Journal of Inclusive Practice in Further and Higher Education

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Transition and Identity

Editorial

I am surprised and delighted by the themed edition of the Journal of Inclusive Practice in Further and Higher Education (JIPFHE) presented here which has been guest edited by our esteemed colleague Victoria Jackson, from Sheffield Hallam University, and partially funded by the LSE Annual Fund. Guest editing is extremely hard work and this publication has been at least twelve months in the making.

I am sure that readers will find the contents challenging and thought provoking as well as practically useful. Disability as a contested identity emerges strongly as a theme and the notion of disabled naming as a gateway to services is problematised as sitting uncomfortably within inclusive institutions. LSE have provided funding because the theme of this edition sits very comfortably with the LSE First Disability Identity Conference of 4th May 2011 and the journal will be made available to delegates of the conference. Some sample abstracts from the conference are included to provide a flavour of the event.

Readers are provided with the opportunity to explore an evidence base, informed by disabled people and allies, against which to examine assumptions and consider practice. A number of questions are sure to arise and further discussion will inevitably take place within and beyond NADP. My concern is always for students, or prospective students, who are not comfortable with disclosure, or do not have the formal medical model diagnosis so often necessary, and are therefore excluded from assistance. Mindful of the significance of diagnostic labels for individuals, NADP plans to launch a research project to explore issues of disabled naming and identity with students over the next twelve months.

Sincere thanks to Vicki, our hard working Guest Editor, to our rigorous Editorial Board and to all contributors.

Nicola Martin: London School of Economics.
Guest Editorial

The original call for papers for this edition of the journal asked for articles relating to transition. For some reason I assumed the articles would simply relate to practical projects and dialogue around organizing transition into HE and into employment. Whilst some articles do report projects of this type, others explore the wider context of transition, encompassing themes relating to personal identity and disability disclosure. As a result I’m very happy to say that we can offer you a stronger discourse and a vital one. Whilst many of us are trying hard to build a fully inclusive approach in Higher Education, equal access remains dependent upon students’ acceptance of the disability label. Without disclosing a disability, students cannot access funding from Disabled Student Allowances (in the UK) and of course find themselves outside the protection afforded by the equalities legislation.

It’s been a great pleasure to include the following articles:

Colin Cameron writes about the experience and meaning of impairment and disability. He takes the social model as a starting point, looks at how disabled people and professionals can be complicit in maintaining oppression and finally outlines the affirmative model of disability as a way of making sense of the experience of living with impairment in a disabling society.

Judith Garrett explores the concept of resilience, relating it to the experiences of individuals with dyslexia in education and in particular, those involved in the transition to HE.

Charlotte Morris reports on an action research project exploring student mental health and wellbeing in relation to learning and teaching interventions within one university.

Jonathan Harvey brings a valuable insider perspective, making recommendations for support in HE, drawing from his personal experience of attending university twice, once as a neuro-typical and once as a neuro-diverse individual.

Jack Tramell reports on a project focusing on the stigmatization of disabled students as they make the transition from secondary to post-secondary education in the USA.

Nicola Martin uses participatory research data from people who identify with the Asperger syndrome label to outline an alternative, inclusive model for the PhD viva.

In a collaborative paper, Rowena Atkinson Claire Gandy, Clare Graham, Sarah Hendrickx, Victoria Jackson, Dr Nicola Martin and Louise Rainford,
discuss aspects of social interaction experienced by individuals with the AS label and outline a small scale peer mentor project run within a UK university for students with the Asperger label.

Louise Loughlin and Sarah Smart, outline a regional project supporting the transition of disabled learners from Further to Higher Education. The project team has delivered a cornucopia of activities over the last two years, from an aspiration raising scheme to a whole calendar of information events for students, parents and practitioners.

Charlene Tait, Catriona Mowat, and Anna Cooper report on a small scale research project investigating the range of support applicants on the autism spectrum might expect when accessing Higher Education in Scotland and in particular, look at the efficacy of a summer transition programme at one university.

Victoria Jackson. Sheffield Hallam University.
# Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Title</th>
<th>Authors</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>The First LSE Disability Identity Conference. Sample Abstracts and Evaluation</td>
<td>Mat Fraser and Nicola Martin</td>
</tr>
<tr>
<td>10</td>
<td>Not Our Problem: Impairment as Difference, Disability as Role</td>
<td>Dr Colin Cameron</td>
</tr>
<tr>
<td>25</td>
<td>The Freshmen Mental Health Project (FMHP) and a Foucauldian Governmentality of the Mind.</td>
<td>Jack Trammell, Ph.D</td>
</tr>
<tr>
<td>37</td>
<td>Promoting Inclusive Practice for PhD Students Near Completion.</td>
<td>Nicola Martin</td>
</tr>
<tr>
<td>52</td>
<td>‘Universities and Colleges are Increasingly Aware of the Needs of Disabled Students’ (Direct.Gov 2010) Are They?... My Experience of Support Through University.</td>
<td>Jonathan Harvey</td>
</tr>
<tr>
<td>59</td>
<td>Open Minds: Enhancing Student Mental Wellbeing and Success through Inclusive Practices.</td>
<td>Charlotte Morris</td>
</tr>
<tr>
<td>77</td>
<td>Resilience, Transition and Disabled Students.</td>
<td>Judith Garrett</td>
</tr>
<tr>
<td>90</td>
<td>Ensuring a Smooth Transition into Higher Education - Establishing a Transition Project in South Yorkshire for Young Disabled Learners and Their Key Influencers.</td>
<td>Louise Loughlin and Sarah Smart</td>
</tr>
<tr>
<td>96</td>
<td>Models of Support for Transition and Retention of Students on the Autism Spectrum at Scottish Universities.</td>
<td>Charlene Tait, Catriona Mowat and Anna Cooper.</td>
</tr>
<tr>
<td>109</td>
<td>Aspects of Social interaction and Buddy Scheme - Supporting Transition and Progression for Students Identified with Asperger Syndrome.</td>
<td>Rowena Atkinson, Claire Gandy, Clare Graham, Sarah Hendrickx, Victoria Jackson, Nicola Martin and Louise Rainford.</td>
</tr>
</tbody>
</table>
The First LSE Disability Identity Conference

A one day conference and evening of entertainment, sponsored by the LSE Annual Fund, exploring the theme of disability identity.

The conference took place on 4th May 2011 at The London School of Economics and Political Science (LSE) and drew exclusively on the research and experiences of disabled people to explore the theme of disability identity and challenge stereotypes.

Disability is problematised far more than it is celebrated as an aspect of diversity. Individuality can be subsumed beneath stereotyping and an assumption of homogeneity by impairment label. Parents who have, or are expecting, a disabled child (or children) rarely have access to positive images.

Impairment and disability are not automatic bedfellows but socially constructed disabling barriers frequently create the biggest source of frustration and limitation encountered by disabled people. Media portrayals of disabled people often project stereotypes which are usually negative and sometimes in the ‘triumph over tragedy’ mode. Disabled people are increasingly challenging this image and describing themselves in positive and affirmative ways and the term ‘disability pride’ is gaining popularity. Disabled students in elite universities are by definition exceptionally high achievers.

The conference Contributors included members of the LSE community, and external speakers, all of whom are personally affected by disability. Well known comedians who are also disability activists provided entertainment in the evening. Mat Fraser (pictured), actor, writer, comedian and President of the National Association of Disability Practitioners, was Master of Ceremonies, and performed in the evening alongside Laurence Clark and Gareth Berlinner of ‘Abnormally Funny People’.
Sample Abstracts:

The Affirmative Model

Identifying disability as a productive as well as a restrictive relationship, the affirmative model is a tool which offers insight into the everyday processes through which people with impairments are turned into disabled people. Disability is not just about what people with impairments are prevented from doing and being, but about what they are required to do and be instead. Whether this involves taking on roles of passive dependency or triumph over tragedy, either way negates the lived experience of impairment and signifies the desirability of normality. While every self-affirming act performed by a disabled person that validates their own subject position as an impaired person involves an act of transgression, the affirmative model demands recognition of impairment as an ordinary rather than an extraordinary characteristic of human experience, and for inclusion within ordinary life on that basis.

Colin Cameron

The Holist Manifesto

The holist manifesto is based on principles of the social model of disability and neurodiversity. It is also underpinned by two realisations that were first articulated in the Bagatelle Model of specific learning differences (Cooper, 2010). The first is that all people with specific learning ‘difficulties’ have two things in common: a strong need to process information holistically for them to be meaningful and difficulties with working memory. The second realisation is that apparent ‘difficulties’ with working memory are a product of a strong need to process information holistically, since unlike sequential processing, holistic processing requires imagination rather than working memory. This then makes holistic learners vulnerable to the charge of appearing to have ‘difficulties’ with any process which requires working memory. (Sequential thinkers could be vulnerable to the charge of a lack of imagination, but sadly, schools are rarely concerned with this inability).

The school sector is dominated by the requirement to process information sequentially, depending on working memory and indeed rote learning creating significant barriers to holistic learners. This is largely because education serves the fundamental purpose of social reproduction. This requires a close control over what is learned, how it is learned, in what order, and how it is assessed. Consequently, holistic learners are unintentional casualties of this arbitrary imposition. We are systematically invalidated, bullied, humiliated, punished, medicated and imprisoned. Yet holistic thinkers (notwithstanding their apparent ‘difficulties’) are at the forefront of original thinking, problem solving and creative endeavours. The world needs us rather more than we need them. The political implications are that we need to challenge the imposition of sequential
thinking, teaching and assessment. There should be no tyranny of ‘experts’, no ‘remediation’ without representation. Holistic approaches and values should be supported in a context of the free association of ideas. Together we represent at least 20% of the population. We are entitled to be different and to learn and work differently for the benefit of all. This is not just about education, it is time for a political and social agenda of neuro-liberation.

Ross Cooper

The Chimera of Choice: Negotiating Disability Identity in the Era of Big Society

I begin this paper by critically examining and analysing the assessment and diagnosis process which involves the defining, categorising, labelling, and classifying of children with learning disabilities or special education needs. I consider the advantages and disadvantages of having a diagnosis and the implications of that in the current socio-economic and political context (i.e., the era of austerity, cuts and Big Society). The Big Society approach, which Prime Minister David Cameron identified as his political priority and ‘defining mission’, is driven by a discourse which privileges a devolution of power from central government to local communities, privatisation, collective action and the transfer of responsibility of providing social services from the state to non-state actors. In the area of education, this approach will lead to the greater expansion of academies and the introduction of ‘free’ schools in England. There are many questions about how these schools will be governed and whether they will be under the same duties as state-maintained schools. Building on my earlier discussion, I finish the paper by examining the possible consequences of increasing privatisation and localism in the area of education for children who are classified as having special education needs. In doing so, I problematise the discourses of ‘choice’, ‘individual and collective responsibility’, and ‘participation’ and ‘empowerment’ which underlie the Big Society approach. My discussion is informed by my personal experience of having a son who was recently diagnosed with Asperger’s Syndrome.

Armine Ishkanian

Representation and Identity

Representation of disabled people in popular media often relies on stereotyping and the discourse of triumph over tragedy. Disabled people are increasingly contesting the homogeneous and largely negative identity that these images impose and seeking to reflect the diversity and ordinariness of their varied lives. The presentation discusses the role of imagery in the social construction of disability. Representation of and by
disabled people in various contexts is considered. Majority world concerns are reflected.

Nicola Martin

**Dwarfism, Identity and Inclusion**

Limited awareness of the social model of disability by non disabled people can lead to stereotyping, a sense of homogeneity, and a lack of understanding of who is disabled and how disability is socially constructed. Stereotypical representations of dwarfs construct a misleading view of dwarfism. Confusion arises around whether and in what sort of ways dwarfs may experience disability. This can lead to problems around identity and social inclusion. Although people with dwarfism have a very visible impairment which attracts a lot of negative attention disabled and non-disabled people are often ambivalent about whether dwarfs are disabled. Using the social and post social models of disability and recent interviews with dwarfs I seek to demonstrate how an unaccommodating built environment and attitudinal barriers disable people who have dwarfism.

Erin Pritchard

**Poetry**

Allan Sutherland is one of the longest standing figures in disability arts. His live performances are legendary. They describe his own experiences of living with epilepsy in such poems as ‘Leaning on A Lamppost’ – a darkly humorous account of being a victim of hate crime while having a fit - and ‘What Happens to Old Epileptics’, which articulates fears about ageing and death for a disabled person. They combine them with such rousing calls to action as ‘Bite The Hand that Feeds You’.

This performance marries these old favourites with remarkable new material from Allan’s recent Leverhulme-funded residency at the Centre for Citizen Participation, Brunel University. These are transcription poems based on oral history interviews with disabled people. They reflect the experience of a range of people including a mental health service user, someone with stroke-related aphasia, a woman with learning disabilities and a hearing-aid user.

Allan Sutherland

**SEN Identities**

This paper investigates the role of habitus in students’ negotiations of ‘special needs’ identities within an ‘inclusive’ secondary school. Focussing on their lived experiences of relationships with peers and teachers, we examine the ‘conditions of possibility’ for hearing the voice of children attributed with ‘SEN’. Using a vignette-based method of fictional scenarios
allowed the students to consider disabling processes and relationships within the doxa of school culture and wider social expectations. The data discussed suggests that disabled young people continue to face considerable degrees of exclusion. Despite the overarching principles of inclusion guiding the management of this school, the students’ experiences speak of oppressive environments and processes founded upon rigid and exclusionary ideas of academic competency and capabilities. Examining gaps between their performances of identity and opinions on inclusion, questions about their perceptions of their future roles in education and society will be raised.

Alison Wilde and Vanita Sunderman

**Evaluation. Mat Fraser**

43 of the 53 delegates completed an evaluation. 37 rated the conference as excellent and 6 as good. Comments were overwhelmingly positive, and from my perspective, The Disability Identity (Pride) conference at the LSE was, in 15 years I’ve had of attending events to do with disability etc, quite the best one I’ve ever been to and taken a part in. I was thrilled to be able to host such a wide range of experienced, inspirational and impressive speakers, refreshingly for once all actually disabled people with the experience and authority to really provide meaningful and useful presentations. This, along with the equally well planned panel discussions, made for a seminal event in disability politics, and social practice, and I think praise is well deserved for Nicola Martin and everyone else at the LSE and NADP. This should become an annual event immediately, in my opinion at a different University location each time, and it above all else proved that Britain really needs many more degree level course in Disability Studies.
Not Our Problem: Impairment as Difference, Disability as Role
Dr Colin Cameron

Introduction

In this article I want to offer what I hope is a useful insight into the experience and meaning of impairment and disability that will be of value to disability practitioners. I am interested in this area both as an activist in the disabled people’s movement and as a disabled researcher who has wrestled with the impact of personal tragedy narratives in shaping my own experience – both in terms of other people’s perceptions of me and the way these have impacted on interactions I have been involved in, and in terms of the impact this has had on my own self-perceptions.

Taking as my starting point the social model, which identifies disability as an oppressive social relationship imposed on top of our impairments – something done to us rather than something we have – (Swain, French and Cameron, 2003) - I want to begin, perhaps contentiously, by arguing that both disabled people and professionals are often complicit in maintaining the practices and discourses by which disabling relationships are materialised. Not knowingly or deliberately, perhaps, but because they conceive some things as given, as being ‘just the way things are’, and see no other way it could all be. As Simon Charlesworth has noted:

We are not simply in the world, we are amidst it, our world comes to inhabit us because we come to know it through our socialisation into a way of being that discloses the world in a certain way (Charlesworth, 2000:91).

Iris Young has suggested that oppression refers to the injustices some people suffer as a consequence of the often unconscious assumptions and reactions of well-meaning people in the processes of ordinary everyday life (Young, 1990).

Following this, I want to outline a recent theoretical development that has emerged within Disability Studies, an idea originally suggested by John Swain and Sally French in 2000 and clarified in my recently-completed PhD: the affirmative model of disability (Cameron 2010). My intention is that this will be of use as a practical tool for making sense of the everyday experience of living with impairment in a disabling society. In order to illustrate my points, I will be drawing upon observations and comments made by participants in my research.
Disabling narratives

In making sense of how we are expected to act and who it is possible for us to be, we draw upon available narratives circulating in the culture we are part of. When I use the term ‘narratives’, I mean ‘stories which tell us about things that have happened or are happening to people’ (Berger, 1997:4) or ‘claims, often conflicting, to see what is going on in any situation’ (Carson, 2009). Reality, and experience of reality, is never just as it is because this is the way it happens to be, but is always socially constructed within specific historical circumstances. Narratives are never neutral, but always reflect power interests and relationships. In terms of disability, this works whichever side of the relationship we are on, whether we are disabled or non-disabled. When we use terms like disabled or disability, we invoke sets of expectations.

I suggest that many disabled people find themselves caught up within oppressive narratives which represent impairment in terms of deficit and abnormality, as something which can only be experienced negatively. Subjection to cultural discourses, which only ever conceive of impairment as something ‘wrong’ with the physical body, has a demoralising impact which can lead to entrapment within feelings of negativity. Donna Reeve describes the damage to disabled people’s emotional well-being and self-worth caused by negative self-evaluation against public narratives of normality, beauty and perfection (Reeve, 2006:100).

While many barriers to the participation of disabled people in ordinary community life have been addressed in recent years, the interviews and observations I carried out in my PhD research indicate that there still remains a fundamental perception of impairment as signifying misfortune, inadequacy, inferiority. This is manifested in the gestures, words, looks, experienced by disabled people in everyday life, and is reinforced by the endless regurgitation of media stereotypes imposing a medical or personal tragedy view. As Cal Montgomery remarks:

> Every few hours I run up against people who feel free to remind me that I’m their inferior and that I should conform to whatever they’ve decided ‘people like [me]’ are supposed to be like (Montgomery, 2006: unpaged).

Describing tensions she has experienced in developing a sexual identity, Sarah, a young wheelchair-user from Leith, comments:

> ...Talking with other young people, it’s like... they don’t see you that way, so how can you expect to see yourself that way... even my gran... my cousins are in relationships, and they’re taken seriously... but me, I’m not... and why... well, because... well, I was going out with a guy who was in a chair... and I just felt like... no one ever said anything, but I just felt that it wasn’t viewed the same way... I don’t know what that is, but I just didn’t feel comfortable...
with the way they would talk to me about it and stuff... so it’s like “That’s your friend...” ...and I’m, like... “No, it’s not... it’s my partner, my boyfriend...” ...and then it would be, kind of, like, avoided... but, yeah... with my cousins and stuff, they’re getting engaged and everything... and it’s viewed a lot more seriously... (Cameron, 2010)

Rose, a wheelchair-user from Perthshire, describes her experiences of visiting the local theatre:

...When it works, the stair-lift goes very slowly... people walk up the stairs past you... they ask “Are you having a nice ride?” or “Are you enjoying yourself?”... or they say “That’s good, isn’t it...” (Cameron, 2010)

Rose talks about the sense of humiliation that comes from being marked out as public property, of being subjected to the unwanted observations and comments of complete strangers:

...It affects everything... er... because... er... it’s back to that thing of... the way you perceive yourself is partly the way other people perceive you... and if you have people coming up to you in the street and saying “Are you enjoying yourself racing along... who’s got the fastest wheelchair...?”... and just approaching you, where they wouldn’t dream of approaching other strangers in the street, as it were... (Cameron, 2010)

In my own experience, I can recall only too well situations when, as a teenager, my father would introduce my brothers and me to colleagues of his:

...“This is Gordon... he’s the eldest... he’s at university studying law... and this is Angus... the youngest... he plays rugby for the school team... and this is Colin... he had an accident...”

It is this invalidating measurement of the experience of disabled people in terms of their supposed misfortune, as if life with impairment is in everything overshadowed by the dark cloud of impairment, and is either to be dismissed as inferior or compensated for with remarks of inappropriate cheerful bonhomie, which can eat into the sense of self. Rose adds that:

it’s about being made to feel, and feeling it... it’s not just about being made to feel, but that you feel it... (Cameron, 2010)

It is in this sense that disability is felt, or sensed, as oppression. Disability is not just about physical barriers which exclude people with impairments from opportunities to participate equally in ordinary life, but is about the kind of people that we are expected to become: acquiescing with the way that dominant, non-disabled, culture represents us and being the sort of people that dominant, non-disabled culture expects us to be.
Discussing media portrayals of disabled people, Charles, a wheelchair-user from Liverpool, commented that:

Ade was another Beyond Boundaries contestant... he’s probably one of the most recognisable disabled people in the country... and there was a Guardian interview with him that I read... and the interviewer asked him is your house... is your home adapted to be accessible... at which point he got angry with the interviewer... and he was saying “I don’t have anything like that... I just get on with it…” ... and the interview said that’s great... what a message to put out... similarly The One Show... they had this sort of feature on people going back to the houses they grew up in... and they had Tanni Grey-Thompson... going back to her house... and she said my dad was the architect but they didn’t adapt the house in any way because they thought it was better that I pull myself up the stairs... you know... and adapt to my surroundings... cos that would serve me well in later life... (Cameron, 2010)

As disabled role models, Ade and Tanni perform the same function as any other celebrities: of naturalising perceptions which reduce social issues to individual challenges. Because they are disabled ‘achievers’ Ade and Tanni are held up as exemplars, not only to other disabled people but to non-disabled people too. The never-ending round of self-congratulation in which the media indulge distracts from structural causes of inequality. Disabled people are exhorted by Ade and Tanni to strive to overcome their individual limitations rather than to value themselves as they are. Simultaneously, as Ben, a neurodiverse man from Coventry points out, a disciplinary discourse is being imposed on non-disabled people:

disability is used... as a warm, human interest story... as a sort of morality fable... but still in order to say if a disabled person can do this... if someone can do it in spite of all this difficulty, why can’t you... you don’t have all these barriers and ‘handicaps’... so you should think yourself so lucky to be who you are and able to do what you can... (Cameron, 2010)

The narrative which states that impairment is a personal trouble to be addressed individually seems almost inescapable, and it is inevitable that many disabled people – probably most disabled people – find themselves caught up in this way of thinking. It is difficult to identify disability as oppression because this oppression happens within what appears as the fleeting, insignificant every day. Fran Martin suggests that the difficulty in seizing hold of and recognising what goes on in the everyday arises:

partly because we are not trained to think of the repetitive activities and apparently banal objects that make up our everyday experience in an intellectual way. Instead, we tend to experience them as a kind of ubiquitous but unremarkable ‘background’ to the things in our life that we think ‘really’ matter (Martin, 2003:1).
The contexts and relationships through which lives and identities are constructed are allowed to pass without critical reflection: they are regarded as something individuals cannot really do very much about because they are just the way things are. It is, then, little surprise that disabled people (and professionals whose ostensive role is to support them) are often complicit, in spite of intentions, in reproducing the ideology which disadvantages them.

Representations of impairment as personal tragedy

Charles Riley argues that nearly all the problems in the representation of disabled people can be traced to the ubiquitous ways in which a medical model narrative is imposed or used to make sense of the experience of impairment (Riley, 2005:12). As a culturally dominant framework, the medical model is rarely perceived for what it is: just one way of looking at things. The assumptions underlying this framework rarely come into focus, are much less questioned. It is regarded as common sense to consider impairment a sign of personal tragedy.

Expressed in the World Health Organisation’s International Classification of Impairments, Disabilities and Handicaps (1981), the medical model defines impairment as:

any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability is identified here as:

any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. (Barnes et al. 1998:22)

In this view, disability is the outcome of impairment and is an individual problem. It is a condition that people with impairments ‘have’, emerging as a result of something ‘wrong’ with their bodies. When people talk of ‘people with disabilities’, they reflect the medical model.

This is a narrative materialised in everyday practice through the myriad of behaviours, decisions, and interactions taking place within the social contexts in which disabled people experience their lives. It is put into practice in and through the ways that services are delivered, plans made, words spoken, texts read.

The medical model is reinforced culturally through the endless repetition and circulation of narrow stereotypes depicting impairment as personal tragedy. Consider, for example, Dickens’ poor, pathetic victim, Tiny Tim (Dickens, 2003); Stevenson’s monstrous Blind Pew (Stevenson, 1998);
Spyri’s plucky, determined cripple, struggling against adversity, Heidi’s friend Klara (Spyri, 1995).

While it might be unsurprising to discover such stereotypes adorning the pages of Victorian classics, what is revealing is to discover how little distance has been travelled in well over a century. In contemporary popular cultural texts, the same negative representations of disability and disabled people appear again and again. Disabled people are either objects of pity, freaks or supercrips.

Caravanning for the Disabled informs us that:

> a disability need not hinder someone's enjoyment of touring and sightseeing, but rather enhance the pleasure of the experience and allow them to enjoy it more intensely. They also realise more clearly how limited their lives would be without the stimulus touring and travel provide. (Caravanning for the Disabled, 2009)

The website report by Thurrock Council News of its Citizen of the Year Awards includes a list of descriptions of various of the town’s disabled citizens saturated with words like bravery, overcoming, living life to the full despite illness, special, inspiring courage, the face of adversity, overcoming personal difficulties, and sheer determination to overcome his disability (Thurrock Council, 2005).

