



Improving the experiences of disabled students in higher education

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Project period: August 2005 – November 2006

Contents

List of Tables and Figures	3
Acknowledgements	4
Executive summary	5
1. Background	9
1.1 Introduction	9
1.2 The national and local policy contexts	9
1.3 Theoretical framework	10
2. Aims	13
3. Methods	14
3.1 Research design and scope	14
3.2 The three strands of the project	14
3.3 Methodological reflections	15
4. Findings	17
4.1 The social and educational profiles of the disabled students (research strands 1 and 2)	17
4.2 Coming into higher education: the disabled student perspective (research strand 2)	24
4.3 Being in higher education: the disabled student perspective (research strands 2 and 3)	30
4.4 Becoming a student in higher education: the experiences of three students (research strands 2 and 3)	37
5. Discussion and conclusions	43
5.1 Disabled students in higher education	43
5.2 The experience of higher education	43
5.3 The transition to higher education	45
5.4 Concepts of disability	46
6. Recommendations	50
6.1 Student identified recommendations	50
6.2 Other recommendations arising from the project	51
References	53

List of Tables and Figures

List of Tables

Table 1. Student groups by cohort and year of entry	16
Table 2. Timing of declaration: the questionnaire sample	26

List of Figures

Figure 1. Total annual intake of students	17
Figure 2. Percentage of known disabled students within annual intake	17
Figure 3. Disabled student intake by level of study: UG/PG trends across intake years	18
Figure 4. Mode of attendance by cohort.	18
Figure 5a. Trend across intake years (total cohort)	19
Figure 5b. Trend across intake years (known disabled)	19
Figure 6. Gender profiles by cohort	19
Figure 7a. Gender by year of intake (total cohort)	20
Figure 7b. Gender by year of intake (known disabled)	20
Figure 8. Age profiles by cohort	20
Figure 9a. Age by year of intake (total cohort)	21
Figure 9b. Age by year of intake (known disabled cohort)	21
Figure 10. Ethnicity profiles by cohort	22
Figure 11. Categories of disability by cohort	22

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Executive Summary

Background

Higher Education Institutions (HEIs) are becoming progressively more engaged with processes of inclusion as the increasingly diverse student body has begun to challenge more taken-for-granted approaches to ways of working in higher education (HE). The Disability Discrimination Act, Part IV and more recently the Disability Equality Duty have impacted on HE, both in terms of strategic planning to ensure compliance, as well as in some cases, redefining how provision may be organised to better meet the needs of students. Within this context, concerns about the student experience have also become more prominent. Questions surround support for disabled students as well as more generally for the wider student body, and the potential exists to think strategically about more inclusive policies and practices.

Aims

In this project we explored some of the processes of becoming and being a disabled student, focusing on the social construction of student identity and the effects of this on the student experience. Our approach was the social model of disability which stresses the difference between individual impairment and the disabling barriers faced by persons with impairments. Within the context of one HEI, the main aims of the project were to:

- explore the educational and social experiences of disabled students;
- identify ways in which their experiences may be improved;
- examine how useful the category 'disabled student' is as a basis for targeting support.

Methods

The project was composed of three strands. Strand 1 explored the educational and social profiles of five entry cohorts, analysed in relation to demographic features. Strand 2 focused on student perspectives of their social and learning experiences, through a questionnaire survey and in-depth interviews. It also included a focus on the perspectives of late-declaring and non-declaring disabled students and students new to the HEI. Strand 3 involved disabled students as co-researchers, both data gathering and in dissemination. Project period: August 2005 - November 2006.

Main findings

- Demographically, and particularly in relation to gender, disabled students entering the HEI were becoming more representative of the total entry cohorts. However, this was not reflected in relation to ethnicity.
- The majority of respondents reported that overall their learning and social experiences of HE were positive. Some respondents (22.4%, 43 students) reported that they were not happy with their learning experiences, others (12.5%, 24 students) that they were not happy with their social experiences, and a small proportion of these respondents (7.5%, 14 students) were unhappy with both learning and social experiences.
- Issues affecting degree of happiness with social and learning experiences included: (1) *teaching and learning*, especially teaching styles and how inclusive or exclusive teaching was; (2) *resources*, for instance structures and systems of support, whether disabled students received what they perceived they needed and / or were entitled to; (3) *tutors and other students*, for

example tutor responses to disabled student needs and their attitudes towards them; (4) *the existence of informal as well as formal structures of academic support*, issues that were often in common with other non-disabled students. It was not always the support itself that was of prime importance, but the way in which that support was provided or organised.

- Many of the negative experiences cited by disabled students were not related specifically to impairment, but were more general student concerns.
- Negative experiences related to impairment tended to result from the absence of, or delay in receiving support. A particularly notable issue raised was the delay in receiving their Disabled Student Allowance. Once support was in place, this tended to have a substantial positive impact on their experience of HE.
- The transition to HE was identified as a time of potential vulnerability: a recurring theme was, in one student's words, *'it's difficult to get started'*. Issues important in transition were related to both the development of social networks and engagement with learning, and included: (i) the importance of previous learning contexts and their influence on expectations; (ii) expectations versus the realities of life in HE; (iii) the ethos and welcome experienced; (iv) the existence of support and the speed of putting this in place; (v) other aspects of their identity (such as being a mature student).
- The usefulness of the category 'disabled student' seemed to lie partly in the power of the label. It had focused minds of policy makers and brought legislative changes which had opened doors to HE and brought 'reasonable adjustments' which could be enabling. It was also useful for ensuring that tutors could identify students with impairments. However, the power of the label was not always positive: it could also be stigmatising and in addition some students were not sure whether the category included people with their condition / impairment.
- In relation to the contexts and processes of HE, what tended to be important was: (i) the notion of a continuum (rather than an either / or categorisation of disabled / non-disabled student); (ii) that difficulties experienced by some students could indicate how the curriculum and organisation could be improved for the benefit of all; and (iii) an awareness of how the contexts and processes of HE could be more or less disabling: barriers experienced by some respondents were not experienced by others. Although all students were aware of their impairment or condition, not all felt disabled within the HEI.

Recommendations

The student identified recommendations for HEIs and policy makers reflected what they had found to be more or less helpful in ensuring positive learning and social experiences. ***The student co-researchers' five main recommendations were:***

- *Communication* – ensure good communication of students' support needs to tutors, as well as effective communication between students and the HEI and between departments and units of the HEI.
- *Accessibility* – ensure access around the HEI takes views of disabled people into account. HEIs shouldn't forget cafes and other social spaces – disabled students want to go for coffee with their peers between seminars. Ensure a good range of courses and programmes which are accessible in terms of time – especially part-time. Be flexible - some tutors were very adaptable.

- *Knowing who to contact / where to go / what support is available* - make sure students coming to the HEI know what support is available and who to contact. It is very helpful when someone from student support is located within departments i.e. who understands the [teaching and learning] situation. A quick response in addressing queries about support on application and before coming to the HEI is much appreciated. Allocate one named person for the student to turn to if a problem arises.
- *Understanding / knowledge / awareness* - ensure provision of a 'normal' life for students through targeted support which is sensitively given. Make tutors and support workers more aware of 'disability' and of the barriers that can exist for disabled students. Beware of singling out, unintentionally segregating or making disabled students feel silly. Sometimes it's the little things that are most important.
- *Moving in the right direction* - students feel that things are generally moving in the 'right direction', but it is important that the government takes a lead as it did through the disability legislation and that HEIs and the government should monitor progress.

Other recommendations arising from the project were:

For Government and HEIs

- Monitor demographic features of disabled student entrants to HE and actively target under-represented groups
- Examine gender differentials amongst HE students with dyslexia
- Ensure information for students prior to entry to HE clarifies the term 'disabled student' and the impairments / conditions it encompasses.
- Be aware of the potentially vulnerable early stages of HE for disabled students and the importance of support needs being in place as early as possible and ideally for the start of the programme. Review timings around DSA and ensure applicants are aware of the importance of ensuring assessments are completed, where possible, early enough to secure provision.
- Review transition arrangements to HE for disabled students to ensure expectations about learning in HE are identified and made more transparent.

For HEIs

- Given the importance of the social experience of HE, ensure a focus on this as well as on the student learning experience: involve students.
- Ensure information to prospective students clearly identifies expectations, especially in relation to procedures and provision.
- The welcome and ethos promoted by the HEI and the positive visibility of disabled students within this is extremely important.
- Promote an awareness of the importance of inclusive curricula for supporting all students, and conversely, the role of the curriculum in the (unintended) creation of barriers and difficulties in learning
- A particular focus is needed on the first year curriculum and 'learning how to learn' in HE which would be of help to many students entering higher education.

1. Background

1.1 Introduction

Higher Education Institutions (HEIs) are becoming progressively more engaged with processes of inclusion (e.g. Thomas and Cooper, 2000) as the increasingly diverse student body has begun to challenge more taken-for-granted approaches to ways of working in higher education (HE). The Disability Discrimination Act, Part IV has arguably had a significant impact on HE, both in terms of strategic planning to ensure compliance, as well as in some cases, redefining how provision may be organised to better meet the needs of students (Adams, 2003: 26). So what is it like for disabled students in higher education today? And how do disabled students starting out in higher education get on? In this report we present the main findings from the HE Academy funded research project which was carried out over a 16 month period from August 2005 to November 2006. The project aimed to explore and develop understandings of what might improve the educational and social experience of disabled students within higher education. It also aimed to examine how useful the category 'disabled student' is as a basis for targeting support.

Theoretically, the project was concerned with the social construction of student identity. It drew on a life-cycle conceptualisation of the student experience, which highlights key stages in the student career (Layer, Srivastava and Stuart, 2002). Focusing mainly on pre-entry, entry and the first year of student life in HE, the project explored student expectations as well as the processes of becoming and being a (disabled) student. Students who declare disabled status once at university (rather than pre-entry) essentially go through two processes, initially becoming a student, and then becoming a disabled student. An understanding of the processes of 'becoming', particularly from the student perspective, may help us understand how we may better support students in the crucial early stages of higher education. Case study data are used to illustrate students' perspectives of their social and academic experiences of higher education as they 'become' a (disabled) student.

1.2 The national and local policy contexts

Moves to improve the provision for disabled students in HE have been slow in coming. It was not until 1993 that the Higher Education Funding Council for England (HEFCE, and similarly SHEFC in Scotland) started to provide funds specifically for this purpose (Tinklin, Riddell and Wilson, 2004). Indeed, until 2001 and the arrival of the amended Disability Discrimination Act (DDA) Part IV, it was not unlawful for HEIs to discriminate against disabled people in the UK. The act brought important changes, for example, HEIs were now required to make 'reasonable adjustments' for disabled students, as well as to anticipate the needs of disabled people and plan accordingly. This meant that instead of starting to think about what adjustments would need to be made once an individual had arrived on campus, there was a duty on HEIs to review and adapt policies and procedures in advance. Although implementation has not always been straightforward, in practice the DDA Part IV has arguably had a significant impact on higher education, mainly in terms of strategic planning to ensure compliance, as well as in some cases, redefining how provision may be organised to better meet the needs of students (Adams, 2003). At the time,

Layer, Srivastava and Stuart (2002) argued that there tended to be little direct connection between HEIs' disability support and widening participation strategies despite involving similar issues and approaches. More recently, the Disability Equality Duty has shifted the focus from individual disabled persons to institutional responses and equity.

These developments have been challenging, not least because they have not occurred in isolation. The context for change has included on the one hand, a drive by the UK government to widen participation more generally in HE, as well as on the other hand, pressures from marketisation of HE and quality demands on staff, for example, from quality assurance audits and the research assessment exercise (Morley, 2003). As Tinklin et al. (2004) have highlighted, this has created a demanding context for the development of provision for disabled students. Nevertheless, even given this context for change, significant moves have been made in terms of the numbers of disabled students entering HE as well as the percentage increase year-on-year, from 4.1% in 2000 to 5.8% in 2004 (HESA, 2006). What we have less understanding of, is the quality of that experience, both learning and social, once the student is in HE (e.g. see Fuller, Healey, Bradley, and Hall, 2004).

The local context for the research was a small, research intensive HEI of approximately twelve thousand students, of whom approximately 7.5% were known to be disabled at the time of the research, a percentage somewhat higher than the national average. The HEI concerned was not alone in finding the development of provision for disabled students challenging, although early developments (such as the establishment of a student support unit, and the addition of a mental health adviser with a background in psychiatric social work) meant that by 2001 and the advent of DDA Part IV, provision for disabled students was identified as an institutional strength. At that time, the proportions of disabled students attending the HEI exceeded national norms and there was also a consistently lower drop-out rate for disabled students (as compared to non-disabled students). However, proportionally fewer disabled students were achieving good (firsts and upper second class) degrees and little was really known about the student experience itself.

These more recent legislative changes have increased student diversity and have forced HEIs to look more critically at the student experience. Within these changing contexts, potential exists to think more strategically about support for disabled students and to develop more inclusive policies and practices. In particular, concerns about the student experience have become more prominent. Questions surround the development of provision, organisation and management of support for disabled students as well as more generally for the wider student body (e.g. see Shevlin, Kenny and McNeela, 2004; Riddell, 2004).

1.3 Theoretical framework

The project aimed to explore and develop understandings of what might improve the experience of higher education for disabled students. In part, it aimed to explore the processes of 'becoming' and 'being' a disabled student, and the effects of this on the student experience, whilst also attempting to access the perspectives of students who do not declare disabled status and thus remain, in an HEI's terms, non-disabled.

In this report, we focus in part on the more detailed experiences of three students to illustrate some of the issues which arose from the project, as well as touch on some of the more problematic aspects of the either / or categorisation of disabled / non-disabled student.

