

**Resisting the tick box: reflexive use of educational technologies in
developing student identities and challenging HE constructions of disability
based on notions of conformity and consistency**

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Abstract

For many students, impairments such as chronic fatigue syndrome (CFS)/ myalgic encephalomyelitis (ME), epilepsy or diabetes have the potential to vary in intensity, and thus impact, on participation in learning activities and on self-perception/ identity. This paper considers some of the factors which may be of influence on the ways in which students with such fluctuating or recurring impairments enact identity within Higher Education in the UK. In particular, it highlights the potential role of Higher Education discourses based on notions of consistency and conformity in constructing disablement in finite ways. It also reviews the potential for reflexive use of communication technologies in offering students ways of promoting or masking selected aspects of identity. The paper concludes with some insights into possibilities for the use of online communication modes in offering flexibility and autonomy in managing student identity and challenging institutional discourses of disability as fixed or finite.

Keywords

Higher Education; fluctuating or recurring impairments; student identity; reflexive educational technologies.

Introduction

In the UK, there has been a continued year on year increase in the number of students disclosing ‘unseen’ impairments when enrolling on full time, taught undergraduate programmes in HE (HESA 2012). ‘Unseen’ impairments, according to the Higher Education Statistics Agency (HESA), include ‘diabetes, epilepsy, asthma’ (HESA 2012). Many ‘unseen’, ‘hidden’ (Matthews 2009; Valeras 2010) or ‘invisible’ (Lingsom 2008) impairments have the potential to fluctuate in intensity over time (as in the case of those used by way of example by HESA), and as such there is consequent potential for varying impact on students’ abilities to plan or undertake learning or assessment tasks at different points in the academic year.

For many students, impairments such as chronic fatigue syndrome (CFS)/ myalgic encephalomyelitis (ME), epilepsy or diabetes, for example, have the potential to vary in intensity, and thus impact, on participation in learning activities and on self-perception/identity. With increasing disclosure, yet limited recognition, of such types of impairment comes a need for Higher Education Institutions (HEIs) to better understand changing impact in terms of inclusion and in observing anticipatory aspects of legislation, as well as furthering insight into how student identities might be negotiated, constructed and enacted.

In an institutional context of dominant educational disability discourses being based on diagnosis, categorisation and quantifiability, institutions are encouraged to revise their vision and values to embrace difference in favour of conformity; to resist the tick box approach to defining disability in responding to what Barnes (2000) refers to as ‘accredited’ impairments.

This paper considers some of the factors which may be of influence on the ways in which students with fluctuating or recurring impairments enact identity within Higher Education in the UK. In particular, it highlights the potential role of Higher Education discourses based on industrial values of consistency in constructing disablement in finite ways. It also reviews

the potential of communication technologies in offering students ways of promoting or masking selected aspects of identity. The paper concludes with some insights into possibilities for the use of online communication modes in offering flexibility and autonomy to students in managing and enacting identities in ways that subvert potentially exclusionary practices.

Disability-related legislation in the UK and its impact on HE policy

Legislative changes that have occurred in the UK in the past few decades have contributed key concepts, phrases and terminology to disability policy and legal debate and influenced the language, constructs and discourse used in Higher Education policy making. The Disability Discrimination Act (DDA) (1995) for example, introduced ‘reasonable adjustments’ as a term for the negotiated provision of access to ‘goods, facilities and services’ that promoted participation and counteracted acts of ‘discrimination’. Part 4, Chapter 2 of the DDA specifically referred to the ‘duty’ of education providers to address ‘reasonable adjustments’. The Special Educational Needs and Disability Act (SENDA) 2001 amended Part 4 of the DDA as well as Part 4 of the Education Act (1996) in a dedicated act that specifically addressed provision of education for students with disabilities, and carried forward notions of ‘duty’, ‘enforcement’ and ‘assessment’ in safeguarding against the ‘less favourable’ treatment of students with disabilities. More recently, the Equality Act (2010) has brought together diverse areas of legislation within one ‘simple, modern and accessible framework of discrimination law’ (Government Equalities Office 2010) to include disability as one ‘protected characteristic’ amongst a group that also includes age, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation (Home Office 2012). Many of these concepts and phrases have found their way into institutional documentation in HE in support of disabled students. Notions of ‘duty’,

‘adjustment’ and ‘protection’ are also of key importance in how students with disabilities are constructed and supported.