Tanya Titchkosky states that texts are always oriented social action, producing meanings: they act on us and help constitute our social contexts (Titchkosky, 2007:23). Popular cultural disability stereotypes, as resources for people with impairments to draw upon, play a key role in limiting the narratives available to use in reflecting on and constructing identities. Whether impairment is represented as a characteristic to be suffered, endured or overcome, a role is created in which the subject position of people with impairments is always invalidated. Impairment is not regarded as something to be emphasised, rather effort must be put into managing and minimising its significance in the process of fitting in.

This is reflected, for example, in the following statement by East Lothian Council:

> East Lothian Council welcomes employment applications from people with disabilities and will focus on their abilities rather than disabilities (East Lothian Council, 2010).

Far from regarding impairment as an important part of making disabled people the individuals they are, as a characteristic of human difference to be valued, East Lothian Council states here that impairment is something to be overlooked. In its claim to be ‘Positive about Disability’, it promotes itself as being forward-thinking, as if seeing the person and not the disability (suggesting that these can be distinguished) is somehow doing disabled people a favour. Similar thinking can also be evidenced in the
recent experience of a postgraduate student with mental health issues at Queen Margaret University, who was advised by a disability officer not to tick the ‘disabled’ box on a job application form.

If the experience of disabled people of the real world is, in Matt Fraser’s words, that it constantly ‘tells us we’re shit because we’re disabled’ (Fraser, 2004) then the imagination is given little to build upon that is positive. The personal tragedy model provides a narrative through which impairment can only be experienced as a discreditable personal characteristic.

**Normality, abnormality and the social model**

Disabled writers have argued that the medical model is a particular manifestation of what Mike Oliver has termed ‘the ideology of normality’ (Oliver, 2009). Normality, Oliver argues, is a construct imposed on a reality where there is only difference (Oliver, 2009). Lennard Davis points out that the term normal, in terms of meaning conforming to, not deviating or differing from the common type or standard, regular, usual, only enters the English language around 1840 (Davis, 1995:24). Disability emerges as a social category with the advent of industrialisation, the rapid growth of manufacturing towns and cities, and the arising need for a standard, replaceable able-bodied worker who can meet the production requirements of the factory system. Against this norm, it became possible to identify and remove individuals who did not match up to the requirements of modern production processes.

Labelled as sick, unfit or incapable, people with impairments found themselves increasingly segregated from mainstream society and confined within a range of institutional settings (Swain, French and Cameron, 2003). Individual abnormality only appears when normality becomes a social requirement. Impairment only becomes identified as abnormality when marked as such by procedures of surveillance. Having excluded people with impairments from the mainstream, there was considered no need to address their needs within the mainstream. It is in this systematic, planned exclusion from society that the relationship of disability arises.

Emerging as a result of the politicisation of disabled people in the 1970s, the social model of disability, first proposed by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976, identifies impairment as:

- the lack of part or all of a limb, or having a defective limb, organ or mechanism of the body

The social model defines disability as:
- the disadvantage or restriction of activity caused by a social organisation which takes no or little account of people with physical
impairments and thus excludes them from participation in the mainstream of social activities (UPIAS, 1976:14).

People with impairments do not ‘have’ disabilities but are disabled by a society which views impairment as inferiority. Social model definitions have been further developed by the Disabled People’s International to include people with sensory and intellectual impairments as well as people experiencing mental health issues (Barnes, 1994:2).

The social model does not rule out the fact that some restrictions of activity may be directly related to, or ‘caused by’, having a physical, sensory or intellectual impairment: not being able to do certain things because of the absence of a limb or the presence of chronic pain or fatigue, for example. It just does not regard these as ‘disabilities’ (Thomas, 1999). This is not, however, simply a semantic issue or a quibbling over words, but involves a critique of the way in which personal tragedy narratives are used to sustain unequal power relations. Disabling barriers exist in the assumptions and expectations that encourage conformity, that place value in ‘normal’ way of doing things – seeing, hearing, speaking, moving, being – and regard other ways of doing things as ‘funny’ or wrong. As Dorothy Smith has noted, the point of developing a critique is to propose something better (Smith, 1987).

The Affirmative Model

A relatively recent development within Disability Studies has been the proposal by John Swain and Sally French (Swain and French 2000) of an affirmative model. Rooted within perspectives emerging from the disability arts movement, through which disabled people have retold their individual and collective stories on their own terms and in their own voices, the affirmative model is identified as a critique of the personal tragedy model corresponding to the social model as a critique of the medical model.

In proposing an affirmative model, Swain and French set out a position from which it can be asserted that, far from being necessarily tragic, living with impairment can be experienced as valuable, interesting and intrinsically satisfying. This is not to deny that there can be negative experiences resulting from impairment, but to make the point that this is not all that impairment is about. While Swain and French make it very clear that the affirmative model builds upon and is a development emerging from the social model, they suggest that the need for an affirmative model is established in that it is not a purpose of the social model to reject a tragic view of impairment:
even in an ideal world of full civil rights and participative citizenship for disabled people, impairment could be seen to be a personal tragedy (Swain and French, 2000:571).

Up to the point where I carried out my PhD, there had been no major research projects engaging with the affirmative model, which remained a tentative proposition rather than a tested hypothesis. My intention was to offer a critical reflection on the affirmative model in the light of the everyday lived experience of disabled people. To this purpose I completed a series of interviews, conversations and observations with disabled people across Scotland and England.

While they had not provided definitions which enable us to state succinctly what the affirmative model is, Swain and French had identified a number of features by which the affirmative model is and is not characterized. The affirmative model is about:

- being different and thinking differently about being different, both individually and collectively
- the affirmation of unique ways of being situated in society
- disabled people challenging presumptions about themselves and their lives in terms of not only how they differ from what is average or normal, but also about the assertion, on their own terms, of human embodiment, lifestyles, quality of life and identity
- ways of being that embrace difference

(Swain and French, 2008:185)

This is reflected in the following remarks by Lola, a wheelchair-user from London:

I haven’t been terribly well and it’s... it’s the grey area of impairment that we don’t yet feel... widely comfortable discussing, I think... it’s starting to change, but... I’d rather be me than not be the whole mix... you know... positive, negative, flawed, happy, sad mixture... that I am... you know... that makes me me... erm... and you know, you can play the sort of games with yourself, thinking... well, if you had that or you didn’t have that would it still make you who you were... and I don’t believe I would be the same person... (Cameron, 2010)

For Lola being who she is, as a disabled woman, is an experience she would not want to be without. While she acknowledges the uncomfortable reality of her impairment, she rejects the futile pursuit of wishing things could be otherwise. She regards her impairment as a core part of her person, something without which she would not be who she is.

Swain and French emphasise that the affirmative model is not about:

- all people with impairments celebrating difference
- disabled people ‘coming to terms’ with disability and impairment
- disabled people being ‘can do’ or ‘lovely’ people
the benefits of living and being marginalised and oppressed in a
disabling society
(Swain and French, 2008:185)

As Roshni, a blind woman from Glasgow, comments:

I’ve yet to meet anybody who is a hundred per cent happy with who
they are... I don’t necessarily think that because you’re disabled you
are extra unhappy with who you are... but equally I’ve yet to meet
the person who’s jumping up and down, celebrating that they’ve got
dodgy eyesight... but, having said that, it’s certainly not... erm... it’s
certainly not a cause for me to cry and weep and wring my hands
and give up on the world... there are lots of things I’m not happy
about... I’m not happy about the fact that I’ve got dry rot in the next
room and the ceiling needs replacing... I think my visual impairment
is on the same scale as that... life happens... (Cameron, 2010)

Roshni suggests that impairment is something to live with rather than a
source of perpetual distress. Her blindness is something ordinary for her,
part of her everyday experience of life. She is realistic about her situation,
recognising that to be blind does not make life any easier, but at the
same time, she does not regard her life as a blind person as being one
long worthless experience. She knows that life is not a rose-strewn path
for very many people and that, within the scheme of things, being blind is
not the end of the world.

While the affirmative model involves a rejection of assumptions of
tragedy, it does require recognition of the oppressive contexts within
which everyday life is experienced by disabled people. Charles recalls
that:

...when I was talking in the pub with Erin and yourself tonight... with
every sentence I wasn’t thinking oh, I’m going to say this sentence
with a speech impairment... blah blah blah... now I’m going to say this
with a speech impairment... blah blah blah... I’m going to move back,
but I’m moving back in my wheelchair... you know... you don’t think...
but... when you catch somebody looking at you... and looking at the
effects of your impairment... concentrating on your impairment... then
you’re suddenly aware... that you’re speaking differently... (Cameron, 2010)

Charles’ point here is that while impairment is not necessarily experienced
as a problem for the person concerned, he finds that it is often made a
problem by other people around. It is not the experience of impairment
which is negative, but other people’s response to impairment.

At its simplest, the affirmative model makes the point that impairment is
not an unfortunate aberration or a deviation from a norm, but is a
relatively common and ordinary part of human life. The impression that
impairment is unusual is a popular fiction given credence by the
continuing societal practice of segregating disabled people within ‘special’
schools, ‘care’ homes, ‘specially adapted’ accommodation instead of ensuring the physical and cultural accessibility of the general environment.

My research data consisted of transcripts of semi-structured interviews with participants about their perceptions of the meaning of the term disability in the light of their own experiences; of unstructured interviews about their perceptions of media representations as resources to draw on in making sense of the disability experience; and of notes of observations of their engagement in a variety of mundane everyday activities. My aim was to develop affirmative model definitions, grounded within participants’ accounts, which would clarify the affirmative model and fashion it as a theoretical tool for practical use. Analysis of my data led me to propose the following definitions:

Impairment: physical, sensory, emotional and cognitive difference, divergent from culturally valued norms of embodiment, to be expected and respected on its own terms in a diverse society.

Disability: a personal and social role which simultaneously invalidates the subject position of people with impairments and validates the subject position of those considered normal.

(Cameron, 2010)

In identifying impairment as difference, the affirmative model establishes the rights of people with impairments to feel okay about themselves and to take pride in who they are, even when they are having crap days, and to be able to have crap days as well as great days or ordinary days without having to pretend otherwise. It also establishes their rights to have great days and ordinary days as well as crap days, to enjoy being who they are as people with impairments rather than regarding impairment as a cloud overshadowing every aspect of their existence. It demands recognition of impairment as an ordinary rather than an extraordinary characteristic of human experience, and for inclusion within ordinary life on that basis.

This affirmative model identifies disability as a productive as well as a restrictive relationship. This involves recognition not just of the parts of life people with impairments are excluded from, but also of the kind of social actors they are required to become. Whether this involves roles of passive dependency or a steadfast denial of the significance of impairment, either way negates the lived experience of impairment and signifies the desirability of normality. It is thoroughly exploitative because simultaneously it distorts relationships for people with impairments and those regarded as non-impaired. Just as being a disabled person involves acting out an imposed role, so does being a non-disabled person.
Conclusion

Ellen Barton states that insofar as disability is thought of socially, culturally, or historically, it is usually represented in terms of progress and improvement. But, she adds:

I would argue that disability also must be defined as a more complex social construct, one which reflects not a benign evolution of acceptance but a dynamic set of representations that are deeply embedded in historical and cultural contexts (Barton, 2001:169).

While environmental barriers to access may be being removed, there exists an ambiguity around meaning and an entrenchment of perceptions that continue to reflect a medical/personal tragedy model of disability. For example, Jane Campbell argues that the current debate on legalising assisted suicide carries a set of implicit assumptions rooted in fears of pain and of being a burden to others (Campbell, 2006(a)). She has stated that the background noise to current discussions around assisted suicide is reinforcing negative perceptions of disability. It feeds into desires for a body beautiful and a perfect life untroubled by illness. It promotes premature death as a choice option, especially for people with severe disability or terminal conditions (Campbell, 2006(b):14)

Tom Shakespeare has described disabled people as being treated as ‘dustbins for disavowal’, onto whom are projected the anxieties of non-disabled people, perpetually anxious to deny their own mortality and physicality:

It is not just that disabled people are different, expensive, inconvenient, or odd; it is that they represent a threat... to the self-conception of western human beings – who, since the Enlightenment, have viewed themselves as perfectible, as all-knowing, as god-like: able, over and above all other beings, to conquer the limitations of their nature through the victories of their culture (Shakespeare, 1997:235).

The metanarratives of Enlightenment, rationality, industrialisation and the societies that are both shaped by and which give shape to the continuing emergence of these narratives require individuals who experience themselves in certain ways that involve making constant comparisons between themselves and all the others around them (Elias, 2001). The competition this necessarily involves demands an ontological price: the relative security and comfort that can be attained by those able to find a reasonably nice place for themselves within the present organisation of the human world is paid for by those who are excluded.

Disability, then, is the ontological price paid by people with significant impairments for the relative security and comfort of those able to occupy what Rosemarie Thomson has termed ‘the normate position’ (1997). This
is a position which is able to recognise itself by comparing itself with those it has excluded. However, it is also a position which is less than fulfilling of human potential and which requires constant absorption with and monitoring of the superficial details of the self. Being normal involves a process of learning to want to act in the ways that society requires one to act. Fitting in requires preoccupation with what we look like, what we wear, what we buy, what we consume, as markers of the self. Brett Farmer states that:

each subject internalises ideological conventions and imperatives, and then unconsciously uses these as regulatory yardsticks with which to measure and modify social identity and comportment (Farmer, 2003:36).

My point is that the requirement for non-disabled people to be normal involves them in being less than they could be, just as does the requirement for people with impairments to be disabled. These are roles which indicate much about the needs of contemporary society but less about what life could be like if, as Michel Foucault suggested, we refuse to be what we have become (Foucault, 1987).

I propose the affirmative model as a tool to be used by people with impairments in making sense of the disabling interactions, pressures and tensions they encounter in the midst of everyday life; as a framework giving the right to be self-affirming as people with impairments, acknowledging their own needs and demanding that their needs be acknowledged and respected, valuing themselves for who they actually are rather than getting caught up in self-oppression because they are not who they are not. I also propose the affirmative model as a tool to be used by practitioners working alongside disabled people in examining their own roles in sustaining or challenging disabling expectations and relationships, and in working as allies who have a role in transforming the structures and institutions by which all our lives are shaped.

References


The Freshmen Mental Health Project (FMHP) and a Foucauldian Governmentality of the Mind

Jack Trammell, PhD

Abstract

The focus of the ongoing Freshmen Mental Health Project (FMHP) is to identify and measure levels of stigmatization that first year USA college and university students experience in relationship to their mental health-related impairments (which in the USA include, Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder, Depression, Anxiety, Obsessive Compulsive Disorder, Bi-Polar Disorder, etc.), and to capture through their own words some of the subjective nature of the experience. The data from the first two years of the project strongly suggest that a latent structural stigma remains solidly in place in post-secondary educational environments in spite of attempts to bring accommodations and universal designs into effect that might counteract stigma. Furthermore, there is evidence that a type of reverse stigma effect may be occurring, whereby many equitable intentions, such as academic accommodations, actually result in sustaining old networks of oppression and occasionally even creating new ones.

Main Text

Latent stigma does not nominally consist of individual acts of overt discrimination. Rather, it is a wide-ranging dispersal of powers that transcend individual actions and narrow timeframes, maintaining a continuous force on a minority or underprivileged population, shaping and regulating their behaviour. It is enforced through bureaucratic rules and procedural routines that are often byzantine in nature and layered with complexity, even as they are cloaked in the semantics of fairness and normality, and constantly reinforced in popular culture. Latent stigma is creeping and subtle, and often goes undetected until an individual crisis emerges, or until the excavations of historians and linguists dig out artefacts and trends which were not so obvious in their contemporary context.

Much has been written about the stigma and governmentality of mental illness, though little has been done to investigate how mental-health-related disabilities impact young people as they transition from secondary to postsecondary education (Tremain, 2005a; Hinshaw, 2007; Angermeyer & Matschinger, 2003; Davis, 2010; Szasz, 1974; Foucault, 1965). The multiple layers of latent stigma that have collectively infiltrated mainstream culture are certainly present on college and
university campuses and, in effect, create receptors at the threshold of equal access that only permit some to pass through unscathed, and even then, only with important caveats.

A major threshold, for example, is the doorway of disclosure (Corrigan, 2005; Price et al., 2005; Robertson & Dykes, 2007). Disclosure is the primary litmus test for receiving accommodations, and is protected in theory by rules of confidentiality. None-the-less, as a governmentality of the mind, it carries with it many public risks and consequences.

In the postsecondary setting, discloser is required to receive accommodations, or in a colloquial sense, "to get help." The simple and presumably liberating act of self-disclosure can in reality be a forced acceptance of socially and biotechnically created labels that bring along with them potentially dangerous assumptions and consequences (Trammell, 2009b; Robertson & Dykes, 2007). If a student wants accommodations that may allow them to access the physical and academic environment more equitably, they must also accept the disability identity and social stigmas that come part and parcel with it; metaphorically, the gum that sticks to the shoe:

*People with mood disorders are weird. You don’t have ADHD, you just need to get serious about academics and work harder. You’re lazy. Everyone has to deal with a little depression, just be tough and deal with it. I don’t see anything wrong with you, you look fine. Mental illness is not a real sickness. Stop acting so “crazy.”*

These are real words, borrowed from students who participated in the Freshmen Mental Health Project (FMHP) and were asked about how other people perceive those with mental health-related disabilities.

A major component of latent stigma comes from the nature of disclosure as a test of proof, a surveillance in Foucauldian terms and a relatively new technology of control (borrowing a phrase from Jeremy Greene and medical sociologists) (Davis, 2010; Tremain, 2005a; Tremain, 2005b; Foucault, 1965). Students must, according to current administrative practice in America and many western countries, “prove” their disability to qualify for services (See documentation guidelines by AHEAD). While this might seem perfectly in keeping with several hundred years of Western rationalism which attempts to address Otherness by identifying, explaining and labelling it (etiology), it also is an inherently reductive process (Davis, 2002; Warshaw, 2006; Goffman, 1963; Scotch, 2009). Whether obvious or not, students have to trade something in order to gain the access they need to accommodations and an environment where educational equity is based theoretically more on potential than on an insular and pedagogically questionable tradition that privileges and enforces certain modes of instruction and “ways of knowing” (Berry, 2006; Johnson, 2001; Yates, 2005).
The FMHP was undertaken as a direct attempt to measure and verify student awareness and self-perception of latent mental health stigma, and to subsequently expose some of the structural mechanisms which remain in place that inadvertently or otherwise reinforce the status quo (Yates, 2005; Hughes, 2005). It is hypothesized additionally that this stigma may be additive; that is, that it increases in the companionship of other minority statuses such as race, gender, etc. Initial participants for the piloting of the project were cohorts of freshmen students at a small liberal arts school on the east coast, very typical of colleges, with small class sizes, an emphasis on meeting individual student needs, and providing a diverse educational experience. The general hypothesis guiding the FMHP is that postsecondary students with mental health-related disabilities suffer significant stigma, and the stigma helps define a broader network of governmentalities of the mind that reflect a long-standing global discrimination in the postsecondary (and larger) environment. The recognition of this oppression is widely discussed in the related literature, and mirrors pioneering works of Eliot Freidson, Ivan Illich, and Michel Foucault, which forecast quite accurately the present medicalization of disability and mental health disorders (Foucault, 1965; Illich, 1973; Freidson, 2006; Tone, 2009).

The FHMP began with qualitative interviews of college freshmen with mental health disabilities as they entered their first year of college. Students were identified through a voluntary self-disclosure process in cooperation with the disability support services and counselling services offices. Those who agreed and followed the procedures for confidentiality were interviewed during or immediately following general freshmen orientation (first two cohorts $n = 46$), with questions focusing on their specific and primary mental health-related disabilities (ADHD, Depression, BPD, etc.), questions related to original diagnostic experience, high school academics and social experience, negative and positive aspects of their “disability identity,” current therapy and medical regimens, family history, and college expectations—all with an emphasis on how the mental health disability impacted their specific and general perceptions. See Table 1 below for demographic data.

**Table 1** Primary Mental Health Related Disabilities by Category as Disclosed ($n = 46$)

<table>
<thead>
<tr>
<th>Category</th>
<th>Students</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADHD Co-Morbid*</td>
<td>32</td>
<td>69%</td>
</tr>
<tr>
<td>Depression</td>
<td>3</td>
<td>7%</td>
</tr>
<tr>
<td>Bi-Polar Disorder</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Obsessive Compulsive Disorder</td>
<td>0</td>
<td>---</td>
</tr>
<tr>
<td>Anxiety Disorder</td>
<td>6</td>
<td>13%</td>
</tr>
<tr>
<td>Asperger’s/Autism Spectrum</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Other**</td>
<td>3</td>
<td>7%</td>
</tr>
<tr>
<td>Total</td>
<td>46</td>
<td>100%</td>
</tr>
</tbody>
</table>
*Co-morbid with another self-reported mental health-related disability and often learning disabilities though, interestingly, students very frequently choose ADHD as their primary identity, rather than the other mental health disorders listed. One suspects this is because ADHD is less stigmatized in the current climate.

**Including Traumatic Brain Injury and other Personality Disorders.

SAT scores, high school GPAs, and demographic data were collected and entered into a master database for later analysis (still in the process of completion for the first two years). Following Institutional Review Board recommendation, numbers were assigned to all names so that all data, qualitative or quantitative, remained blind after initial contact, and fully protected the identity of participants. In the spring of the each year, collection of achievement data was gathered for the cohort. Students’ transcripts and grades were added to the master database, with additional tracking of academic achievement each semester and accumulatively for two years in total. Students were recruited, again voluntarily, to give follow on information in short interviews at the one year and two year marks.

A key component to the FMHP is the use of the Postsecondary Student Survey of Disability-Related Stigma (PSSDRS) (Trammell, 2009a). The PSSDRS measures disability-related stigma using a five point Likert-type scale, and is divided into several domains, including global identity with disability, impact on personal relationships, academics, etc. The scale produces both a total stigma score, as well as ratings in the sub categories. All participants take the PSSDRS as beginning freshmen students to measure perceived levels of stigma, and to help quantify environmental and latent stigma.

Equally as important as measuring attitudes, then tracking their academic achievement for the first two years, students were also given heightened access to mental health resources (Smith, 2009). This included a web page with additional electronic resources, heightened advertising and access to mental health counselling services on and off campus, additional “secondary” academic advising, and access to other resources. Though confidentiality did not allow complete tracking of these services by individual student number in every case, the counselling centre did see significant increases in mental health-related appointments and traffic during each of the two cohort years.

As record numbers of college and university students with mental health-related disabilities attend postsecondary schools, many such students struggle to adjust to campus life and achieve academically (Collins and Mowbray, 2008, Robertson and Ne'eman, 2008). The completion of two cohorts of data gathering highlights the specific interest the FMHP focuses on identification of disparities that college students with mental health-related disabilities encounter that fundamentally impact their academic achievement and quality of life issues, and to foreshadow or openly
identify solutions to such disparities. Students already stigmatized by other minority identities are likely to suffer even greater challenges (race, gender, etc.).

Results and Discussion

Data from the first two cohorts suggests that students with mental health-related disabilities do perceive themselves as highly stigmatized. Interestingly, however, the demographics of the participants varied from that of the institution overall in a pattern familiar to social science researchers. Non-minority female students were relatively overrepresented (see Table 2).

Table 2 FMHP Self-Reported Demographic Characteristics (n = 46)

<table>
<thead>
<tr>
<th>Category</th>
<th>Participant Percentages</th>
<th>Institution**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minority Status*</td>
<td>5 minority (10.9%)</td>
<td>18.9% minority</td>
</tr>
<tr>
<td></td>
<td>41 non-minority (89.1%)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>14 male (30.4%)</td>
<td>46.9% male</td>
</tr>
<tr>
<td></td>
<td>32 female (69.6%)</td>
<td></td>
</tr>
<tr>
<td>Visibility of Disability</td>
<td>3 visible (2%)</td>
<td>No data</td>
</tr>
<tr>
<td></td>
<td>43 invisible (98%)</td>
<td></td>
</tr>
</tbody>
</table>

*Minority status is self-report most often based on race and ethnicity.
**Institutionally reported figures for 2009-2010.

The scores on the PSSDRS were consistent with the results of the interviews; the highest mean scores (most stigmatized) were in the areas of academic concerns and personal identity (see Table 3). The mean overall score for the entire group (both freshmen cohorts, n = 46) was 35.61, on a scale running from 0 (no stigma) to 96 (maximum stigma). These scores were consistent with previous studies using the instrument (Trammell, 2009a).

