

# **Disclosing Disability: Disabled students and practitioners in social work, nursing and teaching**

A Research Study to Inform the Disability Rights Commission's Formal Investigation into Fitness Standards

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SOCIAL  
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# **Disclosing Disability: Disabled students and practitioners in social work, nursing and teaching**

## **EXECUTIVE SUMMARY**

### **About the research**

This qualitative research study was commissioned by the Disability Rights Commission as part of its Formal Investigation into Fitness Standards in Social Work, Nursing and Teaching. It explored the process and consequences of disclosing disability from the perspectives of disabled professionals and asked how they felt disclosure could be promoted. The research focused on professionals with unseen disabilities in statutory agencies; however, those with visible disabilities were also included. Sixty professionals (both students and qualified practitioners) across the three professions and from England, Scotland and Wales, volunteered to participate in interviews with the research team. The study reported in February 2007.

### **Key Findings**

- The majority of professionals interviewed had disclosed information about their disabilities to their Higher Education Institution (HEI) or employer, although a fifth had only partially disclosed.
- Participants described 'losing control' over information disclosed to regulatory bodies as they received little in the way of individualised responses or information concerning the process and consequences of disclosure.
- Three story types emerged: positive, mixed and negative. Those with multiple disabilities or long-term health conditions were most likely to tell a negative story and those with physical disabilities to tell a positive story. Practising nurses and student social workers were the professional groups more likely to convey a negative story.

- Participants considered that disability legislation had given them confidence in disclosing disability and had empowered them in negotiations with employers/training organisations concerning adjustments.
- Disclosure was unlikely to be experienced as a single event, but rather as a series of steps or negotiations. This was particularly the case for students who had to disclose repeatedly to different placement settings.
- Reasons for disclosure varied: for some, there was no element of choice; others considered it a matter of principle or viewed disclosure as a means of obtaining adjustments.
- Stigma, particularly that associated with mental health problems, was cited as a reason for non-disclosure.
- Confidence concerning disclosure increased with experience and seniority in a profession or setting when an individual's track record in the job had been established.
- Managers' attitudes were identified as crucial in determining the organisation's response to a disclosure of disability. Colleagues' responses were also important and could take the form of charges of favouritism or over-protective attitudes.
- Adjustments and accommodations for professionals with unseen disabilities often required flexibilities of working practices, human support or attitudinal changes; managers' and colleagues' attitudes were key to the delivery of these forms of accommodation.
- Students reported that their experiences of attitudes and adjustments in placement settings often compared unfavourably with the responses they had received to disability disclosure from universities or colleges.
- Participants felt disclosure could be made easier by environments becoming more 'disabled friendly'. Ways of achieving this included having a key contact person to advise and support disabled people contemplating disclosure; providing disability awareness training especially for managers and those supervising placements and through publicising positive experiences.

## Conclusions

### **Awareness and attitudes to fitness standards and disability**

The research participants had a limited awareness of fitness standards for their profession. The way in which professionals were asked about disability was found to be important: disability terminology was described as off-putting and inappropriate and was seen to be associated with physical disability. Whilst attitudes were changing, disclosure was still experienced as a high-risk strategy with the potential to exclude an individual from training or employment and affect career progression.

### **Information about disclosure and its consequences**

Having information about where their disclosure went, who had access to it and what the consequences of disclosure were likely to be appeared to be ways in which professionals could predict and manage the personal risks of disclosure. An individualised response to a disclosure was also regarded as valuable. Evidence that disclosure can confer benefits acts as a driver for disclosure and participants identified the importance for them of seeing other disabled people supported in the workplace or university or college.

### **Disability friendly environments**

Research participants emphasised the need to make shifts in attitudes and behaviour within employment and training settings, as well as creating more disabled friendly environments. Such a culture shift could be signalled by providing a key person to offer support and advice on disclosure within organisations, through investing in training for managers so that they better understand their role in implementing the DDA, and by increased visibility of disabled professionals in workplaces and HEIs.

#### **Further information:**

This study was undertaken by Nicky Stanley, Julie Ridley and Alan Hurst at the University of Central Lancashire and Jill Manthorpe and Jessica Harris at the Social Care Workforce Research Unit, King's College London.

The full research report is available in pdf format on the DRC website: [www.drc-gb.org](http://www.drc-gb.org). For further details about the research, contact Nicky Stanley at [NStanley@uclan.ac.uk](mailto:NStanley@uclan.ac.uk)

# **Chapter 1 – Introduction**

## **1.1 Introduction to the study**

This research was commissioned by the Disability Rights Commission (DRC) to inform its Formal Investigation into Fitness Standards in the Professions of Social Work, Nursing and Teaching. The study was undertaken by researchers from the Social Work Department at the University of Central Lancashire and the Social Care Workforce Unit at King's College London between September 2006 and February 2007. It was designed to meet the information needs and the timescale of the Formal Investigation.

The study focused on the process and consequences of disclosing disability in these professions and aimed to explore whether disabled professionals were aware of their rights under disability legislation, their views of the attitudes and practices of the regulatory bodies, whether adverse or positive consequences of disclosure had been experienced or were anticipated, and how disclosure could be promoted. A qualitative methodology that could capture the experiences and perceptions of disabled professionals in some depth was selected for the study. Both practising professionals working in statutory services and students currently undergoing professional training were included. The research explicitly addressed the views of people with unseen disabilities as this was considered to be the group that exerted some control and choice as to when, where, how and whether to disclose disability.

## **1.2 The research context**

The Disability Discrimination Act 1995 requires employers to provide adjustments and support for disabled people and makes discrimination by employers on the grounds of disability illegal. The Act was extended to education providers by the Special Educational Needs and Disability Act (SENDA) in 2001 and also applies to the regulatory bodies for the professions. These regulatory bodies act as gatekeepers for the professions and this aspect of their role has become increasingly prominent following high profile scandals involving professionals such as Beverley Allitt (Clothier 1994) or Harold Shipman (Smith 2005). However, it should be noted that such scandals have tended to involve professionals with unacknowledged mental health problems who did not identify themselves as having such difficulties and for whom disclosure

was not therefore an issue. All qualified social workers, nurses and teachers in England, Scotland and Wales are required to register with their professional regulatory bodies.

In the context of the DRC's Formal Investigation, the term 'fitness standards' is used to mean:

Formal regulation and the policies, practice and procedures operated by higher education institutions, employers, qualifications bodies and other organisation that affect an individual's ability to qualify, register and work in a number of public sector professional occupations. (Sin et al 2006)

Fitness standards are therefore articulated and applied at a number of different levels by different organisations (Audit Commission 2005, 2006, Scottish Executive Health Department and Social Work Services Inspectorate 2004, Institute for Public Policy Research 2005). As Sin et al (2006) comment, the wording of fitness standards varies between professions: health professions tend to emphasise 'good health', while social work calls for 'physical and mental fitness'. However, generally the wording of fitness requirements is vague and non-specific and is therefore open to interpretation and challenges in relation to particular cases. The demands for good physical health and fitness are considered to be particularly high in nursing where the physical demands of the job, together with health and safety concerns, are often emphasised by employers. The point in an individual's career at which fitness for practice is examined also varies, with some groups such as social workers and nurses being required to declare their fitness when registering with their regulatory body, while teachers' fitness is declared at entry to higher education and employment. There are also differences in practice between the three countries: Scotland, for instance, has abandoned fitness criteria for the teaching profession (Scottish Executive 2004).

However, at the level of decision-making on individual cases, employers and staff in higher education (HE) have often struggled to reconcile professional demands and fitness for practice concerns with disability legislation (Manthorpe and Stanley, 1999; Crawshaw, 2002). Such dilemmas are also found in countries outside the UK (eg Cooley and Salvaggio 2002). Some of those participating in Manthorpe and Stanley's (1999) survey of HE staff teaching on professional education programmes would have appreciated more guidance from the regulatory bodies with regard to defining fitness to practice.

Fitness standards can only be applied when knowledge about an individual's disability, health, fitness or character is available. While some of this information is available from other sources such as references or physical health checks, for those with unseen disabilities, the application of fitness standards may rest on their own disclosure of disability. Disclosure is therefore often a key element in the process of measuring individuals against professional fitness standards. Disclosure is also essential if adjustments and support are to be tailored to meet individual need. However, there is a considerable body of evidence demonstrating that in practice, fitness standards, how they are perceived and the fear of exclusion from a profession act as a barrier to disclosure for those in the caring professions (Rooke-Matthews and Lindow 1998, Bodman et al 2003).

Other identified barriers to disclosure include the stigma attached to disabilities and long-term health conditions (Dalgin and Gilbride 2003, Fesko 2001), with mental health problems being perceived as particularly stigmatised (Social Exclusion Unit 2004). Fears of being seen as 'not coping' (Stanley et al 2007) and of being judged as 'intellectually inferior' (Blankfield 2001, Chalkley and Waterfield 2001, Campbell and Crowe 1998) have also been identified as disincentives to disclosure. Such concerns have been voiced by students seeking entry to professional training programmes, despite the efforts of higher education institutions (HEIs) to implement advice on good practice in encouraging disclosure (LSC 2003, Rose 2006). Other explanations for non-disclosure include a reluctance to assume disability identity and the labels that can accompany it (Rocco 2001, Maudsley and Rose 2003). However, Wray et al's (2005) study of social work students on placement found that some disabled students viewed their disability positively in the context of disability rights legislation and saw it as 'opening doors for them', tempering the view that there are common barriers to disclosure (Baron et al 1996).

Within the caring professions and their associated training programmes, individuals' decisions to disclose their disability are complex and a weighing and 'trading off' of the risks involved in disclosure appear to be undertaken by many (Mental Health Foundation 2002, Goode 2007). For students, these decisions are further complicated by having to undertake multiple placements, some of which will be of limited duration, in a range of settings (Phillips 1998, Cowork 2001, Cartney 2000, Sapey et al 2004, Furness and Gilligan 2004, Morris and Turnbull 2007).

Other studies have looked at the consequences of disclosure for professionals in practice. Stanley et al's (2002) survey of 500 depressed social workers found that their nearly half the respondents reported receiving no support from workplace and identified supportive attitudes and flexibility in working patterns as being the types of assistance they would have liked most. Wright's (2000) study of nursing students with dyslexia also found that they were receiving insufficient support. However, positive examples of professionals in teaching, nursing and social work receiving appropriate adjustments and accommodations are also available (Skill 2003, Skill 2005). In particular, students on professional training programmes may have benefited from the advice and support offered by HEI disability services and Wray et al's (2005) study found that nearly half of the students participating in the study reported positive experiences of having their support needs met on placement.

### **1.3 What this report covers**

Chapters 2 and 3 of this report describe the study methodology and key characteristics of the sample of disabled professionals. Chapter 4 explores the professionals' awareness of fitness standards and disability legislation and reports their views concerning disability labels and the various terms used to describe disability. The report then moves to consider research participants' views and experiences of the process of disclosure in Chapter 5. Chapter 6 explores the consequences of disclosure from the professionals' perspectives. In Chapter 7, we report the research participants' ideas and suggestions of ways in which disclosure might be promoted in the professions. The final chapter presents the research conclusions.

Throughout this report, we distinguish between students' and practitioners' views. However, the terms 'professionals' and 'research participants' are used to describe respondent groups that include both students and practitioners. The term 'disabled' is used in preference to other disability terms in line with DRC practice.

## Chapter 2 - Methodology

### 2.1 A qualitative study

This study aimed to capture the views and experiences of disabled students and practitioners in the professions of nursing, teaching and social work. The research was designed to explore whether disabled professionals were aware of their rights under disability legislation; their views of the attitudes and practices of the regulatory bodies in relation to fitness standards; their experiences of disclosing a disability and the consequences of such disclosures. The identified focus was on professionals with unseen disabilities as this group is most likely to wield some control and choice as to when, where, how and whether to disclose disability. However, professionals with visible disabilities were also included in the study.

A qualitative methodology designed to capture the complexity of perceptions and decisions in relation to disclosing disability was developed for the study. The methodology was able to draw on other research which has addressed the experiences of disabled students (Gaulton and Cullen 2002, Harris 2002; Wilson et al 2002, Healey 2003, Wray et al 2005) and those of professionals in practice (Stanley et al 2007, Caan et al 2006). The study was designed to ensure that participants' anonymity would be protected and that data protection requirements were met. A broadly targeted approach to recruitment which allowed disabled practitioners and students to opt into the research was therefore adopted. All participants were given information about the study to ensure their informed consent and were paid a small sum to cover their expenses. Ethical approval was granted by the University of Central Lancashire's Research Ethics Committee.

### 2.2 Constructing the sample

A volunteer sample of professionals was recruited through two separate approaches: one aimed at student populations, the other at practitioners:

1. **Students** were contacted through letters sent to Heads of Department (HODs) in HEIs and colleges in England, Scotland and Wales running professional training programmes. HODs were invited to circulate information about the study including details of how to contact the research team to all their students. This information was circulated to students through internal email

systems. In total, students from 12 professional training programmes (four for each professional group) participated in the study.

2. **Practitioners working in statutory services** were recruited through a range of short articles describing the study and asking for volunteers. These were published in the national, regional and trade press, on relevant websites and circulated by professional association and trade unions in England, Scotland and Wales.

124 practitioners and students responded to the call for participants and completed a short screening interview over the telephone or by email to confirm their suitability for inclusion in the study. Of the 118 who met the study criteria, interviews were completed with 60 with the aim of achieving a sample which included equal numbers from the three professions, balanced representation of students and practitioners and sufficient representation of the professions in England Scotland and Wales. Table 1 shows the breakdown of the sample by profession and by practitioner/student status. The sample includes rather more practitioners than students but, as many practitioners also discussed disclosure in relation to their previous experiences as students, student experiences were considered to be sufficiently represented.