Notably, it has only been since amendments to the DDA in 2005, however, that legislation in the UK has recognised impairments which might fluctuate or recur. These amendments extended the scope of the DDA to include ‘from the point of diagnosis, people with HIV infection, cancer or multiple sclerosis’ and ‘end the requirement that a mental illness must be “clinically well-recognised” before it can be regarded as an impairment under the DDA 1995’ (Inclusion.me 2010). Furthermore, the EHRC advise that the legislation accounts for ‘long-term or fluctuating health conditions...problems with mobility, seeing or hearing, a learning disability, mental illness, epilepsy, AIDS, asthma, diabetes or a condition that gets progressively worse such as multiple sclerosis may be covered under the DDA’ (EHRC 2012). Until 2005, then, limited scope existed for the acceptance of fluctuating or recurring impairments, due to issues of recognition and diagnosis, and even with the 2005 amendment, such impairments *may* only qualify to be included. Similarly, the Equality Act acknowledges the significant impact of ‘long term’ conditions (which it takes to include impairments which have persisted or are likely to persist for twelve or more months) and fluctuating or recurring conditions on daily life.

A key feature of recent disability-related legislation is that measures to ensure access to provision are required to be anticipatory. The DDA, SENDA and the Equality Act all require public sector bodies, including HEIs, to acknowledge and act upon an explicit ‘duty of care’, and carry out ‘impact assessments’ to identify any potential and actual barriers to participation in academic activities for any student with one or multiple impairments. The ‘action plans’ which are the product of the ‘impact assessments’ ensure that ‘reasonable adjustments’ are put in place to enable students to fully participate and meet the pedagogical objectives of their curriculum. Criticisms have been raised, however, that such a focus on the

individual and their bespoke requirements may encourage a more pathologised model of delivery (Slee & Allan 2001; Haggis 2006), which contradicts the notion that embedded processes are more inclusive. Despite this, issues of flexibility, contingency and alternatives are important to consider in supporting the participation of students with fluctuating or recurring impairments.

Indeed, Allan (2005) has argued that a deficit model of provision for students with disabilities has driven educational practices for some time. This has historically been true of much disability-related policy, which has fundamentally been shaped by the medical model of disability, and characteristically compensatory in nature (Christie & Mensah-Coker 1999). Though linguistically problematic by today's standards, the Warnock Report: Special Educational Needs in England, Scotland and Wales (Department of Education and Science 1978), as implemented by the Education Act 1981, marked a move towards more inclusive provision for students with disabilities within education in the UK. Whilst indicative of the improvement-oriented policies of their time, such suggested reforms were essentially developed in response to what could be defined as 'special', in itself determined by what is viewed, conversely, as normal or mainstream education (Barton 1997). Marks (1994) raises associated concerns in positioning students with disabilities within discourses of exclusion unintentionally:

'individuals who are integrated are constructed by and within discourses that valorise normality, and regard difference as deviance . In the Foucauldian sense, students with disabilities are frequently disciplined and punished for their disabilities, even within policies and education systems that espouse commitment to social justice. To have a disability is to be inscribed as other, and as such, requiring of special attention' (p.83).

The Warnock Report and the 1981 Act have been described as 'almost the final product of the old welfare consensus as applied to education' (Oliver 1996, p.80), and arguably marked

a sea change in professional dominance in special educational policy-making from those engaged in medicine to those in education (Riddell et al 2005). The Warnock report laid the foundations for the nature, aims and semantics of much disability related policy since (through direct influence or contradiction), as well as providing a catalyst for dialogue between a growing body of policy makers and researchers who cyclically construct and deconstruct what constitutes acceptable or preferable political or legal documentation, constructs or terminology.

Not measuring up to Higher Education discourses?

In Higher Education, accountability and the need for measurement are central to debate on bureaucratisation and practices of new managerialism (Lane & Stenlund 1983; Avis 1996; Deem 1998). The characteristics and technologies of such an audit culture are components of what, for Foucault, could be construed as governmentality (Shore & Wrights 1999; Shore 2008), impacting upon how individuals within the institution construct the boundaries of their participation and the roles they adopt. ‘Audits, performance indicators, competitive benchmarking exercises, league tables, management by targets, and punitive research assessment exercises and periodic teaching quality reviews’ (Shore 2008, p. 282) are all ways in which new managerialism is enacted within HE. As such, the creation of and allocation of students to various categories (student with disabilities, mature learners, widening participation students) are abundant.

In the UK, UCAS (The Universities and Colleges Admissions Service, through whom applications for study in post-compulsory education in the UK are made) and HESA descriptors of impairment provide access to terminology and categories as regards constructions of disability. Like HESA, UCAS use an ‘unseen (e.g. diabetes, epilepsy,

asthma)' category, as well as '2+ disabilities / special needs' and 'other disabilities / special needs' (UCAS 2012) in reporting data on applications from students with disabilities. These categories are arguably less definable than, for example 'blind / partially sighted' or 'Deaf/ partial hearing', again returning to Barnes's (2000) notion of 'accredited' or more recognized forms of impairment. There is no option on the form to disclose a fluctuating, recurring or indeed long-term condition.

