

**‘Looking okay’: exploring constructions of  
fluctuating or recurring impairments in UK Higher  
Education**

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## **Abstract**

This research explores constructions and understandings of fluctuating or recurring impairments in Higher Education in the UK. It considers ways in which institutional discourses within one UK University have shaped policy and provision for disabled students, and how students with fluctuating or recurring impairments negotiate and enact identities in this context.

For many students, impairments such as chronic fatigue syndrome (CFS)/ myalgic encephalomyelitis (ME), epilepsy or diabetes, for example, have the potential to vary in intensity, and thus impact, on participation in learning activities and on self-perception/identity. With increasing disclosure, yet limited recognition, of such types of impairment comes a need for institutions to better understand changing impact in terms of inclusion and in observing anticipatory aspects of legislation, as well as furthering insight into how student identities are negotiated and constructed in an educational context.

This research uses a social constructionist framework to explore constructions and subjectivities as regards fluctuating or recurring impairments, and comprises both staff and student perspectives. The staff perspective is based on the thematic narrative analysis of interviews with three members of staff, and is presented in conjunction with an example of institutional policy to highlight discourses drawn upon in constructing disability and disabled students. The impact of these discourses on institutional constructions and practice is key to the analysis.

The student perspective is based on two phases of data collection: firstly, 24 semi-structured interviews with students who self-described a fluctuating or recurring impairment; and secondly, five students' responses to six bi-weekly emails over the course of one academic trimester (January – April 2011). Summary data from the first phase is used to frame discussion on issues raised by students regarding institutional constructions and support. A 'hybrid' narrative analysis framework incorporating

positioning analysis as well as both 'big' and 'small stories' has been used in analysing the phase two data. The approach considers the influence of institutional discourses on how students are positioned institutionally and position themselves, as well as ways in which performances of identity may be shaped.

The thesis concludes by considering the implications of the research outcomes for Higher Education. In so doing, it notes the significance of policy implementation and cultural change, and makes recommendations for areas of focus in raising institutional awareness of fluctuating or recurring impairments within existing constructions of disability.

## List of abbreviations

ADC	Academic Disability Co-ordinator
ADHD	Attention Deficit Hyperactivity Disorder
ADT	Academic Development Tutor
ASD	Autistic Spectrum Disorder
CFS/ ME	Chronic Fatigue Syndrome / Myalgic Encephalomyelitis
CWGHR	Canadian Working Group on HIV and Rehabilitation
DDA	Disability Discrimination Act
DOH	Department of Health
DSA	Disabled Student Allowance
EDEN	Episodic Disabilities Employment Network
EDF	Episodic Disabilities Framework
EDN	Episodic Disabilities Network
EHRC	Equality and Human Rights Commission
ELS	Effective Learning Service
GMC	General Medical Council
HE	Higher Education
HEI	Higher Education Institution
HESA	Higher Education Statistics Agency
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability, and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
JISC	Joint Information Systems Committee
LTAS	Learning Teaching and Assessment Strategy



NAR	Needs Assessment Record
OCD	Obsessive Compulsive Disorder
QAA	Quality Assurance Agency
SENDA	Special Educational Needs and Disability Act
UCAS	Universities and Colleges Applications Service
WHO	World Health Organization

## **Chapter One: Research context and rationale**

### **1.1 Introduction**

This research explores constructions and understandings of fluctuating or recurring impairments in the context of Higher Education in the UK. Specifically, the research focuses on the impact of institutional discourses on provision of support for students with fluctuating or recurring conditions, how staff operationalize policy and how students are positioned/ position themselves within these discourses. The research considers the perspectives of staff members and the experiences of students who described their impairment as one which has the potential to fluctuate or recur, and hence have a varying impact on their ability to participate in learning. This chapter outlines the underpinning research rationale and raises some contextual considerations. It also sets out my professional context at the time the research was conducted, and introduces the aim, objectives, and research questions to be addressed.

### **1.2 Research rationale**

I have taught and supported disabled students in a number of different roles for the past ten years, and the learning experiences of students with fluctuating or recurring impairments has, throughout, been a central feature. During this time, I became aware of a variety of complex strategies that students had developed to ensure that they could manage academic workload in periods of uncertainty and unpredictability regarding their impairment. One student, for example, had high impact CFS/ ME. She discussed how she placed Post-it notes summarizing key module content on her bedroom wall to enable her to read and revise whilst physically unable to move from bed. She also described how peer and staff perceptions affected her: for example, fellow students making audible accusations about their perceptions of the student's laziness for using a lift to get to the

first floor of the library or taking a taxi between buildings which were very close together. I was interested in how this student, and others that I had taught, managed anxieties, mental and physical energy and completed study in a complex infrastructure of expectations, competition and suspicion. Such contentious staff and peer perceptions and constructions are explored within this research, in analysis of institutional policy, the contribution of staff perspectives, and through student narratives of identity.

Indeed, the role of visibility in informing the limited legitimacy often attributed to fluctuating or recurring impairments has influenced the title of this thesis. One of the students who contributed to the research described how she had perfected 'looking okay' for a complexity of reasons, as will be discussed in Chapter Seven. By using the idea of 'looking okay' in naming the research, I have tried to highlight the crucial role that visibility of impairment plays in building social constructions of disablement, and specifically in terms of fluctuating or recurring impairments which are often 'unseen'.

My research interest in the locus between learning and disability began whilst undertaking a Postgraduate Certificate in Learning and Teaching in Higher Education (PG Cert LTHE) in 2003 as part of professional development activities. During this time, my formative ideas were influenced by Richardson's work with Deaf, hearing impaired and dyslexic students (Richardson 2001, 2008; Richardson & Woodley 2001; Richardson et al. 2004a, 2004b) as one of few examples of research which focused on a potential relationship between impairment and learning. Richardson and colleagues used quantitative research instruments such as the Approaches to Study Inventory (ASI) (Ramsden & Entwistle 1981), the Course Perceptions Questionnaire (CPQ) (Entwistle & Ramsden 1983) and the Course Experience Questionnaire (CEQ) (Ramsden 1992) to model approaches to learning amongst disabled students based on the core learner attributes of 'deep', 'surface' or 'strategic' approaches to study (Marton & Saljo 1976; Marton et al. 1997; Prosser & Trigwell 1998; Biggs 1999). Whilst a useful basis for considering the learning experiences of disabled students, issues of categorisation within the model raise

questions about the relevance or appropriateness of the outcomes in the context of students with fluctuating or recurring impairments and, indeed, the framework has been heavily criticised as regards over-generalisations in learner identity (Webb 1997; Haggis 2003; Malcolm & Zukas 2001; Greasley & Ashworth 2007). As shall be discussed throughout this research, where the impact of an impairment cannot easily be quantified, measured or predicted, inherent difficulties exist as regards classification and categorisation.

### **1.3 Professional context**

At the time I undertook the research, I was an Academic Development Tutor (ADT) in the School of Health at an urban, modern Scottish university. As part of the role, I provided on-going, developmental academic support for all students on undergraduate nursing and midwifery programmes, as well as to those students returning to engage in post-registration study. The history of such dedicated academic support roles has traditionally been one of a remedial nature, where provision can be characterised as 'bolt on' (Bennet et al. 2000) versus 'built in' (Wingate 2006). The former of the two conceptions carries the propensity to pathologise support offered, and reinforces any deficit perceptions that may be held not only of provision, but of those students who access it (Jacklin & Le Riche 2009). There is a suggestion that the latter approach is preferable (Mitchell 2000; Wingate 2006; Cassidy & Eachus 2000) in supporting integrative, holistic learning. In reality, however, the remedial stigma is difficult to dispel and still has a stronghold on many perceptions, staff and students alike.

The university implemented the ADT roles across the institution, embedded within each of the academic schools in 2008. However, the models of academic development delivery within schools differed significantly, having been tailored to accommodate subject-specific and demographic variations. For example, within nursing, there was a strong vocational

## Chapter One: Research context and rationale

focus which had the potential to eclipse academic engagement (Mckendry et al. 2012), and due to the hugely diverse and often mature nature of the student population, pedagogical approaches were closely aligned with confidence and aspiration-raising principles.

Provision in the schools was complemented by the centralised Effective Learning Service (ELS), which offered similar, but non-discipline specific, support. This 'hub and spoke' model is one that was also applied institutionally to support for disabled students, as discussed in more detail in Chapter Six.

The support continuum to which I contributed ranged from pre-entry outreach events, as has been core in traditional academic preparedness initiatives (Bishop et al. 2009), to more inward-facing, embedded and longitudinal work, including lectures, seminars and small group or one-to-one tutorials. A central component of this work was shaped by academic literacies (Lea & Street 1998; Lea 2004) and the enhancement-led approach of encouraging students to develop 'transferrable academic skills', within the explicit acknowledgement that students need to learn how to succeed in a particular environment (to 'learn how to learn') and highlighting that learning itself may be context dependent and require adaptation of existing skills to new contexts (Ramsden 1992). The importance of developing 'transferrable graduate attributes' was recently prioritised as an area of key focus within the composite Quality Assurance Agency Enhancement Theme relating to Graduates for the 21<sup>st</sup> Century (QAA 2010a). The Enhancement Themes themselves heavily influence professional practices and strategy at the institution where the research was conducted, and are a key frame of reference in informing pedagogical approaches to encouraging 'self-directed' and 'autonomous learning'.

#### **1.4 The ‘questionable legitimacy’ of fluctuating of recurring impairments**

The nature, and very existence, of many fluctuating or recurring impairments, such as chronic fatigue syndrome (CFS)/ myalgic encephalomyelitis (ME), epilepsy or diabetes has long been contested (Wessely et al. 1998; Working group on CFS/ME 2002). As such, historically, limited legitimacy has been offered to some forms of impairment, the effects of which can often be invisible and the severity of impact misinterpreted. Many aspects of such impairments have the potential to vary in intensity, and thus impact on participation in daily activities. Despite such limited recognition, however, in recent years terms such as ‘fluctuating’, ‘recurring’ or ‘chronic’ conditions have been increasingly used in policy, legislation and inclusion studies to conceptualise the lived experience of disability as one which can be unpredictable and changeable.

Today in the UK, organizations such as the General Medical Council (GMC) and Department of Health (DoH), for example, acknowledge the potential for impairments to vary over time. In documentation, the GMC (2010) make reference to ‘fluctuating’ conditions and underscore a responsive and flexible approach to provision of care, noting that suitability of treatment may change according to a patient’s wellness. The DoH (2007) uses the terms ‘progressive’ and ‘fluctuating’ conditions almost interchangeably, and outlines some considerations for employers in making adjustments to accommodate variations in wellness. Both the GMC and DoH note the potential for stigmatisation surrounding HIV/AIDS (a key area in chronic illness research that will be discussed in Chapter Three) and mental health, and acknowledge that this has the potential to negatively affect provision offered for patients.

The Episodic Disabilities movement in Canada (O’Brien et al. 2008, 2009; McKee 2007; Vickers 2001) has been particularly influential in raising awareness and challenging attitudes regarding changes in the impact of impairments over time. Similarly, scholarly work in the area of chronic illness (Strauss 1975; Corbin & Strauss 1985, 1988, 1991;

Glaser & Strauss 1965, 1968; Strauss & Glaser 1970; Strauss et al. 1985; Nordenfelt 1995; Williams 2000, 2010; Bury 1988, 1991, 1997, 2000, 2010; Jackson 2005) has much to offer in framing aspects of the lived experience which vary, in particular those related to participation, identity and perception.

The actuality of living with a fluctuating or recurring impairment, then, is one of inhabiting a transient, liminal space: a spectrum of various states between ability and disability; wellness and illness. Existing research that focuses on the experiences of people with fluctuating or recurring impairments discusses an otherness, negotiating relational identities outwith multiple social or cultural groups, in terms of ‘having a disability “sometimes”’ (Peters 1993, p. 26), being afforded ‘questionable legitimacy’ and of being ‘not disabled enough’ (Lightman et al. 2009). This ‘questionable legitimacy’ directly contradicts the principles and discourses of equality, inclusion and social justice at the centre of much current disability-related policy and legislation, and despite the advocacy of researchers and practitioners active in the field, the impact of fluctuating or recurring impairments remains an under-researched and under-represented area, particularly in the context of learning in HE.

### **1.5 Rise in disclosure of unseen impairments in Higher Education**

In the UK, there has been a continued year on year increase in the number of students disclosing ‘unseen’ impairments when enrolling on full time, taught undergraduate programmes in HE (HESA 2011). ‘Unseen’ impairments, according to the Higher Education Statistics Agency (HESA), include ‘diabetes, epilepsy, asthma’ (HESA 2011). Many ‘unseen’, ‘hidden’ (Matthews 2009; Valeras 2010) or ‘invisible’ (Lingsom 2008) impairments have the potential to fluctuate in intensity over time (as in the case of those used by way of example by HESA), and as such there is consequent potential for varying impact on students’ abilities to plan or undertake learning or assessment tasks at different

points in the academic year. However, in spite of this increasing number of students who have disclosed an 'unseen' impairment which may fluctuate or recur, little research concerning their learning experiences or construction of identities has, to date, been undertaken.

Students with 'unseen' impairments have in recent years, however, become a key focus for organizations such as Skill, the National Bureau for Students with Disabilities (as of spring 2011 no longer in operation), who actively encouraged increased participation in HE by students with 'unseen' impairments (Skill 2007). Indeed, in the institution where the research was conducted, students who disclosed an 'unseen' impairment outnumbered students who disclosed an impairment on the dyslexia spectrum, in line with overall UK HESA statistics (HESA 2012). However, as dyslexia itself could be construed as an 'unseen' impairment, disclosure outwith the confines of the 'unseen' category raises questions about acceptance and recognition of some forms of impairment.

A lack of attention has also been paid to institutional discourses and constructions of disability, and the undeniable potential this has to shape provision, support, attitudes (both explicit and implicit), assumptions toward students and impact on students' self-perception and identities. Policy and practice informed by a widespread construction of disability as an unchanging phenomenon clearly offers limited scope for responsiveness or flexibility, and may typically be reactionary rather than anticipatory. Therefore, institutions potentially risk compromising adherence to anticipatory provision that legislation requires, as well as to a commitment to inclusion in terms of providing equitable access to learning for all students.



## **1.6 Research aim, objectives and questions**

### **1.6.1 Aim**

This research aims to consider the influence of institutional discourses and the operationalization of policy in the negotiation and enactment of identities amongst students with fluctuating or recurring impairments in Higher Education in the UK.

### **1.6.2 Objectives**

- To explore ways in which students with fluctuating or recurring impairments are constructed within and by institutional discourses.
- To investigate how institutional policy is operationalized in providing support for students with fluctuating or recurring impairments.
- To examine ways in which student identities are negotiated and performed within institutional discourses.

### **1.6.3 Research questions**

1. In what ways do institutional discourses influence constructions of disability?
2. How might these discourses frame perceptions of fluctuating or recurring impairments amongst staff in HE?
3. In what ways are the identities of students with fluctuating or recurring impairments negotiated and constructed within HE discourses?

### **1.6.4 Additional practice-based questions**

1. In what ways might a fluctuating or recurring impairment affect student participation in learning and teaching activities?
2. To what extent is the concept of a fluctuating or recurring impairment understood/acknowledged within HE?

3. How does institutional understanding of disability shape provision of support for students with fluctuating or recurring impairments?

### **1.7 Use of specific terminology within the research**

Fluctuating or recurring impairments has been used throughout this research as a term for the types of impairment which the students who opted in to the research described and disclosed (see Appendix 1, Table 2, page 206 for a full list of descriptions). Seeking views on appropriate terminology was part of both the staff and student interviews, and is discussed in the data analysis in Chapters Six and Seven. Students' suggestions have also been summarised in Appendix 2, pages 208 - 209.

As became apparent throughout the research, on-going debate continues to surround the terminological merits of 'people with disabilities' versus 'disabled people'. The social model constructs disability in terms of limitations imposed by individuals, institutions and the built environment (Oliver 1996), and promotes the use of the phrase 'disabled people' to illustrate this. The Equality and Human Rights Commission (2012a), the Disability Discrimination Act (1995 and 2005), the Special Educational Needs and Disability Act (2001) and the Equality Act (2010) use 'disabled people' and 'disabled students' throughout. In practice, the LEXDIS research project (Seale et al. 2008) suggests that 'learners with disabilities' attributes the cause of disability to the student's impairment, whilst 'disabled learner' places emphasis on the inability of the learning environment to provide adequate support. In line with the social model, this latter term underscores the importance of inclusion and flexibility on the part of the institution. 'Disabled students' are referred to throughout this research. I have used the descriptive phrase 'students with fluctuating or recurring impairments' where necessary for specificity.

I have, again, according to tenets of the social model of disability, throughout the research for the most-part used 'impairment' to denote the physical or mental aspect of the lived experience and 'disability' to consider socially imposed limitations to participation ('... it is society which disables physically impaired people. Disability is something imposed on top of our impairments ...' [UPIAS 1975]). This differentiation is well-documented within social model literature as illustrating a divisive medical/physical/ mental versus socially imposed/ created split (Corker & French 1999) within understandings of the lived experience of disability. However, this binary of 'impairment' and 'disability' is contested by Shakespeare (2006), who argues that it is often 'difficult to determine where impairment ends and disability starts' (p. 38), and I have certainly been aware of this in my writing and reporting. Williams (1996) has argued that as regards disability, there is now no neutral language, as all terms and terminology even vaguely associated with conceptualising different aspects of disability carry loaded impetus.

### **1.8 Structure of the thesis**

Following on from this chapter, Chapter Two discusses issues relating to disability categorisations by considering global definitions as well as legislative terminology. In particular, the chapter draws on recent changes to UK legislation in shaping lay awareness of the potential for impairments to fluctuate or recur. As already noted, changes in terminological preferences have had a significant impact on the evolution of the research, and in many ways the continued contestation of terminology compounds the limited legitimacy afforded to fluctuating or recurring impairments.

Chapter Three is a literature review that considers parallels and divergences between models of disability and chronic illness research. The chapter outlines historic origins of contemporary models of disability, and in considering the limitations of the medical and social models of disability as applied to fluctuating or recurring impairments, discusses

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alternative frameworks such as the Episodic Disabilities movement as well as extensive scholarly work on chronic illness. The literature review concludes by considering evidence to support discussion on the construction of identities which have the potential to change along with variation in circumstance, participation or self.

Chapter Four sets out the rationale for using social constructionism as a theoretical framework within which to consider institutional policy and a narrative approach to the staff and student data analysis. It outlines the use of thematic narrative for presenting a staff perspective and a 'hybrid' narrative approach for students that includes both 'big' and 'small stories' and positioning analysis. In so doing, the 'hybrid' approach considers the narrative production and performance of identity through conversation and writing online.

Chapter Five accounts for the decisions taken within the research design and offers detail on sampling, recruitment and the overall research process.

Chapter Six begins with an overview of provision for disabled students at the institution where the research was conducted at the time the research was carried out and discusses a key policy document. The analysis of staff interviews in this chapter then focuses on how staff draw on institutional discourses in operationalizing policy, and considers the impact this has on institutional constructions of fluctuating or recurring impairments as well as on the provision that was accessible to students.

Chapter Seven considers the student perspective. It presents contextual issues raised by students in phase one interviews, and goes on to provide analysis of five student narratives of identity construction in the context of institutional discourses and constructions of fluctuating or recurring impairments.

Chapter Eight brings together the staff and student analysis, and considers the impact of institutional discourses and operationalization of policy on the negotiation of student identities. It also addresses the research questions set out in Chapter One.

## Chapter One: Research context and rationale

Chapter Nine outlines the implications of this research as well as the practice based questions also set out in Chapter One. The chapter considers the role of policy implementation, educational literacy and 'discourse coalitions' in bringing about cultural change to increase institutional recognition of fluctuating or recurring impairments.

In Chapter Ten, I reflect on the transformative experience of undertaking the research, consider the changes in my own positioning and discuss the dilemmas I experienced throughout the research.

## **Chapter Two: Policy and legislative context**

### **2.1 Introduction**

This chapter provides an overview of the policy and legislation that relates to provision for people with fluctuating or recurring impairments. The chapter begins with an international perspective on classifications of disability using World Health Organization classification documentation, in order to consider global definitions of what may constitute disability or illness. The role of UK legislation including the Disability Discrimination Act (DDA) of 1995 and the Special Educational Needs and Disability Act (SENDA) 2001 are considered, and specific attention is given to the Equality Act 2010 as an example of a recent move to influence recognition and improve accountability for inclusion and equity in access to services and support. By illustrating the diversity of often competing terminology used, the potential for continued ambiguity in public perception of the validity/ acceptance of impairments which may vary in impact will be discussed.

### **2.2 Conceptualising fluctuating or recurring impairments: an historical international documentary perspective**

For decades, discussion has surrounded how impairments are internationally categorised, classified, measured, defined and reported. Central to this debate are global definitions of disability set out within the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (World Health Organization [WHO] 1980), the International Classification of Functioning, Disability, and Health (ICF) (WHO 2001) and International Classification of Diseases and Related Health Problems (ICD10) (WHO 2010). As is apparent from the titles and some of the key characteristics of these classification documents, the World Health Organization (WHO) bases its definitions of disability and impairment in terms of health, illness and disease. As will be discussed in depth in

Chapter Three, section 3.5, pages 42 - 45, the complex relationship and often blurred distinctions between concepts of disability and illness often contribute to misconceptions of the legitimacy and severity of a lifelong condition.

The aim of the ICIDH was fundamentally to define and classify severity of disability in order to improve understanding and thus medical and rehabilitative provision (Duckworth 1995). Its language and content were notably shaped by a biomedical understanding of disability and physical aetiology. The ICIDH has been heavily criticised for its alignment with the medical model of disability, as well as its incorporation and use of terms such as handicapped, which is now considered to have associated negative connotations (Bornman 2004). Its successor, the ICF, still has principles of classification at its core, but takes more cognisance of the social model of disability, and acknowledges the complex relationship between disability and health:

‘The ICF puts the notions of ‘health’ and ‘disability’ in a new light. It acknowledges that every human being can experience a decrement in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of humanity. The ICF thus ‘mainstreams’ the experience of disability and recognises it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability.’ (WHO 2001)

Whilst the ICF acknowledges both medical and societal factors in influencing how disability is experienced and lived (through the use of two lists: one of ‘body functions and structure’, and one of ‘domains of activity and participation’ [WHO 2001]), the International Classification of Diseases and Related Health Problems (ICD10), works on an almost entirely aetiological, diagnostic basis. Here, a set of symptoms or mental/ physical characteristics defines the impairment (technically a ‘disease’). Thus, although the mental or physical effects of, for example CFS/ME, are acknowledged (as a ‘neurological

disorder' under the ICD10 [ME Action UK 2001]), the way a person lives with an impairment is not considered, as is the case with the ICF, in a social or cultural context.

Challenges of measurement and quantifiability, such as those that are crucial to WHO definitions of disability and impairment, are twofold in the establishment of a shared understanding of fluctuating or recurring impairments. Firstly, actual estimates of prevalence of fluctuating or recurring impairments are difficult to establish, largely because comparability between different geographical and cultural groups in epidemiology studies can be problematic (e.g. Working group on CFS/ME 2002); and secondly, because of the very nature of the types of impairment under study, definitive inclusion/ exclusion criteria are often not possible to identify or are overly-complex, and again, difficult to draw conclusive, comparable results from (Working group on CFS/ME 2002).

Taking the example of CFS/ ME, much research regarding those whom it affects acknowledges an origin that is post-viral (Deale et al. 1998), and the role of physical attributions in treatment of the condition (Garralda & Rangel 2001; Deale et al. 1998). Increasingly, however, interest has grown in the possibility of a psychogenic origin (Gordon 1988) and again, how this impacts on aetiological attributions and the according effectiveness of treatment. However, whilst CFS/ ME is now widely acknowledged as 'a real entity (which is) distressing, debilitating, and affects a very large number of people' (Calman 1998), a lack of physically obvious symptoms compromise recognition and identification of disabled people. Indeed, the unsympathetic 'yuppie flu' pseudonym attached to the condition from the late 1980s onwards demonstrates this widespread and very public scepticism.



### **2.3 UK disability legislation and inclusion**

Allan (2005) has argued that a deficit model of provision for disabled students has driven educational practices for some time. This has historically been true of much disability-related policy, which has fundamentally been shaped by the medical model of disability, and characteristically compensatory in nature (Christie & Mensah-Coker 1999). Though linguistically problematic by today's standards, the Warnock Report: Special Educational Needs in England, Scotland and Wales (Department of Education and Science 1978), as implemented by the Education Act 1981, marked a move towards more inclusive provision for disabled students within education. Whilst indicative of the improvement-oriented policies of their time, Barton (1997) notes that such suggested reforms were essentially developed in response to what could be defined as 'special', in itself determined by what is viewed, conversely, as normal or mainstream education. Marks (1994) raises associated concerns in positioning disabled students within discourses of exclusion unintentionally:

'Individuals who are integrated are constructed by and within discourses that valorise normality, and regard difference as deviance . In the Foucauldian sense, students with disabilities are frequently disciplined and punished for their disabilities, even within policies and education systems that espouse commitment to social justice. To have a disability is to be inscribed as other, and as such, requiring of special attention' (p.83).

Oliver suggests that the Warnock Report and the 1981 Act were 'almost the final product of the old welfare consensus as applied to education' (Oliver 1996, p.80), and Riddell et al. (2005) argue that the Warnock Report itself marked a sea change in professional dominance in special educational policy-making shifting from those engaged in medicine to those in education. The Warnock report laid the foundations for the nature, aims and semantics of much disability related policy since (through direct influence or contradiction), as well as providing a catalyst for dialogue between a growing body of

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policy makers and researchers who cyclically construct and deconstruct what constitutes acceptable or preferable political or legal documentation, constructs or terminology.

Legislative changes that have occurred in the past few decades have contributed key concepts, phrases and terminology to disability policy and legal debate. The Disability Discrimination Act (DDA) (1995) was largely based on definitions of 'discrimination' and enforcing 'duty' on the part on a 'service provider' in the context of individuals being treated 'less favourably' in accessing 'goods, facilities and services'. The trigger for possible 'less favourable' treatment was 'disclosure', whereby a disabled person formally declared an impairment. The DDA also introduced 'reasonable adjustments' as a term for the negotiated provision of access to 'goods, facilities and services' that promoted participation and counteracted acts of 'discrimination' and advocated 'accessibility strategies and plans' in providing sustainable adjustments. Amendments added in 2005 extended the scope of the DDA to include 'from the point of diagnosis, people with HIV infection, cancer or multiple sclerosis' and 'end the requirement that a mental illness must be "clinically well-recognised" before it can be regarded as an impairment under the DDA 1995' (Inclusion.me 2010). Furthermore, the EHRC advise that the legislation accounts for 'long-term or fluctuating health conditions...problems with mobility, seeing or hearing, a learning disability, mental illness, epilepsy, AIDS, asthma, diabetes or a condition that gets progressively worse such as multiple sclerosis may be covered under the DDA' (EHRC 2012b). Until 2005, then, limited scope existed for the acceptance of fluctuating or recurring impairments, due to issues of recognition and diagnosis, and even with the 2005 amendment, such impairments *may* only qualify to be included.

Part 4, Chapter 2 of the DDA specifically referred to the 'duty' of education providers to provide 'reasonable adjustments'. The Special Educational Needs and Disability Act (SENDA) 2001 amended Part 4 of the DDA as well as Part 4 of the Education Act 1996 in a dedicated act that specifically addressed provision of education for disabled students. As with the DDA, attributes of 'duty', 'enforcement' and 'assessment' persisted in SENDA

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2001, as did a focus on 'less favourable' treatment of disabled students. SENDA also carried forward the need for 'accessibility strategies and plans'.

The Equality Act 2010 brings together diverse areas of legislation within one 'simple, modern and accessible framework of discrimination law' (Government Equalities Office 2010) to include disability as one 'protected characteristic' amongst a group that also includes age, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation (Home Office 2012). The Act replaces most of the former remit of the DDA, though the Disability Equality Duty continues to apply (UK Government 2010). Like the DDA and the Equality Act of 2006 before it, the Equality Act 2010 aims to prevent discrimination of disabled people with regard to employment, access to goods, services and facilities and property ownership. It also builds on the Special Educational Needs and Disability Act (SENDA) 2001 in promoting equality of access and parity in learning.

A key feature of recent disability-related legislation is that measures to ensure access to provision are required to be anticipatory. The DDA, SENDA and the Equality Act all require public sector bodies, including HEIs, to acknowledge and act upon an explicit 'duty of care', and carry out 'impact assessments' to identify any potential and actual barriers to participation in academic activities for any student with one or multiple impairments. The 'action plans' which are the product of the 'impact assessments' ensure that 'reasonable adjustments' are put in place to enable students to fully participate and meet the pedagogical objectives of their curriculum. Criticisms have been raised, however, that such a focus on the individual and their bespoke requirements may encourage a more pathologised model of service delivery (Slee & Allan 2001; Haggis 2006), which contradicts the notion that embedded processes are more inclusive.

## **2.4 Legislative change in the UK with reference to fluctuating or recurring impairments**

The Equality Act 2010 arguably marks an advancement in both recognising and making provision to support people with fluctuating or recurring impairments, in that it acknowledges the significant impact of 'long term' conditions (which it takes to include impairments which have persisted or are likely to persist for twelve or more months) and fluctuating or recurring conditions on daily life. However, interestingly, in light of issues raised in section 2.3 in this chapter regarding the conditional definition of 'special', guidance for implementation of the Act on the UK Government website suggests that 'there are special rules covering recurring or fluctuating conditions' (UK Government 2010). These 'special rules' are related to likelihood of recurrence, identification of a 'substantial adverse effect' on 'normal day-to-day activities' and whether an impairment could be considered 'past' or 'long term' (Office for Disability Issues 2010).

Despite pervading notions of fluctuating or recurring impairments requiring 'special' conditional rules because of their impact on 'normal' activities, the Equality Act does make an attempt at providing clarity on definitions of what constitutes a 'long term', 'progressive', 'fluctuating', 'recurring' or 'past' impairment. However, the issue that persists, as has also been discussed with reference to the ICDH and ICF, is that many impairments are not strictly definable within one category, and in actuality could span several. The content of the Act suggests that long term is the overarching concept; that there are potential variations in each of the forms of disability, if which are the cause of a 'substantial adverse effect', are eligible to be recognised as an impairment provided for within the legislation.

In 2009, legal obligations to recognise and make provision for people with fluctuating or recurring impairments were highlighted in the UK in a House of Lords ruling that amended the DDA (2005) to incorporate people whose impairments vary over time. The ruling

acknowledged that workplace discrimination had adversely affected a member of administrative staff in a packing plant, whose fluctuating and recurring difficulties related to vocal chords necessitated avoiding dusty or smoky work conditions and planning rests between telephone calls. The ruling found that in removing a partition which surrounded the claimant's desk, which raised noise levels and further exacerbated communication problems, the claimant's employer had failed to provide sufficient 'reasonable adjustments' to support her impairment (Disability Law Service 2010).

The case changed the law by altering the meaning and scope of the word 'likely' in the context of the presence of an impairment to add more probability, by amending 'likely to happen' to 'could well happen', and increasing the 'duty of care' on the employer's part to make adequate provision. Though not resolved until 2009, the action was raised in 2001, and through its course undoubtedly contributed to awareness-raising of the existence and prevalence of fluctuating or recurring conditions.

In light of this shift in definition, the launch of the Work Life website in the UK marked a conscious effort on the part of various government organizations and interest groups (such as the Department of Work and Pensions and the Multiple Sclerosis Society) to provide information on employee rights and employer responsibilities for people with what they term 'chronic fluctuating conditions' (Worklife 2011).

### **2.5 Categorisation during application to university in the UK**

The Universities and Colleges Admissions Service (UCAS), through whom applications for study in post-compulsory education in the UK are made, provide advice and active encouragement to potential students on disclosing an impairment (UCAS 2012a), and link to information about the process of ensuring and agreeing on 'reasonable adjustments' (Skill 2007). UCAS use the categories 'unseen (e.g. diabetes, epilepsy, asthma)', '2+

disabilities / special needs' and 'other disabilities / special needs' (UCAS 2012b) in reporting data on applications from disabled students, which are arguably less definable than, for example 'blind / partially sighted' or 'Deaf/ partial hearing'. There is no option on the form to disclose a fluctuating, recurring, episodic or indeed, long-term condition. Data collected by the UK's Higher Education Statistics Agency (HESA), as noted in Chapter One, has an 'unseen disability, e.g. diabetes, epilepsy, asthma' category, as well as data on disclosure of a 'long standing illness or health condition such as cancer, HIV, diabetes, chronic heart disease, or epilepsy' (HESA 2011). Again, challenges surrounding the ease of defining an impairment within one category or description are apparent.

Some HEIs do make reference to potential fluctuations in how disability is experienced in making provision for prospective and continuing students. For example, the London School of Economics (2011) gives details of what types of 'reasonable adjustment' may be provided for those students with fluctuating or recurring impairments, which they refer to as 'long term medical conditions' (including flexible examinations and negotiation of appropriate timetabling). London South Bank University (2011) encourages students to consider the potential for fluctuations in the intensity of their impairment in providing evidence for their application for Disabled Students Allowance (DSA). The Equality Challenge Unit (2010) provides specific advice for HEIs on making reasonable adjustments for students with fluctuating impairments, based on the 2009 House of Lords ruling, that includes building such flexibility into making provision.

## **2.6 Summary**

Despite what would seem to be an emerging increase in public awareness of the potential of some forms of disability to change over time, limited consistency exists within policy, legislation and practice on how rights are upheld and provision offered. This is at least partially inescapable, based on pervading difficulties in applying categories, agreeing

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definitions or measuring prevalence or impact of variations in impact of some impairments: how can the unquantifiable or indescribable be understood or supported?

There is a complex legal infrastructure which has given rise to a multitude of phrases, responsibilities and rights, but as regards fluctuating or recurring impairments, application remains unclear and variable.

Discussion in Chapter Three critically examines differing models of understanding disability and chronic illness in questioning existing constructions of fluctuating or recurring impairments.

## **Chapter Three: Literature review**

### **3.1 Introduction**

This chapter critiques literature from a number of complementary areas contextualising this research. It considers wider societal discourses and constructions of disablement that inform those of the institution where the research was carried out, with particular focus on fluctuating or recurring impairments. In so doing, this literature review provides a basis for the historic, social and cultural facets of disability constructions that contribute to the institutional discourses which shape the policy operationalized by staff in providing support for disabled students. These aspects of constructions of disability within the educational environment are of crucial importance in providing context for the negotiation and performance of student identities.

The literature review begins by considering an historical perspective on disability, components of which may persist in current understandings. This provides an opportunity to consider the relationship between the medical and social models of disability, their origins, criticisms, and their influence on contemporary constructions and conceptualisations. In noting the lack of scope within either of these models to address fluctuations or recurrence in impairment, this chapter also discusses frameworks such as the Episodic Disability movement, as well as extensive scholarly work on chronic illness, in outlining parallels and divergences between concepts of disability and illness. The literature review concludes by considering evidence to support discussion on the construction of identities which have the potential to change.

### **3.2 Origins of disability**

Finklestein's three phases of disability construction (1980) offer an historical perspective on the origins of contemporary constructions of disability. Central to Finkelstein's Marxist-



based argument is the concept of a required homogenisation within the workforce, and the consequences of difference. The three phases identify a continuum in shared understandings of disability. In the first phase, Finklestein suggests general integration of disabled people in society, due to the potential to actively engage in various levels of production processes within agricultural feudalism, albeit at largely low-status levels. In the second phase, mass production techniques introduced during the industrial revolution underscored the supposed effectiveness of uniformity, and thus those who did not conform were subject to exclusion and marginalisation within large scale sanitarium facilities, thus creating a visible and physical social divide. Marks (1999) has suggested that the role this phase has had in the creation of constructions of disability is due to a desire within nineteenth century society to define what 'normality' meant, with 'able-bodied normality' (Ellis and Kent 2011, p.89) meaning effective participation in industry and production, and disability being constructed in terms of dependency. Finklestein's third phase considers possibilities for re-definition of disability through the advent of new technologies.

