





IDENTITY


This discussion paper explores how identity issues shaped the experiences of 29 disabled students in Higher Education. The analyses of the students' experiences of university life showed that students' self perception and their perceptions of how others saw them played a key role in their interactions with institutional structures and processes. For many students assuming or resisting a disabled identity was a complex process. It appeared to be influenced by several factors, including previous educational experiences, interactions with others, and circumstances relating to the timing of their assessment or diagnosis. This paper begins by discussing some identity and disability literature  and moves on to consider  students' views and experiences. It aims to highlight the complexity and role of identity in accessing services in order to provide material for discussion within educational and employment contexts that will aid understanding and inform decisions about the services provided. It concludes with recommendations , and questions  for future research and debate.

DEIP: an introduction

This paper is one of a series of discussion papers produced by the Disability and Effective Inclusion Policies (DEIP) project that was funded by the European Social Fund. The DEIP project is a piece of collaborative research undertaken by Sussex and Lancaster Universities. The project aims to explore ways in which higher education institutions support disabled students through higher education and on into employment.

The research is shaped by four research questions (see **DP1**) which provided the opportunity for considering the influence of disability models with respect to: sector and institutional HE policy; practice as reported by disabled students and university staff at Sussex and Lancaster Universities; the experience of disabled graduates making the transition into employment and the views of employers.

DEIP Discussion Papers

The DEIP project contributes to an increasing body of institutional research surrounding the experiences of disabled students in higher education. For a list of current and future DEIP project Discussion Papers (**DP**) see:  <http://www.sussex.ac.uk/equalities/1-2-9.html> For details of the thematic topics emerging from analysis of institutional policy see **DP1**, methodology **DP2**, an annotated bibliography of other relevant research **DP13** and disclosure **DP3** which is closely influenced by identity issues.

Identity and disability literature

Questions concerning identity and disability have generated much debate within Disability Studies and related disciplines. The discussion below briefly summarises some of the main points in this debate and provides a starting point for understanding the complexity of the issues concerning identities in relation to disability:

1. Adopting a **social model** of disability, the term 'disabled person' as opposed to a person having a 'disability', may be used to indicate that the source of disability lies in the barriers in society rather than being located in the individual. In this model, a person may have impairment but they are disabled by barriers in society, inclusion therefore requires the removal of these disabling barriers.

This contrasts with the **individual** or **medical model** of disability in which the impairment or disability is generally perceived as the barrier to inclusion, thus requiring measures to compensate for the 'deficit' (See DP1 for a further discussion of disability models.)

2. The ways in which the term disability is mobilised in discourse has important implications for understanding issues of identity. Living in a culture in which the medical or individual model has dominated thinking and practice means that it is important question the ways in which people's views and interactions influence a disabled person's self-concept. As Reeve (2002) points out, **oppression** may be **internalised** such that a person may not feel entitled to claim their rights and may not feel able to use the label positively as a platform for political action.

3. The question of the self-management of identity is one raised by other writers (e.g. Olney and Brockelman 2003). The scope for self-management appears to be a complex issue, relating to, for instance: the impairment and whether it is visible to others; a person's previous experiences which may influence future decisions around disclosure; the degree to which a person has access to the resources (e.g. information, social networks) which enable a meaningful 'choice' to made in relation to the self-management of their identity; and the perceptions of others which are inseparable from and constitutive of the social construction of the self.

4. It is important to remember that a 'disabled identity' is only one dimension of a person's identity. It overlaps and interacts with other identities, such as those of gender, class, ethnicity, sexuality and age (Shakespeare 1996). For some individuals, being a woman, a working-class or a Black person may be the primary identity and the barriers emanating from the experience of belonging to one of these groups (e.g. a lack of economic capital) may impact upon the experience of being disabled.

5. Although there is a tendency towards viewing disability in a static way, it is important to recognise *'disability identity as multi-faceted and fluid, rather than a fixed concept'* (Reeve 2002). As other DEIP discussion papers have highlighted, disabled students' support requirements may **change** over time, depending on fluctuations associated with particular impairments and importantly, the extent to which university curricula are inclusive.

From the interviews conducted as part of the DEIP project, it appeared that whilst for some individuals a 'disabled identity' may act as a platform for rights claims, for others, the label of 'disability' may be resisted and negatively perceived. The following discussion highlights some of the major issues emerging from these interviews.

Students' views and experiences: emerging themes

1. The role of pre-university experiences in shaping disabled students' identities

The timing of diagnose and onset of impairment will influence a student's pre-university experience. Learners who have been assessed in a school context may be more familiar with the term Special Educational Needs (SEN) rather than disability. Based on their experience in school, they may have certain expectations about funding, levels of support and who is responsible for organising that support. For example, funding is given direct to the school or FE College on the basis of an assessment and / or statement. Although students are increasingly encouraged to play an active role in this process it is not one that they are likely to have initiated, nor is it something over which they have much control. The HE system is therefore very different in that it places responsibility with the student, requiring the student to disclose details about the disability, apply for funding and to manage the support they receive.