We take as our approach the social model of disability which stresses the difference between individual impairment, and the disabling barriers faced by persons with impairments (Oliver 1996). Many taken-for-granted assumptions about what it means to be a disabled person have been challenged by shifting the focus as Oliver (1990) argues, from what is 'wrong' with the individually impaired person, to what is 'wrong' with society. In direct opposition to what has variously been termed the medical, personal tragedy, deficit or individual model, the social model has helped shape our understanding of the lived experiences of disabled people. Its potential for challenging prevailing understandings has grown and is now gradually being extended, for instance into the field of 'mental health' (Beresford 2002) and also the undergraduate curriculum (Bolt, 2004). However, the social model is not yet a fully worked out social theory of disability, notions of 'disabling barriers' for example are not yet fully understood. As Barnes, Mercer and Shakespeare (1999) highlight, there is a need to examine more comprehensively the 'processes and structures associated with social oppression and discrimination, whether at everyday levels, or in the workings of the state and social policy' (p31). Nevertheless, whilst acknowledging its shortcomings, the approach is a useful one with its focus on the experience of disability.

In this report we explore some of the processes of becoming and being a (disabled) student, focusing on the social construction of student identity (Barnes, Mercer and Shakespeare, 1999; Thomas, 2001) and the effects of this on the student experience. Postmodern and critical researchers stress the importance of focusing on multiple identities and their effects on the lived experiences of individuals (Archer 2003). This is important in this report: for each of the students many factors contributed to shaping their identity as a student and their consequent experience of HE. Impairment was only one of these factors. The complex nature of disabled students' social and educational experiences raises questions about whether disability is always the overriding category (Ferrier and Heagney, 2001; Holloway, 2001; Riddell, Tinklin and Wilson, 2003).

1.3.1 What does it mean to be 'becoming' or 'being' a student in HE?

According to Anderson and Williams (2001), what it means to be a student in HE involves a 'complex interplay' between a number of factors, amongst which identity is crucial. In this paper we take 'becoming' a student to refer to the processes involved in taking on a student identity: a period when the individual does not yet fully see themselves as a 'student'. Processes of 'being' a student come into play when the individual has laid claim to a student identity and is engaged with constructing and reconstructing this identity. We see these processes as dynamic and although theoretically we may be focusing separately on 'becoming' and 'being', in practice this distinction is clearly less apparent. Drawing on work by Jenkins (1996), Anderson and Williams (2001) argue that to 'claim an identity' involves more than personal aspirations, it also needs to be endorsed by others.

This endorsement is a complex, social, psychological and interpersonal process. Some individuals can lay claim to a student identity easily ... their identity publicly endorsed and legitimated. Others are far more uncertain, not sure the system will accept them, or that they have a right to enter, or that the identity 'student' fits with other important aspects of their lives. (Anderson and Williams, 2001: 1-2).

These were important considerations for this project.

2. Aims

In our work with HE students, we found that developing practices have raised many questions which we have found are also taxing colleagues in other institutions. Some of these questions were tackled in this project. Thus, the rationale for the research was embedded in theoretical and policy contexts as well as in practice. In particular, the research had three main aims:

1. To explore the educational and social experiences of disabled students within one HEI;

This central aim of the project attempted to encompass as widely as possible the notion of 'disabled student' and thus also attempted to access the perspectives of students who do not declare disabled status and therefore remain, in the HEI's terms, non-disabled. The project also aimed to explore the processes of 'becoming' and 'being' a disabled student.

2. To identify ways in which their experiences may be improved;

A key aim of the project was to investigate and develop understandings of how the experiences of higher education for disabled students might be improved. We hoped to build on recent work by Fuller, Healey, Bradley and Hall (2004), Weedon and Fuller (2004), and Riddell (2004) by focusing in detail on the experiences of disabled students on entering, and during the early stage of HE. We saw part of the aim of our research being to provide in-depth and detailed descriptions of students' experiences which we hoped would prove useful to other institutions whilst also essentially being a pre-cursor to the development of a larger scale project.

3. To examine how useful the category 'disabled student' is as a basis for targeting support.

The notion of multiple identities and their effects on the lived experiences of individuals was an important aspect of our research. The complex nature of the students' social and educational experiences raises questions about 'simple' targeting of support and whether disability is always the overriding category (Ferrier and Heagney, 2001; Holloway, 2001; Riddell, Tinklin and Wilson, 2003). Given that more recent research demonstrates that the social identity of disabled students is mainly white, male and middle class (Riddell, 2004), the project also sought to explore how inequalities are enacted amidst the disabled students within one institution. In part our project aimed to build on Riddell's (2004) findings by exploring further the problematic nature of the category 'disabled' for the experiences of students and its usefulness for targeting support.

3. Methods

3.1 Research design and scope

The project was composed of three strands. The first strand explored disabled students' educational and social profiles, the second focused on student perspectives of their experiences, and the third strand involved disabled students as co-researchers in the process of data collection. The research methods were mixed, drawing on quantitative analyses of educational and social profiles to provide a context for more qualitative analyses of student perspectives. During analysis, data were disaggregated according to HESA categories of disability in order to explore any patterns within and between categories, as well as across data sets. Tests of significance were carried out (mainly Chi square) as appropriate.

3.2 The three strands of the project

Strand 1. The focus of this strand was on the educational and social profiles of five cohorts of students from the HEI (the 2000-2004 entries). Data were gathered (in Oct 2005) by entry cohort, and analysed in relation to gender, age on entry, ethnicity, socio-economic status, entry qualifications, mode of attendance, domicile (UK / overseas), department / programme and by disability type.

Strand 2. This strand focused on accessing the perspectives of disabled students on (i) what they look for in HE as well as (ii) their social and educational experiences. A questionnaire survey was carried out of all current known disabled students in the HEI, using information from the database held by the HEI's Student Support Unit (SSU). 198 questionnaires were returned, although 6 of these were too late to be included in the quantitative analyses. Five additional responses (letters / notes) were received from students to tell us that they were not disabled. The majority of students who completed the questionnaire had provided names and / or contact details, as a result of which we were able to complete demographic information and confirm queries from the questionnaires. This was a time consuming but very valuable process, enabling an almost full set of data for 192 students known to be disabled at that time. Late-declaring students' experiences were analysed as a sub-group of the questionnaire data.

The questionnaire elicited data in relation to (i) whether students were happy with their social and learning experiences, (ii) whether they felt barriers existed to their social and learning experiences, (iii) the nature of those barriers, and (iv) issues around support. Social experiences included a focus on the social life of the student at the HEI as well as the social experience of learning.

Follow up, in-depth interviews were then held with a sample of 43 respondents, focusing on factors affecting the student experience. All had indicated on the questionnaire that they would be happy to be interviewed.

The sample was chosen to enable more detailed exploration of issues arising from the analysis of the questionnaire data.

In addition as part of this strand: (a) we attempted to identify non-declaring disabled students which was tricky, although we were able to identify and interview five students; (b) we carried out interviews with a further eight students who were new to the HEI (2006 entries) to enable a focus on 'becoming' a student at the time of 'becoming' (i.e. rather than retrospectively).

Strand 3. In the third strand of the project, a group of self-nominating disabled students from across the university acted as co-researchers. The involvement of students as active agents of change has been used successfully as an approach in the primary and secondary sectors of education (Fielding, 2001a and b) and we aimed to extend the technique to the HE sector. A number of students expressed interest (when interviewed) in being involved in the research process. Starting with a focus group approach (using a nominal group technique) with fourteen of these students, we were able to gain a more in-depth understanding, and question more critically some of the findings that were beginning to emerge from the project. A core group of seven students then became engaged more as co-researchers and worked with us during the latter stages of the project, for instance: (i) identifying issues seen as important to the students; (ii) conducting interviews with each other focusing on 'becoming' and 'being' a disabled student; (iii) gathering visual images to illustrate the nature of some of the issues identified (iv) being involved in dissemination of the project findings (the latter is on-going).

3.3 Methodological reflections

Underpinning the aims of the research has been the importance of determining who the 'disabled' students are. This was not unproblematic: although some students declare disabled status on entry to an HEI, some declare once at the HEI and some never declare. Limiting data collection to those students known to the HEI as disabled, would exclude the perspectives of those 'disabled' students who had not yet, or who would never, make known their impairment.

Accessing the perspectives of non-declaring disabled students

A key element of the project was to attempt to access the perspectives of non-declaring disabled students. This raised a number of methodological challenges, not least, how we should identify these students and the ethical issues surrounding this. This group by definition are difficult to identify and also may not want to be identified. We used a number of methods to try to engage non-declaring students without compromising their wishes, including: (1) student to student contacts – snowballing (Cohen, Manion and Morrison, 2000); (2) through developing a better understanding of the perspectives of late declaring students (i.e. those who declare sometime after entry to university) via the questionnaire survey and follow-up interviews; (3) by direct appeal and by providing a choice of who they could talk to / communicate with (e.g. student / non-student researcher, disabled / non-disabled interviewer, etc). The

student researchers proved helpful in this, particularly in relation to the best ways to target the direct appeal, wording of flyers etc.

A further methodological problem we encountered was that if the 'non-declaring disabled' student had declared, would they have been assessed as 'a disabled student'? Should we take this into account, and if so, how? In practice this concern did not become a problem: the 'non-declaring' students generally described conditions which were both severe and long term, involving interventions from various professionals. In addition, we were concerned with their social and learning experiences and reasons for non-declaration, rather than an outcome of a declaration. Their own view of their identity and how this had developed was of central importance.

Issues of sampling

A key issue throughout the project has been the problematic nature of the category 'disabled student'. This also became a methodological concern early in the project. For instance, our first challenge was to decide who to include in the questionnaire survey. Should we only include those known to be disabled by the HEI? Should we include students who were in the process of being assessed even though some may not subsequently be identified as 'disabled'? Should we include students who although not being 'disabled' (i.e. in DDA terms) at that point, were known to have an impairment which may or may not become a disability (for instance one student became a wheelchair user for several months following an accident)?

In the end, pragmatic considerations overrode other concerns in relation to the distribution of the questionnaire and we decided to tackle more problematic questions of 'disability' through the wording of questions and at the analysis stage. We therefore decided to send the questionnaire to all students on the database of the student support unit, although we decided that our target group would be the current known disabled students. Not only would it have been difficult to disaggregate the data at that stage, but we wanted to be sure to include late declaring students. 885 questionnaires were distributed. This included 660 students known to be disabled at the time, and 225 students who either (a) had been referred to the student support unit and were in the process of being assessed, (b) had been a known disabled student, but had recently left the university (but were not yet off the system), or (c) were students who had made enquiries / been referred / self-referred to the student support unit, but where no action was felt to be needed.

Almost all of the 198 returned questionnaires were from the 660 current known disabled students, although it is likely that the time delay in sending out and receiving responses would have meant that some of the respondents would have been in the process of being assessed when questionnaires were distributed.

4. Findings

4.1 The social and educational profiles of the disabled students (research strands 1 and 2)

4.1.1 Introduction

Over the past few years, HESA statistics have shown a year-on-year percentage increase in the proportions of known disabled students (UK domiciled) in higher education, from 4.1% (2000 entry cohort) to 5.8% (2004 entry cohort). Within the same period of time at the HEI where the research was carried out, the proportion of (UK domiciled and EU) disabled students has also increased, rising to a peak in 2002, but appearing to level out in 2003 and 2004 (Table 1).

Table 1. Student groups by cohort and year of entry

Student cohorts by year of entry		2000	2001	2002	2003	2004	Mean for period
The HEI	Whole entry cohort (totals)	4495	4487	4540	4802	4937	4652
	Disabled student cohort (totals)	306	369	412	352	370	362
	Disabled student cohort (as % of whole cohort)	6.8%	8.2%	9.1%	7.3%	7.5%	7.8%
	UK domiciled & EU students: % disabled	7.8%	9.6%	10.2%	8.6%	8.5%	8.9%
	Overseas students: % disabled	1.7%	1.6%	4.0%	2.3%	3.2%	2.6%
UK figures (HESA,2006)	UK domiciled students: % disabled	4.1%	4.6%	5.0%	5.3%	5.8%	5.0%

Looking more closely at the intakes at the HEI over the 2000-2004 period (Figures 1 and 2 below), we can see that the total student intake began to rise in 2002 with a steep increase in 2003. However the percentage of all known disabled students (home and overseas) at the HEI peaked in 2002 and then began to fall. This means that as the student population as a whole has risen over the 5 year period with increased intakes, the proportion of disabled students appears to have fallen, with the highest ratio of disabled to non-disabled students occurring in 2002 and levelling out in 2003 and 2004. Although not directly comparable with HESA statistics (these being for UK domiciled students only), the proportions of disabled students at this HEI, do seem to have been consistently higher than national norms overall year-on-year.

However, caution is needed here: the data from which Table 1 and Figure 2 were derived essentially gives us a snapshot in time of the profiles of students on entry to the HEI. Data were gathered in Oct 2005 and thus some of the late declaring disabled students from the 2003 and 2004 cohorts may not be included. Also, the figures are of known disabled students and part of the increase in percentage of these disabled students may be accounted for by improvements in the way in which the HEI collected data and also their encouragement of students to declare. What is

also noticeable is the increase in overseas known disabled students, particularly in 2002. Interpretations of apparent patterns within the statistics are not straightforward.