Technology can arguably provide alternative routes to participation that may not formerly have been possible, and in so doing challenge otherness and difference in constructions of disability. For example, the use of Braille keyboards in facilitating non-visual interaction with a computer opens up possibilities for distributed forms of communication. Ellis and Kent (2011) argue that Finkelstein 'believes technological change will directly result in a change to institutions, practices, and ideas' (p.88) as regards constructions of disability. However, they also note that 'patterns of technology are influenced by the cultural traditions of the society that produces them' (p.88), and thus innovation is socially and culturally driven. In considering the impact of different social or cultural influences on the adoption of technology, Eijkman (2009) suggests that widespread uptake of collaborative web 2.0 and mobile technologies in HE reflect and respond to an increase in non-mainstream knowledge and discourses which have accompanied internationalisation and

massification of education in recent years. Technology is thus shaped by emerging forms of knowledge and in turn provides support for the evolution and adaptation of such knowledge.

The contributions of such specific social, cultural and historical discourses to the development of knowledge and power are described by Foucault in the concept of the episteme (1971). Discourses within a particular episteme may capture tensions or consensus, and have implications for studies concerned with social justice or inequality. In terms of constructions of disability, the issue of politically loaded terminology, for example, has the potential to change according to legislation and policy, and thus in use amongst researchers and activists. The change in preferred use of terms such as 'impairment' or 'disabled people' as constructs within the social model of disability, or 'reasonable adjustments' within legislation are contingent upon converging social dynamics and based on terminological trends. Indeed, as outlined in Chapter One, section 1.4, pages 14 - 15, the increasing use of terms such as 'fluctuating', 'recurring' or 'chronic' to conceptualise variation of impact of impairment over time in disability studies and policy reflects potential for increased recognition of fluctuating or recurring impairments, due to social and cultural means of being able to discuss this.

In both *History of Madness* (1972) and *Madness and Civilisation* (1961), Foucault examines the impact of changing social contexts on historically dependent constructions of madness and unreason. For Foucault, madness and an absence of morality were co-dependent in the nineteenth century, and this underpinned not only social constructions and understandings of madness, but social practices, such as exclusion and isolation. Central to this account is Foucault's suggestion that discourses of madness (language, conventions and practices) regulate behaviour by constructing discourses of normalisation, which are endemic within practices of institutionalization. Such normalisation characterises Finklestein's second phase of disability construction, where difference and otherness dominate perceptions of disability, and as has been discussed in

Chapter Two, section 2.3, page 25, notions of 'normal' and 'special' continue to influence contemporary provision for and constructions of disability. In Finklestein's third phase, however, technology is charged with the potential to challenge the dominance of 'able bodied normality' in favour of alternative forms of electronic, virtual or remote participation.

The body as a socially constructed rather than corporeal form is central to Foucault's philosophy. Foucault purports that the body exists as a social subject, shaped by knowledge and power. Foucault uses the body in *Discipline and Punish* (1977) as a focal point in discussing changes in punishment and the penal system ( through a continuum of torture, punishment, discipline and prison). For Foucault, the movement of the body from being a highly visible and public entity to one that is regulated by consequence and discipline is key to his argument about the social construction of the body through power. The social construction of bodies, Foucault argues, is driven by the order of representation and by a variety of social principles within this order. Bodies are not in and of themselves material entities, but the effect of social constructions (shaped by value-laden trends in diet, exercise, shared visions of health or wellness, beauty, for example) and subject to society's surveillance, evaluation and expectation. From this point of view, visibility and appearance is an essential component of judgement of the body, with implications in constructing an understanding of disability where aspects of impairment may be unseen and variable.

In considering the impact of disease on the body, Foucault posits two historical responses; exile enclosure and plague (1977). The former encapsulates practices to exclude, isolate or remove diseased persons entirely from society. The latter, alternatively, relies on implementing social order and enacting disciplinary power over diseased persons through hierarchy, surveillance, observation and writing. Foucault's concept of the plague offers the hypothetical existence of a 'town immobilized by the functioning of an extensive power that bears in a distinct way over all the individual bodies - this is the utopia of the perfectly governed city' (p.198). Bodies are subjected within the plague,

regulated (and relegated) by opportunist surveillance and regulatory power-based mechanisms. Again, in considering judgement of the body based on visible symptoms, power is exercised over the body that is seen as different or defective.

Foucault extends the notion of surveillance/ regulation enacted by the rise of prisons in *Discipline and Punish* to other institutions within society – church, school, the workplace . Foucault refers to governmentality and biopower as technologies of regulation that contribute to shaping social processes and interactions:

‘Governing people, in the broad meaning of the word, governing people is not a way to force people to do what the governor wants; it is always a versatile equilibrium, with complementarity and conflicts between techniques which assure coercion and processes through which the self is constructed or modified by himself.’ (Foucault 1993, pp. 203–4)

Siebers (2001) offers ‘statistics, demographics, eugenics, medicalization, sterilization’ as techniques/ examples of biopower (p. 739) to denote subjugation of the body (as self) within social systems and technologies of regulation.

### **3.3 Social and medical models of disability**

Definitions of disability are often seen as ‘vague, malleable and used interchangeably’ (Oliver & Barnes 1998, p.14), and as such it can be difficult to know what policy-makers, researchers and disabled people promote, accept and agree on as appropriate terminology. Marks (1994) notes that ‘new labels and new disabilities...are constantly being created’ (p.76). Oliver and Barnes suggest that, generally, disability definitions can be categorised into those created and applied by professionals and academics, and those adopted by disabled people and organisations (Oliver & Barnes 1998). Strong criticisms have been made of constructions and definitions of disability created by non-disabled people (Davis 1996).

Until the 1980s, policy, provision and discourse were largely dominated by an overtly medical, aetiological approach towards disability. The work of the Union of the Physically Impaired Against Segregation (UPIAS 1975) was pioneering in its application of the concept of 'interpretation' to the field of disability studies, as opposed to mooted a fixed 'model' or 'theory'. The advocacy work of the UPIAS marked a move away from medical dominance in understanding, conceptualising and developing policy specific to disability, and a departure from the influence of the ICIDH, towards the promotion of the social model of disability, most associated with Oliver's work (1983; 1990; 1996), as well as Finklestein and Barnes. Barnes and Mercer (2003) mark this pivotal juncture as denoting a rise in encouragement in independent living (and thus autonomy) and a conscious move away from conceptualising disability as personal tragedy (Oliver 1983; Finklestein 1980).

Indeed, the social model, which, as outlined in Chapter One, section 1.7, page 19, considers disablement to be attitudinally and environmentally constructed and imposed through limits placed on participation, has been praised for encouraging a collective and anti-essentialist disabled peoples' ethnos, which comprises:

'distinct people with a distinct culture, although this should be understood in social constructionist, rather than essentialist terms – a collectivity is not a pre-given essence, but rather only exists to the extent that its members demarcate criteria of inclusion and exclusion as part of their reflexive appropriation of their identity and heritage.' (Humphrey 2000, p.65)

However, others argue that, in fact, aspects of essentialism persist within the social model (Swain et al. 2005). Barnes (2000), for example, cautions that:

'the social world is somehow reconstructed or rectified to accommodate a potentially endless variety of competing and everchanging discourses, which tend to ignore or play down the very materiality of disabled people's lives. The end result is the clouding of the meaning of "disability" as defined by the disabled people's movement and, most importantly, its impact on disabled people's lives' (p. 444)

This 'clouding of the meaning of "disability"' creates scope for the social model of disability to be understood in a breadth of competing interpretative ways and relates to criticism of the model being outmoded in light of increasing heterogeneity of the population (Shakespeare & Watson 2001). For impairments that vary in intensity over time, a potentially reductive perspective such as this is problematic in limiting scope for the recognition of changing circumstances and impact.

Barnes (2000) discusses the social model in terms of enhancing understanding of the lived experience of 'accredited' impairments; that is, those that may be diagnosed, visible or accepted. Barnes and Mercer (1996) argue that the social model does not incorporate perspectives of chronic illness, which, in the context of the debate between constructions of disability and illness, as discussed in this chapter, section 3.5, is of relevance in this research. Despite the social model's strength in encouraging activism, community and identification, issues of exclusion based on 'legitimacy' of an impairment would seem to permeate criticisms.

In recent years, there has been a movement to rationalise the relationship between the medical and social models of disability as existing not mutually exclusively, and essentially providing a false dichotomy (Jones 2001). Studies within the two domains have been described as medical sociology or 'sociology of chronic illness or disability' versus 'disability studies' (Thomas 2004). Thomas suggests that despite the continued bifurcation between the two areas, considerable potential for cross-pollination of ideas exists.

One such example of taking a combined view on disability, as part of a broader model of health, is Nordenfelt's (1995; 2000) understanding of disability, which centres on limitations imposed by non-abilities, both intrinsic (largely medical or physical - impairment) and extrinsic (environment, society - disability). Nordenfelt uses activity based concepts such as 'basic actions' and 'vital goals' to act as a rudimentary measure of disability; that is, with what level of success an individual can carry out not only activities

of daily living, but those activities which will add to their 'quality of life'. Such concepts of 'activity' and 'normality', as noted in Chapter Two, section 2.3, page 25 - 27, persist in current legislation, such as the Equality Act 2010, reinforcing a perspective that disability operates outwith 'normality'.

Harris's concept of disability results from what he describes as a 'harmed condition' that causes a deprivation of 'worthwhile experience' (2000). This broad, biomedical sweep creates a lack of detail within the diverse disability spectrum, and has been criticised for being over inclusive, by encapsulating people with short term injuries as being in such a 'harmed condition', and thus fundamentally disabled and excluded from engaging in a 'worthwhile experience'. Indeed the very subjectivity associated with these concepts of what constitutes a 'harmed condition' and who evaluates the 'worthwhile experience' (the individual or society, for example) has opened Harris's suggestions to criticism (Edwards 2005). Koch (2001) has argued that some of this harm may be inevitable, such as the unavoidable decline in ability to hear higher frequencies as part of the ageing process, and thus eventual limitation in hearing abilities overall.

The rise of the affirmation model of disability (Swain & French 2000) is a direct counter to this resurgence of personal tragedy theory, underpinned by medical principles. The affirmative model supports 'positive social identities, both individual and collective, for disabled people grounded in the benefits of life style and life experience of being impaired and disabled' (p.569). The individual and collective aspects of identity are crucial in forming a construction of disability as one which has the potential to vary over time. Sense of self as well as relationally constructed aspects of identity are of crucial importance in personal as well as social and cultural understandings and experience of disability, and offer scope to consider the complexities of variation in the impact of impairments which have the potential to fluctuate or recur.

### **3.4 Episodic disabilities**

Episodic disabilities has become an increasingly recognised concept in Canada, having been developed as a term to capture fluctuations in wellness in research involving people with HIV (O'Brien et al. 2008; 2009). Research has focussed on, for example, employment rights and access to benefits of people with fluctuating impairments (McKee 2007; Lightman et al. 2009; Vickers 2001). Indeed, the Episodic Disabilities Employment Network (EDEN) and the Episodic Disabilities Network (EDN) are both well-established organisations, and part of an active consortia which also includes the prolific Canadian Working Group on HIV and Rehabilitation (CWGHR), for whom improving understanding and awareness of impairments which vary in intensity is core. Examples given of such impairments include 'multiple sclerosis, arthritis, cancer, HIV/AIDS, diabetes and some forms of mental illness' (CWGHR 2011a). The CWGHR define episodic disabilities as being distinct from what they term 'traditional' disabilities as having characteristic 'unpredictability, and alternating episodes and degrees of illness and wellness, both of which can have a negative impact on employment participation, income security, scheduling and coordination of care, and social inclusion' (2011b).

The Episodic Disabilities Framework (EDF) was developed to model the multi-dimensional nature of impairments that vary over time, and has been a central tool within the Canadian Episodic Disabilities movement in conceptualising how disability is lived and experienced (O'Brien et al. 2008). Its origins lie in the increasing recognition of HIV/AIDS as an on-going condition during which people may experience 'health-related consequences of HIV and its associated treatments, a concept that may be termed disability' (O'Brien et al. 2008). There are three components to the framework; firstly, the four dimensions of episodic disabilities (symptoms and impairments, difficulties carrying out day-to-day activities, challenges to social inclusion and uncertainty), secondly, contextual factors (both extrinsic [societal/ environmental] and intrinsic [personal attitudes]) in how disability is experienced, and thirdly, triggers of significant episodes of disability. The three



components are inextricably linked, and provide scope to consider the experience of living with and impact of an episodic disability from a holistic perspective.

Despite the EDF having been developed specifically through work with people with HIV/AIDS, there are many aspects of the Framework which have applications for any person who experiences episodes where an impairment has a significant, and often unpredictable, impact on their everyday life, including disabled students in Higher Education. Applying the three components of the EDF to the learning experiences of students in HE offers a new, integrated perspective on how a student experiences disability in the academic environment. Firstly, the four dimensions allow focus on the self, identity, participation and peer interaction, whilst the second component of contextual factors provides scope to evaluate the role played by competing institutional discourses, staff perspectives and the impact on constructions of disability within the institution. The third component of triggers incorporates both the student's reflections on variations in their own health, as well as the impact of changes to or inconsistency in resources or adjustments provided by the institution. This type of experiential modelling helps to build a rich picture of not only the ways in which a fluctuating or recurring condition can impact on learning and teaching, but may also help institutions evaluate processes in order to improve flexible and inclusive infrastructures.

The EDF has been useful in this research in considering the many dimensions of the lived experience of disability for students with fluctuating or recurring impairments from a reflective individual perspective, as well in terms of locating those experiences in an educational context. In bringing both of these perspectives together, it is possible to consider the specifics of the individual experience in the collective domain, in considering what recommendations might be made to improve inclusive provision for students with fluctuating or recurring impairments.

### **3.5 Chronic illness: trajectories and biographical disruption**

Unpredictability and variations experienced in chronic, long term illnesses have clear parallels with a lived experience of disability as a potentially ever-changing one. Indeed, the relationship between chronic illness and disability has been long debated (Bury 1997; Williams 2000; Butler & Parr 1999; de Wolfe 2002), with little consensus as to conceptual/ actual boundaries between and shared/ divisive terminology. Many of the same 'dilemmas of concealment and disclosure' (Lingsom 2008, p.2) described with unseen impairments affect public perception, acceptance and understanding of chronic illness. Frank describes the prevalence of living with a long term/ chronic health condition as being part of a 'remission society' (1995, p. 8), in continuing to live with post-treatment symptoms of, for example, cancer or a stroke, and being considered 'effectively well but...never... considered cured' (p.8). Frank describes some members of the 'remission society' as being largely invisible, people and families who manage symptoms of illness or an impairment on a continuing basis, that then becomes an aspect of their identity.

Laurie Edwards is an American academic, author and activist whose 'A Chronic Dose' weblog provides a reflexive insight not only into the anecdotal reality of living with a long term chronic illness, but also of the author's reflections on this intersection of disability and chronic illness, illness and disease. In differentiating between illness and disease, Edwards (2009) argues that disease is essentially objectified medicalization, whilst illness more closely reflects the subjective lived experience. Edwards also comments on apparent contradictions in perceptions and definitions of chronic illness and disability, by stating that 'people with chronic illness may be considered disabled, but people with disabilities do not always have chronic illness' (online). Edwards (2009, online) also offers thoughts on the individuality of chronic illness, on varying impact, visibility, and the effect that this may have on external perceptions and assumptions:

'Despite the fact that many patients with chronic illness also fit under the umbrella of disability, I do believe distinct differences remain. Reading other blogs and

discussion forums, I am often amazed at the sheer variety of chronic conditions out there, by the way some non life-threatening conditions can be really incapacitating, some life-threatening conditions can have the appearance of relative functionality, and how quickly things can change for people. As patients, those with chronic illness have so many different needs and challenges.'

By noting the contradictory nature of 'non-threatening conditions' which are in fact 'really incapacitating' whilst many 'life-threatening conditions' have the appearance of 'relative functionality', Edwards draws attention to the impact of assumptions based on visual interpretations of 'wellness' to shape the limited legitimacy afforded to many chronic illnesses or fluctuating or recurring impairments.

Bury (1988, 1991, 1997, 2000) has written extensively of the impact of chronic illnesses and the 'biographical disruption' people with chronic illnesses, such as Multiple Sclerosis or arthritis, may experience; where symptoms are unpredictable, not immediately visible and, for Bury, where the impact of fear and uncertainty may resonate as strongly as intense physical symptoms. Bury (1997) suggests that there are two possible meanings associated with the lived experience of chronic illness: consequence (what effect) and significance (what does it mean culturally). Bury acknowledges the role of predictability on how fluctuations in wellness are experienced, and of visibility in societal recognition/ordering and as such, representation. He also notes the importance of improving understanding of chronic illness in the context of an ageing global population with greater life expectancy, in that the prevalence of chronic illnesses rises with age, and thus will become increasingly frequently experienced by a large sector of society. Williams (2010, p.206) suggests that much existing research into the lived experience of chronic illness draws on principles of symbolic interactionism by way of affording 'focus on the *meaning* and *experience* of chronic illness and its implications for selfhood and social interaction', in addition to phenomenological studies of the body in 'the chronic illness trajectory' and research which considers 'explicit biological or material dimensions'. The former of these would seem to have more in common with the UPIAS and Finklestein's argument toward

an interpretative focus on disability, and the latter aligned with modelling or theories about relationships and explanations.

In arguing that 'phenomena must be given conceptual names or labels in order to be useful' (Corbin & Strauss 1991, p. 161), Strauss, Glaser and Corbin (Corbin & Strauss 1985, 1988; Glaser & Strauss 1965, 1968; Strauss & Glaser 1970; Strauss et al.. 1985) apply the term 'trajectory' in modelling long term experiences and constructions of chronic illness. Like the EDF, the chronic illness trajectory considers a phased course, development and management of chronic illness over a period of time. In defining their use of trajectory as a term, Corbin and Strauss (1991) state that:

'Trajectory as the illness/chronic condition course requires the combined efforts of the affected individual, family, and health care practitioners in order to shape it. That is, to determine its eventual outcome, manage any symptoms, and handle associated disability. Trajectories are often uncertain. They can be graphed, but only in retrospect. For although each illness has a potential course, its details cannot be fully determined ahead of time. Much depends upon the individual, the action taken to shape that course, and the turn of events that occur.' (p. 162).

Frank (1995) discusses living with a chronic illness within a discourse of adjustment and loss, arguing that CFS is an 'illness that is never really finished' (p.1). Frank describes 'a loss of the "destination and map"' that had previously guided an ill person's life, and that in the re-constructed self, ill people have to learn to 'think differently'. Both Frank and Corbin and Strauss discuss chronic illness in terms of vagueness, uncertainty and unpredictability. However, in discussing an 'eventual outcome' related to 'symptoms' and 'associated disability', Corbin and Strauss suggest that even within this uncertainty, at some point in the trajectory, a chronic illness may become more identifiable. For Frank, the ambiguity is continued.

Charmaz (1983, 1990), too, conceptualises chronic illness through suffering and loss of self, where a 'crumbling away of...former self-images without simultaneous development of equally valued new ones' and 'spiralling consequences such as loss of productive

function, financial crises, family strain, stigma, and a restricted existence' (p. 168 – 169) have a long-term and negative impact. Nordenfelt's (1995) conceptual framework of chronic illness also foregrounds this notion of suffering. Arguably, however, this assumes that in the lived experience of chronic illness, suffering, as opposed to management or integration of aspects of the 'new self', is a default and inherently undesirable condition and an inescapable feature of the future trajectory over time. Asbring (2001), however, has argued, in a study of women with CFS and fibromyalgia, that loss of self may be only 'partial' and thus transformative. Therefore, the experience of living with a chronic illness has the potential to affect individual, collective and relational identity loss, adjustment, renewal or reconstruction.

### **3.6 Constructing identity**

In contrast to the development or acquisition of a new or adjusted identity, Lightman et al.'s (2009) application of queer theory to the concept of fluctuating or recurring conditions highlights on-going 'precarious bodies' and 'fluid identities' which enable people with complex and fluctuating impairments to transition between different understandings and constructions of self. This transitional state potentially limits integration or assimilation into one or more social or cultural groups:

' By elastically crossing material (biological) and experientially shifting boundaries, there are no cast-iron universals of bodies; instead, there are only fluctuating, contingent, fluid bodies and identities that continually contract and expand from one side of the binary (health/illness, ability/disability) to the other, or that resist a divisive embodiment altogether' (Lightman et al. 2009, online).

This important insight provides an opportunity to consider the temporal transience and irregularity of the experience of living with a fluctuating or episodic disability from the perspective of identity. Lightman et al. particularly focus on problematic categorisation

during application for income assistance, and how identities may transcend definitions and bureaucratic conveniences.

The application of queer theory is also central to the fractured identities of research participants in Axtell's (1999) study on identity construction amongst lesbian and bisexual women with impairments or chronic illness. Participants discussed their disabled selves being one identity amongst many, and as being both developmental and having a fluid nature. This theme of fluid identities is a common one in research undertaken under the auspices of 'queer theory', a not uncontested term, but one that is widely used to represent a variety of types of interpretative ways of looking at the lives, identities and experiences of lesbian, gay, bisexual and transgender (LGBT) people (Hall 2003; Watson 2005). For Sumara and Davis (1999), queer theory (or theories) offers a way of 'interrupting commonsense understandings of what constitutes sex, sexuality, pleasure, desire, and the relationships among these and the technologies for learning about and enacting their differences' (p. 192), and is for Waites (2005) where a 'fixity' of sexual orientation persists in the public domain (an either/ or of the heterosexual/ homosexual binary). This opportunity to consider the 'interruption' of assumptions, constructions and definitions has relevance for this research in exploring the origin and prevalence of assumptions surrounding the limited legitimacy of fluctuating or recurring impairments, and in examining institutional constructions and student identities.

Axtell's research considers both individual identity constructions as well as those aspects of identity formed and enacted within relationships and groups. Such variation and fluctuation in identities (formation and performance as well as management) would seem implicit and inescapable when a person's social context and sense of self has the potential to change; true of chronic illnesses in this case, but essentially also for any altering circumstances which directly affect an individual. For those people with fluctuating or recurring impairments, as argued by Lightman et al. (2009), identity may take a fluid form, according to ability to participate in social activities.

For Strauss (1975), understanding the lived experience of having a chronic illness is less about individual or collective identity or controlling associated symptoms than leveraging opportunities for social interaction by way of managing impact. As such, the role of social context is pivotal in considering how people experience chronic illness and consequent fluctuations in wellness and ability. In 1991, Nokes applied the chronic illness trajectory in the context of people living with HIV/AIDS, an emerging area of research interest as awareness and acceptance grew. Others considered the role of multi-faceted identities, the impact/ management of relationships, uncertainty/ change and stigma in 'coming to terms' with an HIV/AIDS diagnosis (Seigel & Lekas 2002; Brashers et al. 1998).

In the context of these shifting, mutable identities in chronic illness, Radley and Green (1987) suggest that 'the idea of sickness as a transition from a state of health to one of illness presumes that these are separate existences, when in fact this may not be so in the experience of many individuals' (p. 179). They also note the phenomenon of adjustment in reference to identity construction, moving between former, current and future identities, based on changes in wellness and ability. For Conrad (1990) the process of change is key to studies of chronic illness, whilst Yoshida (1993) sees reconstruction of identities in this process as crucial.

Barnes and Mercer (2003) have suggested that interest in social theory in the late twentieth century has been characterised by a growing focus on 'flexible', 'multiple' and 'contested' identities (p.70), and as such lends itself to afford close consideration of experiential differentiations within disabled peoples' lives and construction of selves. Indeed, many criticisms of the social model of disability itself hinge on a perceived over-homogenisation of the lived experience (Thomas 2004; Shakespeare & Watson 2001; Shakespeare 2006) and lack of recognition of the potential for disability to vary, not only within a spectrum of cases within one group of disabled people who describe their impairment similarly, but also in intensity over time in the case of one disabled person.

### Chapter Three: Literature review

Limited focus, then, is placed on the potential for temporal variation in construction of identity/ identities.

Constructing identity, in both theoretical discussions and in everyday discourse, would appear contingent upon both sameness and difference (Lawler 2008); in sharing certain characteristics or attributes with others ('British', 'white', 'woman', etc – *social* identity, according to Jenkins [1996]) as well as having our own sense of uniqueness (*individual* identity). Jenkins (1996) notes the importance of identity as a relational phenomenon; that in the relationship between the common and individual, context and interactions are the driver for identity changes and formations. Jenkins goes on to conceptualise the self (and selfhood) as the 'individual's private experience of herself or himself' and to say that 'the person is what appears publicly in and to the outside world' (p.30). For Smith et al. (2009), the interactions of people as inherently active social beings provides an opportunity to focus attention 'on the ways in which personal and cultural realities are constructed, enabled, and constrained in relation to others' (p.343). For Watson (2007), too, 'identity is not something inside us, fixed and unchanging, identity – or better, the process of identification, is contingent and relational' (p.372).

Sabat and Harré (1992) use social constructionism in explaining the negotiation of individual perceptions of self/ identity (singular or multiple) as well as those imposed/ assumed by others, particularly focussing on the role of agency and representation. For disabled people, this agency can be enacted through the choice of when and if to 'disclose' their impairment, depending on their self-perception (for example, whether they consider themselves to be disabled or not ([Watson 2002]) or the social context. For people with disabilities which fluctuate or recur, these influences may change frequently over time.

Lawler argues that components of identity (social or individual) do not exist singularly, but as 'interactive and mutually constitutive' (p.3), and notes the potential impact that each



aspect of identity may have on another (for Lather and Smithies [1997] how women in their research 'negotiate the clash of voices, which ones they invest authority in, which ones they find internally persuasive' [p. 125]). However, Lawler does also acknowledge that some forms of identity are governed by their inability to co-exist, including binaries of man/ woman or homosexual/ heterosexual, for example. This 'dis-identification' involves rejection of one category in favour of another. Brewer and Gardner (1996) consider this plurality of selves in personal, relational and collective terms, and that the potential to self-represent in each of these ways (independently, in dialogic relationships and in groups) co-exist within one individual and are socially produced. Being a disabled student may or may not feature as one of multiple identities for those students whose impairment has the potential to fluctuate or recur. Indeed, many reject the notion of disability within their identities, instead constructing themselves as unwell. This issue is discussed as part of the analysis in both Chapters Six and Seven.

### **3.7 Context, discourse and governmentality in constructing knowledge and identity**

Allan (2008) groups Deleuze and Guattari, Derrida and Foucault within inclusion studies as 'Philosophers of Difference'. Allan argues that Deleuze and Guattari and Derrida have much to offer in considering making the mainstream more inclusive, challenging constructions, discourses and practices, whilst Foucault offers an opportunity to consider the actions of the individual. Foucault's work on ethics and transgression have been noted by Allan (2008) in this context as particularly applicable to debates on inclusive practice:

'Foucault's ethics allows us to envisage individuals as capable of transgression, enabling them to challenge disabling barriers and find new selves, new ways of being in the world.' (p. 85)

### Chapter Three: Literature review

Foucault's philosophical work has been both celebrated and criticised in inclusion and disability related research and debate (Tremain 2005). Foucauldian principles have been influential on disability studies for averting focus from disablism as being a construction/ imposition of the infrastructure and norms of capitalist society/ industrialisation to highlight the pivotal role of discourse and the organization of assumptions in creating knowledge and power (1980). As with Derrida, language, its application, intent and implications are central to Foucault's theses, though Foucault's definition of discourse is as concerned with ways of thinking and practices as it is with the linguistic definition associated purely with language (Hall 1997). The effects of discourse/ discourses in governing social interactions and having implicit regulatory implications are foregrounded by MacLure (2003):

'Discourses within poststructuralism involve much more than language, therefore. They can be thought of, rather, as practices for producing meaning, forming subjects and regulating conduct within particular societies and institutions at particular historical times'. (p.175)

MacLure (2003) also suggests that for Foucault, the role of discourse in enacting power is not necessarily imposed, hierarchical or from an external source, but an implicit technology that circulates within societies and institutions 'producing subjects who exert a 'mutual "hold"' on one another' (p.49). These mutual relationships influence and regulate social interactions, norms and accepted forms of knowledge and conduct. For Marks (1994) the construction of these individual subjectivities are contingent upon 'negotiation, consent, conflict, contest, and coercion' (p.71).

Holland and Leander (2004) suggest that:

'regimes of power/knowledge are conceived to create social categories such as the "disabled," "troubled youth," or "attractive women." A person or group is "offered" or "afforded" a social position when a powerful body, such as a governmental agency proposes a particular sort of subject, a "felon," say, or a "sexual harasser," or an "at-risk" student and calls on an individual to occupy the position' (p.127).

However, Foucault's (1988) concept of the technologies of the self:

'permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection or immortality' (p. 18).

Through strategic use of technologies of the self, individuals can choose forms of self-representation and interaction within society, improve ethical self-understanding, and exercise self-care. For Foucault, writing is one possible form of this, and a potential site of identity construction and revision:

'taking notes on oneself to be re-read, writing treatises and letters to friends to help them and keeping notebooks in order to reactivate for oneself the truths one needed' (p. 27).

I considered this in the research design as a way of promoting choice and self-awareness in building student narratives. Attention has also been paid in the analysis to applying Foucauldian principles in terms of identifying competing institutional discourses and considering ways in which these serve to shape the subject (staff and students within the HEI) as well as affect constructions and influence the creation of knowledge and enactment of power.

### **3.8 Summary**

In considering an historical perspective on current constructions and understandings of disability, it is possible to note that neither the medical nor social models offer much scope to model disability on a varying basis. Some of the transience experienced in studies of chronic illness, however, raises issues of uncertainty and unpredictability, management and variation in participation, echoed in modeling techniques such as the Episodic Disabilities Framework and in concepts such as 'biographical disruption' and chronic

illness as a 'trajectory'. However, in considering these parallels is it important to note the relationship between disability and health, what influence this may have on perceptions and constructions in terms of legitimacy and notions of possible recovery.

Possibilities for the promotion of selected aspects of identity exist in face to face interactions as well as online for students with fluctuating or recurring impairments, based on potential for visual judgement of their impairment. Again, 'disclosure' and self perception are key issues in this context, as regards, for example, whether a student recognises themselves as disabled or constructs their impairment in terms of health. Uncertainty, unpredictability and transience in terms of impact of impairment relate, too, to identity creation, both individually and relationally. Self-perception, integration and 'disclosure' in a social and cultural context of limited legitimacy permits the representation of disability in a multitude of selective ways. In chronic illness studies, identity may be considered in terms of loss, reconstruction (partial or full), transformation and renewal. Identities may thus exist communally, as composite parts of a whole, in cohesion or rejection, or ambivalence.

In the following chapter, I outline the choice of social constructionsim as a theoretical framework for this research and its relevance in considering institutional policy, and of a narrative approach to data analysis in examining staff's operationalization of policy as well as in the negotiation and enactment of students identities in the context of Higher Education.

## Chapter Four: Conceptual framework and research methodology

### 4.1 Introduction

This chapter discusses the conceptual framework of the research and the methodology employed. Here I outline my use of social constructionism as a theoretical framework for conceptualising ‘disability’. I also discuss the research methodology which includes consideration of the impact of a key policy document on both staff and student constructions, and a narrative approach in examining staff and student perspectives. I explain the thematic narrative analysis I have drawn on in analysing interviews with staff, the main purpose of which was to examine ways in which institutional policy is enacted and how prevalent discourses serve to construct ‘the disabled student’. I also set out the ‘hybrid’ approach to narrative analysis I have adopted for analysing student narratives which focuses on the performance and construction of identities.

### 4.2 Overview of the research process

Quantity	Focus	Method of inquiry	Data	Analysis
1	Policy	Retrieval from institution	Policy document	Foucauldian / social constructionist discourse analysis
3	Staff	Face-to-face interview	Transcripts	Thematic narrative analysis
24	Students	Face-to-face, phone and email interviews (phase one)	Written notes	‘Hybrid’ narrative (mainly ‘big story’)
5	Students	Email (phase two)	Email transcripts	‘Hybrid’ narrative (mainly ‘small story’)

Table 4.1: overview of the research process

This research explores constructions of fluctuating or recurring impairments in HE and how these are influenced by institutional discourses. It also examines the ways in which staff operationalize policy and how this may shape the development of aspects of student

identities. I recruited both staff and student participants to contribute to the research (this process is discussed more fully in Chapter Five, sections 5.2 and 5.4). I have analysed the staff perspectives in the context of a key institutional policy document (the Learning Teaching and Assessment Strategy or LTAS) in order to establish how practice may be informed by institutional discourses (both implicit and explicit). In considering the impact of the LTAS, I drew on a Foucauldian perspective of discourse as a form of regulation and order and social constructionist principles of the interactional creation of knowledge to determine ways in which the document represented institutional values.

As outlined in Table 4.1, I conducted and transcribed face-to-face, semi-structured interviews with three members of staff. With students, I conducted preliminary face-to-face, telephone or email interviews (phase one), and recruited a sub-group of these students to maintain contact for the duration of one academic trimester (January – April 2011 - phase two). Participating students in phase two all elected email as their preferred mode of communication.

### **4.3 Social constructionism**

Using social constructionism to identify and challenge potentially dominant disabling discourses (Slee 1997, p.407) within the institution where the research was carried out is fundamental to this research. In Chapter Six, I analyse a key institutional policy document as well as staff perspectives to outline ways in which institutional discourses may position and construct students with fluctuating or recurring impairments. The analysis of student narratives in Chapter Seven is located within these discourses and constructions, in the context of participation in education as a form of social interaction (Biesta 1998).

Social constructionism proposes that knowledge is created within social interactions. In their classic text, Berger and Luckman (1966) discuss the production of meaning through shared social processes of habituation (action and meaning through conscious and

then subconscious repetition) and institutionalisation (reinforcement of meaning through becoming embedded in society). Social constructionism's integral critical perspective offers scope to consider how knowledge and meaning are produced and shared in social contexts. Multiple interpretations of social constructionism have led Burr (2003) to suggest social constructionism is a 'hybrid movement' with a number of influences, including postmodernism, poststructuralism and early sociological writing. Burr argues that:

'Social constructionism cautions us to be ever suspicious of our assumptions about how the world appears to be. This means that the categories with which we as human beings apprehend the world do not necessarily refer to real divisions (p.3).'

Burr (1995) outlines four traditionally overarching themes in social constructionism: that it assumes a critical positioning towards accepted knowledge and concepts; that it is historically and culturally specific; that knowledge itself is sustained by social processes; and that knowledge and social processes are mutually dependent. For Berger and Luckman (1966, p. 13), reality ('a quality appertaining to phenomena that we recognize as having a being independent of our own volition') and knowledge ('the certainty that phenomena are real and that they possess specific characteristics') are integral in creating and sharing understandings of the social world. By way of exemplifying social relativism and its significance in meaning-making, Berger and Luckman note that:

'What is 'real' to a Tibetan monk may not be 'real' to an American businessman. The 'knowledge' of the criminal differs from the 'knowledge' of the criminologist. It follows that specific agglomerations of 'reality' and 'knowledge' pertain to specific social contexts, and that these relationships will have to be included in an adequate sociological analysis of these contexts' (p.15).

Foucault's interest in social constructionism considers its role in the classification and categorisation of people (McLaren 2002), and as such social constructionism has a long and established history in studies of inequality and social justice. For example, social constructionism developed a stronghold in gender and race studies as a challenge to

existing biological and essentialist understandings of gender and race as static and ahistorical (Glenn 2000). Hacking (1999) refers to the interaction that takes place between people and their classifications as the 'looping effect', in that classifications become embedded within institutions, practices and language and are maintained through on-going interactions. Charmaz (1990, p. 1161 – 1162), in underscoring the usefulness of the approach in considering constructions of chronic illness, suggests that social constructionism affords 'an open-ended and flexible means of studying both fluid interactive processes and more stable social structures'. Furthermore, Brown (1995) employs social constructionism in suggesting a sociology of diagnosis and illness, and discusses the role of 'acceptance' and the application of biomedical definitions. With limited acceptance and legitimacy as regards fluctuating or recurring impairments, however, a social construction of diagnosis has limited relevance where mental and physical symptoms vary in intensity and presence. As with all other forms of measurement of impairment discussed in this research (for example, the WHO classifications) diagnosis and definitions are not always possible or applicable as regards fluctuating or recurring impairments.

Within this research, I have used social constructionism as a framework to consider embedded institutional practices and priorities. In considering the values of the institution, I have included detail from a key policy document (the Learning Teaching and Assessment Strategy [LTAS]) that was influential at the time the research was carried out. In so doing, I have used the social constructionist framework of the wider research to consider how implicit institutional discourses within the policy might influence practice and contribute to constructions of 'the disabled student'. Furthermore, by drawing on Foucauldian notions of governmentality and biopower (Foucault 1993), as well as on a Foucauldian interpretation of discourse as language, practice and action (Hall 1997), I have considered the role of discourse as an implicit technology for regulation and the enactment of power. This approach also drew on aspects of Critical Discourse Analysis



(CDA) in seeking to 'explore the relationships between discursive practices, events, and texts; and wider social and cultural structures, relations, and processes' (Taylor 2004, p.435) and as a way of considering the policy as an indicator of the institution's values and goals (Ball 1990).

