gives the world a feeling of vastness that is really unsettling and makes me feel more unable to find my place within it.

Through my research I have found the Predictive Processing Theory akin to my feelings at this time. The theory argues that what human beings are consciously aware of, at any given time, is a calculated hypothesis by the brain as being most likely when sensory inputs, past experiences, prior beliefs, and previous hypotheses are taken into consideration. (Palmer, Seth, and Howay, 2015). Due to the stochastic nature of the world, predictions may be wrong (prediction errors). Each time such hypotheses are wrong, the brain uses these prediction errors to recalculate. The lower the number of prediction errors over time, the more reliable the hypothesis may be perceived to be. Van De Cruys et al (2014) details the flexibility that is required of the brain to assess environmental irregularities and variabilities in each new situation, in determining whether a predictive error has occurred. They advocate that it is this process that an autistic person struggles with, overestimating the importance of such changes and in turn giving too much weight to prediction errors; the High Inflexible Precision of Prediction Errors in Autism (HIPPEA) model.

*"if errors are always deemed important, every new instance will be handled as an exception, different from previous experiences."* (Van De Cruys, 2014, p4).

According to HIPPEA therefore the autistic person struggles to generalise experiences when exact matches of stimuli do not occur. Due to the stochastic nature of the social world an exact match is deemed highly unlikely. Therefore, all experiences feel unpredictable and may result in anxiety provoked by a perception of uncertainty.

For this reason, I have always sought to create a life that is structured and seemingly predictable; timetables are my friend. The PhD life matched these needs well. The university establishes a baseline structure that all students must follow, for example the

PhD is to be completed within a set period of time and every month a meeting had to occur with my supervisors to record where I was at and what I planned to do next. On top of this I could then build my own structure, to complete on a daily level what I knew I would have to report back on at my next supervision meeting. A continual cycle of structure, with minimal prediction errors, that lasted for three years. And as soon as I passed the viva, this structure stopped. My world went from safe and secure to feeling like I was only one very small part of an unpredictable world. Not knowing where I fit within this, I started to feel like the world was going on around me and I was adrift. As such feelings continue over time, I would argue, there is a heightened awareness/perception of prediction errors. As I identified each new error, my self-confidence was eroded. I am acutely aware that I struggle with self-esteem, because of years of negative experiences without knowing I was autistic and how this was affecting my life. Therefore, holding onto negativities to reinforce these beliefs is an action that has unfortunately become well embedded within my consciousness. Low self-esteem and seeking employment are not good bed fellows. Interestingly though little research seems to have addressed the way low self-esteem, especially in autism, may impact someone in their search for employment, focusing more on the impact loss of employment has on an individual's sense of self-worth.

One area I wish to discuss more specifically within the realm of uncertainty is the academic specific structure of research funding. Following my PhD my aspirations were to continue in academia, progressing with research and maybe using my teaching qualifications again by lecturing within my field. It would seem that university lecturer jobs are a bit like gold dust, illusive to track down for most people. Research posts however can be found if funding can be 'won'. This was the approach I was directed towards, however there are key features of this system that are counter-intuitive for autistic students and may be preventing autistic people from gaining research posts as employment. Firstly, funding systems appear needlessly convoluted. By this I mean, what the funders are looking for in applications is not clear and often when an application has been unsuccessful, no feedback is given to explain why this is the case. While I understand this is likely to be as a result of high numbers of applicants, it makes the system, specifically for autistic individuals, very difficult to manage. Secondly, if funding is achieved it is only given for a set period of time, which means any research post is temporary. For anyone like me, that finds uncertainty a trigger for their mental health, a structure that only allows temporary employment is likely to be a big turn off. There will be some people that would contextualise this and predict that once funding is achieved for a research post it is more likely to be achieved in the future, or that this experience will open doors to other academic jobs, however for me, the probability of prediction error here is just too high. Both of these features of academic research funding means, I am negatively impacted in research employment because of my desire to avoid prediction errors.