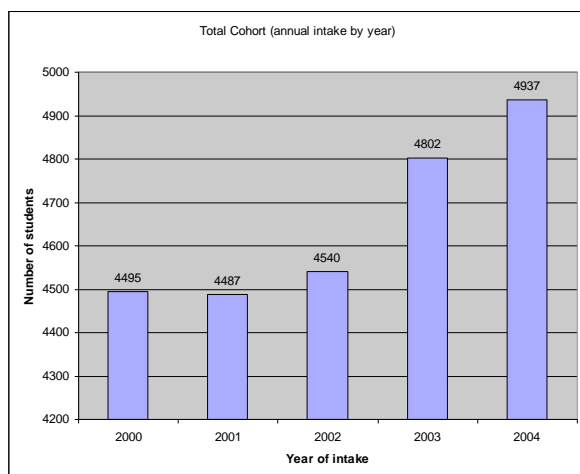


Figure 1. Total annual intake of students

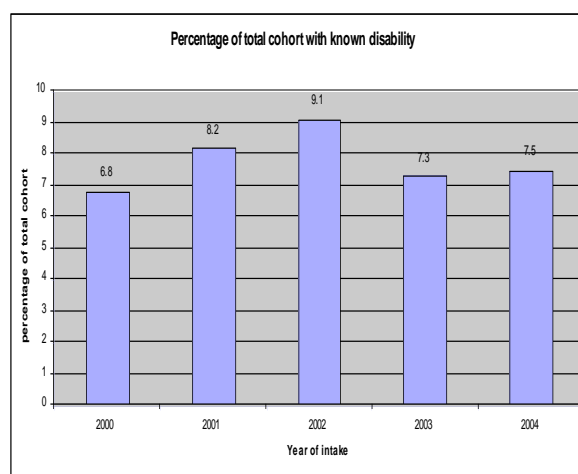


Figure 2. Percentage of known disabled students within annual intake

4.1.2 Demographic features of the samples

This section compares the profiles of the three samples: (i) the total cohort(s), i.e. the total annual intake of students at the HEI for the 5 academic years 2000 to 2004; (ii) the disabled cohort(s), i.e. the known disabled students within the annual intake; and (iii) the questionnaire sample (N=192).

Level of study

For each year of entry, we looked at the percentage of students studying at undergraduate (UG) and postgraduate (PG) levels. We also looked at trends over time. Figure 3 shows that in 2002 the percentage of disabled UG entrants peaked. On the other hand, the intake of disabled PGs shows a trend that is steadily increasing (cf Farrar, 2006). This larger variation in the proportion of UG disabled students may help explain the rise and then fall of the overall disabled student cohorts. If this observed trend continues, then we would expect that the proportion of UG and PG disabled students within this HEI would begin to converge. The increase in PG students has been a strategic focus of the HEI and this appears to be reflected in the increasing proportion of disabled PG students.

Taking a mean across the five years for the total entry cohorts (i.e. all students), there was an average of 37.6% PG to 62.4% UG. In the disabled student cohort there were proportionally less PG students with roughly a quarter PG (25.7%) and three quarters UG (74.3%).

In the questionnaire sample, the proportion of PG to UG disabled students (21.9% PGs and 78.1% UGs) broadly reflected the proportions of known disabled student entrants, although there were again slightly less PGs in the sample. Of the PG students who responded to the questionnaire, a quarter were research students. We also found no significant difference between PG taught, PG research and UG in relation to categories of disability, i.e. levels of study were evenly spread across all disability types.

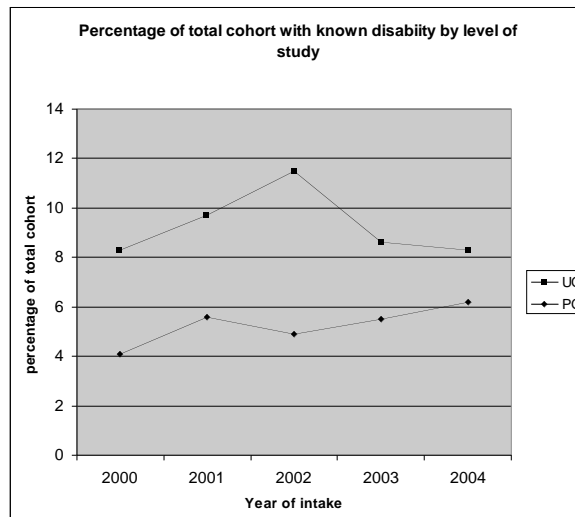


Figure 3. Disabled student intake by level of study: UG/PG trends across intake years

Mode of attendance

The mode of attendance of the disabled student cohort also broadly reflected that of the total student cohort over the five year period (Figure 4), i.e. the distributions of full-time, part-time and 'other' (e.g. continuation status) categories within the known disabled students very closely matched that of all students. The questionnaire sample reflected the general trend of both the total and disabled cohorts: that is, there were proportionally more full-time than part-time students, with fewest in the 'other' category (all PGs). However, the questionnaire sample is more evenly spread across mode of attendance than either the total cohort or the disabled student cohort. Within the questionnaire sample, most of the UGs (91.3%) and more than half of the PGs (59.5%) were full-time

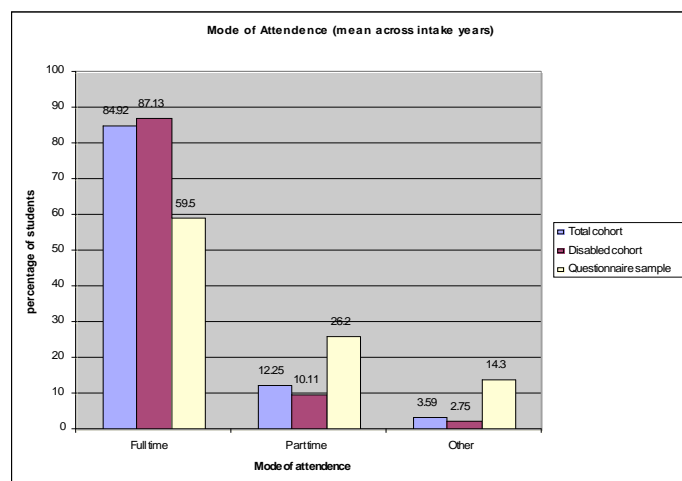


Figure 4. Mode of attendance by cohort.

Looking at the trend across intake years (Figures 5a and 5b), the total cohort, and within it the disabled cohort, both show an increase in relative proportions of part-time students and a slight decrease in the proportion of full-time students over time. In fact the increasing proportion of part-time students does not represent an actual increase in numbers, but is a feature of the data management system which changed

over this period of time to include a previously semi-autonomous unit within the HEI. This could partly explain the higher than average number of part-time students in the questionnaire sample.

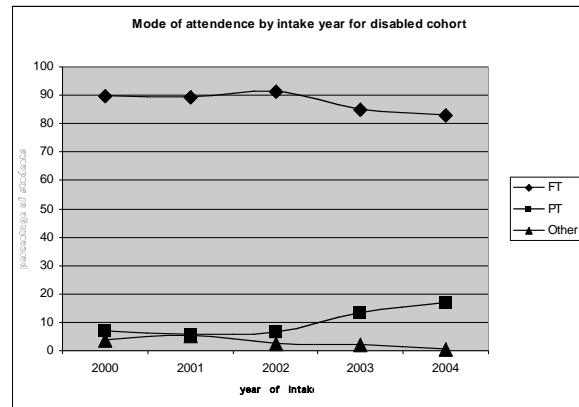
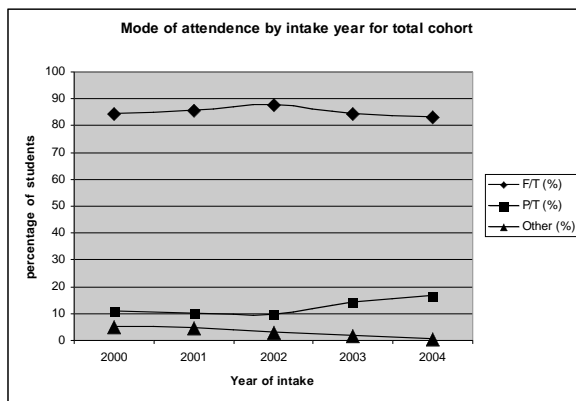


Figure 5a. Trend across intake years (total cohort)

Figure 5b. Trend across intake years (known disabled)

Gender

The ratio of male to female in the disabled student cohort again generally reflected the whole student population (Figure 6). The ratio in the questionnaire sample reflected the general trend but was more pronounced with almost twice as many females to males (i.e. a larger proportion of female students completed the questionnaire).

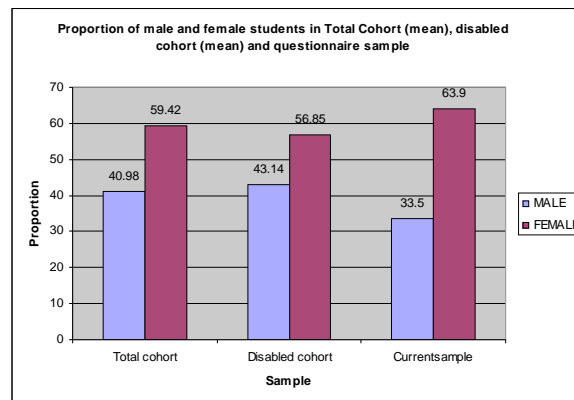


Figure 6. Gender profiles by cohort

Looking more closely at trends over time, we found that within the total cohort (Figure 7a), the male / female ratio has remained fairly stable at 40:60 since 2000. However, the disabled cohort (Figure 7b) has had more variation at almost 50:50 in 2001 to a 40:60 ratio in 2004. This is an important finding and would seem to indicate that the disabled cohort entries in this HEI are becoming more representative of the gender profiles of the total entry cohorts. In 2001 there were proportionally fewer female disabled students relative to the total intake (cf Riddell, Tinklin and Wilson, 2005), however since then, increased proportions of female disabled students has led to ratios more in line with the total entry cohorts.

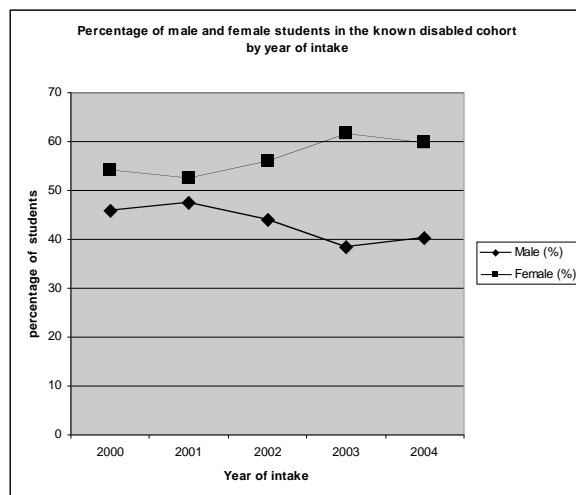
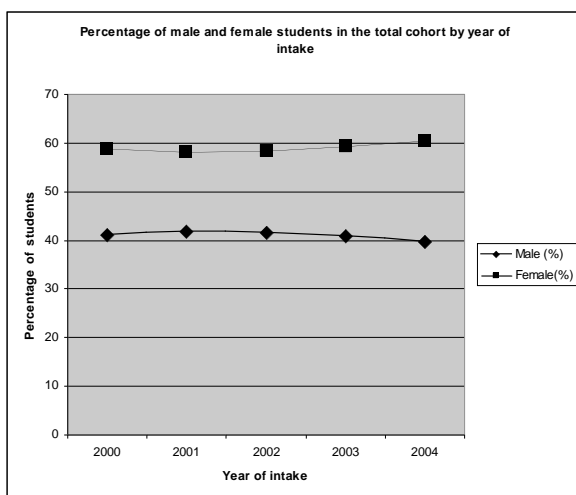


Figure 7a. Gender by year of intake (total cohort)

Figure 7b. Gender by year of intake (known disabled)

When we considered gender distribution across disability categories in the questionnaire sample, we found that this broadly reflected the male / female ratio. The dyslexia category was the most representative of the cohort as a whole with approximately one third male (34.7%) and two thirds female (65.3%) respondents. In all other categories there were more females than males except for the 'blind/partially sighted' and 'a disability not listed' categories in which there were equal numbers of males and females. Given the incidence of dyslexia in earlier phases of education (where there is a marked prevalence amongst males) this result is perhaps surprising and is an issue which has been highlighted by others (e.g. Pumfrey 2004).

Age

Comparing the age profiles of the three samples (Figure 8), again the disabled cohort as a whole largely reflected the total student population. The questionnaire sample was also broadly representative, with the main differences lying within the youngest two categories (i.e. under 20 and 21-30). This could partly be accounted for by the nature of the sample which was cross-HEI and included students from all year groups, not just intake groups (i.e. we would expect some respondents to be in older age categories than they would have been on entry to the HEI).

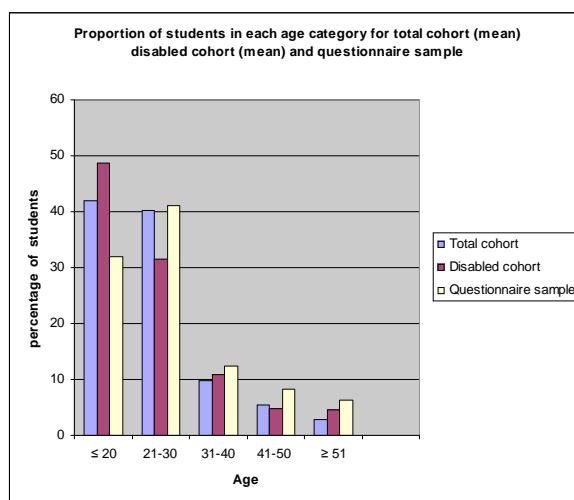


Figure 8. Age profiles by cohort

The main variations between the three samples lie in the youngest two categories (under 20 and 21-30). These variations are partly explained by looking at trends over time (Figures 9a and 9b below). In the total cohort the proportion of students in each age bracket has remained relatively stable, although there has been a decrease in the under 20s at entry and an increase in the 21-30s. This may be as a result of the increased PG population but may also be due to fewer UG entrants coming straight from school.