**Table 1 – Study Sample by profession and by Student/Practitioner Status**

Type of Interviewee	Profession			
	Social Worker	Nurse	Teacher	Total
Practitioner	10	17	11	38
Student	10	4	8	22
TOTAL	20	21	19	60

In determining the numbers of participants from England, Scotland and Wales, attention was given to the spread of practitioners between the three countries in current figures for the three professions (General Social Care Council 2005; Scottish Social Services Council 2006; Care Council for Wales 2005; The Nursing and Midwifery Council 2005, Hutchings et al 2006; General Teaching Council of Scotland 2006; General Teaching Council for Wales 2005). These figures were used to calculate what numbers of practitioners within the sample would accurately reflect the distribution of practitioners across the three nations. These figures are shown in the columns headed 'professional population ratio' in Table 2. Since using this distribution as a guide in constructing the study sample

would have resulted in very low representation of practitioners from Scotland and Wales in the sample as a whole, it was decided to over-sample practitioners and students from Scotland and Wales and the resulting distribution of participants between the three nations in the sample is shown in the columns headed 'sample' in Table 2.

**Table 2 – Distribution of sample by nation and profession**

Country	Social Worker		Nurses		Teachers	
	Pro pop ratio	Sample	Prof pop ratio	Sample	Prof pop ratio	Sample
England	18	14	17	15	15	12
Scotland	1	4	2	4	3	5
Wales	1	2	1	2	2	2
TOTAL	20	20	20	21	20	19

### 2.3 Data collection and analysis

Data were collected through semi-structured individual interviews. The majority of these were held face-to-face, but in 13 cases, interviews were conducted over the telephone. In a small number of cases (6), individuals chose to complete written accounts rather than participate in an interview. Most interviews took place in participants' homes or workplaces or in HEIs. Some interviews were lengthy and, in a few cases, participants who related distressing experiences required additional time to talk and to recover after the interview.

The interview schedule was piloted and amended in the light of feedback received. All interviews were recorded with the participants' permission and transcribed. The data were sorted with the help of NVivo, an automated data processing package and were analysed in relation to both key themes identified from the literature and themes emerging from the data collected. Throughout this report, differences between professional groups and between disability groups are highlighted. Analysis of other variables, such as country or participants' ages, did not produce significant differences between groups and these are not therefore considered.

### 2.4 Summary points from Chapter 2

- 60 professionals, of whom just over a third were students, participated in the study.

- All participants were volunteers recruited via a range of media or through HEI training programmes. Recruitment was targeted on those with unseen disabilities and those employed in the statutory sector.
- In order that their experiences could be included in the study, professionals from Scotland and Wales were over-sampled in relation to the current distribution of qualified practitioners in the three nations.
- Most research participants completed a face-to-face interview with one of the researchers.

## Chapter 3 – The Participants

### 3.1 Participants' characteristics

As shown in Table 1, the sample included 38 practitioners and 22 students. Thirteen of the 60 (22%) were men. This is a similar proportion to that found across the three professions. Five professionals identified themselves as belonging to Black and minority ethnic groups. Participants' ages ranged from 17 to 60. The age distribution of the sample is shown in Table 3 and it is evident that professionals of 45 and above were well represented in the sample, perhaps as a consequence of recruiting participants with long term illnesses.

**Table 3 - Age distribution of participants**

Age	Number	%
17 – 30 years	12	20
31 – 44 years	22	37
45 years plus	26	43
TOTAL	60	100

The length of time practitioners had been in practice ranged from one to 36 years. As Table 4 shows, this was generally a very experienced group of practitioners with over half having spent more than 20 years in practice.

**Table 4 - Practitioners' length of time in practice**

Year of Experience	Number	%
1 - 10	10	26
11 – 20	8	21
21 years plus	20	53
Total	38	100

The students participating in the study included undergraduates and postgraduates. Of the 22, nine were in their first year of professional education, while the remainder were spread across different stages of their training programmes.

The participants described a range of disabilities which are shown in Table 5. Since recruitment had aimed to capture those with unseen

disabilities, these are heavily represented in the sample. A substantial proportion had multiple disabilities and the majority of these involved a mental health problem in combination with one or more other forms of disability.

**Table 5 – Participants’ disabilities and impairments by profession**

Category	Nurses	Social Workers	Teachers	Total number	%
Long term health problems	6	3	8	17	28
Multiple impairments	4	2	4	10	17
Physical mobility impairment	5	4	1	10	17
Mental health problems	3	4	2	9	15
Sensory impairment	2	4	2	8	13
Dyslexia	1	3	2	6	10
<b>ALL</b>	<b>21</b>	<b>20</b>	<b>19</b>	<b>60</b>	<b>100</b>

Half the sample (30) had been disabled at point of entry to the profession and 17 of these 30 were students. Twenty-eight participants had become disabled later on, the majority of these were practitioners (only five students had become disabled later whilst on their course). Two participants were recently disabled.

The majority of participants (46) had disclosed their disability, three had not disclosed and 11 had only partially disclosed. Of the three who had not disclosed, two had been disabled on entry to the profession; two had sensory impairments and one was dyslexic. All disability types except dyslexia were represented among those who had partially disclosed.

### **3.2 Positive and negative stories**

Participants’ accounts of their experiences in disclosing their disabilities and the responses they had encountered were classified by the researchers into three story types positive, negative and mixed. Anonymised examples of these three story types drawn from the study data are provided in Boxes 1, 2 and 3 below. The three resulting groups of accounts were roughly equal in size. It is interesting to note that so many positive accounts were identified as the researchers had

anticipated that those volunteering to participate in the study might be motivated to share accounts of poor treatment at the hands of regulatory bodies, employers or training providers.

### **Box 1 - Positive story**

The professional providing this account is a third year social work student, aged 23, with mental health problems, which he disclosed on the HEI application form. He feels that it would be 'irresponsible not to disclose', and that although people do stereotype disabled people, he considers himself 'strong enough and happy enough' to openly confront and overcome those negative attitudes. He found the HEI very supportive throughout the process of accepting him onto the course. The HEI advised him to have a disabled student assessment in order to establish what assistance could be provided, and as a result he has a lap-top and dictaphone provided by his local education authority, and study support through the University. He has found all parties helpful, and described the HEI Welfare Officer as 'fantastic every step of the way'. The lecturers have 'come up with everything they can possibly think of' to assist him, whilst his personal tutor checks to see that everything is okay. In the beginning, he thought that they were keeping a closer eye on him than on other students, but feels that this was just being responsible, so he found it quite positive.

He disclosed on registration with his regulatory body, and he considers that if he wants to be a social worker then he can't ignore the possibility that he might be unfit to work with people who are perhaps more vulnerable than himself. He had to go through a 'heap of questionnaires and evidence gathering' which took two months, but was approved. Although he found it unnerving, he found the response appropriate and that they were helpful throughout.

For each of the placements during the course, he has completed a profile which is sent to the prospective agency. His HEI placement coordinator has had to convince each agency to give him a placement, as they saw him as a risk, even after two and a half years with no problems. At the interviews for each placement, they asked how he would deal with situations and whether he was robust enough to cope, which he thought were fair questions. He does feel that the placements 'put a label on me', and saw the diagnosis before the student social worker. He described them as erecting a barrier which you have to climb up to, but once you get there you are okay, and after starting each placement he has felt he has been treated normally.

He is in favour of clarity and sharing information and believes that there are things which could be done to make more people disclose, and to allay people's concerns. He is only vaguely aware of the DDA, but knows how to access it and feels that knowing that he has rights that he can call on is very useful.

### **Box 2 - Mixed story**

This is the account of a teacher, aged 56, who has been in practice continuously since qualifying in 1987. She has depression, dyslexia and diabetes and describes herself as used to developing strategies to cope. Her depression was first disclosed by her doctor when she was unwell and off work in the early 1990s. The school doubted that she was able to cope with return to work, and she describes having to educate them as to what depression was, but she found her doctor and psychiatrist extremely helpful. She then had to see the occupational health doctor who was also supportive in assisting the school to

understand her needs. When she was off with depression for a year and had to wait nine months for therapy on the NHS, she approached her employer and was extremely disappointed that they would not contribute to some therapy. She has since campaigned for resources alongside other people in her workplace who have been unwell and they now have a counsellor available in her workplace who many people use. To facilitate her return to work she requested a less stressful timetable, which was agreed but was not implemented. She didn't feel that she could cope, so she approached heads of departments and successfully re-negotiated a new timetable herself. She only recently became aware of her dyslexia, and since then, has disclosed it when opportunities arise. Although this does not usually trigger any response, she has found in recent years that, when going for training, she has been contacted to see if she needs any extra help, which she considers positive. The school reviewed its personnel documents and now asks teachers annually to disclose any illnesses or disability, so she stated dyslexia and depression. Nothing happened as a result, and she feels that organisations ask for information but then file it away rather than acting on it. However, she considered that they were 'a lot nicer' when she was off sick recently, and that they responded 'very sensitively'. She has only disclosed her diabetes, informally, to her manager, who was sympathetic, because she had to have days off for medical appointments. She is perceived as a very fit and able professional, and is constantly invited to join school working groups, including the Disability Equality Scheme, and she is very vocal concerning employers' support for teachers generally. Whilst she wouldn't say she was totally aware of her rights under the DDA, it does make her feel more confident. She feels that there is increased

acceptance of disability and long term health condition within the profession, and that things are changing 'in leaps and bounds' due to legislation and wider social attitudes. However, she is still careful of how she refers to depression in professional settings, and she believes there is room for significant improvements in understanding.

### **BOX 3 - Negative story**

This account is provided by a nurse, aged 41, who has been in practice continuously since she qualified in 1988. She didn't disclose her hearing loss to anybody when training because she had deaf friends who had been refused places on courses. Not disclosing meant that she had to hide the fact that she lip reads, which was demanding, and she experienced additional stress. She disclosed when she became profoundly deaf in 1991 and was no longer able to hide it. She now lets colleagues and managers know about her disability, and that she lip reads, but tries not to draw attention to it or ask for any additional consideration. She describes personnel departments as non-discriminatory, but nursing and hospital management as 'very much discriminatory'. When she started one new post, managers told her that they wouldn't give her any extra help because of her disability. An occupational health adviser said: 'don't ask for support or you will price yourself out of the market'. When studying on an HEI course, her placement mentor said: 'I don't see how I can pass you because you are deaf'. The placement was a poor experience and she became very depressed. She put in a complaint about discrimination and the placement management – a health trust - agreed and asked her to take proceedings against the mentor, but she declined because she didn't feel she could cope with further stress. She started a new job

and a few months later was sent to occupational health because her manager decided that they weren't sure that she was safe to practice and she might have to take medical retirement. She continued in post but was told she could not apply for promotion. However, The Royal National Institute for Deaf People [RNID] and her union agreed to back a case for discrimination so she started proceedings against the hospital. The hospital management then apologised and she secured the promotion at interview. She has recently gone back to an HEI which has done nothing about securing her Disabled Students Allowance, despite her disclosure on application. She has found HEI tutors willing to be supportive, but they often don't know how to assist, and need to be better informed. She believes that there is no climate where it is safe to disclose, and other deaf nurses have said 'please keep quiet or they will sack the lot of us', but she has helped set up a forum for disabled people at work. She considers that the DDA lacks teeth, as you need to go to court which is too stressful, time consuming and expensive for most people to take on. Her experience is that the attitude to disabled staff is still: 'go and take medical retirement, why are you bothering?'

When these classifications were examined in relation to different professional groups, some groups emerged as particularly likely to tell a negative story: practising nurses and social work students were notable in this respect. This may reflect the three professions' different approaches towards and histories of developing fitness standards as discussed in Chapter 1. For instance, the higher proportion of negative stories amongst nurses may indicate the more stringent approach of the nursing profession to fitness standards. Likewise, the fact that social work training programmes have only recently acquired responsibility for checking fitness to practice and may still be struggling to manage this sensitively may account for the high levels of dissatisfaction in this group of interviewees. However, social work practitioners were the group most

likely to tell a positive or mixed story. Teachers and student teachers were fairly evenly divided in the nature of their accounts.

**Table 6 – Story type by profession**

<b>Category</b>	<b>Positive</b>	<b>Negative</b>	<b>Mixed</b>	<b>All</b>
Nurse practitioner	4	9	4	17
Student Nurse	2	1	1	4
Social work practitioner	5	0	5	10
Social work student	3	6	1	10
Teacher practitioner	3	4	4	11
Student Teacher	4	2	2	8
All	21	22	17	60

If story type is considered in relation to disability, those with multiple disabilities or long-term health conditions were most likely to tell a negative story with over half the professionals in these groups doing so. The largest proportion of positive stories was found among those with physical disabilities and this may reflect the less stigmatising nature of physical disability. Those with mental health problems were likely to report mixed experiences.

**Table 7 – Story type by disability**

<b>Category</b>	<b>Positive</b>	<b>Negative</b>	<b>Mixed</b>	<b>All</b>
Physical	5	1	4	10
Sensory	4	2	2	8
Long-term health condition	5	9	3	17
Mental health	3	1	5	9
Dyslexia	3	3	0	6
Multiple	1	6	3	10
All	21	22	17	60

### 3.3 Summary points from Chapter 3

- The majority of those participating in the study were aged over 30 and the practitioners as a group had a considerable amount of practice experience.

- Long term health problems and mental health problems (which were frequently found in combination with other disabilities) were the disability types most highly represented in the sample.
- The majority of participants had disclosed their disability. However, a fifth had only partially disclosed.
- Three story types: positive, mixed and negative – were identified from the participants' accounts. Those with multiple disabilities or long-term health conditions were most likely to tell a negative story. The largest proportion of positive stories was found amongst those with physical disabilities.
- Practicing nurses and student social workers were the professional groups more likely to convey a negative story. This may reflect different approaches towards, and histories of developing fitness standards across the three professions.