## **Role identity**

I have always struggled with a personal identity, by this I mean creating an identity based on chosen categories that produce a sense of self. I personally relate this to the years of living without an understanding of my autism, therefore not having the appropriate language or similarities with others to facilitate identity verification (Burke and Stets, 2009). Watson (2002) argues that a person with an impairment often has a reduced

sense of self as they adapt their lives to try and match the expectations of 'normal'. This is suggested to be heightened for differences such as autism which are classified as 'invisible'. So, when I am asked that dreaded question "tell me about yourself", I have no idea what I am supposed to say, which doesn't go down well when this is the opening 'easy' question to a job interview.

To substitute my lack of personal identity, I rely on role identity. Role identity theory was developed to explain that the role an individual played was central to their identity (Burke, 1980, McCall and Simmons, 1978). A role in this perspective is a set of expectations tied to a social position, such as: student, teacher or male (Burke and Stets, 2009). Equally as important is how the individual internalises these expectations and interprets meaning to them. So, for me, my role as a PhD student became central to my identity, alongside being a mother and a wife. While this does not initially appear problematic, and indeed it wasn't for many years, significant issues occur when this role is taken away. The sudden removal of my student identity, without a new identity to take its place (via employment) meant that I found myself in an identity crisis. Mile (2022) outlines seven signs of an identity crisis;

1. low self-esteem,
2. questioning your value or worth,
3. feeling lost or aimless,
4. not feeling a sense of purpose,
5. difficult regulating emotions,
6. increased feelings of insecurity,
7. increased anxiety or depression.

I'm outlining these here as they succinctly sum up the impact, I felt of losing my role identity, without something to take its place. Once again, I draw attention to the impact such feelings would have on the individual's ability to proactively seek employment. And importantly how prolonged exposure to these feelings, reduced my capacity to engage in employment seeking activities independently. Put simply, if I do not feel I have something to offer, I am not going to believe that anyone else will think I have anything to offer.

## **Lack of focus**

A PhD researcher spends the majority of their time focusing on one topic. This is one of the reasons, I would suggest, that makes PhDs great for autistic students. I have heard so many times that the real benefit of the PhD is that for the first time you are not having to study subject matter just because other people say you should. Instead, you pick the subject matter, and you choose what you want to know about it. According to the theory of monotropism (Murray, Lesser and Lawson, 2005), a central feature of autism is hyper-focus, which is motivated internally by the interest of the autistic individual. Taking this approach, it is easy to see how a structure that not only allows, but actively encourages, sole focus on an area of interest would be so inviting to autistic students.

The flip side of this however, comes when that focus is taken away. After three years of solely focusing on one topic area, that you have total ownership over, there is a significant impact when this is gone. There is cross-over here, with the previously discussed element

of uncertainty. There is a comfort in knowing what you are researching and writing about, once this is taken away, I found it very challenging to fill that void. Primarily because, my research served a purpose, I was working within the structure of the PhD. While I could continue to research in my free time, this would serve no tangible purpose and therefore I lacked the motivation to undertake it. While the development of the popularity of monotropism explores hyper-focus and the impact of interruption on a task, little research appears to address the impact of the natural completion of a period of hyper-focus and the impact this may have on the individual's mental health if no new period of hyper-focus is undertaken. The successful autistic student is likely to be a successful academic researcher, as their skills of hyper-focusing can be used to their and the institutions advantage. However, if we do not support autistic people into such academic roles, we are likely to be missing out on a significant impact potential.

## **Social Isolation**

Devenish et al argue in their personal reflections of the PhD process, "that collaborative peer support has been one of the most valuable enablers to our process" (2009 p61). In direct contrast to this, research has suggested that autistic students experience isolation and loneliness at university. (Gurbuz et al., 2019). This may be due to inaccessible spaces, self-excluding behaviours, or even institutionalised ablism. (Madriaga, 2010). As such, autistic students may be disproportionately disadvantaged due to a lack of peer support leading to lower career ambitions and fewer helpful career contacts.