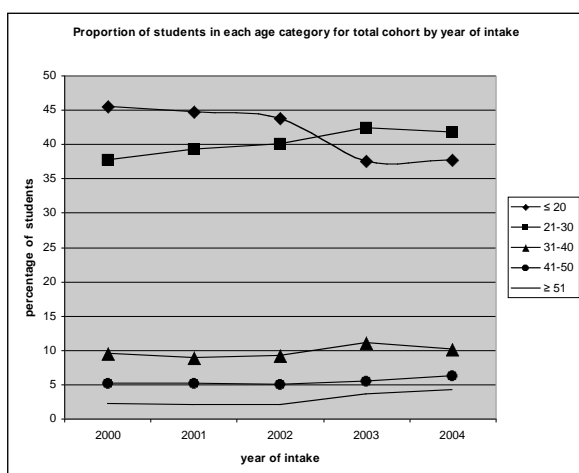


Figure 9a. Age by year of intake (total cohort)

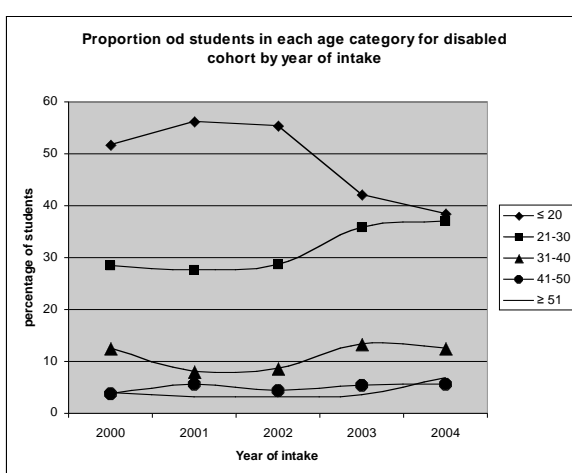


Figure 9b. Age by year of intake (known disabled cohort)

Among the disabled student cohort there has been a greater difference in the number of students in the youngest two age brackets. For example, in 2000 there were more disabled students under 20 than there were between 21-30. This gap continued to increase until 2003 where the numbers in each group began to converge. By 2004 there were an equal number of students under 20 as between 21-30. In the questionnaire sample, the two youngest age groups were relatively evenly distributed across all disability categories with smaller proportions within the older three age groups, again reflecting the overall age distribution.

Ethnicity

Figure 10 shows the ethnic origin for each of the three samples (total cohort, disabled cohort and questionnaire sample). HESA categories were used to gather data, but conflated to those shown because of relatively small numbers in some sub-categories. Three quarters (74.9%) of the total cohort were white, with an even higher proportion of white disabled students (84.9%). The HEI has remained a predominantly white institution over the five year period, with little variation in ethnic intake.

The questionnaire sample was largely representative of the student population as a whole and the disabled cohort. However, there were a higher number of students in the questionnaire sample whose ethnicity was not known (19.1%). Just under half of the questionnaire sample described themselves as White British: all 'White' categories together made up 68.5% of the questionnaire sample. Looking at trends over time, this pattern has remained fairly stable with few non-white disabled students entering the HEI.

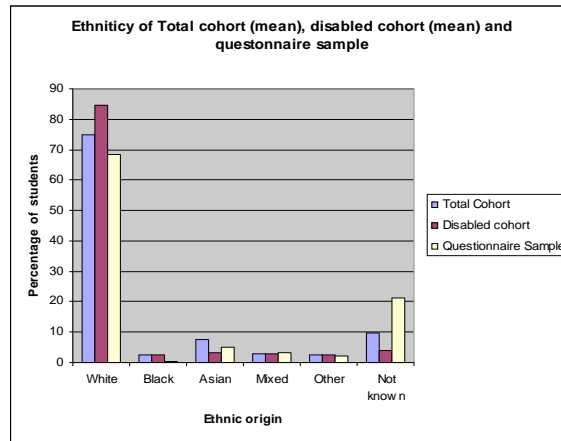


Figure 10 Ethnicity profiles by cohort

Socio-economic status

This demographic was problematic. It was not possible to provide anything meaningful in relation to socio-economic status and disabled students due to the amount of data which was 'not known' as well as changes to the way in which data were collected during the five year period which made comparisons difficult.

School of study

The distribution of the questionnaire sample was representative of the total distribution of known disabled students across the five schools within the HEI, with no significant difference between schools. Only one school (a science school) was proportionally slightly under-represented.

Categories of impairment / disability types

Figure 11 shows the mean proportional intake of students by disability type between 2000-2004 and the proportion of the questionnaire sample in each disability category.

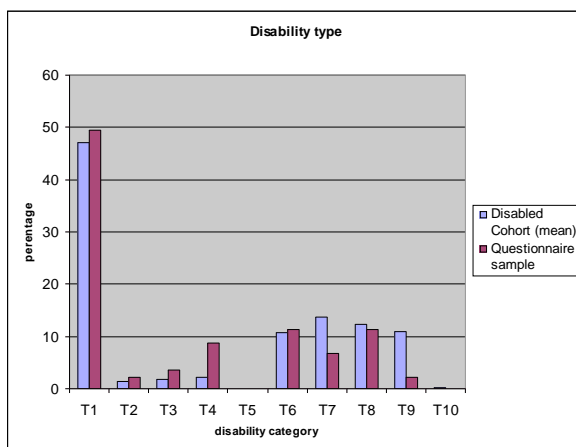


Figure 11. Categories of disability by cohort

Disability categories (as used by HESA & the HEI)

- T1 Dyslexia
- T2 Blind/are partially sighted
- T3 Deaf/have a hearing impairment
- T4 Wheelchair user/have mobility difficulties
- T5 Personal care support
- T6 Mental health difficulties
- T7 An unseen disability
- T8 Multiple disabilities
- T9 Other disability / disability not listed
- T10 Autistic spectrum disorder (including Asperger Syndrome).

In the questionnaire sample, 49.5% of the respondents were dyslexic (T1), making this the most frequent category. 'Mental health difficulties' (T6) and 'multiple disabilities' (T8) were the next most frequent categories, each making up 11.3% of the total sample. In the majority of categories the questionnaire sample was representative of the overall proportion of students within that category across the university. However, students with mobility difficulties (T4) were slightly overrepresented in the questionnaire sample relative to the proportions of students in this category within the university as a whole. In addition the two categories 'an unseen disability' (T7) and 'other disability / disability not listed' (T9) were underrepresented in the questionnaire sample.

In the known disabled student sample, when looking at trends over the five years, we found that the proportion of students within each disability category has remained generally stable (i.e. although there has been an increase in the number of disabled students, the proportions across categories have stayed relatively stable). The only inconsistency was in 2000 where there were relatively more students with an unseen disability than in any other year. However, caution is needed here: because of the possibility of later declaring students not yet being included in the 2003 and 2004 entry statistics, the trends for these two years are less reliable. The T10 category is also a more recent addition and only 2004 had students within this category (previously students with this impairment would probably have been included in T6 mental health difficulties, T7 an unseen disability or T9 other disability / disability not listed).

In summary

Generally, the total cohort has remained relatively stable demographically over the five year period, with main changes being in the relative proportions of PG/UG students and the age of entry. Within the known disabled student cohorts, there was some evidence to indicate that demographically, and particularly in relation to gender, entries to the HEI appear to be becoming more representative of the total entry cohorts. However, this was not so in relation to ethnicity, where few non-white disabled students were entering the HEI: this had remained fairly stable over time.

In the next section, some of the issues surrounding 'coming into HE' are explored, from the students' perspective.

4.2 Coming into higher education: the disabled student perspective (research strand 2)

4.2.1. What did the students look for in a place of study?

What was important to the students when choosing where to apply and why did they choose this HEI? The students gave a wide range of responses, most of which (80.7%)¹ were non-impairment related reasons, for instance, the course of study, reputation, ethos, the HEI's location near a town (for the social life), and so on. Reasons why they chose this particular HEI were often similar (i.e. non-disability

¹ Percentages relate to responses from the questionnaire sample (N=192).

related), but were generally more specifically reflecting concerns about ethos, attitude and welcome experienced, either when visiting the HEI or through earlier communications. For instance:

What was important when choosing where to apply?	Reasons for choosing this HEI	(Student respondent)
<i>A nice environment with a stimulating course.</i>	<i>The campus mainly, I visited at spring and found it welcoming and sunny and happy!</i>	(#53, dyslexia) ²
<i>Reputation, prestige, contact time, campus, location.</i>	<i>Location, the beach, nightlife and the quality of the teaching.</i>	(#93, dyslexia)
<i>Good teaching, good reputation for my course. Nice city and good social life.</i>	<i>Good course. Liked [the city]</i>	(#23, deaf / hearing impairment)

A relatively small but significant number of respondents (16.3%, 31 students, mainly non-dyslexic), gave disability-related reasons concerned with support available, accessibility, acceptance or location. For example:

What was important when choosing where to apply?	Reasons for choosing this HEI	Student respondent
<i>It had a campus so I could find my way around and that I thought I could get support when I needed it. How much I liked the look of the course too!</i>	<i>It was the only university on my list that invited me down for a specific tour around. The day before an open day I had (with my parents) a tour by myself. I got to say which halls looked most helpful for me to live in. Also the campus is small and easy to find my way around in.</i>	(#31, blind / partially sighted)
<i>Faculty, relationships I had built up in my undergraduate years and the support offered by the university</i>	<i>I had just finished my undergraduate study here and so wanted to continue in the same environment.</i>	(#64, mobility difficulties)
<i>Institution with a good academic reputation.</i>	<i>[as left] with good support mechanisms and close to London.</i>	(#99, mental health difficulties)
<i>Good university that did suitable course that was close to home.</i>	<i>Close to home – close to hospital I was having treatment at.</i>	(#47, an unseen disability)

In the case of one student who had multiple impairments, what was important in choosing where to apply was acceptance by an HEI:

² NB all numbers associated with quotations, such as (#53, dyslexia), are respondent identifiers.

Due to personal circumstances, I need[ed] a university that would accept my recent health problems – other universities I contacted (e.g. [...]) would not consider my application until I had been ‘well’ for 2 years! (#147, multiple disabilities)

This student’s reason for choosing this HEI, which did accept them, was the course of study:

[It] was a last minute choice, knew nothing about the university by itself, just the course. (#147, multiple disabilities)

4.2.2 What or who influenced the students’ decision about whether to go to university?

Perhaps unsurprisingly, where students said they were influenced in some way, this generally came from families, friends or school. Again, many reasons were not apparently disability-related and ranged from a ‘natural’ expectation, such as: ‘*I was always expected to go to university*’, or, ‘*There was no question of my not going*’, to encouragement, ‘*One daughter was very encouraging and advised me. My other daughter thought I was bonkers!*’, and at times a cajoling, ‘*[My dad] told me if I didn’t go I’d have to go back to my full-time job and start paying rent*’.

For some students, positive role models or a significant person who believed in them, were of particular importance. For example:

Because he [my brother] did his MA when he was 32-37. It inspired me and gave me the confidence to approach education as a mature student. He also suffers from depression. (#183, mental health difficulties)

Because they [my family and friends] have been [to university] they were able to reassure me that despite my illness I was able to do it if I wanted, that it was possible. There was no pressure to go though. (#99, mental health difficulties)

Self-belief and encouragement. (#100, mobility difficulties)

For other students, general support, encouragement and practical assistance were of most significance:

My father was keen for me to further my studies. He helped me choose which courses might be best to choose from. My family generally have been very supportive, especially my mother - practical help. (#84, multiple disabilities)

And of course, there was always the need by some students to resist any attempts by parents to influence choices!

Well I think they [my parents] would have liked me to go closer [to home]... they wanted somewhere closer. But I just ignored them. (#31, blind/partially sighted)

4.2.3 Advising the HEI about their condition / impairment

Having decided to go on into higher education, when did the students advise the HEI of their condition or impairment? We found that amongst the questionnaire sample, less than half of the respondents advised the HEI via their application form or 'during registration' (this latter phrase was a little ambiguously used but generally referred to the 'coming to uni' time as well as the induction period). However, this figure had risen to just over 60% by the end of their first term. That said, almost a fifth of the respondents were in their second year or later before they advised the HEI (Table 2). This range in the timing of declaration was spread across all disability types and was an important finding given the findings in section 4.1 above and the timings of returns (July) to HESA. We may well be seriously under-estimating the numbers of disabled students in HE today.

Table 2. Timing of declaration: the questionnaire sample (N=192)

Timing of declaration	Number of respondents	Proportion of the questionnaire sample
On application form or during reg.	85	44.3%
During first term at HEI	31	16.1%
During terms 2 or 3 of first year	17	8.9%
During 2 nd year	30	15.6%
During 3 rd year or later	7	3.6%
Timing unknown	22	11.5%

The reasons why students advised the HEI, and advised when they did, varied. Across all disability types, most students (61.7%) advised the HEI because of wanting to avoid a problem or to ensure support. For a significant minority (20%), not coping was their main reason and this tended to either refer to their condition (generally worsening) or to the contextual changes they experienced in transition to HE. Although the former applied to all disability types, the latter was only mentioned by students with mental health difficulties or dyslexia. In all cases of 'not coping' there was no explicit reference to wanting support, but more wanting to let the HEI (or someone) know that they were not coping. For example:

Not coping because of their condition:

The condition worsened and I was hospitalized. I had to miss three weeks. I realized the condition was going to be harder to manage than I originally thought. (#2, unknown disability)

Due to my hearing loss progressing, I am finding it increasingly difficult to keep track of lectures and seminars. (#12, deaf/hearing impairment)

I was finding it difficult to carry on with my studies due to my depression (#91, mental health difficulties)

Not coping because of context change:

I was finding lecture-based learning and the higher level of learning difficult to keep pace with and I knew my mum and granddad suffered with dyslexia. I had previously just struggled through, but thought it was time to see how serious it was. (#5, dyslexia)

Because I was finding it difficult to adapt to uni and was worried about how I was going to manage (#89, mental health difficulties)

I was having problems in my first week of my first year with accommodation and generally coping with the change to being a student (#124, mental health difficulties)

For some students, their main reason for advising the HEI about their condition or impairment, was because they had been advised to do so by others, generally by teachers at school, friends, family or professionals (such as their psychiatrist). Other students reported that their difficulties had been identified by others (e.g. friends or tutors at the HEI), so they thought they ought to seek an assessment (this latter group were all dyslexic students). For a small group of students, their reasons for advising the HEI tended to be entitlement led, e.g. *'To get the extra time and computer equipment I had been told I was entitled to'* (#68, dyslexia) and *'To get extra time, tuition and equipment'* (#145, dyslexia).