Table 3 PSSDRS Scores First Two Cohorts (n = 46)

<table>
<thead>
<tr>
<th>Category</th>
<th>Items</th>
<th>Mean Score</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic Stigma</td>
<td>6</td>
<td>10.65</td>
<td>4.21</td>
</tr>
<tr>
<td>Peer Relationship Stigma</td>
<td>6</td>
<td>7.78</td>
<td>3.27</td>
</tr>
<tr>
<td>Self-Identity Stigma</td>
<td>6</td>
<td>9.59</td>
<td>3.36</td>
</tr>
<tr>
<td>Global Community Stigma</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>24</td>
<td>35.61</td>
<td>11.05</td>
</tr>
</tbody>
</table>
In the limited sample for the first two freshmen cohorts, there was mixed evidence found for additive stigma (see Table 4). In fact, the sub group with the highest degree of overall stigma was non-minority males. The highest score in any subgroup was related to academic concerns, and experienced by female minorities (at least one case, small, of additive stigma). With such a small sample size, little can be read into the question of additive stigma, though the results do suggest interesting results with a much larger and diverse sample.

Moreover, in this small and somewhat limited sample, males were more highly stigmatized than their female peers. This is perhaps another avenue of investigation to pursue in a much larger sample. Contrary to what might intuitively be expected, minority women did not have higher total PSDRSS scores than other sub groups; nor did minorities regardless of gender.

Table 4 PSSDRS Mean Scores by Minority and Gender Status (n = 46) BOLD represents highest.

<table>
<thead>
<tr>
<th>Category</th>
<th>Minority/Non Male (n = 5; n = 41)</th>
<th>Female/Male (n = 33; n = 13)</th>
<th>Female Minority/Male Non-Minority (n = 4; n = 42)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AS</td>
<td>10.40/10.68</td>
<td>10.59/10.78</td>
<td><strong>11.00</strong>/10.61</td>
</tr>
<tr>
<td>PR</td>
<td>7.80/7.78</td>
<td>7.59/8.21</td>
<td>7.75/7.78</td>
</tr>
<tr>
<td>SI</td>
<td>7.60/9.83</td>
<td>9.56/9.64</td>
<td>7.50/9.79</td>
</tr>
<tr>
<td>GC</td>
<td>5.80/7.80</td>
<td>7.53/7.71</td>
<td>4.75/7.86</td>
</tr>
<tr>
<td>TOTAL</td>
<td>31.60/36.09</td>
<td>35.28/36.36</td>
<td>31.00/36.05</td>
</tr>
</tbody>
</table>

AS = Academic Stigma, PR = Peer Relationship Stigma, SI = Self-Identity Stigma, and GC = Global Community Stigma.

The interviews from the first two cohorts revealed several significant and concerning themes that mirrored the results of the PSSDRS (n = 16). Amongst these were: a preoccupation with being perceived as “stupid” or as lacking intelligence; a repeated hesitancy to disclose to the school and/or professors about their mental health-related disability due to fear of negative consequences; a generalized perception that others don’t understand the experience of having mental health-related disabilities; that the most important time to talk about their disability is in relationship to a test or high academic stake; and in general, that the experience of interacting with others who find out about it outside of clinical settings is often negative and stressful. Some of these results are parsed in terms of coded terminology in Table 5, following.
# Table 5

## Major Emergent Themes in Individual Interviews (n = 16)

<table>
<thead>
<tr>
<th>Thread or Emergent Theme with Number of Coded Occurrences across Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Awareness of perceptions of persons with mental health-related disabilities as less intelligent:</td>
</tr>
<tr>
<td>Crazy = 2, slow = 1, dumb = 1, stupid = 3, not smart = 2, below average = 1 (total = 10)</td>
</tr>
<tr>
<td>2. Perception that professors or others may pre-judge them based on disability:</td>
</tr>
<tr>
<td>Not understanding/won’t understand = 8, use it against = 1, treat differently – 5, challenge legitimacy = 1, disregard student ideas = 1, discriminate = 2, prejudge = 1 (total = 20)</td>
</tr>
<tr>
<td>3. Opinion about disclosure and information management decisions:</td>
</tr>
<tr>
<td>Optional = 1, should tell = 4, should not tell = 3, will talk = 4, won’t talk = 5 (total = 17)</td>
</tr>
<tr>
<td>4. Adjectives describing their disability self-identity:</td>
</tr>
<tr>
<td>Embarrassing = 1, not good enough = 3, awkward = 1, lack of confidence = 3, not liked by others = 2, accept it = 3 (total = 13)</td>
</tr>
<tr>
<td>5. Descriptors of hurtful behavior by others:</td>
</tr>
<tr>
<td>Made jokes = 1, Stand-offish = 1, disowned = 1, treated harshly = 1, superiority = 1, accused of being lazy = 2, loss of friends = 1, lack of knowledge about disabilities = 4, (total = 12)</td>
</tr>
</tbody>
</table>

Students reported numerous emotional responses: *It’s none of their business [whether I have a disability or not]; ADD makes you...think in ways others can’t understand; professors were not understanding; it’s not a disability unless you think it is; people discriminate and stigmatize.* The overwhelming idea conveyed was that they felt marginalized by their mental health issues, and were usually reluctant to embrace their disability identity.

Structurally, the quantitative and qualitative results of the first two cohorts suggest several things about a governmentality of the mind and mental health as it relates to postsecondary students. First, students are already stigmatized *before* they likely have significant interactions on
campus. Because the PSSDRS was administered before or shortly after freshmen orientation, it likely measured stigmatization that was not necessarily linked to structural mechanisms on campus, but instead linked to longer periods of experience in public and private high schools, and to a wider general culture of disability stigma. This means that postsecondary institutions, regardless of environment or policy, inherit stigmatized individuals with potentially very special academic and social needs (Fleitas, 2000).

Secondly, the results of the FMHP project suggest, within limitations of scope and within the population of students who self-disclose for academic accommodations, that stigma related to their mental health disabilities is a significant factor in mitigating first year success. Increased usage of counselling services and other resources targeted by the FMHP suggest that there is hesitancy to disclose, discuss, and develop a stable disability identity that can be positively impacted through a process of normalization (Davis, 2010).

Thirdly, a Foucauldian governmentality of the mind must account for the various tendrils of power that emanate from the process and the requirement of disclosure. These include, but are not limited to, the creation of a “secret” file, protected by HIPPA and FERPA and other legal restraints, that adds to the aura of a secret self; the notion of “expert” and the “certification” of disability, essentially creating the Other through a technical and bureaucratic process; the notion that disclosing is in essence telling on one’s self, or giving away a part of the self that can’t be retrieved or reclaimed; and perhaps most importantly, the nebulous but not unfounded fear that somehow this sensitive information may be turned against them not just now, but almost anytime in the future.

Erving Goffman’s stigma research suggested that stigmatized individuals must make very sophisticated and painful decisions about information management—how do you tell, how much do you tell, and when do you tell? Disclosure may in fact be creating the very stigma it was originally intended to ameliorate, and may in fact be evolving into a form of surveillance and control that has serious implications (Goffman, 1963, Trammell, 2009c). One can understand the hesitancy a student might have in bringing their mental health related disability into the light.

**Conclusion**

This study is a smaller version of a much larger planned initiative that will span various types of postsecondary institutions in different regions of the USA, and involve a much larger sample of college students with mental health-related impairments. This two year pilot is intended to be the model for a much larger cohort that represents various types of institutions in different geographical regions and gathers significantly
more data to analyze. In the larger coming study, the PSSDRS and the in-depth interviews, along with more traditional measures of academic achievement such as GPA and SAT scores, will remain the key components of the data collection.

The Freshman Mental Health Project (FMHP) represents a culmination of several trends in postsecondary disability support. It reflects a growing awareness of environmental changes that must take place in conjunction with more obvious classroom accommodations (which were the first changes implemented after the Americans with Disabilities Act in 1990). It typifies and is similar to some of the early experiences teaching K-12 special education students in the 1970s. It therefore, in theory, should be the beneficiary of thirty years or more of research on stigma, and be able to draw on the scholarly inquiry within higher education into pedagogy and the university teaching experience, and even larger work on the questions of social justice. It suggests carefully tracking of retention of disabled students (Wessel et al., 2009).

Unfortunately, the results of this limited study suggest that there is much work left to be done, and many lessons that still haven’t been adequately assimilated. Perhaps most importantly, however, it raises questions about a larger governmentality of the mind. The post-ADA college and university environment rests on a very widely perceived necessity of a college or university degree in order to succeed in the mainstream culture, yet, at the same time, invites students into a network of power structures that are not adapted to their success. These structures include: the chimerical requirement of disclosure; nervous student perceptions of how faculty and staff interpret mental health disabilities in relationships that are already skewed in terms of power; and issues of identity in a setting where the very mission is to question everything.

A persistent belief in the worth of higher education, and the uniquely recent idea of universal educational access, come together with issues of gender, race, and disability to make it critical for scholars and administrators to understand what constitutes equal access, what the barriers to it are, and the extent to which the commitment will require new resources, both monetarily and intellectually (Ingstad and Whyte, 2007, Getzel, 2008, Vogel et al., 2008, Burch, 2009). There is ample evidence that there is no lack of intelligence or motivation in many of these students, but instead a subtle fear and hesitancy about something so new and alien that they have had to this point no context through which to understand it fully. They quickly perceive (rightly or wrongly) an environment that is unable to fully accommodate them, or understand them as learners, and may in fact even be threatening.

In the best traditions of Foucault and other skeptics, the FMHP provides evidence that we should question the system as it currently exists, question the way authority is parceled out through networks of bureaucracy, and evolve a governmentality of the mind that will allow
college students with mental health disabilities to navigate the obstacles more successfully.

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Promoting Inclusive Practice for PhD Students Near Completion

Nicola Martin
Head of Disability and Wellbeing Service
London School of Economics

Abstract

This paper proposes an inclusive approach designed to minimising unnecessary stress for PhD candidates, particularly those near completion. Recommendations are derived from participatory research with people who have the label Asperger syndrome (AS), and from structured discussions with five doctoral candidates who each identified as disabled. Based on logic and clear communication ideas presented here could potentially also reduce unnecessary stress (in an inherently stressful situation) for non disabled PhD students. Adopting an inclusive system in which straightforward information is easily available to all avoids positioning individuals as other and in need of special treatment. It also diminishes the requirement for separate processes for those with and without labels. (Doctoral routes are diversifying in the UK and the terms PhD and doctoral study are used broadly in this paper).

Inclusive practice

Inclusive practice and The Social Model of Disability sit side by side in much of the literature which advocates planning for the whole student body rather than problematising the engagement of some students. (Adams and Brown 2006, May and Bridger 2010). The notion of the Social Model University is aspirational. It is also contested as a label is needed in order to access Disabled Student Allowance (DSA). DSA is an individualised process for providing services to UK disabled students. It requires the student to go through diagnostic assessment, therefore labelling. Dissonance arises because substantial aspects of disability services are dependent on a Medical Model ethos as a result of their reliance on disabled naming, (Madriaga 2008). It is not really possible to match culture and practice in Higher Education neatly with models of disability. Social Model thinking governs the development of the inclusion agenda which advocates a culture of being alive to and addressing barriers to participation, whatever their origin. Alongside the drive for inclusive practice a Medical / Individual Model system operates for disabled students. The contradiction between positions makes tensions inevitable. ‘For inclusive practice to be seen as part of the institutions routine practices (rather than compensatory or additional) an embedded approach was required’ (May and Bridger 2010:36). The notion of embedding an approach which assumes that inclusive practice has
relevance to the wider student body, not just disabled students, underpins the arguments presented in this paper. It is positioned in favour of the Social Model and inclusion agendas.

**Learning from disabled students**


Pressure from perfectionism, low self esteem (possibly connected with bullying) and exceeding parental expectations are well documented issues in relation to AS. (Attwood 2007, Madriaga et al 2008, Tantum 2000). Neurodiverse students have described being motivated by a desire to shake off the 'special educational needs (SEN)' label (BRAIN-HE). When a student from an elite university who had exceptionally high grades described himself by saying 'I used to be a special needs child’ concern about the impact of an imposed SEN identity was brought into sharp focus. (Personal communication with the author). Anxiety around PhD study is not exclusively a ‘disability issue’. The contention that international students who have paid high fees may well be under additional pressure too for example merits further research. Being the first family member to access university may be a source of pride and, or anxiety. Research is thin in relation to the emotional impact of being the first to go for a doctorate.

While research which interrogates sources of stress for PhD students is limited, it is widely acknowledged that doctoral study is inherently stressful. Brabazon and Fearn (2009) identify practical strategies which institutions could adopt to minimise unnecessary PhD stress. Impairment is not isolated as a theme. Straightforward transparent administrative arrangements, a mechanism for regular progress reports, and a procedure for exit interviews, particularly in the event of failure are cited as examples of practices which could be helpful for any candidate. Generic (rather than disability service originated) information will be accessible to individuals with and without (or choosing to reject) an impairment label. Resources which originate from the disability service are behind a wall for those who do not embrace a disability identity (Martin 2008).

Insufficient research from an insider perspective is available. Lessons from the interrogation of views of disabled stakeholders in Higher Education may prove helpful in relation to the broader equality agenda as
the principle of 'nothing about us without us' (Charlton 2000) is extended
to other protected groups. Respect for individuality and multiple identity
has been emphasised within disability focussed research and equalities
context of research originated with one minority group may have
limitations but could provide a useful starting point.

**Considering the notion of ‘Othering’**

‘Othering’, Foucault (1967) is a pejorative term adopted by some
disability academics. Richards (2008), for example explains othering as
an imposed negative identity which marginalises people who are identified
with a minority in comparison with the dominant majority. There is a
growing body of literature on this theme which can only be introduced
briefly here but is very relevant to disability practitioners engaged in
providing services which rely on disabled naming. Positioning an
identifiable group of students as other runs counter to inclusive practice in
which all learners are valued as part of the academy (Adams and Brown
2006). Othering behaviours such as stereotyping, and assuming
individuals with the same impairment label (or from a similar background)
share a wide range of similarities does not sit well within an inclusive
culture.

Student comments relevant to the concept of othering follow and
illustrate the requirement to be sensitive to the potential impact of
labelling.

‘I might be going for a PhD now but I did fail the Eleven Plus. I was
twelve before I could read and Secondary Modern School to PhD is not
what was expected of me. I'm not convinced people think I'm good
enough’.

‘Because I was constantly singled out at school as someone who could
not spell or do well with maths I am sensitive to criticism. I work really
hard but I am so nervous about being found out when it comes to the
PhD. Sometimes I don't really think I should be here to be honest but
often I think that other people have a negative attitude about dyslexia’.

‘Having a diagnosis of Asperger syndrome as a child means that you
can't interact normally with people as an adult because you think they
are judging everything you say as being typical or not typical of
someone with Asperger syndrome. It ruined my confidence and I have
never got over it and I worry all the time about being found out’.

‘I'm self conscious because the dyspraxia label makes me feel clumsy.
People make jokes about dyspraxia and clumsiness without realising
that this is insensitive’.

Much has been written about stereotyping around AS. Images of genius,
inflexibility, obsessiveness and poor social and communication skills are
contested by people with an AS identity (Arnold 2003, Hughes 2007, Lawson 2003). Rain Man (Fleischer 1989) and The Curious Incident of the Dog in the Night Time (Haddon 2003), did much to perpetuate this idea. Students with impairments other than AS have also described concerns about the way other people see them and the negative impact of an imposed othered identity.

Othering is bigger than disability. Stereotyping and marginalising behaviour may well apply for example to: international /non traditional/widening participation /part time students, or anyone else shoe horned into a group identity.

Guidance for PhD supervisors from a range of universities sets out the requirement to get to know candidates as individuals, rather than representatives of groups (such as ‘dyslexics’ or ‘Chinese’). Supporting the process with structured paperwork designed to record discussions, decisions, ideas, concerns and progress may sound dull but may well be highly effective. Those with organisational difficulties or limited cultural capital arising from family experience of how the whole PhD process operates are likely to benefit. Advocates of inclusion argue for standard rather than special practices which by definition single out some candidates, and risk excluding others who may benefit (Valentine 2002).

**Barriers**

Disability is not the automatic bedfellow of impairment (Oliver 2010). AS for example is associated with some characteristics essential to PhD success such as the capacity for immense hard work, and deep interest and originality in academic study (Arnold 2003, Asperger 1944, Baron – Cohen 2000, 2010). Systems which value and nurture such attributes have the potential to facilitate achievement. Social communication, empathy, problem solving, sensory sensitivities and anxiety are highlighted as potential areas of difficulty for people labelled with AS (Bogdashina 2003, Gillberg 2002, Happe et al 2006, Howlin et al 2000, Leeckam et al 2000). As with other neurodiverse students, self esteem organisation and the ability to prioritise can be compromised particularly in the face of ambiguity (Attwood 2007, BRAIN-HE, Beardon and Edmonds 2007, Madriaga et al 2008). Disabling barriers are arguably constructed in environments which are characterised by ambiguous non empathic communication, unnecessary anxiety provoking difficulties and sensory discomfort. Such contexts are unlikely to be conducive to success. Self esteem can be helped or harmed by others and sensitive assistance with prioritisation and administration may well smooth the PhD journey.

The Equality Act (2010) emphasised the requirement to plan Higher Education to facilitate access. As well as the barriers described here which are particularly pertinent for students labelled with AS, obvious physical obstacles still block the road for some doctoral candidates. Two described
being unable to meet informally with peers because the department had located the offices used by PhD students upstairs.

‘I never saw inside the PhD common room the whole time I was studying’.

‘I feel excluded from the social side of study because I can’t spontaneously tag along’.

‘I don’t even know if the graduation ceremony will be accessible to me’.

It is difficult to argue against developing generic (rather than disability targeted) robust straightforward systems and generic quality indicators which aim to identify potential unnecessary barriers and facilitate their reduction. However, a climate of mindfulness is necessary, in order to avoid disability equality slipping down the priority list. The result of this could be, for example, creating an inaccessible PhD common room.

**Administration and organisation**

‘Behind every failed doctoral candidature is a personal tragedy’ (Brabazon and Fearn, 2009:31). The personal tragedy of failure because of an inability to navigate administrative and social communication hurdles may often be avoidable.

Theorists describe a core deficit in executive function as an explanation for organisational difficulties experienced by people labelled with AS (Baron-Cohen and Swettenham 1997). Other neurodiverse students have explained that dealing with administration is often a huge source of stress (BRAINHE). Stages in the PhD journey are preceded and followed up by necessary form filling. The first hurdle may well be the initial funding application. Paperwork may become a focus of intrusive worry. Smoothing the admin path could reduce anxiety and enable the candidate to concentrate on academic concerns.

It is illogical to argue that providing practical sensitive support with form filling, fee paying, visa status for some international students, and all essential administration, could in any way compromise academic standards. The provision of clear written instructions about what has to be done by when as standard also reduces the necessity to make special and potentially othering arrangements for a minority. Brabazon and Fearn (2009) provide systemic guidance on supporting all students in their attempts at navigating administrative aspects of the PhD. When procedures work effectively at a systemic level, the requirement for special arrangements is greatly reduced (Adams and Brown 2006). Bureaucracy would diminish for all (including staff) if processes were made so clear that errors became very rare.
**Supervision**

A systemic approach to tutorial and supervision for all students throughout the PhD journey is advocated by Brabazon and Fearn (2009). Computerised systems can be extremely helpful. Prior experience in another university will not necessarily translate because of local variations in processes. Requirements around upgrading from M.Phil to PhD, for example, may need to be demystified. International candidates will have had very varied prior Higher Education experiences. Simple explanations are helpful because assuming understanding may disproportionately disadvantage particular individuals, including those who have not taken a UK degree previously.

A shared understanding of how the thesis should look could be negotiated rather than assumed. Supervisors could usefully expect and plan for the necessity to reliably offer additional time and input to some candidates during the preparation of the thesis. Resource implications need to be considered and resolved by the institution. An anticipatory duty towards reasonable adjustments for disabled students is required. It is advisable to anticipate that a degree of flexibility over allocation of tutorial time will be necessary. International students already pay very high fees and top slicing to fund additional supervision is not impossible. This may be particularly helpful for those working in their second language. Students contributed the following comments:

‘I need my tutor to be available in the office hours he has advertised’.

‘My main worry is about how to present my thesis and I could really do with a bit more guidance about this’.

**The Viva**

Literature reviewed by The Premia Project (2007:1) on inclusive practice around research degrees, evidenced that ‘many (disabled) candidates approach the viva with high levels of anxiety.’ The following concerns were shared by disabled students:

‘Because of my dyspraxia I have a poor memory so if I am asked long rambling questions and I am already completely stressed out, I won’t be able to recall the question enough to keep hold of the thread’.

‘I want it to be clear that I am reliant on lip reading’.

‘I am afraid of being in a room with a person I have never met, especially because I know that that person is judging me’.

The following comments highlight sources of avoidable stress.

‘I am very stressed out about the viva because I don't know how I am supposed to behave. whether to shake hands...am I supposed to look
at everyone in the room...will they be put off because I find it so hard to maintain eye contact when I am really anxious'.

'I'm broke, I have dyspraxia and I have to work alongside studying so there is a lot of pressure on me. It has already taken me longer than other people in the department to get this far. I feel that there is pressure on me to be perfect in the viva so that I can complete ASAP. The department has been disadvantaged because of the length of time my PhD is taking and I feel bad about that'.

The student that shared this insight about time was not from the UK and had concerns about the visa as well as the viva. Inclusive practice demands empathic sensitivity to the circumstances within which candidates are operating. Poverty, disability and international student status interacted and contributed to levels of stress in this instance.

Candidates with the AS label expressed deep concerns about the social communication required during the viva. Possibly technology could enable the viva to take place in real time in two rooms. The candidate could respond to emailed questions from the examiners and an invigilator could be present to guard against cheating. The idea may be a step too far for many academics but others might see it as a reasonable adjustment.

When a candidate has an impairment which impacts on social communication the viva is likely to be particularly challenging. Defending ones thesis is a foreign language may also be very difficult. Adjustments could be implemented more easily if the external examiner knows something about the candidate in advance. In an ideal world, sensitivity and empathy would render disclosure (of impairment) unnecessary (Madriaga and Goodley 2009). Informed consent for disclosure is a legal requirement and for a whole range of reasons around identity, not everyone is willing to disclose (Madriaga et al 2008, Martin et al 2008). Some candidates may be more comfortable about describing the nature of necessary adjustments without naming their impairment (Martin 2007).

An inclusive approach to viva preparation could incorporate sharing pertinent individual information with the external, about, for example, communication issues. The process need not be disability triggered or bureaucratically heavy. Positioning any section of the student body as other or special (Richards 2008, Valentine 2002) could potentially disqualify non disabled candidates from assistance, as well as causing discomfort to labelled individuals. Those for whom English is a second language may want the examiner to know. Someone with a hearing impairment may wish to share information about a requirement to lip read.

A viva may feel like a test of social communication and personal organisation but The Premia Project (2007:1) provides reassurance in a set of guidelines entitled ‘Preparing for the Viva’.
‘If you feel that the viva will present obstacles to you because, for example....you have Asperger’s syndrome and social communication difficulties, then it is helpful to look at what is not being assessed in the viva....your capacity for reading non verbal signals and esoteric humour...your lack of fear...’

The reader is invited to read that again without the words ‘Asperger’s syndrome’.

Students labelled with AS (and arguable some for whom English is a second language) are likely to become confused and anxious when encountering ambiguity, figurative speech and aspects of social communication. As a result they may come across as socially awkward (Attwood 2007, Beaumont and Newcombe 2006 Bogdishina 2005, Premia Project 2007). Clearly stating for example that it is appropriate to shake the external examiners hand and then sit down might ease those first few difficult seconds. Stating the obvious (without being patronising) reduces the requirement for a potentially very stressed candidate to pick up on subtle clues in verbal and body language (Beardon and Edmonds 2007).

An examiner who is prepared to ask straightforward questions, and to rephrase and clarify is likely to be most helpful for a candidate who is not a confident communicator. Allowing for pauses and thinking time would be less stress inducing than interrupting what may well be a necessary reflective silence. ‘The viva will start when I ask you the next question, this is the last question, and the viva is now over and you can leave the room’ are examples of obvious statements which could smooth the process. The candidate, particularly when anxious, may well struggle to work out what is in the examiners head. Academics in autism refer to differences in the development of theory of mind (Baron Cohen and Swettenham 1997, Howlin et al 2000). When expectations are made very clear, the stress of having to try and read the examiners mind is reduced. This does not only apply to people with the AS label.

Autism theorists refer to deficits in ‘central coherence’ which relates to the ability to prioritise or identify the salient issues within the bigger picture. (Baron Cohen and Swettenham 1997) Statements like ‘I do not want you to focus on that particular detail of your methodology, I want you to consider the broad application of your findings.....’ may seem rather directive but may well be necessary if the candidate begins to perseverate on a seemingly insignificant point. Anyone in a highly anxious state is likely to be better served by an examiner who does this The Premia Project (2007:5) provides guidance on accessible vivas for scholars with a range of impairments Those without impairments are also likely to benefit from such recommendations as ' devise early questions which (the candidate) will be more confident in handling.’