For Fairclough (1992), discourse in the context of language as a social practice offers scope to 'investigate how...practices, events and texts arise out of and are ideologically shaped by relations of power and struggles over power' (Fairclough 1993, p. 135).

Fairclough (1993, p. 137) highlights the concept of interdiscursivity in demonstrating the 'heterogeneity of texts in being constituted by combinations of diverse genres and discourses'. I became aware of the influence of a variety of competing discourses in my evaluation of the LTAS, and which contributed to tensions in how it was operationalized by staff. In Chapter Six, I present extracts from the LTAS in order to consider 'the workings of power and material interests in seemingly the most innocent of texts' (MacLure 2003, p. 9). Giving space to consider the impact of discourse on policy creation, enactment and then influence on practice, according to MacLure (2003) is a way of 'disrupting common sense':

'Discourse-based educational research would set itself the work of taking that which offers itself as common-sensical, obvious natural, given or unquestionable, and trying to unravel it a bit – to *open it up* to further questioning' (p. 9).

This allows for an examination of institutional regulations and policy as an overt form of governmentality and biopower which impact upon academic practice, create standards and objectives, and therefore have an undeniable effect on the student experience through shaping discourse and constructions.

#### 4.4 Narrative production of identity

By framing the research within a social constructionist framework, possibilities exist for challenging current understandings of disability on fluctuating or recurring terms, in wider society as well as within one specific institution. Furthermore, it is a way of considering the role of the socially produced and governed self, and of how individuals negotiate and enact both individual and collective identities. Key to this is the concept of *positioning*, which:

‘can be understood as the discursive construction of personal stories that make a person’s actions intelligible and relatively determinate as social acts and within which the members of the conversation have specific locations.’ (Harré & Van Langenhove 1999, p.395)

Using positioning to consider research participants’ performance of identity through storytelling in relation to some form of other (for staff, other colleagues or students, for students, staff, peers, family or friends) provides an opportunity within this research to consider the collaborative, dialogic construction of self. Considering socially produced identities of the students who participated in this research is central to understanding some of the complexities of the ‘lived experience’ of disability on a fluctuating or recurring basis.

Aspects of identity can be produced and performed through narratives in everyday autobiographical activities, such as conversation or story-telling (Lawler 2008). Indeed, Watson (2012) argues that ‘to the extent that all narratives of personal experience involve the positioning of self in relation to the other, all may be said to be concerned with identity’ (p.460). Narrative analysis thus offers scope to understand identity in socially constructed, contextually dependent ways as ‘telling stories about ourselves to others is one way in which our identity may be accomplished or performed’ (Phoenix & Sparkes 2009, p.220). Smith and Sparkes (2008b) have argued that a narrative approach in disability studies has much to offer, and that ‘rather than reducing people to simply passive recipients of an

embodied behaviour and storyline, narratives also have the potential to investigate agency and structure' (p. 18), in considering the impact of social process and cultural influences on socially produced identities.

Bury (1982, 1997, 2001) has suggested that narrative approaches to research are particularly appropriate in making meaning of acquired chronic conditions – when they occur, how they affect identity and how they might be afforded legitimacy. Narrative research has, indeed, become a popular and frequently used approach in collecting and evaluating 'reconstructions' of chronic illness, characterised by 'a protracted and taxing search for diagnosis, with conflicting interpretations' (Garro 1994, p. 776), as well as in studies of illness which have long term characteristics (Hurwitz et al. 2004). Though, as discussed in Chapter Three, section 3.5, page 42 - 45, chronic illness does not equate, necessarily, with disability (Williams 2000; Edwards 2009), in the context of examining long-term impairments which impact upon participation and identity construction, the role of narrative in examining chronic illness is of interest to this research.

Riessman (1990) has highlighted the significance of temporality in identity formation and self-representation through narrative, in considering the construction of a coherent self where chronic illness has caused significant biographical disruption. Riessman discussed how the main focus of a research study was the evolution of the self during the process of divorce, but that one research participant continually returned to his perceived 'discontinuities in the appearance of a self' (p. 1196) through representations of his masculinity and his increasing poor health through progressive multiple sclerosis (MS). In Riessman's study, the act of engaging in a narrative exercise has, for the research participant, acted as a space for the realignment of focus on his identity. Such evolving stories of personal identity for Polkinghorne (1991) concern an unfolding autobiography, and often incorporate incidental events and unintended consequences of actions.

Such perceptions and concerns associated with changes in the self are integral to the formation of autobiographical narratives according to Becker (1997), and a recurring theme in the narratives of past and current athletes where traumatic injury is often a catalyst for change in self-hood (Sparkes 1996; Smith & Sparkes 2002, 2004, 2008a; Phoenix & Howe 2010). Reticence in accepting new or acquired aspects of identity may accompany discontinuities in self-hood and frustration in changed capabilities, but also carry the potential for 'narrative repair' in adjusting how stories of past and present selves are told according to self-acceptance (Smith & Sparkes 2008a, p. 220). Pals (2006) also considers the construction / re-construction of identity through narratives from a post-traumatic experience perspective, and the associated fracturing of identity which takes place.

For Sparkes (1999), 'body narratives' or stories told about our physical selves in order to better understand body-self relationships, offer a chance to enable us to 'understand the multiple and diverse ways in which people experience their bodies and how these interact to shape identities and selves over time and in specific contexts' (p.18). Smith and Sparkes (2002, 2005; Sparkes & Smith 2003, 2005) have additionally underscored that the body and impairment are socially created and creating. For example, specific types of masculinity may be constructed through participation in aggressive sports, which may in turn be shaped by injury to construct an experience of disablement based on comparison of former ability. Smith and Sparkes (2002) refer to Yoshida's (1993) model of identity adjustment in this context, discussing oscillation between different stages of the disabled and non-disabled self following injury.

### **4.5 Narrative and identity online**

As this research involves students participating via email, an important dimension to consider is the narrative production of identity in virtual contexts. Bowker and Tuffin (2002,

p. 329) argue that online communities are 'deconstructing traditional notions surrounding the concept of identity as a stable and permanent entity'. With specific reference to disabled people, Cromby and Standon (1999) note possibilities for virtual interaction and participation where impairment may be 'masked'. As with many other aspects of disabled peoples' identities, the dynamics of participation may be influenced by disclosure, and whether a person chooses to highlight that aspect of their identity. Online communities therefore create possibilities for selective positioning within online narratives.

Sparkes (1999) notes that in performing narrative, people 'must resort to a mode of telling with which they are familiar' (p .20) to ensure that the narrative is a social practice based on that person's cultural and social 'repertoire' and context. For students in HE, as is the focus of this research, communicating via email (with staff and one another) is an expected and assumed part of institutional practice and therefore a familiar location for possible construction and performance of identities.

Georgakopolou (2002) argues that in storytelling, the narrator is provided with the opportunity to edit presentation of self and formation of identity, and promote different aspects of self at different junctures in the story. This has implications for conversations carried out by email, with the potential for presentation and re-presentation of incidents and aspects of identity. James (2007) used this medium when researching identity construction amongst academics, noting the usefulness of email discussions as a site of identity construction within a dedicated, familiar method of communication to the research participants. This scope to alter representations of self was noted by participants in James's research, who reflected on their choices and decisions relating to sharing or withholding information, and how they presented their experiences.

Mann and Stewart (2000) have argued that scope to reflect on responses adds 'authenticity' to data, as the caution attached to sharing experiences in the 'disembodied environment' (p.210) denotes confidence in participation as opposed to possible risk-

taking in self-representation in the face-to-face environment. Markham (2004) suggests control over the editing and revision process is empowering for the participant, and thus could be viewed as a constructive, confidence-enhancing aspect of online data collection. Such notions of 'authenticity' are problematic in that they may imply the performance of a 'real' self. As has been discussed throughout this research, identities can be transient and fluctuating, and are described by MacLure (2003) as 'copies, imitations and forgery. Identity is always deferred and in process of becoming – never really, never yet, never absolutely "there"' (p. 131). MacLure (2003) also argues that 'self-hood is inescapably mimetic, a matter of masks and copies, whether or not we (know we) are deliberately faking it' (p.157). Such considerations apply equally to face-to-face interviewing and to online data collection.

### **4.6 Approaches to the analysis of narratives**

Narrative approaches have long been used in research as a way to represent the 'lived experience' (Dewey 1938; Labov & Waletzky 1967; Bruner 1991, 2004). Using peoples' telling of events, perspectives or memories creates a flexible, interpretative approach to making the implicit explicit, through decoding meaning that has been 'more or less strongly suggested though contextual, rhetorical, connotative or other means' (Prince 1982 p.36).

Smith and Sparkes (2006, 2008b) suggest that, due to the multiplicity of ways in which narrative analysis is interpreted, it is often best used as an 'umbrella' term for 'a mosaic of research efforts, with varied principles, philosophical assumptions, theoretical musings, methods and/or empirical groundings all revolving around an interest in narrative as a distinctive form of discourse' (2008b, p. 21). Smith and Sparkes also argue that narratives are ways in which narrators (and analysts) organise events or experiences and portray significance through ordering in storytelling.

Smith and Sparkes (2006, 2008b) outline two modes of researcher participation in narrative techniques as either story analyst or storyteller. In the former, they suggest that:

‘...stories do not speak for themselves, but rather are data for systematic, rigorous, principled narrative analysis (e.g. structural or performative). The researcher steps outside or back from the story and employs analytical procedures, strategies and techniques in order to abstractly scrutinise, explain and think about its certain features.’ (2008b, p. 21)

However, for storytellers, Smith and Sparkes argue, the analysis *is* the story; that the move away from abstract theorising in analysis towards the ‘goals of evocation, intimate involvement, engagement and embodied participation with stories’ (p. 21) turns the story itself into a theory. I consider both of these roles to be applicable within this research, as I identify ‘certain features’ in the stories told by staff and students as a story analyst, and am aware of my ‘intimate involvement’ in institutional culture and discourses as storyteller. My role as story analyst is to facilitate the emergence of stories told by research contributors in the form of my own story: the thesis.

#### **4.6.1 Thematic narrative analysis**

Riessman (2008) refers to narrative analysis as ‘a family of methods for interpreting texts that have in common a storied form’ (p.11). In considering how I might be able to narratively analyse the staff perspectives, I drew on Riessman’s interpretation of thematic narrative analysis, which she exemplifies in three differing ways. In the first of these, Riessman considers Williams’s (1984) use of thematic analysis in a study of rheumatoid arthritis. Williams refers to his thematic approach as ‘narrative re-construction’, in inviting participants to reflect on perceptions of the genesis of their illness and the impact that this has had on their current positioning and construction of self. In so doing, thematic narrative analysis as Riessman would have it, offers a way to keep the staff stories “intact” by theorising from the case rather than from component themes (categories)

across cases', (p.53). Riessman (1990) counsels that thematic narrative analysis has distinct differences from grounded theory:

'Unlike traditional qualitative methods, this approach does not fragment the text into discrete content categories for coding purposes but instead identifies longer stretches of talk that take the form of narrative - a discourse organized around time and consequential events in a "world" recreated by the narrator'. (p. 1195)

Riessman and Speedy (2007) further note that adopting a thematic approach to narrative analysis 'explores the extended account rather than fragmenting it into discursive meaning laden moments or thematic categories' (p. 430) as opposed to foregrounding 'snippets of talk (mostly non narrative, stripped of sequence and consequence)' (p. 434). Though I have not included the entirety of the transcripts of the staff interviews, in thematically analysing them I have tried to keep each staff member's story 'intact' by considering the evolution of the conversation chronologically. The staff narratives unfold over the duration of the interview.

By interviewing three members of staff in differing roles, I was able to explore ways in which discourses informed the operationalization of policy to provide support for disabled students. In Chapter Six, I have contextualised the staff narratives by giving an overview of the model of provision at the university at the time the research was conducted, as well as within the institution's values as highlighted in the analysis of the LTAS.

Incorporating the opinions, attitudes and reflections of staff who were active within the institution in strategic, support, teaching or research roles offered a chance to consider some of the discourses which contribute to shaping the student experience. This analysis takes a thematic narrative approach, considering staff members representations of institutional constructs in recounting their own experiences, perspectives and positionings. So doing provides an insight into some of the social and cultural structures and context, which Fraser (2004, p.182) argues is vital in safeguarding the narrative researcher from becoming either a 'witless relativist', ignoring overarching contextual components, or a



'social determinant' who is prone to attribute so much emphasis to social structures and cultural contexts that individual agency is negated. In so doing, the staff narratives offered insights into the social and cultural influences which contributed to enactment of policy, provision of support and both individual and collective constructions of 'the disabled student'.

#### **4.6.2 'Big' and 'small stories'**

Bamberg (1997) identifies two possible interpretations of the role of narrative as a route to understanding personal experience. Bamberg suggests that, firstly, narrative is constituted by the content or nature of the account and the teller's representation of what the past event means/ meant to them. This gives rise to 'big stories'. Secondly, he argues, that the narrative itself is characterised by the teller's performance and the active choices they make in identifying and representing the event. In this way, Bamberg suggests that within the second interpretation, the intended audience becomes pivotal in the telling of the narrative, and in the teller's positioning (of themselves, the events, the other characters). Form and intent of the story as well as how it is delivered by the teller are both crucial to consider in unfolding narratives (Esterberg 2002; Gubrium & Holstein 2000). This form of narrative telling is often more related to 'small stories', where tellings of specific, often seemingly incidental, events, memories or circumstances are given focus.

So called 'big stories' in narrative research offer a holistic, largely biographical approach (Bamberg 2011) to considering aspects of the lived experience, and tend to be based on, for example, interviews which feature reflection on significant past events. Bamberg (2006) argues this approach has dominated the 'narrative turn' until fairly recently, and Ochs and Capps (2001) suggest that an associated emphasis on structure and organisation of events compromises focus on the importance of the accompanying interactions which shape and define them.

Whilst 'big stories' may provide an overall context of aspects of the lived experience (Bamberg 2006), 'small stories' allow for the telling of one incident to act as a site of identity construction in and of themselves (Phoenix & Sparkes 2009). 'Small stories' may seem incidental, and thus are often not identified, let alone the subject of focus (Phoenix & Sparkes 2009). For Watson (2007), small stories are 'ephemeral narratives arising from talk in interaction' (p. 374).

As a narrative approach, 'small stories' (Bamberg 2004, 2006; Georgakopoulou 2006, 2007; Bamberg & Georgakopoulou 2008) offers an alternative (though not necessarily contradictory [Freeman 2006]) or complementary (Phoenix and Sparkes 2009) perspective to 'big stories'. 'Small stories' is used as 'an umbrella-term that covers a gamut of under-represented narrative activities, such as tellings of on-going events, future or hypothetical events, shared (known) events, but also allusions to tellings, deferrals of tellings, and refusals to tell' (Georgakopoulou 2006, p.122), and to provide an opportunity to consider collaboratively formed identities within conversation. This dialogic aspect of the construction and use of 'small stories' is pivotal for Georgakopoulou (2004), who perceives the audience as complicit in the construction of the narrative.

#### **4.6.3 Telling 'small stories' online**

In this research, 'small stories' were told via email. Though these asynchronous conversations still constituted dialogic and collaborative production of a narrative, they did not take place face-to-face with visual prompts or clues. As has been discussed in section 4.5 in this chapter, email as a medium was familiar to the students, and as such (as in the case of James's [2007] research) a potential site for the narration of stories and enactment of identity.

'Small stories', according to Wilson and Stapleton (2010), have three underlying criteria: firstly, a focus on 'natural' as opposed to 'artificial' or contrived data; secondly an

emphasis on the interactional production of stories as forms of discursive practice; and thirdly the use of social theoretical perspectives to assist in explaining 'small story' data. I considered each of these criteria in evaluating email as a mechanism for the telling of small stories. In using online data collection techniques (virtual interviewing, online surveys, etc), Silverman (2006) acknowledges the resulting data as naturally occurring text, where the researcher has limited intervention. Silverman notes that by virtue of the author having the ability to re-read and edit the text, the text itself will have a definite character. Second, online conversations via email are also by nature discursive and interactional in that each email must have a writer, sender, receiver and reader, and thus two-way participation. Finally, in identifying and analysing excerpts from the emails, it has been vital to locate the tellings of events within literature which is relevant to conceptualising fluctuating or recurring impairments. Thus, in highlighting the potential for the existence of conditions appropriate for telling 'small stories', it would seem that email as a communication mode would meet the criteria set out by Wilson and Stapleton.

Storytelling via email does, however, have an extra layer of complexity in a dialogic sense, as on-going dialogue takes place asynchronously and with no visual prompts or clues. However, there are ways of showing emphasis within text that can help the narrator to foreground certain reactions or feelings. Indeed, the role of shared etiquette in email exchanges or any online discussion (often referred to as 'netiquette' [Scheuermann & Taylor 1997; Sturges 2002]) is of interest to consider in how individuals might position themselves within a specific and unique form of virtual communication. In terms of content, the use of phonetic or numeric abbreviations that have found their way into email vernacular as well as into everyday language (Hawley Turner 2009; Drouin & Davis 2009) as a result of the increasing use of mobile technologies are also of interest in considering positioning and the performance of identity. Though this did not feature particularly strongly in the student stories, I was aware that some used abbreviations and contractions

(such as one student's use of 'lol' for 'laugh out loud'). It was also an aspect of email communication that I had increasingly noticed with other students I was teaching.

#### **4.6.4 A 'hybrid' approach to narrative analysis**

In their 2009 paper 'Being Fred: big stories, small stories and the accomplishment of a positive ageing identity', Phoenix and Sparkes combine multiple narrative tools in undertaking analysis of the identity construction of a research participant (Fred). In the research, Phoenix and Sparkes use Fred's 'ontological narrative' (Somers 1994) of *Life is what you make it* to demonstrate the plot that unfolds within Fred's personal 'big story', as a route to representing one way Fred constructed a way of being in the world. This ontological narrative emerged from field notes of interviews as well as notes taken during informal encounters (car journeys, etc) between the researchers and Fred. In considering 'small stories', the authors focus on two of Fred's identities that become apparent: *being fit and healthy* and *being leisurely*, in order to frame Fred's construction and performance of self within the grander narrative. In this account of the research, Phoenix and Sparkes note the role of cultural resources and discourses which Fred makes use of in telling his narrative, as well as the role played by his own material circumstances and position as an individual. They also outline how 'big stories' are an opportunity to present the *whats* of narrative content from a retrospective life history perspective, and 'small stories' the *hows* that offer insight into the ways in which identities are performed.

By combining both perspectives, Phoenix and Sparkes offer 'a promising integrative direction for narrative inquiry' (p. 223), based on the complementary perspectives collected during the interactive interviews and the authors' field notes as 'connections were sought across narrative segments and themes in an attempt to identify patterns and meaning constructed within and between the big and small stories told by Fred' (p.224). The authors discuss how they drew upon principles within categorical-content analysis to

combine data on the participant from both the interview and outwith it to create an interpretative biography of the storyteller. Phoenix and Sparkes then argue that 'an analytical abstraction of the case is produced that highlights the processes in the individual's life, the different theories that relate to these life experiences, and the unique and general features of the life' (p. 224).

As noted in section 4.2, page 53 - 54, the student data comprises two phases: initial interviews (phase one) and on-going email exchanges (phase two). The initial interviews provide a context within which the later email narratives are located, in raising recurring issues discussed by students at interview. Discussion in Chapter Seven, section 7.4, pages 118 - 123 is based on the notes I took during the 24 phase one interviews. I identified recurring issues amongst the students' reflections and present these as a collection of perspectives on the diversity of experience of disability on a fluctuating or recurring basis.

The student narratives from section 7.5, page 124 onwards are based on both the phase one and phase two data. In drawing on Phoenix and Sparkes's research, the 'hybrid' narrative approach I adopted permitted using the phase one data to consider aspects of students' 'ontological narratives' and phase two emails to identify examples of 'small stories' to consider different ways in which students negotiated identities within institutional discourses and constructions.

Such a 'hybrid' approach is extremely relevant in analysing the student data collected for this research. In the initial interviews, students spoke at length about their life histories and the ways in which their impairment had impacted upon their opportunities to learn. By considering recurring themes/ phrases in each student's stories, I suggest a title for an 'ontological narrative' as one of many ways in which the student may have drawn on discourses and material and cultural references in order to position themselves and others. Using such an approach is not intended to be essentialist or reductive, but rather

to afford a focus on one interpretive way in which a student might present their way of being in the world. Similarly, by using a student's own choice of phrase in the telling of a 'small story' identified during the email conversations, I consider aspects of identity performance, again in contextually negotiated ways, in exploring an aspect of a student's complexity of identities as subjected within the wider discourses.

#### **4.7 Summary**

In adopting a social constructionist perspective within this research, an opportunity to question assumptions and understandings of disability and impairment, both socially and culturally influenced, as well as within the institution is presented. Specifically, in considering how particular social constructions and discourses influence policy and practice, it is possible to consider how staff interpret their roles, implement support and construct students with fluctuating or recurring impairments. In turn, this provides a context within which students negotiate, construct and perform identities and position themselves relationally amongst staff and peers. Taking differing narrative approaches to the data analysis allows consideration of how staff and students draw on pervading discourses in their positioning and in socially constructing disability and impairment, as understood and perpetuated by the institution.

In the following chapter, I describe and justify the decisions I took within the research design process in order to enable the research and subsequent outputs to reflect this holistic perspective.

## **Chapter Five: Research process**

### **5.1 Introduction**

This chapter provides an overview of the conduct of the research process, including sampling and recruitment of staff and student participants, conducting staff and student interviews and engaging a group of students in on-going email exchanges over the course of one academic trimester (January – April 2011).

### **5.2 Analysis of institutional policy**

In considering institutional values that influence practice, I have included detail from a key policy document at the institution where the research was conducted. The university's Learning Teaching and Assessment Strategy (LTAS) was, at the time the research was carried out, a crucial strategy which influenced approaches to teaching, assessment and support. Using a social constructionist framework to consider constructions and terminology used in the document provided an opportunity to evaluate some of the ways the university interpreted and implemented provision and constructed students. Analysis of the document highlighted the influence of prevalent discourses in wider HE on institutional values, constructions and practices, as discussed in Chapter Six, section 6.4, pages 87 - 90. The constructions used in the LTAS are considered in the analysis of the staff interviews, in focussing on how staff operationalize the policy in practice.

The LTAS was selected to represent institutional interpretations, constructions and values as it was, at the time the research was conducted, the only policy which may have a bearing on the university's interpretation of 'social inclusion', and as such of constructing 'disability' and 'the disabled student'. During the research, there was no specific institutional policy on inclusion or supporting disabled students, therefore the research

made use of the LTAS as one way of considering institutional ambivalence as regards this.

### **5.3 Staff sampling, recruitment and data collection**

Through my disability-related work over the past seven years at the institution where the research was carried out, my extended community of practice (Wenger 1998, 2000) grew to include colleagues in academic, support, research and strategic roles. My approach to sampling, then, was highly purposive, in recruiting those staff members whom I knew acknowledged fluctuating or recurring impairments. A purposive approach is common in research exercises involving academic staff's direct experiences and familiarity of particular aspects of practice (Salmon & Jones 2004; Samarawickrema & Stacey 2007). However, the use of such a sampling strategy necessarily defines those colleagues as a sub-set of practitioners with a strong ethical and practical commitment to inclusion that is perhaps not typical of attitudinal trends across the university. Had I wished to gain an overview of staff perceptions I would have extended the call for participants more widely, across the institution and in a variety of roles. However, as the purpose of this part of the research was to consider ways in which policy discourses concerning the concept of fluctuating or recurring impairments may shape practice, this sample of key members of staff was judged to fulfil the purpose of the research. Whilst the colleagues that I interviewed offered considerable insight into institutional processes and a valuable opportunity to consider various aspects of tensions in their own positioning, the limitations of the perspectives of such a small group must be acknowledged.

I carried out the three interviews in October 2010. I contacted the participants by email to invite them to interview. In advance of the interview, I emailed a copy of the staff participant information, consent form, and interview schedule (see Appendices 3 and 4, pages 210 - 212) as I was keen for the participants to have the interview questions in



advance to allow them to consider experiences and reflections. The interview schedule was developed in order to capture examples of having provided support to students with fluctuating or recurring impairments as well as to gain insights into the establishment and perpetuation of institutional constructions of disability. In keeping with principles of ensuring clarity of purpose and participation, I asked the participants at the outset of the interview if they wished for clarification of any aspect of the research before requesting permission to make an audio recording. I also offered colleagues the opportunity to have a copy of their transcript, though none of them followed this up.

#### **5.4 Staff data analysis**

In accordance with Riessman's (2008) interpretation of the use of thematic narrative, the intent with the analysis of the staff data was to offer space for the stories that the members of staff told to be considered in both an institutional context and in terms of making use of wider social and cultural values and discourses, 'rooted in everyday understandings' (p. 57). I was particularly interested in how staff used the institutional values alluded to in the LTAS in their practice, and in their constructions of disability. In considering the dialogic narratives of each participant in turn, I aimed to keep the story "intact" by theorising from the case' (p. 53), as noted in Chapter Four, section 4.6.1, page 63. I refer to sequentially ordered extracts through the unfolding interview as opposed to the full transcript for each participant.

I transcribed the three interviews myself and read them thoroughly and repeatedly. In keeping with Riessman's interpretation of thematic narrative analysis, I considered each interview in its entirety and issues raised by the participants in sequence. Though to an extent the responses were structured by the questions within the interview schedule, the three participants drew on their own positioning and constructions in their responses, weaving detail from their reflections, biographies and practice into differing accounts. As a

result of asking specific questions within the interview schedule, some discussion topics engaged all participants (for example, the construction of the 'Disability Champion'), though again to differing effects and drawing on differing institutional values and constructions. In carrying out the analysis of the transcripts, I considered the ways in which the participants drew on local (institutional) as well as global (cultural, societal) discourses in constructing disability, students and in positioning themselves. Throughout the analysis I was particularly interested in the language and concepts used in constructing fluctuating or recurring impairments, and how this was represented by the staff members.

I was interested to consider how, in MacLure's terms, the analysis of the discourses (in terms of language, practices and relationships) could 'unravel' some of the implicit constructions of disability within institutional documentation and practices. I chose to record and transcribe the interviews as I wished to compare colleagues' terminology with that used in institutional documentation, by way of identifying operationalization and impact on practice. This complementary component of using documentation to frame language, values and practice provided valuable scope to consider the context, culture and constructions of the institution (Fitzgerald 2007).

### **5.5 Student sampling, recruitment and data collection**

In September 2010, I met with the university's central Disability Team to discuss the research. As well as being keen to have their feedback on the appropriateness of the research/ need for greater understanding of the learning experiences of students whose impairments may vary over time, I had also initially hoped to recruit students to participate in the research via an opt-in email circulated by the Disability Team, as in line with data protection protocol, I was not able to access individual contact details. The team agreed that they would identify students who they believed had types of impairments that had the

## Chapter Five: Research process

potential to fluctuate or recur and would initiate contact if I sent them participant information to which interested students could then respond. Whilst to an extent randomised, again the sampling approach here is purposive, as has been demonstrated in research involving 'invisible' or 'non-obvious' disabilities (Dale Stone 2005; Portaway & Johnstone 2005).

Throughout October and November, I received emails from two students who were interested in taking part in the research. I met with one of the students, who was unable to commit to contribution as she was anticipating a bereavement in her immediate family, and I was unable to secure a meeting with the second student.

The lack of response through this route necessitated a revision of my recruitment strategy. Due to the 'hidden' and undisclosed or unrecognised nature of the types of impairment that the research focuses on, I anticipated that identifying students through central records might be problematic. Not only did accessing students through the Disability Team add a further layer of subjectivity, but also did not account for non-disclosure. To account for those students who had not disclosed or who would self-describe as having an impairment which had the potential to fluctuate or recur as part of their constructed student identity, it was vital that I extend the call to be more universal.

I thus contacted the Students' Association and asked, following guidance from the School of Health Ethics Committee, if it would be possible to have a call for participants distributed to all students as part of a bi-weekly newsletter. The communication officer responded to alert me to the existence of a dedicated Student Research email address which circulated such calls for participation across the entire student population. Having supplied some background on the research and my own contact details, an email was sent to each student in the university on my behalf (please see Appendix 5, page 213).

From the 14<sup>th</sup> - 28<sup>th</sup> January 2011, I received 42 responses from students across all academic disciplines and at all levels of study. I arranged to speak with 28 of the students,

21 of whom participated in interviews (18 face to face, 3 via telephone), 3 of whom returned email questionnaires, and 4 of whom were unable to keep their appointment. In all, then, I collected data on type of impairment, level and subject of study, disclosure, nature of 'reasonable adjustments' in place, impact of impairment on learning and conceptual understanding/ terminological associations of fluctuating or recurring impairments for 24 students. A summary of my notes from each of the interviews is provided as Appendix 8, and the data itself is analysed in Chapter Seven. I have used my notes from the 24 phase one interviews to outline recurring issues within student perspectives of experiencing fluctuations or recurrence in impairments in HE in Chapter Seven, section 7.4, pages 118 – 123.

At the interview, I gave students a paper copy of a student information sheet and the opportunity to ask any questions about the research. I then asked them to complete a consent form (see Appendix 6, pages 214 – 216 for both the student information sheet and consent form). For those students I interviewed by telephone or email, I requested that a completed consent form was either returned by email or by post. I devised a basic pro-forma on which to record details about the student (see Appendix 7, page 217), which were largely demographic, with the exception of an open ended question about how the student felt that their impairment impacted upon their learning. The students were thus free to select any aspect of their impairment in representing themselves and their experiences, and hence the topics students chose to reflect on varied enormously. I recorded the discussions in note form during the interview.

### **5.6 Student interviews (phase one)**

In collecting data during the phase one interviews, I decided against audio recordings primarily because the interviews with students were a contextual starting point to establish some of the ways in which students experienced being institutionally constructed and

positioned as students with fluctuating or recurring impairments, and what this meant for the support that they received. I was interested to discuss students' ways of being, past and present, in relation to the impact of their impairment on participation in learning, as well as on their identity. Back (2012) has cautioned that:

“There is [also] a sleight of hand in the claim that the authenticity of a person can be rendered through a faithful transcription of their voice. It also confers on the person coming to the interview a self that is as much a historical product as it is an authentic biography to be disclosed in the telling” (p. 12)

Additionally, due to the potential sensitivity of the interview topic, I was keen to be discursive and informal in order to make the interview a collaborative and conversational process and event (Hiller & DiLuzio 2004). I anticipated that recording the interview may compromise this; the visible, physical presence of the audio recorder and the act of beginning the recording have, in my previous research experience, often impacted negatively on the interview process. By capturing the students' reflections in note form, I felt much more present in the dialogue; by paying close attention to recording key phrases, events, or dates, for example, I was more able to converse with the student about their experiences.

However, as a result of this I must acknowledge the nature of the data that I did collect, versus that which would have been captured verbatim through recording and transcription. By taking notes based on my own interpretation of what the student was discussing, I have immediately added a layer of my own interpretation. Whilst I did capture specific phrases or facts that the student noted, I also abbreviated, summarised and joined statements from different parts of the interview together. For example, if a student had forgotten a detail about a particular event and returned to add to their description after several other topics had been discussed, I would return to the area of my notes about the original telling and add the supplementary information. In narrative terms, the potential for significance in the ordering of telling of events, according to Bamberg's suggestion, was not preserved in my notes. Without an audio recording I am also unable to reflect on

intonation or emphasis (Fasick 2001) and am reliant on memory and the observations which I made at the time. The purpose of the data collected within the phase one interviews was to present an overview of some of the ways in which students experienced variation in impact of an impairment in HE, and not for analysis of narrative per se.

I was very aware of the generosity of the students in sharing their experiences and time, and although I had not offered any incentive to take part in the research, for some the catharsis of the discussion was appreciated, which May (1991) argues is a typical by-product, along with reflection and disclosure, of research participation. After a fairly intense conversation with one student he told me that he 'felt great' after getting some of his experiences 'off his chest'. Indeed, this therapeutic role of the interview itself and the positive impact of participation has been noted in research methods literature (Gale 1992; Murray 2003), and in particular in research which may involve sensitive topics (Dickson-Swift et al. 2007).

### **5.7 Student email data (phase two)**

I chose to take a convenience sample of the first ten students who participated in interview as the basis for the on-going data collection phase. I was keen for there to be an unfolding, temporal aspect to the data, albeit limited to one academic trimester (academic term January – April 2011). I wished this aspect to be open to students in order that they could document fluctuations in participation over the period of a few months, whilst they were planning and completing various assessments. Though a limited period which is merely one concentrated episode within a student's life, the trimester-long data collection offers a way to consider some of the issues which affect student engagement, performance and identity over a short period of time.

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The first ten students provided diversity in terms of the impairments that they described, a balance of male and female, and a range in age and subject area (see Appendix 1, Table 4, page 207). I was keen for the narrative part of the research to focus on a small number of cases, as can be typical in research concerning 'hidden or hard to access populations' (Adler & Adler 2012, p. 8), and in terms of allowing detailed focus appropriate to the narrative method (Charmaz 2012). I chose a sample of ten as I estimated that not all of the students would continue to stay in contact, and to allow for attrition.

Each of the first ten students who took part in interview were invited to keep in touch for the duration of one academic trimester, through whatever means they preferred. After ten students had agreed, I removed the section about maintaining contact until April from the participant information sheet that I gave students at interview so that from then on, students only opted in to the short discussion. This meant that the 14 students who I interviewed subsequently were not invited to contribute to the phase two data, and potentially some interesting perspectives were not collected.

As part of the information sheet, I suggested a suite of communication routes (blogging, text messages, email, post-its, digital photos) to those students who had agreed to keep in touch. Universally, the students opted for email, and after discussion it was agreed that contact every two weeks would not be too intrusive (hence a total of six would be sent from January to April). I was conscious of a number of issues in this process: firstly, providing the student with choice; secondly, that I was relying on their willing participation as no incentive was being offered; thirdly, that this gave me an opportunity to structure communication and prompt responses from the students; and fourthly, that email was an accepted route to institutional communications that offered scope to engage in on-going dialogue. As noted in Chapter Four, email as a qualitative research method has been underscored as offering strengths in capturing online narrative and in offering a space for identity construction (James 2007), and so created interesting opportunities in considering students' positioning and representation.

Of the ten students who agreed to maintain contact, five continued to regularly do so. The other five students sent either singular email responses or did not contribute at all.

Perspectives from these students' initial interviews have been included in discussion in Chapter Seven, section 7.4 and summary information is available in Appendix 6.

Each of the bi-weekly emails I sent to students participating in the phase two emails were open-ended and invited students to comment on any aspect of their participation in learning which had been particularly significant at that time (a summary of each of the weekly emails is included as Appendix 9, pages 230 - 232). The only exception to this was the fifth email, in which I asked four questions to try to capture more focussed responses. With the last of the six emails, I sent all ten students a £10 Amazon voucher by way of thanks.

### **5.8 Student data analysis**

I used both my notes from the phase one interviews and the emails transcriptions from phase two in analysing the student perspective. In using a 'hybrid' method similar in intent to that employed by Phoenix and Sparkes (2009), I sought to use the notes I made from the initial interview to consider the conversational production of a 'big story' or 'ontological narrative' and the telling of an incidental occurrence within the course of an email conversation as a point of focus for a 'small story' about identity. I identified the 'big story' through considering phrases and constructions that students drew on in representing their experiences as one way of considering their reflexive way of being (in some cases I have also used extracts from emails to further illustrate this). I also selected a 'small story' from an email as a focal point to consider the relational production of identity in the context of learning as a social interaction.



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In analysing the data, I considered recurring phrases, themes or topics raised in the interview and discussion to build, as Phoenix and Sparkes (2009) suggest, an 'ontological narrative' or 'big story', as discussed in the outline of the 'hybrid' approach suggested in Chapter Four, section 4.6.4, pages 68 - 70. This 'ontological narrative', according to Phoenix and Sparkes, is a composite story built from inferences made from participants' tellings and interactions that provides a chance to consider one of their ways of being in the world (the *what*). I have used concepts and reflections from the phase one interview data to suggest an 'ontological narrative' or 'big story', and an incidental 'small story' told as part of email dialogue to interpret an aspect of negotiated identity (the *how*). I acknowledge that the selves presented by students during the data collection period constitute those current to their circumstances at the time, and make no claims about persistence of these identities or representations throughout the students' futures. Quite opposed to being reductive or essentialising, I have taken this 'hybrid' approach to offer one way of considering students' perspectives in a specific context with specific discourses. Indeed, the very fact that I have positioned/ constructed them principally as students, merely one small aspect of their identities and lives, has an undeniable effect on the way the data have been interpreted.