4.2.4 Non-declaring (ND) students: Why don't students advise the university?

Students had different reasons for choosing not to advise the HEI about their impairment. For some there were concerns about labelling, and for others they wanted to be seen as *'normal'*, rather than as *'a special case'*:

The reason I haven't registered is, I am not sure that I want to be labelled as disabled and I toyed with this idea as to whether to register or not, and I think what happens when you are labelled in a particular way and people have different expectations of you, and so far I've been able to disguise it...and pass as normal...Quite often people think of disability as someone in a wheelchair, or blind, you know, quite profound physical and mental problems, but there are health problems as well. (ND#1)

I don't want to be a special case, I don't want to have any special help, I want to be a normal student. I don't want any exceptions to be made for me I want to do this properly.... I don't want people to give me, 'oh if you need an extension on this paper', and, 'you need more help'. I don't want that. I just want to be normal. To do things like everyone else does them, you know because of my own merit and not because I need anything else. (ND#5)

Other students expressed some ambivalence about whether or not they would be seen by the HEI as *'disabled'*. This arose especially in cases where a student's impairment or condition was unseen and / or a health issue. The question *'Am I disabled?'* was asked on a number of occasions (and also by students who had advised the HEI of their condition).

For the first couple of years I've been suffering with depression. Over the past 18 months to 2 years it's just been really bad. I had a really intense year last year and also I have problems with anxiety and eating disorders as well....I wouldn't say I was disabled but I'd say I'd got a disability if that makes sense. I wouldn't say I'm impaired but I've got a long term health issue, that's quite different. I didn't really want to [declare] for me, because it's not like it was a physical disability – I don't know if they included that. (ND#2)

One student, when asked if they considered themselves to be disabled, explained that they perceived the idea of a disability as negative, whereas they saw their impairment as positive:

I try not to think of [my impairment] like that. I don't know, I try to think about it as just. 'oh this makes my life interesting'. It's just how life is for me now and I'm not going to let it cramp my style too much. It makes things difficult sometimes, but I think otherwise I have a great deal more depth than what I had before, and greater maturity which I appreciate in my work as well, not only in my life. So it's been in some cases that it's been an obstacle, but not one that I haven't been able to overcome. But in other ways weirdly, it's almost been enabling....So strangely it has been quite an experience. And not all negative. (ND#5, treated brain tumour and epilepsy)

One student was close to becoming a 'late' rather than a 'non-declaring' student, because they were having difficulties coping:

I've just been slow to get in touch with the student advisor and sort it out and say this is going on, whereas in hindsight I wish I'd said at the beginning and just sorted it out...because they'd have let my tutors know from the beginning rather than just missing things. (ND#2, mental health difficulties)

A theme which emerged from a number of the student respondents, was the importance of support which could best be described as 'being in the same boat' as someone else. However, this issue came through most strongly from non-declaring students, for instance:

It would be really good if I knew some of the people that are going through similar things. I know with the counselling they do group therapy I think that they're still trying to sort it out but they do one for anxiety. It would just be nice if either the school or the department set up a group that you could go to that you meet people with the same thing and your disability that would affect their work, and you'd feel like you weren't alone. (ND#2)

I feel that epilepsy and seizures are sort of an invisible problem. But they're actually more common than people know, seizures are I mean. But nobody talks about it. Nobody. Well maybe they're lucky and there's control or whatever, they're on different medication and treatment that they've had, but sometimes I just feel terribly alone and I think that if I wanted anything it would be to know that [there are] other people out there....I don't know how to describe it. You just don't feel so alone. I remember an anecdote that maybe will help to explain it. When I had my brain surgery to remove the tumour that

was causing the seizures originally - there's a hole that's caused by the seizures - it actually left a strange ridge in my temple like a bony ridge that was kind of a little concave part the way the bone healed I think that this is actually quite common now for brain patients or surgery patients. I think a year after that, I met a man and I noticed that he had this same ridge that I had and seeing him and then talking to him, he was an older man and he'd had an aneurism but it was finding another of your species almost. It was the incredible, 'Oh you've been through something that I've been through!' Even not talking about it originally we started talking about it 'cos we were like, 'oh hey you know, I look like you look like'. But then you know we just talked about other things and his kids and his restaurant and my studies. But it was just nice talking to someone then knowing if I have a seizure he's not going to be freaked out by it. (ND#5)

4.3 Being in higher education: the disabled student perspective (research strands 2 and 3)

4.3.1 The social experience of higher education

What contributed to a positive social experience within higher education? Did the students feel that barriers existed, and if so, what was the nature of those barriers?

67.2% of the questionnaire sample (N=192) indicated that overall, they were happy with their social life at the HEI, 12.5% disagreed and 18.8% felt this wasn't important to them. The results were broadly similar across all disability categories.

Of the 12.5% who disagreed, 92.3% felt there were barriers to their enjoyment of the social life of the HEI and 80.8% felt that at least some of these barriers were related to their impairment. 57.7% felt the university could help improve their social experience.

A significant association³ was identified between the student's age and whether they were happy with their social life at the HEI: the majority (85.2%) of 18-20 year olds saying they were happy overall, with this percentage decreasing with age.

Perhaps unsurprisingly, those students who reported that they were happy with their social life and the social experience of learning in HE, tended to have made friends (generally from the same course, or where they were living) and were doing social activities and / or had living arrangements that suited them (for example, a flat on campus, sharing with friends in the local town, etc): *'I love it here, the friends I have made here are amazing'* (#154, unseen disability). Some students got involved with the social life of the HEI with support from friends, while others relied on friends from outside the HEI who they felt understood them *'[I] socialise 'outside', with previous friends, closer to my age who know my probs'* (#21, mental health difficulties). In some cases a positive social experience had not necessarily been expected e.g. *'I enjoy learning and the social life is a bonus'* (#183, mental health difficulties).

³ Chi square χ^2 (12) = 42.14, $p < 0.001$

Some students who indicated that overall they were happy with their social experience of higher education (either their social life or the social experience of learning), also talked about barriers experienced, which they perceived as being related specifically to their condition or impairment. For example, those with health difficulties:

When I first started in my first term of the first year, I made a lot of friends and I went out quite a lot, but since May my disability has got worse, I'm less social than I would like to be now...It's quite difficult to go out. (#175, mental health difficulties)

I isolated myself...I wouldn't go out in the evening...I mostly just work...that's how the illness manifests itself. You want to stay focused and work extremely hard and a by-product of that is that you don't go out and you don't socialise because that would detract away from working. (#147, multiple disabilities)

I haven't got involved enough in extra curricular activities and poor attendance has meant I haven't met many people. (#59, unseen disability)

In other cases, happiness tended to relate to being able to 'pick-up and drop' as health allowed. This was a particular issue for students with mental health difficulties, as the following quotes illustrate:

I am able to participate in any and all social activities when feeling well. (#28, mental health difficulties)

Although the first few weeks were hell, I am starting to settle down and make friends. The academic side of freshers' week coupled with hectic [student union] activities made it hard to manage my mood. (#99, mental health difficulties)

Students with sensory impairments tended to refer to how their impairment could lead to social barriers, often commenting specifically about their ability to join in, or being made to feel 'silly':

To be honest I find it difficult to make friends...there have been a couple of times when I have gone to the bar with a few other students and in that situation it sometimes has been difficult to hear what they're saying. (#165, deaf/hearing impairment)

I don't know, but I don't always spot posters for events up around campus.... And the signs on the side of buildings are so small, I've got to go right up to them and that makes me feel silly. (#31, blind/partially sighted)

Students who felt that a social life at the HEI was not important to them, tended to be mature learners, or postgraduates students who had established social networks outside of the HEI. Where students indicated that at times they were not happy with their social experiences, this could be for a number of reasons, including:

a) Work taking a long time:

My reading takes me so long and makes me so tired I don't have time or energy to make friends (#81, dyslexia),

- b) Living arrangements that were not conducive to developing social networks:
I travel into the university and am happy with the friends I have met but feel that as I live further away from the campus this makes it more difficult for me to attend social events within the university (#128, dyslexia),
I have to live at home due to my disability & can't always get back to campus for evening events (and get home later/after) so miss out (#71, unknown disability),
- c) Problems 'fitting in':
[there's] not much support if you don't fit into the crowd (#187, mobility difficulties),
- d) Attendance difficulties:
At the moment [I'm] more focussed on trying to get over hurdles preventing me from attending each day. (#87, mobility difficulties),
I haven't been able to get involved with activities other students do (e.g. sport and going out)...I get tired very easily. (#22, unseen disability)
- e) The built environment and issues around accessibility:
[things could be made better] by improving accessibility of certain venues (#70, mobility difficulties)
- f) Attitudinal barriers - tutors and / or other students:
A lack of understanding among students and staff, and obnoxious, snooty or rough students who see people like me as too weak, pathetic and inferior to be worthy of them. (#4, mental health difficulties)

Some students felt that the responsibility for improving any difficulties experienced lay with students themselves, rather than the university:

I don't think that the university has a requirement to do anything other than ensure my academic life is of a sufficient standard. (#16, dyslexia)
I see this as my responsibility. (#64, mobility difficulties)

However, where it was work that was perceived as being the barrier to a positive social experience, students tended to feel the HEI could do more to improve things:

Yes. A long hard look at what amount of work is necessary for both students and faculty. Everyone seems to be too busy. (#183, mental health difficulties)

Absolutely. For a start, it would help if lecturers weren't over-ambitious when setting reading for the week. This has proved unnecessarily excessive and makes us prisoners in our own homes. (#73, unknown disability)

If they organised lectures to actually hand out quality notes at the beginning of each lecture, a breakdown of their lecture, it would be really helpful. If I've got that in front of me all I need to do is add in my own thoughts and it's much quicker. (#66, dyslexia)

Although at times where work was the barrier, this was related more to support needs:

Due to lack of proper support during study I spent an inordinate amount of time keeping up and eventually played 'catch-up'. This was due to accessibility issues with technology. (#52, blind/partially sighted)

4.3.2 The learning experience of higher education

73.9% of respondents (N=192) indicated that overall they were happy with their learning experiences at the HEI. 22.4% disagreed (3.6% did not respond). Again, results were broadly similar across all disability categories.

Of those students who felt they were generally happy with their learning experiences, 57.1% felt there were barriers to their learning and of these, 68.6% felt barriers were related to their impairment. Of the 'happy with learning experiences' sample, 79.3% agreed that appropriate support had been identified for them and 66.4% were receiving the support that had been recommended.

Of the 22.4% of respondents who indicated they were not happy with their learning experiences, 84.1% felt there were barriers to their learning and most of these (81.8%) felt at least some of these barriers were related to their impairment. Of this 'not happy' sample, 59.1% felt that appropriate support had been identified but only 43.2% were receiving the recommended support.

So what contributed to a positive experience of learning in higher education? For many students, this tended to relate to having settled into life in the HEI, enjoyment of the course and / or feelings of having 'learnt a lot', for example, 'I'm having a great time and am enjoying my course', and '[there is an] uneven pace, but it has pushed me to learn lots of new things effectively'. Many, often non-dyslexic, students accompanied or qualified their expressions of happiness about their learning experiences with comments about their impairment, support or tutor awareness, for example,

Impairment

Overall I am [happy], but I feel at the limit of what I can do. If I am ill for a week I don't think I could keep up and that worries me. (#99, mental health difficulties)

[I'm happy] with my experiences yes, with my learning no. I wish I could learn more, I wish I could study properly. (#26, dyslexic)

Support

[I'm happy with my learning experiences] because of the support I get (#70, mobility difficulties)

Very [happy]. Once being supported by an LEA allowance, my whole learning experience dramatically changed. From getting a 2.2 on my undergrad course I

completed my MA with marks averaging around 80% after the support started. (#129, dyslexia)

The support is good - the course is great. (#131, mobility difficulties)

Tutor awareness

Course is excellent. Lecturers are happy to cater for my requirements. (#37, deaf/hearing impairment)

I can't really think of a time when I have been severely limited by my hearing...In seminars and tutorials that I've had, they've all been really clear and all the tutors seem to know about my hearing so that really helps. (#37, deaf/hearing impairment)

Some students identified the existence of barriers to a positive learning experience, some of which were related to mainly non-disability specific issues such as:

a) A lack of contact time with tutors

Although I am happy with the teaching, I am angry about the limited contact hours and seminar reductions. (#149, dyslexia)

Too many cut backs e.g. larger classes and lack of assessed work. Too many exams too. (#173, multiple disabilities)

b) Tutors' teaching approaches

Lectures are a very outdated method of teaching especially when no handouts are provided or where there isn't a PowerPoint presentation to guide you. (#170, multiple disabilities)

[I am happy], but some tutors need to improve their lecturing from an old fashion, stand and talk, to a more interactive experience. (#57, dyslexia)

c) Academic related issues, such as course content or availability of texts

It is exactly the same as A-level, content-wise and there is no-one who knows what they are talking about to offer guidance. (#189, dyslexia)

Contact hours and copies of texts in the library are both limited for my course. (#28, mental health difficulties)

Where barriers were more specifically related to the student's impairment, support issues featured highly:

When they said to me that you can have someone who can spend an hour with you every week, going over any academic problems you have, whatever you're struggling with, I just thought that was the most amazing thing. I could not believe that someone was prepared to provide me with a person for an hour every week. It's been my lifeline, my absolute lifeline. (#89, mental health difficulties)

What they're (student support) very useful at doing is putting a lot of the funding in place. But what you also need is the actual practical communication with lecturers and everyone else who's involved in all the courses you're going to do, to get the actual materials you need to do the course. ...I found everything has

been done in power point – you probably know I'm totally blind – and that isn't a problem in itself but you find the handouts are condensed onto 6 slides on one piece of A4 so I couldn't even scan them because the scanner can't cope with that to get into a text format. All these are very simple things that if I'd have sat down with the lecturer beforehand, and said what do you do? How do you present it? Half an hour or an hour's chat would have made a massive difference. (#52, blind /partially sighted)

And equally, students were often quick to also identify their own role in relation to their learning and learning experiences:

I get out of my study, as much as I put in. (#64, mobility difficulties)

I sometimes had difficulty keeping my attention on the lectures but that's not really a learning disability, that's more a laziness thing. (#165, multiple disabilities)

I have a dyslexic brother, my dad is quite dyslexic and my mum's very dyslexic...it's in our family. But I suppose part of my family's ethos is that you don't actually let things like that hold you back...I can't really actually tell the time. I have problems recognising numerical patterns and time telling is really difficult but I have a digital clock, so you just get round things. (#16, dyslexia)

A particularly important theme arose from many of the students' experiences: this concerned the significance of relationships established in the degree of perceived support. This may be illustrated through the experiences of one student:

When I got there [to the HEI] I quite quickly felt that this is an environment where if I were having any problems I could go to tutors and I could go to student advisors and I could get help and that I wouldn't just be told to go away or be penalised...particularly last year when I was having problems with my ears and my attendance was low, the tutors were great, I got a lot of support through email...They were very co-operative...The tutors always know you by name, and know who you are and what your situation is. It makes such a difference to the learning experience 'cause if you feel like you can trust the teacher and that they know you and your situation then you feel a bit more confident working with them (unknown disability)

4.3.3 Were the same students who were happy with their social experience of the HEI, also happy with their learning experiences?

Almost all (96.4%) of the questionnaire sample (N=192) responded to questions relating to both their learning and their social experiences at the HEI. Of these students, just over half (55.1%) indicated that overall they were happy with both their social life at the HEI and their learning experiences, while only 7.5% said they were unhappy with both. There was a significant association⁴ between the students' happiness with their social life and with their learning experiences. In other words, students were more likely to be either happy or not happy with both their social and

⁴ Chi square $\chi^2(6) = 30.1, p < 0.001$

learning experiences, than they were to be happy with one and unhappy with the other. Some of the reasons students gave were disability related, some non-disability related, although those students who were unhappy with both social and learning experiences were more likely to give reasons which related to their impairment, for example:

Happy with both:

Happy with social experience of HEI	Happy with learning experience at the HEI	(Student respondent)
<i>I knew [the city] well before I came to uni, my fiancé lives in [a local town], I meet up with my old friends in London regularly and I've made many new friends at uni - I'm very happy at the moment.</i>	<i>I've enjoyed returning to study and am getting on well with the course.</i>	(#138, mobility difficulties)
<i>Because I am a mother most of my out of hours commitments are at home - socialising happens through being on the course - our year get on very well together.</i>	<i>I am given good support where possible. The [student support unit] have been very helpful.</i>	(#84, multiple disabilities)
<i>I have made really good friends.</i>	<i>I love my course!</i>	(#191, dyslexia)

Unhappy with both:

Unhappy with social experience of HEI	Unhappy with learning experience	(Student respondent)
<i>I am here to get a degree - as a mature student and nothing to do with my dyslexia. I have not mixed well with the younger students - this although at times somewhat isolating, has not been important.</i>	<i>I think that the teaching is appalling. Too many PhD students teaching who do not have the abilities to control/explain complicated subject adequately.</i>	(#16, dyslexia)
<i>Whilst there is understanding in certain [parts of the HEI] there doesn't seem to be communication of this to the tutors so that they can keep an eye on us.</i>	<i>There is so much to read. I am a slow reader. I fall behind and begin to feel stupid.</i>	(#24, multiple disabilities)
<i>I did not feel welcome enough to join in the social events with the other students, although a couple used to make an effort to talk to me during coffee breaks. But on one occasion two students came up to my</i>	<i>The only barriers to my learning experience have been those caused by those providing the course and their inability to make the necessary adjustments required when teaching a deaf student.</i>	(#54, deaf / hearing impairment)

signer and they asked us to stop signing because they did not like it.

In the next section, the experiences of three students, Claire, David and Jason are drawn on as illustration of some of the findings highlighted in the earlier sections of this report. Jason and David were two of the student researchers on the project.

4.4 Becoming a student in higher education: the experiences of three students (research strands 2 and 3)

The focus of this section is on the experiences of three undergraduate students: Claire in her first term in higher education, David a second year, and Jason a third year student who graduated during the course of the research. Through the experiences of these students, some of the issues relating to becoming a (disabled) student raised thus far in the report will be illustrated. It is important to note that as a first year, for Claire her experiences of becoming and being a student are of the moment – she is currently living through the first term in HE and doesn't have the benefit of hindsight, nor of knowing whether or not things will work out (most of this section of the report focuses on her experiences, as they happened). For David, he is looking back at his experiences of starting out in HE from the perspective of a second year student (i.e. he has successfully completed his first year), while Jason is viewing things from the relative 'comfort' of having successfully recently completed his degree.

4.4.1 Becoming a (disabled) student: Claire

Claire was assessed as having dyslexia when she was in primary school. She received additional learning support for four to five years in the upper primary and lower secondary years of schooling, after which it was generally felt that extra support was no longer needed. When Claire applied to university, she was clear about what she had looked for in higher education. Uppermost was the subject she wanted to study, followed by the location of the HEI and then thirdly the existence of the student support unit on campus.

It had a good course for [subject].... not too far away from where I lived and it had a good reputation for having a good student support unit, which was important to me because I'm dyslexic

She was swayed by the HEI she put as first choice following the open days attended, both because of its ethos and the subject:

It was friendlier than the other university I visited. I like the way everything was all on one campus and all the students that showed us around seemed very happy with being here

Following a gap year, including four months in North America, Claire returned to England with two weeks to spare, which she spent back at home with her parents. In these two weeks, what was on Claire's mind was not so much that she was starting

at university, but the fact that she was leaving home: as she said '*I was more going, oh my god, I've got to leave [home].*' The first step in becoming a student for Claire was loosening ties with home.

Starting out in higher education: early days

Claire initially experienced a mixture of excitement and anxiety, although she was generally looking forward to this next stage in her life.

I was excited to come, it was a bit like oh my god I'm actually going to go, even though I had about a year to prepare for that. It's a daunting idea as well. It's not the biggest university I applied to, which I liked. I didn't want to go to a massive university. So I was looking forward to living on campus and living in a house with some people, with different people.

In the first few days at the HEI, perhaps unsurprisingly, Claire's main concerns were making friends and getting on with housemates.

I was nervous when I arrived. It was OK. My housemates were all very friendly. We all went out together in the evening. Everyone worked really well in my house. I'm quite lucky in that all my housemates are very nice and there's 12 of us. [I was concerned about] not getting on but that's not been a problem at all, which was a slight concern, I thought oh god what if I don't get on with the people in my house and it was a big disaster. So that was OK. We all look out for each other now, so definitely a good thing...I wouldn't say I know anybody outside of my house that well which is a shame but I do definitely know these 11 people.

Next, concerns began to revolve around 'getting into' the life of the HEI and the degree programme itself.

[I was] quite apprehensive, quite excited as well, this is all new, this is quite scary. It's OK for people finding it new and scary as well. Yeah. A lot of the people find freshers' week the best week of university I didn't personally but that might be because I'm not usually into pub crawls and that sort of thing. I didn't find a huge amount of alternatives to it...I did evening activities, like there was a latte evening or something like that, that was very good...discovered what was around really. The campus tour and the library tour that kind of thing. The department meeting about your course and that kind of thing.

Claire generally enjoyed induction, both to the social life of the HEI and to the programme and department. She was able to deal with the newness of the situation and the apprehension of the transition into HE, and reassured herself that things would be OK, for instance as she said, '*it's OK for people finding it new and scary*'. In 'becoming a student', the main problem Claire seemed to encounter was the drinking culture. She often referred to this as being the part of being a student with which she felt least comfortable. She also said she had some (not unpleasant) surprises, in relation to the academic content of some courses she would be following.

Getting started: the first weeks

With induction over, during the first few weeks of term, Claire described how, in terms of work, she went about trying to find out what it meant to 'be a student': for example she said she was:

...running around trying to find out how things worked and understanding what was expected... how much they expected me to prepare for seminars and lectures and whether it was a better idea to go to a lecture and then do reading afterward or before...understanding how the library worked and trying to work out a way that you could get books out before other people did.

Claire was trying hard to work out what was expected of her, the student. She wanted to become a student in the HEI's terms, to know for example, whether 'students' should do the reading before or after a lecture, how they should prepare for seminars, and so on. At the same time she was trying hard to suss out the system – how could she get the books out of the library before other students got them? During this period, Claire was uncertain and very much 'becoming a student', partly because she wasn't exactly sure what this notion of a 'student in HE' actually was.

Claire explained that it was also during the first few weeks of term, as she was trying to come to grips with being a student, that she also found the work starting to take over.

I find...what I do takes me longer than anyone else. So I didn't really go out that much and I don't anyway. I joined a few classes at the sports centre that sort of thing to make sure that I did get out a bit....people would say things like do 8 hours of reading a week per unit and that's a rather strange way of telling someone how long they should work because everyone works at different speeds... I'd probably only read about half a chapter of a book.

She then described how the dyslexia, which had ceased to be an issue when at secondary school, started to concern her. She said it was very quickly:

...at the front of my mind, because I thought I've got to get this sorted out, as soon as possible because if I leave it too long I'm going to have to struggle for longer...[in school], it got to the point where they said you don't need us anymore. [At] that level I didn't, but then again I didn't have to do the same style of work and now it's a lot more obvious that I have problems and I can't do it on my own...As soon as you start getting work, I start feeling behind because I know it's going to take me that much longer and already I haven't finished whatever I was supposed to do before, and it's piling it on....Then around all this work you've got to fit in normal living like cleaning your house and doing your laundry and stuff like that.

So within a few weeks of starting out in higher education, Claire was beginning to struggle. Adapting to being a learner in HE was not as straightforward as she had expected. Work was taking longer to do and this was beginning to impact on both social and educational aspects of her life as a student. Taking on a student identity, with all its many facets, was beginning to be more challenging than Claire had anticipated. In particular, there seemed to be tensions developing between the

'learner in HE' identity (which she was attempting to take on) and aspects of the 'dyslexic identity' (which she had not anticipated would become so obvious).

Mid-way through the first term

By week 6 of the autumn term, Claire was finding that the different styles of teaching and learning she encountered in HE were proving to be challenging. As she explained:

I didn't think it would be this hard. I'm finding it a lot harder than I thought it would be in terms of transition of how you're suppose to learn and how you're supposed to get on with everyday life and keep yourself going with all your studies and that kind of thing. I find it quite strange how, not really cut off but you're not spoon fed in terms of your education here, but it's quite a sudden change which I wasn't really prepared for....I didn't expect finding my learning difficulties being as difficult a problem. It's never been this big a problem to me before. But then again I never had to learn like this before.

An example she gave was the 'two-page booklists' that she had received. She said she knew that this didn't mean that she had to read them all, but that without specific guidance on how to prioritise and organise her reading, she found the booklists overwhelming.

I put an awful a lot of effort into my work and don't get very far and I'm not getting practical help with it, that's partly because I needed to be reassessed for dyslexia, which I was, now it's partially because my LEA is being slow on my request for DSA, but everything is taking a lot longer than I expected it to... Everything I've said sounds very negative, I don't hate this place - at least not yet. But I just find it a little bit more difficult than I thought I would, which is a little concerning that's all. It's like, am I doing the right thing? should I be here? I don't know.

As term progressed, Claire still appeared to be endeavouring to claim a 'student in HE identity'. This involved getting to grips with both social and educational aspects of being a student and then coping with emerging difficulties associated with her impairment. Her identity seemed to be gradually changing, initially becoming a student in HE, then becoming a disabled student, and then beginning to question whether she should be becoming a student at all. The effects of this are perhaps most starkly highlighted in the excitement of one of her initial comments '*I'm actually going to go [to university]*' which later became '*I didn't expect finding my learning difficulties being as difficult a problem*', and then within a matter of weeks, '*should I be here? I don't know*'.

Barriers existed to Claire's transition to being a student in HE. She talked about how the styles of teaching and learning she encountered were significantly different to that which she had encountered in school. In addition, the time it took for the Disabled Student Allowance (DSA) to come through and the consequent delay in the organisation of her support impacted on her ability to engage with the learning process. This was essentially a barrier of a different kind.

Claire had quickly found herself to be at a relative disadvantage to other students, partly because she had not anticipated the difficulties she later encountered. She had thought that sorting out support needs on arrival (rather than before arrival) at the HEI would be unproblematic. Then, although getting increasing behind because she perceived that work was taking her longer than it did other students, at the same time, she was investing a lot of additional time in work, which had the effect of leaving less time to spare for social activities. She was increasingly spending the first few weeks of term playing catch-up while at the same time becoming more isolated from her peers.

Having looked at the experiences of Claire as she entered higher education, and who is perhaps still in the process of becoming a (disabled) student, we turn now to Jason and David who have both become (disabled) students and who were asked to reflect back on these initial stages.