A number of DEIP participants, particularly the students with dyslexia, had only recently been assessed. Their response to services, strategies for communicating with tutors, friends and peers were different for students who already identified themselves as disabled. Whereas students assessed in school may have already developed their own learning strategies and worked through issues concerning how they present themselves to others, students assessed while at university

may respond differently and require different support. People may also feel resentful that they missed the opportunity for support during their previous education.

One challenge for university services is how to identify, reach and support students who may be initially reluctant to ask for support. For example, Mary did not disclose her Mental Health Difficulties on her UCAS form because she did not realise that her problems would be recognised as MHD and that she was entitled to access services:

I thought ... everyone has those problems, don't worry about it. I didn't realise actually until my first modules here when we actually looked into Generalised Anxiety Disorder which is one of my problems ... I thought it was just - oh yeah, you worry too much. I didn't realise it was actually a disorder at all so I didn't write it down. But if I'd known, I'd definitely have written it down.

Some students may have fears based on the previous reactions of others such as close friends and family. For instance, Sally recalled that her father had told her that it was no use disclosing at university since there would be no support available anyway and Debra, who had recently been assessed as having dyslexia, felt angry with her parents. It appeared that she had been tested as a child but implied that her parents had not wanted to acknowledge that she had dyslexia.

2. Shifting identities

As already mentioned identities are multiple and change over-time. In relation to disability, these fluctuations may be linked to shifts in particular impairments. For example, Megan stated: '*Now that the panic attacks don't affect me as badly I would be less inclined to state them*'. Mark, who had Asperger Syndrome and dyspraxia, said:

I'm not really sure if I see myself as someone with a disability. Someday I do and someday I don't, it really does vary. Some days I can see myself without it and other times I realise my limitations and in some contexts I can function almost normally and in other I can't so yes and no is probably the best answer.

Changing identities may also be associated with a change in the learning context (e.g. different curriculum, different learning situations) and an individual's self perception as they move through their university career (e.g. through the influence of peer groups and social networks).

A student may think about the future differently because of being considered 'disabled' whilst at university. According to one learning support co-ordinator:

Many dyslexic students don't find out they are disabled until they are at university so they are having to deal with that knowledge and change of identity and it often throws up the questions - does this mean I can't have certain careers?

For some students, an increasing knowledge of their rights as a disabled person may mean a greater willingness to see themselves as 'disabled' and use this in a positive way to counter the oppression experienced in everyday life.

3. The 'label' of disability

For some students, the label of disability appeared to have negative associations, which possibly relate to the dominance of the medical model of disability in society whereby disability is related to deficit. As Donald stated:

I really don't like this word disability – I think there is a stigma that goes with it. ... I think the main thing is to get this disability label really understood as it's got some really nasty connotations

Debra explained her rationale for resisting the disability label. She did not like the questions from friends about where and why she was going for speech therapy or having the disability label:

To explain the whole thing when you are young is very uncomfortable, having something at secondary school that marks you out as having a disability wouldn't be something, it would discourage me.

While students may resist the term 'disability', in some instances taking up the label may be necessary or even useful for strategic purposes in securing access to support. Mark explained that he had 'used' the label to secure university accommodation:

Me and a couple of friends were going to get a house in [name of town] but it didn't work out so I used my disability to reapply for campus housing which I got for the second year and should get for the third year.

Similarly, Derek voiced objections to the use of the label disability but he had 'ticked the boxes' to gain access to specific services.

4. Possible consequences of the disability identity?

For some students, perceiving themselves as disabled appeared to be associated with feelings of difference, being stereotyped and, in some cases, fearing that others would judge them as gaining an unfair advantage. For example, Dan said:

I suppose it makes them aware, although it might put you at an advantage, I don't know but it kind of separates you from the rest of the group, by saying you're dyslexic and saying you should be given an extra 5% or marked leniently, which is maybe unfair.

However, other students' experiences appeared to have led to greater self awareness and had a positive impact on the ways in which they perceived themselves. For example, Maria discussed the connection between her depression and experience of higher education:

Having a disability helped. Having a couple of years of really being forced to know myself and also being exposed to politics through reading about depression. When I came back to university ... I was more politically switched on and thinking in a much more critical way so the depression led to growth that helped.

Paula, a wheelchair user, who had initially been resistant to the notion of defining herself as 'disabled', had found herself becoming increasingly involved in student union activities.

... when I came to uni I wasn't going to have anything to do with disability at all, but what I noticed straight away was that a lot of disabled students... wouldn't stand up for their rights and things were happening to them that shouldn't have been. (Paula)

Paula felt that her previous work in disability organisations and work in student union meant that she had done 'so much more than most people of my age'. However, she expressed mixed feelings with regard to whether she wanted to pursue a career related to disability issues.

✓ Recommendations

- To include an exploration of identity issues in disability awareness staff development.
- To publicise and promote the social model of disability in disability services
- To provide information and support for school staff about DSA and HEIs' support services.

? Questions for future research and debate

- How does disability identity interact with other factors that impact on student identity?
- How could an understanding of the social model of disability be promoted and what impact would this have on perceptions of the label 'disability'?

For further information about DEIP Project

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