Within the phase two emails sent during the January – April data collection period students discussed, amongst a variety of topics, their varying levels of ability to participate in learning and the impact that this had on academic engagement, preparation for upcoming assessments, frustrations surrounding group work and variations in levels of support. Many of these stories seemed useful focal points for locating student narratives, in considering their positioning of selves, peers, staff and the institution. These tellings provided an insight into students' constructions of themselves as learners, within a specific cultural setting (the institution) as well as within a specific group (students whose impairments have the potential to fluctuate or recur), allowing for the consideration of both social and individual identities (as per Jenkins 1996). As such, including a 'small stories'

component in analysis provided scope to consider the data in a way that was not bound by the canonical beginning, middle and end conventions of traditional narrative analysis (Georgakopolou 2004, 2007). Indeed, Georgakopolou argues that email can act as a conduit for story formation by merging on and offline identities.

## **5.9 Ethics**

There were a number of issues I had to take into consideration in ensuring that the research was ethically sound and acceptable to both the University of Stirling School of Education's Ethics Committee as well as that at the institution where the research was conducted. I had a responsibility to ensure the anonymity of all participants (staff and students), to ensure that there was no risk associated with participation. With staff, I did not mention specific job titles, academic schools where they worked or specific aspects of their role which I felt may identify them. With students, I removed reference to year of study to decrease likelihood of identification, though specified whether they were undergraduate or postgraduate, and have maintained detail on academic discipline and on impairment.

A key consideration, however, was of the identity of the institution itself. Whilst I have not named the university directly, it has not been possible to ensure anonymisation, as some of the concepts and terms used within policy, which have been crucial in allowing examination of the identification of institutional discourses and the consideration of how policy is operationalized, are unique to the institution and therefore could identify it. In Chapter Six, where I have included extracts from university policy or from areas of the university's web site, I have not added references for this reason. I consider the implications of this well documented practitioner/ researcher tension and 'divided loyalties' (Bell & Nutt 2002) in Chapter Ten, section 10.2, pages 173 - 174.

## Chapter Five: Research process

In line with the British Educational Research Association's Ethical Guidelines for Educational Research (BERA 2004), I devised clear and concise participant information, comprising an information sheet, a consent form and an interview schedule which I sent or showed to all participants in advance. Staff information, consent and interview questions are included in Appendices 3 and 4. Student information, consent and questions are included in Appendices 6 and 7. I also ensured that any participants were aware they could contact me at any point if they required clarification on any aspect of the research or their role in it.

As disabled students are often referred to, in terms of educational research, as 'vulnerable adults', and, indeed in the School's Research Project Request for Ethical Approval Form question 1.4, I was also required to demonstrate a commitment to ensuring wellbeing. In response to the question 'What steps will you take to ensure that they understand the nature and purpose of the research process?' I answered,

'By being as clear as possible in the participant information documentation, and by arranging a face-to-face meeting at the beginning of the research where participants are invited to ask any questions or offer any suggestions. As the student blog part of the research is longitudinal, I envisage, and would welcome, on-going informal dialogue.'

Question 7.1 of the same form asked for information on any potentially ethically problematic aspect of the research, and I provided the following information:

'The inclusion of students with potentially very serious and unpredictable disabilities, such as mental health difficulties. I aim to give all students the opportunity to contribute and also the flexibility to withdraw should they be uncomfortable in continuing. I will also work alongside disability support staff to ensure that my conduct is as supportive and unobtrusive as possible.'

In terms of my own conduct, in response to question 8.1 about the safety of research staff I included an action plan based upon my networks to ensure that support could be put in place should I be concerned about a student's health or wellbeing:

'It is possible that I may become concerned about a student if they appear to be

having a negative episode during the blog postings. I intend to closely monitor the posts, and seek confidential advice from disability support and wellbeing colleagues should I have any concerns.'

### **5.10 Summary**

In presenting both staff and student perspectives as regards institutional constructions of fluctuating or recurring impairments, I have adopted a variety of narrative techniques to consider operationalization of policy in positioning students. From a staff perspective, this relates to what provision is offered to students and in what way, and for students, to ways in which identities are negotiated and performed. The samples for both the staff and student perspectives are small, with the result that the following analysis is detailed. This has been necessary in order to weave together institutional values and discourses that have shaped policy and provision, staff narrations of policy operationalization and constructions of disability, as well as student reflections on ways in which they draw on institutional discourses, constructions and positionings in developing identities.

In the following chapter, I consider institutional constructions of fluctuating or recurring impairments through staff perspectives. This is intended as a way of considering how policy is operationalized in positioning students, and provision implemented. It also provides the discursive context for the evolving student stories collected and interpreted in Chapter Seven.

## **Chapter Six: Analysis of staff perspectives**

### **6.1 Introduction**

The purpose of this chapter is to analyse the ways in which policy is enacted to implement student support in the context of institutional constructions of fluctuating or recurring impairments. The chapter first presents an overview of the model of provision for disabled students at the university where the research was conducted at the time the research was carried out, and outlines the university's Learning Teaching and Assessment Strategy (LTAS) as an example of a key institutional policy which informed practice. In presenting the analysis of staff interviews, I consider how staff made use of the discourses implicit within the LTAS in constructing and providing access to support for students with fluctuating or recurring impairments. The analysis uses a thematic narrative approach to consider three staff members' perspectives as regards institutional practices and reflexive positionings.

### **6.2 Revisiting the research questions**

This chapter contributes to answering the first two research questions set out in Chapter One, section 1.6.3, page 17:

1. In what ways do institutional discourses influence constructions of disability?
2. How might these discourses frame perceptions of fluctuating or recurring impairments amongst staff in HE?

### **6.3 Overview of model of provision**

At the time the research was conducted, provision for disabled students at the university where the research was carried out operated on a 'hub and spoke' model. Centrally, within Learner Services (the collective title for all library, welfare and support services)

there was a small Disability Team (also frequently referred to by staff as the Disability Service), at the time resourced by two full time and two part time members of staff (Disability Advisers), who were responsible for first contact with disabled students, co-ordinating assessments, processing claims for Disabled Students Allowance (DSA), and drawing up Needs Assessment Records (NAR), the agreement that the university entered into with students to provide appropriate 'reasonable adjustments'. There were also three members of staff in an associated Mental Health and Wellbeing Team who provided counselling and 'positive living' advice.

Students who disclosed an impairment during the applications process were contacted by the Disability Team prior to enrolment. They were sent information about the support available at the university and invited to make contact with a member of the Disability Team to discuss support. Information for current and prospective students regarding different types of support was available on the Disability Team's web pages. For staff, the available resources to guide practice on supporting students on these web pages consisted of a hyperlink to the Teachability project ('good practice' guidelines developed by a consortia of HE partners that concluded in 2006) and a section on legislation with no content. At the time the research was carried out, there was no formal guidance on the procedural elements for supporting disabled students available to staff. Additional information on the Mental Health and Wellbeing Team's web pages offered a variety of links for students. A menu item entitled 'Information for staff' described possible consultancy and liaison with the Mental Health and Wellbeing Team and also some opt-in workshop activities, but again, no specific procedural documentation.

In each of the academic schools, there was a named Academic Disability Co-ordinator (ADC), typically a member of academic staff with a responsibility for the ADC role in addition to their existing teaching, research and other administrative commitments. The primary role of the ADC, as outlined on the Disability Team web pages, was to:

‘Forward on copies of Needs Assessment Records to appropriate staff. They will also liaise with Disability Advisers and provide academic related advice to students and act as contacts within their own School and Department’.

The ADC was the key school-based contact for students, and worked across the school to ensure that information about a student’s requirements had been communicated amongst staff and actioned. Again, at the time the research was being conducted, there was no standardised job description outlining the responsibilities of the role, though a move towards one had been part of on-going discussion during a restructuring exercise that happened in early 2011, after data collection had concluded. I discuss the subsequent impact of this restructuring more fully in Chapter Ten.

#### **6.4 The influence of the Learning Teaching and Assessment Strategy (LTAS)**

The Learning, Teaching and Assessment Strategy (LTAS) was a much cited document within the university, used to guide both strategic and day-to-day activity. The LTAS began its introduction with the following rousing statement:

‘The overarching theme of [The University]’s mission is a commitment “*to the common weal*”. As noted in the [University] Mission this means that we will use our skills, facilities and knowledge to make a positive contribution to society. This approach permeates all aspects of the university’s business and no more so than in learning and teaching. Through innovative curricula enhanced by curiosity-driven applied research, designed and delivered by highly skilled, reflective and creative staff we seek to engage students in the joy of learning. We aim to provide a high quality, inclusive and flexible learning and teaching environment which makes the best use of technology enhanced learning, creating a bold, innovative and distinctive approach. This moves us away from a perception of students as consumers of knowledge and towards students as partners in the development of knowledge, thus preparing them to become confident, problem solving graduates who are able to make a positive contribution to society.’

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The LTAS, like much of the university's policy and promotional materials, noted the central idea of 'the common weal' as being integral to all university activity, and the vehicle by which its 'positive contribution to society' is achieved. The university made frequent reference to social justice and its social mission within its publications, alluding to its civic pride in being a working class institution in a working class city. According to the LTAS, as well as the university making a positive contribution to society, so too will the students it 'prepares'.

However, in addition to nurturing 'the common weal', the LTAS also described an institution whose vision was driven by productivity, skill and innovation. These industrial terms hint at institutional priorities which reflect the manufacturing of graduates through high quality processes and technologies, whilst its statement to 'deliver' and 'develop' reflect the impact of managerialist language on HE policy and discourses. Indeed, in outlining its commitment to 'the common weal', the 'university's business' was invoked as being the collective term for absolutely everything that happened there. The use of such an overtly commercial phrase to encapsulate the scope of the LTAS and all associated activities alludes to the institution as a corporate provider of commodified educational experiences and the production of high quality graduates.

Critics of neo-liberalism and the increased commoditisation of Higher Education (Gibbs 2001) argue that educational transactions may be given privilege over student engagement, corresponding with notions of performativity (Ball 2000; Fielding 2001), and echoing arguments that in the increasingly competitive market to provide the best student experience possible, research, teaching and student support are all largely driven by institutional accountability and efficiency rather than pedagogical enhancement (McInnis 2001). Fairclough (1993, p. 143) has argued that universities 'operate (under government pressure) as if they were ordinary businesses competing to sell products to their consumers'. The 'university's business', then, was to secure the institution's place within the educational marketplace as a leading competitor and service provider, trading in high



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quality learning, teaching and research, and producing highly competent graduates. For Drummond (2003) in the 'knowledge economy', it is knowledge itself which has become a commodity (Lyotard 1984; Grineski 2000; Naidoo 2005), and in the context of the LTAS, commitment to 'the common weal' is contingent upon the smooth running of the 'university's business'.

Accountability and the need for measurement are central to debate on practices of new managerialism in HE (Lane & Stenlund 1983; Avis 1996; Deem 1998). The characteristics and technologies of such an audit culture are components of what, for Foucault, could be construed as governmentality (Shore & Wrights 1999; Shore 2008), impacting upon how individuals within the institution construct the boundaries of their participation and the roles they adopt. 'Audits, performance indicators, competitive benchmarking exercises, league tables, management by targets, and punitive research assessment exercises and periodic teaching quality reviews' (Shore 2008, p. 282) are all ways in which new managerialism is enacted within HE.

Discourses of excellence and notions of competition and achievement were also characteristic of the university's promotional material. For example, a welcome on the university's website attested that the institution was:

'A distinctive, inclusive and forward-looking university that is committed to its social mission to promote the common good. We have become an international centre of excellence in higher education, promoting employability and global citizenship in our graduates.'

As was apparent within much institutional documentation and practice, here a tension existed between social responsibility and, to all intents and purposes, customer service. In highlighting priorities and values, this statement notes *commitment* to the institution's social mission, but the actual *achievement* of excellence. As in the preceding extract from the LTAS on page 87, it would seem that 'the common weal' permeates as an aspiration, whilst the activity and measurable outcomes of 'university business' actually exist.

The LTAS was thus underpinned by both civic and industrial values (Boltanski and Thévenot 2006) that created tensions within which an ambiguous construction of inclusion existed. With no explicit policy or guidance to outline the institution's interpretation of inclusion and no formalised information for staff, many of the procedures and protocols remained tacit and vague. The following analysis of staff perspectives will consider how this ambiguity translated to the practice of staff who drew on the implicit discourses and values of the LTAS in order to provide support for students with fluctuating or recurring impairments.

### **6.5 Analysis of interviews with staff**

As discussed in Chapter Five, section 5.3, page 72, I interviewed three colleagues about their role in teaching and supporting disabled students – Alison, Marie and Susan. Alison had a strategic, policy-based role and was responsible for promoting and fostering 'good practice' in inclusive student support across the university. Marie and Susan were both academic members of staff, who had at various times held an Academic Disability Co-ordinator post in addition to their main teaching, research and support roles, and thus had detailed insights to share on how the institution not only defined but upheld its principles of inclusion and flexible access. They also discussed how they interpreted their own roles and positioned themselves institutionally. The analysis of the staff interviews provides scope to consider ways in which students with fluctuating or recurring impairments are constructed institutionally, the discourses which influence these constructions and in what ways staff might operationalize policy.

I have used extracts from the interview transcripts in sequence according to the course of the interview to illustrate perspectives and positionings. This is done, as I have explained in Chapter Four, section 4.6.1 page 63, as per Riessman's (2008) intent to use a thematic approach to narrative which will keep the unfolding story "intact" by theorising from the

case' (p. 53). Though I have not used the entirety of the transcripts, the extracts are sequentially ordered and themes emerge from individual perspectives and positionings. As I use some of my own statements to demonstrate the collaborative production of the narrative, each quotation is preceded by the respondent's initial by way of differentiation. Ellipses have been used to show pauses and hesitations, and any insertions I have made to promote clarity are denoted by square brackets. The participants have been given pseudonyms.

### **6.5.1 Alison**

Alison had been employed by the university for ten years, and discussed having a role across a network of contacts throughout the university. I opened each of the interviews by asking staff to briefly describe the main components of their role, and Alison spoke about how her role was predominantly staff-facing rather than directly supporting students:

A: 'My role is to work with schools, departments, staff and students to make sure that we comply with the range of equalities legislation so...it covers all the strands, all the...legislation that we've had, uh...including disability, which is one of the...I guess, most visible and obvious strand ...so, I do a lot of work directly and indirectly with the staff and students on a range of issues, whether that's training, policies or...sort of responding to specific situations or...challenges.'

Alison's immediate reference to legislative compliance gives a strong indication that she interprets the main responsibilities of her role in terms of the law. Her suggestion of the 'visible and obvious' nature of the disability 'strand' (of her work and in legislation) contrasts with the lack of disability-specific institutional policy and the vagueness that surrounds institutional provision. Throughout the interview, Alison was very comfortable using legislative terminology/ discourse about 'disclosure', 'reasonable adjustments' and 'requirements', and frequently drew on these when describing her own role as well as in

framing her interpretation of the support that the university provided. Her construction of the disabled student was thus informed by notions of legal entitlement and rights.

In discussing the institution's responsibilities and compliance, Alison went on to highlight the importance of 'disclosure':

A: 'We used to have a difficulty where...students would be very reluctant to disclose for a number of reasons, as you probably know from your work. I think it has improved over...over time, I think there's an issue about systems being adequate and ...and when we ask the question...as well as how confident the person is...giving us that information, so I think it's...partly down to the university's...you know, basically stuff like forms, you know, and whether they're, you know, accessible and electronic or...things like that.'

In this part of the interview, Alison refers to the shortcomings of 'systems' as problematising the process and act of 'disclosure', as opposed to solely the confidence of the student, reflecting a social interpretation of disablement that is contingent upon the environment as opposed to the individual. In discussing the institution's mechanisms as part of this environment, Alison also outlines the importance of timing in asking students what additional support they may require, and notes that this is contingent upon the student ('person') having confidence to request this support. 'The question', as Alison constructs the transaction that ultimately enables support to be put in place, positions the student as under scrutiny, and obliged to part with potentially sensitive and personal information, if they are to have access to adjustments. 'The question' is the process that turns 'disclosure' into institutional data that then becomes part of the 'university's business', as outlined in the LTAS. Answering 'the question', then, at the beginning of the student journey, during the application stage (through UCAS) and before any relationship with the university has been established, is essentially what initially constructs the disabled student as other or different.

In beginning discussions about fluctuating or recurring impairments, I asked Alison about her awareness of 'unseen' disabilities. Alison noted a pervading lack of legitimacy/

continued suspicion surrounding 'unseen' impairments, as has been discussed in some depth in Chapters One, Two and Three of this research. She particularly noted the area of mental health, describing 'a lot of taboo and a lot of sort of...um...discrimination that still takes place' and how 'people still don't accept it as a reasonable or acceptable disability on a par with the others'. I picked this issue up with Alison, noting that this lack of acceptance had been a major influence on the research.

V: 'I think that's one of the things that actually kind of interested me in doing the research is that things like, you know, mental health difficulties and chronic fatigue and things can manifest themselves in different ways and certainly from work that I've done in the past, people have approached it with a certain level of cynicism...and, you know...just because things do vary over time, but...you know, it's less valid than something that's constant...'

A: 'Yeah...I think, if it's not presenting today, then...you know, on face value the stereotypical lecturer will say, you know "you're the same as everyone else, get on with it...", not...recognising the journey, you know...before and after, you know, as you say...um, conditions that do fluctuate, um...so the state isn't just...as, as is seen there...on, on this particular day, it might sort of have a very negative impact the next day or the day before.'

Alison notes scope for limited acceptance of fluctuating or recurring impairments within the institution by constructing the 'stereotypical lecturer'; an other who is dismissive and lacking understanding or empathy, and whose ambivalence reflects tensions in wider institutional discourses. Paradoxically, in Alison's account, the 'stereotypical lecturer' responds to a lack of visible signs of impairment by normalising students. But being 'the same as everyone else' here is punitive rather than inclusive. A condition of being 'the same as everyone else' is that students are expected to 'get on with it', with minimal fuss. The journey that Alison uses to conceptualise students with fluctuating or recurring impairments, which is not an unfamiliar metaphor in studies of fractured identities within chronic illness (Frank 1995), is, according to Alison, largely ignored institutionally.

Alison returns to the staff-facing aspect of her role, saying that in maintaining regular contact with the central Disability Team she can be kept up to date with student issues. In this context she sees herself as a potential conduit in enabling communication to ‘the top’ – the executive of the university:

A: ‘There’s a...sort of whole infrastructure of staff, as you probably know, around disability...disability co-ordinators in the academic schools, we’ve got the disability team, I sort of...see them regularly, well, I try to see them regularly...not seen them recently, but...try and consult with them and get their feedback, get their thoughts...cos as I said earlier, they’re the people that have that direct contact, direct experience...so, I might not be able to help with the specific issue...but institutionally and...from a policy or strategy point of view, if we need to fund something or we need to...influence people that are...are making the decisions at the top, then...I guess I’m part of the route to that message getting...getting across.’

In describing how she is ‘part of the route to that message getting across’, Alison outlines her function as conduit within the infrastructure that enables information to move and action to be taken. Alison constructs herself, the process and the institution within this infrastructure in spatial terms – herself centrally, the Disability Team and ADCs ‘around’, the people making decisions at ‘the top’ and the process (‘the message’/ Alison’s role) across.

Alison notes, however, that the process/ ‘the message’ is not without difficulties. For her, it seems that blame lies with inconsistency across the university; with the peripheral actors who implement ‘the message’ differently, in non-standardised ways. If, in industrialisation terms, standardisation and consistency mean increased effectiveness or productivity, then in line with protecting the ‘university’s business’ as outlined in the LTAS, this is highly desirable, and for Alison, the key to promoting equality. In so doing, Alison highlights the importance of discourses of quality and effectiveness, such as those which inform the documentation of the Quality Assurance Agency for Higher Education (QAA), in guiding her practice and constructions.

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In this context, I asked Alison for her opinion on the usefulness of having a shared term to describe fluctuating or recurring impairments, in order to broaden recognition or acceptance. Alison's immediate reaction was to raise concerns about 'labelling', which she worried 'could be used in a negative way'. However, Alison also noted the benefits of having a shared term that need not necessarily equate with the negative effects of stigmatisation (Riddick 2000), but that could have benefits in increasing recognition and improving legitimacy:

A: 'I think it's helpful to...to give it a title, I'm trying to think of what that could be, but if there was a label that was commonly accepted, then people might begin to understand and take it seriously on a par with the other ...I mean, the word fluctuating...I don't know if that features technically ...if that could be used, cos that's quite illustrative and an active description...but I dunno if there's a neat, sort of one...phrase or one word...that I've come across...'

Here, Alison speaks hesitantly and with uncertainty. Despite deciding that a shared term would be useful, and making a speculative suggestion, she continues to make reference to a 'label'. The institution's ambiguity as regards inclusion and the lack of acceptance of fluctuating or recurring impairments in wider society does not allow Alison access to adequate or familiar language to use confidently in suggesting her own interpretation or description. She also demonstrates her own ambiguity in discussing the negative effects of labelling as well as the positive effects of a shared term.

It seems that for Alison, institutional ambiguity and ambivalence as regards disability and support for disabled students is evidenced by the disparity of provision that exists within academic schools, as opposed to the robust model of support that she constructs at the centre. It is in the outposts of the academic schools, with irregularities and differences, that, as Alison sees it, difficulties which compromise inclusion lie. Conversely, at the centre, with legislation on her side and specialism on the part of the Disability Team, excellence, for Alison, is assured:

A: 'What I'm trying to do is get a consistency and, you know sometimes it's very difficult, um...to get the ear and get the influence of...the people that are putting resources into place...around disability, so...I think some...you know, it's patchy around the schools. I think centrally it's excellent, you know...learner support have always provided a really good service, they've got a Disability Team, they've got the Effective Learning Service, they've got Mental Health and Wellbeing...team now, which...you know ...relatively new, but...I guess the demand and the impact suggests that, you know...they...they're meeting a need.'

In demonstrating her perceived excellence of the centre, Alison problematizes practice in the schools. By way of example, she draws on the construct of the Academic Disability Co-ordinator, noting how the responsibilities of the role might vary according to how it is interpreted by a school, and thus going against the 'consistency' grain. Alison suggests this is largely determined by influences such as the school's specific culture, academic priorities or professional affiliations. In discussing the ADC role in this focus, Alison raised the issue of marginalisation of disability roles institutionally:

A: 'The other thing was that...because we've got disability...named people with that type of thing...disability word in their job role or job title, it's automatically...I may have said this to you before, Vic, but...it's given back to them, it's their responsibility, they can deal with it, whereas...in fact it should be everybody taking a role, you know, as a lecturer or a programme leader...they should be providing the same level of support, you know, that the co-ordinators...you know, a lot of the time, trying to... prod and facilitate and make sure that other people are doing their job, but...it's kind of the other way round...'

V: ' So in many ways the important part of that job...that aspect of the job title is the co-ordinating part rather than the disability...'

A: ' Yeah, yeah...absolutely...'

V: '...so the onus is on the entire academic team to make the reasonable adjustments...'

A: ' Yeah...and you've mentioned the law there, and...yeah...I mean, that's sometimes what it takes. Um, and you mentioned LTAS earlier, you know, I think we're trying to make sure that the core strategies that we have should, you know



include disability, you know, whether it's learning and teaching or, you know, we've got an international strategy, we've got all these different...we've got widening participation, so we've got all these things...but you know, I'm not sure that it's explicit enough or...you know, committed enough to...to show where we stand on disability.'

As part of demonstrating the potential effectiveness of 'all these things', Alison used the construction of the 'Disability Champion' to discuss her aspirations for future institutional revisions and improved clarity of provision for disabled students. The 'Disability Champion' as a construct is part of the discourse of excellence outlined in the LTAS, in positioning the institution as a competitor in the delivery of learning and teaching.

A: 'Um...it's a recent, um...er development but we've got all these...strand specific working groups, I can't remember if I've given you any of this already...but we've got a disability working group, for example...which is a formal sub-group of the equality and diversity committee...and we've got other strands, we're sort of trying to set them up...for gender and age, race, etc...so we've got a good sort of core group there...that helps influence what we're trying to do. And we've also got equality champions who are senior level champions, so [name] is our disability champion, so he's an excellent advocate and, you know...he knows his stuff...basically, so he is quite an influential figure, or will be...this is still early days...but in terms of the attitudinal and sort of cultural changes that I've mentioned a few times, then I think these things will help keep it alive, and keep it alive at a senior level.'

Alison returns here to disability being one 'strand' amongst many in her role and the institution's legal obligations. She constructs the multiple working groups as development; part of on-going progress and not only a source of optimism, but of life-sustaining responsibility for keeping 'it' (the quest to establish a clear model of inclusion) alive. The senior level champion is one way in which Alison hopes that action will be taken at the executive level, and the presence and visibility of disability-related issues strengthened.

### 6.5.2 Marie

Marie was a member of academic staff who was also an ADC. She had been a member of staff in the same department since 1997, and described how a lot of her work in supporting disabled students was based on experience and knowing ‘what is possible’ within existing institutional processes:

M: ‘I suppose at this stage for me a lot of it’s...based on experience but that, it...looking at what is possible within the context of maintaining academic integrity on courses and what...what reasonable adjustments can we do without undermining the academic integrity of the course...what the procedures and principles are in terms of things like putting in place an alternative assessment to an examination, as an example, so working with the quality control procedures and understanding that, so...really to do the job you need to have kinda quite a lot of experience of the university...looking at how policy has changed, and in particular the impact of how the Disability Discrimination Act has changed over the years.’

Marie immediately, at the outset of the interview, positions herself within the role of academic; her governing priority is that ‘academic integrity’ is not compromised. As with wider institutional ambiguity, the concept of ‘academic integrity’ is open to multiple interpretations. For example, it could be construed in this context as referring to equitable access to core components of an academic programme for all students or as Marie’s intent to safeguard the credibility of her discipline or department. In discussing the ‘academic integrity of the course’, however, Marie suggests that it is the syllabus that is, for her, the priority, and the implementation of ‘reasonable adjustments’ which acts as a potential threat.

Marie’s practice is informed by what she loosely refers to as the institution’s ‘procedures and principles’, and how these construct ‘what is possible’. The ‘procedures and principles’ are not specifically named because they do not exist: as noted in this chapter, section 6.4, page 90, at the time the research was conducted there was no formal policy on inclusion and no documentation on protocol for supporting disabled students. In

referring to the 'quality control procedures' that also influence 'what is possible', Marie operationalizes the LTAS values of rigour and reliability in process and production as part of an overall discourse of excellence. For Marie, this ensures that she can contribute to the 'university's business', as also outlined in the LTAS, and be instrumental in the production/ preparation of the LTAS's 'confident, problem solving graduates'.

By contrast, Marie was specific in naming examples of legislation and commenting of their, to her, discernible impact on institutional accountability as regarded disability:

M: 'I think the biggest change, when it really started to hit the university was when SENDA came in...although the Disability Discrimination Act...was active at that time, I think when SENDA was kind of looming on the horizon...things started to change and people were taking...there was a lot of awareness raising having to take place...and I think that's really was really the nub of when things were really, really starting to change place...take place, because we could...we were required by law to do certain things...and I think the other thing about SENDA was that individuals were...could be taken to court, I suppose..'

Like Alison, the points Marie raises here are located in observations of obligation, compliance and, crucially, the legal advancement in individual accountability. However, Marie's implication that changes to practice occurred as a result of being 'required by law to do certain things' creates a tension within the university's commitment to protection of 'the common weal' in the interests of social justice, where an extrinsic motivator of legislative compliance (or risking punishment) would not seem to align with principles of equity or inclusion. Marie, however, discusses the impact of the legislative changes in fairly general and abstract terms. There are no actual examples of change to practice or principles, but more to ideas and aspirations through 'awareness raising', again echoing the LTAS's interpretation of 'social inclusion' as an ideal or goal rather than in the implementation of a clear and practical framework.

In discussing fluctuating or recurring impairments and the type of support that she had negotiated with students in the past, Marie drew on flexibility and disclosure as being vital

components in making support available. Flexibility is the central concept which, for Marie, enables both students and staff to have contingencies in place, but the functionality of this comes with the pre-requisite of disclosure. Whilst Alison referred to the potential inadequacy of 'systems' in influencing a social model based interpretation of institutional or environmental disability, for Marie it would seem that the timing of the act of disclosure is key to ensuring that provision is made available for students:

M: 'Students have periods where they're not as well and when they are as well, and what we try and do is...put flexibility into the system. We try and encourage students to disclose even if they're feeling very well...with the view to being able to put...rapidly put the reasonable adjustments in place...if and when they're required ...because if we...if you wait until there's a problem...it's not too late, but you're having to rapidly kind of mobilise support ...and that can take a bit of time, you know...it can...if you take away all the kind of the legalistic and policy procedures that are associated with things like Disabled Students Allowance and you're actually working in the environment of like the academic support, you're having to mobilise things quite quickly.'

Marie represents disability in health/ illness terms here, and suggests that for students, times of ill health may constitute 'a problem'. This is the crucial point where contingencies that have been previously agreed can be actioned, and where support for students with fluctuating or recurring impairments who have not disclosed may be difficult to establish. Marie's encouragement of disclosure at an early stage is intended to counter these difficulties by being anticipatory, a key feature of disability-related legislation such as the DDA and SENDA. In her advocacy for students to disclose before 'a problem' occurs, then, Marie operationalizes the values and principles of legislation.

The concept of flexibility was further weaved into specific examples Marie gave about supporting students with fluctuating or recurring impairments:

M: 'I can think of one particular case where a student had quite severe mental health difficulties, and was unwell throughout the duration of their studies, but had periods of being relatively well in comparison to how ill they could become. So, a

quite easy reasonable adjustment to put in place is flexibility in deadlines. Now, some people interpret that as giving the students extensions, it's not really it's a kind of formalisation of recognising that there may be periods in that student's academic experience where they need more time, and it might just be more time to process, it might be that they get particularly fatigued, so the amount of work that they can do in the course of a day is actually limited.'

In describing 'some people' as misunderstanding the purpose of flexible deadlines, Marie alludes to a negative interpretation of assessment extensions. In so doing, Marie reinforces a perception that any change to the initial submission deadline (under the auspices of protecting 'academic integrity') is undesirable and may potentially add to suspicion of a student's capabilities. Marie, as with Alison's 'stereotypical lecturer', constructs 'some people' as an other which allows her to position herself as an inclusive practitioner who understand and promotes values of flexibility. 'Some people' share the suspicion and mistrust of the 'stereotypical lecturer' as regards fluctuating or recurring impairments, which requires 'formalisation', on Marie's part, in order to add rigour and 'academic integrity' to the process of establishing the alternative submission mechanism. Thus, students with fluctuating or recurring impairments may be constructed by 'some people' through the student's participation in alternative assessments, which themselves are viewed negatively and outwith 'normal' academic practices.

In further reflecting on strategies for supporting students whose impairments vary in intensity, Marie constructs two differing ways in which students might experience fluctuations, and comments on what this might mean for support:

M: 'So for some...some students who are perhaps in that situation, they...like to kinda pack all their...their studies into a certain day to give them a day of rest, but for some students that really doesn't work, because they become totally exhausted...so for other students what...although they're in every day you would think well maybe that's not actually necessarily...common...logically you'd think we'll give...make sure they have a day at home...it's...in terms of managing the fatigue, and their poor...their conc...cos the've maybe got concentration problems, em... is doing small amounts each day.'

In constructing 'some students' who benefit from concentrated activity and prolonged periods of rest and 'other students' who spread learning over a longer period of time, Marie cautions that even within a construction of fluctuating or recurring impairments, variation exists in how students experience and manage their impairments. During the interview, this was a useful reminder to resist compartmentalising all students whose impairments varied in intensity into one category or typology. Whilst there may be commonalities in some aspects of the students' experiences of living and studying with a fluctuating or recurring impairment, the individual continuum in the collective spectrum cannot be reduced to a finite set of characteristics or attributes.

Marie's representation of her position in the process of encouraging and creating flexibility was collaborative; she positioned herself as part of the collective 'we' that enabled the flexibility to take shape, to become a 'reasonable adjustment' and to be implemented. She also spoke about the importance of maintaining regular contact with students and evaluating/ revising the arrangements or contingencies which have been agreed within the Needs Assessment Record (NAR). The NAR itself was another institutional construct which was assimilated into the university's disability discourse, yet was not unproblematic. Being based on 'Need', for example, infers a deficit discourse of requirement that is informed by an exclusionary, supplementary model of provision. However, for Marie, the NAR is a vehicle for flexibility, seeing 'what works and what doesn't' and adjusting 'what is possible' accordingly.

M: 'With the Needs Assessment Records, looking at reviewing them regularly as part of...you know, as part of the whole process, to meet the student and say, well how did it work? Because the first...probably the first semester and even probably the second semester...it's a bit of trial and error to see what works and what doesn't...work, you know...so that...it's also sort of saying, now...once that's done, that's not the package of support that's going to be there. It might change over time, there might be more there might be less...but it's about having...taking cognisance that things are not static, and may change...'

Such mechanisms for providing flexibility and for consolidating the intangible concept of fluctuating or recurring impairments were important in helping Marie navigate the difficulties of 'getting that message across to staff' (that students' participation may vary) amongst institutional ambiguity and ambivalence. She cited competing institutional technologies such as the NAR and Special Factors Board (the exceptional exam board that considers all cases with mitigating circumstances) as being complicit in causing these complexities, as they themselves are contingent upon institutional constructions of disability and illness respectively. So, as Marie's rhetorical dilemma indicates here, what are the conditional or appropriate circumstances for a student with a NAR to have their case considered at Special Factors Board? And as has been discussed in Chapter Three within this research, where does illness end and disability begin?

M: 'I think one of the challenges that we face as Academic Disability Co-ordinators...maybe even the disability team, is actually getting that message across to staff...that this student may be well one day, but the next week they may be very unwell. Em, so...it's about...and sometimes that can be difficult to, em...to get across, that message can be difficult to get across. Em...particularly if...say, for example, a student is unwell, and they can't sit their exams, and it goes to the Special Factors Board. Now, I would like some very clear guidance from the university on that, because in one sense, some people argue, well the Needs Assessment Records are in place, the reasonable adjustments are in place...so this is not Special Factors.'

Again, Marie refers to 'some people' in highlighting institutional ambiguity and constructing an unsympathetic other as regards lack of institutional recognition/ acceptance of the possibility for impairments to fluctuate or recur, as well as a pervading ambiguity on protocol and in operationalising inclusion. By having one agreement in place, the option to engage in another without considerable justification is precluded. There would appear to be limited scope (or at the very least, confusion) for the two technologies of the NAR and Special Factors to interface, which underscores the vague and often contradictory nature

of institutional constructions as regards disability. For Marie, this influences a construction of the disabled student that is informed by perspectives of health and illness.

In drawing on existing institutional constructions, Marie, like Alison, was optimistic about the effect of recent developments such as the 'Disability Champion' in raising the profile of disability-related issues and discussions.

M: 'I think we've still got a way to go, but I think things are changing because we now have a Disability Champion, em...so I think that will change, I think you really need buy-in at executive level, and I think we're getting there with that, I think there's been quite a change over the past few years. Whereas before, because we didn't have...like...an exec...direct link to an exec, member of the exec...issues weren't going up, so it was more frustrating. So hopefully now that will...that's...changed...'

For Marie, the progress of 'getting there' with executive level support carries the potential for positive future action. The significance of having a link 'up' to the decision makers in the hierarchy for Marie has the potential to challenge past frustrations and foster improvements. Again, in her comment here, Marie speaks in ambiguous terms about change, and does not specifically discuss what form this change may have assumed, or indeed attest that it even occurred. Marie constructs the 'Disability Champion', in commercialised terms, as effecting 'buy-in' to the 'social inclusion' that the LTAS outlines on the part of the executive. In so doing, she aligns with the values of the executive with the market-driven priorities of the 'university's business', as also discussed in the LTAS.

### **6.5.3 Susan**

Susan was a member of academic staff who also held the ADC role in addition to her main responsibilities. She discussed how, in keeping with the guidance on the Disability Team website outlined in section 6.3, page 87, the management in the school where she worked saw the ADC role as largely administrative in making sure that NARs were sent to



the appropriate contacts. Susan began the description of her own interpretation of the role by discussing being 'given' it and 'told' what the post entailed:

S: 'When I was given the role, I was told that it was a mainly administrative role...um, so I was told that the job involved really distributing the students' Needs Assessment Records to the various, um tutors that they would come into contact with...during their time, during their course...and I've kind of developed that role a little bit so that I've got a bit more input with the students and act as a sort of liaison between the students and the school and the disability service.'