Some people labelled with AS are strong visual learners (Grandin 1996) and this also applies to other neurodiverse learners (BRAIN-HE). It may
be possible to exploit this strength during the viva (and preparation phase). Mind mapping (Buzan 1974) may well assist the formulation of a response to a question like ‘what would you say is the original contribution of your thesis to the area of study.’ Engaging in the process of drawing a diagram during the viva could well enhance focus and clarity and reduce stress.

‘I used Inspiration software to plan the structure of my thesis and I use a massive whiteboard so I can organise my ideas’.

Poor sleep is often a characteristic of AS (Beardon and Edmonds 2007). This can also be the case for individuals with chronic health conditions or high levels of anxiety. Timetabling an afternoon viva may be the answer. Rest breaks (with appropriate security) could be considered if necessary. Encouraging consumption of a light meal and a drink in advance of what is likely to be a draining experience could be useful. Without a reminder a stressed candidate might forget. It would be considerate to equip the room with water and a fan, or heater, depending on the season. Ramadan would be relevant to timing for Muslim scholars.

‘I have always taken a drink and a snack into exams because of my diabetes’.

Maslow’s 1970 writing on the Hierarchy of Needs serves as a useful reminder that people can not readily engage in higher order activities, such as giving of their best in a viva, when they are tired, hungry, thirsty, the wrong temperature, anxious and feeling that they do not belong. Treading softly around PhD candidates is recommended, especially as the viva approaches.

‘There is no way I will be able to think clearly if I am petrified’.

The Premia project (2007) considered potential awkwardness arising from not knowing what the word ‘viva’ means, and suggested routinely providing a definition. Doing so could ameliorate the disproportionate disadvantage which may otherwise arise for those who do not have a rudimentary grasp of Latin. False assumptions about the viva automatically marking the end of the journey could also be countered by a simple explanation. While those who have seen other family members go through the process may know this, others may not.

After the Viva

Scant research is available but it is possible that post viva stages may be particularly stressful if they are poorly understood. Surprise was expressed for example by a candidate labelled with AS who had assumed that the viva marked the end of the PhD journey. Candidates, without the luxury of a family doctoral tradition, or access to information about the likely requirement for further work post viva may well be disadvantaged. Some international scholars could be surprised by UK practices. Clarity
about routines and conventions would be useful for any student but
arguably particularly crucial for anyone for example experiencing an
episode of poor mental wellbeing which is manifesting itself in acute
anxiety. Those with organisational difficulties or lack of familiarity with UK
postgraduate level study could also benefit.

Unnecessary worry may be avoided if the social context and expectations
of the viva were to be mapped out simply, and the likelihood of further
work clearly articulated. Possible advantages of routinely telling all
candidates about the way the viva will be structured, and explaining
follow up arrangements (rather than assuming understanding) include
equitable access to information and avoiding positioning some candidates
as other.

Ideally candidates will approach the viva fully aware that it is not likely to
be the final hurdle. This has not been left to chance. They will have been
told routinely and repeatedly that corrections are normal. Written and
verbal Information reinforcing this understanding will have been provided
by supervisors and administrators. Tender loving care in the form of tea,
cake (or a suitable gluten free alternative) and useful feedback is likely to
still be needed after the viva, even if this is the case.

A humane approach would be to provide written pointers to back up
careful feedback discussion preferably later the same day. The candidate
would benefit from being able to leave the room with a sense of
achievement and an understanding of what they need to do next.
Appropriate support may well be necessary in order to assist with the
practical, academic and emotional implications of information received at
this point, particularly if the news is not good.

‘The PhD feels like a matter of life and death to me’.

Concluding remarks

In an inclusive culture the requirement for reasonable adjustments and
special arrangements for an othered minority may well be reduced.
Suggestions presented here are a starting point and require further
evaluation with a range of candidates (with and without impairments).
Guidance which follows is designed to be straightforward and generic and
aims to avoid positioning some doctoral students as other. While the
focus of the discussion has been on the final stages of the PhD, in order
for the following pointers to be most useful, earlier stages are also briefly
considered.

Good practice suggestions

1. Inclusive practice is good practice and not a disability thing.
   Routinely excellent administrative systems are essential for all
   PhD candidates. This should including written guidelines and
   appropriate support with form filling if necessary.
2. Regular supervision sessions which involve careful recording and action planning are useful throughout the process.
3. Not all disabled candidates wish to disclose. The benefits of doing so need to be real and made explicit.
4. Negotiating information the candidate is prepared to share with the external examiner in advance may be helpful if there are likely to be any communication difficulties.
5. Familiarisation with the layout of the room in advance could be helpful. Drinking water and comfortable temperature may alleviate sensory sensitivities.
6. The candidate should be told approximately how long the viva is going to last, who will be present, and the follow up activity that will take place. The opportunity for a break may need to be built in and arrangements for how this could be organised should be worked out in advance (e.g. that they will be accompanied if they leave the room). A brief written note of this sort of information will provide something to refer back to.
7. It is useful to acknowledge to the candidate that everyone is nervous to an extent when taking their viva. This could minimise the potential for feeling that being anxious is a personal failing.
8. Specific advice about what can be taken into the room would be useful as part of a set of clear written guidance about the process.
9. In a non patronising way it would help if the candidate was advised to have something to eat and drink and to go to the toilet in advance of the viva.
10. When several people are going to be present at the viva, the rules of engagement may need to be made very clear. Otherwise the candidate may struggle, for example, with an unspoken assumption that it is not necessary to look at the supervisor or include them in conversation.
11. Ambiguous questioning may fluster the candidate and s/he should be provided with specific strategies to seek clarification, such as saying ‘Please will you repeat /rephrase the question’. The examiner should be encouraged to ask short clear questions, to allow time to respond, and to ask supplementary questions if further elaboration is needed. Having the opportunity to practice asking for clarification may be useful.
12. The examiner could be briefed to use phrases like ‘I’m going to stop you there and ask you a slightly different question on the same theme’ if the candidate is going off the point or floundering. Questions like ‘can you say a little more about that’ might be a bit too ambiguous (and could elicit a yes-no response) therefore a degree of prompting may be necessary. The candidate should be briefed that the examiner may use such strategies (which could be demonstrated in a practice session).
13. Post viva feedback needs to occur as soon as possible and be very specific and sensitive. The candidate should leave the feedback session knowing exactly what they have done well, and what they need to do in order to complete. It is also important to spell out that it is usual to have to make some amendments (a topic which should have come up during viva preparation). All feedback should be followed up in writing ASAP by an agreed date.

14. Assistance should be made available for any follow up action and this should be clarified in writing, and discussed carefully, in order to avoid unnecessary rewriting.

15. If the candidate fails their PhD, it is essential that a safety net is put in place. An M. Phil is likely to be perceived as a fail and very careful discussion, on more than one occasion, around the merits of this award, will be necessary.

16. The presence of an advocate may help when the viva is discussed and candidate should be given this option.

17. Graduation should be accessible.

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Are they?... My Experience of Support through University

Jonathan Harvey

Abstract

Within this paper I will describe my personal experiences and outline the way I feel higher education could be organised in such a way that better suits neuro-diverse individuals. However, due to the magnitude of different presentations of neurodiversity, there is no single method of organising higher education institutions in such a way that accounts for every person’s uniqueness. It follows therefore that an individual approach needs to be adopted.

Introduction

I am a 28-year-old British man who at 19 left my parents home and set off to study physiotherapy at a UK University. After completing the first two years of the course, I suffered a serious traumatic brain injury which led to me having to withdraw from my studies. After several years of rehabilitation, I embarked on a three-year BSc (Hons) degree at another English University. I graduated in June 2010. Throughout this paper I will include excerpts of my own experiences of going to university as both a neuro-diverse and a neuro-typical individual.

Having completed my degree, I feel well positioned to comment on some of the difficulties that the transition into higher education involved for me as a neuro-diverse and neuro-typical individual. I prefer to use the term ‘disabled’, which in my opinion does not reflect individual diversity. I find terminology such as ‘disabled student’ or even ‘neuro-diverse student’ unhelpful and over generalised. Disabled naming risks compartmentalising groups of individuals and suppresses individuality.

I believe there are three key areas which determine the success of services for neuro-diverse in higher education. Firstly, the process of transition; the time leading up to the start of university brings many difficulties, fears and challenges for neuro-diverse individuals. Secondly, individually tailored services may be necessary during the programme of study. Finally, neuro-diverse individuals need to be provided with expert assistance when the time comes to enter the job market as graduates.
Arguably, widening participation policies have increased diversity and the inclusion of ‘non traditional’ learners:

‘A higher education qualification could help you take charge of your future by building skills and confidence and opening up new opportunities.’ (Direct.Gov 2010)

Whilst I believe this is an encouraging development, higher education establishments now need to recognise and be aware of the challenges that entry into higher education presents to neuro-diverse individuals. Challenges associated with transition are often underestimated and this is a time which is typically full of uncertainty for all students. These feelings are often accentuated for neuro-diverse individuals in transitional (Burgstahler 2001, McEachern and Kenny 2007). The diary excerpt below documents my memories of the day I left to go to university as a 19 year old ‘neuro-typical’ individual. (i.e. before I suffered my head injury.) If these thoughts and feelings in any way reflect what any ‘neuro-typical’ individual faces, then I would suggest that the level of trepidation and uncertainty felt by a neuro-diverse individual facing a similar situation may well be far greater.

It is the morning that I am due to go to the University of x for the first time. As a 19 year old who has never lived away from home, I am fearful of what lies ahead. I pace up and down my parents' lounge without direction, contemplating what lies in wait. My head is full of uncontrollable thoughts and questions. Who will I live with? Will they like me? Will I be able to make friends? And of course ... what about the course? More thoughts of a similar nature hit me. Will I be able to make friends? Will I be able to cope with the course? Is this what I really want to do with the rest of my life?

Disclosure

Neuro-diverse students are encouraged to provide details of their condition to allow the higher education institution to prepare for their arrival and make transition as smooth as possible. On the face of it this seems a very sensible proposal which may ease transition. However, according to research by Blundell and Vickerman (2010) which examines the experiences of disabled individuals within higher education institutions, it was found that although 75 per cent of students declared a disability on their application form, only 47 per cent of these students were contacted prior to the commencement of their studies. Failure to contact students at the pre-entry stage may well exacerbate anxiety. I was lucky. I disclosed my disability to the University prior to enrolment and I was offered an interview to discuss my requirements. I was also given support in completing my application for a disabled student's allowance. The fact that I knew the University was aware of my disability greatly eased my sense of trepidation and in my opinion this helped my
transition into higher education considerably. My reflections which follow however still illustrate some nervousness.

*I am due to start university (again!). Once more I have similar worries. Will I be accepted? Will I be able to cope with the course? Will I be able to make friends? And what about access? At least the University knows all about my disability and has supported me and encouraged me to embark upon the course. As I park my car, I am fully aware of the great changes that are about to take place in my life and the hard work that lies ahead. Oh well, here we go!*

The huge impact that pre entry and early support (or conversely its absence), can have is easy to underestimate. Fear amongst many neuro-diverse people that the disclosure of an impairment will lead to stigmatisation may well limit willingness to disclose. This fear was recognized by Jacoby and Austin (2007) when discussing the discrimination in relation to epilepsy. Acknowledgement of this fear by practitioners in diverse roles within higher education is advocated.

**Induction Period at University**

Initial reassurance about entitlement-based services during the induction process is likely to be necessary particularly for students who fear discrimination.

Higher education institutions therefore need to make the disclosure process as informative and accessible as possible. Riddell, Tinklin and Wilson (2005) suggested that the approach to disclosure in many universities at the time of their research (2005) did not always lead to social justice goals being met. For example, they state that:

‘Dyslexic students who tend to be male and middle class have been the greatest beneficiaries (of the current system), whereas poorer disabled students and those with more significant impairments have been less likely to be included.’

(Riddell, Tinklin and Wilson 2005: 623)

The wide ranging nature of disability/impairment that neuro-diverse students face, necessitates that each individual requires and receives, different levels and types of support. Increased individualisation during induction may be a good way to start arranging more targeted services. The system that I encountered did not, in my view, take sufficient account my specific requirements. Without adequate consideration of individual differences, people with the same label may find themselves with a standard package rather than tailored services. (Neuro-diverse individuals are) ‘different in their support needs, in their aspirations and in their values’ (Shakespeare 2006: 51)
Life at University

Since the mid 1990’s, higher education has become far more accessible to students with disabilities. I believe this is largely due to the influence that groups such as SKILL (National Bureau for Students with Disabilities) have exerted within the sector. Previously, university was less accessible to neuro-diverse individuals and given the complete absence of any official inclusion policy, any necessary adjustments were made by universities on an ad-hoc and individual basis, (Barnes cited in Riddell et al. 2007). The introduction of Disabled Student’s Allowances and core funding to support disabled (neuro-diverse) students created, for the first time, a more consistent opportunity for students to be judged on their academic ability.

Defining neuro-diverse students as ‘non-traditional’ students has led to criticism from many (eg. Riddell et al. 2007) because of connotations of othering and ‘abnormality’. The fact of the matter for me, however, is that as a neuro-diverse learner, I did require extra support. It made a positive difference to my experience. Moreover, I personally feel that the attention paid to theoretical ‘models’ of disability, distracts from ensuring that neuro-diverse individuals, such as myself, receive the individual support that enables us to attend university equitably. Inclusion of neuro-diverse individuals into mainstream society at graduate level is beneficial for neuro-diverse individuals, but also to society as a whole. A move away from discourse surrounding ‘models of disability’ would, in my opinion, represent a real progression in the search for equity for ‘disabled’ individuals. A focus on specific issues such as identity which can create inequities is now needed. This is stated by Claire Tregaskis in her (2002) critique of the social model of disability:

‘More attention needs to be given to further developing theory-level responses to problems like the persistence of disabling attitudes, and to the possibilities and the problems which may derive from working with non-disabled people’. (Tregaskis 2002: 467)

A focus on how society can include neuro-diverse individuals through such schemes as the disabled students allowance is in my opinion an example of the promotion of inclusion.

I remember the day when I had just begun work on my first assignment as a student at the University of Plymouth. My Disabled Student’s Allowance enabled me to be provided with a dictaphone in order that lectures could be recorded, as I was not able to take notes effectively. This allowed me to listen to the lectures at my own pace and in my own time, which undoubtedly improved my chances of completing my assignments successfully.
Having now completed my degree, I cannot help but think of the criticism that such schemes as the 'Disabled Students Allowance' have received. Frankly, any thoughts of whether such schemes may or may not be 'politically correct' do not figure in my mind. I am just very pleased and grateful that the 'Disabled Students Allowance' has made my life as a student far easier.

A likely source of concern for neuro-diverse students is whether the teaching and more importantly, the assessment processes at the university will cater for their individual requirements. I feel that an individual needs-based assessment at the beginning of the course is essential in order to ascertain what it is that the student requires rather than what it is that a label dictates.

Under the Disability Discrimination Act, universities have a duty to take 'reasonable steps' to prevent disadvantage for disabled /neuro-diverse students and promote equality. My own experience fell short of this and illustrates how a system set up with the best of intentions does not always manage to deliver.

It is the morning of my first exam at the University of x. I take a last glance at my notes and walk into the exam room. I am in a separate room to the rest of the students on my course, as I require my answer paper to be transcribed by a non-medical helper. This task is being completed by a postgraduate student whom I have never met. To add to my fear of the exam, the postgraduate student who is to transcribe my answer paper is not from the UK, and his grasp of the English language is far from perfect. My heart is racing and my mind is full of fear and trepidation before the exam has even begun!

Long term plans and entering the world of work

Blundell and Vickerman (2010) suggest that there is little doubt that the Disability Discrimination Act has greatly increased the awareness of the issue of disability in the world of work. Opportunities for employment are notionally becoming more readily accessible for neuro-diverse individuals, however, I have found the transition from education to employment to be an extremely difficult time. I have to compete with my 'neuro typical' counterparts in the job market to demonstrate my ability and be acknowledged in the employment market.

I feel that the most significant test of the inclusion that neuro-diverse individuals strive for, lies with the cooperation, or otherwise, of individuals in the work place. Only when disabled /neuro-diverse individuals work
Alongside ‘neuro typical’ individuals in all areas of society, can society be judged as truly inclusive in my view.

‘Most disabled people experience their actual physical impairment as the least of their problems. It is the attitudes and reactions of others to the impairment which are felt to cause the most frustration.’ (Wilson 2006: 177)

This statement from Wilson (2006) conceptualises the difficulties that many neuro-diverse individuals face. Equity demands attitudinal change. In an inclusive society, specialist employment databases for ‘disabled’ workers may be a thing of the past. This is not to criticise these systems, but their very existence, with slogans such as ‘local disabled workers fulfilling local needs’ (Disabled Workers Database 2010), proves beyond doubt that disabled /neuro-diverse individuals are at a disadvantage when entering the employment market.

Summary and concluding thoughts

This paper has explored three specific areas in which neuro-diverse individuals who study at higher education institutions require support.

Before embarking upon a higher education course, neurodiverse students need encouragement to disclose relevant information in order to allow institutions to provide necessary services. Transition from further education or sixth form colleges to higher education can be particularly difficult and support package should be tailored to the individual. Requirements may change on programme and provision needs to be kept under review systematically. Finally, effective advice services are necessary for a smoother transition from education to the world of work.

As a neuro-diverse person who has experienced all of these periods of transition, I have tried to provide advice and some solutions from an insider perspective. My experience tells me that the individual identity of each neuro-diverse student is relevant to the tailoring of necessary services. Categorising and providing for neuro-diverse individuals by label, rather than individual requirements must be avoided at all costs. Disabled students, including those experiencing neurodiversity, are each absolutely unique.

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Open Minds: Enhancing Student Mental Wellbeing and Success through Inclusive Practices

Charlotte Morris

Abstract

This paper responds to current concerns about the mental health and wellbeing of students in Higher Education and reports on the findings of Open Minds, a University of Brighton project run over two years from the Centre for Learning and Teaching. This action research project has explored student mental health and wellbeing in relation to learning and teaching through surveys and ongoing evaluation of interventions over two years at the University of Brighton. Through investigating perceptions of staff and students and identifying factors which impact on student wellbeing, especially during transitions, the project links student wellbeing with effective learning. It identifies inclusive strategies which have the potential to enhance wellbeing and learning for all students, as well as enabling students who may be experiencing mental health difficulties (whether disclosed or not). This paper therefore argues for the mainstreaming of inclusive teaching and learning strategies to optimise student wellbeing and success.

Introduction

Open Minds is a research and development project run from the Centre for Learning and Teaching at the University of Brighton (2008-2010), funded internally through HEFCE funds allocated for Widening Participation. The project was designed to work collaboratively with colleagues from across the university to explore ways to enhance (1) the learning experiences of students with identified mental health difficulties and (2) the wellbeing and success of all students. Building on previous research in this area, the project has taken a three-pronged approach to enhancing the learning experiences of students with mental health difficulties including awareness raising / anti-discrimination campaigning; research into inclusive practices and student experiences to underpin staff development and resources and the promotion of mental health and wellbeing, linked to pedagogic practices.

This work set out initially to identify barriers to learning that students with experience of mental health difficulties face and ways in which universities can best enable and empower students with experience of mental health difficulties. It then focused on ways in which universities can support student mental wellbeing, thereby adopting a preventative approach and identifying effective ways of creating an inclusive, stigma free learning culture. To this end, the project sought to capture student and staff
An aim of the project has been to address stigma surrounding mental health, which can be a major barrier to participation for people with mental health difficulties (Thornicroft, 2007). Activities have included mental health promotion and awareness raising events, which have helped to raise awareness of mental health difficulties among staff and students, and the piloting of academic staff development sessions in conjunction with Student Services. Furthermore, due to the importance of taking a preventative approach to mental health promotion and awareness raising events, which have helped to provide strategies for managing student difficulties, and these may potentially trigger or exacerbate episodes of mental health difficulties.

The term "mental health difficulties" refers to a wide spectrum of diagnosable conditions, including depression, anxiety, phobia and bipolar disorder. These can range from mild to severe and can be short or long-term. According to the DDA (Disability Discrimination Act), students who have mental health difficulties which have an ongoing debilitating effect on daily life for a year or more are classed as disabled. However, with low disclosure rates it is impossible to gauge the full extent of mental health difficulties among students. Many students may therefore experience milder forms of stress associated with higher education and these may potentially trigger or exacerbate episodes of mental health distress which can be triggered by stressful events such as bereavement and this may have a debilitating impact on their studies. The prevalence of students with experience of diagnosable mental health difficulties would, however, be likely to be at least as high as the general population, which in Britain is 1 in 4 in the course of a year (World Mental Health Foundation, 2006). Furthermore, previous studies have identified students as being a particularly vulnerable group, as mental health issues tend to emerge in late adolescence / young adulthood. There are particular stresses associated with student life such as being away from support networks, financial and academic pressures, social isolation and lifestyle issues, such as exposure to drugs and alcohol (Royal College of Psychiatrists, 2003). Many students may therefore experience milder forms of stress associated with higher education and these may potentially trigger or exacerbate episodes of mental health difficulties.
current practices around student and staff mental health and wellbeing, to plan for and build on initiatives and to identify sustainable ways to continue to promote and embed wellbeing across the university. As stated in the Wellbeing in Higher Education group ‘Guidelines for Mental Health Promotion in Higher Education’:

Effective mental health promotion involves not only attending to the needs of those with mental health difficulties, but also promoting the general mental wellbeing of all staff and students, which will in itself bring significant benefits to the HE institution. Improved general mental wellbeing will impact on institutional reputation, staff and student recruitment and retention, performance in general and on community relations. (Crouch, Scarffe and Davies, 2009).

Consideration of student wellbeing moves the focus from labelling students with mental health difficulties to attending to the wellbeing of the entire student population, fostering a preventative ethos. This inclusive approach underpins the fact that anyone can be susceptible to mental health and other health difficulties and so contributes to destigmatising mental health difficulties. It focuses on positive mental health: ‘A state of wellbeing in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community’ (World Health Organisation). Research suggests that by attending to the wellbeing of a whole population, the incidence of extreme problems such as stress-related illness is likely to diminish (Chapman and West-Burnham, 2010). Throughout the past 10 years, the concept of wellbeing has been utilized by industry with businesses keen to address stress-related absence and under-performance and to optimize performance and business success in their workforces. It has also been a concern for schools, keen to address health and educational inequalities and more recently the Government has funded research into the importance of wellbeing for life-long learning (Forsight report, 2008). The costs to society of stress-related problems is enormous in terms of staff sickness, unemployment and health costs (Mental Health Foundation) and studies, measuring specific criteria, have shown that the UK lags behind other European countries in terms of supporting the wellbeing of its young people in particular (UNICEF, quoted in Chapman and West-Burnham, 2010). While the New Economic Foundation (2007) has identified that wellbeing should be seen as an indicator of quality in Higher Education and increasing numbers of universities are attending to staff and student wellbeing as part of a health promoting strategy, wellbeing has remained inconsistently theorized and underdeveloped as an educational concept. An underlying aim of Open Minds has, therefore, been to develop the notion of wellbeing and operationalise within a Higher Education context. In the current economic climate, it can be argued that the development of wellbeing strategies throughout the educational career is essential for
young people to engage fully in fast paced, diverse, ever changing and uncertain job markets and working environments:

The world’s economies and businesses, emerging from a period of increasingly rapid change, need a new set of behaviours and skills. Young people leaving education will need to demonstrate adaptability in dynamic and complex environments. At a personal level, they need to acquire, develop and secure skills, behaviours and strategies. This knowledge also needs to have significant personal meaning so that they can feel confident adapting ideas in different situations. At a social level, their attitude needs to translate into behaviour that demonstrates both tolerance and acceptance of different perspectives within a culture of increasing diversity.

(Chapman and West-Burnham, 2010)

The University of Brighton is already highly engaged in developing wellbeing, for example through allocating resources and dedicated spaces to health and wellbeing, employing a Curriculum Development Worker for Counselling and Wellbeing and incorporating wellbeing concerns into learning development activities. While the main focus of the research was developing the links between student wellbeing and learning and teaching, the project took a holistic approach to enhancing student wellbeing in the long-term, working collaboratively with colleagues across the university and in the wider community towards a shared vision, and coordinated effort to develop positive practice in relation to mental health and wellbeing at the University of Brighton and beyond.