## Chapter 4 - Fitness Standards, Disability Legislation, Labels and Language

### 4.1 Awareness of fitness standards

Most participants in this research were uncertain as to what professional fitness standards were and whether they would be relevant to them. Some lacked information about fitness standards, others considered that they were not specific enough:

I don't know, I've got no information, no. I haven't....perhaps it's my fault for not having sought information but I didn't know I came under any banner so to speak.

Teacher Practitioner

Obviously you know in the back of your mind it's fitness to practice, but to what degree? There's no cut-offs...I couldn't find any stipulation that said if you are beyond this level of capacity or this level of functioning you will be struck off the list. I couldn't find anything that said that.

Teacher Practitioner

In some cases, fitness standards were understood as associated with 'good character' or suitability for practice rather than with disability:

I don't usually see that as meaning disability....I see it more usually in terms of whether they are appropriate for a particular type of job....somebody who might be accused of sexual harassment of women then going into, say for example, a prison setting working with women.

Social Work Practitioner

However, in a few cases, professionals felt that they were reasonably well informed about fitness standards, although even this information could fall short of what was required:

I am aware of the 'fitness to practice standards for the nursing profession. I found out about them through the NMC website and publications.

Nurse Practitioner

...in the handbook this year for the BA Social Work there's a very clear passage on fitness levels and it's about mental health and physical health and if you're not deemed not to be fit enough then you're off the course but it doesn't state what constitutes not fit enough.

Social Work Student

## **4.2 Attitudes to fitness standards**

Professionals' attitudes towards fitness standards and the extent to which they were prepared to acknowledge them varied. Some of those interviewed were not prepared to accept that they had any relevance and argued that they should define their own fitness:

I went through them [the fitness standards] carefully when I first registered with the GSCC. I did not consider that I was unfit and therefore don't consider they affect me.

Social Work Practitioner

However, others considered that fitness standards had validity and could be useful in alerting individuals to the implications for their practice.

Some professionals emerged as assertive in their engagement with the fitness standards for their profession. They were prepared to challenge employers' judgments and to collect evidence of their ability to do the job required of them:

....does she comply with the fit to teach criteria? This was one of the questions that was asked. And what I did was basically presented a lot of evidence at that, medical evidence and actually teaching evidence that I was a good teacher.

Teacher Practitioner

While some participants had succeeded in obtaining acknowledgement that they were meeting fitness standards in their present posts, they noted that the issue of fitness standards could act as a barrier to moving on, either in terms of promotion or to new areas of work.

## **4.3 Disclosure to regulatory bodies**

There was considerable variation in whether participants had disclosed to their respective professional regulatory bodies: this reflected the different

requirements of the professional bodies as noted in Chapter 1 and echoed their experiences of disclosing to employers and HEIs (see Chapter 5). Understanding the process and implications of disclosure, and how the information would be used were important issues for those practitioners and to social work students who registered at the outset of professional study:

It was a bit unnerving this disclosing to this great big GSCC when you have never met anyone, and don't know anything about other than all the paraphernalia that you get. You know no one really knows what happens if you disclose something ... because it doesn't say on that form, it says that they might want to talk to your GP or whoever, and they might want to talk to you, but why, what do you want to know? ... Just to put your own mind at rest.

Social Work Student

There was uncertainty among the participants about whether regulatory bodies had or hadn't asked them to disclose information about disability:

They don't ask you, I don't think they ask you, I can't remember them asking the last couple of times I've applied.

Nurse Practitioner

I don't think I've actually informed the Care Council [Wales] because there was nothing on the form that actually gave me the opportunity to disclose.

Social Work Student

Those who became disabled later on after entering their profession were further confused about whether they were required to contact the regulatory body and inform them about their disability. This posed a particular dilemma for those professionals who did not consider the disability affected their ability to do their job, as well as those who did not consider their particular impairment to confer disability. There was also confusion among all professionals about how often the regulatory body updated its information with some believing this to be a one-off event. In addition, requirements regarding disclosure appeared unclear for those with fluctuating conditions:

This has just been introduced this clause, so ... when I re-register in two years time I will have to sign to say I'm of sufficiently good health ... but then there may be a time in that period when I'm not, and the concern for me is ... that I'll have to sign that at a time

when I'm unwell ... so if that comes in when I'm relapsed, how do I sign, what do I say?... I'm not sure what they would do.

Nurse Practitioner

There was some adverse criticism of the way in which regulatory bodies requested information about disabilities. Most regulatory bodies included a tick box question on the registration form which asked whether or not they were disabled. Again, those who were of the opinion that they were not disabled sometimes chose to ignore this box. Others ticked the box but with reservations because generally there were no supplementary questions asking for more qualitative information such as how the disability affected them as a person or offer of information or support. This was identified as a serious shortcoming in the way in which regulatory bodies asked professionals to disclose disability:

I disclosed the information that I had epilepsy ... I was sent no information from them about disabilities, how they treat it within the Nursing and Midwifery Council, the kind of support that's offered or anything else.

Nurse Practitioner

Disclosing to a regulatory body was perceived as having mainly negative consequences. The Regulatory Body was seen as remote and potentially threatening – some participants described it as 'Big Brother'. The process of disclosing to the Regulatory Body was experienced as impersonal and there was a sense that the consequences of such disclosure could not be controlled by the disabled professional:

With the GSCC it is very difficult because they have foreclosed in their information about what they do with it and...the threat of putting restrictions on your practice. It just seems like a very closed organisation that you don't know what to expect of your disclosure, so it is a bit more scary.

Social Work Student

A number of nurses and social workers reported not disclosing to their regulatory bodies in anticipation that disclosure would affect their ability to practice:

I am registered with professional bodies and I do not consider disclosing when my registration is updated. My reasons are due to the potential negative impact on my career.

Nurse Practitioner

Some felt the need to limit the extent of the disclosure and this appeared to be one way in which the individual professional could experience a sense of exerting some control over the process of disclosure:

I want to have control over when I disclose it ... I only want to play safe, so to have it disclosed on a national thing, although logically there wouldn't be any implications, but I would be anxious about it, I only keep it where I can keep control over it.

Social Work Practitioner

However, some professionals interpreted the remoteness of the Regulatory Body as indicating that their disclosure would not be available to others:

I would be happy to give it to them and say, in respect that I see them as a more distant body, it's not somebody I'm working with at the moment, the information they have on me, they hold on a file and nobody else ever sees it or has anything to do with it.

Nurse Practitioner

#### **4.4 Awareness of disability legislation**

As a group, the professionals, both students and practitioners, were more aware of disability legislation and its relevance for them than they were of fitness standards for their profession. A number of those who were familiar with the legislation were able to apply it to their own situation and some had made use of it to protect their position or to obtain adjustments:

Yes, I've read it [the DDA] a couple of times and as I go down it I think there's two things that my employer isn't doing and they are in breach of.

Nurse Practitioner

Yea, yea [I'm aware of my rights under the DDA], and it's a good job I am, that's all I can say, 'cos I think I'd get walked all over if I didn't. I know what I'm entitled to, I know what I'm not entitled to as well. I think that's why I got my ....when I was actually in the workplace at the City Council, that's why I got all of what I did, it was because I knew my rights.

Student Teacher

Students were particularly likely to have a well-developed level of awareness and a number of social work students mentioned that they had received teaching about the DDA as part of their programme of study.

However, nearly a quarter (14) of those interviewed described themselves as being unaware or having only a vague awareness about their rights under the DDA. Teachers and Nurses were more likely than Social Workers to be unaware or uncertain:

I'm not aware of anything because I haven't read up on anything. It's not something I've looked into....

Teacher Practitioner

I am probably not as aware as I should be to be honest with you. I know that employers have to adhere to these rights but I don't know what my personal rights are.

Nurse Practitioner

Participants had acquired their information about the DDA and associated legislation from a range of sources. The internet was one such source:

I'm aware of my rights under the DDA and made sure I got it clearly set out by surfing the net.

Social Work Practitioner

Other such sources included relevant unions, voluntary organisations and the DRC:

I got a lot of that information myself and also from my union. My union have actually been very good at finding things out and getting information.

Teacher Practitioner

....that was the best thing I ever did because the DRC gave me all the information that I needed. They sent me lots of literature for employees and employers, what my rights were, what their rights were, what procedures should be taken and all relevant material and I read through them all and without the DRC and without that information, I would not have been able to do anything at all.

Nurse Practitioner

Four respondents who were familiar with disability legislation were somewhat critical of it and considered that it 'lacked teeth':

It seems very wishy-washy: I have to have reasonable adjustments and I think that they can be interpreted as they like or they [the employer] can use it as they like, because at the moment they are saying that they can't give the reasonable adjustments that I require and therefore I have to be redeployed.

Social Work Practitioner

I feel the Disability Discrimination Act has very few teeth. If you look at race discrimination, sex discrimination and look at the compensation levels set, the level of compensation for disability discrimination is very low in comparison and so people don't worry. There is also the fact that it has to be reasonable adjustment which is a very subjective point, it is very easy to say it wasn't reasonable.

Nurse Practitioner

#### **4.5 Impact of disability legislation**

The word most frequently used by participants when describing how the DDA had affected them was 'confidence'. Professionals felt confident that they could disclose disability and described themselves as being more assertive in their attitudes as a result of knowing that the legislation was there to provide 'back up' or clout:

It gives me confidence that I can disclose, I can tell them that I know that I've got legal backing should I need it and I've got some legal rights that they can't discriminate. They can't turn round and say, 'you're not fit to practice'.

Social Work Student

Well I think that the fact that it [DDA] exists does give you a bit of courage, yeah, I don't know whether on the immediate grounds of disclosure it helped me there but, for instance, when the car parking issue came up, you know I felt confident enough in myself to say, if they start asking me for money I'm going to have a grumble because I'm sure that's discrimination....

Social Work Practitioner

It gives me clout, it gives me something to say, 'will you do this?' and if they say, 'no', I'll say, 'well look you're going to have to do this because I'm entitled to it'.

Student Teacher

Professionals considered that they were in a stronger or more protected position as result of the DDA:

I did feel more protected....when Occupational Health said to me I was protected under the Disability Discrimination Act, I felt a bit safer.

Nurse Practitioner

Participants also described themselves as more determined as a result of knowing that their position was supported by legislation:

....made me more proactive....it's made me stick it out longer that I should, should have done, because I knew that I could be accommodated in that environment. I didn't think that it was unreasonable what I wanted: basically an aid and to be able to sit down a bit more....

Nurse Practitioner

They also noted that the existence of the legislation had led to formalised means of support:

I think just knowing that I could call up somebody in the Union to help me and quote the Act, I think that is one concrete way that it helped me.

Social Work Practitioner

However, a small number of interviewees considered that their expectations that the DDA would protect them had not been fulfilled and they noted that the aspirations of the legislation were not always met in practice. Some made the point that the legislation was not as effective for those with unseen disabilities as the adjustments required were often attitudinal ones rather than physical adjustments:

I think people with long term health problems, especially perhaps those with mental health problems, they are the ones I feel are at a disadvantage and I don't think the Act covers them as fully as it perhaps should because people are reluctant to employ people with long term health problems....

Nurse Practitioner

Participants across all three professions expressed a lack of confidence in how widely the DDA was understood or implemented. For some the concern was that not all professionals knew their rights:

A lot of people are still wary, I think of disclosing changes in, you know, health ... but I think that goes back to they don't know the policies and they don't know they are protected.

Nurse Practitioner

Another concern was that organisations as a whole, or individuals within organisations, were not fully implementing the DDA:

I am aware of legislation and rights under the DDA but feel that these rights are not always upheld.

Nurse Practitioner

## 4.6 Disability labels

Participants expressed a wide range of views about the labels and language used in relation to disability. Understandings of such terms affect people's experience of being asked about disability and how they respond; different terminology may be used in different contexts. Some research participants did not regard themselves as being disabled according to the meanings they interpreted others to attribute to this label. Some did not perceive themselves as being impaired nor even as having a long term health condition. Others accepted one label or another.

Views were polarised between those who took a pragmatic view and considered labels a necessary evil providing access to help and support, and those who clearly felt stigmatised by any label, but in particular by the label 'disabled person'. All three professions included some who felt that any label was unhelpful and distracted from seeing them as an individual:

Everybody's an individual regardless of what term you put on it.

Nurse Practitioner

I think the labels are negative irrespective...and personally I think there's a danger of seeing that label before you see the person and that does happen.

Social Work Student

Those with dyslexia were least likely to accept labels. Dyslexia was described as meaning doing things in a certain way and trying to 'make sense of them in a way that suits me'. Another person described dyslexia as a 'social inconvenience' rather than as a disability or impairment and certainly did not perceive it to be a long term health condition. However,

dyslexia was also identified as a condition listed as a disability by the DRC and, as such, was seen to function as a label that facilitated access to necessary support.

The positive side of accepting a label, particularly 'disabled person' as defined under the DDA and by the DRC, was that this facilitated access to support and instigated 'reasonable adjustments' to enable the individual to manage their studies or maintain them in the job. As one social work practitioner commented, 'I don't like the label...but it is actually a good position to be in because you can ask for adjustments to be made.'

Those with unseen disabilities, such as mental health problems and more recently identified conditions such as ME, experienced the labels as particularly stigmatising:

I think when you are talking depression you are talking mental problems, and when you are talking mental they think Schizophrenia - someone losing their block.

Nurse Practitioner

I think there's still a stigma with some people who think ... if I say to anyone that I've got ME, they think it's all in my mind and you know and that's why a lot of people don't talk about it openly.

Teacher Practitioner

However, other responses suggested a sense that times were changing and that wider societal understanding and acceptance of disability and impairments, including mental health problems, could be found. However, not everyone agreed with the sentiment expressed by the following Practitioner:

Up to recent years I wouldn't have used them at all, I think it is a very much case of the minds of people have moved on, the acceptance of certain usage of words have become more familiar and accepted, and the social aspect has become more accepted. Depression was never talked about openly.