However, despite the role being imposed on Susan, she negotiated the boundaries in order to interpret the role in her own way. Susan rejected the limitations of the role by positioning herself pivotally, and determining a liaison/ advocacy role with the students, school and central team, and constructing herself as a crucial figure in mediating and negotiating discussion and support. In taking action to develop the role outwith the confines of administrative expectations, Susan interpreted the administrative construction of the role as insufficient. Like Alison, Susan also constructed her role spatially 'between' the different areas of students, the school and the Disability Team.

Susan discussed not having received any 'formal training' as regards supporting disabled students, despite having requested this from the school. With no institutional support, Susan sought out opportunities to collaborate with and learn from peers and colleagues in her community of practice, both in external organisations and within the university. The 'formal training' that Susan was unable to secure with the support of the institution was pursued through a tacit, collegiate route, and again, in defiance of the school's interpretation of her role.

S: 'So, really what influences my practice is mainly advice from the disability service, I'm also in contact with some of the professional organizations that are involved with our students, for example, the Autistic Society, I have a bit of contact with...um, with them in relation to one of our Aspergers students, um...but no sort of formal training at all.'

Susan, as was also the case with Alison, praised provision at the centre of the model of delivery by aligning the Disability Team (Disability Service) with other 'professional organisations' whose advice influences her practice. For Susan, the collegiate and collaborative route to improvement based on shared knowledge reflected the civic values of the LTAS, in allowing Susan to test the limitations of her role with the hope of providing a more integrated support model for students. In contesting the efficiency of provision in the academic schools through rejecting how the ADC role has been constructed, Susan, like Alison, problematised distributed practice. In so doing, like Marie, Susan also relied on the informal discursive mechanisms of sharing practice and guidance in the context of pervading institutional ambiguity, as opposed to adhering to specific institutional policy, which does not, in actuality, exist.

Susan gave a number of examples of supporting students with fluctuating or recurring impairments during the interview, and here too raised the importance for her of relationships in encouraging dialogue. Specifically, Susan mentioned her discomfort in the pre-requisite within existing university technologies for students to have sufficient confidence to negotiate support, and crucially acknowledged a desire to be able to, again, take an active part in this herself:

S: 'One of the students in particular just finds it very difficult to go and speak to tutors and say I'm having a problem...we have another student that suffers very badly from depression and he um...constantly worries about being judged by his tutors, and while his um...grades reflect that his academic ability is very high, he is really concerned about his tutors judging him, feeling like he's making excuses, feeling like he can't get things submitted in time...so it it it does become very difficult for them to do that. I can sort of step in to a certain extent, but then again the student doesn't want to be kind of seen that someone else is kind of fighting the battle for him, so...yeah, it does put a lot of pressure on the students who are already, um...vulnerable.'

In this context, Susan raised the issue of perceptions/ judgement and students feeling staff are constructing them in a particular way because of changing ability to participate in

learning activities. The 'tutors' that Susan constructed through the students' experiences shared the same suspicions as Alison's 'stereotypical lecturer' and Marie's 'some people', and the issue of possible negative judgement resonates with both Alison and Marie's accounts of the prevalence of limited legitimacy as regards fluctuating or recurring impairments. Susan's positioning here is pastoral – she invoked ideas of student struggle (through constructing the student as suffering, having a battle to fight and being vulnerable) and her own interventionist role as one which interrupted this. In noting that one specific student had sufficient academic ability, Susan constructed the student as capable, but disabled by the mechanism of having to negotiate flexibility with his tutor.

In constructing fluctuating or recurring impairments, Susan acknowledged that variation is something that all students experience, and advocated an inclusive approach to providing flexibility that offers scope to provide support for all students. In arguing for provision that would 'benefit all of our students', Susan again operationalized the holistic, civic values of the LTAS, and outlined her own ascription to principles of inclusion:

S: 'All students have varying needs over time, and that they all need an individualised provision and what would meet the needs of disabled students, if it was put in place, would very well benefit all of our students...sort of no matter what their needs are.'

In noting the value of such provision, however, Susan highlighted that this was not something that was currently in place. As with Alison and Marie, Susan acknowledged that the institutional perspective on the LTAS's 'social inclusion' was ambiguous and unclear, and that some aspects of a flexible infrastructure to support this did not exist.

Like Marie, for Susan, flexibility was paramount in ensuring that students had autonomy in learning. Inbuilt to this was, in Susan's perception, an obligation on the part of the institution to offer adaptations to existing support based on a period of review rather than unwillingness to revisit provision. This would seem yet another example of institutional ambiguity and disparity in practice across the academic schools as outlined by Alison –

whilst in the school where Marie taught provision was negotiated and reviewed, for the students in Susan's school there were far fewer opportunities to do this. Susan invoked the challenges presented by the centre-periphery discord noted by Alison in discussing a limited amount of staff (resources) at the centre, and the consequent inflexibility this created in the school to review requirements regularly:

S: 'It's a very difficult decision to make at the beginning of a 4 year period, or a longer period what a student is going to need through that whole time. Um, so I really think that extra resourcing in the disability services is a key issue, and and something that needs to be taken an awful lot more seriously by those in charge of the purse strings for that service. I actually have in the past felt quite embarrassed speaking to students about it and sort of, them asking me whether or not, um...their needs would be reviewed and that's something that they may have been used to having, perhaps at school...um, and having to tell them, no...without sort of official request from them, that they won't be looked at again...'

Susan constructed those 'in charge of the purse strings' as those ultimately responsible for limitations in central resourcing, and the knock-on effect in schools. As with Alison and Marie, Susan acknowledged that, hierarchically, action and change is limited without endorsement from the executive. In suggesting that resourcing needs to be 'taken an awful lot more seriously' by the decision-makers, Susan suggested that, at the time of the interview, she did not perceive that it was an issue of importance or urgency, reflecting the ambivalence of the LTAS as regards inclusion as an aspirational idea, but lacking in presence.

Susan saw herself (and other Academic Disability Co-ordinators) as being part of a potential solution to the central limitation in this resourcing, but as with other aspects of her ADC role, her ability to do so was restricted by the school's priorities, and indeed she positioned 'this School' negatively. In so doing, Susan echoed Alison's concerns about the lack of consistent practice across the ADC group, significantly in terms of awareness of fluctuating or recurring impairments:

S: 'And that would work OK if the disability co-ordinators were well-trained in things like sort of recognising changing needs on the student... on the part of the student over time...but you know, obviously, as I've said it's viewed as an administrative role in this School, so there's no real kind of...back up for the disability service in that sense, I mean, in my view I could be being much more useful than I am to the disability service, it would help address some of that resourcing issue, but...there's no opportunity for that...at the moment.'

With both Alison and Marie's optimism in the appointment of the 'Disability Champion', I was very interested in what Susan thought, especially in light of her perspective that she projected responsibility for change onto the executive in providing financial support. Until I had conducted the first two interviews I had been unaware of the 'Disability Champion's appointment, so considered it a fairly recent development, as had been outlined by both Alison and Marie:

V: 'And do you think... I understand there's a new Disability Champion within the university...'

S: 'Yes...'

V: '...do you think that's likely to change things at maybe a kind of a political level?'

S: 'I know he was put in place quite a while ago but I haven't met him, I haven't had any contact with him, I haven't heard of anything that is being done by him to change the situation, um...I...I just...I don't want to be cynical about it, but I hope it wasn't just a case of ticking a box and making sure there was someone in that role and then it isn't sort of being followed through.'

Susan illustrated her interpretation of the role as a passive one, resonant of the institution's ambivalence, in describing the Disability Champion' being 'put in place'. The lack of change that Susan noted as a result of the appointment further reflected institutional ambivalence, in line with the LTAS's allusion to the importance of inclusion in its priorities, without a commitment or evidence of actualisation in practice. Susan cited the performative 'ticking a box' accountability values also alluded to in the LTAS as a possible reason for the creation and implementation of the role. By attributing cynicism to

this perspective, Susan constructed it as undesirable, reflecting her priorities of social justice, and alignment with the LTAS's values of promotion of 'the common weal'.

The distance and discontinuity used in constructing the space of 'not following through' was also invoked by Susan in illustrating a chasm between students, schools and the centre. Again, she returned to the idea of resourcing as being the solution to bringing the disparate areas together, and staff development as the activity which will enable change. She noted the impact of the lack of existing guidance already documented in this chapter as instrumental in not giving staff the knowledge or awareness to be able to 'cope' with disabled students.

S: 'I think that there needs to be a lot more staff training so that, for example, disability co-ordinators are able to um...bridge the gap a little bit more between the student and the disability service in terms of things like recognising changing needs over time and the academic staff um...responsibilities need to be changed, I think there could be a lot more training for the academic staff as well, for example, how to um...cope with having dyslexic students in class, there's very little in the way of that at the moment, but again it all comes back to a resourcing issue – we need someone in the disability service to offer that kind of training, but, you know on one hand I'm saying they don't have time, to deal with the students they're working with, whilst also asking them to provide a whole additional service in terms of staff training, so...resourcing is the key.'

Susan operationalized the prevalent institutional ambiguity here in having dual (and unrealistic) expectations of the Disability Team. She was aware of the pressure that the team are under, but also believed they should do more. Susan acknowledged her own contradiction, which echoes institutional tensions as regards institutional provision for disabled students. Susan's comment here chimed with Alison's point of issues being 'given back' to certain people (as 'resources') who had disability in their title as opposed to adopting a more distributed model of provision. The idea that 'responsibilities need to be changed' allowed Susan to articulate her belief that a distributed approach to provision

was required within a cultural change of universal, and equal, responsibility. In so doing, Susan again drew on legislative constructions of responsibility and equity.

## 6.6 Discussion

Marks (1994) notes, in directing attention towards the way in which policy discourses may position subjects that:

‘Individuals may resist or contest the way they are constructed by policy documents and perspectives, and actively choose to construct their own subjectivity as other than compliant and conservative . Adopting such a position does not necessarily guarantee emancipation or empowerment however, but rather involves individuals in constant negotiation and renegotiation regarding the ways they are constructed. Often too, texts such as policy documents may construct individuals, such as students with disabilities, as resistant or compliant depending on the situation or the reading of previous policies, texts, discourses and practices’ (p.75).

The tensions between the values of social justice as well as accountability, quality and commercialisation which characterise the LTAS effected a model of support which was ambiguous and ambivalent, mirroring wider social constructions of fluctuating or recurring impairments. The three members of staff who took part in interview discussed the operational shortcomings of the ‘hub and spoke’ model of support for disabled students as an example of the operationalization of this ambiguity, in creating a model which could be implemented with either ambivalence or rigour, and which, as such, created discord and contradiction and a lack of clarity in terms of continuity and student expectations. As a form of regulatory biopower, the model’s lack of coherence impacted negatively on its effectiveness.

Alison regarded central support as excellent, with the variation and non-standardisation/ inconsistency in the various academic schools as being problematic. This perspective was

echoed by both Marie and Susan who were located within academic posts in the schools. They too noted difficulties in the ambiguity of the model, and in the scope for provision to be interpreted, constructed and operationalized in varying ways. For Susan, it was a limitation in the 'resources' at the centre which precipitated the variance in schools, and she suggested that investment was needed to address this and improve overall flexibility and inclusion. In so doing, Susan challenged the aspirational way in which the LTAS presents inclusion as constructing the vague goal as actually achievable if given resources and taken 'a lot more seriously'.

All three staff members used technologies of disability legislation and legalistic constructions of 'disclosure', 'needs assessment' and 'reasonable adjustments' in constructing disabled students. These phrases gave the staff members access to recognised terms in which to frame their practices in the context of a vague and ambiguous social construction of fluctuating or recurring impairments, as well as to formalise various aspects of supporting disabled students in the absence of specific university guidance. In frequently using these terms, as well as in making explicit reference to specific legislation, or to notions of equity or protection, staff highlighted the crucial role which the law played in their practice and constructions of disability. Alison noted the law as both a 'primary driver' as well as 'lurking in the background' for her practice, and Marie discussed the impact of individual accountability in changing the culture of support delivery institutionally. In this context, in representing the act of 'disclosure' staff noted limitations in information systems as well as students' individual confidence in outlining conditions for effectiveness. In participating in the process of 'disclosure', the act of sharing information (for Alison, asking 'the question') is the point at which the student becomes other, but not necessarily disabled. Staff argued that disablement was as likely to be the result of perceptions (again, Alison's 'stereotypical lecturer', Marie's 'some people') and a pervading lack of trust in recognising impairments



which varied in impact or were not immediately visible as well as logistics (limitations on 'resources' according to Susan, or the protection of 'academic integrity' for Marie).

Marie invoked 'quality control procedures' as a way of ensuring that the LTAS's goal of producing high quality graduates could be assured in the quest for 'academic integrity', hinting that whilst vagueness and ambiguity were operationalized in providing support for disabled students, there were also undercurrents of accountability and robustness to assure rigour. However, for Marie, 'reasonable adjustments' may threaten 'academic integrity', and as such disabled students could be perceived as problematic. By example, Marie constructs flexible deadlines for assessments as extensions, and thus as negative for 'some people', as a reflection of student inability to participate in learning. This pathologisation of flexibility in favour of the expectations and regulations of academic practice immediately problematises students with fluctuating or recurring impairments as non-compliant. With uncertainty being a central feature of living with a fluctuating or recurring impairment, and a key feature in wider social constructions, participation based on measures of predictability immediately compromise possibilities for inclusion.

Vague and competing institutional technologies, such as the NAR and Special Factors, as well as lack of explicit policy or guidance on supporting disabled students, for Marie created further ambiguity in constructing students, particularly those with fluctuating or recurring impairments in terms of health and illness as opposed to on-going disability. This led her to discuss students with fluctuating or recurring impairments in terms of periods of 'wellness' or otherwise, alluding to the possibility of recovery, a not unproblematic concept as discussed with reference to Frank's (1995) 'remission society' in Chapter Three, section 3.5, page 44.

## 6.7 Summary

The staff members who contributed to interviews discussed ways in which they interpreted and actioned institutional policy, as well as drawing on wider legal discourses in relationally positioning themselves amongst colleagues and students. This allowed them to represent a flawed model of delivery for supporting disabled students in a culture of ambivalence, ambiguity, judgement and mistrust. The tensions implicit within the competing discourses of social justice and marketisation within the LTAS contributed to a vague, interpretive practice space where staff had the opportunity to comply with or reject the institution's values in constructing disability, and in particular fluctuating or recurring impairments.

Staff positioned themselves against various others in underscoring a pervading lack of legitimacy or acceptance as regards fluctuating or recurring impairments, located within institutional ambiguities and ambivalences. Where institutional constructions of disability are vague and often based on physical participation in learning or ability to abide by the rules of 'academic integrity', scope to recognise forms of impairment which are difficult to predict or quantify remains limited. With strong, high level institutional values of marketisation and production, difference and lack of uniformity are undesirable and other. For Marie, this difference influenced a construction of disability as being 'unwell', and for Susan being 'vulnerable'.

In the absence of institutional clarity, legislation and legal constructions of 'reasonable adjustments' and 'disclosure' played important roles in allowing staff access to language and notions of institutional and individual responsibility as regards support for disabled students. Whilst the staff members used various constructions and values from the LTAS in outlining their practice, in the absence of a specific policy on inclusion or supporting disabled students, the law provided a frame of reference for protocol, responsibility and practice.

## Chapter Six: Analysis of staff perspectives

In the following chapter, I consider student narratives in the context of institutional discourses, and the ways in which policy was operationalized by staff in order to provide support. Institutional discourses, constructions of disability and technologies will be considered in the context of the negotiation and enactment of student identities.

## **Chapter Seven: Student narratives and identity constructions**

### **7.1 Introduction**

This chapter first considers some of the issues which students discussed in the initial (phase one) interviews relating to their experiences of disability as one which has the potential to fluctuate or recur. Following this, I present analysis of five student narratives, and adopt a 'hybrid' approach to using 'big' and 'small stories' in considering students' ways of being and the negotiation and performance of identities. In so doing, I aim to highlight aspects of the students' 'ontological narratives' and identity constructions. The first part of the chapter uses notes from 24 initial student interviews. The student narratives from section 7.5 onwards are based on five students' initial interviews and transcripts of email conversations between January and April 2011.

### **7.2 Revisiting the research questions**

This chapter considers ways in which the analysis of student data will contribute to answering the third research question set out in Chapter One, section 1.6.3, page 17:

3. In what ways are the identities of students with fluctuating or recurring impairments negotiated and constructed within HE discourses?

### **7.3 Student interviews and emails**

Marks (1994) has argued that considerable disparity exists between 'the way policies construct students, and the ways students construct themselves both within and outside the policies' (p. 72). In framing the following student data analysis in the context of emerging institutional discourses and operationalization of policy by staff, I aim to locate

## Chapter Seven: Student narratives and identity constructions

the student narratives within multiple environmental influences which may affect the creation and management of identities.

The chapter begins with an overview of some observations on constructions and experiences of learning with fluctuating or recurring impairments collected within the initial student interviews. These are considered within the context of the institutional discourses and the operationalization of policies as discussed in Chapter Six, and are intended to contribute to discussion within this research on how students with fluctuating or recurring impairments may construct identity. In this discussion, as described in Chapter Five, section 5.6, pages 76 - 78, I use the notes which I took during the interviews to illustrate points, and have put extracts or phrases in quotation marks for emphasis.

I then consider five student narratives, again using interview data, as well as the transcripts of on-going email discussions between January and April 2011. As noted in Chapter Four, section 4.6.4, pages 68 – 70, I have adopted a 'hybrid' narrative approach to analysis of this data, drawing on positioning analysis (Harré 1993) and considering 'big' and 'small stories': in particular using Phoenix and Sparkes's (2009) focus on 'big' and 'small stories' to present 'ontological narratives' and aspects of identity construction respectively. I have used my notes from the initial interviews to suggest a biographical 'big story' for students and an incidental 'small story' shared during the email exchanges to consider a way in which each student negotiated an aspect of their identity. The suggested titles for these stories were informed either by a phrase the student actually used or an issue that they discussed at length. In presenting the students' stories and considering the effect of institutional discourses on how these unfold, I first offer a brief description of each student's circumstances and learning context.

## **7.4 Fluctuating or recurring impairments from students' perspectives**

As noted in Chapter Five, section 5.5, pages 74 - 76, I undertook interviews with 24 students either face to face, by phone or by email (see Appendix 7 for the interview proforma). I gave students space to discuss any aspect of their lived experience of disability as one which fluctuated or recurred by asking the open question: 'in what ways do you feel your impairment impacts on your learning, if at all?'. This created a broad scope for students to reflect institutionally, and in their wider lives, on their own personal constructions, perceptions of other peoples' constructions as well as the influence of context and environment on how fluctuating or recurring impairments were conceptualised.

Amongst a variety of reflections, students shared their experiences of difficulties in articulating changes in their ability to participate in learning and teaching activities, limitations on appropriate language to facilitate this, feelings of judgement from peers and staff and a pervading lack of understanding about variation in impact of impairment. Students also reflected on existing institutional mechanisms and ways in which these may impede inclusion for fluctuating or recurring impairments through inflexibility.

### **7.4.1 Representation, perception and disclosure**

A universal issue raised by all students in both the interviews and throughout the email discussions was the difficulty that they experienced in articulating what it meant (personally and academically) to be able to fully participate in academic activities one day and not the next; as Lingsom (2008, p.2) would have it, 'explaining the unexplainable'. Students spoke about having 'good days and bad days', and noted either arrangements in place for this or the associated difficulties they had experienced in negotiating flexible support. For example, some students discussed having flexible attendance arrangements where they could make contact with staff if they had low energy or mood, and arrange that

they would not attend class. For others, this was not a possibility, and non-attendance would be construed as non-participation. A university attendance policy stated an expectation that students would attend all scheduled learning and teaching activities, with no contingency for flexible or negotiated attendance. The policy discussed attendance or absence (with an absence of five consecutive days or more requiring medical certification) and outlined the consequences of prolonged non-attendance. Therefore, the potential for a 'reasonable adjustment' of flexible attendance for students with a fluctuating or recurring impairment was difficult to implement.

Students discussed how their difficulties in explaining 'good days and bad days' were linked with perceptions (staff and peer), reflecting Alison's construct of the 'stereotypical lecturer' who expects students to 'get on with it'. The participating students noted how these perceptions impacted upon the choices that they made in terms of representation, for example in selective disclosure or recognising themselves as having a medical or health condition, as opposed to being 'disabled'. The relationship between disability and health has been considered throughout this research, in particular in Chapter Three, and was influential institutionally in both staff perspectives as well as in the effectiveness of some of the institutional technologies, such as the NAR and Special Factors Board. For Marie in particular, one way in which institutional ambiguity as regards disability and health was effected was that she constructed disability, particularly fluctuating or recurring impairments, in terms of wellness. Marie constructs variation in student participation as being contingent upon periods 'where they're not as well and when they are as well'. This implies an element of expected recovery which for some of the students who participated in the research was not conceivable. For example, one student with CFS noted that even extended periods of rest had no effect on her energy levels; she noted she could 'sleep for a week and still not feel better'.

For those students whose impairment is not uniform in impact, presence or visibility, fitting into a construct of disability as measurable and finite, in keeping with institutional values of

measurement and quantifiability may be problematic. This complexity is magnified when a student may not recognise disability as part of their identity, representing themselves instead as having health problems or rejecting disability entirely. Humphrey (2000) notes this selectiveness in her work on disabled people's participation in trade unions.

Humphrey discusses the ways in which many aspects of identity other than disability (such as gender, sex, age or race) may be integrated in conjunction with one another, whilst other aspects related to disability may be either/ or/ and (for example, deaf *not* disabled, deaf *and* disabled [p.66]). Humphrey also highlights how giving vague detail or talking evasively about an impairment may give rise to 'silencing' (p. 66) and describes how this contributes to a range of 'impairments with no name' (p. 67). In the context of institutional ambivalence as regards fluctuating or recurring impairments, the reciprocal ambiguity on the student's part regarding disclosure compounds difficulties for increasing recognition and legitimacy.

Furthermore, 'disclosure' is the mechanism by which support for disabled students is mobilised. If students do not disclose, or selectively disclose, then they may not have access to appropriate support; a student must declare themselves 'disabled' in order to receive specific 'reasonable adjustments'. Such a transaction is flawed if the student does not wish to disclose, or if they do not consider themselves 'disabled'.

#### **7.4.2 The role and influence of terminology**

Institutional ambivalences were borne out in the students' choices of language, and the difficulties they had in suggesting appropriate descriptive words and phrases. All students thought a shared term would be useful in constructing a sense of what constituted a fluctuating or recurring impairment, and in raising awareness and underpinning improved legitimacy, but many had difficulty in articulating what that should be. Having given students the information sheet (please see Appendix 6, page 214) and provided some



context at the beginning of the interview, they had been introduced to terms such as 'inconsistent', 'episodic' and 'fluctuating', and these did feature in what students suggested to be viable terms. However, there were also a considerable number of suggestions which were based on the students' own experiences. The terms suggested by students and some rationales for doing so are listed fully in Appendix 2.

Amongst the terms suggested and supported by students were 'episodic', 'inconsistent', 'fluctuating', 'unpredictable', 'variable', 'changeable', 'unseen', 'capricious', 'seasonal' binaries such as 'on/ off', 'up/ down' and 'come and go'. However, there were also strong criticisms of some of the terms. For example, one student felt that 'episodic' carried an assumption of regularity (as in an episode of a TV programme of the same duration at the same scheduled time) which contradicted his experience. Similarly, several students considered 'inconsistent' to carry negative connotations of control on the part of the student. This was complemented by a binary perspective by some students, who chose a coupling of opposite terms to describe their experience, as opposed to the continuum alluded to in some of the other suggestions.

### **7.4.3 Constructing difference**

The continuum used by some students in constructing experiences of fluctuating or recurring impairments was invoked by way of positioning themselves as other. In describing feeling 'judged' or 'misunderstood' or the existence of 'stigma' or 'prejudice', students discussed the difficulty of living with uncertainty, as per Corbin and Strauss's (1991) description of chronic illness, as part of the continuum of experiencing disability on a fluctuating or recurring basis. They also noted their perceptions of the impact that the uncertainty had on constructions by other people: if predictability and regularity cannot be assured then trustworthiness is compromised. This echoed the suspicions of Alison's 'stereotypical lecturer' and the judgement that Susan, in reflecting on student perceptions,

also attributed to staff. Furthermore, examples of the problematisation of flexible deadlines or flexible attendance reinforce the importance, institutionally, of consistency and certainty in constructing 'academic integrity'.

The continuum of experience was also used by students in constructing themselves relationally to other students with fluctuating or recurring impairments. In so doing, students made reference to 'knowing people who are worse off' or not considering themselves 'that disabled', or, indeed, disabled at all. Interestingly, two students with mental health difficulties reflected that they did not consider themselves to have a disability as their impairment was not physically visible; one of the students citing a wheelchair user to represent their own construction of a disabled student, and the other noting that they did not identify with being disabled as they had been unaware until recently that poor mental health may constitute an impairment. This is perhaps unsurprising when limited procedural information or clear guidance on entitlement exists for students, and again, is informed by institutional ambiguity as regards the relationship between disability and illness.

Other students used this relational, comparative positioning in representing their experiences of other people's constructions. One student noted that a colleague at work had told him 'you're not disabled under my radar', and another student discussed how he had experienced what he described as 'disability envy' where a classmate intimated that he should 'think about people who were really affected'. Such perspectives reinforce the scepticism and limited legitimacy that has been discussed throughout this research as regards fluctuating or recurring impairments, and indeed, seemingly perpetuated institutionally.

#### **7.4.4 The role of communication in inclusion**

Communication featured as a recurring aspect of how students interpreted institutional perspectives and experienced support which enabled them to participate in learning. Many students described difficulties in retrieving accurate or appropriate words in academic settings: for example, as part of giving a presentation or in a written exam. Several students also noted having extra time in formal exams for this reason, but also discussed 'not needing it' or 'not using it'. For many, this was because the extended time meant sitting the exam in a different room, away from peers. Indeed, this very act of division had resulted in some students being put in a position where they have been required to disclose their impairment to other students by way of justification for their absence in the exam. Whilst the principle of this alternative assessment arrangement may be to aid the student's concentration and provide extra time to process, recall and write, the separatism reinforces the 'special' arrangement for the assessment as different and other, characteristic of many of the ways in which the university constructed disabled students, for example, through the implication that disabled students require some form of advocacy by the Disability Champion. Though the student may not be disabled by an alternative exam arrangement, they are constructed as other by the process.

Students also noted the importance of communication in discussing the necessary flow of information regarding 'reasonable adjustments', either within the academic school or to a placement area. Where a breakdown in this flow of information occurred, not only were adjustments not put in place, but students discussed feeling 'like a trouble maker' for having to ask, or, indeed, too intimidated to raise the issue at all. This was symptomatic of the huge variation between and within academic schools that existed as regarded implementing support, as noted by all staff participants in this research in describing the inconsistencies in the distributed model of support. The role of the Academic Disability Co-ordinator was crucial to this process, but again, in keeping with institutional ambiguity, was not implemented in a uniform way across the institution.

The following student narratives are located in the context of these diverse perspectives.

### 7.5 Student narratives

As outlined in Chapter Five, section 5.7, pages 78 - 80, of the ten students who agreed to keep in touch throughout the trimester, five continued to stay in touch whilst the remainder either sent single replies or withdrew. The five participating students discussed differing ways in which they had experienced variation in participation based on fluctuations in their impairment in the course of the email conversations. These tellings unfolded in the context of the institutional discourses and technologies that have been outlined, and are considered in the following part of the analysis as possible influences.

The narrative analysis makes use of both 'big' and 'small stories' in considering how students draw on social, cultural and institutional references, technologies and discourses in making sense of their experiences and in constructing aspects of their identities.

Pseudonyms have been used for all participants. I emphasise the titles of what I have suggested to be the 'big' and 'small stories' in italics, and quotes or excerpts from student emails or my own notes are within quotation marks. All of the email extracts are verbatim and the original spelling and punctuation have not been changed. Any additions in square brackets are for clarification.

<b>Name</b>	<b>Level</b>	<b>Subject</b>	<b>Impairment</b>
Laura	Undergrad	Nursing	Multiple (ADHD, ASD, depression)
Emily	Undergrad	Optometry	Chronic back pain
Douglas	Postgrad	Computing	MHD
David	Undergrad	Computing	OCD
John	Undergrad	Nursing	Multiple (dyslexia, epilepsy, depression)

Table 7.1: Summary of phase two participants

### 7.5.1 Laura

Laura was an undergraduate nursing student who described multiple impairments, including attention deficit hyperactivity disorder (ADHD), autistic spectrum disorder (ASD) and depression. I had taught several classes that Laura had attended, so when she was one of the first students to respond to the email call for participants (with a short and emphatic 'Hi Vic. I'd love to help'), we had an existing familiarity, and subsequent email dialogue was very conversational. Whilst this existing relationship might have been construed as problematic for the research, I was keen to include Laura in the sample: as a member of staff immersed within the institutional culture and discourses, I was unable to position myself as a detached researcher and therefore decided against excluding students from the academic school where I taught in the interests of collecting perspectives from students in a variety of disciplines.

The short initial contextual interview in which Laura took part was informal and relaxed, and she was extremely frank about her experiences. In my notes from the interview, I commented on some of the ways in which Laura described herself as 'actress Laura' and 'irritating', in particular when she was learning in the clinical area and felt she had to overcompensate for her own perceived shortcomings.

In summarising our conversation I wrote:

'On placement, flips into 'actress Laura' – [she] needs people [family, peers, clinical staff, academic staff] to be proud and know how hard she's working.

Had episode on placement where [she] told mentor [that she] need[ed] a minute to regroup, [this] escalated amongst a group [of other students] (Laura used the word bullying), and ended up in [her being given] a warning, as her behaviour wasn't understood.

Always gives 150% and was told in placement to back down a bit ([a mentor said] "you're a student, you don't need to know this yet") – [she] considers herself irritating.

[She] Wanted an attack to happen on placement to see how she/ [the] place would cope – [this] happened in [the] second week.

[Laura has] Extremely high expectations of herself.'

Laura's positioning here was complex. She wanted to impress people, but was also aware of the lack of understanding that surrounded her impairment. The consequence of this was the enactment of a 'false', larger than life identity ('actress Laura') that compounded her difficulties in 'fitting in'.

In contrast to the lack of understanding that Laura discusses receiving from other people, Laura herself was extremely self-aware and reflected on an acute attentiveness to triggers for what she described as an 'attack' or 'episode' (characterised by fear, anxiety and nausea), and discussed strategies of attempting to prevent such episodes by exercising regularly, eating well and having a well-developed study plan to afford her structure.

By returning to her self-awareness frequently throughout the initial interview, I termed a possible 'big story' or ontological narrative for Laura to be about *knowing myself and what works*. In recognising the onset and management of 'episodes', *knowing myself and what works* emerged for Laura through discussion of her well-developed regime of self-care (personally as well as in academic terms). Laura underscored the importance of her own self-understanding in pre-empting or responding quickly to triggers that may compromise her participation. Self-awareness and self-care have been identified as being crucial aspects of living with lifelong fluctuating conditions such as HIV/AIDS (Lather & Smithies 1997). For Foucault, this *rapport a soi* (1986) or relationship with the self is a way of engaging in ethical practices in order to promote wellbeing, and a way of governing the self. In Laura's telling of *knowing myself and what works*, the simple act of using 'nice paper with a nice pen' was enough to counteract stress attached to increased academic workload. The strategies within the 'big story' of *knowing myself and what works* offered Laura the indispensable tool of organisation in ensuring that she still owned some aspect of control within uncertainty and unpredictability of her impairment.

A key difficulty that Laura experienced was extreme sensitivity to repetitive noise, such as pen clicking. In recounting a 'small story' in an email about one particular class where this caused substantial disruption, an aspect of Laura's identity that I describe as *putting things (support) in place* emerged. In the 'big story' of *knowing myself and what works*, Laura discussed a strategy of chewing gum or wearing ear plugs to block out the noise, and lip-reading the tutor if in class. Within the recounting of the 'small story', however, Laura describes uncertainty in *putting things in place* when her tried and tested strategies to cope with intrusion of noise fails. In an email on 26<sup>th</sup> January Laura wrote:

'Things are a bit stressy right now and I'm finding it hard to know what I should do next.  
on tuesday (25th), I had a bit of a melt down in psychology seminar. I became extra sensitive to noises and thus, the pen clickings sent me running out of class. When I'm stressed out, the noise just sends me into a melt down. I've asked people sometimes to not do it, cos in seminars/tutorials its even louder but these people find it funny that it annoys me. I wish it only annoyed me - it gets so loud its quite terrifying.  
So, I don't know what to do. I spend the time out of these smaller classes worried about the next one.  
Any suggestions?'

Interestingly, here, Laura has escalated her usual 'episodes' to a 'melt down'. The 'people', and even the noise itself, position her through fear as unable to be active in *putting things in place*. Laura constructs 'these people' as taunting, taking pleasure in what they misinterpret as irritation on Laura's part. In the context of institutional ambivalence as regards Laura's form of impairment, the only guidance the 'people' have in the scenario is from Laura herself, their peer who exhibits unusual reactions to seemingly innocuous stimuli. Again, this is symptomatic of limited understanding within the institution, and a lack of institutionally-produced guidance, of some impairments (unseen, unexpected or irregular) to be recognised as impacting on learning. In this scenario, and at odds with her usual ability to draw on self-awareness to manage her ability to participate, lack of understanding of Laura's needs, within an institutional

discourse of ambiguity and lack of legitimacy of fluctuating or recurring impairments, has diminished her capacity to have a clear focus of what self-care to enable.

I responded to Laura with a couple of recommendations about relaxation techniques or asking the facilitator of the class if pens with lids could be distributed, for example. By the time I had contacted her, Laura was already *putting things in place* through undertaking research, seeking further support and having contacted a member of academic staff directly:

‘I was doing so research and I think its 'misophonia' that I have. Its rage/meltdown reactions to specific sounds including pen clicking and sniffing! They suggest white noise but that's hardly useable in lecture/tutorial scenarios.

I have an appointment with mental Well-being people today and, I think, they do cbt which might be good. Hypnotherapy would also be good to look at but I'm nervous about prices (and making chicken noises randomly).

I have a meeting with (tutor's name) today to discuss her tutorials and ill suggest the dispensing of pens.’

I emailed Laura a couple of days later to ask if she had managed to find a resolution, and she said that the tutor had ‘thought providing pens for the class was “too much” - and not a good idea’. Again, a lack of understanding of the severity of Laura’s reaction to the noise and limited cultural and institutional recognition of this as a form of impairment influenced an ambivalent response from the tutor who perceived the distribution of pens as a form of ‘reasonable adjustment’ as an excessive interruption to the protocols of ‘normal’ behaviour or perhaps even a threat to ‘academic integrity’. In her ambivalence, however, the tutor does not suggest an alternative, merely negates Laura’s suggestion, and as such, Laura is positioned as problematic. In the absence of any institutional policy or procedural documentation, ambivalence toward students with fluctuating or recurring impairments is enacted.



The 'small story' interruption of Laura's *knowing myself and what works* ontological narrative was resolved by Laura's ability to return to the part of her identity committed to *putting things in place*. By actively seeking solutions to the difficulties that she experienced as a result of the repetitive noise, Laura improved ways of *knowing myself and what works* to be able to ensure better results from *putting things in place* in future disruptive episodes. Laura was disabled by institutional ambiguity and peer and tutor ambivalence. Ambiguity as regards guidance to support Laura's form of impairment and limited legitimacy that persists was institutionally operationalized in her 'small story' in a way that did not enable her to participate.

Throughout telling the *knowing myself and what works* 'big story', Laura's positioning changed markedly, from being very much in control of her wellbeing through her practices of self-care, to subjection and an apparent lack of autonomy when the repetitive noise begins to disrupt her participation. However, her commitment to *putting things in place* encouraged her to ask me, the mental health and wellbeing team and academic staff for help and to undertake her own research. In so doing, Laura positions herself as independent and solution-focussed.