4.4.2 Becoming (disabled) students: Jason and David

David is a second year student who started at the HEI, like Claire, a year after leaving school. In his case this was because of what he described as 'a flare up' of his impairment (Asperger syndrome). In addition, David has both hearing and visual impairments: he has a severe loss in one ear, is profoundly deaf in the other, and in one eye has peripheral vision only. Jason was a third year mature student with severe mobility difficulties which affect all movement: he is an electric wheelchair user. Both David and Jason chose an HEI near to where they lived for different reasons. In David's case, he did not want to leave his established (local) social network and he also wanted the support of his parents in relation to his impairment. For Jason, who was married with children, his prime consideration in choosing an HEI was not wanting to uproot, or move away from his family.

Both Jason and David viewed getting started in HE as having been quite a challenge. Their perspectives are important, because unlike Claire, who is reflecting on the immediate past, but essentially still part of a process of becoming a student, David and Jason are reflecting on their experiences of their transition into HE, two and three years on, respectively. As the following quotes illustrate, both perceived aspects of their identity, to be equally, or more important than their impairments. For Jason it was being a mature student, for David, his shyness.

David: *...my deafness isn't a big thing. As long as they don't mind me asking to repeat the occasional thing. It's not really a visual thing as compared to other people's disabilities. It's not really that much. In general I find it difficult to make friends which has always been my disability. I think that one's bigger. That was a bigger hindrance, my shyness, not really good at making friends. When I actually know people I'm not very shy at all. But when it comes to making new friends I'm shy, so that was probably a bigger hindrance to meeting new people and talking to people with my disability. Most of the time I just left the lecture and went off on my own.*

Jason: *I know on the first day, I found that being in a wheelchair was a real barrier and in myself I thought, it's going to put people off talking to me and stuff like that and the second thing was because I was a mature student, that's going to*

put people off talking to me as well. So I don't think you're alone in thinking what you were thinking.

David: *There's plenty of things for me that might make me feel a bit like there's a barrier. Like for instance, other Christians sound embarrassed about going round the secular world, and there's the deafness, so it could be difficult talking people through that.*

Jason: *I think there's a misconception when people start uni it may be in some cases that you know it's fed into you that the first day you start uni it's going to be one big party and you're going to get to know everybody and make loads of mates. And sometimes that's just not the case.*

David: *It's difficult to get started.*

For Jason, and largely for David, both perceived their impairment as very much part of their identity. When discussing whether or not they declared their impairments they commented:

I had to put that I was in a wheelchair because you can't hide it, they're going to see a wheelchair anyway. (Jason)

I was a bit in denial that I have Aspergers syndrome, this was before it flared up. So I was probably in denial, so I probably didn't [declare it]... I mentioned my hearing. There's only been a few occasions where I haven't... Some jobs I wouldn't have, but the universities, I think I was quite trusting. (David)

David was always very clear that, as he said, '*my deafness isn't a big thing*'. This is not to say that he did not find life difficult at times but throughout the interviews and through his work on the project, he conveyed a sense that deafness was very much part of his identity. In contrast with this, to some extent he was still coming to terms with, and accepting, the more recent Asperger diagnosis: this did not yet appear to be part of his identity. It is interesting to note that David rarely, if ever, mentioned his visual impairment. For both David and Jason, it was not the impairment itself that was '*a big thing*', but the barriers they faced.

It would be easy to assume that for students like Jason, factors relating to the built environment and independent aspects of learning (e.g. speed of note-taking) would provide the most significant barriers. In Jason's case these factors were significant, but once his Disabled Student Allowance (DSA) and support requirements were sorted out, Jason was faced with what he perceived to be a particularly significant barrier. He described organising note-takers, their payment etc. as being '*like running a business alongside being a student*'. In David's case, he felt the main barriers he faced stemmed from his shyness, not his impairments. He did not view shyness as resulting from either of his sensory impairments. He acknowledged that difficulties making friends was partly as a result of Asperger syndrome but none-the-less he felt his shyness compounded this. Assumptions about barriers which do not take into account the students' perspective are not always accurate.

The experiences of these three students illustrate some of the issues concerning expectations and reality which emerged from our research as being important in the processes of becoming and being a (disabled) student in HE, and which are

encapsulated in David's comment that '*it's difficult to get started*'. The next section brings together some of the main findings of the project.

5. Discussion and conclusions

5.1 Disabled students in higher education

Increasing numbers of disabled students are now entering higher education: HESA statistics (HESA, 2006) have shown a year-on-year percentage increase from 4.1% in 2000 to 5.8% in 2004 (UK domiciled students). In the HEI where the research was carried out, there was also an increase in the number and the proportions of disabled students over the same period of time. At the time of the research, approximately 7.5% of all students were known to be disabled, a proportion higher than national norms.

An underestimation? Despite this actual and percentage increase, the findings of this project indicate that we may be underestimating the numbers of disabled students in HE today. Whilst approximately 60% of the disabled student respondents had advised the HEI about their condition / impairment by the end of their first term, almost a fifth were in their second year or later before so doing. Returns to HESA would not include these later declaring students.

Social and educational profiles of known disabled students. There was some evidence to indicate that demographically, and particularly in relation to gender, disabled students entering this HEI were becoming more representative of the total entry cohorts. However, this was not reflected in relation to ethnicity, where few non-white disabled students were entering the HEI: this had remained fairly stable over time.

Reasons for advising the HEI of their condition / impairment. Across all disability categories, most students (61.7%) chose to advise the HEI in order to avoid a problem or ensure support. For a significant minority (20%), 'not coping' was their main reason for advising the HEI and this tended either to refer to their condition (generally worsening) or to the contextual changes they experienced in transition to HE. In all cases of 'not coping' there was no explicit reference to wanting support, but more wanting to let the HEI (or someone) know that they were not coping.

Non-declaring students. Students had different reasons for choosing not to advise the HEI about their impairment. For some 'non-declaring' students there were concerns about labelling, and for others issues of stigmatisation: they wanted to be seen as 'normal', rather than as 'a special case'. For other students, the question 'am I disabled?' lay behind reasons for late/non-declaring, especially where the condition was 'unseen' or a health issue.

5.2 The experience of higher education

The social and learning experience of HE. The majority of respondents reported that overall their learning and social experiences of HE were positive. However, a significant minority reported that they were not happy with their learning experiences (22.4%), others that they were not happy with their social experiences (12.5%), and a small proportion of these students (7.5%) were unhappy with both learning and social experiences.

Issues affecting degree of happiness with social and learning experiences. Students raised a number of issues around: (1) *teaching and learning*, especially teaching styles and how inclusive or exclusive teaching was; (2) *resources*, for instance availability of structures and systems of support, whether disabled students received what they perceived they needed and / or were entitled to; (3) *tutors and other students*, for example tutor responses to disabled student needs and their attitudes towards them; (4) *informal and formal structures of academic support*, issues that were often in common with other non-disabled students.

Issues specific to impairment. Whilst there were a number of issues raised by the disabled student respondents that could have been raised by any HE student (such as availability of lecturers or the number of contact hours they received), there were some issues perceived as important depending on the student's impairment: for example, *the built environment* was an important issue for some students who had mobility difficulties; *signage* for students with visual impairments; *the stress of starting in HE or around exam time* by students with mental health difficulties; and *teaching and learning styles* were often raised by those with specific learning difficulties.

Reasons why students were not happy with their experience of HE. Many of the negative experiences cited by students were not related specifically to impairment, but were more general student concerns, for instance, having sufficient time with their personal tutor, availability of books in the library, or feeling under pressure to become part of a student 'drinking culture' in order to feel 'included'. In relation to the student's impairment, negative experiences tended to result from the absence of, or delay in receiving support: for example, some students felt that tutors were not aware of, or not acting on reasonable adjustments, other students reported a delay in funding for identified resources. A particularly notable issue raised was the delay in receiving their Disabled Student Allowance. Once support was in place, this tended to have a substantial positive impact on their experience of HE. However, an important issue raised was that it was not always the support itself that was of prime importance, but the way in which that support was provided or organised as the following two quotes illustrate:

I get extra time to stand up and stretch and things like that, and there was one lecturer that said, 'cause we have to go to a different room, one lecturer said put your hand up if you're special needs. I thought, oh no, I don't want to put my hand up. I thought I don't know whether to or not 'cause you know he's going to look around. And then he said well you'll be this side of the room. I thought, you don't need to do that. (#138, mobility difficulties)

What I like is that everyone gets treated the same, each individual gets treated like everyone's the same. Like my tutors know about my health problems but they don't ever come up to me and do you know what I mean and sympathise with me or patronise me or anything like that. But then also I get extra help because I do need it but that's somewhere that I can go to and choose to go to if and when I need it. My disability advisor she's really amazing, she's really good. So I guess I can be like a normal student with this extra support. (N#1, multiple disabilities)

5.3 The transition to higher education

A recurring theme in the research was, in David's words, *'it's difficult to get started'*. For some respondents, the transition to HE and the processes involved in becoming a student proved to be difficult at times: loosening ties with home, moving into a new environment, and making new friends all posed challenges which were in part similar to those experienced by many non-disabled students. For some students, juggling family and university demands or needing to fit into a different, unfamiliar culture, were priorities. However, some disabled students appeared to face substantial additional challenges related to their impairment, such as we saw happening in Claire's case, as she made the transition to HE.

The processes involved in taking on a 'student in HE' identity are complex. All students new to higher education are likely to need to adapt to new ways of learning, and the transition generally involves some re-positioning of their learner identity. The period of 'becoming' a student, which we have taken in this report to refer to the period when the individual does not yet fully see themselves as a 'student', was a time of particular potential vulnerability. For example, during her first few weeks in HE, Claire's 'dyslexic identity' went through a process of reconstruction as she encountered unexpected barriers to learning (e.g. the two-page unprioritised booklists). The additional time she spent on her work had the effect of detracting from spending time establishing herself within the new social networks of the HEI, resulting in increased isolation. As she attempted to lay claim to a 'learner in HE' identity, this appeared to become incompatible with her reconstructed 'dyslexic identity'. From a social model perspective, the number of structural and social barriers she encountered resulted in her feeling that a student identity may not be for her: *'should I be here? I don't know'*.

Issues of expectations versus the realities of HE emerged as particularly important to many of the respondents during transition. The importance of previous learning contexts and their influence on expectations were especially pertinent. Often students had preconceived ideas of what life in HE would be like, and misconceptions existed. For example, Jason highlighted the expectation that life at university was *'going to be one big party'* and that *'you're going to get to know everybody and make loads of mates'*. This proved to be particularly problematic for a number of the disabled students who described increased isolation. For some students this was related to their impairment (as we saw with Claire). For other students, such as Jason, it was other aspects of their identity which were more likely to affect the development of social networks. For instance, as time went on, it was not Jason's impairment, but being an off-campus mature student and going home to his family at the end of each day that, from his perspective, led to him not making *'loads of mates'*.

5.4 Concepts of disability

One of the aims of the project was to examine how useful the category 'disabled student' is as a basis for targeting support.

The importance of the label. From the student perspective, the usefulness of the category seemed to lie partly in the power of the label. It had focused minds of policy makers and brought legislative changes which had opened doors to higher education and brought 'reasonable adjustments' which could be enabling. In addition, some students commented on tutors being aware of their needs: the category 'disabled student' was administratively useful for enabling tutors to recognise the students with impairments. However, the power of the label was not always positive: it could also at times be stigmatising.

Disability is a relative concept. From a social model perspective, while a student may have an impairment or condition, whether they are also disabled relates to the existence or absence of disabling barriers. The data highlighted how the contexts and processes of HE could be more or less disabling: barriers experienced by some students were not experienced by others as was illustrated through the two quotations in section 5.2 above. For Claire who came from what she perceived to be a non-disabling context, it was the context and processes of HE that proved to be disabling. There were counter examples within the research where some students were aware of their impairment, but did not feel disabled within the HEI (for instance this was evident in the experiences of some of the non-declaring students). From a social model perspective, in some sense the category 'disabled student' was doing its job. The relative nature of disability meant that although not all students with impairments or conditions were identified, those who perceived themselves to be disabled, or as potentially disabled or who became disabled by the contexts and processes of HE tended to be identified.

So am I disabled? The extent to which the students saw themselves as 'disabled' varied. In some cases although they did consider themselves to have an impairment or medical condition, they did not consider they were disabled, for example:

I find it an odd category because I don't consider myself disabled. I consider myself to have an illness, but it's not as debilitating as 'disabled' may sound. (#147, multiple disabilities)

Other students described themselves as just beginning to see themselves as 'disabled':

I guess from a personal point of view it's taken me a long time to accept that I'm disabled because it's not an outwardly thing, I'm not in a wheelchair or lost a limb...but reality is that yes, I am disabled so in a way it was part of my own pride to actually accept that...Having accepted that I was a disabled student, I think for me it took the pressure off. (#117, an unseen disability)

And some students believed that their condition did not fall into an officially recognised 'disabled' category:

People could be made aware of the fact that you don't have to be someone who is blind or in a wheelchair or the kinds of people who are recognised disabled by the government. ...On my application it said if you are a disabled student tick here and that kind of thing, I never considered myself as a disabled student

because my condition is not recognised as a disability by the government... So even though I'd been hospitalised with a mental illness it's still not something which is recognised as a disability (#89, mental health difficulties)

Thus the relativity of the concept also concerns the extent to which an individual perceives themselves to be disabled, and the extent to which they have laid claim to a disabled identity. This also appeared to relate to some extent to what the student understood to be an 'officially' recognised definition of 'disability'.