Social isolation was a part of my university journey. While I knew other students, and was even part of some 'chat groups', I did not feel confident to engage with these beyond superficial conversations surrounding which article people had read, or whether they were attending an event. This meant that I did not have a friendship circle to draw upon to discuss future plans, or to discover support services others had used. What I did reply on, and hugely value, was my monthly supervision meetings. My two supervisors were professionals I became to know well, I respected them as academics and valued them as personal connections in my life. What's more, the structured nature of the PhD and the requirement to meet with my supervisors on a monthly basis suited my autistic needs. Having a timetabled meeting meant I never had to take it upon myself to reach out, because we had a set time when I knew they would be there. I didn't have to think of what to say, because I knew we would be discussing my work. But crucially, because of the frequent nature of our meetings they began to know me on a personal level, and I developed a trust in them. Meetings would often start with them asking about my life, or how the kids were, which meant I never had to find a way to share I was struggling on a personal level, because this was facilitated. Research suggests that not all supervisors are as good as mine were, so I know I am lucky to have had the support I did. It is important to acknowledge though, that I do not think I would have been as successful as I was with my PhD, without their expert support.

The positive experiences of mentoring by my supervisors are important to reflect upon. Mentoring is often recommended to universities as an effective way to support autistic students, however there is little literature demonstrating what good mentoring should look like and for how long it should last. In line with my experiences, Lucas, and James (2018) argue that the relationship between the mentor and autistic mentee is crucial, and that the effectiveness of the partnership is dependent on a personalised approach to the student's

needs. The dyadic relationship of a mentor-mentee is reported to have a twofold function; first, a “career function”, helping the mentee to reach their academic potential and second, a “psychosocial function” (Huskins et al., 2011). Regarding the first function, despite the suggested recognition of support into employment, research in this area has focused on the suggestion that academic performance has significantly been improved through mentoring (Asgari & Carter, 2016). Psychosocially, peer mentoring has been shown to improve students’ wellbeing making them feel more integrated within the university community. (Collings et al., 2014; NADP mentoring CPD, 2023).

The limited literature on mentoring, highlights that universities use mentoring to focus on university attainment and wellbeing while at university (Huskins et al., 2011). Therefore, once the student has completed the examination for their level of study, mentoring stops. The trouble with any positive support mechanism is the void it leaves when it is gone, and this is a significant issue when completing a PhD. The support structure that suited my needs so well, disappeared. The void this left was amplified by the lack of peer connections I had because of my autism. At a crucial stage in my academic life, when I had to navigate the untaught skills of seeking employment, I was left alone and unsupported. My experiences are reinforced in the work of Lucas, Cage & James (2022) who reported that participants in their study did not feel well supported in the transition to employment from university. It would seem that while support for students transitioning into university is now generally underpinned by evidence-based research (Elias & White, 2018; Van Hees et al, 2015; Beresford, 2014), there is a significant lack of research into support systems for autistic students transitioning out of university. (Vincent et al, 2020; Bublitz et al, 2017). This is despite the potential for more uncertainty post university, meaning the need for support may be greater.

A lack of peer support, alongside a void caused by the end of successful mentoring provision can amplify the difficulties the autistic person experiences in seeking employment. By replicating the positive structure of the PhD supervision meetings, through a mentoring programme and extending it to provide support in managing transitions out of university, we may positively impact on levels of attainment and successful employment for autistic academics.

## **Visibility of University support systems**

In the blackness of the post-doctoral black hole, the ability to ‘see’ support systems is impaired. It is important to acknowledge therefore that support may be available to students seeking employment, and indeed they may have been available to me. But once the implications of uncertainty, impaired identity, removed focus and isolation occur, it is difficult to independently find and use them. I reflect and reinforce, once again, the importance of self-management skills in any employment model (Goleman, 2020). Not only did the mental health implications impact my ability to self-manage, but it also negatively impacted on my ability to reach out and seek support from others. Indeed Gurbuz, Hanley and Riby (2019) reported that many of their participants felt it was very difficult to ask for help. Advocating that this is an important factor to be taken into consideration when developing a support structure based on the ablest notion that everyone can self-advocate.