Challenges of measurement and quantifiability, such as those that are crucial to UCAS or HESA, definitions of disability and impairment, are twofold in the establishment of a shared understanding of fluctuating or recurring impairments. Firstly, actual estimates of prevalence of fluctuating or recurring impairments are difficult to establish, largely because comparability between different geographical and cultural groups in epidemiology studies can be problematic (e.g. Working group on CFS/ME 2002); and secondly, because of the very nature of the types of impairment under study, definitive inclusion/ exclusion criteria are often not possible to identify or are overly-complex, and again, difficult to draw conclusive, comparable results from (Working group on CFS/ME 2002). Lightman et al's (2009) application of queer theory to the concept of fluctuating or recurring conditions highlights ongoing 'precarious bodies' and 'fluid identities' which enable people with complex and fluctuating impairments to transition between different understandings and constructions of self. This adds additional difficulty in bounding groups of students in different categories, in that people with fluctuating or recurring impairments experience ongoing and dynamic fluctuations in self:

'By elastically crossing material (biological) and experientially shifting boundaries, there are no cast-iron universals of bodies; instead, there are only fluctuating, contingent, fluid bodies and identities that continually contract and expand from one

side of the binary (health/illness, ability/disability) to the other, or that resist a divisive embodiment altogether' (Lightman et al 2009, online).

Positioning and identity are thus crucial in considering the learning experiences of students with fluctuating or recurring impairments within the discourses of HE.

Negotiating identity

Sabat and Harré (1992) use social constructionism in explaining the negotiation of individual perceptions of self/ identity (singular or multiple) as well as those imposed/ assumed by others, particularly focussing on the role of agency and representation. For people with disabilities, this agency may be enacted through the choice of when and if to 'disclose' their impairment, depending on their self-perception (for example, whether they consider themselves to be disabled or not ([Watson 2002]) or the social context. For people with disabilities which fluctuate or recur, these influences may change frequently over time.

Components of identity (social or individual) do not exist singularly, but as 'interactive and mutually constitutive' (Lawler 2008 p.3), and people may be required to 'negotiate the clash of voices, which ones they invest authority in, which ones they find internally persuasive' (Lather & Smithies 1997 p.125) in making sense of or rationalising conflicts. However, it is also the case that some forms of identity may be governed by their inability to co-exist, including binaries of man/ woman or homosexual/ heterosexual, for example (Lawler 2008, p.3), in which a 'dis-identification' involves rejection of one category in favour of another.

This plurality of selves could be considered in personal, relational and collective terms, and the potential to self-represent in each of these ways (independently, in dialogic relationships and in groups) co-exist within one individual and are socially produced consider (Brewer & Gardner 1996). Being a student with a disability may or may not feature as one of multiple identities for those students whose impairment has the potential for fluctuate or recur. Indeed,

many may reject the notion of disability within their identities, instead constructing themselves as unwell. A not un-complex intersection between chronic illness and fluctuating or recurring impairments has means that both students and institutions might draw on constructions of health or wellness in either representing themselves or in interpreting students' impairments (Boyd 2012).

Choice in representation presents a significant tension for those with 'hidden' impairments in that 'they are constantly negotiating when, where, why, and how to disclose and adopt the disability identity or to 'pass' and give society the impression of 'able-bodiedness' (Valeras, 2010, online). This potentially creates a dilemma in terms of concealment and disclosure of impairments in that:

'persons with invisible impairments are not assigned subject positions as disabled people initially. Persons with invisible impairments may on occasion "pass as normal". They are in a position where they may continually reflect upon whether or not, when, how, and to whom they should attempt to conceal or reveal their impairments' (Lingsom 2008, p.3).

This choice to engage in 'passing as normal' or 'looking okay' (Boyd 2012) as regards fluctuating or recurring impairments has the potential to contribute to institutional misinterpretation of students' physical attendance as equating with ability to participate in learning. For students with fluctuating or recurring impairments who experience low energy or mobility difficulties, for example, this may not be the case, therefore a more nuanced approach to negotiated support which might reflect changing needs should be considered by institutions in considering anticipatory responses to providing 'reasonable adjustments'.