**Literature**

There has been increased interest in and research around student mental health following the Special Educational Needs amendment to the Disability Act (SENDA) 2001, requiring educational institutions to make adjustments for and in anticipation of the needs of disabled students, including those with experience of mental health difficulties. A wide range of research has been conducted in universities across the UK to raise the profile of student mental health and to initiate discussion, new resources and further research in the HEI sector and beyond. According to the Mental Health Foundation, 1 in 4 of the British population suffer from mental health issues in any one year, and 18 – 25 is the age during which issues are most likely to surface. In addition, university life contains many complex stress factors and characteristics, which may exacerbate these problems (Royal College of Psychiatrists, 2003) including transition, financial pressures and sometimes high risk behaviour. It is therefore highly likely that academic staff will come into contact with students with mental health difficulties during the academic year, although these may not always be apparent or disclosed. In a University of Hull study (Stanley et al, 2000), 35% of academic
supervisors reported recent experiences of student mental health problems, 28% of problems described as ‘severe’ or ‘life threatening’. A UK Universities/SCOP paper ‘Reducing the Risk of Student Suicide: Issues and responses for Higher Education Institutions’ (2002) concludes that there may be significant risk of suicide and deliberate self-harm amongst a small proportion of the student population in any higher education institution and higher education institutions (HEIs) therefore have a responsibility to minimise that risk as far as possible.

However, despite apparently rising levels of mental health issues among young people and students, a study carried out at the University of Lancaster (2003) found that ‘many students do not declare any mental health needs at application or prior to entry.’ They identify that this is common because of continuing problems over stigma and mental health in our society. The 2007 UCLAN / PAPYRUS study of student suicide suggests that there is a need for a focus on early intervention when problems emerge and that HEIs should therefore adopt a preventative approach to students developing severe problems and potentially being at risk (Stanley, 2007).

Broad based quantitative research undertaken in universities, as exemplified by the University of Leicester 2001 study (Grant, 2002), has provided a crucial source of information with regard to the extent of mental health problems in student populations and factors in the learning environment, which may have a detrimental effect on mental health, with implications for student progression, retention and achievement. In a survey of over 1000 students, a high proportion (50-60%) of students reported concerns regarding academic progress, particularly in terms of their ability to manage coursework and assessment (60%), the ability to set priorities, make decisions and manage time (59%), concentration (58%) and the ability to meet academic/career goals (63%). Other concerns included adjustment to student life, especially in terms of dealing with inadequate finances (58%), managing psychosocial health (i.e. depression, mood), personal development and relationships. It was found that one in six students are likely to be experiencing at least moderate symptoms of depression and a similar number displaying obsessive-compulsive symptoms. In terms of seeking help, it was found that students are most likely to turn to those they know best such as friends and family (65%), and Personal Tutors (54%) as opposed to the Counselling service (7%). The study concludes that widening participation brings a particular set of responsibilities to ensure that ‘the learning environment in each institution is as responsive as possible to the needs of the full range of students’ (Grant, 2002, p.100).

More recently, a study of 750 students across 3 universities (Mitchell, 2008) and based on the psychological health questionnaire designed as part of the earlier University of Leicester study (Grant, 2001) found that 35.5% were experiencing high levels of stress in term 1 and 34% in term
2. A significant number of students (up to 72%) were experiencing stress related to studying and academic performance. Significantly more stress levels were reported by those with no family history of Higher Education. As with the first study, it identified academic staff as key personnel in terms of help seeking and it identified that students are often unaware of the available support. The study recommends improved arrangements for feedback; a return to more personal tutors in terms of pastoral care and the provision of more information to prospective students.

Studies have shown how academic difficulties can be managed through a range of personal coping strategies, institutional and external support. They suggest the need to target the raising of awareness in university populations as a whole, to improve knowledge and challenge the stigma of mental health, so that students are more likely to seek help and receive adequate responses. Providing students with effective wellbeing strategies potentially equips them to cope with their studies and prepares them for entering the workforce. The Open Minds project acts and builds on this body of research, but has aimed to develop a fuller consideration of the role of learning and teaching in developing an inclusive, “mentally healthy” and wellbeing friendly university.

Social / Medical Models of Disability

The project follows a social model of disability, which sees the barriers preventing disabled people from full participation in any situation as ‘the problem’, rather than the impairment. This model of disability is particularly useful in higher education and enables an emphasis on identifying and addressing barriers to learning, achievement of potential and full participation in the student experience.

Under the social model, disability is caused by the society in which we live and is not the ‘fault’ of an individual disabled person or an inevitable consequence of their limitations. Disability is the product of the physical, organisational and attitudinal barriers present within society which can lead to discrimination (OU, 2006).

Disabling barriers for people with physical impairments may include the physical environment as well as prejudice, discrimination, fear, pity and underestimation of disabled people’s ability to achieve and to contribute to society. For those with mental health difficulties, socially created barriers such as fear, ignorance, negative media images, stereotypes and discriminatory language may be extremely difficult to overcome and can lead to self-stigmatisation and anticipated stigma, whereby they expect to be devalued and devalue themselves (Thornicroft, 2007). While some students with mental health difficulties may find that their learning is affected through their condition or side effects from medication, stigma is a major barrier to full participation in HE which can exacerbate the problems, lead to social isolation, low academic expectations and prevent
students from accessing advice, information and support. Low expectations and the assumption that additional support will be required tends to homogenize students with mental health difficulties, ignoring internal strategies for self-management that students may have developed as well as external support networks. Furthermore, a consideration of how the learning environment and learning, teaching and assessment practices may impact on student mental health is essential.

**Inclusive Teaching Practices**

Inclusive teaching practices aim to encourage, include and value a wide diversity of learners. Rather than making adjustments or alternative arrangements for an individual or specific group of learners only, inclusive practices are embedded in the planning and delivery of learning. For disabled students, this can diminish labelling and inclusive practices can have benefits for all students, emphasising that all students have different learning styles and needs. An example is that students with mental health difficulties may need guidance on managing their time, clear, easily accessible lecture notes provided in a variety of formats and a range of assessment options. Incorporating these adjustments into course design may benefit a great number of students and support their wellbeing by reducing stress and enable success. It also overcomes the danger of stereotyping disabled students, avoids the risk that individual students’ disabilities are seen as a problem and reduces the need for individualised adjustments.

As universities continue to develop their practices, in response to widening participation and changing legislation, further research is required in this area. Individual institutions are conducting internal research, impact assessments, reviews and monitoring of their processes and practices with regard to student mental health issues; there may be also many benefits associated with collaboration with other HEIs and the wider community at local, regional and national levels. Studies have consistently recommended a whole institution approach to challenging stigma, to promoting positive attitudes and support seeking and to adopt a preventative approach to student mental health. These studies and perspectives inform the Open Mind project’s three-stranded approach of research into inclusive learning and teaching strategies, university wide anti-discrimination work and the promotion of student mental health and wellbeing – working collaboratively across the university to support developments in this area.

**Methodology & Methods**

This action research project involves the piloting and evaluation of interventions, such as awareness raising, anti-discrimination, mental health promotion and staff development activities, developed in
collaboration with colleagues at the University of Brighton. It has followed an action research model of cycles of planning, implementation, reflection and further planning with the goal of raising awareness, challenging negative perceptions, empowering staff to develop inclusive practices and ultimately to contribute to cultural change. Mixed methods were applied with both quantitative and qualitative data drawn from surveys distributed to staff and students. As well as gauging an extent to which mental health issues are a concern to staff and students, the surveys were designed to capture a range of positive strategies in terms of both self-management of wellbeing and inclusive classroom strategies. In addition to the surveys, personal perspectives of coping with mental health difficulties in HE are being sought from students through interviews, in order to provide unique insights into their experiences in Higher Education and coping strategies and / or support mechanisms that proved useful while in HE.

A Staff Survey was designed and piloted with 30 academic staff at a learning and teaching conference. It was then distributed online across the university and received 46 responses. It is intended to gain staff perspectives on working with students with mental health difficulties, identify staff development needs in this area and capture positive and inclusive teaching practices which staff have found to be effective.

The survey was designed to capture qualitative data on (1) experiences, perceptions, positive practices (2) any concerns or staff development needs and (3) what staff consider the university can do to enhance the learning experiences of students with mental health difficulties. The surveys were designed to produce qualitative data alongside the quantitative analysis required, in order to assess the level of need for academic staff development across the university.

Staff indicated a high level of need for staff development in the area of student mental health and wellbeing. One of the main issues of concern for academic staff was identification of mental health problems and lack of knowledge about what constitutes a mental health problem. Some members of academic staff required clarification that mental health difficulties are a disability. There was a lack of distinction between mental health difficulties and other disabilities; also between diagnosable problem and symptoms which could indicate a range of problems (such as shyness, struggling with academic work, poor social skills). Over 50% had worked with students with depression and a high number had worked with students experiencing anxiety, many of which were undiagnosed and so not included in the university’s official disability data.

In terms of teaching practices, some academic staff find adapting their teaching practices challenging / confusing and are uncertain of the value of adapting teaching practices for students with mental health difficulties. This may be partly due to confusion because of the range of disabilities staff may need to adapt to and such staff therefore tended to adapt on an
individual needs basis rather than changing their practices to become more generally inclusive. The survey suggests that many academic staff lack confidence and knowledge around teaching students with mental health difficulties, wanting to see further staff development in this area. There may be a tendency to see the student’s condition as the main problem, rather than the environment or learning culture. One barrier identified was the staff to student ratio: ‘with teaching groups of over 100 students, identifying vulnerable students and helping them is generally impractical.’ Some staff also indicated that they felt overwhelmed with the number of disabilities they were required to adjust for. There tended to be an emphasis on making adjustments for individual students identified by Disability Services and some staff were unaware of the prevalence of mental health difficulties, believing that they would only come into contact with students with mental health difficulties by chance. There were particular anxieties about identifying students with mental health difficulties and how to refer these students to Student Services. One problem with this approach is that not all students with mental health difficulties choose to disclose or indeed recognise themselves as disabled. However, as we have seen, a high proportion of students are likely to be vulnerable to mental health difficulties. The fact that students may choose not to disclose is hardly surprising, given the level of stigma that surrounds mental health difficulties in wider society. The project responded to these concerns through awareness raising, which focused on the prevalence of mental health difficulties, and highlighting, wherever possible, the availability of mental health awareness training and the Mental Health Policy which includes details on referral. The Centre for Learning and Teaching continues to work closely with Student Services with regards to staff development and resources. Many staff also came forward with excellent examples of inclusive teaching practices which can easily be incorporated into mainstream practice, including use of formative assessment to build confidence; small learning sets and buddying programmes; establishing ground rules; making course materials as accessible as possible in a variety of formats; providing clear learning outcomes; allowing for different learning styles, e.g. through use of visual aids; offering feedback as a “praise sandwich” and providing choice in assessment. These staff, through their comments, demonstrated a good understanding of and commitment to inclusivity in their practice, recognising the benefits for all students:

‘All material should be clear and easily interpreted by students from a wide variety of backgrounds – I see any sort of modification of this sort as an extension of that. Good teaching material is good teaching material for all.’

‘I might set up sessions to incorporate small group work (3 people) rather than a whole group seminar (30 people) takes the pressure off speaking in public and encourages student support networks.’
‘I’ve only been teaching in HE for 1 year and have minimal experience both as a teacher and especially teaching students with mental health difficulties. However, I think similar principles to adapt teaching / assessment to suit students with learning difficulties could apply (e.g. providing more time when needed for assignments, ensure materials are available on Student Central in advance of lectures, and being available for students to provide feedback and tutorial support.)’

‘Reduce stress on students, adapt for different learning styles’

Staff also highlighted the importance of the physical, social and emotional environment in which learning takes place: ‘All learning environments should be as stress free as possible in terms of the physical environment and teaching processes.’ Some staff felt that more teaching in smaller groups would be more inclusive and others recognised the importance of making the learning environment safe and comfortable:

‘Learning environment needs to be made very safe for students to share experiences if appropriate’;

‘A comfortable learning environment reduces stress’;

‘Making the learning environment clearly structured and informal makes it easier for students to relax and to know where they stand.’

‘Teaching methods where students do not feel “put on the spot”’

In addition to ensuring inclusive practices are incorporated at course design stage for the benefit of all students, staff recognised that students have many individual support needs. Staff availability was seen as the most important factor in ensuring the needs of students experiencing mental health or wellbeing concerns are met: ‘Availability and approachability of staff are generally valued by students, but these are particularly relevant for students experiencing mental health issues.’ While some staff were concerned about time management, strategies such as keeping specific surgery hours were suggested. There was a recognition of the vital part one-to-one support can play, especially through the personal tutoring system, and the importance of developing skills in empathetic listening alongside developing knowledge of mental health difficulties and how to respond positively and effectively when problems arise, to ensure early intervention when necessary. Understanding roles, responsibilities and boundaries of academic and support staff along with effective communication is crucial when supporting students in crisis. These are seen as vital skills for all staff and it should be recognised that better awareness and knowledge about
mental health difficulties can help to reduce the fear, anxiety and stigma which can surround these issues and contribute to a more inclusive learning culture:

‘Mental health should be a concern for everybody. Anyone can have a mental health problem. Lecturers and others should develop basic skills to deal with basic mental health problems. Dealing with and minimizing mental health problems improves the performance of everyone.’

‘Students need to know that mental health issues are not shameful, do not have to hinder their degree progression, and that staff can be approachable, reassuring, supportive and accept them as they are.’

A Student Survey on mental health and wellbeing was designed in order to capture the stress factors at university generally and in learning and teaching activities in particular; it also aimed to gain a sense of students’ own coping strategies and ways in which they feel the university could improve in supporting the mental health and wellbeing of students. The survey was distributed online and in person, forming part of the activities of a Wellbeing Week. Findings indicate that students feel it is very important to care for their wellbeing while at university and that they employ a range of coping strategies. In line with findings from earlier research, friends, family and academic staff were perceived to be the most important sources of support for students. Academic work, especially the workload, deadlines (perceived to be too close together) and assessment and exams in particular, are the main source of stress in university life.

Out of 202 respondents, 70 (35%) reported experience of a recognised mental health difficulty; 50% of these formally disclosed / received some form of formal support within the university. Reasons for non-disclosure included where the student had recovered, was in recovery and the condition was being managed through self-management strategies, medication or other treatment; the student, while having a history of mental health difficulties is currently well; the student is unsure how to access support; mental health difficulties are not perceived as a disability (other disabilities may be disclosed); the student already has external support in place; there has been experience or expectation of stigma; the student does not want to be labelled; their mental health difficulties are emergent, not yet diagnosed or may not be defined as a disability under the current DDA definition.

The term ‘wellbeing’ has a variety of meanings for students, usually relating to positive functioning, and responses highlight the connection with their learning and ability to study effectively:

- Holistic (physical / mental / spiritual)
For students, when asked why it is important (or not) to manage their wellbeing at university, 35% indicated that coping with academic demands was the most important reason, followed by coping with the stress of university life generally (20%). Other reasons included the importance of staying well (12%); achieving academic potential (8%); enjoying the university experience (7%); coping with the transition to university (5%); preparing for graduation (5%) and general quality of life (8%). Responses indicated the importance of caring for wellbeing at university. All responses included are from students with experiences of mental health difficulties but reflect concerns voiced from many students and are applicable to all students:

‘University can be incredibly stressful and affect wellbeing. Also, wellbeing is vital in attaining good results, attendance and the high level of work that is needed at university.’

‘Wellbeing is important when at uni because the stresses of uni life including all the academic responsibilities students are faced with which would we would not be able to deal with if we are suffering with problems that we cannot effectively deal with due to low self-esteem, lack of confidence and other emotional wellbeing issues . . .’

‘Uni for most people is the first taste of complete independence and if we are not in a good state of mind the responsibilities we have to ourselves and others are neglected.’

‘Being physically and mentally 'healthy', for example, being able to cope with the levels of university work whilst also balancing some leisure time, exercise and healthy diet and maintaining relationships with friends and family outside of university.’

As with previous surveys (Grant, 2001), students identified that they tend to seek support from those they are already close to rather than specialist services and that apart from family and friends, in university this tends to be members of academic staff, whether personal tutors or lecturers. The most important sources of support were friends (29%); family members (21%); academic staff (16%); partner (5%); self-management (5%); peers (4%) and student services (4%). Other examples included spiritual guidance, faith and the Student Union.
Aspects of university life students reported as impacting most on their wellbeing, again in line with other research, included factors related to academic work (60%); poor work-life balance (10%); financial issues (9%) and administration issues (6%) such as correspondence, timetabling and rooming. Other issues identified included adjusting to independent living; social integration – problems with peers; coping away from family / friends; peer pressure (for example pressure to drink alcohol); the university environment; accommodation; issues in personal lives and worries about the future.

Specific aspects of academic work students struggled to cope with included deadlines (especially when too close together); workload; exams; coursework; staff unavailability; feedback; lack of information about what is expected at each level and teaching styles which may not always differentiate to meet different learning needs.

‘Assessments and exams could be spread more over the year. Currently they are all in the same 2-3 week period.’

‘I don’t feel as though I’m given enough information for me to feel confident and assured in what I’m doing.’

‘Clearer assignment tasks – currently vague and open to interpretation meaning that one tutor says one thing while another will mark you down for it – very stressful as you have to try and find a ‘happy medium.’’

As with academic staff, students identified a range of inclusive teaching strategies with the potential to support the wellbeing of all students, as well as those with recognised mental health difficulties:

- Clear expectations, learning objectives
- Clear, accessible course information (available online)
- Staggered deadlines
- Approachable / available academic staff
- More study skills development (especially groupwork, presentations, essay writing, coping with exams)
- Allowing for different learning styles
- Regular, clear feedback
- More opportunities for interaction with other students
- Building confidence
- ‘Asking for more feedback from students to check they feel confident to work independently.’ (student with anxiety)

Furthermore, students highlighted the importance of visible, accessible support; social integration; awareness of mental health and an
environment and wider academic culture conducive to wellbeing: ‘When wellbeing is not balanced, or there are things in one’s life that are difficult to deal with, the feeling of no support or time to change things can really affect one’s academic performance.’ Along with academic staff, students identified the importance of awareness and good communication to ensure an inclusive culture where students feel accepted rather than judged:

‘Better awareness so tutors treat mental stress and illness as an illness rather than a “lazy” student.’

‘I’ve experienced severe depression, and have not sought help at uni, tried, but felt uneasy about [support services] being at uni campus!!!!!! Don’t want it to be labelled.’

‘Understanding of problems/mental health issues which may occur - may reduce stress.’

Transitions

Transitions into and through university have previously been identified as particularly stressful times for students (Stanley, 2007) and concerns around transition came through in many student comments in this study, highlighting the difficulties around managing academic work alongside other responsibilities which students do not always feel adequately prepared for:

‘It is for many the first time living away from home, having to manage money, work, uni and home life in a new town with strange people. It can blow your mind!’

‘It poses stresses that you may have not encountered before, academic stress, housing, personal life and health’

‘There are so many pressures and new experiences which you have not had to cope with alone before. You are being thrown out into the world with little to no support, and it is easy to become distracted or carried away with something, or if you do not feel comfortable, to take it out on your self’

One of the main concerns around transitions related to social integration, with students struggling to make friends and finding group-work stressful. These issues could potentially be countered with careful introduction and management of group-work, including ground rules, enabling students to develop essential skills in collaborative team working. The theme of the social, emotional learning environment re-emerged:
‘Segregation among students; poor integration of students from different backgrounds. This causes me stress because I am very sensitive to bad vibes; I don't concentrate well on things and spend time worrying on why everyone just doesn't get along; I get paranoid and my self confidence is also badly affected. The time spent worrying can be used to study or come up with creative ideas. Everyone functions best in a friendly and happy environment.’

‘Team building... then I might actually meet people at uni’

‘Groups of people that stick together... I think that more could be done to diversify groups and allow people to mingle more with different people. I think it should be encouraged’.

In terms of academic work, throughout the course students need help to prepare for what lies ahead, to build confidence, develop the necessary skills and to understand what is expected of them. This is an essential aspect of inclusive practice:

‘Before the third year, more exposure and help with preparing for the year coming’.

‘Guidance is given but I am not sure what is expected of a 1st grade exam or assignment, explanation of this would be good’.

‘Introduce skills earlier to make people familiar with them (like presentations, essays, critical thinking.’

Conclusions

Inclusive teaching strategies which are characterised by good communication, clear information and opportunities for students to develop effective learning skills can contribute to minimising stress, improved wellbeing and student success. Learning, teaching and academic staff play a vital role in student wellbeing. Inclusive teaching strategies are shown to potentially benefit a wide range of students, supporting their wellbeing and success and so these should be mainstreamed and considered at course design stage. Learning development activities are also vital to enable students to manage their studies and wellbeing effectively and there is much potential in encouraging as much peer support and interaction as possible.

Since SENDA 2001, universities have worked to ensure their legal requirements towards students with disabilities are met. However, working towards an inclusive, stigma free culture which empowers students with mental health difficulties is a complex and ongoing task, which should be appropriately resourced. Stigma in our society is highly
pervasive and there is much misinformation (Thornicroft, 2007). It is essential, therefore, that all staff are equipped with knowledge and understanding about mental health difficulties and effective ways to respond when a student is in crisis, to ensure that universities are meeting their Duty of Care towards students. Adopting a preventative approach can contribute to de-stigmatising mental health and help to highlight the fact that everyone has mental health and we all need to adopt strategies to manage wellbeing while rising to the challenges of learning and working in academic settings.

Students reported that wellbeing is vital to optimise learning and academic performance and is an essential part of their personal, professional development. By supporting and enhancing the wellbeing of our students as they transition through university, we are maximising their learning potential and increasing the likelihood of their success. Moreover, this offers a more sustainable approach to supporting student mental health than a crisis-led model of intervention. Empowering students to maintain their wellbeing at university could potentially mean equipping students with essential life skills, which engender long-term learning and health benefits, optimising academic achievement and building resilience for future lives and careers in uncertain and fast paced job markets and environments. Much can be achieved through mainstreaming inclusive teaching practices alongside prioritising resources which support student (and staff) wellbeing and developing an inclusive learning culture and ethos within universities.

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Resilience, Transition and Disabled Students
Judith Garrett

Abstract

Many students identified with dyslexia report negative experiences in education. Complaints identified include low expectations, lack of support, lack of understanding, and negative attitudes from staff and peers. These experiences can significantly impact on individuals’ sense of self-esteem and self-efficacy, and affect decisions at transition, such as whether to aim for HE in the first place, and whether to apply for support. However, the way individuals react to life stressors are many and varied. Attempts to understand why people react so differently to similar or identical life events led to the study of the concept of resilience.

It should be noted that it is the attitudes, practices, and negative expectations within education that cause the problem for individuals with dyslexia, rather than the dyslexia itself. Disablist attitudes and practices are perpetuated, both consciously and unconsciously, in education and in wider society. The medical model of disability sees disability as ‘something wrong with the individual’. The social model of disability sees disability as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others, due to physical and social barriers (Cameron 2007). Unfortunately, the medical model is still apparent in education, involving the need for formal and official labels in order to access support. The label of dyslexia can be perceived both positively and negatively.

Resilience is defined as the ability to thrive against the odds, and involves the complex interactions of numerous personal and environmental risk and protective factors. In the context of transition to HE, protective factors may include personality traits, supportive structures and institutions to provide gateways to HE, supportive relationships such as support tutors and peers, role models, positive self-images, and the development of effective coping strategies.

The aim of this article is to discuss the concept of resilience in the context of disabled students, in general, and dyslexic students, in particular, at times of transition into further or higher education. Dyslexic students frequently report having very difficult and stressful experiences at school, yet reactions to these experiences are many and varied. A study of the concept of resilience suggests some of the factors involved that may explain these differing responses, such as risk factors, protective factors, and coping strategies that can interact to influence decisions and choices. For example, a range of factors interact when people are deciding whether to apply for further or higher education in the first place, whether
to disclose a disability and seek support, and subsequent emotional responses and attitudes to the experiences of post-16 education.

Research dating back to the 1990s consistently suggests that children within compulsory education, who have dyslexia, often experience negative psychological, social and emotional consequences as a result; such as chronic lack of confidence, feelings of inadequacy and generalised emotional distress, poor self esteem, and feelings of failure and frustration (Riddick 1996, 2000, Edwards 1994, Burton 2004, Passe 2006: quoted in Armstrong 2006) (Madriaga 2007). Even when individuals have apparently developed coping strategies and come to terms with their experiences, they may have spent years struggling with literacy and not understanding why, with all the potential for anxiety that this may cause, and anxiety and stress interfere with learning (Pavey 2010).

Complaints about school and college experiences usually tend to fall into 4 main categories: low expectations, lack of support, lack of understanding, and negative attitudes from staff and peers.

Young disabled people have been identified as having low expectations and aspirations, which can inhibit their life choices, and educational professionals can create and perpetuate this situation by not challenging disabled students academically.

A lot of the time the teachers don’t push the kids if they got special learning needs. They don’t push them. ‘It does not matter darling, if you have not done your homework’ (female wheelchair user age 30 - quoted in Madriaga 2007 p403).

For most of the students interviewed by Madriaga, education professionals were frequently perceived negatively because their advice was seen as misinformation: for example, one respondent (female, dyslexia, age 20) claimed that the advice from teachers, when she was seven years old, was inaccurate. As a result of the advice, her parents did not think she could aspire to higher education. As she stated:

‘the money that they [parents] would have probably saved if I did go to university, they never saved because they thought I never would’ (Madriaga 2007 p403).