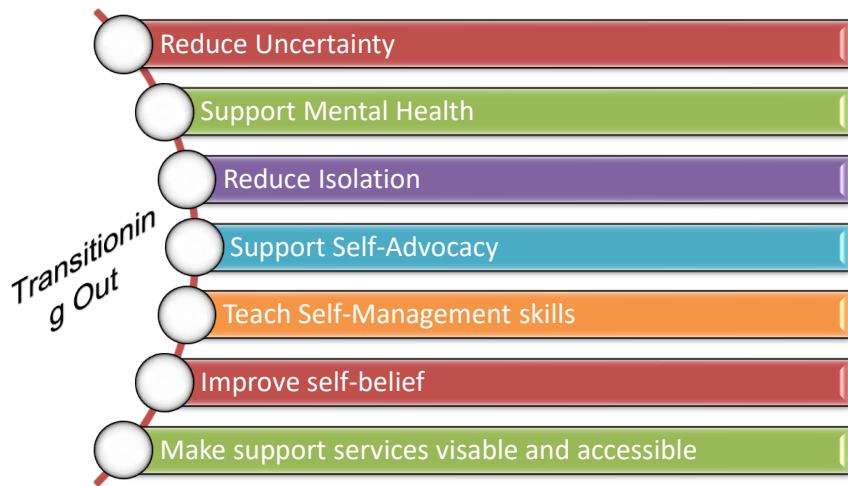
In reference to the discussion above regarding mentoring, it is suggested that where support systems are in place, the mentor may provide a metaphorical 'light' to breakdown the darkness the autistic person may experience. By providing a mentoring structure that incorporates a focus on transitions out of university, the mentor can help the autistic student see where the support systems are available and support them in accessing them. This maybe as simple as making initial contact with career services or attending meetings with the student and making notes.

With a specific focus on autistic students pursuing a career in academia, universities need to recognise that the successful autistic student is likely to possess a range of skills and abilities that make them desirable as future employees, such as passion for their subject, attention to detail, honesty, loyalty, willingness to work longer hours and punctuality (Lorenz et al., 2014; Scott et al., 2017). As such universities should develop support systems that seek to promote active recruitment of autistic students into academic roles. This would not only provide the university with an effective workforce, but would also develop positive role models, and possible mentors, for future autistic students.

### **Concepts that bridge all educational settings**

While the focus of my reflections has been on post-doctoral transitions into employment, consideration can be given as to the transferability of the concepts discussed into all educational settings. Indeed, having achieved doctoral level education I have experiences to draw upon at all other stages of education alongside my years as a special needs co-ordinator in mainstream secondary schools, that can enable me to position my knowledge on a wider scale. The current system of education focuses on what can be done while the autistic person is in their care, to get them to achieve an academic qualification. Support is given when the person transitions into the establishment, but little thought is given to when they leave. Indeed, there is a sense that it is no longer the institutes 'problem', but where does that leave the autistic individual? Their needs don't just stop because they are leaving. Equally, educational establishments are focused on enabling students to achieve academic levels, as I have alluded to, these do not equate to successful employment. And furthermore, that assuming they will, can unintentionally set a person up to fail in the long term. There is an urgent need for educational settings to consider how they are supporting the autistic student to learn self-management skills and transferable skills required for employment.

To reinforce this argument, the *Transitioning Out* diagram is present here to highlight areas that, the reflections outlined here suggest, educational establishment should be aware of and planning for when an autistic student is moving onto the next stage of their career, whether it's onto another stage of education or into the workplace. It has previously been highlighted that there is a significant lack of evidence-based practice and research into provision for students transitioning out of a setting, the use of the diagram presented here would provide an ideal opportunity for future research into current provision and target areas for improvement.



Future research would be beneficial to explore the comprehensiveness of the diagram as presented, alongside exploration of evidence-based practices for support. Initial evidence suggests mentoring is an effective system of support for autistic students and therefore the use of mentoring in delivering a *Transitioning Out* programme of support would also benefit from further research.