Playing with online identity

Much interest surrounds online representation of identities, and in particular in the application of technologies of the self within virtual spaces and through social networking (Abbas & Dervin 2009; Parsell 2008). One model suggests a process of online identity construction based on Foucault's principles of 'self-fashioning' (which is equated with Foucault's work on self-governing [1991]) in order to conceptualise a developmental process of being caught between liminal perceptions of the internet being viewed by some as a source of liberation and facilitating personal autonomy, and by others as restrictive and highly regulatory. In this model, Aycock (1995) offers four components which characterise his model: (a) the private 'inner substance' that is believed to be the ultimate source of personal identity; (b) the degree and kind of commitment that is made to a given activity; (c) the personal routines or disciplines that are adopted to reshape one's identity; (d) the eventual goal of the personal transformation that has been undertaken. Whilst Aycock values the possibilities for thematically analysing online interactions and identity constructions in this way, he also moots caution in online ethnographical research, in acknowledging the potential for the researcher's construction of the participant's own identity constructs to be largely driven by language rather than interactions (i.e. what they say as opposed to what they do). In using online chess news groups as a focus, Aycock suggests that the internet may act, in the interests of facilitating an active social construction of identity, as a technology of the self (Foucault 1988), through presenting possibilities or selective participation (e.g. 'lurking' or mastery) in virtual groups with a shared interest.

Online interactions involve identity play or experimentation with provisionalism, pluralism and liminality (Savin-Baden & Tombs 2010). It is important that educators recognise the potential impact of this vis a vis connective, social media and what this might mean for the development of students' multiple selves (Facer & Selwyn 2010). Where these selves may be

in conflict, negotiation or a state of becoming, as potentially in the case of students with fluctuating or recurring impairments, space for autonomous reflection might offer a powerful tool for developing self-awareness or dialogically enabling support. Through recording and sharing practices of the self, students can acknowledge technologies of self-care and discuss potential for practically operationalising these within the institution. As such, a student may be engaged in personal storytelling, reflective practice and deepened self-awareness with a view to leveraging possibilities for flexible provision.

In narrative practices such as storytelling, the narrator is provided with the opportunity to edit their presentation of self and formation of identity, and promote different aspects of their selves at different junctures in the story (Georgakopolou 2002). This has clear implications for conversations carried out digitally and virtually by email, in the potential for presentation and re-presentation of incidents and aspects of identity. This medium has been used in research on the construction of academic identity amongst staff (James 2007), and the usefulness of email discussions as a site of identity construction within a dedicated, familiar method of communication to the research participant noted. This scope to alter representations of self was noted by participants in James's research, who reflected on their choices and decisions relating to sharing or withholding information, and how they presented their experiences.

However, it has been argued that for this is just as likely in face-to-face interactions, due to the transient, fluctuating and progressive nature of identity, defined by 'copies, imitations and forgery. Identity is always deferred and in process of becoming – never really, never yet, never absolutely "there"' (MacLure, 2003 p. 131). MacLure also argues that 'self-hood is inescapably mimetic, a matter of masks and copies, whether or not we (know we) are deliberately faking it' (2003, p.157). An alternative position suggests that this selective process in fact adds 'authenticity' to online texts, as the caution attached to sharing

experiences in the 'disembodied environment' denotes confidence in participation as opposed to possible risk-taking in self-representation in the face-to-face environment (Mann & Stewart 2000 p.210). Control over the editing and revision process could be viewed as empowering for the author (Markham 2004), and thus could be viewed as a constructive, confidence-enhancing aspect of authoring digital texts. All of these considerations are equally important in enabling experimentation with online identity play.

Disability and reflexive use of educational technology

Finklestein's (1980) third phase of disability construction considers possibilities for re-definition of disability through the advent of new technologies. In this phase, technology can arguably provide alternative routes to participation that may not formerly have been possible, and in so doing challenge otherness and difference in constructions of disability. For example, the use of Braille keyboards in facilitating non-visual interaction with a computer open up possibilities for distributed forms of communication. As a result, it has been argued that 'technological change will directly result in a change to institutions, practices, and ideas' (Ellis & Kent 2011, p.88) as regards constructions of disability. However, 'patterns of technology are influenced by the cultural traditions of the society that produces them' (Ellis & Kent 2011, p.88), and thus innovation is socially and culturally driven. In considering the impact of different social or cultural influences on the adoption of technology, Eijkman (2009) suggests that widespread uptake of collaborative web 2.0 and mobile technologies in HE reflect and respond to an increase in non-mainstream knowledge and discourses which have accompanied internationalisation and massification of education in recent years.