Tutors often did not take positive steps to ensure that disabled students acquired equal access to learning, and did not expect student respondents to excel academically or pursue higher education. Unsurprisingly, the action or inaction of school tutors impacts on the attitudes and confidence of individuals at transition, when making decisions about the pursuit of higher education. (Madriaga 2007, Du Pre, Gilroy & Miles 2008).

Individuals categorised as dyslexic also often tell of lack of support in education (Pavey 2010). This can take a variety of forms; including failing to identify dyslexia in the first place, inaccessible teaching strategies,
failure to accommodate different learning styles, unrealistic demands, and inflexible attitudes. Even when students ask for help, this is not always forthcoming; for example:

*I emailed one of my lecturers after my first maths assignment to see if they could help me. Then, they never emailed back. So, it was things like that. But, I know if I got things before the lecture at least I will be able to go over it. I might understand a bit of it by going over it twice to help me sink into it a bit more.* (female, dyslexia, age 19) (Madriaga 2007 p408).

Often, this lack of support can be attributed to a lack of understanding about the nature of dyslexia. A 13-year old dyslexic boy expressed his frustration at being told by teachers that he must ‘try harder’ to spell correctly. He pointed out that they wouldn’t tell the child with partial sight to try harder to see (Riddick 2001 p231). Another student explained:

*Another problem that I had was with a tutor in college. When I told him I was dyslexic, he started speaking slower to me. I can understand what you are talking about. You don’t have to do this slow talking and patronise me. I think if people understand what the problem is then I don’t think it will be a problem.* (male, dyslexia, age 22 – quoted in Madriaga 2007 p406).

Students are often not identified as dyslexic until they reach higher education, but instead are subject to negative attitudes and informal labeling based on mistaken assumptions that literacy skills are linked to intelligence. The most common informal labels that children and students perceived they had been given at school were that they were ‘thick’ ‘stupid’ ‘lazy’ or ‘careless’. (Riddick 2001 p231). Some students internalise these messages or informal labels; "I truly thought I was thick and just couldn’t do it” (quoted in Riddick 2001 p231). Consequently, often an important part of having a formal label of dyslexia is that it may counter the negative view generated by the informal labelling process.

It is these kinds of experiences and attitudes that hinder students’ confidence in their pursuit of higher education. Memories and future outlook are significant as they impact on self-identity and how students see themselves through others (Goffman, 1969; Jenkins, 1996 – in Madriaga 2007). Elements such as self-esteem and a sense of efficacy – a belief in one’s ability to cope – can be severely shaken by negative experiences in education (Pavey 2010).

However, it is important not to assume universal processes and reactions to the educational experiences of people identified as dyslexic. Studies are often small-scale and predominantly based on qualitative data, and also have a tendency to under-represent individuals who, psychologically,
educationally and emotionally, deal with dyslexia in successful ways. A more pertinent question might be; what characterises successful coping strategies amongst individuals who are identified as having dyslexia? (Armstrong 2006 p27).

It may be possible that feelings of reduced academic self-concept or self-worth in young people who experience dyslexia may ameliorate as they become older (Burden 2008) or as literacy skills improve (Pavey 2010). Some people resist the informal labeling process and become more determined than ever to succeed; for example, a mature student who was not identified until his mid 30s, and had very negative experiences at school, nevertheless objected strongly to the school’s notion that he was careless and lazy. (Riddick 2001 p232). Madriaga’s findings were also interesting in this context, since his research involved 21 case studies of students who had successfully made the transition into higher education, despite experiencing low expectations and negative attitudes. 16 of the 21 students had been assessed as having dyslexia (Madriaga 2007). So, what processes operate to encourage transition to HE, for those students who have experienced stressful and disabling experiences at school?

Speaking more generally, it is important to also clarify at this stage that it is the attitudes, practices and negative expectations that cause stress and frustration for disabled people in general, and those identified as dyslexic, in particular, rather than the impairment itself (Swain & French 2004). Hence, it is not the intention of this article to promote the ‘tragic but brave’ discourse; (Cameron 2007 p2), and present dyslexic students as tragic sufferers nobly struggling to overcome huge odds because of their dyslexia. Cumulatively, research into the psychological dimensions of dyslexia indicates that severe and persistent difficulties with literacy are not per se the most profound barrier to educational success and achievement. (Armstrong 2006 p31). In other words, it is not dyslexia itself that constitutes a risk factor, but the norms, practices, and inherent assumptions that are the problem.

Evidence presented by researchers such as Madriaga (2007), Swain & French (2004) and Cameron (2007) suggests that there are some in all sectors of education, and within wider society, who may perpetuate disablist attitudes, either consciously or unconsciously. Mainstream social practices and interactions generally provide a negative range of stereotypes around the notion of disability, and frequently represent disabled people as pitiable, evil, or tragic but brave (Cameron 2007). Within education, Holloway (2001) has argued that the disabled student experience is determined by practices arising from the medical model of disability, a view supported also by Madriaga’s findings (2007). For example, many respondents in Madriaga’s study had not disclosed their impairments to lecturers as they did not want to be seen as a problem, a typical medical model perception of disability. (Madriaga 2007).
The medical model of disability focuses on disability as an individual problem, which is caused by people with impairments having ‘something wrong with them’, to be responded to by making rehabilitative, compensatory, therapeutic or reconstructive interventions in the lives of people with impairments (Cameron 2007 p 2). Unfortunately, this approach is still very evident within education, and within wider social institutions and practices.

The medical model was challenged by the social model of disability, which differentiates between impairment, and disability. In the social model, impairment is identified as ‘the loss or limitation of physical, mental or sensory function on a long-term or permanent basis’ while disability is defined as ‘the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (Barnes 1994 – quoted in Cameron 2007 p4). In other words, resources and opportunities are distributed in society without taking the needs of people with impairments into account (Cameron 2007 p4). In education, this means that the needs and strengths of dyslexic students have frequently not been catered for. The current forms of teaching and assessment are overwhelmingly based on reading and writing, but this ‘status quo’ is culturally and historically specific, is based on decisions, and is not inevitable.

The social model of dyslexia regards dyslexic individuals as ‘disabled’ by societal expectations, rather than by dyslexia itself, with theorists highlighting how current assumptions, norms and practices within education and wider society serve to disadvantage people identified as dyslexic (for example, see Cooper 2006, Riddick 2001). Singleton (1999) stated that the deficit model of dyslexia is steadily giving way to one in which dyslexia is recognised as a difference in cognition and learning (p27). However, definitions often continue to define ‘difference’ as ‘deficit’, and fail to highlight the many strengths associated with dyslexia, and focus on the difficulties that dyslexic individuals experience, rather than on the nature of the disabling expectations that lead to these difficulties (Cooper 2006) (for examples of ‘deficit’ theories of dyslexia, see Rice and Brooks, 2004, pp133-147).

The implications of this are significant. For example, if dyslexia is assumed as ‘deficit’, then the problem lies within the individual and the focus lies with remediation to try and help the individual to ‘overcome their difficulties’ in order to fit in to societal expectations. A social model of dyslexia, however, calls for the development of attitudes and strategies that are more inclusive, value diversity, and are less likely to disable anyone (for a fuller discussion of the social model of dyslexia see Riddick 2001, Cooper 2006, Amesbury 2007).

From a social model of disability perspective, it appears that it has to be demonstrated that individuals with dyslexia have a legitimate impairment
before it is possible to consider how cultural practices and norms have added to the degree of disability (Riddick 2001 p232).

The effect of the labels used to describe and categorise different impairments is also complex and culturally specific, and labels can act as either a positive or a negative force. For example, the label of dyslexia is a term that only becomes relevant in particular contexts and cultures, linked to the importance of literacy skills within different societies at different times. At transition, some dyslexic students struggle with the concept that they are now, officially and politically, regarded as ‘disabled’, and have to accept, if not embrace, that concept in order to apply for support through Disabled Students Allowance. This perception of themselves as a ‘disabled student’ can influence decisions about whether to apply for support at all. For example, predominant discourses linking disability with dependence can raise concerns about the nature of support being offered, and many students worry about how they will be perceived.

Alternatively, however, the label of dyslexia can also be very positive for students, since it can enable them to challenge the informal labels applied in school, and alter their self-perception to a point where the idea of higher education becomes a real possibility.

With regard to disclosure, some respondents in Madriaga’s study expressed concerns. For example, when one student was asked whether she was open about her dyslexia to classmates on her computing course her response was:

Yes and no. I have had a quite a lot of problems when I first started. Because they do not understand what it is. That was the main thing. This leads to a lot of problems and stuff. But, I am thinking they are coming to grips of it. But, it is just better to deal with it, to yourself, do you know what I mean? It is just easier to do it that way. If people do not understand, then what is the point.

(female, dyslexia, age 19)

Her response demonstrated a lack of confidence in other people understanding dyslexia. Thus, she internalised her impairment as her problem, not the problem of others. (Madriaga 2007 p407).

Feedback from trainee teachers suggests that many departments bar them formally or informally due to concerns about ‘standards’ - opposing forces for inclusion and higher academic standards (Riddick 2001 p232). Some trainees who did declare their dyslexia encountered negative attitudes and comments about their dyslexia “When I said I’d got dyslexia some places wouldn’t touch me with a barge pole”. One trainee was told “there will be zero tolerance of spelling errors” (Riddick 2001 p 233)

Nevertheless, trainee teachers reported that they coped well on their teaching placements – but were frightened of being ‘found out’ and would have welcomed more support on developing their coping strategies. Most
teachers and trainee teachers were selective about whom at school they
told about their dyslexia, because of fear that it would be seen as
incompatible with being a competent teacher: “I feel like sometimes I
scraped by because sometimes you cover it up and nobody knows”
(Dyslexic teacher – in Riddick 2001 p233). Goffman (1968) uses the term
‘passing’ to describe these kind of strategies where a person tries to hide
some aspect of his or her self for which they think they might be
stigmatised (op cit).

More recent research by Madriaga (2007) indicates that dyslexic adults
still have anxieties about disclosure, especially at times of transition, and
have experienced discrimination following disclosure on job applications
and in employment.

Yet, despite these barriers, and sometimes difficult and stressful
experiences in education, many students progress successfully, and it has
been frequently observed that individuals respond very differently to
similar or identical life events, stresses and risk factors. Attempts to
understand these differing responses developed into study of the concept
of resilience. In this context, a consideration of resilience may help to
explain why individuals identified as dyslexic, who have experienced
similar stressful experiences at school, react in such different ways at
transition, in terms of whether they apply for HE, and how they approach
the HE experience.

Resilience is defined as the ability to cope with stress and thrive in the
face of adversity (Connor & Davidson 2003 p76). Studying resilience
focuses attention onto understanding the positive processes and
motivations underlying resilient qualities. A key question, linked to the
topic of individual differences, is why people seem to react so differently
to seemingly similar or identical experiences? Most studies identify a
range of personal and contextual interacting factors, summarised in
Garmezy’s ‘triad of resiliency’ as including personality disposition, family
environment, and external support systems (Richardson 2002 p309).
Reactions are immensely complex and variable, and individuals can show
differing levels of resilience to risk factors in different circumstances and
at different times.

Risk factors have been defined as personal and/ or environmental
elements that predispose people to developing psychological problems
(Carr 2006), or which can cause serious harm to physical and mental
health and well-being (Schoon & Bartley 2008). Current approaches to
learning consider that the cognitive and affective domains are inextricably
linked, so that anxiety, stress, and levels of self-esteem and self-efficacy
impact on learning (Pavey 2010).

An extensive range of environmental risk factors have been identified that
appear linked to the development and exacerbation of psychological
problems, especially if individuals have not managed to develop effective
coping strategies in previous stressful situations. These include attachment issues, family discord, or life stresses such as bullying, abuse, or rejection (Carr 2006). Some researchers consider disability to be a risk factor. In the personal tragedy theory, disability, or rather impairment, is thought to inevitably cause suffering and blight lives (Swain & French 2004). Miller (2002) described ‘having a specific learning disability’ as a risk factor.

However, Cameron, (2010) makes the point that impairment is not a deviation from the norm, but a relatively common and ordinary part of human life (Cameron, this publication). The point, in this instance, is that reactions to impairments can constitute a risk factor which requires resilience to overcome the effects; however, this is not inevitable, and constitutes one risk factor within a myriad of other risk and protective factors interacting to influence outcomes. It also became clear to researchers that risk factors affect some people’s behaviour and reactions much more than others, and even with the most severe stressors it is unusual for more than half of individuals to succumb (Rutter1985, Richardson 2002). Sometimes stressful life events can toughen an individual – the ‘steeling’ effect – so that they become more resilient in future having successfully resolved a problem once. At other times, stressful experiences can serve to ‘sensitise’, leaving individuals feeling helpless and more susceptible to later stressors (Carr 2006, Rutter 1985).

An example of the ‘steeling’ effect could include students who progress to HE partly in an attempt to prove wrong the people at school who doubted their abilities, or to prove something to themselves; a major factor shared by most respondents interviewed by Madriaga, with regard to pursuing higher education, was having experienced discouragement:

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\text{I would love to have a \textit{university} degree to prove that I am not stupid. Maybe, I have a chip on my shoulder from people thinking I am stupid, from school and that.} \quad \text{(male, dyslexia, 28 – Madriaga 2007 p405)}
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\text{It does not matter if they think you are lazy and you know that you are not, then it is an incentive to prove them wrong.} \quad \text{(female, dyslexia, age 19 – Madriaga 2007 p405).}
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People also deal with stressful situations in many different ways; some of these methods have been categorised as ‘defence mechanisms’ or ‘coping strategies’. Defence mechanisms were identified within the psychodynamic tradition, and are assumed to operate unconsciously. They are used to regulate the negative emotional states that accompany conflict. Coping strategies are deliberately adopted patterns of behaviour used to manage stressful situations, and include measures such as seeking social support, accepting responsibility, or engaging in physical
exercise or relaxation routines (Carr 2006). For example, dyslexic teachers and trainee teachers interviewed by Riddick used effective coping strategies to overcome literacy difficulties they had in the classroom; such as recognising the importance of planning and preparing ahead (Riddick 2001).

Connor and Davidson (2003) have identified four broad outcomes to stressful life events: firstly, the experiences provide an opportunity for growth and increased resilience; secondly, individuals survive and get past the experience but remain much as before, neither strengthened or weakened; thirdly, individuals recover but with loss, for example lose confidence or self-esteem, or health is affected; fourthly, the experience can leave the person in a dysfunctional state where they have become reliant on maladaptive strategies or self-destructive behaviour to cope with the risk factors – such as long-term denial, pessimism, or taking little responsibility for solving the problem. Responses can depend on protective factors, and coping strategies.

Protective factors are elements that can counteract the effect of risk factors, and help individuals to cope positively with stressful life events. Some of the many personal protective factors identified by researchers include an ‘easy’ temperament, high self-esteem, optimism, internal locus of control, and effective coping strategies (Carr 2006 pp44/45). Similarly, Peer suggested that successful dyslexic adults appear to have particular personality traits that include; a strong need for achievement, enthusiasm, optimism, a willingness to act, well developed social skills, higher persistence and maturity than their peers, self-confidence, and no significant levels of anxiety (Peer 2003 pp5/6). Respondents in Madriaga’s study frequently identified need for achievement as a motivating factor in their decisions at transition; for example:

I just wanted to get a better job. A better job and better myself, that’s it. ... To get a good job and in my life to get more money and the way to do that is to educate yourself. (male, dyslexia, age 24) (Madriaga 2007 p404).

However, as Schoon and Bartley point out, too much focus on personality traits can be damaging and misleading, as it can lead to the unhelpful assumption that everyone can make it if they try hard enough – a situation of blaming the individual (2008). Factors are always interacting and multi-faceted, and temperament both affects, and is affected by, the environment (Carr 2006). For example, students identified as dyslexic who have been assessed and supported at school are more likely to achieve at A Level and progress to HE. These students usually have an awareness of their learning styles, and tend to be proactive in ensuring that they apply for the support available at university (Jamieson and Morgan 2008). Individuals without this supportive background experience need realistic options and routes into higher education to enable transition to take place; such as the range of courses in FE Colleges to build
confidence, skills and qualifications to enable them to apply for HE in the first place (Du Pre et al 2008).

Adoption of functional or dysfunctional coping strategies may therefore depend partly on the presence or absence of contextual protective factors, such as good social support networks, peer support, effective coping strategies, and positive role models (Carr 2006). Rutter (1985) identified key factors as secure stable affectionate relationships, and experiences of success and achievement, while Yoeli et al (2007) regard resilience and adaptability as innately embedded within relationships.

Early risk factors don’t necessarily lead to a fixed outcome, and if early experience is discontinued the effects can fade (Clarke & Clarke 2008). However, they can set a chain of events in motion, and risks can also increase sharply when several adversities co-exist (Rutter 1985). Later protective factors, though, may ameliorate earlier risk factors and assist people in developing resilience through the adoption of more effective coping strategies. For example, a positive later educational experience may be a rich source of resilience to students who have had difficult experiences in early education; (Pavey 2010, Burden 2008) maybe by providing the relationships and experiences of success and achievement highlighted by Rutter and Yoeli et al.

In this context, the role of effective educational support staff has been identified as crucial in envisaging educational transitions. In a study based on a one year project to explore disabled learner transitions into higher education, findings suggested that students often credited support workers for helping them along the way to higher education:

*They gave me not just physical support, like by loaning me equipment. They gave me a lot of emotional support. Because you get to the point where you really find it hard and you want to give up. So, it is nice to have someone at the end of the phone saying ‘everybody goes through this’. Just offering a bit of support that is enough to like get you back on your feet again. Because you do get things that will knock you off. You just have to climb up again.*


Support from peers can also be crucial, and can help students to feel confident in disclosing; for example:

*The good thing about nursing is that it is a very nurturing environment. It is a rule, especially among the students. So, you will have plenty of students who will come forward. If you are open with them, they will be open back.*

(female, dyslexia, age 36 – in Madriaga 2007 p407)

A positive self-image, and the examples of role models, can also help students to develop resilience and achieve success. For example, Peer
outlined that many successful dyslexic adults have family members or friends who are dyslexic and have achieved, and tend to view themselves as having ‘learning differences and abilities’ rather than learning difficulties (Peer 2003).

Swain and French (2004), in challenging the personal tragedy theory of disability, point out that being disabled can have benefits, and that many disabled people are demanding the right to be the way they are – equal but different. Similarly, for dyslexic students, the deficit model of dyslexia is now steadily giving way to one in which ‘dyslexia is increasingly recognized as a difference in cognition and learning’ (Singleton 1999 – in Riddick 2001 p232).

So, for example, teachers and trainee teachers felt that being dyslexic was an advantage to them as a teacher because it made them more empathic to children who were struggling. Those who had been given specific support for their dyslexia felt that they were able to utilise those strategies in supporting children and suggesting methods of support to their teaching colleagues. However, teachers were also in the contradictory position of feeling their disability enhanced their teaching performance, but might discredit them in the eyes of the wider educational establishment (Riddick 2001 p233).

In conclusion, this article has considered how the concept of resilience can be applied to decisions at transition by individuals identified as dyslexic. Research indicates that individuals with dyslexia often have difficult and stressful experiences in education; however reactions to these experiences are many and varied, and depend on a range of risk and protective factors, both personal and environmental.

Findings quoted in this article suggest a number of motivating factors that seem to encourage students identified with dyslexia to persevere and progress to HE. It should be noted, however, that many of the students will almost certainly have been ‘sensitised’ and weakened by their previous experiences, in terms of their confidence, self-esteem, and anxiety levels for example, rather than strengthened by them. Nevertheless, factors have emerged from the research that appear to act as protective factors, and enable people to continue and achieve despite the odds. In particular, this article has highlighted the role of personality traits, supportive institutions and structures to act as gateways into HE, good social support networks such as support staff and supportive peers, role models, positive self-images, and effective coping strategies. It is to be hoped that, as environments become more inclusive, the need for resilience in ‘surviving’ education, for individuals with dyslexia, will become less apparent.
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Ensuring a Smooth Transition into Higher Education - Establishing a Transition Project in South Yorkshire for Young Disabled Learners and their Key Influencers

Louise Loughlin – Disability Outreach Officer, University of Sheffield  l.loughlin@shef.ac.uk

Sarah Smart – Head of Sheffield Regional Assessment Centre, Sheffield Hallam University  s.smart@shu.ac.uk

In January 2009, a three year AimHigher collaboration project was launched by The University of Sheffield and Sheffield Hallam University. The project aims to support the transition process of disabled learners from Further to Higher Education and to raise the aspiration of disabled learners across South Yorkshire. Encouraging early disclosure of disability is a significant theme running throughout all of the activities and events undertaken on the project.

Research undertaken within previous AimHigher projects in South Yorkshire showed, based on feedback from disabled learners and their parents, that there is a need to improve the availability of information about services disabled students can access to enable them to participate and succeed in HE. Also, education providers supporting transition into HE do not have coherent access to relevant information in order to enable them to support students in the transition process (Jackson, V and Martin, N 2007). Previous AimHigher funded research undertaken by Manny Madriaga also indicated that disabled students face barriers to accessing HE, which arise from low expectations of professionals and parents who have made assumptions that university is not an option. Elliot, T and Wilson, C (2008 p.92) explain that it is necessary to explain the real possibility of HE to those 'gatekeepers' who do not consider HE a viable option for disabled young people.

The aim of the 2009 Disability Outreach project is to raise aspirations and motivations of potential learners in HE through outreach work in schools, colleges and community groups; to develop information, advice and guidance materials and to deliver events which raise awareness about the process of gaining support in HE. Ultimately, the project aims to develop strategies and guidelines to fill the information gap during the transition period from school/FE into HE and help disabled learners and their key
gatekeepers (parents/carers/teachers/advisers) to make more informed choices about their study and career routes.

Initial project activities picked up on the widening participation work that had previously been undertaken by the two institutions, which had specifically targeted students with Specific Learning Difficulties (SpLD). This work focused on up-skilling staff within FE Institutions on the support available for disabled learners in HE and information sharing within the sector.

As the project got underway the focus was aimed primarily at students with hidden disabilities, including SpLD, Mental Health Difficulties and Aspergers Syndrome. Research shows that students with hidden disabilities are less likely to access the support offered within HE and do not even realise that their impairment is classed as a disability. Elliott T and Wilson, C (2008, p.93) recommend that AimHigher and HE staff need to actively target learners with Hidden disabilities as some may not think that HE is for them.

As the project has progressed, so has the range of activities undertaken by both Institutions, who have worked both collaboratively and separately on specific areas.

The University of Sheffield has focused on the aspiration raising aspect of the project and began working with a team of student ambassadors, all with SpLDS and all accessing the University disability services. These students were proactive and keen to discuss the support they were receiving throughout their studies and how this had impacted on them. The work was, and still is, very much student led. The student ambassadors work with small groups of Y12/13 students and talk about all aspects of university life, from living away from home to accessing their student loans. As well as this they talk about what disability support involves, how it’s different from support at school/college and how to access it. Even at the outset, it was clear just how powerful the student voice is. The college students asked questions freely and without reproach, knowing that they would get an honest answer from someone who had “been there and done that”. Elliott, T and Wilson C (2008, P.92) recommend that pre-entry information to students should include disabled student role models in publicity and aspiration raising materials and activities, as these can have an important impact on the aspirations of disabled learners.
At Sheffield Hallam University the activities were focused towards students across the South Yorkshire region who were currently within the FE-HE transition process, and were likely to be accessing HE disability support that year (Y13). Students were met with on a one-to-one basis, as early as January, and were taken through the process of applying for Disabled Students’ Allowance (DSA). Any concerns and questions that student had about HE were able to be answered in a confidential and encouraging environment. The aim of these sessions was to encourage early DSA application to ensure that the student had support in place before their course started, wherever that may be. Goode (2007) found that a significant number of disabled students were beginning university without the support described in their DSA assessment being in place. These sessions proved to be extremely popular and in 2010 over 120 individual one-to-one sessions were arranged.

Although these individual activities have proven extremely beneficial, and have continued throughout the project, it is the collaboration activities that have proved essential to the success and impact of the project throughout South Yorkshire.

Early on, an external design agency was engaged to produce a memorable and easily identifiable project identity. After consultation with key stakeholders to ensure that the chosen marketing theme was appealing to the target audience, the strap line ‘Everyone Is Different’ was agreed on. The use of cartoon images showing many different faces was used to imply that everyone is different. Marketing literature was produced and distributed to every school and FE College in the South Yorkshire region. This included a poster, a leaflet, a calendar of events and individual postcards.

In August 2009 a calendar of events was developed for the next academic year.