Teacher Practitioner

The main objection to any label, but in particular that of 'disabled person', was that it 'puts everyone under the same umbrella', and detracted from the individual and their impairment or long term health condition and how it affected them.

## 4.7 Perceptions of the term 'disabled person'

Those who were happy to use the label 'disabled person' about themselves in relation to disclosure explained that they were comfortable with it in this context as this was the term used by their employer. Others explained that use of this terminology meant that they were covered by the DDA or that, when it came to 'form filling', they considered themselves as disabled. Accepting the label had other associated benefits, such as entitlement to Disability Living Allowance and practical support and access to the disability support services whilst at University. As one Teacher Practitioner stated, 'technically on paper I consider myself to have a disability.'

Dyslexia was accepted as a disability by some of those with dyslexia, although not without reservations:

I've now started to put that I am disabled yes. It has an effect on certain work, academic work especially, so I have to put it in order to obtain certain assistance. Academically, I perceived it to be accepted but within my profession I don't consider it to be accepted, or my particular disability shall I say? So I am happy to use the term that I am disabled if you like but I have to be selective with who I use it with.

Nurse Practitioner

The term 'disabled person' was the most contentious with the professionals in this study, which may in part be related to the fact that a high number of the participants had long term health conditions compared to other disabilities. Although not initially considering Multiple Sclerosis (MS) as a disability as such, there was acceptance that a long term health condition such as MS, with fluctuating impact and periods of remission, could result in disability:

We're classed (in the DDA) as disabled because I could wake up in the morning and have the same vision impairment I had 18 months ago or it could be loss of an arm or use of an arm or loss of use of a leg.

Social Work Student

A research participant with mental health problems reflected the complexity of applying the label 'disabled person' to someone with mental health problems:

When I read the sort of concept of standardised forms of disability I don't relate to what they define it as, but I do consider myself to be disabled in some respects because of my variation in mood, which at times can be quite severe and...I find it very difficult to function adequately to sort of maintain...a work role if you like...I suppose in that sense there's a definite disability, there's an impediment as far as work is concerned.

Social Work Student

Being disabled was invariably seen as synonymous with physical disability, as one Social Work Student suggested, 'nine times out of ten, people think of disability as physical or learning disability', and associated it with 'people in wheelchairs'. As another Social Work Student observed, 'people tend to discern disability as something that is physical, that is observable'. Associating visible physical disabilities with definitions of a disabled person was reflected in several responses. A Social Work Student with dyslexia stated: 'I'm perfectly able bodied but I would say that I have a disability'. Another Social Work Student reflected the dilemma when he/she stated that: 'I have a disability but I don't see myself as disabled...seems to imply a larger physical disability that you can see'.

For some, adopting this label clearly implied being at the extreme end of a spectrum of difficulties or problems:

I sometimes feel like if I say I'm disabled I'm being a bit of a fraud because I see people around me who are much worse off.

Teacher Practitioner

The terms 'disability' and 'disabled person' were perceived by many as being the most stigmatising of the three terms, and professionals associated being a disabled person with 'feeling inferior', 'you aren't able', 'not full human beings', or being 'one of the weaker members of society'. One participant stated: 'I don't consider myself to be disabled but I don't know that anyone really ever does.' Another research participant suggested there were that 'a lot of negative connotations with the word disabled', all of which served to distract from the individual and their capacities:

The word itself suggests that you're incapable, the whole stigma that goes with it says you can't function, you can't do something, it's negative in itself.

Social Work Student

The ambiguity in the label was reflected repeatedly in participants' comments, which came from professionals from all disability categories and from all professional groups:

It depends upon what environment I am in, sometimes the environment makes you feel more disabled than others, and so it is not a straight yes or no answer. But if you are looking at it in the medical sense, then yes. From day to day I would say no.

Nurse Practitioner

A Social Work Practitioner who stated: 'do I consider it a disability? No not in the slightest', went on to say that her/his impairment was just a 'natural part of my life' and that only from a legalistic viewpoint was she/he disabled. A Student Teacher was uncomfortable with the term 'disabled person', arguing for the phrase - 'I have a disability' - because this was 'more as though it's me as an entity'.

#### **4.8 Perceptions of the term 'impairment'**

Many of those with sensory impairments or physical health problems were happy to refer to themselves as having a 'long term health impairment', 'mobility impairment', 'hearing impairment' or 'sight/visual impairment'. Some of those who were dyslexic described this as an impairment, although if not diagnosed until later, they might 'not feel impaired'. In relation to having a hearing impairment, one student commented:

I would never think of myself as disabled...I would probably use the term impairment because I think people are kind of used to that and...if I wanted them to pay attention to the fact I would use a term like that just because they would listen to that.

Student Teacher

Both Nurse Practitioners and Student Nurses who identified themselves as having mental health problems were unhappy to use 'disabled person' to describe themselves but referred to being 'impaired in certain ways', and preferred such terms to others. However, this view was by no means universal. Another Student Nurse reflected:

I think that intellectual impairment is like people with maybe a learning difficulty and I don't feel that that applies to me, and I don't

think people with mental health problems, but because they are mentally ill doesn't mean that they are stupid, that type of thing.

Student Nurse

A Student Teacher only considered him/herself to have an impairment if experiencing a 'manic episode or depressive episode', and did not currently feel impaired because 'I am quite on the normal side'. A Social Work Practitioner with mental health problems clearly articulated the perceived stigma of being labelled as someone who has impairments:

I wouldn't want to ring Social Services to say I've got an impairment, as far as I'm concerned I have a condition that I live with...it's that thing about stigma, I wouldn't want to be seen as somebody who had an impairment.

Social Work Practitioner

Impairment was perceived as relevant when describing the impact of a long term health condition on an individual and/or their ability to perform their job. For instance, one Nurse Practitioner stated that 'it's obvious by the way I walk that I have some kind of impairment', and others that:

I would say an impairment is something that you've got all of the time that you can't necessarily do anything to improve and you have to learn ways of managing the impairment...if you have an exacerbation of that impairment then you become disabled.

Nurse Practitioner

In contrast, others had a strong negative reaction to using the term 'impairment' considering this to imply that 'it is worse than it is'. The following are typical of the comments from all professionals:

If you said to somebody 'I was impaired', the pictures that they would generate in their head would be different to 'I was disabled'...that's possibly because I work in psychiatry and we think impairment and we think mental impairment.

Nurse Practitioner

I don't like the word impairment, it is not a nice word, I would rather describe myself as disabled, rather than impaired.

Student Teacher

## 4.9 Perceptions of the term 'long term health condition'

Generally speaking, research participants categorised for the purposes of the study as having long term health problems and some of those with physical impairments, were comfortable with the label 'long term health condition'. This included people with epilepsy, MS, rheumatoid arthritis, ME, urinary and bowel problems, congenital heart problems, and spinal problems. Some preferred related terms such as 'chronic health conditions' or 'chronic illness', but were broadly comfortable with using 'long term health condition'.

However as the following comment from a research participant with physical impairment demonstrates, this did not fit every situation neatly:

My interpretation [of long term health condition] is someone who has Diabetes, Epilepsy, Heart Disease; a condition that is in some cases controllable in others not, but perhaps precludes them from doing certain occupations. Perhaps somebody who is registered blind could have a long term health condition or... more medical conditions I would class as being long term health conditions. .

Nurse Practitioner

In contrast, a Practitioner with sensory impairment did not consider the term to be relevant to him/her but stated that for some purposes, for example, completing insurance forms, he/she might tick the box that asks for declaration of 'long term health condition' as this 'best describes what I'm trying to convey for the purposes of their form'.

The term 'long term health condition' was considered by some to be either 'more positive than labelling somebody as having a disability', or was felt to be 'more neutral' than either impairment or disabled person. Or, as one person stated, it is both 'more realistic' and also 'more ambiguous'. Being described as having a long term health condition was 'descriptive' of an ongoing condition or health problem and as such, was 'quite acceptable', both to describe physical and mental health conditions:

I feel as if I have a condition that is continuous because the effort I have to put into functioning during the day I'm convinced is far greater than the majority of people...based admittedly around my capacity to handle stress.

Social Work Student

I have definitely got a long term health condition in terms of depression and a tendency towards depression.

Student Teacher

In fact, several of those who described themselves as having mental health problems said that this term was preferable to 'disabled person' and, depending upon the stage of their illness, more accurate than 'impairment'. Some participants with multiple disabilities thought that they might use this label to describe their mental health situation:

Well it would be both. Health condition would be the depression and the impairment would be the hearing, so yes to both.

Nurse Practitioner

#### **4.10 Summary points from Chapter 4**

- Participants were generally uncertain as to what the fitness standards for their profession were.
- There was considerable variation as to whether participants had disclosed their disability directly to their regulatory body.
- Regulatory bodies were generally seen as remote and threatening organisations; professionals were concerned that they 'lost control' over information disclosed to their regulatory body and that they received little in the way of an individualised response or information concerning the consequences of disclosure from such bodies.
- In contrast, participants were more aware of their rights under the DDA and had acquired information from the Internet, trade unions, voluntary organisations and the DRC.
- Participants considered that disability legislation had given them confidence in disclosing disability and had empowered them in negotiations with employers/training organisations concerning adjustments.
- Participants varied in their readiness to accept a disability label, but those who did so acknowledged that a label facilitated adjustments.

- The term 'disabled' was seen as conveying physical disability by many participants.
- Participants were divided as to whether the term 'impairment' was acceptable to them.
- 'Long term health condition' appeared the most acceptable term, although it did not fit all disabilities equally well.

## Chapter 5 – Disclosure: Experiences and Barriers

### 5.1 Experiences of disclosure

This chapter describes students' and practitioners' experiences of disclosing their disabilities or long term health conditions to their employers and HEIs and considers the factors, both positive and negative, that influenced their decisions. Here, disclosure is taken to mean the communication of information about a disability by the individual concerned to an employer or HEI, when it is understood that the information will be retained and will evoke a response. Completion of a confidential monitoring form does not constitute disclosure for the purposes of this study. Disclosure is conceptualised in this report as an irrevocable step, although it may be partial or gradual.

Whilst only three of the participants interviewed had not disclosed at all within their professional settings, the experience and extent of disclosure of the remaining 57 was very varied. Whilst some described having disclosed fully at every opportunity within their profession, others had disclosed only one of a number of disabilities, disclosed only at particular stages of their careers, or to particular organisations or individuals within them, or had understated the extent of their disability.

As noted earlier, participants' accounts of disclosing their disabilities ranged between positive, negative and mixed. Some long-established practitioners described how they felt that the work environment was becoming increasingly supportive of disabled people and therefore supportive of disclosure, albeit this was often seen as a slow, incremental process:

A real improvement, in my working career, I think 25 years ago people still didn't really know how to ask for the information and deal with it, and I think there has been a number of trends not just to do with disability, under equal opportunities, certainly a lot of public bodies have taken on board the need to not discriminate on the grounds of race, gender, disability whatever and look at how they do that.

Social Work Practitioner

However, for some, the process of disclosure had been wholly negative:

If you don't declare and things go wrong then you're dropped in the shit, and if you do declare it and things go wrong then you get dropped in the shit.

Nurse Practitioner

I think they are awful. I think they try to tell people you have got to disclose, you are legally obliged to disclose, and then when you do it is like being shot in the face, it is like: 'oh my goodness right we are going to stop everything'.

Student Nurse

## 5.2 The act of disclosure

For most of the research participants, disclosure was more than a single act at one point in time. For those who were disabled on entry to their profession, the initial act of disclosure, on application to an HEI, had been a multi-staged process:

First I went for an interview, I didn't have to disclose at that point but I chose to ...part of the pack which came for all the admin. to be filled in, all the details for the LEA, so there is a medical health questionnaire as well and I filled that, it required disclosure of all health conditions ... In response to this they invited me to an interview with the occupational health consultant ... I went along to the interview there and I had a very reassuring interview and passed it.

Student Teacher

Similarly, the act of disclosure, once people were established within the workplace or an HEI, had rarely been a single act, but often a series of decisions or negotiations:

It's a bit like coming out of the closet, it's something you're constantly doing, you don't just disclose it once... because you're going on a placement, when you are on placement you might go and spend a couple of weeks with another institution, so each new place you go to, actually means is that you're disclosing all over again ... it's not just you fill in a form and you've disclosed it, that just tells the University ... and for me it means every client I meet I'm making that disclosure to, it's on-going, it's continuous.

Social Work Student

### 5.3 Motivations for disclosure

Those students and practitioners who had some control over disclosure, described a number of reasons for deciding to disclose to their employers or HEIs, including legal, ethical and practical motivations, and the benefit of receiving reassurance from an 'expert' source. For some, their obligation under employment law and the possibility of reprisals if they were 'found out' underpinned their decision:

I have always been very honest and disclosed my disability on forms that say disability, because I know that if I don't disclose it, the fact that I am deaf, and it is found out later, it can be used to sack me.

Nurse Practitioner

You get into all sorts of messy situations if you withhold something which is potentially relevant, you find you have negated your contract of employment, so that you have got this cloud hovering around behind you, you may get rumbled at any time.

Student Teacher

Choosing to always disclose was a matter of principle for a number of respondents. This was seen as an ethical stance that outweighed personal concerns about responses to disclosure:

I have never lied about my condition, I don't see the point, it is part of me, it is part of my life, and it is who I am.

Nurse Practitioner

Some who advocated the principle of disclosure, particularly younger practitioners and students, articulated a sense of empowerment or pride in disclosing, in being trailblazers:

I am not ashamed to say that I have it, and I am proud of the fact that I have managed to get this far, considering I have extra needs that many people don't have.