### **7.5.2 Emily**

Emily was an undergraduate vision science student who experienced chronic back pain due to a slipped disc injury. During the initial interview she described being in almost permanent discomfort, referring to a 'baseline of pain' which helped her to identify 'bad spikes' in her health. Emily noted that her back pain was exacerbated by long periods of standing or sitting, such as in two hour lectures, and also spoke of the impact that the pain relief medication had on her ability to concentrate. Emily's sense of self, throughout the interview and the email exchanges, was very much constructed by her perceptions of how others (academic staff, peers, family and friends) saw her. In positioning herself as a

disabled student, Emily contrasted how she perceived she had been constructed in differing ways during ‘assessment’ exercises in an institution where she had previously studied as well as at the institution where the research was carried out. In my notes from the initial interview, I wrote:

‘[Emily] Went to disability services (at previous institution) – [they were] ‘dyslexia experts’ and [Emily] didn’t get much help as [her] slipped disc [had] happened whilst on [her] course [at the time], they [the disability services] wouldn’t make provision as it [Emily’s back injury] ‘might get better’. Went for assessment at (another institution) and they had more experience than just dyslexia, and told Emily she was entitled to support.’

Here Emily positions staff in the disability service as those with knowledge and power, the ‘experts’ (her words from my notes) who evaluated and defined her impairment. If, for these ‘dyslexia experts’ dyslexia equals disability or impairment, then the construct of a condition which was brought about by injury may not qualify, within their parameters, as a recognised impairment. The allusion to improvement that they use to negate Emily’s impairment completely undermines its status as a fluctuating, recurring or potentially lifelong aspect of her identity. Echoing Franks’ ‘remission society’ (1995) and the importance of recovery in misconceptions of chronic illness, the ‘dyslexia experts’ have constructed Emily as unimpaired. In contrast, the other assessors whose understanding of impairment extended beyond dyslexia were confident to construct Emily as a disabled student. This tension between Emily’s identities of being a student and a disabled student was evident throughout our discussions.

During both the interview and emails, Emily returned on several occasions to constructing this struggle and tension in the telling of a ‘big story’ of *fighting a losing battle*, both with the institution and with herself. Emily used this phrase in both the interview and subsequent email conversation. *Fighting a losing battle* was referred to in connection with multiple frustrations, including the impact of changes to the academic calendar on the intensity of coursework and assessments, limited acceptance amongst staff of variation in

ability to participate and Emily's reflections on her own ability to engage in learning based on the unpredictability of her impairment. Emily's struggle took place in an institutional culture of ambivalence, with little clear course of resolution for the struggles she experienced.

On 25<sup>th</sup> January, Emily contacted me about low levels of motivation related to her accumulating coursework and upcoming assessment:

'I'm a bit stressed out at the moment. We have an assessment tomorrow morning and I'm not very prepared for it. I haven't been able to get motivated at all.

Quite a few of our lectures are continuing on from last year and I'm finding that I don't remember a lot of the material that was taught last trimester. I feel like it's a bit of a losing battle - every time I sit down to study, I'm a little overwhelmed because I feel I have last term to catch up on as well. We have one lecturer who bombards us with paperwork (he uploaded about 20 research papers to Blackboard before we even returned from Christmas break) so I really don't know where to start!

This assessment tomorrow involves our class standing in a hallway, waiting for our turn (each assessment takes about 10 mins). They won't release the 'running order' in case someone doesn't turn up, which would affect the timings of the rest of the class. Instead, we stand waiting outside the door for anything up to two hours. I don't think anyone has thought this through but I don't want to make a fuss. I'm tired of hunting down various staff members and arguing with them over stuff like this.'

Again, as with Laura's experience in the tutorial group, procedures and protocol here (as 'academic integrity') are protected at the expense of inclusion. Having students waiting in a corridor serves no academic purpose in the context of the assessment, but is a technology whereby regularity can be ensured in scheduling student attendance. Providing flexibility or information in advance would threaten the logistics of the assessment, and therefore is non-negotiable. Emily constructs 'turning up' as part of the

assessment. The priority of attendance in a particular mode has a disabling impact on Emily in the context of this assessment.

In this extract, Emily highlights how she is *fighting a losing battle* from the perspective of her own motivation, the volume of work she has to complete and as regards the procedures put in place for her upcoming assessment. Her lack of motivation is locked in a mutually unproductive relationship with the amount of academic work she has: the more she perceives needs to be done, the less she can focus and the more unlikely she is to complete tasks. Though this may not be an aspect of the student experience specific to disabled students, the impact of this deadlock is magnified by low energy and institutional mechanisms which make flexibility difficult, such as a perception that the logistics of the assessment must run smoothly and that full attendance must be assured. Again, institutional discourses of efficiency, productivity and regularity take precedence over inclusion and flexibility. Emily is expected to align with a mode of assessment that highlights a lack of trust and takes no account of (and indeed pathologises) students not attending and not being uniform and in waiting order. Her participation echoes Foucault's (1977, p.136) concept of *dressage*, in that she complies in order to give an appearance of conformity in the context of institutional regulation and surveillance. Despite this compliance, Emily is critical of the purpose of having students wait in line.

Notably here, Emily also mentions that she does not want to 'make a fuss', conceding that she is, by virtue of limitations in her ability to participate in the organisation rather than the actual academic exercise, other and excluded. This recurring theme of not wanting to draw attention to herself, of constructing herself as problematic and controlling the visibility of the impact of her impairment was an aspect of Emily's identity that she described in a 'small story' as *looking okay*.

During both the interview and on-going emails, Emily discussed how she made an effort not to draw attention to her impairment. She spoke of being selective in terms of which

members of staff she disclosed her impairment to. Valeras (2010, online) suggests that this choice in representation presents a significant tension for people with 'hidden' impairments in that 'they are constantly negotiating when, where, why, and how to disclose and adopt the disability identity or to 'pass' and give society the impression of 'able-bodiedness'. Lingsom (2008) notes a dilemma in terms of concealment and disclosure of impairments in that:

'Persons with invisible impairments are not assigned subject positions as disabled people initially. Persons with invisible impairments may on occasion "pass as normal". They are in a position where they may continually reflect upon whether or not, when, how, and to whom they should attempt to conceal or reveal their impairments' (p.3).

For Emily, it would seem that her drive to ensure that she is *looking okay* actually contributes to her *fighting a losing battle*. In an email on the 6<sup>th</sup> April Emily outlined her perception of a lack of staff empathy/ understanding of staff as regards the experiences of students who experience variations in wellness:

'I don't think the lecturers understand what it's like to be a student with health problems. Some of them seem to think that anyone who has a problem is putting it on to get out of going to classes. Just because I look okay, doesn't mean I'm not in tremendous pain. I've lived with this for 10 years so looking okay is something that I've perfected. I try hard not to make an issue out of it: it makes people uncomfortable (friends and loved ones can't do anything to help so end up feeling crappy) and, well, in the end, this is something personal. I don't want people to know. I like the fact that, on most days, people can't look at me and immediately tell I have a bad back.'

In keeping with ambivalent institutional discourses surrounding disability and impairment, Emily notes a 'health problem' and a 'bad back'. In working towards, as Lingsom put it, 'passing as normal', Emily constructs her impairment in terms of health and wellness as opposed to disability. In recounting her concerted efforts to ensure she's *looking okay*, Emily discusses the centrality of her wish to exercise choice over who knows about her impairment and who remains unaware of periods of adverse impact, achieving apparent

'normality' by controlling visible symptoms (Strauss et al. 1985). In her acts of selective disclosure, Emily limits the flexibility of support that is available to her institutionally, in particular in terms of advance disclosure which could enable contingency arrangements if Emily is unable to participate. However, with ambiguous institutional provision, even this flexibility cannot be assured, as in many areas it is deemed as secondary to 'academic integrity'.

For Emily, the lack of visibility of her impairment, her prior diagnosis experiences with 'experts' who did not construct her as disabled, as well as the inflexibility of institutional support contribute to the complexities of *looking okay in fighting a losing battle*. In describing the misinterpretation of 'problems' on the part of staff as a lack of students' willingness to participate, Emily underscores the institutional suspicion which surrounds the legitimacy of unseen or fluctuating or recurring impairments, and the use of 'academic integrity' and protocol.

### **7.5.3 Douglas**

Douglas was a post graduate computing student. He had mental health difficulties as a result of a brain injury and subsequent surgery. Douglas spoke openly in both the interview and email discussion about the tendency for his symptoms to vary considerably ('some day's I'm up, some days I'm down'), and of his uncertainty as to which of his symptoms could be attributed to injury and which were as a result of his anti-anxiety and anti-depressant medication. He discussed how he tried to stay positive; that he felt confident and capable, mostly, at his best, but was aware that a period where he was not as strong and his memory and cognition more weak was never far away. However, he also said that he used the achievements during his well periods to buoy him through his periods of low energy.

A central and recurring topic of discussion in the interview as well as in the emails was the frustration Douglas experienced post-operatively regarding memory and recall. He viewed himself before and after the accident as fundamentally very different, and drew frequent pre and post-accident comparisons. This allusion to a changed self (reconstructed, modified or partially new) is well-documented in both research on chronic illness (Frank 1995; Charmaz 1983, 1990; Asbring 2001), as well as in post-injury identity studies (Sparkes 1996; Smith & Sparkes 2002, 2004, 2008a; Phoenix & Howe 2010). Douglas discussed how his engagement in education in one form or another since 2000 had been an active decision on his part to work towards overcoming the limitations he perceived; a potential path to reconstructing his identity. Throughout the initial interview, in describing aspects of how he constructed his impairment, Douglas frequently drew on metaphors as well as lists of characteristics or details about particular events or scenarios as a matter of course. In my notes on the interview I wrote:

[Douglas] Uses meditation as a calming technique – [it] helps organise [his] thoughts ('like having all the pots in your kitchen in the right place', 'like having a shower'). Uses it to focus – [like listening to] one person's voice in a pub and filter[ing] out noise. Likens busy environment to being like a bouncy ball – when on his own [he sees himself as] the same ball resting in water.

During conversation [he] recalled lots of facts – names of books, quotations, authors, meditative practitioners, names of classes, OU module number, etc.'

For Douglas, a high degree of detail, fact and imagery in conversation seemed to provide structure and triggers to facilitate recall and construct a public self that was knowledgeable, articulate and informed. He acknowledged that, whilst many people may experience difficulties with remembering facts or details, this took a particular form for those people whose memory had been affected by injury or post-traumatically. For example, after the festive break he could not remember the sequence of numbers on the door of the postgraduate computing lab.

## Chapter Seven: Student narratives and identity constructions

Douglas positioned himself as part of a wider group of people who experience magnified difficulties with memory in describing how *for us, it's different*. I have used this phrase to suggest a possible 'big story' or ontological narrative for Douglas as difference was a key theme that recurred in Douglas's interview, and something he discussed in an email he sent on 27<sup>th</sup> January:

'Last night I met one of my friends from the brain injury rehab, it was good to sit and chat with someone who suffers the same conditions e.g. memory problems etc. I asked him about his memory and how it affects him and he too has fluctuations and its more short term memory that is affected. He was saying that if he knew me for a long time he would remember me but if he had just met he would forget me or my name etc. I understand this is common in most people. Though believe me for us it's different, we know it is not how our memory previously functioned.'

Undeniably, in the big story of *for us, it's different*, Douglas's identity is vastly altered post-brain injury. In his narrative, Douglas discussed a sense of commonality and shared identity with a friend, based on 'suffering'. Douglas spoke at length in the interview and in the emails about changes in his identity over time and through his recovery, and how he had consciously tried to reconstruct some aspects, through routes such as rote memorisation techniques and conscious engagement in learning to improve his ability to store and retrieve information and detail.

Douglas's commitment to adjusting to and accepting his current self was illustrated in a 'small story' about group work, where I identified his use of the phrase *I'm fine, but people are not* as alluding to a possible aspect of his adjusted identity wherein he accepts himself, but perceives that others do not. In telling the 'small story' in an email on 14<sup>th</sup> February, Douglas positioned himself as outside the decision-making process of a group task:

'I'm fine, but people are not lol [laugh out loud]  
Let me explain, as a group we had agreed on a scene for our project,  
however I got told in a round about way that the group had changed scene,



I was not involved in this discussion as they decided this while in Paris and I never went.

The below is email is how I was told:

*'Bonjour!*

*I have attached some pictures from an area in Paris that we can model I will have to give you the rest in class next week as they are too big to send.*

*I know we previously agreed to model the Porte Saint Denis area but there were not a lot of suitable buildings there and as a result we have agreed on modelling this area.'*

After explaining to one member today that this was a group decision, the reply was 'but you weren't there'

Aha know I know why she is at uni! If only I would have thought of that at the time  
:Op [text emoticon for face with tongue sticking out]

I had problems with the group last term too, different members same outcome.'

The divisive *I'm fine, but people are not* aspect of Douglas's identity conflicts with the cohesiveness he talks about in *for us, it's different*. Having taken many years to adjust to his new post-injury identity, Douglas discussed the importance of empathy and inclusion, and the peer support experienced with others who had experienced similar life and identity changing events. Douglas's perception that *I'm fine, but people are not* shows his acceptance of his new way of being, but also highlights his perceived shortcomings in the ambivalence of others, who have not experienced the 'suffering' that people who have experienced traumatic injury have. As with Laura, Douglas's peers' ambivalence as regards his impairment would seem based on lack of understanding of experiencing an impairment on a fluctuating or recurring basis. Indeed, in the absence of a clear university perspective, it is unlikely to be part of students' conceptualisation. For the students in this group, their priority was completing the assessment (according to the expectations of 'academic integrity'), and through Douglas's absence he is excluded. Like Laura, the exclusion that Douglas experienced was shaped by ambiguity and ambivalence within the

institution and in wider society as to how variations in participation might constitute laziness, apathy, dishonesty or, indeed, give rise to 'invisibility'.

#### 7.5.4 David

David was an undergraduate computing student, and was the first to respond to the call for participants email. He had disclosed his Obsessive Compulsive Disorder (OCD) diagnosis on joining his programme at university, having had adjustments in place at school, and worked with the university's Disability Team to ensure that his Needs Assessment Record reflected appropriate support.

David described his form of OCD as mainly related to timing and organisation, which, during our initial interview, he noted had the potential to impact on learning. He discussed how tasks often took longer than he anticipated, and as a result he could fall behind in his academic work. David described how he responded well to having very structured and full days. In my notes from the initial interview, I wrote:

'Notes anxiety and [the] role of consequence [and] immediacy. The more demands he has on [his] time, and the more under pressure he is, the better [his] symptoms are. [David] Struggles if [he's] not in university day to day as [he] tends to over-think and deny that life is functioning normally outside.

If friends suggest meeting in an hour, [he's] happy to do so as knows whether or not will be busy, but [David finds it] difficult to imagine [planning activities] with a few days distance, e.g. in the next hour [is] fine, [but] Saturday [is] not as doesn't know what [his] plans will be.'

For many of the students who took part in the research, uncertainty and unpredictability surrounding impairment was a source of considerable frustration. For David, however, such limited structure or regularity magnified the impact of his symptoms and decreased the extent to which he felt able to participate in learning. From this point of view, timetabling and regularly scheduled classes were of benefit to David, and the notion of

flexibility counter-productive. Therefore, the regularity and mechanistic values implicit within institutional discourses gave David access to the potential for environmental structure, predictability and thus opportunity to participate.

David discussed how he had experienced specific difficulty as a result of lack of structure in his timetable. On the 9<sup>th</sup> April, David wrote in an email:

‘My biggest issues this semester have been the mental impact of things. Obviously I would ask you to keep it confidential that I have been having some issues with mild depression (I wouldn't label it that way, I more feel just a bit flat and unmotivated but that's probably the technical term). I only have two classes a week to attend and this is actually harder to motivate myself for than if I had a full calendar, because overall your week is pretty empty so you get a bit bored and down, and you aren't in seeing people as much as before. That has a knock on on your overall get up and go so getting out of bed in the morning on time is a challenge especially if you don't think it's a vital class.’

David interestingly downplayed the potential role of depression in the difficulties he'd been experiencing but highlighted the importance of self-motivation. In describing limited expectations of participation and opportunities for interaction with 'people', David noted that a lack of motivation could prevent him from engaging or attending, relating back to his recognition in the initial interview of the vital role of regular and structured participation in university activities in managing the impact of his impairment. This need for structure and assistance with timetabling was highlighted by Marie as one of the ways in which she had supported students with fluctuating or recurring impairments, though with variation in practice across academic schools, this support may not have been open to David. In addition, Susan noted the potentially problematic nature of relying on students' ability to negotiate support if they lacked confidence – feeling 'flat and unmotivated' may, in this context, impede David's ability to engage in discussion about appropriate support.

Like Laura, David was aware of particular triggers that contributed to stress and anxiety, but often struggled to take action as a result of his difficulties with motivation. David spoke

about the need for structure in managing the impact of his OCD and his attempts to enact a form of self-management through keeping active as a member of various societies and the Students' Association. However, his difficulties with motivation had the potential to limit the effectiveness of this, as told in a 'big story' or ontological narrative that I suggest might be called *trying to keep busy*.

Though *trying to keep busy* was a purposeful and active measure on David's part, he was not always successful in his ambitions as a result of his motivational difficulties. For example, David discussed his thoughts on future ambivalence in continued engagement in an institutional initiative:

'I signed up for the Active Mind project (sure you have heard about this but its basically a six week program of support at the Arc for those referred by the Mental Health and Wellbeing folks) on the idea that physical activity helps mental illness. I did go to the initial assesment and to the gym once but to be honest I find the gym a bit of an unfriendly place and I knew that even if I went lots during that six weeks (which I haven't) I would then go back to my normal ways afterwards. I am hoping to find something more sustainable that I can do at home whenever I feel like it. Maybe Zumba or something who knows!'

The intent behind the Active Mind project, which implies that poor mental health may be attributed to passivity, seems aligned with David's strategy of managing the impact of his OCD through activity. However, in noting that the environment of the Active Mind initiative (the Arc is the university's sport centre) was unwelcoming to him, David sees a possibility for disengagement and returning to his 'normal ways'. Despite this, he attempts to go back to *trying to keep busy* by considering alternative activities.

In the context of *trying to keep busy*, David discussed variation in how he experienced OCD in telling a 'small story' of having an impairment that he described as being able to *come and go*. For David, the 'fluid identities' (Lightman et al. 2009) discussed in Chapter Three within studies of, for example, chronic illness and within the Episodic Disabilities Framework, have relevance in the changing impact of his OCD. In one email David noted

that his motive to become involved in the research was because 'it is about 'come and go' disability which I don't think gets addressed enough'. As part of constructing this *come and go* aspect of David's identity, his 'small story' reflected on the impact of variations in wellness from a practical point of view:

'A problem I've found with the uni in general but has been more acute for a come and go illness like mine is that academic staff are terrible for mentioning things in classes then never emailing it out. For someone like me who can occasionally miss classes at short notice or only go to certain classes and not others (I don't go to lecturers because I passed the exams in my original year for instance) this is really unhelpful. When you're not in to bump into classmates who might mention it it's really easy to miss deadlines because you simply don't know about them. The university needs to be much better at communication from this perspective.'

David here notes the impact of what he had previously referred to as a 'knock on' effect: because of his *come and go* impairment he can be disadvantaged in receiving vital university information. Without a full timetable, David's motivation and therefore attendance can be low. If he is unable to observe the academic protocol of attendance, then he is unable to access information, and is thus excluded from engagement when he feels unable to participate. He also describes no alternative route to receiving the required information and constructs staff as interpreting attendance as participation. When David's timetable is sparse, non-attendance and thus exclusion are possible for him. Lack of structure for David thus becomes disabling.

#### **7.5.5 John**

John was an undergraduate nursing student who had disclosed multiple impairments, including dyslexia and epilepsy. He had also been diagnosed with depression, but had not disclosed this to the university, as he felt considerable judgement continued to surround depression and mental health difficulties. Significantly for John, as a nursing student, he was expected by the Nursing and Midwifery Council Code (NMC 2008a) to disclose any

impairments which he considered may affect his Fitness to Practice, the term used in the Code to denote a 'fit and proper person'. Both the NMC Code and the 'Good Health and good character' document (NMC 2008b) state that nursing professionals (which students are considered on joining their academic programme) must be able to provide care to patients with competence and without direct supervision. The NMC (2008b) also states that students must feel safe that any disclosure will be responded to positively, focusing on reasonable adjustments and support. Clearly, this has not been the case for John. In simultaneously being a student and fledgling member of a profession, John was caught between further competing discourses of education and professionalism (Darbyshire & Fleming 2008). Both of these impacted on expectations of his conduct and participation, and contributed to his own self-perception and uncertainty and affected which aspects of his identity he privileged in self-representation.

In the initial interview, John spoke about the role of judgement in his perceptions of how others constructed him, and the effect that it had on his participation. In particular, he discussed difficulties in capturing information quickly and accurately, and how this compounded his own interpretation of his shortcomings. In my notes on the interview I wrote:

'Note taking on placement has been difficult and [John] has had to develop strategies. [He] Feels that [he] overcompensates to counteract peoples' judgements and ends up making errors in other areas. [This] Affects [his] confidence and exacerbates depression.'

John's strategies to help with note-taking on placement included coloured lenses in his glasses and using coloured note paper. John noted that part of his difficulties were logistic, as in the past he had worked with a scribe to take notes but had had to develop his own strategies to do this independently. However, John also noted that his perceptions of other peoples' judgements of him also had a significant impact on his ability. This encouraged John, in his own words, to be 'dishonest' in representing himself, a notion

also reflected in Laura's construction of 'actress Laura'. The need to *not* be seen as different was very important for John, and a topic that he returned to throughout the emails. This was particularly evident when he was participating in public activities, such as note taking on placement, where he felt aware of the visibility of his 'unseen' impairment through the ways in which he participated in learning tasks or scenarios, and even the subtle visual clues of his glasses or coloured paper. As a student with 'unseen' impairments, John was extremely aware of the potential role of visibility in judgement, echoing wider discourses related to limited or 'questionable legitimacy' (Lightman et al. 2009) of fluctuating or recurring impairments, as well institution-specific issues of judgement, as highlighted by Susan and in other student narratives (for example, the ambivalence that Laura experienced, and the lack of flexibility that Emily had access to in terms of assessment processes).

In the initial interview, John discussed the tension he felt between such differing aspects of his identity and described how it encouraged him in *not being honest about bad days*. I have suggested John's use of this phrase as a title for a potential 'big story' as *not being honest about bad days* was equally true of John's participation in learning at university as it was in placement, with him citing examples of feeling discomfort discussing his feelings 'honestly' with members of staff in both areas; for example, scribes in exams and mentors in placement. *Not being honest about bad days* on placement generally occurred when John felt a lack of confidence in his knowledge and understanding of clinical processes due to a low mood. John represented his 'dishonesty', in an email on the 17<sup>th</sup> January, as being induced by fear relating to Fitness to Practice and his potential inability to meet the associated standards for his profession:

'From a personal point of view, the fear of fitness to practice encourages me to be dishonest regarding my thoughts and feelings, for example on the day of my first exam in second year, from when I woke up in the morning I just didn't feel right, I felt confused, very tired and withdrawn. During the exam I had a problem understanding the questions and difficulty conveying my answers to the scribe,

what made it worse was the fact that all students were given those exact questions to study for the exam. I knew the answers to those questions, on another day I would have got a high mark but as it stands I just scraped past.'

John's acknowledgement that he did not 'feel right' on this particular occasion, meant that, despite having advance knowledge of the exam questions and being able to prepare responses, he was unable to articulate them. Like Emily, John consciously controls the visibility of his impairment to 'pass as normal' where possible. Whilst Emily's decision to selectively disclose her impairment was based on an observation that it was 'something personal', John constructs his impairment as 'dishonest', implying that he is deliberately withholding information that he believes he should actually share. The catalyst in this is fear: fear that the on-going concerns he has about how he is judged by others will influence his future career if he fails a Fitness to Practice assessment. This is the ultimate reason why John is actively engaged in *not being honest about bad days*.

John told several 'small stories' about how his confidence and participation were affected by how others viewed him, and I have suggested a title of *other peoples' perceptions* to encapsulate the complex impact of this on the development of many aspects of his identity ('dishonest' or otherwise). The significance of *other peoples' perceptions* was as prevalent in the ways that John constructed and positioned himself in both academic and clinical terms, and he told stories to illustrate the tensions in each. In one account of a group presentation in which he had to participate, John spoke, in an email on the 26<sup>th</sup> January, about the tension he experienced in not having 'come to terms' with being dyslexic, and how this impacted upon how he represented himself in front of others.

'Today has been a pretty stressful day, I have been trying to put together this power point and do some more of my essay, and I just feel that there not enough time in the day! I think I'm just annoyed with myself for not looking at things in a positive manner, such as this presentation tomorrow, instead of looking at it as a challenge and a way of improving my knowledge; I let my fear overwhelm me. The thing is, I know the cause of my fear, I haven't come to terms with being dyslexic, and I let it strip away my confidence. I let it rule me in everything I do because I no



that tomorrow during my presentation it will be quite obvious as it has been in other presentations that I am dyslexic because I mix words up when I'm reading, I find it difficult pronouncing some words and I read very slow! The thing that gives me mixed feelings is that every one seems to except the fact that I am dyslexic, no one ever comments how slow I read, when I mix up words, they even help me pronounce the words I can't say instead of letting me struggle. I suppose I just wish I wasn't different and I could do the same academic things as every one else, and that way people wouldn't have to make allowances for me.'

The mixed feelings that John describes in this 'small story' demonstrate the tension between the expectations he has of himself and his ability to manage his overwhelming fear in, albeit a supportive and empathic, group. There is an otherness to John's positioning as regards *other peoples' perceptions* here: in constructing himself as 'different' and noting the concessions and allowances that his classmates make for this, he seems outside and divided from the peer group. His own rejections of 'being dyslexic' and references to fear further exemplify his discomfort with being 'different'. As with his example of note-taking on placement, the visible signs of his impairment, such as his difficulties with words and pronunciation, are a potential source of judgement, on his own part, as well as from others. The presentation as a form of assessment within academic practice positions John in a scenario where he is a focal point for attention, and the characteristics of his impairment obvious. Again, 'academic integrity' takes precedence over inclusion.

Throughout discussing aspects of his identity construction through *other peoples' perceptions*, John noted the impact on his confidence and perceptions of his intelligence and academic ability. Toward the end of the data collection period, on 25<sup>th</sup> March, he emailed to say that he felt an increased sense of awareness of the potential impact of his mood on wellness and ability to participate in learning:

'Over this time I have learned that I do have some brains. And by doing a daily log I can actually see how much my thoughts, feelings and emotions fluctuate and the impact they have on my daily life. I realise with all my issues I am still able to pass

everything that is given to me at uni and placement, so I wonder, what would my life be like and how successful would I be if I didn't have all this bagedg in tow.'

John went on to say that keeping a journal of his thoughts and feelings had been suggested as a way of him taking greater control over his health in the past, which had not proven particularly successful. However, in writing for a specific purpose (for the research) he was able to engage more fully with the process, and in Foucauldian terms, employ an enhancement based technology of the self of writing to improve his self-awareness and care.

## 7.6 Discussion

Students discussed a variety of complex ways in which they relationally positioned themselves within institutional ambiguities and constructions. They also spoke about ways in which they negotiated identities in the context of existing institutional technologies and staff and peer perspectives. Judgement, selective disclosure and otherness were all raised as issues by students in highlighting the aspects of the university experience that influenced their participation and enabled them to enact aspects of identity.

There was a discernible divide regarding construction and management of identities between those students who had always lived with an impairment and those for whom it was acquired. As borne out in the literature discussed in Chapter Three, discussions on reconstruction, adjustment, loss (Charmaz 1983, 1990; Yoshida 1993; Sparkes 1996; Smith & Sparkes 2002, 2004, 2008b; Phoenix & Howe 2010), frustration and unpredictability (Bury 1988, 1991, 1997, 2000; Frank 1995) characterised stories that students told regarding acquiring an impairment post-trauma or through injury. The dual identities of before and after were pronounced for Douglas, for example, who spoke in terms of knowing his current limitations in the context of the scope of his previous abilities. For Douglas, his current post-trauma disabled identity is one which experiences both

cohesion and similarity (in the case of his friend from the brain injury unit in his ontological narrative of *for us, it's different*) and exclusion (as highlighted by his 'small story' about exclusion and marginalisation in group work of *I'm fine, but people are not*).

Transitional, fluctuating identities (Lightman et al. 2009) were integral to the stories that students told about having 'good days and bad days', in terms of self-acceptance and the profound impact of the perceptions of others. John, for example, discussed how he still had not come to terms (Brashers et al. 1998) with 'being dyslexic' and reflected in depth on the impact that *other people's perceptions* had on his sense of self and confidence to learn or participate. His concern about how others perceived him encouraged him to be dishonest (in his ontological narrative of *not being honest about bad days*) and, as a result, over-compensate in other aspects. Similarly with other students, John had exceedingly high expectations of himself that at points in the emails he sent were portrayed through stories about frustration and disappointment, a theme in research on adjusted identities (Smith & Sparkes 2007; Pals 2006).

For other students, frustration was directed at the institution and individual members of academic staff as a result of their apparent lack of empathy in a culture of ambiguity that privileged 'academic integrity' over inclusion, and had the potential to pathologise 'reasonable adjustments' which may undermine this 'academic integrity'. Emily's 'ontological narrative' of *fighting a losing battle*, for example, was peppered with accounts of struggle and difficulty, from a point of view of the lack of flexibility or inclusive practice within the institution as opposed to her own ability to participate in learning. In her 'small story' of *looking okay*, however, Emily summarises one of the key debates within the literature cited throughout this research specifically focussing on the tension between unseen, hidden or invisible impairments and legitimation. Emily's role within her story is further complicated by her own choices to minimise the visibility of her impairment, and thus represent herself as being unimpaired. For Emily and Douglas, expectations of

attendance as a mechanism within academic processes, and inflexibility regarding this, had a disabling effect on their participation.

Peer interaction was another mechanism by which students were constructed and positioned themselves as either integrated or other. As was apparent from a number of the student stories, some experienced difficulty in group work scenarios regarding managing aspects of their impairment and the peer group's ambivalence toward the student's impairment. For Laura, her extreme discomfort in the tutorial group brought on by repetitive pen clicking compromised her participation to the extent that she felt she had to leave the room, and seek support from other areas in the university. For Douglas, his exclusion from the decision-making process regarding a fieldwork exercise undermined his place in the group and scope for active participation. Difficulties were noted in this area amongst many of the students who contributed to the research, compounded by aforementioned difficulties with confidence. The lack of acceptance and legitimacy as regards fluctuating or recurring impairments as a theme that runs throughout the research, as well as institutional ambiguity, was also very apparent here in the wider student population.

## **7. 7 Conclusions**

The discourses identified in Chapter Six which influence institutional constructions of disability undoubtedly have an impact on how students position themselves and construct identities. Students draw on these discourses in representing themselves in selective ways, in the form of larger than life or 'synthetic facades', some of which are portrayed as unimpaired. In creating these personae, students exhibit an acute awareness of their own habits, preferences and abilities in order to selectively portray themselves in an educational context. For Laura, such a process is about exercising self-care and minimising difference: for Emily, it is 'something personal and no-one else's business'. For

## Chapter Seven: Student narratives and identity constructions

John, however, this process is achieved through 'dishonesty', which ultimately compromises adherence to professional values at the outset of his career.

Each of the student narratives is framed within an institutional discourse of ambivalence, judgement, mistrust and doubt. Created by existing institutional ambiguity as regards the construct of disability, through lack of documentation, policy or guidance documents, and associated ambivalence toward fluctuating or recurring impairments, this discourse replicates those perspectives prevalent in wider society that attach suspicion and a lack of validity to fluctuating or recurring impairments. In contrast, the contributing students exhibited considerable self-awareness and recognition of the impact of their impairment, echoing Marks's (1994) acknowledgement of the disparity between policy's construction of students and students' construction of self.

The students who participated in the research shared extremely diverse experiences of living with an impairment on a fluctuating or recurring basis, regardless of whether the impaired self was a recently acquired aspect of their identity or whether the management of this had been 'perfected' over some time.

In the following chapter, I discuss both the staff and student perspectives in establishing some characteristics of the institution's interpretation of fluctuating and recurring impairments.

## **Chapter Eight: Discussion**

### **8.1 Introduction**

This chapter brings together findings from Chapters Six and Seven and analyses the ways in which constructions of fluctuating or recurring impairments within the institution where the research was carried out had the potential to impact on the student experience. The chapter also considers the impact of these constructions on how students themselves negotiate identities, participation in learning and recognise/ represent their fluctuating or recurring impairment. In particular, this chapter highlights dissonance between the staff and student perspectives on fluctuating and recurring impairments and the implications of these incongruities.

### **8.2 An institutional perspective on fluctuating or recurring impairments within existing constructions of disability**

The competing civic and corporate values (Boltanski and Thévenot 2006) implicit within the Learning Teaching and Assessment Strategy (LTAS) effected a tension in influencing institutional discourses toward disability which were both ambivalent and ambiguous. Whilst the promotion of 'the common weal' and the institution's commitment to the advancement of 'social justice' is highlighted within the LTAS, staff and students passed little comment on how these values were operationalized and implemented in practice. As discussed in Chapters Six and Seven, with no explicit institutional policy on inclusion, considerable scope existed for vagueness and indecision in terms of practice as well as constructions surrounding disability.

Research on vagueness in judicial decision-making suggests 'when what is required is unclear, it is more difficult to argue that a government has failed to respond appropriately' (Staton & Romero 2011, p. 2). In relation to the LTAS, then, whilst the vagueness of

policy relating to inclusion may limit compliance with the policy (ibid) and thus compromise support for students, it also protects the institution against criticisms that it has not met its legal obligations. However, while the ambiguity that this policy vagueness gives rise to may produce incoherence, for example, between the centre and the periphery, resulting in fractured practice, there is also the potential to produce positive effects, since vagueness may serve to open up some of the surrounding issues and underpinning values for discussion: as McLaughlin (2000) argues to 'illuminate complexities, sharpen dilemmas... and encourage further discussion' (p.451) and that 'vagueness and ambiguity may have a lubricative and constructive effect'. Both responses were evident in this study. Thus Alison talked about the excellence of the centre in contrast to the patchy provision in the departments, but Susan developed her role and used the lack of direction to develop links with external bodies.

The ambiguity and ambivalence afforded to the institutional model of inclusion and provision for disabled students extended to constructions, understanding and acceptance of fluctuating or recurring impairments. With institutional perspectives and practice as regards disability in general being informed by managerialist institutional values of measurement and quantifiability, and within legislative notions of assessment, protection and duty, constructions of fluctuating or recurring impairments were vague and inconclusive. Both staff and students who participated in this research discussed issues that align with the main themes to emerge from the supporting literature, such as lack of visibility of some forms of impairment (Matthews 2009; Valeras 2010; Lingsom 2008), limited social or cultural references in gaining acceptance (Peters 1993; Lightman et al. 2009) and unpredictability in the impact of severity of an impairment in creating experiences around fluctuating or recurring impairments (CWGHR 2011a; Bury 1997; Frank 1995; Corbin & Strauss 1991) that were difficult to define. For staff as well as students, this variation in ability to participate meant that constructions of fluctuating or recurring impairments were often based on concepts of health, wellness and illness (Bury

1997; Williams 2000; Butler & Parr 1999), and the possibility of recovery as opposed to the acceptance of impairment as an on-going (Frank 1995), changing (and legitimate) facet of the lived experience of disability.

This undeniably influenced the operationalization of policy and the creation and implementation of technologies such as the 'Needs Assessment Record', 'Special Factors Board' and the 'Disability Champion'. Whilst intended to provide 'reasonable adjustments' and advocacy on the part of disabled students, in particular the discord between the NAR (based on the anticipatory 'duty' of the legislation making 'reasonable adjustments') and 'Special Factors' (being based on health, mitigation and contingency) illustrated the problematic conceptual relationship between disability and illness (Barnes & Mercer 1996; Edwards 2009) and exemplifies institutional ambiguity as regards this. For Marie, a construction of fluctuating and recurring impairments was based on student participation and being 'not as well' or 'as well' at different junctures, as opposed to being impaired. For some students too, aspects of identity that related to health and not disability were promoted, either in students' reflections or in positioning themselves to others through 'disclosure'. Technologies such as the NAR, 'Special Factors' and 'Disability Champion' all reinforce a perception of the additional nature of adjustments, based on an understanding of disability which does not necessarily allow for variation, as opposed to the existence of an holistic, inclusive approach. Indeed, these inflexible technologies, based on possibilities for measurement and quantifiability, in fact further exclude students with fluctuating or recurring impairments from participation.

