INSTITUTIONAL DISABILITY POLICY ANALYSIS

DEIP: an introduction

Funded by the European Social Fund, the Disability and Effective Inclusion Policies (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 into employment.

The DEIP project has explored the experiences and understanding of services with current disabled students and university staff including policy makers and practitioners from Sussex and Lancaster, and analysed institutional documentation. The views of UK disabled graduates and employers have provided a wider context of post university experience. The inter-relationship between each of these stakeholders is complex and in a state of constant change, with each stakeholder's perspective influenced by their position as recipient or provider of services. Consequently, each stakeholder influences the roles, responsibilities, expectations and actions of other stakeholders in the system either explicitly or implicitly, and to a greater or lesser extent.

The research is shaped by four research questions which provided the opportunity for considering the influence of disability models with respect to sector and institutional higher education policy and practice as reported by disabled students and university staff at Sussex and Lancaster University as well as the experience of disabled graduates making the transition into employment and the views of employers.

Forthcoming discussion papers

This discussion paper provides an overview of the DEIP project, an outline of the data collected and a summary of key themes, which will be reported on in more detail in thematic briefing papers and journal articles in the coming months. For a list of current and future discussion papers (**DP**) please see:

http://www.sussex.ac.uk/equalities/1-2-9.html

Planned discussion papers will address student experiences of Higher Education and transitional phases in the student life cycle; the perceptions and role of university policy makers and practitioners; issues of disclosure and confidentiality; transition; specific disabilities, employment aspirations and experience of employees and employers.

Institutional Disability Policy Analysis

In this briefing paper the specific focus is on the higher institutions' disability policies. The key research question informing the analysis was to assess how far the medical model of disability and the social model of disability inform university policies? Before providing an indication of the major issues which will be the focus of future thematic briefing papers, it is important to outline the background context and describe the key features of each model of disability.

Background Context

National Legislation

In the past decade and with the introduction of the 1995 Disability Discrimination Act (DDA) there has been a rapid increase in legislation, which has impacted on all aspects of life placing a positive duty on disability equality that covers general living issues, employment and education. Of particular relevance to higher education is the 2001 Special Educational Needs Disability Act (SENDA). For further information about disability legislation including a summary of the key considerations see http://www.drc.gov.uk/thelaw/thedda.asp

Student Participation

National Audit Office (2002) reported that disabled students aged eighteen were less than half as likely to go to higher education. The most recent figures for disabled students from the Higher Education Statistical Agency (HESA) cover 2003-04. It is important to note that there is considerable variation in the participation of students with different disabilities, so for example, Dyslexic students account for 41.06% of the total number of disabled students who have disclosed their disability, whereas mental health students constitute 4.94%. As noted by Tinklin et al (2004), disability is only one of the factors contributing to unequal participation and it is important to take account of the interaction of other factors including class, gender, race and age.

Category student	Total Students	Total Disabled Students	% Disabled Students
Total Students	857505	45545	5.31%

HESA: 2003-04

DEIP Research Approach

The DEIP project adopted a mixed method approach collecting a combination of qualitative and quantitative data using a range of data collections strategies (questionnaires, interviews, documentary evidence) from a number of key stakeholders (institutions, three disabled student cohorts – with experience of dyslexia, mental health and physical or sensory impairments, HE staff, graduates and employers). Research tools and data collection were informed by an analysis of policy and research literature including literature relating to models of disability.

A common debate regarding disability research relates to who undertakes and participates in the various stages of the research process. The DEIP research team includes staff with personal as well as professional experience of disability. This has shaped decisions regarding data collection and informed the process of analysis, including time to explore the impact of the research on the researchers as well as research participants.

Models of disability

Identifying the model that informs or underpins institutional policy and action is not always straightforward, because of the difference between declared intention and eventual action. Models of disability can be important for explanatory purposes (Llewellyn and Hogan, 2000), and may assist those involved in understanding, examining and changing policy and practice. Models can be seen as shorthand for describing practices, or a tool for helping to understand roles and responsibilities. The adoption of a particular model by an institution ought to have implications for institutional practice, however, there is no guarantee that institutional policy statements advocating a particular model will automatically result in corresponding practice and it is likely that in periods of change traces of previous ways of thinking and acting remain alongside more recent discourses. Change is typically uneven across different sections of an institution as a result of varying levels of awareness, professional allegiance or the centrality of the issue.

