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**The social organisation of learning  
difficulties at university: a qualitative  
study of four Higher Education  
Institutions in the North East Region of  
England**

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**February 2011**

I declare that this thesis, which I submit for the degree of Doctor of Philosophy at the University of Durham is my own work and is not substantially the same as any which has previously been submitted for a degree at this or any other university.

## **Abstract**

The last decades there is a clear shift in people's attitudes towards disability and the participation of disabled people in society and especially in education. The new disability law and the anti-discrimination legislation changed the relationship between disabled students and Higher Education, allowing them access and providing support for their needs. The current research aims to discuss support and provision for students with learning difficulties within Higher Education Institutions. Specifically, within the framework of North East Universities in England (Newcastle University, Northumbria University, Durham and Sunderland University) the research addresses the issues around provision for students with learning difficulties at Durham University. The experiences of the students themselves, as well as the views of the Directors of the Disability Support Unit (DSU) from all four universities combined with the perspectives of lecturers and College Officers from Durham University only, they create a framework within which support and provision are discussed. This project used qualitative methodology as it was considered appropriate for the nature of the research problem. Semi-structured interviews were used for the data collection and were combined with the secondary literature (such as journal articles, papers, websites, documents provided by the institutions etc) to draw a more complete picture of the issues of interest. In the end, the sample consisted of 18 students with learning difficulties who studied in the four Higher Education Institutions, 4 interviews with the Directors of the DSUs from these universities and 7 interviews with lecturers and college officers from Durham University only. Clearly, from the findings of the project some of the changes in Higher Education are steps towards an inclusive educational environment where the needs of all students will be taken care of, regardless of disabilities or abilities of students. However, there are still concerns, which were expressed from both students and Directors of DSUs, about 'attitudinal barriers', which are necessary to change, in order to achieve the inclusive education for all. The research also concluded that in order to achieve an all-inclusive educational system it is necessary to focus more on personalised services and treatment for students with learning difficulties, where all the individual needs of students are met. The bureaucratisation of the services and

the turn of the education towards marketisation where institutions compete for students and promote the market behaviour have to be replaced by personalisation in services and support for disabled students.

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# 1 Introduction

Disability, discrimination, inclusive education and provision for disabled students are not new issues, and they have been the focus of study for many researchers (Oliver, 1996; Shakespeare, 1998; Alberecht et al., 2001; Williams, 1996; Zola, 1993; Chappell et al., 2001; Altman, 2001; Goffman, 1990[1963]), in the last decades. Throughout the 1980s, there were numerous efforts to introduce anti-discrimination legislation, which intended to allow access to disabled people into “*the mainstream economic and social life of society*” (Barnes, 1991, p: 1).

The good news about disability is that people have started to see it as something that has a place within the political agenda. They have shown interest in the participation of disabled people in society and especially in education (Bowker and Star, 1999 in Albrecht et al., 2001; Riddell, Tinklin and Wilson, 2005; Borland and James, 1999; Hurst, 1999; Holloway, 2001). With the help of the anti-discrimination legislation, there has been an undeniable change in the integration of disabled people in education, over and especially in Higher Education (Barnes, 2007). Up until the 1990s, disabled students and staff had almost been denied access to most of the Higher Education Institutions (Barnes, 2007; Barnes, 1991). However, after 1993, when the Further and Higher Educational Act (1992) came into force and encouraged more students with disabilities to enter Higher Education, disability related issues have been the main interest for many researchers.

The last decades, there has been a clear shift in attitude towards education in integrated or mainstream settings and now there is a drive towards inclusive education. There are many opportunities for students for Higher Education, but at the same time, this means that some of these students will be disabled young people (Wong, 1996). Data from the Higher Education Statistics Agency (HESA), “*Students in Higher Education Institutions 2005/06*”, show that the proportion of university students declaring a disability at all levels of study continues to rise, as the next table illustrates and the total number of disabled students has risen by just over two thirds (HESA, 2007).

**Table 1**

<b>Academic Year</b>	<b>Total number of disabled students<sup>1</sup></b>
<b>2003/2004</b>	115,595
<b>2004/2005</b>	128,185
<b>2005/2006</b>	137,945

This increase in the number of disabled students who enter Higher Education can be seen as the result of the fact that people have started to have more disability awareness and recognised the right of the students with disabilities to be educated as other students without disabilities. At the same time, there is a shift from the medical-individualistic model of disability, towards the social model of disability, which recognises the social barriers that could prevent disabled students accessing Higher Education.

The problems of the disabled people, initially, were seen only as individualistic-medical problems, and as such, they had nothing to do with changes in society and anti-discrimination legislation. Later, the “*social model*” of disability, as it was used by Oliver (1996[a]), in order to explain the Union of Physically Impaired Against Segregation (UPIAS) (1974) definitions of disability, described disability as the result of the way that society is organised and the social barriers that cause problems to people with impairments. The social model of disability was seen as the “*big idea*” of the disability movement in Britain (Hasler, 1993 in Shakespeare & Watson, 2002). It shifted the weight of the responsibility from the individuals with impairments towards society’s failure to provide for these people (Hughes and Paterson, 1997). Disability became part of people’s consciousness and entered the political agenda, and now it is a case of changing attitudes, as well as laws and legislation, in order to protect and accommodate disabled people.