## Conclusions

Within this ethnographical account, the first-hand experiences of an autistic individual seeking employment post university has facilitated the exploration of factors that when left unsupported may impede the process of seeking employment. While much research focuses on the role of the next institution, either educational or employment, to provide supportive structures for the incoming autistic person, it is the findings of this case study that more focus needs to be given to the role of the current institution in developing and providing support to enable the autistic person to make the next step of their journey. If education is like a relay, and employment the finishing line, we need to make sure that at every stage the baton of support is passed on effectively, to enable the autistic person to achieve to their potential.

## References

Allen, M., and K. Coney. 2018. "What Happens Next? A Report on the First Destinations of 2016 Disabled Graduates." Accessed 5<sup>th</sup> September 2022. [https://www.agcas.org.uk/write/MediaUploads/WHN\\_2018\\_final\\_version\\_20\\_August\\_2018.pdf](https://www.agcas.org.uk/write/MediaUploads/WHN_2018_final_version_20_August_2018.pdf)



- Asgari, S. and Carter Jr, F., 2016. Peer mentors can improve academic performance: A quasi-experimental study of peer mentorship in introductory courses. *Teaching of Psychology*, 43(2), pp.131-135.
- Autistica, n.d. *Autism and mental health A guide to looking after your min.*
- Beresford, B. A., Moran, N. E., Sloper, T., Cusworth, L. S., Mitchell, W. A., Spiers, G. F., et al. (2013). *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions*. SPRU Working Paper, Vol. DH 2525. New York, NY: Social Policy Research Unit
- Bogle, D., D. Michel, J. Eggermont, and J. Willem van Henten. 2011. "Doctoral Degrees Beyond 2010: Training Talented Researchers for Society." *Procedia - Social and Behavioral Sciences* 13: 35–49.
- Bologna Policy Forum. 2018. "Statement of the Fifth Bologna Policy Forum." Paris, May 25.
- Bublitz, D. J., Fitzgerald, K., Alarcon, M., D'Onofrio, J. and Gillespie-Lynch, K. (2017). Verbal Behaviors during Employment Interviews of College Students with and without ASD. *Journal of Vocational Rehabilitation*. 47(1), 79-92.
- Burke, P.J., (1980). "The self: Measurement implications from a symbolic interactionist perspective." *Social Psychology Quarterly* 43. 18–29.
- Burke, P.J., and Stets, J. E., (2009). *Identity Theory*. Oxford: Oxford University Press.
- Collings, R., Swanson, V. and Watkins, R., 2014. The impact of peer mentoring on levels of student wellbeing, integration, and retention: a controlled comparative evaluation of residential students in UK higher education. *Higher Education*, 68(6), pp.927-942.
- Dacre Pool, L. and Sewell, P., (2007). The key to employability: developing a practical model of graduate employability. *Education + Training*, 49(4), pp.277-289.
- Devenish, R., Dyer, S., Jefferson, T., Lord, L., van Leeuwen, S., & Fazakerley, V. (2009) Peer to peer support: the disappearing work in the doctoral student experience, *Higher Education Research & Development*, 28:1, 59-70, DOI: [10.1080/07294360802444362](https://doi.org/10.1080/07294360802444362)
- Elias, R., and White, S. W. (2018). Autism goes to college: understanding the needs of a student population on the rise. *J. Autism Dev. Disord.* 48, 732–746.
- Goleman, D. (1998), *Working with Emotional Intelligence*, Bloomsbury, London
- Goleman, D., (2020). *Emotional intelligence*. Bloomsbury Publishing.
- Guldborg, K. (2020). *Developing Excellence in Autism Practice*. London: Routledge.
- Gurbuz, E., Hanley, M., and Riby, D. (2019). University Students with Autism: The Social and Academic Experiences of University in the UK, *Journal of Autism and Developmental Disorders*, 49, 617 – 631.
- HESA (2022) Higher Education Statistics Agency. *HE Student Data: Who's studying in HE?* <https://www.hesa.ac.uk/data-and-analysis/students/whos-in-he#characteristics> [Accessed 25<sup>th</sup> July 2022]