Social Work Practitioner

The principle of honest and complete disclosure was acknowledged to be a risky tactic as students considered that it might jeopardise their chances of being accepted onto a course:

I disclosed fully, the reason being that I just think it is a generally good policy to be honest in these things, but it was with a little hesitation, however, because I felt that if I disclose maybe I will be barred from doing a course, which would be quite bad because I really wanted to do the course ...so those were the two factors, but the general policy of being honest overtook the other one.

Student Teacher

As noted above, some participants described the work environment as becoming more supportive of disabled people; however they did not report any acknowledgement within their professions that experience of disability offered the workforce additional strengths or insights. Some of those who had disclosed a disability in their course application reported meeting off-putting and confrontational attitudes at interview:

I decided to put it in the last paragraph that I had been a mental health service user in the past, and I put words along the lines of 'I think this is going to help me to empathise with people'... I got called to interview and I was quite open and honest about it, at the time I felt they gave me a really hard time about my mental health problems.

Student Nurse

For those concerned that disclosure would be professionally damaging, receiving expert advice or reassurance was identified as a factor that increased their confidence in disclosing. As our interviews only included those who had successfully entered the professions, it is not possible to identify whether others who had been advised to disclose had been excluded from entry on the basis of disclosing their disabilities:

We had a meeting with one of the guys from the GSCC and asked him about disclosure and stuff and he said 'it is better' .....

Social Work Student

For participants who described practical reasons for disclosure, whether at the outset of their profession, or at a later stage, disclosure could be an enabling process for the individual, as a prerequisite to procuring adjustments and support and even in transferring responsibility onto the employer or HEI:

They [placement] can only treat me the way they should if they're well informed, so then I think, well then, I should tell them.

Social Work Student

I'm essentially an honest person and I believe that if you disclose things and problems do occur then the onus is very much on the education institution or your employers to have made adaptations in order to keep you safe.

Nurse Practitioner

For students in particular, the decision to disclose was influenced by the positive consideration of triggering access to financial and technical support or adjustments:

I felt that ... it can't be that bad to say you have a disability if you get all this stuff, of course that shouldn't be the only reason, but I was at the time [a student], it helped me to decide.

Social Work Practitioner

In the cases of some professionals who had previously chosen not to disclose, a change in their disability or their work environment created a new need to secure adjustments from employers or HEIs. This made disclosure an unavoidable necessity, rather than a positive decision:

I have told the University because I am having treatment ... if I wouldn't have told the University, like missing every Wednesday from lectures would be a problem ... if I had a choice, no, I wouldn't have informed them, but I haven't got a choice.

Student Nurse

Then I became profoundly deaf and it wasn't easy to hide so then I had to disclose it.

Nurse Practitioner

The issues of control and confidentiality within the process of disclosure were frequently raised as areas of concern. For a number of participants there was no element of choice in whether to disclose. This included not only those whose disabilities were visible, but those who had accidents or fell sick whilst at work:

I was unwell and therefore it was actually disclosed by my doctor first.

Teacher Practitioner

It became very apparent that I was depressed, I just kept crying everywhere so that is a strong indicator, so I had to go to Occupational Health.

Nurse Practitioner

Confidentiality was also identified as important in facilitating the initial process of disclosure. Participants repeatedly stated a desire for some control, or at least information, about who would be told and when:

I was told that it was confidential and that for me was a big thing.

Social Work Student

For some professionals, for whom the onset of disability came soon after entering an HEI course or employment, disclosure and lack of confidentiality were experienced as particularly difficult as they were experienced at the same time as people were struggling to come to terms with their diagnosis:

I did disclose to my personal tutor and I was informed ... [that] everybody now had to know about it, the university had to officially know about it and my placement to where I was going had to know about it, and I was really unhappy with that ... I've just been diagnosed ... it was very personal to me, I'd just found out and I just wasn't ready to disclose.

Social Work Student

## **5.4 Disclosure to practice placements**

All students on professional training programmes undertake placements in relevant agencies and this was described as necessitating a series of negotiations around disability disclosure with different practice agencies. While for some, this was acceptable because they did not want information about their disclosure made public knowledge, for others it was frustrating and meant there was a need to disclose repeatedly, especially where courses required students to undertake multiple placements. On courses with large numbers of students competing for placements, it was felt that disabled students who disclosed could be disadvantaged, especially in relation to the allocation of short placements. It was suggested by one Social Work Student that the process of allocation was rather arbitrary and did not take account of disabled students' needs – 'some receptionist in admin's just going to put my name against a placement and it's worrying.'

It was also feared that rejection by one placement on the grounds of mental health problems might jeopardise a student's place on the entire training programme:

But if I tell them that I am going for treatment for post trauma stress disorder and they see that I am coping well at placement, they will say 'oh she can cope, although she is going through a hard time she will get through.' But if they see it the other way round, the placement will not accept me and the university will stop my course.

Student Nurse

However, some students saw it as important to disclose to each placement, as this was considered the only way to ensure that appropriate support and accommodations were made for their particular circumstances. Students also emphasised their responsibilities to disclose to other members of the care team whilst out on placement:

I'm putting other members of staff at risk so I did feel that for the sake of other people as well as myself I had to disclose to them.

Social Work Student

## **5.5 Confidence and disclosure**

When exploring the factors that supported their disclosure, a number of practitioners across the three professions reported that being well established or having achieved seniority in a work environment offered them a sense of security in the process of disclosing and, importantly, the ability to evidence their capacity to do the job:

I have been employed by a college to teach adults and for the last five years without the college having any issues about it, and that is something which was, that was something I felt stronger than any kind of legislative protection.

Student Teacher

One nurse practitioner, who had not disclosed, was reassured that her established record in the role would protect her from any negative response:

If I was to say disclose now, my employer was to say 'oh wait a minute, there's a problem here, you're dyslexic you can't do this', then I'd say 'well, I've been working well for the past two years, I've been fulfilling the requirements for my job, you've not given any indication that there was any problem in these areas, why now that you know, are you saying that I can't do the job?'

Nurse Practitioner

However, following disclosure, acquiring colleagues' support and confidence was often a lengthy process and one social worker described a reluctance to move on and have to repeat the process in a new setting. This had significant implications for professional career progression:

I was in my last job ever since I was diagnosed, I was within that job nine years ... I think it took me nine years to have the confidence to go for another job and have to have to talk about it.

Social Work Practitioner

Other practitioners echoed this concern, that the sense of security accrued in one work environment was often not carried across to a new work setting. Instead, they described a recurring process of determining whether to disclose, assessing each new environment to establish whether it would be supportive. The potential for regular changes within the professional environment meant that this might need to be repeatedly negotiated, even if people had not chosen to seek new employment:

The problem would be if I was redeployed, I would have to start again with a whole new set of people, and actually work with them and do a lot of work to show how I work, what support I needed and I don't... I feel I've proved and that I can do a very good job, you know I get over one hurdle ...and then something else comes along, and I have to start it all again almost.

Teacher Practitioner

## **5.6 Environments supporting disclosure**

Participants described a number of factors within their employment and HEI environments, both practical and attitudinal, that had positively supported their disclosure. An important feature across all three professions was having a positive organisational culture. This was described as, in part, the attitude of the organisation, and those working within it towards disabilities:

I feel that it is very, very open and ... positive to employing disabled people, they haven't got an issue with it.

Nurse Practitioner

I was coming into an organisation that was pro-active and had a very enlightened attitude.

Social Work Practitioner

These attitudes were, importantly, underpinned by evidence of support processes in place for people disclosing disabilities:

I had my attitude changed slightly, I went out to work at the University, in their Student Support section on a temporary contract and it was the positive attitude towards supporting students through disabilities there that actually finally convinced me that my own problems weren't going to be held against me in that way.

Student Nurse

Encouraging environments were, importantly, evidenced by having other disabled people in the workforce or HEI:

The University has been really good, I think they have a good system going ... they are very high up on having disabled students and disabled teachers working with them.

Student Teacher

Having evidence of other disabled people with unseen disabilities would seem to be particularly significant, as the type of disability appeared to influence the attitudes to and experiences of disclosure that participants reported. Both students and practitioners expressed the view that hidden disabilities were more difficult to manage:

I think it's kind of harder sometimes when it is like a disability that you can't see, to have to bring it up, and sometimes feel like you are making a big deal out of it when you're trying not to.

Student Teacher

It was noted that within a genuinely positive organisational culture, this supportive environment was established at the outset rather than as an afterthought:

On day one X came in and said, 'my name is X, I'm the Disability Officer, none of you need to tell me now in this group ... but if

anybody has a disability issue or they have something that they want to speak about then come along to my room', and I think that that was done in the most effective way, because she told us right at the start ... so when I did feel I needed someone it was easy for me to go along and see her.

Social Work Student

Practitioners reported that, when disclosing, the overall organisational culture was mediated by the attitude of their immediate managers. As will be further discussed in the following chapter, the decision to disclose was influenced by having someone supportive in a position of authority:

Somebody who you can trust, you can tell them because you've built up that trust.

Teacher Practitioner

For me it would be very easy ... I've got, got a very good manager. If it was the manager above him I wouldn't want to tell him anything.

Social Work Practitioner

Where managers were considered to be unsympathetic to disclosure of a disability, it was sometimes possible to bypass them:

My initial line manager was very negative, and wanted me to be finished, as far as she was concerned I was no use to her ... I actually then bypassed my line manager and went to her line manager ... and I told her everything.

Nurse Practitioner

## **5.7 Barriers to disclosure**

Participants also described barriers that had inhibited their disclosure. A significant number from all three professions reported their belief that disclosure would preclude entry to study, and they had therefore not disclosed their disabilities when applying to their HEI:

I just thought I wouldn't be accepted on the course...I don't know if that's right or not ... so no, I didn't.

Social Work Practitioner

When I first applied to do my MA I didn't tell the University that I had a problem because I was worried that they may not take me on.

Student Nurse

As noted in the previous chapter, this assumption derives in part from the lack of information about how disclosure would be used:

The fact that they're saying ... you've got to give this health questionnaire and you may be refused a place on the fact of your health or your disability, but not giving any guides to what they're looking for, may prevent people with any sort of disability applying.

Social Work Student

Similarly, practitioners anticipated negative responses from prospective employers to a disclosure of disability, and therefore chose not to disclose within job applications:

I, from a personal point of view, wouldn't want to disclose to them because they might expect somebody to be off all the time, and somebody like myself I don't have a history of absences, I've a very strong work ethic.

Teacher Practitioner

Some unscrupulous managers, and there are a few around, might, or people on interviewing panels might think actually no, we've had a bad experience in the past or no, I think you know it's going to be too costly from a budget point of view, or we can't support them.

Social Work Practitioner

In response to these widespread fears about disclosing, some practitioners had chosen a compromise position of partial disclosure, sometimes by disclosing only one of a number of disabilities, and often by understating the extent of their disability or disabilities:

What the NHS don't know is how progressive my disease is ... I do believe if they did know what was going to happen to me in the next few years ... they probably wouldn't employ me.

Nurse Practitioner

Once established in the workplace or HEI, disclosure of unseen disabilities was often managed incrementally, and tested out with particular colleagues, if confidentiality within an organisation made this a possibility:

I haven't disclosed to my peers, I haven't disclosed to a lot of tutors ... if I don't perceive them to be trustworthy I don't.

Student Teacher

When considering the barriers to disclosure, several participants noted that the administrative process could be onerous in itself, and a deterrent to disclosure:

The medical health questionnaires are off-putting though because it is quite long and it does cover a lot of things which you might think should really be known by, say, your family doctor or the doctor who is your specialist ... I could see quite a lot of people not disclosing, and I was tempted not to disclose because of that.

Student Teacher

For some who had chosen not to disclose, or to disclose only partially, their current attitudes were influenced by past negative experiences:

I will put down that I am epileptic because I have to, if I'm being honest, if asked how recent the fits were, I'm not sure I would open up and tell the truth anymore because of my experiences from disclosure in the past.

Nurse Practitioner

## **5.8 Stigma and labelling**

The issues of stigma and labelling were raised by those interviewed, and some noted the irony that within professions whose role it was to empower others, these processes remained evident, and represented significant barriers to disclosure. Whilst participants had suggested that all unseen disabilities were more difficult to manage, most professionals with mental health problems perceived that their disabilities carried additional stigma, and reported that this was instrumental in them not disclosing to their workplace or HEI:

I don't mind disclosing about my back, I guess for me it doesn't carry the embarrassment factor, I mean anyone can get physically ill but mental illness is a different thing, there's a stigma related to it and it's not something that you talk about.

Student Social Worker

This additional stigma was also noted by those who had disclosed physical impairments:

God knows how people who have got mental health problems [disclose].

Nurse Practitioner

As noted in the previous chapter, the use of particular labels or terms was contentious and terminology was a significant factor in disclosure. A number of participants chose not to disclose as they did not identify their impairment or long term health condition with the concept of 'disability', even though they fell within DDA definitions:

If it says 'are you disabled?' I tend to sort of put 'no, but I have a mobility problem', because I don't class myself as being disabled.

Nurse Practitioner

I really don't consider myself disabled, so any sort of question that asks 'have I a disability?' I always say 'no'.

Social Work Student

Examples were given of professionals responding differently to opportunities to disclose, depending on the wording of different forms:

I can't remember the actual application form, it may have said 'do you have a disability?' but not included dyslexia ... so I possibly got round it that way, whereas it was specifically stated on my student nurse application form and therefore I felt I had to disclose it there.

Nurse Practitioner

The decision of whether to disclose was also influenced by an individual's attitude to the label of 'disability', even if they understood that the term did apply to them. The label was viewed by many practitioners as being damaging within the workplace:

There's a hell of a lot more to it than just a label if you like, you know it, because there are several aspects of my abilities that I can do, but then disclosing I have a disability kind of wipes those out.