→ 👤 ← The individual (medical or clinical) model of disability

The medical model focuses on the individual medical condition, attributes the problems to the individual and views disabled people as dependent, deserving of pity, or acclamation for overcoming their diversity (see Oliver, 1993 for discussion of this model). The model assumes that the individual with treatment or support can change and be helped to overcome their limitations, the expectation or view that changes in society might assist the overall adaptation is not part of the equation (Llewellyn and Hogan, 2000: 157-165). Until recently, this model dominated policy and practice within higher education and, together with educational opportunities within the compulsory education system, contributed to constraining the participation rate of disabled people entering and engaging successfully in higher education.

The administrative and welfare models emerging from the individual model of disability have relevance for the DEIP project and analysis of higher education policy and practice. The administrative model relies on criteria to categorise or label disabled people. Although criteria are often presented as definitive, evaluation of European Union disability policies reveal that there is considerable variation in definitions used. The welfare model often relies upon administrative categories in order to determine the level of financial assistance or welfare support to which an individual is entitled.

The Student Disability Allowance (DSA) is an example of financial support which is allocated according to individual assessment of impairment. Whilst the administration systems used within the DSA are influenced by the medical model, the rationale underpinning this source of funding is that of enabling disabled students to be independent learners, and is thus concerned with recognising and removing barriers associated with the social model.

🌍→ 👤 →🌍 The social model of disability

The social model shifts the emphasis from the individual to society. Various definitions exist, which differentiate between impairment and disability, for instance the Union of the Physically Impaired Against Segregation (UPIAS), World Health Organisation (WHO), and throughout European Union there are a host of definitions influencing who is or is not categorised as disabled. Within these definitions impairment refers to the individual condition, whereas the term disability is regarded as the result of physical, environmental, legal, cultural and attitudinal barriers experienced by a person with impairment. As (Swain, et al, 2003: 24) explain: *disability is not something one has, but is something that is done to the person … being excluded or confronted on a daily basis by barriers*.

Amongst disability activists, academics and within higher education, the social model has become the dominant model, yet as with other models it covers a multitude of perspectives, which are actively debated. A useful exploration of theory and research relating to the social model of disability and the psycho-emotional dimensions which recognise the external, attitudinal and internalised oppression was stimulated by a recent ESRC seminar series reported in the Barnes and Mercer's (2004) edited collection 'Implementing the social model of disability: Theory and research'.

Within the social model, there is a shift from individual need based on personal inadequacy, or abnormality, which is often associated with the medical model, to one of disability rights. Whilst there appears to be a general consensus that the model has been, and continues to be, invaluable as a stimulus for action, the shift to adopt the social model is not without its difficulties. For example, there is the potential of exclusion resulting from setting up a dichotomy between disabled and non-disabled individuals (Humphrey, 2000). Deciding where to locate the responsibility for change depends on whether the gaze is directed toward the student (individual model) or the university as an institution (social model) and who or what is seen as 'deficient' or 'lacking'. According to Barnes '*disability will be eliminated only through profound and wide-ranging political and cultural change*' (Barnes 2002: 314).

Issues emergent from policy analyses

Overall, the analyses of a sample of documentary evidence suggested that while the institutions stated an allegiance to the social model of disability, in practice the texts often reproduced a more individual model of disability. These issues are discussed with some illustrative examples from policy documents and reference to other research; they provide a focus for future briefing papers:

1. Organisation, access and interpretation of documents

Historical context, institutional organisation of services, underpinning philosophy of individual staff or sections within each university influenced the location, format, and style of disability policy and supporting guidelines. Although similar documents existed in both universities they often took different forms and were located in different sections of the university and its websites. For example, the 'disability statement' which HEIs are required to provide was referred to by one of the HEIs as the 'University policy on disability' while the other called the relevant document 'Disability: A statement for current students and applicants' which took the form of a student handbook. Inevitably perhaps, the naming, content and terminology used within disability policies across the institutions was not consistent. Both HE institutions adopted terms used in legislation such as 'reasonable adjustments', which are not only open to interpretation but also dependent on size, context and circumstances. Not surprisingly there is considerable variation in the way terminology is interpreted by students and staff. These differences, the implications for practice and the extent to which policy and guidelines are used will be explored in relation to the interview material.

