



DISABILITY: DISCLOSURE

Disclosure is an issue about which students need to make decisions not only when they apply to and enter higher education, but also as they apply for jobs and enter the world of work. It is a key consideration during transition into and out of higher education. For students with a hidden impairment it may be possible to 'pass' as a non-disabled student, however, in deciding on this course of action students may be reducing the extent to which an institution is able to provide appropriate support. For each student the decision and manner in which they choose to disclose is personal and for many may be a complex process. This paper outlines current advice to students, explores the issues surrounding disclosing including to whom, when and how to disclose, the possible implications and communication issues, as well as exploring disclosure in an employment context. 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 an analysis of institutional policy see **DP1**, methodology **DP2**, and an annotated bibliography of relevant research **DP13**.

The decision to disclose

The Disability Rights Commission advises that all disabled applicants to education courses should be encouraged to disclose their impairments and discuss their requirements with a disability adviser. The decision to disclose is influenced by the nature of the impairment. With dyslexia, students may resist asking for help and drawing attention to themselves depending on the status of their assessment and existing coping strategies. Mental Health Difficulties (MHD) are also not immediately obvious to the observer or may fluctuate over time, which can make the decision to disclose more complicated. The visibility of physical impairments raises different issues, as the student is unable to make a choice about disclosure, while sensory impairments may or may not be visible. See Briefing Paper **BP14** Employment Advice for decisions about disclosing to an employer and refer to following web sites for useful information:

 http://www.skill.org.uk/dda_quiz/

 <http://www.natdisteam.ac.uk/resources.php?id=301>

The decision to disclose continued

- **Amongst the dyslexic students the attitude towards disclosing varied.** Some students stated that they made a point of disclosing when the opportunity arose. For example, Derek saw no reason not to disclose: *I'm not ashamed of being dyslexic.* Desmond wanted to get it out of the way and disclosed as soon as possible through his educational life, and Diane made light of her dyslexia to the point that she sometimes made a joke about it to people.
- **For some students deciding when to disclose can cause anxiety.** Students who experience MHD may find their problems are cyclical or intermittent so that the need to disclose is not always present, or having disclosed, they may find the problem has diminished. As Morgan said:
Now that the panic attacks don't affect me as badly I would be less inclined to state them.
- **Some students choose not to disclose.** For some, disclosure may be difficult if the student is experiencing issues around low self-esteem, feels unable to trust others with confidences, or is withdrawn. Like other students with a Mental Health Difficulty (MHD), Martin explained that depression limited his capacity to get on with people, as well as making him more sensitive to certain issues as his self-esteem was low. As a result he chose not to disclose to staff or to fellow students. Similarly, Megan did not disclose because she did not want to be seen as someone who *'is constantly up and down'*. Thus, the need to 'fit in' at university may be prioritised over the need for support and may result in non-disclosure.

Decisions about who, when and what to disclose

- **There does not seem to be a definite point of time to disclose which suits all students.** Each student has different expectations in terms of how they need people to react to disclosure.
- **Most students seem to learn by experience how they feel about disclosing.** Melanie felt that disclosure of her MHD in the past had made people uncomfortable, but was still prepared to disclose and felt that it was important to do so. Paula, a wheelchair user, wished she could have chosen when to disclose, rather than having to fit in with application requirements and Mary wished in hindsight that she had taken the opportunity to disclose when it was offered to her.
- **Students may be selective about what and to whom they disclose.** Dawn initially chose only to disclose her dyslexia but felt forced into a position of disclosing her mental health difficulties because of the pressure from tutors who sent *'nasty emails'*. Following her disclosure of MHD she received more support and felt her difficulties were taken into account. Some of the students with dyslexia were not sure what they gained by disclosing to student support as teaching staff did not always seem to be aware of their needs. Nevertheless, students tended to assume that what they told student support would be shared with academic staff and in effect this meant they did not need to disclose to their tutors:

Dan: I've not really disclosed to tutors, I have used yellow sticker [scheme for indicating dyslexia], but I just assume they know, but if they don't I'm not fussed.

The benefits and disadvantages of disclosure?

Guidance about disclosure needs to be explicit and supportive and the advantages of disclosure and the disadvantages need to be spelt out very clearly. Disclosure may bring advantages in the form of equipment or extra understanding of learning needs, but disclosure also brings new problems for students who may feel that the process has singled them out as different.

- **Students are more likely to disclose if they are aware of the financial benefits.** For example, Dave was not going to mention his dyslexia, but decided it might be to his advantage when he realised he might be eligible for money from Disabled Students' Allowance (DSA) for equipment, whereas Dylan chose not to disclose because he could see no benefit.

- ***Disclosure is a source of worry and sometimes criticism from other students.*** Disclosure brings its own consequences in terms of both positive and negative reactions from others; students can be reluctant to be treated as a 'special case' and to be seen as receiving favours. For example, Michael did not disclose to his supervisor, but later chose to disclose both depression and ADD to quite a few people at university. He then worried that people would think he was using ADD as an excuse as in his experience '*academics just want to deal with work and not the whole person*'. Dee experienced criticism from her peers after being open about the fact that she had been given a computer because she was dyslexic.