Nurse Practitioner

Several participants acknowledged, however, that their sense of their own identity and their personal level of comfort with the label contributed to such decisions:

I have been told by HR ... it may be to my benefit to ...describe myself as disabled, they keep telling me it is not as it used to be..... if I need to be redeployed in any way because I can't do my own job it may be helpful in the future.... I think that once I label myself I will feel different, so I decided not to do it at that time.

Nurse Practitioner

Students considering disclosure reported their concerns at being perceived or treated as 'different' from their peers. These concerns were often proved founded, as discussed in the following chapter:

I felt they'd perhaps question my fitness levels or put too much undue emphasise on 'oh she's got a disability, do you know?' and I didn't want to go down that road, I just wanted to be like any other student on the course.

Social Work Student

## **5.9 Consequences of non-disclosure**

Those who had chosen not to disclose and had managed to conceal their disabilities, reported that there had been implications for them. Some described practical consequences, such as having to work harder:

I've learned not to disclose because I don't think it is positive to disclose, and the negative consequences of that are perhaps it does take a little bit longer to do physical things than it does other people.

Social Work Student

In addition there could be emotional consequences of not disclosing:

I feel like a liar, I feel like people don't know the real me.

Student Teacher

Some acknowledged that by not disclosing they had possibly missed out on support, but that their fear of negative outcomes had outweighed this:

There may be benefits if I could disclose it but I don't feel comfortable to do so, that I would necessarily get the understanding.

Nurse Practitioner

## 5.10 Summary points from Chapter 5

- Disclosure was unlikely to be experienced as a single event, but rather as a series of steps or negotiations. This was particularly the case for students who had to disclose repeatedly to different placement settings.
- Reasons for disclosure varied: for some, there was no element of choice; others considered it a matter of principle or viewed disclosure as a means of obtaining adjustments.
- Disclosure was acknowledged to be a risky process which could jeopardise entry into and progression through a profession.
- Confidence concerning disclosure increased with experience and seniority in a profession or setting.
- An organisational culture which signalled support for disabled people was considered to promote disclosure.
- A failure to convey how disclosure of a disability would be used and who would have access to the information was considered to mitigate against disclosure.
- The stigma attached to disability, particularly that associated with mental health problems, was identified as a major barrier to disclosure.

## **Chapter 6 – Consequences of Disclosure**

This chapter analyses responses to disability following disclosure within workplaces or educational settings. It starts with reports of the attitudes encountered by practitioners and students. The chapter then moves to discuss experiences of adjustments and accommodation.

### **6.1 Attitudes encountered**

#### **6.1.1 Managerial support**

The previous chapter noted the importance of managerial support or its absence. This issue was referred to in all professional accounts and the relationship between professional and manager appeared to be key in facilitating a supportive environment, instilling confidence and in accessing wider organisational adjustments. The opposite, was also true: a negative, indifferent or discriminatory manager made work stressful, difficult and for some, impossible. Many participants referred to the range of attitudes they had encountered from managers they had worked with, and noted that individuals did not always reflect the wider organisational culture:

The boss that appointed me for this job is very, was very good about my depression, so that's why I took the job in the end but he's moved into a different department, so I'm back with a new person and I found that very difficult.

Social Work Practitioner

Well the barrier appeared ... that felt it was there because when you're in a workplace and you work and somebody new comes along and you don't know them it's a difficult one, or if you come back to the workplace and there's been a change of management, a total change in management structure, it's even harder.

Teacher Practitioner

#### **6.1.2 Colleagues' attitudes**

Many of the participants commented on the attitudes of colleagues and the ways in which these were supportive of or contributed to their

problems. From each profession came reports that colleagues might perceive accommodations as favouritism or letting down the team:

It was a bit of a shock going onto half-time and I hadn't in any way, because I am a bit selfish I don't know, I hadn't anticipated that it might cause resentment within my colleagues because I assumed that they knew I had cracked up and it wasn't as though I was sitting around doing nothing, I wasn't going home every afternoon, I was sitting in the office producing teaching materials and you could argue it wasn't useful to anyone else, or it wasn't the right sort of teaching, but I was doing something, visible, it just wasn't ...it upset them basically and I was aware that I had upset them, at least two people.

Teacher Practitioner

Others however, reported feeling that their disclosure had led to reactions of a different kind, in that they had been treated with an attitude that bordered on or crossed from understanding and empathy to being condescending:

I do feel that I have been penalised a bit then because I got the job, but I have been off sick for four months in the past and that period of illness is quite significant on my application form, and then when something insignificant happens at work 'oh we don't want you to get ill again', and you know it is like over-reaction from their part not checking with me whether that is what I want, which is nice of them to be aware and give support but on the other hand it is a bit like babying....It left me with the impression that I am this fragile thing which people have to be aware of...which is....I don't know it might be me being oversensitive, because on the other hand I suppose I wanted people to know that they were sensitive to my needs.

Social Work Practitioner

### **6.1.3 HEI attitudes**

Students reported their experiences of the attitudes of HEI staff and also the attitudes encountered during their professional placements. In a minority of instances, the attitudes of HEIs were not perceived to be positive, One Social Work Student spoke of feeling that tutors were too busy to talk to her and that she felt their body language indicated that they did not have time for her. A Student Nurse said:

...it is just that every time she (tutor) sees me she puts her head on one side 'How are you...?' and it is just unbelievable, I think she thinks I am just going to keel over and die there and then and ...she treats me like I am like this little special friend who needs to be...I don't know....

Student Nurse

However, in contrast to this small group, other students were quick to point out that they felt they had been treated very sympathetically and positively, with due attention to the appropriate balance between being supported and given autonomy:

So until they got to know me I think they were perhaps keeping a closer eye, maybe ...I don't know perhaps, but you know I think that is just kind of being responsible really, so I didn't mind that at all. It was just the impression I got and I thought that was quite a good thing.

Social Work Student

Many students also described their appreciation of the rapid delivery of equipment that arrived when they were studying. HEI disability services were also commended for their understanding and practical help.

In a small number of cases, the positive attitudes of HEI staff were contrasted with the negative attitudes of practitioners encountered on placement. This group included students who had received what they considered to be highly prejudiced responses to their disability, such as being told that their disability would hinder them in their career or was attributable to 'God's punishment'. Such experiences were however limited to a minority and students recognised that such views were extreme.

#### **6.1.4 Boundaries of confidentiality**

In a minority of interviews, there were reports of confidentiality not being respected to the extent that the professionals or students would have wished:

A letter was sent, it was quite a long letter, detailing all aspects of my illness, was sent to my Ward Manager and was read by the Deputy Ward Manager who disclosed it to staff in the ward.

Nurse Practitioner

However, some of those interviewed acknowledged that people might hold different views about information sharing and that these might relate to personal factors or to feelings of stigma:

I'm quite a private person so no, I just don't want to share it, personal information with the unit, and the reason I don't want to share that is the fear of being seen as different.

Social Work Student

It was evident that, for many of those interviewed, negative or inappropriate reactions to the disclosure of their disability affected how they attempted to control information by using confidentiality as a way of protecting their privacy:

As far as I've experience of, you know, with confidentiality and everything like that, but I mean sometimes I, you know you're careful to pick and choose who you ...tell about these things, I mean sometimes you know, people can overreact to something ...

Student Teacher

There were particular concerns about confidentiality where mental health problems were involved. One student nurse commented:

I wouldn't feel safe disclosing to my other nursing students: 'oh yes, by the way I was a patient in the ward'. I just would not feel at all safe that that confidence would be respected.

Student Nurse

In a small number of instances, those interviewed thought that more people would have been informed about their disability than in fact was the case. One student nurse described how she thought that telling one member of staff would mean that the information had been circulated to other staff members:

There was one week when I was ill and I couldn't walk but I thought I don't want the lecturer seeing me like this, I am not turning up so I spoke to him directly and said look I can't walk properly, you know I have got MS and he said 'Oh you have MS' and I thought, God, I thought they all talked behind everyone's backs and everyone would know, but he hadn't been told so he was absolutely fantastic as soon as I told him.

Student Nurse

## 6.2 Experiences of adjustments and accommodations

### 6.2.1 Promptness and availability of adjustments and accommodations

Practitioners and some students commented on the timing and appropriateness of the adjustments made by their employers following disclosure. It was possible to classify these into positive, negative and mixed experiences, but all accounts were highly individual and related to context. In 11 instances, practitioners and students encountered generally positive responses. One social worker referred to her rather 'cool' piece of furniture that was greatly admired by other staff. Some practitioners received help from Access to Work, and this could be in the form of help with expenses, such as taxi fares, or with the provision of a support worker, to accompany a social worker on home visits, for example, or to be present in the classroom, or a guide dog.

However, for some, there were delays in receiving advice or equipment:

I've gone through Access to Work, which they didn't tell me about until I had a health review, and they came out and did an assessment and I'm still waiting for some of the equipment.

Nurse Practitioner

It took three months before I got the equipment that I needed, and I was sitting on an ordinary little chair that was really uncomfortable, the desk wasn't the right height, the computer hadn't been sorted out, and I probably moaned and groaned my way through that at that time and so then when I got the chair that was wonderful, it made all the difference. It just made all the difference.

Social Work Practitioner

There were occasional instances of practitioners from all professional groups reporting that accommodations had been refused on apparently negative or prejudicial grounds:

I said 'I know, I know my walking's not that good but what about if I used, I used an aid?' Thinking, I've spoken to my line manager, she said that would be okay. (The ward sister said) 'No, can't have an aid, health and safety, no, you aren't having an aid'.

Nurse Practitioner

I felt I was being pushed out in a very underhand manner. I didn't want to deliver other courses as I didn't have the interest or expertise in these other areas. They weren't concerned about my health and safety and did not help me to transfer training equipment up and down flights of stairs to my car, despite the fact I was still having physiotherapy.

Nurse Practitioner

Three professionals reported mixed experiences of receiving adjustments and accommodations, with some items appearing or some flexibilities being introduced, but not others. For example, one nurse received computer equipment, but the workplace itself was not flexible in patterns of work or shifts.

### **6.2.2 Types of adjustments and accommodation**

Adjustments and accommodations for professionals with unseen disabilities were often not in the form of equipment but rather involved introducing flexibilities in work practices, as these nurses explained:

I worked in the acute sector so there was a lot of admissions, it was a very, very fast pace, things changed very quickly, so I moved to a continuing care unit where there is a lot of terminal care, which I really enjoy, so I moved there, the patients don't change, they're there probably for up to six months, ... there isn't change for me to deal with on the same scale that I was dealing with before. Initially I had been sent there temporarily and he (manager) suggested that I might like to stay there long term but there was no pressure put on me, if I had wanted to return to my previous ward I could have but I opted to stay in the new area.

Nurse Practitioner

I worked from home and that was nice because it ached quite a bit so if I was working here or in the study room on the PC and I felt tired I could go and rest.

Nurse Practitioner

In other instances, human support was the main form of adjustment delivered or required:

You know there are ways of describing things, you know I've gone into somebody's house and the Support Officer, you know rather, you know rather than saying, 'be careful it's quite a low chair', what

they've actually said is, 'you know this is a lovely low chair'. What the service user picks up is, 'this is a lovely chair', what I pick up is the low bit.

Social Work Practitioner

There was no support whatsoever as far as going back to work went except that I went back and did my very, very best the two and a half days that I was there but there was no extra help in the classroom for me or any support whatsoever, so I used to go home at night exhausted.

Teacher Practitioner

Managers' attitudes were central in securing this type of support, as this social worker outlined:

My first or second manager overcome the problems of the phone, for me, she made it possible for me, she made, she got it, the whole concept that's, some admin staff that would help me with phones, right? So obviously this is the whole thing, that works through a lot of things about people's fitness to practice probably, is whether or not people are prepared to think through what the actual problem is and find a solution....

Social Work Practitioner

However, colleagues' attitudes were also key in eliciting this form of human support. These two contrasting accounts display the importance of the team culture and ethos:

I have not found colleagues helpful: they all say 'fine give me a ring' whatever and then when you do they are busy, busy and they haven't got notes to share.

Social Work Practitioner

The only support I have actually had is the fact that a lot of the staff are understanding when I turn round and say 'I'm going', you know, they turn round and say 'right, I'll keep an eye on your class'; you know if I'm in by myself. So I do tend to get that you know amount of support, whereas I think if I hadn't disclosed the fact I had it, they'd say 'flippin' heck!' you know 'where is she going now?' you know, whereas because they know and it actually becomes a standing joke how quickly I can run down that corridor when I am desperate. So, no, don't get me wrong, I mean with a lot of the staff

I do get sympathy and I do get support and that's the only reason I've had to disclose basically.

Teacher Practitioner

### **6.3 Placement attitudes and adjustments**

Commonly, students who had disclosed to their placements found that placement agencies were less flexible and accommodating in their responses than the HEI had been and they considered that this reflected narrow- mindedness among some employers and that outdated prejudices about disabled people in the workforce were still operating:

At University, my deafness wasn't a problem, however I had a mentor on placement and it was a problem for her. She had never met a deaf nurse before and found it difficult to understand how I could be a G Grade Sister in the Community and be deaf. She was happy for me to be a lower grade but not to be a senior nurse.

Nurse Practitioner

Students were disappointed to meet less flexibility and understanding in placement situations than they had anticipated. Some considered that it was the employer not the student who needed to be flexible:

It was up to them to make reasonable adjustments like at the University.

Social Work Student

Dyslexic students appeared to find the contrast between the support offered by the HEI and the placement agencies particularly noticeable:

They knew before I went, it was all there and nothing was done and then three weeks before the end of my placement the link worker decided to make comment about my spelling in reports which caused me a lot of distress.

Social Work Student

It was suggested by those who had experienced placements in both the statutory and voluntary sectors that there was greater openness and flexibility in voluntary sector agencies.

There were however some reports of positive responses to disabled people from participants who had been provided with appropriate adjustments on placement:

I was fortunate on placement because the Local Authority actually agreed to get various software for me which would alone have cost about £500 for an 80 day placement so that's actually a commitment from that authority which I'm ever so grateful for because it means I'm here now where I am.