### **8.3 Impact and effects of the operationalization of policy and discourses**

The tensions and ambiguities within the LTAS informed an overall model of support for disabled students at the time the research was conducted that was vague, variable and inconsistent. The difference in provision made between the centre and periphery, and on



into the individual academic schools, was used by staff in positioning *themselves* as inclusive practitioners, as well as in reflecting on the flaws in the distributed model being unclear and provision patchy. For Alison, the centre represented excellence, and the school-based inconsistencies were problematic: attitudinally toward students with fluctuating or recurring impairments (through the perceptions of the 'stereotypical lecturer') as well as in access to flexible provision. For Marie, flexibility was enabled through 'disclosure' at an early stage, in order that contingencies may be put in place if a student is unable to participate. However, whilst Marie herself argues that such procedures may be 'relatively easy' to implement, a lack of formalisation (in the context of non-existent institutional policy and procedural documentation) enabled others to construe measures such as flexible deadlines or attendance as undesirable and as an interruption to 'normal' participation and assessment practices and hence a threat to academic integrity. As has been discussed in the student narratives, this perspective of negative disruptions to participation, largely based on procedural elements of attendance and order (for example, in Emily's example of waiting in a corridor prior to an exam), disables students. Indeed, Marie constructed 'reasonable adjustments' as a potential threat to 'academic integrity' in the context of her awareness of the importance of safeguarding institutional assessment procedures, influenced by notions of academic rigour and accountability. Conversely, Marie's ambiguous construction of 'academic integrity' which could also be interpreted as ensuring quality of provision for disabled students (Chapter Six, section 4.5.2, page 98), also gave rise to the situation in which students were disabled by the very practices put in place to support them, for example, separate exam arrangements which in effect force disclosure.

From a student's point of view, societal and institutional ambivalence and indeed 'questionable legitimacy' (Lightman et al. 2009, online) as regards fluctuating or recurring impairments, meant that the act of 'disclosure' may not have been straightforward, and in turn impacted upon the support available to them and recognition of their form of

impairment as 'accredited' (Barnes 2000). 'Disclosure' is the act which initially constructs the disabled student and advance 'disclosure' (in some areas of the university, as suggested by Marie) has the potential to facilitate flexible support for students with fluctuating or recurring impairments. However, where institutional ambiguity as regards fluctuating or recurring impairments informs a construction based on health and illness, potential exists for students to not recognise or accept their impairment as part of a disabled identity. In mirroring institutional vagueness, as Humphrey (2000) cautions, many impairments can be 'silenced' through lack of explicit discussion and the expectations of staff and students in contradiction.

The construction of disability in terms of health and wellness as opposed to being a lifelong aspect of identity as regards fluctuating or recurring impairments was one of a number of incongruities to emerge between staff and student narratives. Whilst for staff, students' non-participation may be based on notions of unwellness, and thus implied recovery, for students uncertainty in impact of impairment was part of a continuum without a conclusion. With variation in ability to participate students discussed fluctuations in identity and positioning, which was not something accounted for in the vague institutional construction of 'the disabled student'. From a staff perspective, the process of becoming a disabled student commenced with 'disclosure', and students spoke about often not wishing to identify themselves publically as disabled. The disabled student and associated implementation of 'reasonable adjustments' could act as a threat to the maintenance of academic integrity, which was perceived as fundamental to the operation of Higher Education by staff, and conversely about process and protocol by students. Whilst 'disclosure' (or 'the question' as Alison constructed it) is the point at which for staff a 'student' becomes a 'disabled student', the student cannot be guaranteed that the construction, or indeed adjustments, will be appropriate for a disabled aspect of their identity.

The vagueness created by the lack of institutional documentation as regards disability limits the recognition that fluctuating and recurring impairments can be given, and in turn impacts on the development of an integrated and inclusive model of support. For those students who experience fluctuations in the impact of an impairment, and thus ability to participate, procedural aspects of assessment that may be, for example, based on attendance ('turning up', as Emily described it) may have an exclusionary effect. Furthermore, the contribution of perspectives which favour the importance of protocol and procedures construct students with fluctuating or recurring impairments as extremely problematic in compromising not only academic integrity but also existing constructions of disability and the disabled student, as the methods through which participation may be facilitated (flexible deadlines or attendance) are construed as negative. This dissonance between staff and student perspectives in prioritising process over participation and regularity over variation is a key area to consider in addressing the vagueness that surrounds both institutional interpretation and provision, and in providing an opportunity to move toward McLaughlin's (2000, p.451) 'lubricative and constructive' discussions about how current perspectives may be adapted.

### **8.4 Students and negotiating identity**

In the context of these incongruities, there are a number of complex issues which may contribute to the construction of student identities. 'Disclosure' has a crucial role to play in how a student may choose to represent themselves institutionally and amongst peers. Students discussed how they chose to 'disclose' selectively (Emily in doing so as a form of control) or partially (John in enacting 'dishonesty') based on the misconceptions or judgement that they felt surrounded disability. For many of the students who participated in the research, a lack of visibility as regarded their impairment contributed to tensions within their experiences; in, for example Emily, 'looking okay' she is expected to 'be okay'.

## Chapter Eight: Discussion

Visibility and visual indications of having an impairment were vital for students in constructing disability, both from their own perspective as well as relationally amongst peers and staff. As noted in Chapter Seven, section 7.4.3, page 122, some students drew on social constructions of disability to conceptualise a disabled person as, for example, a wheelchair user, and discussed their prior negation of the validity of mental health as an 'accredited' impairment due to impact often being 'unseen'. Some students used their own institutionally influenced ambiguities to form vague constructions of fluctuating or recurring impairments, and discussed how they had experienced similar perspectives from peers and staff. For example, in talking about incidents where impairments were misunderstood or mistrusted, such as in Laura's tutorial experience or Douglas's exclusion from the field trip, students demonstrated awareness of a widespread lack of understanding of the role of unpredictability and variation in experiencing disability.

In contrast to some of the research participants demonstrating considerable ambiguity as regards constructions of fluctuating or recurring impairments institutionally and in wider society, some of the students who contributed to the research discussed acute self-awareness and the use of anticipatory self-care in managing the impact of their impairment. Advance implementation of, for example, regular exercise, helped some students to have an influence over the unpredictability of their ability to participate in learning and teaching activities; if students were able to put preventative measures in place, they felt better placed to deal with unexpected situations which may negatively impact upon them (for example, Laura's tutorial experience – whilst at the time she reacted disruptively, she was able to draw on her self-care techniques to resolve the difficulties she experienced).

In considering how issues such as 'disclosure', judgement and practical participation strategies such as self-care might impact on student identities, it is important to refer to Marie's statement that students' disabled or impaired identity is one amongst a composite multitude (Lather & Smithies 1997; Axtell 1999). As I have previously noted in Chapter

Five, section 5.8, page 81, emphasising the 'student' part of the student participants' identities has constructed them contextually within the research in a specific way. For the students, as with possible identification with an impaired self, this is one of many aspects of identity. For the student participants whose impairment was acquired, the issue of multiple selves was even more nuanced as they discussed selves of before and after, adjustment, reconstruction and transformation.

## **8.5 Responding to the research questions**

### **8.5.1 In what ways do institutional discourses influence constructions of disability?**

As this research was carried out in one institution, clearly the discourses and policy specific to that institution were vital in considering the construction of fluctuating or recurring impairments and the design and implementation of support. However, in discussing some of these discourses, values and constructions, other institutions may find an opportunity to reflect on their own practice, as regards what perspectives may be present institutionally in conceptualising and making provision for impairments which may vary in impact over time. I make a number of recommendations for practice in Chapter Nine.

Crucially, for the institution where this research was carried out, tension created within a key policy document by competing civic and commercial values gave rise to an institutional ambiguity and ambivalence that effected a vague model of support, limited recognition of fluctuating or recurring impairments, and a non-committal interpretation of inclusion, as evidenced by lack of specific policy and procedural guidance on supporting disabled students. Furthermore, staff who contributed to the research drew heavily on legislative discourses in using concepts of 'need', 'requirement' and 'duty' in discussing

the university's role. The law gave staff a way of articulating their 'responsibilities' toward disabled students.

This need for measurement, central to the audit culture and new managerialist language and practices that have become prevalent in HE, have informed constructs such as the 'Disability Champion', the 'Needs Assessment Record' and 'Special Factors Board'. Such constructs reinforce a construction of disability itself as excluded and other; outside 'normal' pedagogical practices and student support mechanisms, and in contradiction of underpinning principles of inclusion (Slee 2001; Slee & Allan 2001). These technologies are problematic in that they claim to correspond with supporting disabled students, but are predicated on different constructions of disability itself; for example, the NAR is a vehicle to implement 'reasonable adjustments' in accordance with legislation, whereas Special Factors is contingent upon health and wellness.

The institutional ambiguity and ambivalence regarding disability, and in particular fluctuating or recurring impairments, effected a model of disability support that itself was contradictory; it was at once 'bolt-on' and 'built-in'. The 'hub-and-spoke' distributed student support model which incorporates the Disability Team centrally and the school-based Academic Disability Co-ordinators has simultaneous elements of additional provision as well as embedded support. With limited staffing at the centre and unclear guidance and varying expectations of the school-based roles, considerable potential existed for differing interpretations of what constitutes inclusion and student support.

This inconsistency was noted by the members of staff who took part in the research in reflecting on institutional provision as well as in positioning themselves. For Alison, the inconsistency in, for example, the implementation of the ADC role in different academic schools not only compromised opportunities for equality, but served as an 'other' which relationally strengthened the value and practice at the centre. For Marie and Susan, the

inconsistency meant that, in the case of the former, the Needs Assessment Record was an open and negotiable technology and in the latter a fixed agreement.

### **8.5.2 How might these discourses frame perceptions of fluctuating or recurring impairments amongst staff in HE?**

In the interviews, staff discussed a number of ways in which they constructed disabled students and positioned themselves in a variety of advocacy, pastoral or otherwise protective roles. In operationalizing the law to discuss the implementation of 'reasonable adjustments', Alison and Marie outlined the 'rights' of students in access to learning opportunities. However, for Marie, 'reasonable adjustments' had the potential to compromise 'academic integrity' and established procedures and protocols. This potentially problematises the student who requires modification of, for example, an assessment deadline as not able to adhere to the expectations of 'academic integrity'. This undoubtedly contributes to institutional mistrust of impairments which may impact in varying ways at differing times. Staff used these pervading attitudes in representing the wider institution (Alison's 'stereotypical lecturer', for example) in demonstrating ambivalence and ambiguity towards fluctuating or recurring impairments. Susan discussed students' concerns about being judged by staff, as well as, in existing institutional technologies, being required to ask for support, and to an extent, disabled by this mechanism.

Drawing on wider discourses of the similarities/ boundaries between health, illness and disability, both conceptually and in terms of terminology, was a way in which Marie operationalized and contributed to an ambiguous construction of fluctuating or recurring impairments. Such observations potentially influence a perspective which considers impairments to be 'curable' (again, invoking Frank's 'remission society'), and reinforcing

the limited legitimacy that pervades. Such positionings and constructions serve to blur already fuzzy boundaries even further.

### **8.5.3 In what ways are the identities of students with fluctuating or recurring impairments negotiated and constructed within HE discourses?**

The institutional discourses, policy and practices that have been discussed in Chapter Six had a significant impact on how students negotiated, constructed and enacted identities. As has already been outlined in Chapter Three, socially constructed identities are entirely context dependent and based on interactions. Harré (1993) suggests that through interactional positionings 'human beings become persons by acquiring a sense of self. But that can only occur in social milieu in which they are already treated as persons by the others of their family and tribe' (p. 4). For the students who participated in this research, different tribes (peers, staff, etc) were a catalyst for the relational construction of identity through either participation and cohesion or through experiences of exclusion. Stories were told about each position, and had a notable impact on how students represented themselves and their impairment as an aspect of either individual or collective identity.

Pervading institutional ambiguities as regards fluctuating or recurring impairments established ambiguous and inconsistent support for students. Partially informed by wider discourses of 'questionable legitimacy', but also guided by lack of explicit institutional policy on inclusion or procedural documentation, limited recognition existed of the potential of some forms of impairment to vary in intensity over time. Fundamental to this were academic procedures related to attendance and assessment, based on physical presence at a specific place at a specific time. These processes (as 'academic integrity') and notions of regularity align with the LTAS's priorities of quantifiability, measurement and quality. For students who find this regularity problematic based on variations in ability, potential for participation is immediately compromised.



Disabled students are constructed as other and different by requiring alternatives to academic processes, and within this, students with fluctuating or recurring impairments as carrying further complexities in defying categorisation. This effected an institutional model of fluctuating or recurring impairments that was based on health and wellness, and possible recovery, as opposed to on-going impairment. For the students who participated in this research, this influenced identity construction in that they often regarded themselves as having 'health problems' or as not disabled. This, in tandem with widespread limited legitimacy, meant that students often did not disclose their impairment to the institution, and thus did not relate to nor were constructed as disabled. Students discussed how this might encourage them to develop aspects of identity which they may have thought of as facades ('actress Laura' and John's 'dishonesty').

Self-care and awareness were also important for students in managing uncertainty and unpredictability as regards their impairment. Many of the students took anticipatory measures to ensure as full participation as possible, and used this self-awareness in negotiating support and social situations (such as Laura *putting things in place*). This acute self-awareness contradicts the pervading institutional ambiguities and ambivalence as regards fluctuating or recurring impairments, in recognising the likelihood of unpredictability in participation depending on impact of impairment, and recognising the legitimacy of forms of impairment which may not be visible, which are uncertain and which vary over time.

### **8.6 Conclusions**

The lack of 'formalisation' of an institutional perspective on inclusion, as evidenced by no explicit policy or guidance documentation, immediately compromises the university's commitment to supporting disabled students. Furthermore, expectations of measurement and predictability influence negative positionings of students with fluctuating or recurring

## Chapter Eight: Discussion

impairments, in their varying abilities to comply with some of the technologies of 'academic integrity'. However, this institutional vagueness, despite contributing to a persisting lack of legitimacy of fluctuating or recurring impairments, may also open up possibilities to bring together incongruities in staff and student perspectives in revising current constructions and policy. For example, in considering opposing perspectives on the role of disclosure (for staff the point at which the 'disabled student' emerges and for students a choice which requires reflection on the role of impairment within their identity followed by a conscious decision to position themselves as 'disabled') or in discussing pervading notions of illness as disability and the associated impact on modes of assessment and academic procedures.

Implicit problematisation of students with fluctuating or recurring impairments through inflexible and contradictory institutional technologies (such as the NAR and Special Factors), perceptions of participation (attendance, inflexible modes of assessment) and constructions of disability as illness position students in a complex culture within which identities are negotiated. Central to this negotiation are the incongruities between staff and student perspectives, as evidenced through Laura's disruptive tutorial experience, Emily being assessed on 'turning up' and John's 'dishonesty', for example. These circumstances and dynamics encouraged students to evaluate and adapt their ways of participating according to self-awareness and the masking or promotion of different aspects of identity.

In the following chapter, I draw on this chapter's discussion in considering the implications of this research in making recommendations for the promotion of a flexible approach to considering participation of students with fluctuating or recurring impairments in Higher Education.

## **Chapter Nine: Implications and recommendations**

### **9.1 Introduction**

This chapter discusses some of the implications of this research before returning to the practice-based questions set out in Chapter One. In particular, it considers the effect of discourses of ambiguity and ambivalence on providing flexible and inclusive support, and argues for increased clarity in institutional intent to inform a model of provision which in turn encourages recognition and acceptance of fluctuating or recurring impairments. In so doing, it considers the complexities of bringing about long term cultural change as regards institutional constructions of disability on a fluctuating or recurring basis, as well as influencing changes to practice and provision for disabled students.

### **9.2 Changing practice**

Trowler (2003) has suggested that in education, staff attitudes toward and interpretation of educational issues are key in the enactment of policy. For Ball (2008, p. 5) it is ‘the ways in which policies are spoken and spoken about, their vocabularies, [which] are part of the creation of their conditions of acceptance and enactment’. However, acceptance and enactment cannot be assumed – staff, as has been outlined within this research, may also potentially enact their practice outwith policy, through resistance or alternative. Ball (2008, p. 7) argues that:

‘Policies are contested, interpreted and enacted in a variety of arenas of practice and the rhetorics, texts and meanings of policy makers do not always translate directly and obviously into institutional practices. They are inflected, mediated, resisted and misunderstood, or in some cases simply prove unworkable’.

For the staff who participated in this research, the influence of a fairly general policy (the LTAS) with broad aims could be interpreted and implemented very differently, both in their

own practice as well as amongst the others they constructed in positioning themselves. The LTAS's reference to the institution's intent to 'promote social inclusion' was, at the time the research was conducted, the only institutional statement on the university's recognition of its responsibility in this regard. Stating this intent in the context of a policy which was created to guide practices of learning, teaching and assessment and which exhibited competing civic and commercial discourses led staff to portray an institution where constructions of disability were vague and ambiguous and where inclusion issues should be taken 'a lot more seriously.'

Scott (2000) argues for the necessity of teaching staff to be 'educationally literate', to question the creation and bounds of policy by considering implications and alternatives. Scott suggests that the educationally literate practitioner 'has the capacity to resist and indeed transcend the powerful messages which inform and structure educational texts and documents' (p.2). Adopting such a critical positioning to policy enables staff to surface power relations and consider how they themselves may be positioned in reflecting on the values and knowledge that underpins their practice. This has been problematic for staff within this research given the vague nature or non-existence of policy as regards inclusion. However, staff did make reference to legislation and legal discourse in reflecting on their practice and in positioning themselves as inclusive practitioners.

As I have noted previously in this research, the participating staff all recognised the potential for impairment to be experienced on a fluctuating or recurring basis. In discussing their perceptions of this and reflecting on incidences of supporting students with fluctuating or recurring impairments, the staff members constructed others institutionally who did not share this recognition in order to position themselves as inclusive practitioners. Despite pervading difficulties in access to language, these staff members may constitute the basis of a possible 'discourse coalition' (Hajer 1993, p. 45) who share recognition of a social construct and can 'give meaning to ambiguous social circumstances'. Recognition of the potential for disability to be experienced on a

fluctuating or recurring basis amongst such a coalition has the potential to influence widespread cultural change in the absence of specific acknowledgement in existing policy or practice, and to effect a 'bottom up' form of institutional cultural change based on reflection and experience.

The establishment of an inclusive, flexible support structure for disabled students, however, requires more than prescriptive policy and legislation (MacLean & Gannon 1997) and 'buy-in' at executive level (Quality Assurance Agency for Higher Education 2010b). Access to learning and provision of support for disabled students is a multi-layered issue which incorporates physical, attitudinal and curricular issues and considerations (Shevlin et al. 2004), as well as commitment from staff, provision of structural and material resources and adequate funding (Hornby 1999) and clear and accurate guidance for staff.

### **9.3 Mapping the additional practice-based questions**

At the outset of the research, in Chapter One, Section 1.6.4, pages 17 - 18, as well as the three research questions, I also posed three additional practice-based questions:

1. In what ways might a fluctuating or recurring impairment affect student participation in learning and teaching activities?
2. To what extent is the concept of a fluctuating or recurring impairment understood/acknowledged within HE?
3. How does institutional understanding of disability shape provision of support for students with fluctuating or recurring impairments?

In returning to these questions, I make recommendations for the sector in improving awareness of and support for students with fluctuating or recurring impairments. These recommendations are the result of having identified, thorough staff and student

perspectives, areas of focus which may improve awareness and recognition of the tendency for some forms of impairment to vary in impact.

### **9.3.1 In what ways might a fluctuating or recurring impairment affect student participation in learning and teaching activities?**

As noted in Chapter Seven, students who participated in the research spoke about difficulties in describing their experiences of having a fluctuating or recurring impairment, and being able to adequately convey unpredictability or uncertainty. Doing so was compounded by issues of inflexibility in institutional technologies which were based on constructions of disability as other, and staff perceptions of fluctuations in students' ability to participate in learning influenced by a culture of mistrust. Fundamentally, students' difficulties in conveying varying ability to participate influenced an institutional perception of fluctuating or recurring impairments that was not compliant with existing processes associated with 'academic integrity'. In the absence of documentation which offered a clear institutional perspective on inclusion, or indeed, any procedural documentation on supporting disabled students, the legitimacy of disability itself was undermined. Mirroring wider perceptions of limited legitimacy of fluctuating or recurring impairments, an institutional model based on ambiguity and ambivalence contributed to ad hoc, indecisive provision which was often constructed by staff (for example, flexible attendance or assessment deadlines) as negative and unwanted.

The student data provides numerous examples of ways in which students' participation in learning and teaching activities were affected by an impairment which varied in intensity over time. Key issues surrounding learner confidence, motivation and the development of complex strategies of self-care were all raised in interview and on-going email discussions in students' self-representation and positioning. Staff and student perspectives reinforced the importance, however, of the student's identification with an impaired self as one of

many possible personal attributes/ characteristics which may impact upon the student experience, along with individual responsibilities (family, work, etc) and learning preferences, as part of multiple co-existing identities. This was borne out in the student stories, too, in discussing their own constructions of impairment as one aspect of their lives, which often required adjustment according to differing environments or social situations.

### **9.3.2 To what extent is the concept of a fluctuating or recurring impairment understood/ acknowledged within HE?**

Staff and student perspectives highlighted an awareness of the potential for impairments to vary over time, but, in line with wider societal interpretations (McKee 2007; Lightman et al. 2009; Vickers 2001; O'Brien et al. 2008, 2009), scepticism and a lack of legitimacy persisted. This was compounded by institutional vagueness, in many forms, as regards the institution's stance on disability provision, and inflexibility on the part of institutional mechanisms. For example, the contradictory model of support, undocumented processes and protocol and subsequent reliance on tacit knowledge, as well as disparity in how technologies, such as the NAR, were implemented.

Whilst awareness and recognition of the potential for impairments to vary over time existed amongst the staff and students who participated in this research, they attributed little recognition on the part of the 'others' they constructed ('stereotypical lecturer', 'some people'). The role played by a lack of visible indicators of impairment, unpredictability, and limited access to wider social or cultural references as regards fluctuating or recurring impairments informed an ambivalent understanding of fluctuating or recurring impairments, often based on notions of health and illness, as opposed to long term disability. This is perhaps unsurprising when a construction of fluctuating or recurring impairments is undermined by a lack of language to articulate the concept (for both staff

and students), and when the underpinning construction of disability itself is vague, ambivalent and non-committal. Whilst other institutions may have publically available guidelines on supporting disabled students, and indeed note the existence of and provision for fluctuating or recurring impairments (London South Bank University 2011; London School of Economics 2011) those who do not offer little stimulus for consideration by educationally literate practitioners, in refining their own practice or, indeed, offer a discursive basis for the formation of a 'discourse coalition'.

### **9.3.3 How does institutional understanding of disability shape provision of support for students with fluctuating or recurring impairments?**

The lack of clear articulation of the university's approach to promoting inclusion creates a vague space for discourses to be constructed and enacted. This then fosters much disparity in how support is implemented, creating variation in provision within and across academic schools. The 'hub and spoke' model offers scope for confusion and inconsistency, specifically in relation to the way that the ADC roles are constructed and enacted within the schools (based on culture, priorities and professional alignments, as well as how the staff members with these roles position themselves). The lack of guidance documentation to which staff and students can refer demonstrates the level of prioritisation which has been given institutionally to formalising information mechanisms as regards disability. Instead, relationships and information exchange are privileged in guiding practice. Informal dialogue amongst colleagues within the university or with external 'experts' is a key route to shaping undocumented knowledge and practice. The inconsistency and disparity in provision within schools is testament to a lack of clarity as to, for example, the implementation of the NAR or the role of the ADC. The lack of 'formal' or documentary recognition of the university's commitment to supporting disabled students is a barrier which in itself creates disability. In effect, by not having access to a



supporting strategy or protocol, students cannot access with ease, or indeed inform, the information which constructs them in staff perspectives.

#### **9.4 Discussion and recommendations**

Despite allusions to its social mission and being a 'forward looking and inclusive institution', provision for disabled students, and in particular for students with fluctuating or recurring impairments, was developed and operationalized within discourses of ambiguity and ambivalence. A number of recommendations might be made in recognition of this for other institutions to consider in improving awareness and support for students with fluctuating or recurring impairments.

- **Recognition of fluctuating or recurring impairments**

A strategy on making provision for disabled students, which constructs disability in terms of access, flexibility and equity in participation is essential in challenging ambiguities and ambivalence. The existence of a policy which outlines an institution's approach to inclusion and provides an overview of the underpinning principles offers a route to legitimising some forms of disability as variable and long term, as opposed to reinforcing health-related constructions which imply recovery. Procedural guidance on supporting disabled students could promote flexibility as a key part of making 'reasonable adjustments', and counter perspectives that this compromises 'academic integrity'.

Furthermore, explicit institutional recognition of the possibility that some forms of impairment may vary in intensity over time offers possibilities for flexibility and inclusion by way of providing for changing participation. Any student experiences

changes in circumstance throughout their degree period, and building negotiable support in to existing documentation would underscore recognition of fluctuations in participation as being supported by the institution.

- **An integrated and accessible staff development programme**

Whilst many staff members may acknowledge supporting disabled students as an integral part of professional practice, institutional priorities that require staff to 'concentrate on proving rather than improving' (Allan 2004, p.418) create potential for limited engagement in staff development activities aimed at enhancing inclusion. Boud (1999) underscores the importance of both situatedness and peer learning in initiatives involving academic development, in recognising environmental influences in the creation of academic identity. In encouraging staff to participate in activities that address improving recognition of and provision for students with fluctuating or recurring impairments, such factors should be considered in the design of a collegiate programme that encourages participation as opposed to disengagement. A staff development programme which acknowledges the tension of conflicting institutional expectations of productivity, accountability and inclusion could offer opportunities for professional reflection and development through sharing practice and engagement with context specific examples of effective, negotiated student support.

- **Facilitating student autonomy**

Many of the ways in which students who contributed to this research negotiated their identities and participation were based on positive accounts of self-awareness and care. Advanced self-understanding allowed students to enact control over unpredictability and to subvert exclusionary technologies by finding alternatives to participation. In the context of improving recognition and awareness of fluctuating or

recurring impairments, the development of such in-depth self-knowledge is to be encouraged amongst students in resisting institutional practices that may disable them. Markula (2004, p.302) describes the use of Foucault's technologies of the self as 'practices of freedom that are characterised by ethics of self-care, critical awareness, and aesthetic self-stylization'. Such core attributes which refer to students' self-management and self-representation have strong implications for participation in HE, in challenging dominant discourses and practices that may exclude. In engaging students in discussion about their practices of self-care and awareness during meetings with disability support staff, for example, students may be made aware of their existing accomplishments in ethical self-understanding and how these may be transposed to the academic domain. Students may have an awareness of the practices and procedures in place that may offer 'support' or of their 'entitlement' to specific reasonable adjustments, and supplementary awareness of the value of their own self-practices in implementing these is of benefit in enabling students to consider themselves active participants rather than passive recipients. Recognition of students' abilities to engage in self-care as part of their student identity should also be embedded in staff development activities, in order to facilitate an empowered view of autonomous and solution-focussed students.

### **9.5 Summary**

The recommendations made within this chapter reflect addressing both the practice based questions in the context of the discourses which shaped institutional constructions of students with fluctuating or recurring impairments and ways in which other institutions may reflect and modify their own processes to encourage increased legitimacy of and provision for fluctuating or recurring impairments. Re-consideration of constructions of disability and access to disability-specific policy and documentation carry potential to counter ambivalences and misconceptions based on lack of visible indicators, uncertainty of

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recurring impact and on health-based constructions which may assume recovery. Explicit institutional recognition that some forms of impairment have the potential to fluctuate or recur and acknowledgement of the university's role in providing flexible support offer scope to increase recognition and legitimacy of fluctuating or recurring impairments. Furthermore, developmental and iterative staff development using specific examples from practice and providing opportunities for on-going dialogue and thus modified support are also ways in which flexibility may be embedded within institutional procedures.

In the final chapter, I conclude this research by offering an account of some of the dilemmas and transitions I experienced as part of the process, and how this has impacted upon the transformative experience of undertaking the research.

## **Chapter Ten: Reflections on the research process and my own positioning**

### **10.1 Introduction**

In this chapter, I have taken an opportunity to reflect on some of the critical decisions which have shaped this research and some of the dilemmas I encountered in the decision-making process. In so doing, I draw from premises of previous chapters as well as from entries to my own blog, in documenting how I experienced tensions, how my understandings changed and what effect this ultimately had on the shape of the research.

The extracts from my blog are denoted by date and quotation marks.

### **10.2 Positioning myself**

In the context of this research, my position was complex. I was, at once, student, staff and researcher, and each of these perspectives/ identities came with a different set of responsibilities, perspectives and dynamics. Many of the research decisions did not come easily, and I was very aware of what often felt like divided loyalties to the institution and the research (Bell & Nutt 2002). Throughout my EdD journey I became increasingly aware that in the past, prior to starting the programme, my participation and engagement in the latter two of Crotty's four questions on developing the research process, namely application of specific theoretical perspectives and the epistemology that underpins them (Crotty 1998), had been governed by the epistemological steer of funders. Reason and Bradbury (2000) note the importance of this negotiation between the epistemological leanings of the research commissioners/ practitioners and the practical needs of the organisation as being a key driver in research design. With these boundaries, and the

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almost habitual interview-transcript-thematic analysis expectation removed, I found myself with a bewildering choice of avenues, and considerable baggage to unpack.

Allan (2008) outlines some of the tensions felt by research students in inclusion studies, in terms of the impact of institutional dynamics, lack of clarity/ relevance in existing research precedents and potential lack of scope (or ability) to be explicit about ontological or epistemological beliefs. Allan notes that the uncertainty created within these parameters can lead research students to look for measurable, quantifiable answers:

‘If they are lucky enough to be given encouragement to remain open to contested meanings, they may find this difficult to handle alongside other epistemological uncertainties and insecurities about theoretical positions and paradigms. In the scary world of postgraduate research, the definable and measurable may prove more comfortable and reassuring.’ (p. 51)

At the outset of the research, the definable and measurable was exactly the kind of comfort and reassurance that I sought. I struggled in recognising and locating my subjectivity, finding it difficult to shake off some of the positivist objectivity which had been a central part of my research practice. I experienced difficulty in moving away from my long-held belief that the researcher should be an impartial, uninvolved instrument in the research, lest they ‘skew the data’ or have some influence on the outcome. Indeed, at the end of my first EdD conference presentation, a colleague challenged a closing remark I had made about not knowing ‘where to put my subjectivity’ by commenting that I was very much treating it as though it were a commodified and measurable research variable in and of itself.

As part of the reflexive process, I attempted to embrace the discomfort of recognising my thoughts, emotions and judgements in the research to become part of it. Given researchers’ (and indeed, specifically doctoral students’ [Glaze 2002]) long standing commitment to using diaries or journals to collect such reflections and observations (Van Maanen 1990; Peshkin 1998), I recorded some of my thoughts and decisions in a weblog

(blog) throughout the research decision-making and data collection. This has enabled me to have my own temporally unfolding narrative of the research process, capturing the feelings and tensions which informed decision making or articulated assumptions.

### **10.3 On opting for a narrative approach**

In deciding on a narrative approach to data analysis, I was able to consider the influence of discourses on how staff operationalized policy in practice and students' experiences of learning within this context. In both the staff and student analysis I was looking for commonalities as well as divergences, and using differing narrative approaches permitted me to consider context, language, assumptions, otherness and identity. The staff perspectives reflected on institutional values, and highlighted the disparate ways in which staff understood fluctuating or recurring impairments, either through their own practice and values, or of the 'others' used in positioning themselves. With the students, I aimed to join perspectives in the phase one data analysis, and offer observations on the individual experience in the collective context in the phase two analysis. Using a combination of thematic narrative analysis for staff, as well as drawing on positioning analysis (Harré 1993) and Phoenix and Sparkes' (2009) composite 'big' and 'small stories' approach, offered a flexible way to let discourses, operationalizations and contextual identity constructions emerge.

My initial ventures into using narrative had been tempered by institutional trends of representing the 'student voice', which in recent years has been criticised as being yet another victim of the audit culture; a commodified resource (Fielding 2004; Tett 2009). Indeed, the responsibility of interpreting staff and student stories weighed incredibly heavily for the duration of the research, and I found the analysis process initially extremely uncomfortable, belying my positivist sensibilities and suspicion of subjectivity. I acknowledge that this thesis is but one way in which context, discourses, perspectives

and lived experience may be joined together and interpreted within discussion on a highly complex and contested issue.

#### **10.4 On format**

Due to the students who opted in to the on-going aspect of the research unanimously choosing email as a communication medium, I also had to change my perceptions of the evolution, format and nature of the data. In my initial research proposal I had envisaged that blogging would give students an autonomous and dedicated space for reflection. I have also discussed, in Chapter Five, section 5.7, page 79, how I diversified the choices which I offered students vis a vis keeping in touch to foster creativity and provide choice for reflective preferences. It seems that as well as being institutionally embedded, email was also the least intrusive of the methods that the students had access to, and provided them with an opportunity to reflect and share as thoroughly or as superficially as they wished.

In my blog on 26<sup>th</sup> January, I somewhat disappointedly noted:

‘Email less intrusive and less commitment than blogging. Blogging lovely, but too much.’

However, it actually transpired that the email conversations, as the students were positioning themselves in dialogue with me, were very personal, interactional and extremely rich. On reflection, blogging could have been reflection potentially out of context; email was a way for students to tell stories in a familiar space *to* someone. The intent and construction of the stories may not have been nearly so clear had the virtual dialogic relationship not been present. The contributing students were all familiar with who I was, having taken part in an initial face to face interview. Thus, when writing emails, they were positioning and representing themselves to a specific, known person that they had met and constructed in a particular way. As a researcher, this offered me the opportunity



to draw comparisons between students' on and offline selves/ identities, and offered students the security of writing for a purpose and to a specific person.

### **10.5 On considering tone**

An associated issue which pervaded during both the phase one interviews and the phase two emails was my own positioning and how I communicated with the students. I have noted that I was keen for students to describe their own interpretation and recognition of their impairment, and as such, took their lead in using any associated terms by asking specifically how they would describe their impairment (please see Appendix 2 for a summary of the students' self-descriptions). I was extremely aware of my choice of phraseology in the interviews and throughout the email conversations, as demonstrated in my blog on 26<sup>th</sup> January:

'Exhausted after interviews - always watching what I say and trying to be respectful. Taking notes and writing them up as soon as poss to try to make interviews more informal, and to put students at ease. No audio recording as would be too much to process and not really the purpose of this phase. This is mostly background stuff, but there suddenly seems loads of it. Wonderful but bewildering.'

I was also aware that if I were to start regular contact with the students who had agreed to participate in the on-going email data collection, by looking ahead in my diary, that I had to begin this process sooner rather than later to maintain contact, keep the dialogue going, and maximise the amount of data that could be collected before April (as previously noted, six emails overall). Again, I captured my reflections about the tensions I felt in circulating primary contact at such an early stage, as well as my considered approach to writing the emails themselves. In my blog, on 26<sup>th</sup> January, I wrote:

‘Just sent out first update email to students. feel poss a bit too soon, but eager to start 'real' data collection. Felt awkward not starting it with 'hope you're well' as I always do with emails.’

As a result of the types of impairments that students had discussed during our conversations, I did not feel that I could use my regular opening pleasantries when writing to them, as I knew that ‘wellness’ could not be assumed at any stage of the research.

### **10.6 On maintaining the staff/ researcher/ student divide**

This caution was characteristic of my on-going communication with students. I was aware from the outset of a staff/ student divide that I perhaps had not quite anticipated, and having to maintain an impartiality in my emails as regarded engaging in informal discussions as well as being non-committal to criticisms that students made of university support in my capacity as a member of staff. Smith et al. (2009) discuss the tensions within negotiating research boundaries; ‘how close is too close to a research participant, how far is too far, and how do we know when we have gotten it ‘right?’ (p. 343). Whilst I was keen to put the students at ease, I was aware of the potential to blur the boundaries, based on my dual role of university staff and researcher.

In two separate entries (the latter entitled ‘politics’) on 18th March, I wrote:

‘Very aware of how I'm communicating. Trying to maintain a line of impartiality that feels really false. People sharing deeply personal things and I'm replying 'thanks for keeping in touch'? Trying to be as empathic as I can without overstepping the mark. V. difficult.’

The staff/ student divide was most acutely nuanced when communicating with students who were on programmes within the school where I worked, particularly on nursing programmes. Laura, for example, was a student who I had taught on a number of occasions and with whom I was very familiar. Throughout our communications I felt on-

going fluctuations in my own identity, from researcher to staff to adviser to ally, based on her changing positionings within the research as well as working with her in parallel on academic issues to do with assessment planning and her engagement in taught activities.