1. 'Information into HE' Events: Aimed primarily at Y9 - Y13 students and parents, but attendance from interested staff was encouraged. These events took place during ‘twilight’ sessions, allowing people to attend without missing any work/school. These sessions were disability specific and we focussed on SpLD, Mental Health and ASC. The sessions all included a student perspective from students currently accessing disability services, as well as a brief introduction to the DSA processes and an exploration of some of the support that may be available in HE.
2. **Practitioner CPD Events**: Aimed at practitioners involved in supporting students through the transition stages (teachers, head teachers, AH co-ordinators, SENCOs, Careers Advisers – though this list is not exhaustive). Usually half-day events, these events focused on particular aspects of the support process. One of the more successful events was discussing SpLD support.

3. **Campus Visits**: Aimed at groups of younger students (Y9 – 11), with a view to raising their aspirations and motivate them into pursuing an FE course. These visits also gave them a flavour of what university life is like and involved input from student ambassadors, a campus tour, an activity in an academic department and lunch in the student union.

The project team targeted all of the four regions in South Yorkshire including; Sheffield, Rotherham, Barnsley and Doncaster. Direct and regular links have been made with 13 schools and colleges in the region with a number of schools and colleges getting involved by attending individual activities, reaching out to 185 staff and parents and 182 learners.

The work of the project team has been very well received and it is clear that the activities we are providing are much needed within the South Yorkshire region:

“Really pleasantly surprised at the level and quality of support available”

“Thank you for an excellent session – I am now clear about what my son can access - if he chooses!”

“I was not thinking about going [to university] but now I am”

During 2009/2010, the project focussed on delivering one-off events and information sessions aimed towards students, parents and FE practitioners, developing marketing activities, undertaking one-to-one guidance appointments for individual students and the recruitment of disabled student ambassadors to undertake aspiration raising activities for students.

In 2010/2011, the emphasis of the project will be focused more towards developing online activities and training sources, raising the profile of the project, as well as working towards embedding sustainable aspiration raising activities within schools and colleges. The project will focus on four main areas including:
• Events and activities for students and practitioners
• Marketing the project effectively: both on a local and national stage.
• Creating sustainable resources
• Evaluating the impact of project

In addition to the above, together with Leeds Metropolitan University, funding has been secured from Action on Access to explore and create a regional, sustainable disability network.

So far, the work of the project has not been without its difficulties. Often it has been difficult to contact the right people, in the right places; hence the focus on marketing the project extensively over the course of the last academic year.

Each month has seen the team hold a different event, so that the interest of a wide audience has been attracted. Having a presence at local and national events and conferences has also further enabled raising the project’s profile.

The persistence and enthusiasm of all the staff involved has really contributed to the success of the project. Networking with colleagues, who are doing similar outreach work in neighbouring regions, has also provided necessary support and reassurance to the project team.

Throughout the project, it has become clear that what works for one group of students or practitioners may not work for another group. Ensuring that events and activities are focused towards the individual has been essential to their success. Flexibility has been a key element when delivering events, and learning what works, and what does not work, has been a steep learning curve.

The project will shortly be entering the evaluation stage and a report will be produced, which explores the successes and difficulties of the project in more detail. For further information about the project and all the planned 2010/11 activities please see www.aimhigher.ac.uk/syorks.
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Models of Support for Transition and Retention of Students on the Autism Spectrum at Scottish Universities

Charlene Tait, Catriona Mowat and Anna Cooper

Abstract

A recent parliamentary inquiry concluded that in the UK a “dearth of provision” and a lack of understanding of autism among professionals was failing young people with autism in making effective transition to adulthood (The All-Party Parliamentary Group on Autism, June 2009). A need for more robust transition arrangements to Higher Education has also been acknowledged by the Scottish Government in the extension of ‘Partnership Matters’ guidance to Higher Education (Scottish Government May, 2009). The impact of autism on transitions, and the consequent importance of effective planning for transition, is spelled out in the Scottish Government’s guidance for schools on supporting pupils with a diagnosis on the autism spectrum (Scottish Government, April 2009).

This paper reports on a recently undertaken small scale research project that sought to investigate the range of support provided by institutions to individuals on the autism spectrum prior to and during their time at university.

The transition and retention at one university are explored from the perspective of students who have engaged with a summer transition programme and who receive ongoing support from trained mentors. Findings show that currently a range of approaches to supporting students on the autism spectrum are taken by Higher Education institutions across Scotland. Access to a formal programme prior to entry to university is valued by applicants on the spectrum. The use of trained mentors utilising specific guidance can improve retention of students on the autism spectrum.

Background and Context

Since 1995 Higher Education institutions have been charged with an increasing range of duties under the Disability Discrimination Act (DDA). It was, however, not until The Special Educational Needs and Disability Act (SENDA 2001), which gave rise to amendment of the DDA to include part IV, that it became unlawful for Higher Education (HE) institutions to discriminate against disabled peoples. Additionally, institutions are required to prepare in advance for such students (Viney 2006).

Asperger’s syndrome (AS) is recognised as being part of the autism spectrum (Wing 1996). By definition, individuals with a diagnosis of AS
will have no intellectual impairment, but will have a range of qualitative differences in social interaction e.g. use of non-verbal behaviours and in developing relationships with peers. Individuals with AS are also likely to have restricted interests as a result of rigid and inflexible thinking patterns and processes (World Health Organisation 1992; American Psychiatric Association 1994). The range of impact on development and functioning is variable and can be subtle. AS is part of the autism spectrum. It is currently recognised and understood as a neurodevelopmental condition. Attwood (2007) suggests that there are issues relating to the diagnostic criteria, an example of which is the relevance of early language development. The fine detail of such issues becomes less relevant for adults who have a diagnosis and who are aiming to engage with a range of life experiences including accessing Higher Education. Of greater relevance is that needs are understood and supported, in order that individuals with AS are not unreasonably disadvantaged in gaining access to the typical life experiences enjoyed by their peers.

Core areas associated with AS, such as differences in social interaction, social communication and social imagination (Roth 2010) present challenges for the individual, but also require staff within institutions to be ready to accommodate a different way of interacting and communicating. Differences in perception, sensory processing and cognitive processing are also recognised as being associated with AS (Boucher 2009; Wall 2007).

Hendricks & Wehman (2009) suggest that in terms of transition, preparation is key. For individuals with AS, such preparation is potentially multifaceted and will need to take account of individual needs on a range of levels that include conceptual, environmental, and contextual. Areas to be addressed may therefore include establishing what ideas, views and image the person has of university and student life. Environmental aspects may need to go beyond basic orientation to include identifying areas for time out or where sensory processing issues might cause distress. There is also a major shift in moving from a relatively cosseted environment, such as a school, to large institutions where there is a high expectation to be independent. Contextual issues are legion in that there are different modes of behaviour and engagement required in different settings. This may range from the relatively passive involvement associated with being in a lecture with hundreds of other students, to collaborative lab work, to the entirely different environment of the student union. It is therefore likely that in addition to the obvious and significant issues pertaining to transition, such as study skills or accommodation, the minutiae associated with a range of different aspects of university life will be of significance to the person with AS.

According to Ralph & Boxall (2005) the recruitment of disabled students is not a priority for most universities and that they could be more proactive in this regard. They also suggest that most non disabled students will
identify their preferred institution on the basis of the course of study. Conversely, students who are disabled will base their choice primarily on where they believe they will have their needs met in relation to their disability, with their academic needs being a secondary consideration. It should be noted that the motivation behind the introduction of the summer transition programme at the university in this study was not part of a drive to increase the number of applicants with AS to the university. It was rather to ensure that those who applied, on the basis that the institution could best meet their academic needs, found that they were proactively supported by the institution in relation to needs that result from AS.

There is a developing literature on the needs and experiences of young people with AS in relation to transition to Higher Education and employment. University is an attractive and realistic goal for many individuals with Asperger’s syndrome. It can provide an opportunity to build self esteem through academic achievement and can also be a platform to pursue areas of special interest. There is also a broader economic imperative to being able to provide access to Higher Education that may in turn lead to employment. In their study of the economic impact of autism on the UK, Knapp, Romeo and Beecham (2009) estimate that the cost of supporting adults across the autism spectrum amounts to £25 billion per year. There are of course multiple, complex factors that result in this estimate. It is, however, important to recognise that as well as the potential loss to the economy, there is arguably the greater loss in terms of personal health and well being that results from lack of opportunity to realise potential.

If securing a Higher Education qualification is a positive means of enhancing future employment and earnings potential, then the most recently available figures on school leaver destinations among disabled pupils in Scotland is worthy of note. In 2009, the Scottish Government reported that 35.2% of non-disabled leavers from publicly funded schools progressed to Higher Education. Only 14.9% of disabled school leavers made this transition. A disproportionately higher number, 47.6%, compared to 26.7% of non-disabled pupils instead progressed to Further Education courses (Scottish Government 2009). In their study of twenty one youngsters with high functioning autism, Camarena & Sarigiani (2009) found that they and their parents had aspirations relating to accessing Higher Education. They also harboured serious concerns regarding the readiness of institutions to meet needs.

**Aims**

This study aimed to understand the range of arrangements that are in place at universities across Scotland to support the transition and retention of applicants and students with AS. The study also sought to ascertain the perceptions and views of participants of a summer transition programme established at one university in conjunction with the National
Autistic Society. Finally, the role of mentors in supporting the retention of students with AS was examined.

**The Project**

In 2006, the Disability Service of a Scottish university approached the National Autistic Society (NAS), a national charity with a remit which includes providing services to Higher Education students with a diagnosis on the autism spectrum, to discuss a model of transition support which might better assist applicants with AS in making the transition from school/college to university. Arrangements to assist a very small but increasing number of incoming students with orientation and preparation were ad hoc. Individual applicants were contacted by the Disability Service prior to entry, and an individual programme of visits, tours and meetings would be agreed. Concerns had arisen that a disproportionate number of applicants with AS were cancelling or withdrawing their applications prior to contact from the Disability Service.

The decision was taken to pilot a summer transition programme, which would bring together incoming students with a diagnosis of AS, to explore in small group settings areas of common concern related to transition to university. This approach was somewhat counter-intuitive to the architects of the programme, accustomed to developing models of inclusive practice which would anticipate the needs of disabled persons, and considering the needs of applicants on an exclusively individual basis. The ‘Teachability’ model for promoting inclusive teaching and assessment practices (University of Strathclyde, 2000), which would anticipate the needs of disabled students often without the need for recourse to individual adjustments, was an approach, and philosophy, embedded within the practice of the Disability Service and the wider university.

Reservations held prior to the initial pilot included concerns that applicants might object to this generalized ‘impairment specific’ approach, and that potential participants in the programme would present with very different needs and issues which would not be best addressed in a group setting.

Set against this backdrop of reservations, a pilot summer transition programme was launched by the university, in conjunction with NAS in 2007. The aims of the programme were to: provide a smoother transition to incoming students from school or Further Education; to improve take up of offers of places on courses and to assist with assessment of needs prior to the start of the academic session. Improving retention was not a specific aim of the initial pilot programme.

The programme was jointly promoted by the university and NAS to applicants with a confirmed offer of a place, each being sent a letter of invitation along with an itinerary for the first session. The programme was designed to run over 3 sessions (two half days and one full day) in the six weeks prior to the registration period. The itineraries for each of the days
set out a programme of small group discussion and activities based on issues and concerns thought to be common to students with AS: time management; understanding changes/differences between school/college and university; self advocacy and assertiveness; advice around disclosure; managing stress and relaxation techniques, and orientation.

Roberts (2010) suggests that preparation for transition should address a number of areas including exploring career options, setting academic goals and identifying learning styles. Additionally areas such as self-advocacy, academic supports, technological aids and time management should be explored. The summer transition programme contains a number of these elements, but was primarily informed by the experience of supporting a number of previous applicants with AS.

The immediate advantage the university identified, in offering a programme, was that applicants knew what to expect in regards to transition and orientation and that as a formal programme as opposed to ad hoc arrangements, it could be more easily evaluated. Participants were asked during the first session to rate their confidence in a range of aspects to be covered in the sessions, including: knowing what the differences are between school, college and university; knowing who to go to for help with support at university; identifying what support I think I might need at university, and knowing more about what to expect at university and what it will be like. A further confidence rating evaluation was administered at the end of the programme. The responses assisted in tailoring some of the sessions to meet the needs of individual participants, but also assisted the Disability Service in understanding and assessing the needs of these incoming students.

Participants in the summer transition programme were also provided with mentoring support. Mentors were employed and supported by the Disability Service and received training from both NAS and the National Centre for Autism Studies (NCAS). For some students, mentors provided assistance during only the first year of their course, to assist with the transition period and settling into a new routine of university life. For others, mentors continued to provide support in managing their studies and participating in University life throughout their student career.

In 2007/08, four incoming students participated in the programme, all of whom went on to complete the first year of their undergraduate degrees successfully. The summer transition programme was subsequently continued, in 2008/09 with four participants and in 2009/10 with seven participants.

In 2009, the Scottish Funding Council invited bids from university Disability Services for funding to support one-off projects and initiatives which might enhance the experience of disabled students. The university made a successful bid which included a grant to carry out research into models of transition and retention support at other HE institutions in
Scotland: to facilitate workshops on this theme to share the findings of this research; to further explore the needs of incoming students with AS and what models and approaches might best met these in individual institutions.

**Research Methods – Study 1 – Investigation into provision made by Scottish universities**

A total of twenty questionnaires were distributed to disability advisors based at Scottish universities. Named recipients were identified by the Disability Service from contacts within the National Network of Disability Coordinators in Scotland.

Questionnaire respondents were invited to participate in a semi-structured follow on interview.

**Results of Study 1**

Of the twenty questionnaires sent, a total of six were returned giving a response rate of 30%. Of the six respondents, five agreed to participate in an interview. The six respondents had knowledge and experience of nineteen individuals currently enrolled on a programme of study who were on the autism spectrum, fifteen of whom had a formal diagnosis. The relatively low response rate has to be acknowledged as results can be viewed as indicative rather than representative. Due to limited returns, and to ensure confidentiality, the findings from questionnaires and interviews have been truncated and are presented in a narrative format.

Participants were asked to indicate what transition arrangements are currently in place for the AS population at their institutions. No other Scottish university offers a formal summer transition however existing arrangements include: extensive liaison with current school or college, summer school (typically offering participants ‘top-up’ academic classes and experience of Higher Education study methods) and peer mentoring. The most commonly identified support in relation to transition was orientation visits prior to commencing study.

On being asked to identify the main needs of this group, participants identified the following:

- Assistance with structure in relation to studies
- Access to the structures in place at university.
- A longer lead in period due to difficulties with using timetables particularly understanding and managing any gaps.
- The environment as a whole was a recognised challenge thus the emphasis on orientation visits.
- Residential accommodation
- The need to consider transition out of, as well as into, university
The strengths and limitations of what is currently offered by respondents were identified as follows: in terms of strengths it was felt that a flexible rather than formal programme of support could enable Disability Services to respond to the individual presentation of needs. It was also felt that the absence of a formal programme could inadvertently lead to the provision of more one to one support. Two main limitations were cited, these being that time constraints were an issue in providing individual support and that non-standard admissions such as late offers meant that planning time was limited.

Respondents were asked to speculate as to what the potential pros and cons of a formalised programme may be. The greatest advantage was thought to come from being able to address more within the time available, as support would be directed to larger numbers rather than individuals. The main drawback which was identified was the potential for confusion if a general approach was taken. It was suggested that the entry of students with AS into the university had highlighted gaps in existing provision and the need for a more formal programme to address needs in the longer term required further consideration.

Participants were asked to identify the factors they felt impacted on the retention of students with AS. A number of areas were identified:

- Monitoring: internally - that is by the disability service – and externally by the academic department the student was associated with.
- Staff awareness of the needs of disabled students in general and in terms of this study, AS in particular
- Mentoring
- Importance of combined supports- it was felt likely that individuals may need a range of different types of support for different situations.
- Student related factors- like other students the extent to which they are academically suited to their chosen course of study was a factor in retention.

Forms of support currently available to students from participating institutions were reported as follows, and are shown from most to least frequently mentioned:

- Links to external agencies for support, information or other
- Mentoring
- Study skills tuition/learning support
- Academic support
- Social network/social support
- Services or programmes specific to the needs of students on the autism spectrum
When asked to identify the supports they would ideally like to be able to offer students with AS, responses were as follows:

- The capacity to see students on the spectrum on a more regular basis
- Early communication with relevant parties
- Informed staff and increased tolerance from all staff
- Increased awareness among fellow students

The findings of Study 1 will be discussed later in the paper alongside those of Study 2.

**Research Methods – Study 2 – Investigation into the experiences of students participating in a formal transition programme**

Routine evaluations of the Summer Transition Programme (STP) are undertaken. However, part of the rationale for making such provision is the hypothesis that it may have longer term impact on retention of students with AS. It was therefore necessary to undertake a more arm's length evaluation of the programme in order to ascertain longer term perceptions in relation to impact.

Questionnaires were distributed to fifteen summer transition programme participants, who had taken part in the programme in years 2007/08, 2008/09 and 2009/10. Seven completed questionnaires were returned giving a response rate of 47%. The research aspects of the study were conducted independently from the Disability Service that offered the programme. Students were supplied with a stamped addressed envelope to enable them to return questionnaires directly to the researcher rather than the Disability Service.

**Results of Study 2**

The results of this study are again presented in a predominantly narrative format to preserve the confidentiality of participants.

The students were asked what their concerns had been about progressing to university, prior to the start of their course. The main concerns, reported by a majority of respondents (4 and 5 respectively) related to social issues and orientation. Other reported concerns included independent living and transition.

Students were then asked what had helped in alleviating these concerns. A range of responses were provided. All respondents mentioned attendance on the Summer Transition Programme. A majority (5) acknowledged attendance at open days and visits to their academic departments. Others reported benefiting from discussion of their concerns with family or friends. Meeting with the university Disability Service,
practicing the journey from home to university and finding their teaching buildings in advance of the start of semester, were also cited as helpful.

When asked what the three most important things that the university had provided in supporting them with the transition to university, the three top responses were the support of a mentor, open days and the Summer Transition Programme. Other responses included: being allowed to stay a night in student accommodation in advance of making the move to university; summer school; a campus tour; contact with the Disability Service; contact with the academic department disability contact, and provision of assistive technology.

Participants were asked to identify what, in their view, was the most enjoyable aspect of being a student. The following offers a range of indicative comments given by participants.

"Flexible hours and occasional exclusive afternoon workloads. I’ve grown to enjoy independence greatly. I also appreciate the continuous assessment for classes as I believe it better reflects my ability.”

"I enjoy the freedom, as it is a totally different atmosphere to that of school. You can leave the room freely and are treated as an equal.”

"Additional freedom/independence. New learning material now open to me. Opportunities to meet new people.”

"Acquiring life-enhancing skills and knowledge for a future career. Made new friends that will stay with for life. Sense of achievement”

"Variety of courses, flexibility of time.”

It can be seen there is an emphasis on the enjoyment gained from having more freedom and independence, and also on flexibility.

Participants were asked to identify what the benefits of having a mentor had been to them. This generated responses covering a number of key areas that included academic support, but also emphasised the perceived social and emotional aspects. Areas identified were:

- Academic Support
- Social/Emotional Support
- Personal Development e.g. Confidence
- Support with orientation and/or resources

Participants were asked to identify the three main things that the university does to support them in regards to their continued participation in study. All acknowledged the importance of individual adjustments, such as advance provision of notes or additional time in exams, and the support of the Disability Service. Others noted subject specific support,
the support of their mentor and personal development planning at the end of each semester.

When asked what else could be done to enhance support the following comments were made:

―Minor check-ups/ status reports every 3 or 6 weeks nor (sic) 12. Greater visibility of academic staff i.e. they could try a little harder to ensure their availability in case of academic difficulties. Introduction to class discussion boards, so they’re actually used.‖

―Shorter lab sessions – they are too long‖

―More one-to-one student/lecturer meetings to discuss assignments‖

Discussion

It has to be acknowledged that there are a number of limitations to this study. The low response rate from institutions clearly makes it difficult to establish a definitive view of transition and retention supports that are in place across the university sector in Scotland.

Reference to the literature relevant to the needs of people with AS in relation to transition would however suggest that the feedback that has been obtained highlight issues that could be said to be expected.

Numbers accessing the Summer Transition Programme, have to date, in relative terms, been low. It is therefore difficult to assess how consistent and sustained over time the positive experiences expressed by participants may be replicated with a larger number of participants. The findings do however suggest that acknowledging and responding to the needs of individuals with AS in such a manner can contribute to a smoother transition and is likely to be a factor in the retention of students with AS attending university.

It is interesting to note that none of the participants cite academic issues as being of concern to them prior to coming to university. Responses tend to focus on social issues and matters related to the transition itself. Whilst this may be indicative of the nature of AS where social interaction differences are core, it does appear to highlight the need for such issues to be addressed by some means.

Having access to and the support of a mentor was important to the participants of this study. In addition to providing academic support, they assist with social support and general orientation. Drawing on experience gained as a result of the summer transition programme, it is clear that the skill and quality of the mentor are key in terms of the success of the relationship between mentor and student. It is important that the student finds the mentor credible in terms of feeling they are able to engage with them at their own academic level.
Mentors working with individuals with AS need to be mindful of their social challenges and appreciate that these may result in barriers to learning. As a response, an outcome of this study has been to develop a set of guidelines for mentors, shortly to be published by NAS.

The reflective tone of the student remarks is interesting. Staff involved in the programme recognise these to be much more considered remarks when compared to the immediate evaluation. This suggests that participants are recognising the enduring value of sustained engagement with supports that were introduced during the summer transition programme. It is also suggestive that the individuals involved have learned to use the support available to their advantage and are able to identify and articulate concrete examples of this from their experiences.

A side benefit of the summer transition programme is that it provides early access to a peer group. It should however be stressed the intention is not that individuals with AS should be restricted to engage solely with others who have the diagnosis. The significant factor here is that they have a shared experience; Participants therefore shift from having a condition in common to having an experience in common.

The findings from participating institutions are interesting. It is clear and indeed entirely appropriate that a range of supports are available to meet needs. The Summer Transition Programme is by no means offered as a definitive model. It is however a model that is proving effective in supporting applicants to make the transition to university.

Similarities can be drawn between what the participating disability advisers identify as being needed and what the students themselves suggested e.g. more frequent check ups. Resourcing is always going to be an issue. The programme gives the opportunity to provide relatively intensive support at the start of a person’s academic career. This is a time when anxiety is likely to be at its greatest and where applicants/students are most probably feeling overwhelmed. The estimated cost of the programme is around £70 per head, and feedback would suggest that there is a relatively high return on this initial investment in terms of student retention. The Disability Service noted with interest an apparent significant improvement in the academic progress and retention of students with AS since the introduction of the Summer Transition Programme. This presented a marked contrast from the experience of the Disability Service in supporting a small number of students with AS in previous years who had encountered significant difficulties with progression, attendance and often non-completion of their courses.

In conclusion, this study has set out to establish the range of supports applicants with AS might expect to have in place when accessing Higher Education in Scotland. This has provided the broader context to the work undertaken at one university to establish the efficacy of a summer transition programme specifically for such applicants. The philosophical
dilemma of providing condition specific support is acknowledged, however, it is offered as a model of practice that is potentially beneficial to individuals who have aspirations to access and succeed in Higher Education.

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Aspects of Social Interaction and Buddy Scheme - Supporting Transition and Progression for Students Identified with Asperger Syndrome (AS)

Rowena Atkinson, Claire Gandy, Clare Graham, Sarah Hendrickx, Victoria Jackson, Nicola Martin and Louise Rainford

Abstract

This paper explores aspects of social interaction for people with the label of Asperger Syndrome (AS) and presents preliminary evaluations of a small scale 'Buddy Scheme', which aimed to benefit students identifying with the AS label and non-disabled students studying at a large 'Million Plus' University. The understanding of AS which underpins this paper is as, "an autistic spectrum 'condition' (although the word 'condition' is contested), which can result in often subtle differences in aspects of social behaviour, communication and application of mental flexibility" (Martin, 2008).

The authors are acutely aware that difficulties experienced by people with the label of AS are often socially constructed, arising partly from the impact of long term social exclusion and 'othering'. Greater success and learner autonomy of students labelled with AS and the enhancement of their university experience through improved social inclusion were desired outcomes of the Buddy Scheme. The work spanned nine months and included the development of a stakeholder group; a recruitment and training process for non-disabled students; the evolution of a set of project boundaries; supervision for the Buddies and an evaluation methodology. Initial evaluative data revealed positive perceptions of the scheme from all of the students labelled with AS and all of the non-disabled students. Some evidence pointed to heightened learner autonomy amongst the students with the AS label in terms of self-directed learning and participation in social interaction including group work. Proposals for a longer term project, which will include involvement of pre-entry students labelled with AS during their transition to the university from schools and colleges have emerged. It is anticipated that the findings may be of use in other universities thinking of setting up similar schemes.

What is AS?