- Howlin P, & Moss P. (2012). Adults with autism spectrum disorders. *Canadian Journal of Psychiatry Revue Canadienne de Psychiatrie*, 57(5):275–83.
- Huskins, W.C., Silet, K., Weber-Main, A.M., Begg, M.D., Fowler, Jr, V.G., Hamilton, J. and Fleming, M., (2011). Identifying and aligning expectations in a mentoring relationship. *Clinical and translational science*, 4(6), pp.439-447.
- Lorenz, T., Frischling, C., Cuadros, R. and Heinitz, K., 2016. Autism and overcoming job barriers: Comparing job-related barriers and possible solutions in and outside of autism-specific employment. *PLoS one*, 11(1), p.e0147040.
- Lucas, R., and James, A. I. (2018). An evaluation of specialist mentoring for university students with autism spectrum disorders and mental health conditions. *J. Autism Dev. Disord.* 48, 694–707. doi: 10.1007/s10803-017-3 303-1
- Lucas, R., Cage, E. and James, A. I. (2022) Supporting effective transitions from university to post-graduation for autistic students. *Frontiers in Psychology*, 12. 768429.
- Madriaga M. 'I avoid pubs and the student union like the plague': Students with Asperger Syndrome and their negotiation of university spaces. *Children's Geographies*. 2010;8(1):39–50.
- McCall, G. J., and Simmons, J. L., (1978). *Identities and interactions*. New York: Free Press.
- Miles, M., 2022. Are you going through an identity crisis? 5 ways to cope. [Blog] *BetterUp*, Available at: <<https://www.betterup.com/blog/identity-crisis>> [Accessed 20 August 2022].
- Murray, D., Lesser, M. and Lawson, W., 2005. Attention, monotropism and the diagnostic criteria for autism. *Autism*, 9(2), pp.139-156.
- NADP (2023). Working Effectively with autistic university students online. Available at: <https://nadp-uk.org/conferences/working-effectively-with-autistic-university-students/> [Accessed 20<sup>th</sup> May 2023]
- Nicholas, D. B., Hodgetts, S., Zwaigenbaum, L., Smith, L.E., Shattuck, P. Parr, J.R., Conlon, O., Germani, T., Mitchell, W., Sacrey, L. and Stothers, M.E. (2017). Research Needs and Priorities for Transition and Employment in Autism: Considerations Reflected in a 'Special Interest Group' at the International Meeting for Autism Research. *Autism Research*, 10, 15–24.
- Nicholas, D. B., Orjasaeter, J. D., & Zwaigenbaum, L. (2019). Considering methodological accommodation to the diversity of ASD: A realist synthesis review of data collection methods for examining first-person experiences. *Review Journal of Autism and Developmental Disorders*, 6, 216–232.
- Palmer, C.J., Seth, A.K. and Hohwy, J., 2015. The felt presence of other minds: Predictive processing, counterfactual predictions, and mentalising in autism. *Consciousness and Cognition*, 36, pp.376-389.
- Remington, A. and Pellicano, E. (2019). Sometimes you just need someone to take a chance on you: An internship programme for autistic graduates at Deutsche Bank, UK. *Journal of Management and Organization*, 25, 516–534.