Social Work Practitioner

Some students had had both positive and negative experiences of attitudes and adjustments on placement and this reflected different employers' attitudes to inclusion of disabled people.

#### **6.4 Continued professional development**

All professionals have to undertake continued professional development and a number of respondents referred to this. For those in work, this might require proactive negotiation about the ways in which this could be achieved. One teacher, for example, outlined how he had used the advice and status of the Disability Rights Commission to argue for adjustments:

We have to put in an extra five hours a week of our own time after hours to doing professional development and so on, now I approached the school and said look by 4 o'clock I'm washed out with the diabetes...I would like to do my professional development time etcetera in the morning, come into work three-quarters of an hour before I have to, be able to sit down and do my work there, so what I was saying to them basically is, 'I'm not saying I can't do this or I won't do this, I want to do this but I would like to negotiate with you over the time of when to do it.'...at first this wasn't taken on very well...I went back to the school and spoke to them but I let drop that I had phoned the Disabilities Commission and straight away the attitude changed and I was allowed to do my professional time in the morning but I, I mean instead of accepting a sensible suggestion then, I virtually had to fight with them to get it.

Teacher Practitioner

Others, who had undertaken continued professional development outside the workplace, also explained how they had sought to test out what was available. In a number of cases, professionals had been surprised that accommodations and adjustments had been easy to achieve and that

their requests did not seem to be out of the ordinary for educational providers:

I actually told the lecturers that I had a bit of difficulty hearing and I had to sit at the front and did they mind if I asked questions, and they said 'oh no, that is fine.'

Nurse Practitioner

In another account, a teacher identified a proactive approach arising from his/her medical assessment that had proved helpful in setting down in writing what he/she would need from any educational provider:

One of the things that came out of the medical was a letter for any training providers for me which I think was very sensible, that basically it informed if I was going on a course that I would have problems with the light input of any PowerPoint presentation or DVD presentation, this type of thing and was therefore, was the course suitable? Was it suitable if there was a small part of course that was to be presented this way, could I be given the material in a written form? And I would actually take myself out at that point and then return into the room once it had finished, and I felt that was a very positive aspect of it.

Teacher Practitioner

## **6.5 Occupational health services**

Twenty-five of the 60 professionals reported their experiences of Occupational Health Services. The largest group describing such contact were nurses (10 practitioners and 3 student nurses), but eight teachers (including one Student Teacher) and four social work practitioners outlined their contact with the service. This profile means that most of the comments on Occupational Health Services relate to experiences of practitioners and to the NHS Occupational Health Services which the nurses in this study had contacted. Of the 25 accounts, the majority (20) were positive, two were negative and three had limited contact, or did not indicate if their contact was positive or negative.

Professionals who were in contact with Occupational Health Services were, in the main, clear about the remit of the service. Many appeared to have been proactive in their contact with the service, and the support of the Occupational Health Service enabled them to feel confident in their ability to work and, in some cases, to provide a source of recognised expertise in challenging opinions of managers. Words such as 'useful',

'fantastic', 'really good' were used by professionals in relation to Occupational Health Services:

I found that my employer's Occupational Health Service was brilliant in not only supporting me, but also protecting me from the line manager, bully.

Social Work Practitioner

The support described in such examples seemed to be related to the personal qualities of Occupational Health staff, but also related to the service's role in confirming a professional's own opinion about their capabilities. In some cases, Occupational Health was perceived as acting in an intermediary role with employers who considered that the professional might not be still able to continue in practice. At times, Occupational Health staff were characterised as advocates who would challenge employers' opinions. For example, one teacher explained how Occupational Health made representations to the School where he/she worked:

You know they actually sent me to see the occupational therapist and the occupational therapist turned around and told them that, you know, they should give me more time off work when I wasn't feeling very well with the diabetes and so on, they didn't like it at all.

Teacher Practitioner

In another instance, Occupational Health staff had recommended that their service could ameliorate a difficult situation by talking to the nurse colleagues of the disabled practitioner to help them to be more accepting and understanding.

However, despite these overwhelmingly positive experiences, some had a more negative view of the advisory role of the Occupational Health Service, seeing it as limited in its capacity to enforce its recommendations:

I self-referred to Occupational Health when I came out of hospital. Occupational Health have always been supportive and I returned to work probably nine months after I had been in hospital and there was nothing in place for me, it was very much Occupational Health said I shouldn't take charge for the first like two months... I went back... (but) on my second night, I was left in charge and that continued.

Nurse Practitioner

The interviews revealed a variety of approaches to making contact with Occupational Health among practitioners when the onset of disability occurred after they had qualified. A small number of students (4) also outlined experiences with Occupational Health Services. These students had found that Occupational Health was a source of help and considered the service supportive, although as one student nurse explained, she had felt initially cautious:

I really was a bit suspicious of them originally because I had been sent, and you have MS, go to Occupational Health... so I never told Occupational Health about any of the real stuff that was happening, my relapse, I never gave them any real symptoms; I didn't go through any of it until the last month.

Student Nurse

Occupational Health Services were generally viewed positively by the research participants. Some contrasted their experiences of Occupational Health as a supportive and unprejudiced service with their negative experiences of their managers' attitudes.

## **6.6 Experiences of disabled managers**

This chapter ends with accounts from managers, since these were particularly interesting as a number of these participants had both a lengthy experience of disability as a professional and could also describe how the profession had been supportive of their career developments. The caring professions have high numbers of disabled managers in comparison with the rest of the managerial workforce and there are lessons to learn from the experiences of those who may have been pioneers and are now in a position to balance the multiples needs of the organisation. For some, their managerial position gave them insight into the resources of the organisation and the confidence to access them as this senior nurse professional explained:

Straight away, because of my condition anyway, and being a manager, I've been self-referring to occupational health anyway, so they know and they've known for a good few years.

Nurse Practitioner

Another nurse referred to the strength of her position now she was in a senior role:

When you are lower down in nursing you felt that they were ten a penny, so if you weren't right they would sack you and get another ten that were waiting for your job, but as you become more specialist and more ...almost indispensable even if you are not, there is no such thing, but I just felt that they would have more to lose if they did.

Nurse Practitioner

This small group emphasised the importance of managerial responsibility in mediating between the needs of the organisation and the needs of the disabled professional:

We have an absence management process which is quite tough, but it has certainly brought down the sickness levels quite dramatically, but you know one of the questions, certainly as Manager when pulling in forms after one of my staff has been off sick, there is a question which says are there any DDA implications here? So there is a great recognition that there are staff for whom the DDA is appropriate and that may have an impact on their health and their working pattern, so appropriate recognition of that and it is dealt with appropriately.

Social Work Practitioner

As suggested above, these individuals were more confident in their expectations of adjustments and accommodations: rather than thinking that these would never happen, they were aware of their rights and identified delays and attitudes that they perceived to be below the standards that might be expected from caring organisations.

## **6.7 Summary points from Chapter 6**

- Managers' attitudes were identified as crucial in determining the response to a professional's disclosure of disability.
- Colleagues' responses were also important and could take the form of charges of favouritism or over-protective attitudes.
- Some professionals found that, following disclosure, their confidentiality was not protected to the extent they would have liked.

- Variations were found in the speed with which adjustments had been implemented and to what extent. In some cases, adjustments or accommodations had been refused.
- Adjustments and accommodations for professionals with unseen disabilities often required flexibilities of working practices, human support or attitudinal changes; managers' and colleagues' attitudes were key to the delivery of these forms of accommodation.
- Students reported that their experiences of attitudes and adjustments in placement settings often compared unfavourably with the responses they had received to disability disclosure from HEIs.
- Professionals' experiences of Occupational Health Services were mainly positive although, in some cases, Occupational Health staff were seen to lack the power to implement their advice.
- Disabled managers were more confident in their expectations of adjustments and accommodations but recognised that these had to be balanced against other organisational imperatives.

## Chapter 7 - Promoting Disclosure

### 7.1 Messages from experience

Given the range of both positive and negative as well as mixed experiences within all three professions, it was important to consider possible ways to improve the disclosure process, to provide better safeguards which would encourage more people to disclose and to enable organisations to become more supportive to disabled people. While the research identified a minority view that disclosure was primarily a 'personality thing' and therefore immune to influence from HEIs, employers or regulatory bodies, the majority of participants identified practical ways that would improve the process of disclosure and these are summarised under key headings below. Some of these suggestions pick up and develop themes identified in earlier chapters.

### 7.2 Disabled friendly environments

Professionals considered that HEIs, employers and regulatory bodies could encourage greater numbers of people to disclose by making it explicit that they were positive about including disabled people on courses and in the profession. Responding positively to disclosures was believed to instil 'confidence to be a bit more honest with employers and university and so on.' In the experience of one Social Work Student, the issue of 'whether you get a positive or negative reaction' was crucial.

Participants across all three professions underlined the importance of 'attitudinal change', and of developing a 'disabled friendly' culture or organisation. They referred to the need for acceptance and acknowledgement that 'individuals, no matter what that disability may be, can be very effective in what they are doing'. Commenting on his experience of negative workplace culture in the NHS, one Nurse Practitioner described the effect this could have on individuals' decisions to disclose about impairments:

It's attitudinal change which takes years to affect. The one thing that I've learned and it goes against all my principles and the way I've been brought up is, if you can get away without disclosing anything don't disclose, you know keep quiet.

Nurse Practitioner

One indicator of the extent to which a work setting was perceived as 'disabled friendly' was the way in which employers dealt with periods of sickness and absence for disabled staff. Professionals questioned whether it was appropriate to apply traditional approaches to managing sickness and absences to disabled employees. A small number of those interviewed, mainly practitioners rather than students, described how policies on sickness and absence were experienced by staff with long term health conditions or mental health problems:

Been sent to employee healthcare several times and I would say, as a manager myself, I would say they'd done that to cover themselves. I haven't seen it as a helpful, and what happens every time they send me, as a manager I understand they'd to do that sometimes, I don't have a problem with it, but every time they send me, they'll say the same thing, either have a direct link to psychiatrist and a direct link to a behaviour therapist and I can ring those two any day I want.

Social Work Practitioner

In some workplace cultures, sickness absence policies had been used in what were perceived as punitive and discriminatory ways. One Nurse Practitioner commented that 'the way they [the employer] feels about the sickness absence thing is malingerers'. As one Teacher Practitioner explained, this type of underlying negative and unsupportive attitude was sometimes covert:

They're: 'oh God, he doesn't want more time off again?', but they don't actually physically say that but you can tell.

Teacher Practitioner

Practitioners described being 'disciplined on my sickness' and of getting official warnings for having more than one episode of sickness during a specific period of time. Others referred to adverse comments from colleagues in relation to taking periods off sick, such as, 'I wish I had a doctor like them who would give me a sick note for six months'. In contrast, other workplaces had used sickness absence policies flexibly to differentiate those whose long term health condition or impairment meant regular time off work from other staff taking frequent sick leave. In such circumstances, disabled professionals felt the employer had recognised 'a genuine problem'. Clearly, some organisations adopt more 'disabled friendly' policies than others and this was perceived as making a difference.

The impact of a 'good manager' who was prepared to adapt policies not always designed with disabled people in mind, was emphasised. Practitioners repeatedly described their vocation to be a nurse, social worker or teacher and how their desire to continue in their job had or had not been supported by their employer. They highlighted the need for supportive workplace cultures which promoted diversity and actively sought ways to sustain disabled individuals within the profession.

### **7.3 Messages about creating 'disabled friendly' environments**

Professionals wanted to deliver the following messages about what contributed to a 'disabled friendly' environment:

1. There needed to be far greater acceptance and understanding of disability and a more positive attitude towards disabled people in the workforce – more 'disabled friendly' organisations
2. Sickness Absence policies required examining to ensure they were not discriminating against disabled people and that absences for long term health conditions and impairments were treated appropriately.
3. Wherever possible, sickness record should be taken into account after the decision to offer a place on a course or a job
4. Employers should themselves be subject to an audit, for example, by regulatory or inspection agencies, concerning their fitness to manage and include disabled people.
5. Attention needed to be paid to the accessibility of workplace environments as this signalled a positive or 'disabled friendly' workplace culture.
6. Employers needed greater support from the Government through Access to Work and other schemes to enable them to adequately resource 'reasonable adjustments'.

### **7.4 Clear and transparent processes**

As discussed earlier in this report, one of the main barriers identified to disclosure was the uncertainty and confusion arising from a lack of information about disclosure procedures and the resultant fear that applicants would not be successful on their chosen career path. Not surprisingly therefore, participants were advocating for clearer and more transparent processes across the board. As a Social Work Student suggested, this should typically include 'what it means to disclose and what should be expected' as a result.

One Nurse Practitioner spoke about being ‘very frightened to disclose information because I thought I would be dismissed’, acknowledging that this was a perception was held by many people in the profession. Instead of being met with negativity, this Practitioner was ‘reassured’ and proposed making more people aware of what support was available and what happens following disclosure of a disability.

It was argued that it was important that the disclosure process offered opportunities to explain the meaning of the particular impairment or health condition for the individual:

It would be nice to see room for explanation, or the chance to explain on the phone not just a yes or a no, because I have some pretty able disabled people. What is the impact of your saying ‘yes’ on a form, what does it mean and what do they do with the information?

Nurse Practitioner

Written statements would need to state the rights of disabled students or employees. This was considered as important in fostering greater confidence and creating a more positive environment in which to disclose. From a student’s perspective, one Social Work Student felt that the HEI statement about disclosure should make it clear that disclosure will ‘not affect any of your marks’. According to one Teacher Practitioner, knowledge of the process including that support will be forthcoming as a result of disclosure, would ensure disclosure was ‘done willingly’.