This level of variation is potentially confusing for students reviewing institutional support during the application process and reduces the possibility of developing national guidance for institutional staff whose contact with disabled students may be sporadic and whose awareness of support services and terminology is limited. O'Connor and Robinson (1999) highlight the dangers of ambiguity and Konur (2000) expresses doubts about the effectiveness of disability statements for students who have to find out where and how to access policy before they can even begin to try and make sense of the content.

2. Politics, terminology and definitions

Several commentators have emphasised the importance of the use of language in policy statements in contributing to the social construction of disabled people (Oliver 1993; Riddell 1996).

Barnes (1994: 2), who adopts a two-fold classification of disability (loss or limitation of opportunities to take part in the normal life of a community on an equal level with others due to physical and social barriers) and impairment (functional limitation within the individual caused by physical, mental or sensory impairment), argues that to refer to *individually-based functional limitations as disability... would undermine what limited progress has already been made in establishing the latter as social restriction.'*

The use of terminology and its constant evolution is an inherent and ongoing challenge for policy makers and practitioners, however it is important for consistency that changes are made to all key documents not simply in opening rationale. Insufficient attention was given to the language used in the documents. While proposing to follow the social model, the documents tended to use the terms impairment and disability interchangeably (e.g. 'types of impairment/disability) and referred to 'students with disabilities', which is more consistent with the individual model of disability.

Within and between documents there was confusion over how terms were used. At various points particular impairments appear to be defined differently. For example, individuals with dyslexia seemed to be excluded from the category of 'disabled students':

> *This booklet provides a summary of services, facilities and site accessibility for disabled students **or** for students with dyslexia/specific learning difficulties.*

> *Library Guide — Students with Disabilities or Dyslexia This guide describes some of the features and equipment in the University Library, which may be of use to students or others with disabilities.*

Mental health difficulties (MDH) tended to occupy an ambiguous position in the documentation (one institution having a specific mental health policy, the other having no comparable document at the time the documents were collected). This might reflect the more recent inclusion of mental health as a disability category within the UCAS forms.

3. Disclosure and confidentiality

Issues of disclosure and confidentiality were mentioned in a range of institutional documents by both HE institutions. One of the difficulties is that support is often contingent upon student disclosure of impairment even though these students may not perceive themselves as disabled or may consciously resist disclosure due to fears of discrimination based on past experience.

Overall, institutional policies require staff to be proactive and encourage students to disclose. However, the policy position highlights the complexity of the situation. For example:

> *If the disabled student has told someone within the University about his or her disability, then the University may not be able to claim that it did not know. If the University might reasonably have known or found out about a person's disability, then it cannot claim that it did not know.*

In practice, this may be difficult. As Parker (2000) notes, staff working with disabled students may confront a number of tensions: providing support at the same time as upholding confidentiality, acting as an advocate for students whilst an employee of the university.

Furthermore, placing students in the position of needing to declare themselves as 'disabled' may meet resistance from, for example, Deaf applicants who see themselves as members of a linguistic minority rather than disabled. However, since support (e.g. Disabled Students Allowance) is contingent upon students' participation in assessment procedures, resistance could result in students' claims to support being undermined.

Student feedback on the topic of disclosure is discussed more fully in briefing paper 3. Student stories highlight how important it is to receive a consistent and positive response to disclosure. This presents HEIs with the challenge of ensuring that practice mirrors the approaches within written policies and guidelines.

4. Responsibility: Pro-active students or pro-active institutions?

Documents from both HEIs suggested that students needed to be pro-active in seeking support. This tends to assume a 'rational actor' model of action in which individuals are perceived as having knowledge, motivation and capacity to act. For example, in one of the disability statements:

> *You will already have noticed that studying – and day-to-day life - at university is a much more independent process than at school or college. The onus is very much on you to be pro-active in seeking the support.*

Unfortunately, this view ignores the inherent social, economic, cultural, and emotional factors to all action that may present barriers to seeking support (e.g. fears and misperceptions).

The documents also tended to place emphasis upon students accessing support systems as soon as possible given the length of time required for some procedures (e.g. assessments). Placing responsibility upon students to be pro-active may pose difficulties for particular groups who may not wish to disclose their disability, be unaware of their entitlement and/or the change in approach to support between educational providers, and/or lack the confidence or skills to adopt the proactive approach required. Reeve (2002), in drawing attention to the psycho-emotional dimensions of disability, suggests that this may be the case for some disabled students in that 'internalised oppression' may constitute a further barrier to inclusion by preventing students from accessing the support to which they are entitled.