- Scott, M., Jacob, A., Hendrie, D., Parsons, R., Girdler, S., Falkmer, T. and Falkmer, M., 2017. Employers' perception of the costs and the benefits of hiring individuals with autism spectrum disorder in open employment in Australia. *PLoS one*, 12(5), p.e0177607.
- United Nations (2006) Convention on the rights of persons with disabilities (CRPD). Article 24; Education. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-24-education.html> [Accessed 5th September 2022]
- Van de Cruys, S., Evers, K., Van der Hallen, R., Van Eylen, L., Boets, B., De-Wit, L. and Wagemans, J., 2014. Precise minds in uncertain worlds: predictive coding in autism. *Psychological review*, 121(4), p.649.
- Van Hees, V., Moyson, T., and Roeyers, H. (2015). Higher education experiences of students with Autism Spectrum Disorder: Challenges, benefits and support needs. *J. Autism Dev. Disord.* 45, 1673–1688. doi: 10.1007/s10803-014-2324-2
- Vincent, J. (2020). Employability for UK University Students and Graduates on the Autism Spectrum: Mobilities and Materialities. *Scandinavian Journal of Disability Research*, 22 (1), 12-24.
- Vincent, J. and Fabri, M. (2020). The Ecosystem of Competitive Employment for University Graduates with Autism. *International Journal of Disability, Development and Education*. Available at: <https://www.tandfonline.com/doi/pdf/10.1080/1034912X.2020.1821874?needAccess=true> [accessed 05/09/2022]
- Watson, N., (2002). Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person; identity and disability. *Disability & Society*. 17:5. 509-527.
- Williams, J. (2007). 'Disadvantage in higher education: A view from the institutional careers service,' *Tertiary Education and Management*, 13(4), pp. 349

## **A review of ‘Visual Thinking: The Hidden Gifts of People Who Think in Pictures, Patterns, and Abstractions’, Temple Grandin (Rider Books, 2022) Reviewed by Roddy Slorach**

Roddy Slorach, Imperial College London

Temple Grandin is an animal behaviourist and US livestock-handling consultant who also lectures and writes widely on autism. Having first defined herself as a visual thinker in her memoir *Thinking in Pictures* (1995), she expands on the concept in this detailed and hugely stimulating discussion.

The book’s central argument is that our education system and wider society (at least in the US), is systematically biased in favour of verbal thinkers “who are social, organised and think in linear sequences.” Visual thinkers, on the other hand, comprise two broad groups: object visualisers who think in pictures, and visual-spatial thinkers, who think in abstract patterns. Verbal thinking is slower than visual processing, but visual thinkers may be slow to learn speech and struggle with traditional teaching methods but can make rapid associations. Grandin stresses that these three types are not strict cognitive categories but exist on a continuum.

Research has shown that no two people have the same intelligence, even identical twins, but our society tests everyone in the same way. Despite numerous critiques of their use, IQ and standardised tests favouring mathematical and linguistic intelligence continue to stack the odds against those whose strengths lie elsewhere. Hands-on activities which develop and reward visual thinking such as woodwork have largely disappeared (along with field trips) from most school curriculums. Grandin argues that a narrow focus based on a standardised testing regime damages individuals as well as wider society. Exams may not predict professional success as well as is commonly believed: one study cited here showed that performance on a standardised high-school maths test had no correlation with performance on a complex real-world quantitative task.

The book provides memorable examples of collaboration between thinkers of different types. Rodgers and Hammerstein, the famous composers of Hollywood musicals, rarely met in person. Hammerstein wrote the lyrics first and sent them to Rodgers, who then composed the melodies. As Grandin puts it, “a verbal thinker and a spatial thinker made beautiful music together” (p.151). My favourite example concerns the makers of the spacesuits worn by the first Apollo astronauts. The design contract was won in 1965 by the International Latex Corporation, parent company of bra and girdle maker Playtex. With each suit comprising a reported “21 layers of gossamer-thin fabric”, the seamstresses found their work sometimes differed from the precise drawings of NASA technicians (p.144). Designers who come up with the concept for a product are often visual-object thinkers, while those who work out how to build it are more likely to be visual-spatial thinkers.

Grandin emphasises the complex interaction between genetic and environmental influences. She describes the cerebrum (the part of the brain that mostly controls speech) as like a road. “In my own case, a detailed MRI showed that I had narrower ‘streets’ for speaking, which would have been determined by genetic factors. But it was the environment (intensive speech therapy) that would determine whether I could learn to speak, the increased use slightly widening these narrow roads” (p.170).