The advent and integration of web 2.0 technologies in education could be paralleled with both a shift in focus of HE providers toward lifelong learning, as well as the increasingly fragmented lifepaths which students now follow (McLoughlin & Lee 2007). The facility that,

for example, blogging offers in terms of lateral sense-making, joining content from different sources through hyperlinking text, media and self-authored materials, affords students an opportunity to bring often seemingly diverse aspects of their biographies or narratives together. Blogs provide a space to explore relationships between information, reflections, self and identity.

In the 'digital age', the use of blogs has grown exponentially in both learning and narrative contexts, as well as in studies of health and wellness (Heilferty 2009) as a vehicle for reflection. The recent increase in blogging for educational purposes parallels the trend of embedding other so-called web 2.0 and social networking technologies as an expected and assumed component of the academic experience (Kim & Bonk 2006; Kamel Bouols & Wheeler 2007). Importantly for education and educators, and for narrative itself, blogging logistically brings together opportunities for combining a diversity of content: links, commentary and personal notes, reflections or narrative (Blood 2002). Blogs as learning tools offer considerable scope in encouraging students to participate in ongoing reflection and analysis (Ferdig & Trammel 2004), offer agency to authors and contributors (Pachler & Daley 2009) and can engage those students who may be at risk of isolation (Dickey 2004). Indeed, many reflective writing tools (individual or collaborative) are integrated into commercial virtual learning environment software products as distance and entirely online modes of learning grow in popularity.

In line with developments such as increasing use of distance learning opportunities for formal accreditation and massive open online courses (MOOCs) for multiple formal and informal ways of learning, physical attendance at a higher education institution has become a contentious and multi-layered issue. Whilst in traditional, more didactic modes of teaching physical presence might equate with academic engagement, with growing use of non-standardised information and non-linear engagement, some aspects of learning are now

embedded in everyday activities and not restricted to the classroom. However, physical attendance is arguably still a primary indicator of participation (Boyd 2012), despite the potential its potential for misinterpretation. This is particularly problematic for students with fluctuating or recurring impairments who might experience periods of low energy or mobility difficulties, for example. An alternative, digital form of participation could offer flexibility and alternative, without compromising, necessarily, the integrity of an academic exercise.

In capturing ongoing reflections of learning, various types and forms of diaries and journals have been used as narrative ways of engaging students (Moon 1999; Langer 2002; Gleaves et al 2007). Creme (2008) has suggested that reflective writing in learning journals provides a useful transitional space between academic writing and life narrative. Narrative possibilities and tools (learning journals or diaries, reflective blogs) provide students with an opportunity to combine different aspects of their selves in a wider context and actively experiment with identity, positioning and self. Furthermore, such reflexive opportunities encourage students to develop ways of communicating in new virtual, public (or private) spaces, and engage in the iterative processes of digital authorship as outlined by Mann and Stewart and Markham.

Conclusions and recommendations

Pervasive use of communicative technologies in education creates flexible opportunities for all learners, who may or may not position themselves as disabled or impaired. As well as developing confidence in various modes of communication (virtual or otherwise), students engaged in reflexive online learning can both perform selected aspects of identity as well as the create digital texts as a form of ethical self care and technology of the self (Foucault 1988). Foucault suggests that:

‘taking notes on oneself to be re-read, writing treatises and letters to friends to help them and keeping notebooks in order to reactivate for oneself the truths one needed’ (1988, p. 27).

Based in a context of institutional discourses which may be influenced by wider constructions of disability as measurable/ quantifiable and based on categories, enacting selected aspects of identity in virtual ways allows students choice and autonomy over self-representation.

Students are able to resist compartmentalisation or being assigned to a specific social or cultural group if it does not correspond with their sense of self.

Markula (2004, p.302) describes the use of Foucault’s technologies of the self as ‘practices of freedom that are characterised by ethics of self-care, critical awareness, and aesthetic self-stylization’. Such core attributes which refer to students’ self-management and self-representation have strong implications for participation in HE, in challenging dominant discourses and practices that may exclude. Using integrated educational technologies or connective social media to play with identity and examine effective practices of self care both for reflective purposes and to negotiate support with the institution offer a powerful application of readily available and accessible online tools. Potential also exists for the contestation of potentially disabling institutional practices of interpreting attendance as participation in opening up discussion about alternative modes of participation based on principles of flexibility through remote engagement.

Furthermore, participation in a Higher Education culture which privileges consistency over diversity need not limit students who have an opportunity to negotiate and enact identity online. In this way, disabling discourses can be contested and resisted, and flexible possibilities for participation by students with fluctuating or recurring impairments can be encouraged rather than pathologised. If inconsistency is a threat to both marketised education delivery and industrial notions of disability, then a revision based on encouraged difference

and diversity amongst student identities may encourage scope for a more inclusive perspective on disability and impairment.

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