Beardon (2008) describes AS as a neurological difference on the autism spectrum and suggests that the impacts are unique to individuals and manifest themselves differently over time, probably as a result of factors such as personality and life experience. Aspects of communication, social
interaction and flexibility, are identified as problematic in diagnostic
criteria (Frith 1989). Sensory sensitivity (Bogdashina 2003) and issues
with executive functioning and central coherence (which impact on
planning and organisation) and theory of mind or empathy are also cited
as areas which present challenges to a greater or lesser degree (Baron-
Cohen and Sweetnam 1997; Beaumont and Newcombe 2007, Happe
1994; Happe et al 2006; South et al 2007). Anxiety (often around
change) and depression (frequently about loneliness), occur often,
probably as a result of negative experiences including social exclusion,
poor services and bullying (Attwood 2007). In-depth interests are often a
characteristic and these can be a source of joy and achievement. It is not
unusual for others to describe these using the pejorative term
'obsessions' (Baron-Cohen 2000). People with an insider perspective
provide valuable insights about their personal experience of living with an
AS identity. (Aston 2003, Edmonds and Worton 2006, Grandin 1995,
Stanford 2003, Williams 2003, and others). It is incumbent upon
researchers to attempt to understand from an insider perspective but to
be mindful of stereotyping (Martin 2008).

Social Interaction and the AS label

Foucault (1967:251) used the term 'othering' to describe positioning
people, in a pejorative sense, as 'other' (in comparison with the dominant
majority) and 'other' as in, 'less than'. Stevenson (2008:201) appears to
be influenced by Foucault, suggesting that 'othering' narratives of autism
draw a picture of people who are 'laced with strangeness'. Often literature
written by professionals could be characterised as 'othering', in that the
emphasis is frequently on the qualitative difference in social interactions
in comparison with individuals defined as being part of the neurotypical
(NT) majority. Writing from people who have an AS identity (and insider
perspective) often contradicts conventional (and controversial)
stereotypes of coldly logical individuals whose feelings for others are
qualitatively different from those of NT's, largely because of an inability to
empathise. Instead, uncertainty and low self-esteem arising from bullying
and limited opportunities for social interaction appear as pivotal factors in
relation to difficulty with the formation and maintenance of positive
friendships and intimate contacts. Terms like 'condition' and 'disorder' are
problematised by advocates of the view that AS is a neurological
difference which, in itself, brings with it many positives, arguing that
difficulties associated with AS are often socially constructed, given that
they frequently arise from social exclusion. (Beardon and Edmonds 2007,
Beardon et al 2009 and Martin 2008).

Sources of information about AS

With the exception of the ASPECT survey (Beardon and Edmonds 2007), it
is mainly small scale studies and individual narratives which provide an
insider perspective, directly from people with the label, rather than from
carers, parents, professionals and so on (Grandin 1995, Williams 2003, Lawson 2005 and others). The results of ASPECT (in which 237 people identifying with AS participated) were thematically analysed and formed a rich qualitative data source about daily life experiences, frustrations, requirements and desires. Beardon et al (2009) further interrogated ASPECT responses relating to experiences in higher education and found challenges presented by the social environment, social exclusion, bullying and finding NT’s hard to understand, to be commonplace. Madriaga et al (2008) cautioned that over-generalisation of the views of a few can result in stereotyping. Respect is requested for the diversity that exists under the umbrella of the AS label. Mindfulness is also necessary around the concern that while people who are prepared to identify as having an AS label may be willing contributors, others who are not comfortable with the association will not, therefore representation is necessary skewed (Martin 2008).

The Social Environment

Involvement in the social environment often creates difficulties for individuals identified with AS, but this is the result of interactions between people rather than solely factors within those with the label (Attwood, 2007, Beardon and Edmonds 2007, Martin 2008). 'People have to bear in mind that if you have AS, you have probably been bullied for most of your life', (Beardon and Edmonds 2007:243).

Diagnostic criteria for AS (DSM IV, 1994) do indicate the likelihood of differences in the manner in which a labelled individual would be likely to relate to others. Although not covered in DSM IV, sensitivities in sensory perception are often described. These can precipitate anxiety and result in reluctance to engage with noisy crowded (social) environments (Attwood, 2007, Beardon and Edmonds 2007, Bogdashina 2003). Multiple instances of social exclusion are common for people labelled with AS, and the potential impact on self esteem is obvious (Beardon and Edmonds 2007). An intimate relationship may be the first sustained friendship for someone who has grown up excluded by peers. Ideally, this would be with an accepting and genuine person, but lack of experience of every day friendship in itself can place the person with AS in a vulnerable position when it comes to sexual predators (Stanford, 2003).

ASPECT (Beardon and Edmonds 2007) present many examples of bullying and exclusion, three of which follow by way of illustration.

- 'When schooling was proving very, very difficult I lost all my self esteem and didn't have friends' (p222)
- 'People have to bear in mind that if you have AS you have probably been bullied for most of your life. I was bullied in school, in more than one workplace, and also by family members' (p243)
- 'You find me somewhat bitter when it comes to relating to those human beings we dubiously call neurotypical'(p221).
Arguably, many (but not all) NT individuals develop adequate social skills in childhood and continue to hone them with constant practice throughout their lifetime. People with an AS label are placed at a disadvantage by others through lack of opportunity to join in because of limited access to friendship outside the family (Beardon and Edmonds 2007, Martin 2008). Sustained bullying and exclusion by NT peers while growing up is not likely to boost confidence or raise self esteem, placing the person with the AS label in a further socially disadvantaged position (Attwood 2007, Beardon and Edmonds 2007). Exclusion from the social arena (by external oppression or by internalised oppression arising from feeling unworthy) makes it impossible to hone social skills through social interaction.

Anxiety about not knowing how to approach people or how to respond to approaches from others, as well as experiences of bullying, are frequently described by people identifying with AS (Attwood 2007, Beardon et al 2009). The notion of problematising the idea of labelling is articulated by one young man with an AS label.

- 'Having a diagnosis of AS as a child means that you can never interact normally with anyone as an adult because you know they are looking at what you do as a symptom of AS' (Martin 2008, personal communication).
- Locating difficulty with social interaction as a problem for people with an AS identity absolves NT's from the part they play in othering and exclusion, an irony not lost on ASPECT participants.
- 'NT's need to stop thinking they are better than us. They should accept us for who we are instead of only accepting us if we try to be like them and rejecting us and being mean if we make a mistake or get confused or stressed, or just don't want to socialise' (Beardon and Edmonds, 2007:221)

Social Networking

Internet based social networking appears to be fast becoming an alternative inroad to a form of social life. On-line conversations do not demand an understanding of body language, or require participants to make eye contact. Participation in on-line communities is often around a theme, which may be autism or a shared interest. Numerous web fora, message boards and sites are emerging specifically for people identifying with autism and their associates (carers, parents partners and colleagues), providing the opportunity for unlimited on line conversation. (www.aspiesforfreedom.com. www.wrongplanet.net) People may identify others they have not physically met as close friends and confidantes, thus redefining the traditional terms of friendship and relationships. Madriaga et al (2008) found that students expressed a
preference for communicating electronically for social and academic purposes. The Buddying project did not explore this avenue but future interventions are planned, which will include a social networking element.

Attwood (2002) cites evidence that suggests that social life can becomes easier for some people labelled with AS once they reach their late twenties (often after leaving higher education). Parties cease to be obligatory and potential friends and partners possibly become more open minded with increasing maturity and maybe less interested in nightclubbing and socialising in large groups themselves. Qualities such as stability and reliability may begin to be seen as more valuable than being the life and soul of the party. Diversity may be accepted more as people leave the education system and take up diverse roles in society. Sadly, Beardon and Edmonds (2007) did not find the view that social inclusion improved with age, expressed by ASPECT participants, some of whom talked about loneliness and under employment after graduation. University alumni structures may wish to consider this concern as part of their equality and diversity strategy.

The University 'Buddy Scheme' Project

The number of students enrolled at the university labelled with AS has risen from 3 students in 2004/2005 to 32 in 2009/2010. This rapid increase may well continue, as there is evidence (from student and parent feedback) to suggest that the institution has an excellent reputation for supporting students identified with AS. Widening Participation is a key objective at the university, with inclusive practice as integral to this agenda. Students with the AS label are currently spread disproportionately across the university, with 17 out of the 32 students studying in one of the four faculties in which computing, engineering, arts and sciences courses are delivered (CEAS). Martin (2008) evidenced a concentration of students described as being on the autism spectrum in specific curriculum areas, including those represented in CEAS, so arguably this is following a trend.

Those identified with AS are more likely than other students to struggle with socialisation and communication. The impact can be highly stressful and their student experience is often characterised by feelings of isolation and loneliness. These difficulties can impact significantly on peer and tutor interactions, potentially compromising individual, group work and placement outcomes (Atwood 2006, Madriaga et al 2008, Martin 2008).

Prior to the commencement of the project, the Disabled Student Support Team (DSST) had received requests from prospective students labelled with AS who were keen to join a university run peer support scheme. In addition to student feedback, interviews undertaken by DSST practitioners indicated that many learners identifying with AS were finding the transition from school or college to higher education to be very challenging. Some students currently accessing higher education can be
affected by the pedagogical gap in the transition from school or college to higher education, with a shift from direct to independent styles of learning (Martin 2008 and Fry et al 2009). Evidence taken from research projects conducted by the National Associate of Disability Practitioners (Martin 2006) and the Higher Education Academy (Madriaga et al. 2008; Madriaga and Goodley 2008), suggested that the development of a buddy/befriending scheme could be of value to enhancing learner autonomy for students identified with the autism spectrum. Facets of learner autonomy considered here are characterised by the capacity for self-directed learning and effective social interaction for academic purposes, for example in group work. The concept is broader than this and deeper engagement is beyond the scope of that which can be presented here.

The project aimed to benefit both students labelled with AS and non-disabled students by promoting opportunities for students to develop greater learner autonomy (as defined here) via increased confidence in group interactions and social situations, as a precursor to using these skills to improve self directed learning (by recognising the requirement for assistance and asking appropriately for example). Specifically the scheme focussed on:

- encouraging and supporting participation of students identified with AS in a wide range of university activities, with a view to reducing social exclusion
- enabling all the participating students to develop a range of skills and attributes potentially helpful towards gaining graduate employment
- improving the relationship between students labelled with AS and their peers
- gathering further evidence and resources to develop a future scheme, possibly focussing on transition

Anonymity of participants is protected and students confirmed their willingness for the findings to be used to improve practice and potentially benefit others.

**Purpose and goals of the project**

Work undertaken by the University's Improving the Student Experience Group - Retention and Student Success, considered a range of research to inform the development of a Retention Policy and Framework. To summarise, the research undertaken by Yorke (1999), Yorke and Longden (2008), the National Audit Office (2007) and House of Commons Committee of Public Accounts (2008), the main reasons that students withdraw are:

- Inadequate preparation for Higher Education
- Poor institutional and course match
• Not coping with academic demand/ making poor progress/ lack of engagement
• Poor social integration with their peers and academic/ support staff
• Financial issues and personal circumstances

There is a clear rationale, therefore, for considering models of student support which are likely to improve social inclusion. A focus on the experiences of students with the AS label seems appropriate given the issues which have been highlighted in the preceding brief literature review. Mindfulness about the potentially 'othering' nature of an insensitive approach was clearly identified as an influence on the project development. Jones (2008), in his review of widening participation, student retention and success, recommends that institutions assist students in developing a sense of belonging through induction, student centred learning and social integration and this was congruent with the project agenda. The buddying scheme was conceived to enhance belonging of participants, rather than to reinforce 'othering' and a participatory research methodology was critical to this aim.

Peer mentoring has been identified as a key priority in the university's Corporate Plan, as part of a strategy of developing the support for students which is available at key points of transition. This initiative clearly sits within this strategic framework and has enabled the institution to evaluate a particular model with a view to collectively improve and develop practice. It is anticipated that the project will have application beyond informing the institution's policy and practice in disabled student support provision. Longer term plans extend to examining the benefits and costs of a particular method of enhancing student engagement which may benefit all students.

Concept

The project built on the work of Martin et al (2009) Promoting Learner Autonomy through Mentoring, which evaluated existing mentoring provision and developed a training programme for mentors.

Central to the work of the Disabled Student Support Team (DSST) is the promotion of an inclusive approach to teaching and learning and of encouraging student autonomy.

Assumptions and Context

The approach taken was premised on the notion that by developing a Buddy Scheme (peer mentoring), students with the AS label would gain the opportunity to have social conversations with fellow students in a reliable, empathetic and supportive context with potential for:

• some reduction of general feelings of isolation and loneliness
some development of specific skills in the art of holding a conversation, thereby enabling each student to make progress towards becoming a more autonomous learner by increasing social confidence

- an increase in confidence in terms of participating in a specific social context (while being cognisant of evidence that transfer of skill across contexts cannot be assumed (Martin 2008) and specific generalisation or activities may be necessary.

Without stereotyping students identified with AS, mindfulness was necessary around potential barriers, along with the understanding that the students are not all the same just because they share a common label.

**Methodology and Approach**

The main project team consisted of two members of the DSST Management Group and two mentors who were employed to carry out the research and prepare materials to be used with participants. Two further academics contributed to the background study. An action research paradigm was implemented employing an ethnographic methodology (Denzil and Lincoln, 1994). A background study to identify peer support schemes within other organisations did not reveal other research projects focusing on the specific area of enquiry identified here, either in higher education or conducted by organisations such as the National Autistic Society.

In addition to external research, the team contacted various departments and academic faculties within the university, a relevant research centre, and the Students' Union, with the aim of identifying examples of peer support schemes currently in operation within the University. The University Volunteering programme has significant experience of running a befriending scheme for people identifying with AS, and the project team were able to draw on their experience.

A two stage approach for the research with students was agreed with input from a stakeholder group, chaired by a student identifying with AS and a series of interviews with students with the AS label. Literature cited also drew heavily on insider narratives from people with an AS identity.

The Stakeholder group included:
- 5 Current students with the AS label.
- A representative from the Students' Union
- 3 Representatives from the Disabled Student Support Team
- A representative from the Learning and Teaching Institute
- Representatives from a relevant research centre
- 2 DSA Mentors
• A graduate of the university

The Discussion Group took place in December 2009 and was chaired by one of the students with AS. Disabled students were members of the Stakeholder Group, Their involvement provided the project with an authentic student voice, and ensured student influence in the direction, implementation and the dissemination of the overall findings. The initial meeting provided a good starting point for sharing ideas and views about the role and scope of the proposed Buddy Scheme. Training materials were devised (for the Buddies by members of staff within the Disabled Student Support Team). The stakeholder group participated in creating a set of boundaries within which the scheme would operate.

Student interviews undertaken by members of staff within the Disabled Student Support Team were used to generate further ideas about the purpose and practices of the Buddy Scheme.

**Recruiting Buddies**

Following the research stages, a role description for Buddies was generated and advertised within the University by the research team (with input from the stakeholder group). Advertising took place over two weeks via the intranet, the Students' Union and via direct emails. Twelve responses were received from students who were interested in becoming volunteer buddies. None of these students identified with the AS label. Eight fulfilled the requirement of submitting a CV and personal statement by the deadline, all of which fulfilled the criteria; therefore all eight were invited to a half day recruitment event.

During the event the team presented information about the project and existing services provided by the DSST. Following the introductory presentation, the candidates were asked to complete a group activity which tested their views and understanding of the boundaries of the buddy role. Two members of the research team then carried out individual interviews. Unsuccessful candidates were offered feedback and the six who were successful were invited to a further half days training two weeks later. The event covered:

- The role and boundaries of a Buddy
- Disability Equality
- Confidentiality and Duty of Care
- Support for participants

All candidates were deemed to have met the role criteria and were invited to the Buddy Scheme launch. Prior to the launch, the team met to decide how volunteers would be matched with the students who had requested a Buddy. Four groups were planned, two groups of three people and two of two.
The launch and roll out of the scheme

The launch session comprised of two parts. The first part was allocated solely for the students identifying with AS who had requested a buddy and provided a confidential opportunity to ask questions before the buddies arrived. Boundaries were clarified and a discussion took place about suitable activities for buddy groups.

During the second part, the non-disabled students were included and all participants were given a structured opportunity to introduce themselves. An 'icebreaker' was devised to help create a semi-informal atmosphere (within boundaries) for the introductions. Smaller group discussions followed to allow more time for participants to get to know each other and to arrange their first meeting.

The event concluded with a short presentation from the team to clarify issues such as confidentiality, duty of care and the scheme boundaries. On-going support was offered to all students involved with the scheme.

Four students with the AS label and six buddies were matched into three separate buddy relationships (the planned two groups of two combined into one group of four). Buddy meetings then took place over a period of ten weeks. The non-disabled students were offered a monthly support session with a member of the DSST team to confidentially discuss their role and any issues or concerns. Students with the AS label were offered the opportunity to raise any issues with either their DSA Mentor or a member of the DSST team.

Evaluation

All three buddy relationships were successfully maintained during the period of the scheme and all participants kept within the agreed boundaries. Participatory research was the premise of this study with the stakeholder group comprising both students and staff. Summative evaluation comprised three separate questionnaires for the students with the AS label, the buddies and the project team. Separate focus group were held for students identifying with the AS label and for volunteers, with the aim of capturing student narratives regarding their expectations of the scheme and the impact of participating.

Quantitative analysis of the questionnaires was not appropriate as the numbers completed was small; 4 from the students identifying with the AS label and 4 from the buddies. The focus groups and the questionnaires raised similar feedback.

Summary of feedback

The questionnaires revealed the following:
All respondents rated the recruitment, training, matching event and buddy meetings as Good or Very Good.

There was a consensus regarding the boundaries of the scheme from both students identifying with AS and Buddies. All agreed that they had been appropriate except for the restriction for the Buddy meetings to be limited two named university campuses. There were six specific requests/suggestions for the meetings to take place 'close' to the campus, e.g. in a quiet coffee shop. Three respondents suggested that this should be allowed to happen once the Buddy relationship had become well established.

**Finishing sentences in the questionnaire, students identifying with AS commented:**

- "The most useful learning experience for me, with regards to the scheme was... it gave me the opportunity to learn outside my lectures and seminars: understanding social skills; working as a group"
- The thing that I feel is most valuable about the Buddy Scheme is ... helps integrate students with AS into university life
- "It has made the adjustment to University life more easier. I felt a bit unsure before. Now the Buddy Scheme has changed all that. I certainly would do schemes like this in the future. I thoroughly enjoyed the Buddy Scheme and I think it should continue".

**Comments from the students not identifying with AS, when asked what skills they had developed as a result of their participation in the scheme:**

- A greater understanding of AS. My interview skills have developed through the feedback given.
- Understanding of how non-verbal signals, i.e. silences can affect someone. This has affected the way I interact in group situations.
- Empathy & sympathy, time management, communication

**Comments made in the focus group for students identifying with AS**

**In terms of positive outcomes of the project:**

- "Well, it's helped with social skills and it's helped me to integrate more into the university life."
- "It helped me settle in a bit more"
- "I think it's helped me boost my communication, boost my confidence talking to other people"
- "I suppose it's put me at ease in some way, and it's just helped take my mind off some things, when I'm feeling stressed out about certain things it has helped to put my mind at ease."
"I've found more of a social life with the Buddy Scheme, because I felt a bit lonely really, didn't really talk to anyone very much, but I have really enjoyed it. I hope it continues next year."

"You learn that there are people who want to learn about AS"

"I've felt … I can still speak my mind even with a learning disability …. It's just kind of helped me open up a bit more I suppose, in some ways."

"The group experiences and how that might have helped towards how in employment you have to work in groups …"

**In terms of what they enjoyed most about the scheme**

- " ... being out socialising, and being out with people you can trust and have confidence in"
- " ... just social stuff that you look forward to"
- "you learn how to be more independent, arranging meetings and so, it's like a team of individuals"

**In terms of the need for a longer term scheme and recognition that the process of developing communication skills is long term:**

- "The scheme is only a stepping stone in a way because you can't go 'right I've learnt this' in one scheme or a few months you've literally gotta carry on for a year or more so. It's like doing a course, you can't do 2 weeks and then bang!"

**Comments made in the focus group for the students not identifying with AS**

**In terms of employability:**

- "... it ... really helps you critique your own behaviour, like with time management and ... leading the meetings and knowing when to take a step back and when not to, and what questions to ask if you thought someone didn't want to disclose something, the empathy you've got and just everything. ...I helped to look back at what you've done ... what went well or didn't go well if it got awkward with silences or something ... it was good just to analyse how I was."
- "... I usually don't bother about being 10 minutes late .... But to be honest it (time management) has improved, and I never wanted to be late ..."

**Summary of the main findings of the project:**

While findings cannot be over generalised, the small scale scheme was viewed as a positive experience by all participants. Some reduction in
feelings of isolation and loneliness were described by students identifying with AS. Ethically, maintaining the structures for buddy support after the research ended was critical, but long term research follow-up is not planned.

Outcomes in the short term suggested a higher degree of inclusion into university life, the development of specific social skills by the students identifying with AS, and empathic responses from the volunteers. Improvement in social interaction may translate into skills which could be useful in group work and ultimately employment but this, and other aspects of the development of learner autonomy, require systematic interrogation over time in order for more reliable conclusions to be drawn. The limitations inherent in having a small number of participants are obvious. However, a small scale evidence base has been generated and may provide a catalyst for others thinking about implementing a similar scheme.

Going forward, the University is now committed to increasing the opportunities for peer support available to students with the AS label and different incarnations of the pilot scheme are emerging. Mindfulness about the 'othering' impact of labelling will influence future activity. Encouragingly, one of the students, identifying with the AS label and involved in last year's scheme, is currently setting up a new 'social' society within the University's Student Union. He is joined in its Management Committee by four of the other students involved in the scheme (two who identify with the AS label and two who do not). Within the DSST, a 'Peer Mentor' role has been instigated via funding from Disabled Students Allowance. Although time-limited, supporting only students in their first semester, early feedback from the five students supported via DSA is very positive. It is hoped also that over the next few months, opportunities will be explored, working with the University's student volunteer scheme and a number of academic departments whose focus lies in developing students' professional skills in the areas of psychosocial practice. On-line social networking activities will also be considered and students with an insider perspective of identifying with an AS label will be encouraged to mentor others. Student evaluation methodologies, yet to be worked out, will be employed in order to ascertain the ongoing effectiveness these programmes. Consideration of how to support people who do not want to 'disclose' will also be explored.
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Yorke and Longden (2008), *The first-year experience of higher education in the UK*, York, The Higher Education Academy

Improving the Student Experience Group– 'Retention and Student Success', *Retention Policy, Framework and Recommendations*
Editorial guidelines

- Articles should be between 2500 and 6500 words, usually around 3,500 to 4,500. You may be asked to reduce the number of words even if your article is less than 6500, if the referees feel that you could express yourself more succinctly. Communication on your submission will be via the NADP office.

- An abstract of no more than 300 words is required for research based articles (not for reflective pieces about personal experiences-which will mainly be from disabled /neurodiverse people).

- Contributions from disabled /neurodiverse people about their own experiences of post 14 education and training (in its broadest sense) are very welcome.

- Harvard referencing is required and at least 50% of your references need to be no more than three years old.

- Contributions should reflect ethical participatory /emancipatory research, which involves disabled /neurodiverse participants and results in interventions which improve services for disabled /neurodiverse people in the post 14 (education and training) sector.

- Ethical guidelines prescribe that research participants should not be identifiable, and confidentiality must be respected.

- Language reflecting the social model of disability is expected.

- Articles must be original and should not be being considered by another journal when they are presented.

- Formats must be accessible to screen reading software.

<table>
<thead>
<tr>
<th>Editorial Board</th>
<th>Proof Reader</th>
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<tbody>
<tr>
<td>Professor Mike Adams</td>
<td>Val Morgan</td>
</tr>
<tr>
<td>Dr Colin Cameron</td>
<td>Kelsey Beninger</td>
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<td>Dr John Conway</td>
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<td>Mrs EA Draffan</td>
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<td>Dr Manny Madriaga</td>
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Copy Editor

Beverley Fraser
Thank you for Dr David Pollak who has now retired from the Editorial Board but continues to support the development of the Journal and the work of NADP.

**About NADP (National Association of Disability Practitioners)**

**Information about NADP**
NADP is a Professional Association for those working in the post compulsory education sector involved in the management or delivery of services for disabled students. We aim to promote disability equality and excellence in the quality and consistency of educational services provided for disabled students. We work to improve the professional development and status of disability service staff in the post-14 education sector through peer support, education, communication and leadership.

**We get involved in:**
- representing disability staff at national meetings as appropriate
- drafting codes of practice
- encouraging Continuing Professional Development
- peer support and peer mentoring
- information on qualifications and training
- disability equality training
- conferences and educational events
- dissemination of good practice

**Contact details**
Web site: [www.nadp-uk.org](http://www.nadp-uk.org)
To discuss the content of individual articles, please contact the author directly.

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