So what is a 'disabled student?' The findings from the project highlighted how the category 'disabled student' does not describe a homogenous group. It describes a group of people with multiple identities and with a range of interests, perspectives and priorities who bring with them into HE a multitude of experiences, expectations and learner needs. What they have in common is an impairment or condition which lies on a continuum of degree of severity and somewhere, a cut off point exists which separates disabled students from non-disabled students. Non-declaring students will also share this feature (i.e. a condition or impairment), but are categorised as non-disabled by HEIs. Some in this latter group will become disabled students later in their student career. Although the either/or categorisation is administratively useful (e.g. for determining DSA), in relation to the contexts and processes of HE, the notion of a continuum is more important, as well as an awareness of the multiple identities of the students where disability may not be the overriding concern, e.g.:

It was because of my disabilities that I didn't come to university until the age of 23...to an 18 year old that is a lot older. So it's very difficult to sit in with other people in the class which then makes me very self conscious which affects participation Probably everyone when they first go to university find it really difficult...everyone's very nervous of each other and I really felt that because I was older people didn't want to talk to me. But really by the time I got back after Christmas in the first year, that passed and it's never been a problem since. (#89, mental health difficulties)

5.4.1 The educational implications of being a 'disabled student'

There are different ways in which HEIs can respond to the educational implications of impairment.

(i) HEIs can focus on the individual student – the medical model approach where the frame of reference is the individual and reasonable adjustments aim to change or support the individual student in order to facilitate their participation in processes of HE. Examples would be the provision of the radio aid for David, or a laptop and voice activated software for Claire. This approach helped open up higher education to individually impaired students, but can be problematic as it does not also challenge the role of the HEI in potentially enabling or disabling students.

(ii) HEIs can focus on the individual within the context of the HEI – the frame of reference here is wider – not just on the individual student per se, but on the student within the context of the HEI. Thus the aim is to both support the student and / or

modify systems through the identification and elimination of barriers (a social model approach). For example, in David's case, in addition to provision of the radio aid, tutors and fellow students were made aware of effective methods of communication, and adjustments were made to teaching situations. Reasonable adjustments are therefore framed more widely to include adjustments to the context and processes of HE (we saw in Claire's case the problems that can be encountered when this does not happen).

This approach has done much to improve the experience of higher education for disabled students, and arguably, this is where many HEIs are likely to be at present as they develop, implement and monitor their Disability Equality Schemes (DES) as a result of the Disability Equality Duty (DED). The anticipatory duty of the DDA (part4) and the subsequent DED has helped shift the focus away from barriers experienced by individual students and towards responses at organisational and curriculum levels.

With the increasing numbers of disabled students in HE, and bearing in mind the continuum identified above, if the focus remains on the individual student (albeit within the context of the HEI), this can become problematic. HEIs are being required to respond to increasing numbers of individual student's reasonable adjustments and at times, even the most conscientious lecturers can begin to feel overloaded - it may well have been this that made the lecturer in the quote in section 5.2 above, respond as they did. In addition, there is a danger that the disabled student is increasingly being (and will remain) cast as the 'other' within a context and culture which is geared to non-impaired individuals. The third approach looks more inclusively at the HE context and takes into account the multiple identities of the disabled students who have been the focus of this project

(iii) Structural, social and curriculum limitations – the frame of reference is widened again here with a focus on provision and practices *for all students*. The basic assumption is that barriers encountered by individuals can be taken to indicate how the curriculum and organisation can be improved for all students. In David's case for instance, employing techniques of good communication, has the potential to improve teaching approaches and make things clearer for all students, and in Claire's case, guided reading lists would have been helpful to other students, not just removed a barrier for Claire.

In some sense, disabled students act like 'canaries in the mine', an analogy used by O'Rourke (1999) who, in relation to mature women learners, argues that rather than viewing difficulties experienced by students as '...arising from their 'unique problems', it can be useful to examine how their response may be an indicator of the potential impact of the situation on many more people.' (page 100). Healey, Bradley, Fuller and Hall (2006) have argued similarly in relation to continuums of learner differences, pointing out that '...in the long-run, the main beneficiaries of disability legislation and the need to make suitable adjustments in advance are the *non-disabled* students...' (p41). There was evidence of this within the project.

Overall, the social and learning experiences of the disabled students in this project were positive, but positive or not, we have much to learn from their experiences.

6. Recommendations

6.1 Student identified recommendations

Student co-researchers identified 5 key issues and associated recommendations for policy makers and HEIs. These were compiled as part of the students' involvement in the project and arose both from their engagement in the research process, as well as from their experience of what they had found to have been more or less helpful in ensuring positive learning and social experiences.

(i) Communication

- Ensure good communication of students' support needs to tutors and also between departments / units of the HEI. Make clear to the students what lecturers have been told and ensure information is kept up-to-date and accurate. It is extremely helpful when this happens, it smoothes communication between lecturers and students and prevents students having to keep repeating needs to different groups of people.
- Lecturers should ensure they read the information that they are sent so they are aware of which students are disabled.
- Students find it very helpful when tutors are good at keeping in touch with them.
- Listen to students' views.

(ii) Accessibility

- Access to buildings and around the HEI needs to take views of disabled people into account. HEIs should have a point of contact so students can discuss access issues. Good access includes signs.
- For students with mobility difficulties, ensure distance between lecture / seminar rooms is taken into account when timetabling. HEIs shouldn't forget cafes and other social spaces – disabled students want to go for coffee with their peers between seminars.
- Ensure a good range of courses and programmes which are accessible in terms of time – especially part-time.
- Support workers need to be understanding and helpful.
- Be flexible, especially when encountering specific needs which the HEI hasn't come across previously. Some tutors were very adaptable e.g. happy to meet in location convenient for the student rather than their office.

(iii) Knowing who to contact / where to go / what support is available

- It is very helpful when someone from student support is located within departments – having someone to whom you can go to sort out issues is extremely helpful. In particular, one person who understands the [teaching and learning] situation.
- A quick response in addressing queries about support on application and before coming to the HEI is much appreciated.
- Make sure students coming to the HEI know what support is available and who to contact.
- Allocate one named person for the student to turn to if a problem arises. HEIs can be big and complex places and disabled students have additional points

of contact / units to access because of their support needs which can add substantially to this complexity.

(iv) Understanding / knowledge / awareness

- Ensure provision of a 'normal' life for students through targeted support which is sensitively given. Students don't like being singled out or made to feel embarrassed.
- Make people more aware of 'disability'; the message to convey is 'people can't help being disabled'.
- Ensure tutor awareness so they know about and understand what to do to support students (i.e. not just know who they are).
- Beware of unintentionally segregating disabled students or making them feel silly. Sometimes it's the little things that are most important.
- It is important that note-takers and support workers, as well as lecturers are aware of the barriers that can exist for disabled students.

(v) Moving in the right direction

Students felt that things are generally moving in the 'right direction'. For example, there are signs of a greater understanding of student needs and a more positive attitude from lecturers. This project and students' experiences being taken seriously were further examples. Some of this it was felt may have been as a result of the DDA.

- It is important that the government takes a lead as it did through the disability legislation.
- HEIs and government should monitor progress.

6.2 Other recommendations arising from the project

Government and HEIs

- Monitor demographic features of disabled student entrants to HE and actively target under-represented groups
- Examine gender differentials amongst HE students with dyslexia
- Promote more flexible provision (especially part-time pathways)
- Ensure information for students prior to entry to HE clarifies the term 'disabled student' and the impairments / conditions it encompasses.
- Be aware of the potentially vulnerable early stages of HE for disabled students and the importance of support needs being in place as early as possible and ideally for the start of the programme. Review timings around DSA and ensure applicants are aware of the importance of ensuring assessments are completed, where possible, early enough to secure provision.
- Review transition arrangements to HE for disabled students to ensure expectations about learning in HE are identified and made more transparent.

HEIs – general

- Given the importance of the social experience of HE, ensure a focus on this as well as on the learning experience. Similarly, that equal weight is given to social spaces as to learning spaces.

- Involve students: the difficulties experienced by some individuals can be taken to indicate how the curriculum and organisation can be improved for all students.
- Facilitate times / locations where disabled students who wish to, can meet each other.

HEIs – admissions: “it’s difficult to get started”

- Ensure information to prospective students clearly identifies expectations, especially in relation to procedures and provision. What students found particularly helpful was a meeting with support staff prior to entry / registration. This helped clarify both the student’s expectations of the HEI and the HEI’s expectations of the student.
- Identify a single point of contact for queries concerning impairment / disability
- The welcome and ethos promoted by the HEI and the positive visibility of disabled students within this is extremely important.

HEIs – curriculum

- Develop curricula which make visible disabled people as positive role models.
- Promote an awareness of the importance of inclusive curricula for supporting all students, and conversely, the role of the curriculum in the (unintended) creation of barriers and difficulties in learning
- A particular focus is needed on the first year curriculum and ‘learning how to learn’ in HE. This would be of help to many students entering higher education.

Further research

Greater understandings are needed of:

- the contexts from which students are coming to HE
- the perspectives of late and non-declaring students
- support needs, especially during the early stages of HE
- the nature of inclusive curricula

References

- Adams, M. (2003) Disability Discrimination Act Part IV: One Year On, *Inclusion: a focus on disability and widening participation in higher education*. (Action on Access and the National Disability Team) Issue No. 1, Autumn 2003, pp26-7.
- Anderson, P. and Williams, J. (2001) Identity and Difference: concepts and themes, in P. Anderson and J. Williams (Eds.) *Identity and Difference in Higher Education*. Aldershot: Ashgate Publishers.
- Archer, L. (2003) Social class and higher education, in, L. Archer, M. Hutchings and A. Ross (eds) *Higher Education and Social Class. Issues of exclusion and inclusion*. London: RoutledgeFalmer.
- Barnes, C., Mercer, G. and Shakespeare, T. (1999) *Exploring Disability. A sociological introduction*. Oxford: Polity Press.
- Beresford, P. (2002) 'Thinking about 'mental health': towards a social model', Editorial, *Journal of Mental Health*, 11 (6) pp581-4.
- Bolt, D. (2004) 'Disability and the rhetoric of inclusive higher education', *Journal of Further and Higher Education*, 28 (4), pp 353-8.
- Cohen, L., Manion, L. and Morrison, K. (2000) *Research Methods in Education* 5th edition. London, Routledge/Falmer.
- Farrar, V. (2006) Equal to the task: disability issues in postgraduate research study, in, M. Adams and S Brown (eds) *Towards Inclusive Learning in Higher Education: Developing curricula for disabled students*. London: Routledge.
- Ferrier, F. and Heagney, M. (2001) Disadvantage is complex: targeting special groups is not enough!, in, Thomas, L., Cooper, M. and Quinn, J. (Eds) *Access to Higher Education: the unfinished business*. Stoke-on-Trent, The Institute for Access Studies, Staffordshire University & European Access Network.
- Fielding, M. (2001a) Students as Radical Agents of Change. *Journal of Educational Change* Vol. 2, pp123-141.
- Fielding, M. (2001b) Beyond the rhetoric of student voice: new departures or new constraints in the transformation of 21st century schooling?, *Forum*. 43 (2) pp100-10.
- Fuller, M., Healey, M., Bradley, A. and Hall, T. (2004) Barriers to Learning: a systematic study of the experience of disabled students in one university. *Studies in Higher Education*, 29 (3) pp303-18.
- Healey, M., Bradley, A., Fuller, M. and Hall, T. (2006) 'Listening to students: the experiences of disabled students of learning at university.', in M. Adams and S. Brown (eds) *Towards Inclusive Learning in Higher Education. Developing curricula for disabled students*. London: Routledge.
- Higher Education Statistics Agency (HESA) (2006) *Student Data Tables 2000/01 – 20004/05*. <http://www.hesa.ac.uk/holisdocs/pubinfo/stud.htm>
- Holloway, S (2001) The experience of higher education from the perspective of disabled students. *Disability and Society* 16(4) pp597-615.
- Layer, G., Srivastava, A. and Stuart, M. (2002) *Achieving Student Success: an analysis of HEI widening participation strategies and the proposed impact on student success*. University of Bradford, Action on Access.
- Morley, L. (2003) *Quality and Power in Higher Education*. Buckingham: Open University Press
- Oliver, M. (1990) *The Politics of Disablement*. Basingstoke: Macmillan
- Oliver, M. (1996) *Understanding Disability: From Theory to Practice*. London: Macmillan.

- O'Rourke, J. (1999) 'Canaries in the Mine? Women's experience and new learning technologies', in A. Tait and R. Mills (eds) *The Convergence of Distance and Conventional Education: Patterns of flexibility for the individual learner*. London: Routledge.
- Pumfrey P. (2004) *Moving towards a dyslexia friendly higher education system in the UK? Challenges and responses in higher education policy, provision and practice*. Paper presented at the sixth BDA International Conference, 28th November 2004
- Riddell, S. (2004) *Disabled Students and Multiple Policy Innovations in Higher Education. Full Report of Research Activities and Results* (ESRC funded: R000239069).
- Riddell, S., Tinklin, T. and Wilson, A. (2005) 'New Labour, social justice and disabled students in higher education', *British Educational Research Journal*, 31 (5), 623-43.
- Riddell, S., Tinklin, T. and Wilson, A. (2003) *Disabled students in higher education: a reflection on research strategies and findings*. . Paper presented at the BERA: Conference, Sept 2003, Heriot-Watt University.
- Shevlin, M., Kenny, M. and McNeela, E. (2004) 'Participation in higher education for students with disabilities: an Irish perspective', *Disability and Society*, 19 (1), 15-30.
- Tinklin, T., Riddell, S. and 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 (5), 637-57.
- Thomas L and Cooper, M. (2000) (eds) *Changing the Culture of the Campus: Towards an Inclusive Higher Education*. Stoke-on-Trent, Staffordshire University Press.
- Thomas, C. (2001) Disabled women enter the academy, in P. Anderson and J. Williams (eds) *Identity and Difference in Higher Education*. Aldershot: Ashgate Publishers.
- Weedon, E and Fuller, M. (2004) *What is it like for you? Surveying the learning experiences of disabled students in four HE institutions*. Paper presented at the 5th Teaching and Learning Research Programme Annual Conference, 22-24 Nov 2004, Cardiff.