The extent to which students are 'pro-active' in seeking support and/or staff are pro-active by reviewing accessibility of curricula or reactive in making adjustments in response to individual needs (Elliot 2005; O'Connor and Robinson 1999) will be explored further in future papers which will also incorporate an exploration of the reach of disability awareness amongst students and staff and its translation into action in the institutions.

5. Integration v targeted support: the positioning of disabled students

In general, the focus in many of the guidance documents was upon strategies and support available to enable equal access to the existing curriculum with the curriculum positioned as somewhat static. The implication is that it is the student who needs to acquire the necessary strategies and support to integrate. This perhaps explains the prominence of assessment within a range of documents and the need for students to provide evidence in order to claim support necessary for them to cope. To varying extents, documents were concerned with the assessment of disability.

> The purpose of an assessment is to identify study aids and strategies required to provide equal access to the curriculum, within the context of a chosen course of study. If you wish to be assessed you should first of all contact your Local Education Authority (LEA) or Funder for permission to be assessed, and for confirmation that they will cover the cost of the assessment.

Despite positioning institutional support within a social model, the requirement for students to provide statements and undergo assessment can be viewed as working within a welfare model of disability (Finkelstein 1993). The location of services, often within the welfare arena, also tends to reinforce the medical model (Borland and James, 1999). Yet, as student feedback suggests, it is these services that enable them to operate independently. There is thus a tension between 'adding on' extra services for students with impairments and beginning to change institutional culture and practice, so that wherever possible mainstream practice is inclusive and accessible.

Inevitably there are dangers with both strategies. For example, O'Connor and Robinson (1999) cautions against disability becoming submerged in an integration strategy, whereas Crooks (2005) refers to resistance to targeted support.

The extent to which 'individual solutions' and 'institutional change' are necessarily opposed and in tension is debatable since the former may be effective in bringing about, in the longer term, wider changes and the acceptance of these changes. However, in practice, implementing change concerns power relations between different groups with those in positions of power requiring others to relinquish control or recognise that previous policy and practice might be improved. Student support service staff clearly provide a valued service, and their job, status and service is often dependent on supporting students. Policy documents currently refer to their expertise and responsiveness, which ironically allow teaching staff to avoid making mainstream changes, which in some cases would result in disabled students being able to operate as autonomous learners accessing support as part of an integrated approach.

6. Transition

Transition is a theme running throughout the student life cycle. It is increasingly used within policy and in the organisation of services as a framework for considering the experiences of students at various stages in their educational journey. The application, admissions and induction process associated with entry into higher education mirrors the activities associated with transition into employment. Whilst some documents such as the disability policy refer at least in passing to all stages in the lifecycle, the more detailed guidelines dealing with different phases including transition into and out of higher education are prepared by specific sections of the university, for example admissions or careers service. Although assistance is provided, it is left to the student to be aware of how financial, social, academic issues might impact on their transition into HE, the role of the careers service, work experience and making decisions about disclosure as part of their transition and preparation for employment. For a further discussion of transition issues see **DP5**.

A framework for future analyses and policy development

Below are a number of general questions, which policy-makers, practitioners and researchers may wish to consider when evaluating and reviewing policy documents:

Nature and content of policies

- Who has produced the documents – disability specialist or service specialist?
- When was the document produced, and how is it positioned in terms of the historical context of disability equality?
- Does the policy identify those with responsibility for implementing and reviewing inclusive disability policy?
- Are the documents themselves easily accessible and how are they *used* by students and staff?
- Do the documents lie primary within 'student support / welfare' or do they view disability issues as integral to information for *all* students / staff?
- Do policies work towards institutional change (e.g. rethinking methods of assessment) or view disability equality as a matter of making adjustments on an individual case-by-case basis?

Terminology and discursive positioning

- Are the terms used complicit with a more individual or social model of disability? (e.g. 'students with disabilities' or 'disabled students')
- Is terminology used consistently and guidelines informing practice regularly updated to reflect the changing usage within the institution and wider higher education sector?
- Is the provision of support / adjustments contingent upon students accepting the identity of being 'disabled'?
- Is responsibility located with students or the institution? i.e. Are students required to be pro-active in seeking support and demanding adjustments?