An additional complexity which arose in this context was in relation to John's representation of multiple impairments. Whilst he had disclosed dyslexia to the university, he had not highlighted depression. The Nursing and Midwifery Code of Conduct asks that students declare impairments on application to a programme of study, and, as discussed in Chapter Seven, section 7.5.5, page 142, John had not felt supported in doing so. As a member of academic staff who taught on nursing programmes, I was aware that John withholding information was in contradiction of the professional organisation's stipulations, but as I was not a registered member of the nursing community, resolved that my responsibility was to protecting John's confidentiality in the context of the research. I sought advice on this matter from a number of colleagues.

### **10.7 On transitions**

Personally, I also noted a number of transitions and transformations as an integral part of the research process. I had an opportunity to reflect on some of my projections (and assumptions) for the research when I took part in a pilot interview for another research project looking at dilemmas amongst doctoral researchers. I noted in my blog how useful I had found the discussion, as it helped to clarify where I thought I may encounter difficulties (logistically and attitudinally), but what I had not necessarily envisaged was the impact of my own positioning and pressures. In my blog on 17<sup>th</sup> August 2010, I wrote:

‘Just had the most fascinating afternoon w M. She interviewed me for her research, about the spoken and unspoken dilemmas that professional doctorate students face. I thought I'd prepared quite well for the interview, categorising my dilemmas into institutional, student based, and self.

M spoke about her ideas on transitional space, and how we (students) are all

inhabiting such transient loci and will do until we finish. It's frustrating, scary, invigorating.

M also mentioned guides of transitional objects, based on attachment theory. They're used to negotiate transitional space. Turns out mine is writing! My safety blanket that means I can delay the inevitable hard stuff. I also use fear, failure and dilemmas too. Ace!'

My admission in the interview, and in the blog, that I use unfocussed writing to test and capture ideas was a technology I used to make myself believe that I was making conceptual progress (despite acknowledging that this is very much a displacement for engaging with 'the inevitable hard stuff'). Whilst I spoke in interview about knowing that I am able, at times, to write quickly, I am never fully convinced of the rigour or quality, but the physical presence of text ('my safety blanket') provides a tangible source of comfort. This liminal, transitional space was brought into focus in November 2010 when, during on-going reading and research I became aware of the Episodic Disabilities Framework, as discussed in Chapter Three, section 3.4, pages 40 - 41. My initial reaction was not, interestingly, one of useful international context for my own research, but of fear that 'it's all been done', as I entitled the entry to my blog on 22<sup>nd</sup> November:

'So, today, in my research for some stuff for my lit review, I came across a small matter called the Episodic Disability Framework, and the minor point that the phrase episodic disability seems completely and widely accepted in Canada. And a bit of Oz. It seems to be restricted to the workplace and mainly with people with HIV to date, and only seems like quite a recent thing. Feel embarrassingly arrogant that I've been harbouring it as my own idea for the past 10 odd years.'

As it was, my discovery of the EDF at this stage was enormously helpful in clarifying the purpose of my research and also establishing the limits of research in the area as regards students in HE. The EDF also provided an opportunity to consider possible extrapolation to the learning experiences of students in HE through the three dimensions used in modelling in terms of context and environment, crucial components throughout the research in terms of the construction of student identities within contextual discourses.

At the outset of this research, my focus was very much geared towards unpacking learning experiences and how students with fluctuating or recurring impairments negotiated participation in the HE landscape. However, I rapidly realised learning was one constituent part of a bigger picture; that yes, students attend university with learning as a purpose, but that the discourses, institutional constructions, forms of governmentality and social practices shape provision and perspectives in ways that then impact on how students perceive and represent themselves. Therefore, a study that began about largely the individual experience very quickly took on a form that necessarily drew on social and institutional constructions and discourses to establish a context within which identity is formed and enacted. Using a narrative approach to do so provided me with an opportunity to foreground some of the students' own constructions by joining some aspects of 'big' and 'small stories' to consider their ways of being as students with fluctuating or recurring impairments, and the *whats* and *hows* respectively. If I were to consider the hybrid Phoenix and Sparkes approach to my own location within this research, I believe my 'ontological narrative' would be about experiencing a process of transformation that was *wonderful but bewildering*. The 'small story' that would form a part of my constructed identity would be concerned with *being careful*: being careful in how I communicated with students verbally and via email, in managing the staff/ researcher/ student divide, and in positioning myself within research carried out in my place of work.

### **10.8 On change**

As part of institutional restructuring, my own role underwent considerable changes. In Chapter One, I described how my role as Academic Development Tutor (ADT) was embedded within the then School of Health, and how this was complemented by the centralised Effective Learning Service (ELS) – another 'hub and spoke' model. In the restructuring, six academic schools became three, each with a Learning Development

Centre (LDC) to provide academic support. The central ELS was dissolved and ELS staff relocated to LDCs. The new School of Health and Life Sciences' LDC was staffed by five ADTs from two prior schools as well as one member of staff from the former ELS and an ICT Skills Tutor. Strategic focus for the LDCs became increasingly generic, and the remedial stigma often attached to academic support strengthened.

Within the LDC, I opted in to the role of main liaison with the central Disability Team. This role was not defined in any way (or, indeed, replicated in the two other LDCs) and quickly became politically charged. Rather than students having access to discipline specific support, they were now referred to 'the disability person' in the LDC. I thus experienced a lot of what Alison described of 'things being given back' and taking a mediatory role in negotiating support, as opposed to providing academic guidance. In actuality, the academic issues discussed by disabled students were very similar to those students who had not disclosed an impairment. What was different was the impact of the impairment on participation.

In February 2012, I left this role and the institution where I conducted the research to pursue a learning technologies related post in another Higher Education Institution. The new role encourages and supports the innovative use of educational technologies, and has a strong accessibility focus as a result of the high proportion of dyslexic students studying on creative courses there. Interestingly, I have noted many similarities in how nursing and art and design students learn in terms of shared underpinning principles of reflection, critical synthesis and evidence based practice. I have also seen parallels between the importance of academic and digital literacies in both seemingly disparate areas – despite extremely different domains of practice, it is vital that assumptions are not made of students' confidence and competencies in transitional stages. Indeed, I have been able to make use of a social constructionist framework in undertaking an analysis of the construction of 'Digital Natives' (Prensky 2001), which has recently come under criticism for its reductionist principles (Luckin et al. 2009; JISC 2009). I am currently

undertaking a research project which aims to contribute to a student-authored interpretation of the concept, as little evidence to date exists in this area.

I was extremely concerned, having left the institution where the research was carried out, that my relationship with the institutional discourses, technologies and practices, and most significantly the data, may weaken. If anything, however, I believe the distance actually opened scope for me to consider the existing model and associated constructions with a bit more clarity, as a bona fide outsider with the benefit of seven years of familiarity. I have also felt more free to critique strategy in a way that I may not have felt comfortable doing as an employee of the university. I was also encouraged to learn in discussions with former colleagues that a number of initiatives, including staff development and formalisation of the remit of the ADC role, are planned for the near future.

### **10.9 Conclusion: On limitations and aspirations**

The evolution of the research, in retrospect, seems like a natural progression, although at every junction, changes to the initial research proposal seemed seismic. My own awareness of the tensions, influences and dynamics on institutional perceptions and provisions has become considerably more acute, as has my appreciation of the complexity of factors, both explicit and implicit, at play in the formation and management of student identities.

As noted in Chapter Five, section 5.3, page 72, I chose to interview colleagues who I knew had experience of working with or on behalf of students with fluctuating or recurring impairments by way of establishing what *could* be discussed in this regard. Though access to language and terminology was difficult and fraught in trying to conceptualise through categorisation, discussions with the staff members offered an interesting insight into the ambiguity, ambivalence and mistrust which permeate current institutional constructions. I would be interested, in future, to repeat the exercise with a more diverse

## Chapter Ten: Reflections on the research process and my own positioning

group, in order to capture some of those more sceptical constructions and positionings from those who perpetuate the lack of legitimacy afforded to fluctuating and recurring impairments, as opposed to those who use the doubting 'other' to ratify the concept.

Also, experiences of learning during one academic term merely offer a 'snapshot' of student lives and selves at a particular juncture. In designing this research, I was very aware of making demands on students' time and energy, particularly when ability to participate in learning (or the research) was unpredictable. I would very much like to be in a position to carry out more longitudinal work with students, but am aware of recruitment and retention difficulties associated with this.

I am extremely keen to continue research on the experiences of both students with fluctuating or recurring impairments, and to extend the focus on identity construction to staff. Through informal discussions about my research with colleagues, many disclosed that this, too, was an aspect of their identity. I have discussed with a former colleague, who is undertaking his doctoral research on transformational learning amongst older members of the LGBT community, potential collaborative research in this area. We have mooted the possibility of research based on queer theory to examine liminal and transitional identities, located within discourses of professionalism and ageing. This would provide an opportunity to complement the research presented in this thesis in considering the impact of fluctuating or recurring impairments from a personally experienced staff perspective.



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## Appendices

### Appendix 1: Summary data for participating students

*Table 1 Distribution by level/ year of study*

Level 1	5
Level 2	8
Level 3	4
Level 4	4
Post grad	3

*Table 2 Distribution by impairment (based on self-description by students)*

ADHD	1
Arthritis	1
ASD	1
CFS/ ME	6
Chronic pain	4
CIDP	1
Depression (inc BPD)	5
Dyslexia	3
Epilepsy	3
MHD	3
MS	2
OCD	1
PTSD	1
Raynaud's syndrome	1

N.B. Overall does not total 24 as 5 students described multiple impairments

## Appendices

*Table 3 Distribution by subject*

Business	2
Computing	3
Engineering	1
Allied Health Professions (optometry, podiatry, physio, radiography, social work)	7
Law	1
Nursing	5
Social sciences	5

*Table 4 Overview of participants in phase two*

<b>ID</b>	<b>Gender</b>	<b>Year</b>	<b>Subject</b>	<b>Impairment</b>
18	M	Undergrad	Nursing	Multiple (dyslexia, epilepsy,
3	M	Undergrad	Computing	OCD
8	F	Undergrad	Social work	PTSD/ chronic back pain
2	F	Undergrad	Physiotherapy	CFS/ ME
6	M	Undergrad	Podiatry	Epilepsy
4	F	Undergrad	Social science	Multiple (dyslexia, depression)
10	F	Undergrad	Optometry	Chronic back pain
7	F	Undergrad	Nursing	Multiple (ADHD, ASD, depression)
12	M	Postgrad	Computing	MHD
11	M	Undergrad	Computing	Arthritis

**Appendix 2: Participating students' suggestions on terminology**

ID	Terminology
18	Inconsistent, as there is no stability to disability.
3	Inconsistent seen as unreliable, has negative connotations. Episodic too regular, like TV programmes. Thinks term would be helpful, but not sure what is appropriate.
8	Variable, fluctuating. Inconsistent has negative connotations.
2	Term would be useful. Disability should be part of it to convey seriousness as well as something to capture the impact of variation in wellness.
6	Inconsistent may exacerbate cynicism. Changeable. Takes exception to being called 'an epileptic'.
4	To an extent, anything is labelling. Difficulties, changing needs. Important to ask disabled person's opinion.
10	In past has used mobility difficulties or unseen disability, but feels neither really fit. Episodic appropriate – gives impression of on/off nature. Changeable, gradient.
7	Definitely useful to have a term. Fluctuating good, or environmental – though not sure that would mean avoidance of environment.
12	Terminology would be useful but couldn't suggest a term.
11	Non-committal on usefulness of a term and didn't make any suggestions.
28	Definitely useful to have a term. Noted that disability usually means visible. Fluctuating gives idea of up and down. Inconsistent possibly negative.
27	Would be useful. Not episodic or inconsistent. Possibly unpredictable.
30	No suggestions.
34	Not keen on episodic. Likes fluctuating or recurring.
20	Fluctuating – up and down.
25	Term would be useful. Frustrated as has had recent diagnosis after long period of illness, but now no support. Suggests unseen.
39	Capricious
23	Would be useful. Seasonal – not just weather, but course as well.
35	Shared term would be useful to challenge prejudices but also wary as could become outdated very quickly, replaced in 5 years and just cause more confusion.
17	Fluctuations in mood doesn't mean student is moody. One term would be difficult to represent all experiences.
33	No suggestions.
36	Would be useful as recognition is important. A phrase that conveys understanding. Periodic disabilities.



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38	Fluctuating – people think can either get better fast (e.g. virus) or stay the same. Stressful when people assume you're ill when it suits.
26	Fluctuating and episodic.

### **Appendix 3: Participant information (staff)**

#### **Aim of the research**

This research aims to consider the learning experiences of students with fluctuating or recurring impairments in the context of a shared understanding that disability is constant and unchanging. It is being carried out as part of my (Vic Boyd) Doctorate of Education.

The research will gather perspectives from students and staff to provide an insight into the learning experience of students with fluctuating or recurring impairments, such as Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ ME), epilepsy or post-traumatic stress disorder, and how their support needs are met.

The outcomes of this research will promote discussion on how on-going and appropriate support for students with fluctuating or recurring impairments can be negotiated within policy and practice.

#### **Your involvement**

As a member of staff who is involved in supporting students, I would like to invite you to take part in a short interview, based on your experiences. I am particularly interested to find out if you have experience of supporting students with fluctuating or recurring impairments, and also your reflections on how adequately you think the university provides support.

With your consent, the interview will be transcribed and analysed as part of the overall data analysis.

#### **How your contributions will be used**

Your contributions (the 'data') will be used in writing my thesis, and may be used in journal articles or conference presentations. All contributions will be anonymised, and you will not be able to be identified.

#### **The small print**

The research proposal has been passed by both the University of Stirling's Ethics Committee and (Scottish HEI's) Research Degrees Ethics Committee.

#### **My contact details:**

**Participant consent form (staff)**

I agree to take part in the research study being by Vic Boyd for her Doctorate of Education. I have read the participant information and have had a chance to discuss it.

*I understand that:*

	YES	NO
I agree to my interview being recorded and transcribed.		
I may ask for the information I have given to be withdrawn from the study at any stage.		
The information I give will be treated as strictly confidential and will be stored securely.		
Any information I give will be used for research only and will not be used for any other purpose.		
I agree that anonymised quotes from my contributions may be used in project outputs.		

NAME:.....

SIGNATURE.....

DATE:.....

#### **Appendix 4: Questions for staff**

1. In your role of supporting disabled students, what types of impairments have you helped to make provision for? Could you give examples?
2. In supporting disabled students, what influences your practice? (prompts: experience, legislation, policy, training, etc)?
3. As far as you are aware, does the intensity of any these impairments fluctuate over time?
4. What do you understand by the term fluctuating or recurring impairment?
5. Do you have experience of providing support for students whose disability could be described as fluctuating or recurring? If yes, could you reflect on this?
6. Institutionally, how flexible do you think (Scottish HEI) is in making provision for all disabled students?
7. Can you see any challenges associated with (Scottish HEI) policy as far as putting flexible support in place for student with fluctuating or recurring impairments?
8. What do you think the institution could do to improve flexibility of provision?

**Appendix 5: Student email - initial contact**

Subject: Are you a disabled student? Do you experience fluctuations in how your disability affects your learning?

Much discussion surrounding disability works on the assumption that it doesn't change, but for many students, this simply isn't true. Students with CFS/ME, epilepsy, or mental health difficulties, for example, may feel well one day and not the next. I'd like to talk to students whose disabilities vary in intensity about their experiences, and if their learning is affected. If you would like to take part, please contact me for further info: Vic Boyd, School of Health, email or 0141 331 3481.

## **Appendix 6: Participant information (students)**

### **Aim of the research**

This research aims to consider the learning experiences of students with impairments which vary over time, in the context of a shared understanding that disability is constant and unchanging. It is being carried out as part of my (Vic Boyd) Doctorate of Education.

The research will gather perspectives from students and staff to provide an insight into the learning experience of students with fluctuating or recurring disabilities, such as Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ ME), epilepsy or post-traumatic stress disorder, and how their support needs are met.

The outcomes of this research will promote discussion on how on-going and appropriate support for students with fluctuating or recurring disabilities can be negotiated within policy and practice.

### **Your involvement**

You are invited to take part in a short, informal interview about your experiences. Thereafter, you are also invited to record any thoughts or feelings that you have about learning over one academic trimester (January – April 2011) through whatever means you prefer. These may include:

- blogging
- Twitter posts (Tweets)
- Emails
- Text messages
- audio recordings (via handheld audio recorder)
- photographs
- Post-it notes

I am available to meet regularly with all students who contribute throughout the research. I am also willing to provide technical support should it be required.

### **How your contributions will be used**

Your contributions (the 'data') will be used in writing my thesis and journal papers. All your contributions will be anonymised, and you will not be able to be identified. If you choose to use a blog or Twitter, access levels on your account will be restricted so only you and I have access.

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The contributions from all student participants will be analysed to gather (anonymised) key messages to feed back to staff and the university's management team who make decisions about student support policy.

### **What's in it for you?**

By taking part, you'll not only be contributing to important research which will help our university, other universities, and in turn, students across the UK, but you'll also have the chance to try new different technologies and types of writing.

### **The small print**

The research proposal has been passed by both the University of Stirling's Ethics Committee and (Scottish HEI's) Research Degrees Ethics Committee (LREC).

### **My contact details:**

**Participant consent form (students)**

I would like to take part in the research study being by Vic Boyd for her Doctorate of Education. I have read the participant information leaflet and have had a chance to discuss it.

*I understand that:*

	YES	NO
I may withdraw from the research at any stage without giving a reason and without affecting my position at the University.		
I may also ask for the information I have given to be withdrawn from the study at any stage.		
The information I give will be treated as strictly confidential and will be stored securely.		
Any information I give will be used for research only and will not be used for any other purpose.		
I agree that anonymised quotes from my contributions may be used in project outputs.		

NAME:.....

SIGNATURE.....

DATE:.....



**Appendix 7: Student Interview pro-forma**

Date: \_\_\_\_\_

Student ID: \_\_\_\_\_

Year: \_\_\_\_\_

Subject: \_\_\_\_\_

Type of impairment: \_\_\_\_\_

Disclosed to uni: \_\_\_\_\_

NAR details: \_\_\_\_\_

How affect: \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Suggestions for terminology: \_\_\_\_\_

Further participation: \_\_\_\_\_

Format: \_\_\_\_\_

**Appendix 8: Student interview summaries**

ID	18
Level	2
Subject	Nursing
Disability	Multiple (dyslexia, epilepsy, depression)
Disclosed	Partly – dyslexia and epilepsy: yes, depression: no
NAR	Scribe, extra time in exams, yellow paper in class
Discussion	<ul style="list-style-type: none"> <li>• Support from university mainly in relation dyslexia. Feels judgements around depression and cannot be honest about 'bad days'.</li> <li>• Note taking on placement has been difficult and has had to develop strategies. This sometimes includes what student feels is 'over-compensation' to counteract judgements which can lead to errors.</li> <li>• Exam performance varies – has had difficulties in past where scribe is member of staff. Has felt intimidated and unable to articulate answers to full ability.</li> </ul>
Terminology	Inconsistent, as there is no stability to disability.

ID	3
Level	2
Subject	Computing
Disability	OCD
Disclosed	Yes
NAR	Currently in negotiation
Discussion	<ul style="list-style-type: none"> <li>• OCD affects timing and organization. Some tasks can take longer than anticipated.</li> <li>• Finds OCD easier to control when extremely busy and has several demands on time. Easier to deal with immediate consequence than something that may take place in future – less tangible.</li> <li>• At school, OCD related to perfectionism in writing. Content didn't change but would change wording of sentences again and again.</li> </ul>
Terminology	Inconsistent seen as unreliable, has negative connotations. Episodic, too regular, like TV programmes. Thinks term would be helpful, but

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	not sure what is appropriate.
ID	8
Level	4
Subject	Social work
Disability	PTSD/ chronic back pain
Disclosed	Yes
NAR	Voice recognition software, ergonomic desk and chair
Discussion	<ul style="list-style-type: none"> <li>• Due to chronic pain, student studies or writes in short bursts.</li> <li>• Enjoys academic work and is confident. Usually doesn't edit writing too closely, but now at dissertation stage has to do this much more.</li> <li>• Has experiences difficulties in reasonable adjustments not being communicated between staff in university and placement.</li> </ul>
Terminology	Variable, fluctuating. Inconsistent has negative connotations.

ID	2
Level	2
Subject	Physiotherapy
Disability	CFS/ME
Disclosed	Yes
NAR	Extra time in exams, flexible deadlines and flexibility in attendance
Discussion	<ul style="list-style-type: none"> <li>• CFS caused by flu when 16. Affects concentration and memory. Gets frustrated by lack of energy. Timetabling in rest periods vital.</li> <li>• CBT has helped student to adjust to disability. 3 hour commute to /from university each day, but this is easier than living on own as has valued support network at home.</li> <li>• Has experienced negative comments from students in previous study ('lazy') as couldn't walk far.</li> </ul>
Terminology	Term would be useful. Disability should be part of it to convey seriousness as well as something to capture the impact of variation in wellness.

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ID	6
Level	3
Subject	Podiatry
Disability	Epilepsy (acquired)
Disclosed	Yes
NAR	Extra time in class (but doesn't like to use it)
Discussion	<ul style="list-style-type: none"> <li>• Acquired epilepsy after surgery to remove brain tumour. Feels going through transition – fits to tumour to surgery to epilepsy. Has taken 5 years to accept.</li> <li>• Has problems with verbalisation and concentration. When studying does concentration exercises, then practices by revising.</li> <li>• Enjoys keeping fit, but balance of physical and mental activity difficult. Worries how will be perceived in the future if visibly active but struggles to cope with work.</li> </ul>
Terminology	Inconsistent may exacerbate cynicism. Changeable. Takes exception to being called 'an epileptic'.

ID	4
Level	2
Subject	Social sciences
Disability	Multiple (dyslexia, depression, general poor health)
Disclosed	Yes
NAR	Extra time in exams, own room, scribe, purple paper, assistive technologies.
Discussion	<ul style="list-style-type: none"> <li>• Full time carer and also bought young brother up when family broke up. Involved in lots of volunteer work.</li> <li>• Very nervous when first joined university as lacked confidence. Now student mentor and takes part in orientation for new students.</li> <li>• Learns by listening, and feels disadvantaged if cannot get books scanned. Has a photographic memory that allows reproduction of graphs in exam conditions, but cannot interpret meaning.</li> </ul>
Terminology	To an extent, anything will be labelling. Difficulties, changing needs. Important to ask disabled person's opinion.

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ID	10
Level	2
Subject	Optometry
Disability	Chronic Back pain
Disclosed	Yes
NAR	Extra time in exams, ergonomic chair
Discussion	<ul style="list-style-type: none"> <li>• Has difficulty in sitting for long periods of time, so 2 hour lectures problematic. Sits at back of class so can walk around if needed.</li> <li>• 'Body not in pain but mind thinks it is'. Can experience months with no symptoms and 3 or 4 days clustered together of extreme discomfort.</li> <li>• Has found change to trimesters problematic as assessment workload much heavier pre-Christmas.</li> </ul>
Terminology	In past has used mobility difficulties or unseen disability, but feels neither really fit. Episodic appropriate – gives impression of on/off nature. Changeable, gradient.

ID	7
Level	1
Subject	Nursing
Disability	ADHD
Disclosed	Yes
NAR	Voice recorder, PC.
Discussion	<ul style="list-style-type: none"> <li>• Can tell when episode is imminent and ensures exercise, eating well and study plan to maintain equilibrium.</li> <li>• Coping strategies include chewing gum to block out noise of pen clicking. The noise can cause nausea and extreme distress.</li> <li>• If gets stressed whilst writing uses 'nice paper and a nice pen' and feel more in control. Strong emphasis on organization and planning.</li> </ul>
Terminology	Definitely useful to have a term. Fluctuating good, or environmental – though not sure that would mean avoidance of environment.

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ID	12
Level	Postgrad
Subject	Computing
Disability	MHD (acquired through head injury)
Disclosed	Yes
NAR	Extra time in exams
Discussion	<ul style="list-style-type: none"> <li>• Difficulty with memory and recall. After Christmas break could not remember order of digits in room number for lab. Has consciously taken part in lots of learning over past 10 years to aid recall, and notes an improvement.</li> <li>• Takes anti-anxiety and anti-depressant medication which affect memory so not sure which effects are from this or from head injury.</li> <li>• Likens a busy environment to feeling like a bouncy ball, but when on own like a ball resting in water.</li> </ul>
Terminology	Terminology would be useful but couldn't suggest a term.

ID	11
Level	3
Subject	Computing
Disability	Arthritis
Disclosed	Yes
NAR	Extra time in exams, scribe
Discussion	<ul style="list-style-type: none"> <li>• Extremely shy student who didn't give much detail of disability, only that it is exacerbated by cold weather and discomfort is managed by painkillers.</li> <li>• Feels that some members of staff judge his intelligence based on his physical disability.</li> <li>• Has concentration problems, but attributes that more to lack of engagement with learning materials than anything to do with disability.</li> </ul>
Terminology	Non-committal on usefulness of a term and didn't make any suggestions.

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ID	28
Level	2 (on medical time out)
Subject	Social science
Disability	MHD
Disclosed	Yes
NAR	Extra time in exams
Discussion	<ul style="list-style-type: none"> <li>• Has taken a long time to come to terms with disability. Considers self 'not that disabled', though says that if it wasn't for family she wouldn't get out of bed in the morning.</li> <li>• Extreme mood disorder, with worst times being 'bottomless pit of despair'. Experiences concentration problems, which are exacerbated by medication.</li> <li>• Finds talking to people difficult. Discussed putting on make up to leave house to boost confidence, which adds to complication as 'looks fine' but feels awful ('look good, feel crap').</li> </ul>
Terminology	Definitely useful to have a term. Noted that disability usually means visible. Fluctuating gives idea of up and down. Inconsistent possibly negative.

ID	27
Level	2 (PT)
Subject	Law
Disability	MS
Disclosed	Yes (but selective about who he tells)
NAR	Extra time in exams, software, laptop and voice recorder.
Discussion	<ul style="list-style-type: none"> <li>• Has slow reading and processing speed and can be easily confused e.g. may not be able to articulate self properly.</li> <li>• Heat and fluorescent light trigger bad spells and makes studying in library and often exam settings difficult.</li> <li>• Experienced 'disability envy' where he disclosed to fellow student with CFS who considered his own case much worse and told student with MS to 'think about people who are really affected'.</li> </ul>
Terminology	Would be useful. Not episodic or inconsistent. Possibly unpredictable.
ID	30

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Level	Postgrad
Subject	Psychology
Disability	Depression
Disclosed	No
NAR	N/A
Discussion	<ul style="list-style-type: none"> <li>• Depression affects concentration and motivation, and student notes 'vicious cycle'. Concentration poor even when well, and can affect how much is processed when reading.</li> <li>• Lack of confidence stops her from using the library (would rather buy a book), though gets material online. Confidence levels also affects recall in exams.</li> <li>• Extreme fatigue. Knows that even if sleeps for long periods will only feel marginally better.</li> </ul>
Terminology	No suggestions.

ID	34
Level	3 (PT)
Subject	Business
Disability	CFS/ ME
Disclosed	Yes
NAR	Extra time in exams
Discussion	<ul style="list-style-type: none"> <li>• Extreme fatigue affects concentration and joint pain is intermittent.</li> <li>• Uses lifts and has attracted negative comments. Also colleagues at work do not consider him disabled as not visible.</li> <li>• Feels currently that support mechanisms are a tickbox exercise. Provision needs to be flexible. Gives example of texting lecturer to say will be late.</li> </ul>
Terminology	Not keen on episodic. Likes fluctuating or recurring.



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ID	20
Level	4
Subject	Radiology
Disability	CFS/ ME
Disclosed	Yes
NAR	Extra time in exams
Discussion	<ul style="list-style-type: none"> <li>• Poor concentration and fatigue. Has arrangement with placement where she can make time up if she is unwell enough to attend.</li> <li>• Thinks health has improved in past year, though still has 'bad spells'. Can forget limits when feeling well.</li> <li>• Text 3</li> </ul>
Terminology	Fluctuating – up and down.

ID	25
Level	CFS/ ME
Subject	Nursing (on medical time out)
Disability	CFS/ ME
Disclosed	Yes
NAR	No
Discussion	<ul style="list-style-type: none"> <li>• Concentration problems affect ability to study, and performance in exams. Also impedes ability to hold conversation, study or write.</li> <li>• Violent sickness and tremors associated with ME which make her physically weak. Frustrating as motivation to study and learn is there but not mentally or physically able.</li> <li>• Doesn't consider herself disabled as feels stigma attached. Makes her think of wheelchair users and she is afraid people will judge her.</li> </ul>
Terminology	Term would be useful. Frustrated as has had recent diagnosis after long period of illness, but now no support. Suggests unseen.

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ID	39
Level	Postgrad
Subject	Social science
Disability	CIDP
Disclosed	No
NAR	No
Discussion	<ul style="list-style-type: none"> <li>• Extreme fatigue by early evening meaning all study takes place during weekend.</li> <li>• Pain also affects concentration.</li> </ul>
Terminology	Capricious

ID	23
Level	2
Subject	Business
Disability	Raynaud's syndrome
Disclosed	Yes
NAR	Extra time in exams
Discussion	<ul style="list-style-type: none"> <li>• Stress and cold weather bring on symptoms. Lost ability to write with right hand in school so taught herself to be ambidextrous.</li> <li>• In exam, recently based choice of question on which was shortest answer to minimise writing. Takes heat pads into exams to help.</li> <li>• Planning assessment important, though if not at a particular stage at a particular time gets stressed and this exacerbates symptoms.</li> </ul>
Terminology	Would be useful. Seasonal – not just weather, but course as well.

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ID	35
Level	1
Subject	Nursing
Disability	Epilepsy
Disclosed	Yes
NAR	No
Discussion	<ul style="list-style-type: none"> <li>• As yet, time at university unaffected by epilepsy as medically controlled. Student knows triggers and ensures enough rest, minimal stress, etc.</li> <li>• Has experiences discrimination in applying for jobs because of epilepsy, but not at university. Has not informed her placement of epilepsy('it never crossed my mind')but intends to.</li> <li>• Understands stigma attached to unseen disabilities as works with someone with depression – 'you look fine so you're just a bit down. If you break your leg, that's fine'.</li> </ul>
Terminology	Shared term would be useful to challenge prejudices but also wary as could become outdated very quickly, replaced in 5 years and just cause more confusion.

ID	17
Level	4
Subject	Social science
Disability	BPD
Disclosed	Yes
NAR	No
Discussion	<ul style="list-style-type: none"> <li>• Affects focus and concentration, thus ability to study at different times.</li> <li>• Struggles with large exams as likes to be alone when feeling bad. Has had panic attacks and feels stressed by exams for different subjects taking place in same location.</li> <li>• Thinks mental health awareness training should be compulsory for all staff to improve understanding.</li> </ul>
Terminology	Fluctuations in mood doesn't mean she's moody. One term would be difficult to represent all experiences.

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ID	33
Level	3
Subject	Optometry
Disability	Dyslexia
Disclosed	Yes
NAR	No
Discussion	<ul style="list-style-type: none"> <li>• Diagnosed at university. Relief, but still struggles with volume of workload and concentration. Mainly downs with some ups.</li> <li>• Difficulty reproducing detail in exams. Revises with peers but cannot make decisions on where to focus revision and becomes very stressed</li> <li>• Feels that has been given help, but no long term support. Describes being in a 'freak out circle' between academic departmentt, disability team and central effective leaning service.</li> </ul>
Terminology	

ID	36
Level	4
Subject	Engineering
Disability	MHD
Disclosed	Yes
NAR	Flexible attendance, extra time in exams
Discussion	<ul style="list-style-type: none"> <li>• History of depression, agoraphobia. Unable to leave house, fell behind with coursework. Feels may have been marked unfairly due to prejudices (staff interpret non-attendance as laziness).</li> <li>• Social anxiety disorder: assumes people think the worst of him - makes it difficult to ask for help. Did not consider himself disabled, but spoke to friend with MS who discussed MHD as form or impairment. Offered same support as friend, but recognises own needs not physical.</li> <li>• Having disclosed to university, if unable to leave house telephones to let people know.</li> </ul>
Terminology	Would be useful as recognition is important. A phrase that conveys understanding. Periodic disabilities.
ID	38

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Level	1
Subject	Psychology
Disability	Multiple (CFS/ ME, fibromyalgia, IBS, ligament damage)
Disclosed	Yes
NAR	Extra time, use of computer in exams
Discussion	<ul style="list-style-type: none"> <li>• Easily tired and concentration lapses in lectures/ tutorials.</li> <li>• Uses Blackboard when in extreme pain – can revisit the slides when feeling better.</li> <li>• Symptoms worse with stress and nerves, so presentations are particularly problematic.</li> </ul>
Terminology	Fluctuating – people think can either get better fast (e.g. virus) or stay the same. Stressful when people assume you're ill when it suits.

ID	26
Level	1
Subject	Nursing
Disability	Depression
Disclosed	Yes
NAR	Extra time in exams
Discussion	<ul style="list-style-type: none"> <li>• Can affect performance and attendance.</li> <li>• Concentration lapses and disjointed thinking an speech. Can affect essay writing and taking notes.</li> </ul>
Terminology	Fluctuating and episodic.

## **Appendix 9: Summary of prompt emails to student participants in phase 2**

*(1) 25<sup>th</sup> January 2011*

Hi X,

Thought I'd drop you a quick line to follow up on last week's chat. As I mentioned, I'm keen to hear about how things go for you this trimester, and am really interested in your reflections about learning and time at uni.

So, I'd be delighted if you were willing to share any observations or comments on how you're feeling or what you're working on, for example. Comments can be as long or as short as you like.

Thanks again so much for your time last week. I do really appreciate it, and look forward to keeping in touch this trimester.

All the best for now. Vic

*(2) 9<sup>th</sup> February 2011*

Hi X,

I just wanted to drop you a quick line to see how everything's been going. I hope the trimester is going well so far.

I've now spoken with 22 students as part of the research, so have lots of great information that I'll be working on putting together over the next few months – a big, but hugely interesting, job!

I'd be really keen to hear how things are going for you, and really appreciate you sharing your experiences.

Best wishes for now. Vic

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*(3) 24<sup>th</sup> February 2011*

Hi X,

Just a quick email to see how things are going. It's amazing (and slightly terrifying) to think we're into March next week!

I do hope things are going well at the moment, and do appreciate you keeping in touch.

Thanks and best wishes, Vic

*(4) 10<sup>th</sup> March 2011*

Hi X,

Just checking in to see how things are going. I know it'll be a busy time in the trimester for you, and would be really keen to hear how you're getting on.

As ever, thanks for keeping me updated. I really appreciate your time.

Thanks and best wishes, Vic

*(5) 23<sup>rd</sup> March 2011*

Hi X,

Hope things are going well for you at the moment.

You'll be relieved to know this will be my penultimate email, with the week after next being the final instalment.

I am extremely grateful for all the insights you have offered, and in your taking the time to keep in touch. I've got some great ideas and really valuable research information from the students who have been kind enough to share their experiences over the trimester, and I hope to be able to feed back to you on this in the not-too-distant future.

Just a few very short questions this week, to ask about your reflections on this trimester so far:

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1. How would you describe your learning over this trimester? (you can say as much or as little as you like)
2. Have there been any significant events in your learning or your wellness which have affected your study during this trimester?
3. How are you feeling about any upcoming assessments?
4. What have you learned about yourself as a learner this trimester?

Thank you so much again for all your time and commitment. I genuinely appreciate it.

Talk to you soon. Best wishes, Vic

*(6) 10<sup>th</sup> April 2011*

Hi X,

I hope things are progressing well for you this trimester.

As I mentioned last time, this will be my last email about the research for now. I hope you might be able to take a couple of minutes to respond (in amidst the million and one other things that are going on at the moment) to let me have any final thoughts that you think may be important. You're of course welcome to contact me at any time with any additional comments – I'd be very glad to hear from you.

As I've said before, I'm keen to stay in touch and let you know how things are going with the research and the write up. That's likely to be over the course of the next 6 months or so, and I hope you might find some of the updates useful.

I am so grateful to everyone who has taken part in the research, without whose participation the next stages of analysis and feeding back to the university would not be possible. Your contribution has been absolutely invaluable, and I can't thank you enough for all of your time over the trimester, when I know that you are extremely busy with study and work.

Thanks so, so much again, and I look forward to keeping in touch.

With best wishes, Vic