This author of over 100 scientific journal articles and eight books was not diagnosed with autism until she was an adult, and only began to read at the age of eight: “my third-grade teacher and my mother developed a plan for my mother to teach me reading at home. I was highly motivated... because my mother read to my sister and me almost every day” (p.65).

Dyslexia “is associated with greater activity in the right frontal lobe, an area that is also the locus of spatial visualising”. Society’s linear view of intelligence can lead us to interpret the visual skill of film director Steven Spielberg as compensation for his dyslexia. As Grandin puts it, “We would never say of a great writer that his or her literary gift compensates for poor visual or mathematical skills” (p.175).

This enthusiastic advocacy of visual thinking leads to occasional overreach. Autistic people, Grandin argues, are more likely to “see” problems others are unaware of. However, it’s quite a stretch to claim that various disasters, from California wildfires and Deepwater Horizon to Chernobyl and Fukushima, could have been prevented if only a visually oriented person had been consulted. In similar vein, genius may well require divergent thinking as well as intelligence and creativity, but this doesn’t mean “most geniuses” are likely to be neurodiverse or “visual thinkers” (p.191).

Grandin stresses that autism exists on a spectrum but finds it “ridiculous that adults who cannot dress themselves have the same label as people with undiagnosed mild autism who work in Silicon Valley” (p.80). Later in the book, however, she argues (correctly in my view) that we should “eliminate the terms high- and low-functioning autism. I would prefer to call them verbal and nonverbal. There are some nonverbal individuals who have significant artistic, mathematical or musical abilities” (p.101).

The most intriguing part of the book for me is its discussion of emotional intelligence in both humans and animals. Grandin begins with a tantalising quote from Darwin’s *On the Origin of Species*: “It is a significant fact, that the more habits of any particular animal are studied by a naturalist, the more he attributes to reason, and the less to unlearned instinct” (p.242). Grandin cites recent research showing that, aside from verbal activity, cognitive processes in humans and animals are fundamentally alike. Both experience new environmental information via sensory images. Pigeons, for example, “use landmarks on the ground and compass headings to get home. Some birds can remember where they’ve hidden nuts. These are all great feats of sensory-based cognition that do not require verbal thinking” (p.255-6). The ‘emotional primes’ - seeking, rage, fear, lust, care, panic and play - are based in the brain system below the cortex. Emotions, as Grandin puts it, “underlie learned behavior and are genetically ingrained to drive inherited behavior systems” (p.263).<sup>1</sup>

Disability practitioners, not least those working in the field of neurodiversity, will find much food for thought in this accessible and thought-provoking book. As with other pioneers, Grandin occasionally pushes her claims beyond those proven by the research she cites. However, the many strengths of *Visual Thinking* – a compelling blend of personal experience, insightful analogies, historical examples and scientific studies - far outweigh these weaknesses.

Roddy Slorach [r.slorach@imperial.ac.uk](mailto:r.slorach@imperial.ac.uk) is Senior Disability Advisor at Imperial College London. He has written widely on disability issues (several of his longer articles are available at academia.edu). His book *A Very Capitalist Condition: a history and politics of disability* is currently only available as an e-book but is due to be reprinted later this year.

Editorial Board	Acting Editor: Current Edition
<p>Ms. Marissa Hill</p> <p>Professor Nicola Martin</p> <p>Ms. Sharron Sturgess</p> <p>Ms. Christina Healey</p> <p>Mr. Paddy Turner</p> <p>Ms. Lynn Wilson</p>	<p>Ms. Marissa Hill</p>

National Association of Disability Practitioners CIC

Telephone: 01273234793

Email: [admin@nadp-uk.org](mailto:admin@nadp-uk.org)

**Published by:**

National Association of Disability Practitioners CIC

ISSN: 2398-5976 (Online)

JIPFHE is an Open Access journal

June 2023

---

<sup>i</sup> Grandin's views on this issue are remarkably similar to those of neuroscientist Mark Solms, in his mind-blowing book "The Hidden Spring: A Journey to the Source of Consciousness" (Profile Books, 2021)