Definitions and clarity

- Are definitions used clearly and consistently in the documents or is there ambiguity concerning inclusion of different impairments within the category of 'disabled students'?
- Are mental health issues included within a focus on impairments?
- Do the policies incorporate clear advice and guidance to staff and students or is the information contradictory?

Practice as integral to policy: further questions for research

The analysis of the documentary evidence relating to disability is only one dimension of any policy analysis. As Trowler (2002: 2) emphasises, policy is also "*made as it is put into practice because important social processes necessarily occur as this happens and because unforeseen circumstances on the ground mean that actors need to exercise discretion*". Thus the scope of policy analysis must extend beyond textual documentation to an exploration of the everyday practices of implementation 'on the ground'.

Within the DEIP project the views of students and staff provide personal accounts of individuals' lived experience of how policies are interpreted and implemented in practice. The stories reveal considerable diversity in the student experience, which seems to be influenced by a multitude of factors, which highlight the complexity of the social processes involved in policy implementation. For example, students' previous experiences, their identity, attitude towards disability, their willingness to assume the disability label to access financial and certain support services, their ability to complete the necessary administrative tasks associated with assessment and the DSA, the extent to which they access the right service, and feel that they trust, like and rate the staff providing support and / or services outlined in policy statements.

References and resources

Reference list refers to literature referred to in this briefing paper, for an annotated bibliography of other texts relating to the broad themes addressed by the DEIP project see Discussion Paper 13

Barnes, C. (1994) *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation*. London: Hurst & Co.

Barnes C (2002) 'Introduction: disability, policy and politics', *Policy and Politics* 30 (3): 311-318.

Barnes, C. & Mercer, G. (2004) *Implementing the social model of disability: Theory and research.* Leeds: The Disability Press.

Borland, J. & James, S. (1999) 'The learning experience of students with disabilities in higher education', *Disability and Society,* 14 (1): 85-101.

Crooks, B. (2005) 'A Quiet Revolution', *Inclusion,* 5 (Autumn): 35-37.

Elliot, T. (2005) 'Changes and challenges- the disability agenda in learning and teaching for higher education', *Inclusion,* 5 (Autumn): 11-18.

Finkelstein, V. (1993) 'Disability: A social challenge or an administrative responsibility?' in J. Swain, V. Finkelstein, S. French & M. Oliver (Eds.) *Disabling barriers - enabling environments.* London: Sage Publications.

Humphrey, J. (2000) 'Researching disability politics, or some problems with the social model in practice', *Disability and Society,* 15 (1): 63-85.

Konur, O. (2000) 'Creating enforceable civil rights for disabled students in higher education: An institutional theory perspective', *Disability and Society,* 15 (7): 1041-1063.

Llewellyn, A and Hogan, K (2000) 'The use and abuse of models of disability', *Disability and Society,* 15 (1): 157-165.

National Audit Office (2002) *Improving student achievement in English higher education.* London: NAO.

O'Connor, U. and Robinson, A. (1999) 'Accession or exclusion? University and the disabled student: a case study of policy and practice', *Higher Education Quarterly.* 53 (1): 88-103.

Oliver, M. (1993) 'Disability and dependency: A creation of industrial societies?' in J. Swain, V. Finkelstein, S. French & M. Oliver (Eds.) *Disabling barriers - enabling environments.* London: Sage Publications.

Parker, V. (2000) 'Developing a code of practice for disability coordinators', *European Journal of Special Needs Education,* 15 (3): 275-284.

Reeve, D. (2002) 'Negotiating psycho-emotional dimensions of disability and their influence on identity constructions', *Disability and Society,* 17 (5): 493-508.

Riddell, S. (1996) 'Theorising special educational needs in a changing political climate' in L. Barton (Ed.) *Disability and society: Emerging issues and insights.* London: Longman.

Swain, J, French, S and Cameron, C (2003) *Controversial issues in a disabling society*. Buckingham: Open University Press.

Tinklin, T., Riddell, S. & Wilson, A. (2004) 'Policy and provision for disabled students in higher education in Scotland and England: The current state of play', *Studies in Higher Education,* 29 (6): 637-657.

Trowler, P. (2002) 'Introduction: Higher education policy, institutional change' in P. Trowler (Ed.) *Higher Education Policy and Institutional Change.* Buckingham: SRHE and OUP.