## **7.5 Messages about clear procedures for disclosure**

Professionals wanted to see:

1. Clear policy statements about an organisation’s approach to disability including information about what decisions are made on the basis of health questionnaires and what happens after disclosure.
2. HEIs, Employers and Regulatory Bodies to provide a flowchart diagram stating individual rights, explaining the process of disclosure, what will happen as a result of disclosure, and what support is available.

## 7.6 Communicating with and listening to the individual

Related to the need to have a positive and 'disabled friendly' culture was the importance of finding out what the impairment or long term health condition meant to each individual and how they were affected by it, as well as what assistance or support they needed. For instance, those with dyslexia emphasised that this was a complex condition, affecting people in different ways, and as such, required tailor-made rather than off-the-shelf responses. As one Nurse Practitioner proffered - 'the big lesson to be learnt is communication' - and a Teacher Practitioner noted that: 'listening is the most important issue'. Professionals suggested that this needed to be a dynamic, ongoing process, not a one-off event. Given that an individual's situation and their health could change over time, the dialogue needed to be continuous and responsive to changes in the environment. As one Teacher Practitioner explained her disability needed to be considered when change was imminent:

It's taking care to say oh there's a new school initiative here, are there going to be any problems in that?

Teacher Practitioner

In relation to HEIs, students felt that the approach to disabled students generally should become more 'student led', because the 'person themselves knows what their limitations, what their capabilities are' and was best placed to advise on what support they needed:

More emphasis should be on the student and their comfort levels and what they're comfortable disclosing and you know whether the student feels as though their illness or disability will impact on, on their place as a student or on placement. I think it should be more student led

Social Work Student

A key issue was the need for HEIs to be proactive in asking individuals how the impairment affected them personally. While it was considered that greater understanding of different impairments and long term health conditions would be helpful, participants acknowledged that HEIs, Employers and Regulatory Bodies could not possibly be expected to be informed about every impairment or health condition, but argued that they should take an interest in how this affected each individual:

I think once someone has disclosed to them...you can't expect everyone to have a knowledge of everything so as soon as

someone discloses they should do something to find out something about that condition, and I think that's where a lot of them go wrong because they don't know about it, they're naïve to it.

Student Teacher

Several participants who had disclosed, particularly students, identified poor communication between tutors on courses and, as noted in Chapter 5, students had found that that they needed to disclose repeatedly to every placement. Both Teaching and Social Work students commented they would have preferred for information about their support needs to have been passed onto placements in a positive way. Participants suggested that best practice would entail being asked if they minded information about their disability being passed onto tutors and placement supervisors.

## **7.7 Messages about communicating and listening to individuals**

Professionals emphasised that:

1. Responses to disclosure should be positive and, individualised and support should be person centred.
2. An individual's right to privacy following disclosure should be respected but they should be given the option for information to be shared with relevant staff if they wish.

## **7.8 Key contacts within an organisation**

Both practitioners and students highlighted the necessity for an identified person within the organisation whose role it was to offer advice and access to support, and to discuss the impact of the on the individual. This was seen as essential for those whose impairment or health condition occurred later on in their professional lives as there was often an absence of information and newly disabled people were uncertain of their rights in the workplace. One Nurse Practitioner commented:

There is a lot of information out there but unless you know you need it you can't get it until it is too late. You never find out until you have already muddled through it and you found it out by mistake, or you find out half way through I should have done this at the beginning...and then I wouldn't have had all these problems.

Nurse Practitioner

The Human Resources Department was identified as having a key role to play in advising 'what avenues to go down' and having knowledge of alternatives. As one Teacher Practitioner argued:

I think maybe from a Human Resource Department...it would be quite nice if somebody would perhaps have a meeting with the person who had been ill and lay down you know the steps that could or couldn't be taken to help that person get back to work. I was absolutely fine and then to be hit with this and then really to be left in a sea of just no knowledge, no idea how to go about trying to get back to work, no idea if I could be helped to get back to work...I just felt that I had to do it all myself.

Teacher Practitioner

One of the obvious benefits from having such a role within an organisation would be in providing reassurance to individuals faced with the decision about making a disclosure:

People need to be aware that if they do become unwell or if they are diagnosed with a chronic illness that the support is there for them. I think it's safer in the long run that people don't struggle on, I think that there is support and people are willing to help but they need to come forward and say what's wrong, that they are unwell and then the support is there.

Nurse Practitioner

For some Social Work Students, the key issue was having access to someone within the organisation who would accept and take the time to understand their situation, and importantly that whatever was shared with this person remained private and confidential. It was also important that such discussions were not abstract but resulted in needed support being put in place, hence the need for this to be action orientated and solution focused:

If I was able to speak on a one-to-one basis, privately and talk it through with somebody and if I knew that that didn't immediately get broadcast all over the place, you know the issue that we discussed was confidential and would stay that way and that if there was any help that could be offered

Social Work Student

While some wanted this role to be taken on by someone who could effect change within the organisation, others emphasised that a key feature of such a role should be independence:

An independent body....I wouldn't want to speak to anyone at my university because I think a lot of people are very two-faced and I wouldn't want to speak to a professional organisation for the same reasons. I would like someone independent.

Student Nurse

Further, participants considered it would be particularly valuable for the person offering this support and advice to be a disabled person themselves, thus demonstrating clearly a disability friendly culture. As one Nurse Practitioner argued, someone who was able to say: 'I was a service user and then I qualified, now I am a Staff Nurse' would send out a strong message that would be much more powerful than a written policy statement or 'a paragraph on an application form'. Participants envisaged this role as being one of providing support, leading individuals through the process, and providing practical advice.

As noted in the previous chapter, this key contact role had been assumed by Occupational Health staff in some cases. Sometimes, other colleagues had taken on the role of mediator in the workplace, particularly when direct line managers were perceived to be unapproachable. One Teacher Practitioner for example, described how s/he 'knew instinctively that it would be alright to trust' her/his colleague who had effectively taken on an informal advocacy role, oiling the wheels of communication between the disabled teacher and the Head Teacher.

## **7.9 Messages about key contacts**

Professionals wanted employers and HEIs to:

1. Consider how they might provide a personalised service to disabled students and employees through offering key contacts to advocate on the individual's behalf. This support would be available for people facing the decision to disclose as well as those who had disclosed.
2. Appoint staff to this key contact role who had personal experience of disclosing disability.
3. Promote and disseminate publicity about independent telephone helplines or sources of independent advice and information such as the DRC.

## **7.10 Disability awareness training**

It was suggested that University staff and practitioners involved in supervising student placements in all professions could benefit from increased awareness and understanding of disability and its impact on individual students and employees. Disability awareness training for managers was considered an essential element, indeed a 'mandatory' requirement, in creating a positive culture of acceptance and understanding of disability within an organisation:

I think every Manager, everyone who is a team leader, whether manager or supervisor should have some information about managing people with disability...every job has an induction booklet and if that job means managing people whether supervisor or lead in a team then the disability issue should be brought into that. So when you're managing people you should be aware that some people may or may not be able to do everything that is expected of them in the role, or some people may take a little longer.

Nurse Practitioner

NHS settings and managers came in for particular criticism with several Nurse Practitioners advocating the need for disability awareness and DDA training for NHS managers to address what they considered to be the lack of acceptance of disabled staff in the NHS. A Student Nurse suggested that there was a 'huge educational issue' in the profession and that HEIs, regulatory bodies and employers needed to 'take the Disability Rights to heart' and to implement 'the spirit, not the letter' of the law.

## **7.11 Retaining disabled people within the workforce**

The argument was made repeatedly about the importance of providing support to disabled professionals to ensure that the professions retained skilled and experienced practitioners:

I do feel that the professions could well be losing quite capable people who would bring a very different and worthwhile insight to the profession and be just as capable of meeting its standards given the right conditions in which to do so.

Student Nurse

A Teacher Practitioner argued that there needed to be more support to encourage people to return to work and to recognise that 'when you are disabled, the job gives you a purpose in life'. Participants emphasised the importance of redeploying professionals who acquired disabilities and building on their skills and experience which would otherwise be lost to the professions.

## **7.12 Promoting positive stories**

On a positive note, it was suggested there was a need to highlight and disseminate examples of positive experiences; such stories would act to dispel myths that disabled people were unfit to take on professional roles:

Having a disability isn't the end of the world and the Disability Rights Commission can make that positive...it can happen to anyone' you know it can be anybody from the richest to the poorest person and that was my main point in coming forward for saying that you know even though I do have these health problems, I still am achieving you know getting myself into a job. I don't want to be on Incapacity Benefit for ever.

Social Work Student

Similarly, information about circumstances where HEIs and Employers were getting it right or best practice case studies could be disseminated. Participants noted that one way of encouraging more people to disclose would be through providing tangible evidence of the organisation's track record in supporting disabled people.

## **7.13 Summary points from Chapter 7**

- Participants considered that work or educational environments should be 'disabled friendly' and identified some key elements of such an environment.
- Professionals wanted organisations to develop clear processes for disclosure which went beyond the tick box approach and were sensitive to the needs of the individual. Clarity about the likely consequences of disclosing disability was identified as helpful.
- Practitioners and students argued that employers and HEIs needed to communicate with and listen to the individual disabled person

- An identified key contact within the organisation who had responsibility for advising and supporting disabled people was seen as vital. This key contact would have a degree of independence which would allow them to offer confidentiality and advise staff who were contemplating disclosure.
- Disability awareness training for employers, those teaching on professional courses and those supervising placements was identified as important.
- Research participants argued that there was a strong 'business case' for retaining disabled people within the workforce.
- Professionals interviewed suggested that positive stories could be promoted and would have the effect of promoting disclosure.

## **Chapter 8 – Conclusions**

### **8.1 Awareness of fitness standards**

As a group, the professionals had limited awareness of the fitness standards for their profession. Their views were often vague and uninformed. Regulatory bodies were experienced as remote and threatening organisations in relation to disclosure. In contrast, the research participants were better informed about the DDA which they tended to view positively and see as empowering them in their negotiations with employers and training organisations. However, there was some feeling that the legislation ‘lacked teeth’ and was not always implemented.

### **8.2 The language of disability**

The language used to enquire about disability was significant in eliciting disclosure from professionals. They were concerned about the use of disability labels, although some acknowledged that these were necessary to deliver adjustments. The majority of those included in this study had unseen disabilities and many felt that the term ‘disabled’ applied only to those with physical disabilities. The participants were anxious about the stigma attached to different terms and, as a group in which long term health problems and mental health needs predominated, they found the term ‘long term health condition’ more acceptable.

### **8.3 Disclosure as a risky process**

The majority of research participants had disclosed their disabilities, although some had chosen to partially disclose. There was acknowledgement that attitudes were shifting and a third of those interviewed gave accounts of their experiences of disclosing disability and receiving adjustments that were generally positive. However, disclosure of disability was considered to be a high risk strategy which could have the effect of excluding an individual from training or employment and affect progression in the professions.

### **8.4 Stigma of unseen disabilities**

Participants in this study judged that the risks of disclosing unseen disabilities were compounded by the stigma attached to them. Mental health needs were seen to be particularly stigmatised.

## **8.5 Managing the risks of disclosure**

Retaining some sense of control in the process of disclosure was important to the professionals participating in this study and they considered that their sense of control was enhanced when they had knowledge about where their disclosure went, who had access to it and what the consequences of disclosure were likely to be in advance of the event. Such information appeared to be a means by which professionals could predict and manage the personal risks of disclosure. An individualised response to a disclosure was also regarded as valuable.

## **8.6 Experiences of adjustments and accommodations**

The delivery of adjustments and accommodations was in some cases experienced as slow. In a number of cases, adjustments requested or recommended were refused. In making a decision about disclosure, professionals will weigh the anticipated benefits of disclosure against the potential losses. Evidence in the workplace or training setting that disclosure can confer benefits will act as a driver for disclosure and participants identified the significance for them of seeing other disabled people supported in the workplace.

## **8.7 Adjusting attitudes and behaviour in relation to unseen disabilities**

Participants emphasised that some of the adjustments and accommodations required in relation to unseen disabilities, which included mental health problems and painful medical conditions, were shifts in attitudes and behaviour within the workplace.

## **8.8 A supportive environment**

A supportive environment was felt to be key in encouraging disclosure. Such an environment was characterised by information about support for disabled people being provided at the outset of employment or training. Other features of a disability friendly environment included clearly articulated and disseminated policies on support for disabled people and special consideration being given to the sick records of those with long term health problems. The visibility of disabled others within the work or training setting was another means of signalling a supportive environment.

## **8.9 An identified individual**

Professionals identified the importance of having access to an identified individual within their organisation who could provide them with information and advice on the process and consequences of disclosure. This information and advocacy role appears to be particularly relevant given the participants' low levels of awareness about the requirements of their regulatory bodies in relation to disclosure. Confidential access to such a person was felt to be important as the identified individual was conceptualised as someone who would offer the opportunity to consider and weigh up the risks of disclosure rather than as the person to whom disclosure would be made. Participants suggested that such a person would be able to offer the sensitive, individualised response to disclosure of disability that was not offered by regulatory bodies.

## **8.10 Managers**

In common with other studies (Gilbride et al 2003; Stanley et al 2007), this research found that managers played a key role in mediating the workplace or HEI response to an individual's disclosure of disability. Professionals reported varying responses and attitudes from managers and argued that managers required disability awareness training to ensure that they contributed to a culture that supported disabled staff in the workplace and that they understood their role in implementing the DDA.

## **8.11 Accumulating evidence to promote disclosure**

This study provided evidence that, despite the barriers to disclosure identified, many professionals in nursing, teaching and social work feel sufficiently empowered by disability legislation to disclose unseen disabilities in training and employment settings. However, their expectations of support are not always met and, unless there is accumulating and concrete evidence and information available concerning the benefits of disclosure in the workplace and in training organisations, professionals' willingness to take the risks involved in disclosure may not be sustained in the future.

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