Communication issues relating to disclosure

- ***There are usually systems in place to pass information between student support services and academic departments.*** But for a host of reasons information is not always communicated to teaching staff, and students can find they are put in a position of having to disclose individually in order to get teaching support. Two students found that the information they had given had not been passed on to teaching staff and this caused problems for them in terms of disclosure. Donald solved this by showing his dyslexia assessment to his tutors in order to get support and then found the reaction of his tutors to be more positive, but Debra told how she had disclosed to one tutor and didn't get a good response, while 'my other tutor I'd already done the essays so I didn't think there was any point.'
- ***Generally students are reluctant to disclose within academic departments.*** This may be because they, probably rightly, assume that student support will automatically advise the academic department and they feel awkward about checking that the system is working. For first year students it can be particularly difficult to know who to talk to amongst teaching staff.

Disclosure in employment

- ***The issue of whether to disclose in a job interview is problematic for disabled people.*** It may be difficult for people to keep their impairment hidden when employers have application systems in place which are designed to highlight an employee's disabled status. Pre-employment medical tests and 'health' related questions on application forms might screen out disabled job applicants. Some interviewees will not disclose impairment during an interview because they want to demonstrate their abilities. Just putting 'disability' on the application form is often felt to lead to immediate rejection (Duckett, 2000). The decision not to disclose was a common intention, which may be based on a student's lack of self-confidence, or uncertainty about prospective employers.
- ***Advice about disclosure varies.*** One student, whose mother was also hearing impaired, had seen her mother struggle to get an adapted phone into her work place and was aware that disclosure in the work place was a difficult issue. She felt that you could not predict how people would react to disclosure of need and that advice on disclosure varied with some people saying '*don't disclose*' and other people saying '*you'll have to because they are going to find out sooner or later, especially if you have to say I can't understand you*'.
- ***Experiences of disclosure at university can influence decisions to disclose in employment settings.*** Students who have either had a positive or negative experience of disclosure may be either encouraged or discouraged from disclosing their disability. For those who have not disclosed at university they assume there will be no need when they get a job, whereas others have not yet thought about the issue.
- ***Students vary in their attitudes towards disclosing to future employers.*** One said he would tick the box if there was one, one said it would not look good on a job application, another said she would not publicise her dyslexia and would cover it and not mention it at interview. Dawn demonstrated some confusion when she said:

I don't like lying, some people manipulate forms, unless they specifically ask I won't say, but otherwise I say yes

In contrast, Dan intended to disclose because he was interested to see if they would still employ him. Other students felt there was no need to say, or that they did not want to be employed because they have dyslexia, or that they wanted evidence that they would not be discriminated against if they did disclose. Donald felt he did not want to be judged and hoped therefore that he would not have to disclose his disability when applying for jobs. As he explained:

If it said on the application form I suppose I'd have to tick [the box], but it is that label of disability I don't like.

- **Many students were uncertain or unrealistic about the need to disclose, and did not recognise the possible benefits.** According to the Jobcentre Plus Disability Employment Adviser this may be problematic. He felt that if people do not disclose, they are "heading for a fall". Other students are more realistic, recognising they would have to explain gaps in their CVs, for example, and also seeing disclosure as an advantage or a means of protecting themselves from the pitfalls of not disclosing. Being entirely practical, and also demonstrating the inevitability of the disability label for some students, Pat said:

I would have to disclose on an application form. I don't think I can protect myself from discrimination. If I put 'wheelchair user' without describing my condition I think alarm bells would be ringing.

For further insights into the issues of disclosure see **DP14** about disabled graduates.

- **The nature of the disability sometimes dictates whether disclosure is necessary.** Those with visible impairments may have no choice about whether to disclose. Students with MHD may be particularly fearful that the consequences of disclosure will be rejection. Dyslexic students in particular, tend to hope that disclosure will not be necessary once they leave education. This may be because they feel that dyslexia is only an issue in education settings, that education has helped them to overcome their difficulties, or that when they disclosed in the past the information was not passed on and disclosure made no difference.

✓ Recommendations

- To have clear institutional guidelines concerning disclosure and confidentiality (for students and staff).
- To communicate to both students and staff the benefits of, and reasons for, disclosing a disability.
- To support students to make informed decisions about when, how and if to disclose when applying for jobs.
- To raise disabled graduates' awareness and where possible employers' awareness of schemes designed to support disabled employees.

? Questions for further research and debate

- How can information disclosed to previous educational providers be used to support the transition of disabled students into higher education?
- What are the obstacles associated with the effective use of information disclosed by disabled students, and how might these be tackled?

For further information about DEIP Project

Sussex University – Pam Coare and Liz McDonnell

Centre for Continuing Education, The Sussex Institute, Essex House, University of Sussex, Falmer, Brighton, East Sussex, BN1 9QQ Tel: 01273 877888 <http://www.sussex.ac.uk/equalities/1-2-9.html>

Lancaster University – Ann-Marie Houghton, Jo Armstrong and Linda Piggott

Dept of Educational Research, Community Access Programme, County South, Lancaster, LA1 4YD
Tel: 01524 592907 <http://www.lancs.ac.uk/fss/projects/edres/cap/index.htm>