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<sup>1</sup> Based on HESA 2007

Even though it is difficult to define disability, without leaning towards one or the other model, a definition of disabilities makes it easier for someone to understand what disability really is. However, it has to be clear that disability is more than what a definition explains. As will be shown below, the medical model of disability, alone, does not describe the life experiences of the disabled people, and it does not explain the problems that they face. At the same time, the social model accepted some criticism both from within (disabled people) and from outsiders, such as medical sociologists, doctors etc, for reasons that will be explored in the literature review later (Barnes, 1991; Barnes, 2007; Oliver, 1996 [a]).

Among the disabled students who have started entering the Higher Education Institutions are students with learning difficulties, which are disabilities that are not directly visible by others, like in cases of physical disabilities, but none the less, they can cause significant difficulties to students' efforts to study. The use of the term 'learning difficulties' can cover different conditions, depending on the nature and degree of individual's impact. Most often learning difficulties fall into three broad categories that affect academic skill acquisition. The general categories, based on the Learning Disabilities OnLine (LD OnLine<sup>2</sup>) (2008) webpage, include

*"...reading disabilities (often also referred to as dyslexia); written language disabilities (also often referred to as dysgraphia); and math disabilities (often called dyscalculia). Other related categories include disabilities that affect memory, social skills, and executive functions such as deciding to begin a task..."* (LD OnLine, 2008, Accessed online in 2008)

Some individuals have only one learning difficulty (such as dyslexia), while others may have more than one or a combination of conditions related to learning difficulties such as Attention Deficit Hyperactivity Disorder (ADHD) or Asperger's

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<sup>2</sup> LD OnLine is the leading website on learning disabilities, learning disorders and differences. Parents and teachers of learning disabled children will find authoritative guidance on attention deficit disorder, ADD / ADHD, dyslexia, dysgraphia, dyscalculia, dysnomia, reading difficulties, speech and related disorders (LD OnLine, 2008).

syndrome etc, which again can have an effect on their learning abilities (Latham, 2002).

The use of the term ‘learning difficulties’ instead of ‘learning disabilities’ has caused arguments among academics, students and disabled people. Sometimes, people believe that someone with a learning disability has only reading problems, which is not always a case. Learning disability also includes other types of academic and non academic learning difficulties such as problems with mathematics, writing and spelling, perceptual problems, language (auditory and visual) and visuomotor problems (Wong, 1996). According to the Foundation for People with Learning Disabilities<sup>3</sup> (2007) someone who has a learning disability does not acquire information as quickly as other people and may need more help and support to learn. It has to be clear that as a consequence of the de-medicalisation of disability, carried out by the disability movement, learning disabilities are now not considered an illness. It may be a permanent condition, but with the right kind of help, many people can acquire practical and social skills even if this may take them longer than usual (Foundation for People with Learning Disabilities, 2007, online).

Many professionals and service providers prefer the term ‘learning disabilities’ instead of ‘learning difficulties’. On the other hand, some self-advocated organisations in the UK, like People First, prefer to describe themselves as people who have difficulties and not disabilities. Research conducted by Simons (1992) indicated that people with learning difficulties preferred that term (learning difficulties), in order to describe themselves because “*it seemed to be the positive ‘learning’ possibilities implied by the term that make it attractive.*” (Simons, 1992 in Harris, 1995, p: 344) The term ‘learning difficulties’ can be used to cover different conditions which in many ways can affect someone’s learning abilities. Therefore, it is a broader category under which someone can find conditions like dyslexia, which is the most commonly known learning disability, dyspraxia, dyscalculia, dysgraphia as well as ADHD, Asperger’s syndrome etc.

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<sup>3</sup> The Foundation for People with Learning Disabilities is part of the Mental Health Foundation, a national charity, and operates as a directorate within the charity (Foundation for People with Learning Difficulties, 2007).

On the other hand, the White Paper by the Department of Health (2001) "*Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*" clarifies that

*"Learning disability includes the presence of: a significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development"* (Department of Health, 2001, p: 14)

This definition encompasses people with a broad range of disabilities, however "*'learning disability' does not include all those who have a 'learning difficulty' which is more broadly defined in education legislation*" (Department of Health, 2001, p: 15). Therefore, the White Paper (Department of Health, 2001) defines learning disabilities as something different from learning difficulties and makes clear that it concentrates on people with learning disabilities.

Research by Riddell et al., (1994) examines the different conflicts between parents and educational authorities over the use of terms like 'learning difficulties' or 'specific learning difficulties'. The research showed that authorities see children with specific learning difficulties "*...as part of a continuum of all those with learning difficulties...*" (Riddell, et al., 1994, p: 134). On the other hand, as the research showed, the majority of parents want their children to be separated from the general group of children with learning difficulties and to form a discrete group of children, which is different from the general group. Parents as well as education authorities both aimed to improve the quality of educational experience of children and to remove the stigma that is associated with their difficulties. However, the majority of parents aimed to have individualised treatment and provision for their children and by dissociating their children with specific learning difficulties from those children with more global learning difficulties, they tried to avoid the stigma that this label is attached to. On the other hand, education authorities aimed to give support to all children with learning difficulties and to eliminate stigma that it is attached to all with learning difficulties. (Riddell, et al., 1994)

Overall it is difficult to provide a definite answer to the question whether we have students with learning difficulties, learning disabilities or specific learning difficulties, as different groups (students, parents, HE Institutions, organisations etc) identify and define differently each 'category'. The same and even bigger ambiguity exists about dyslexia, its methods of identification, treatments and adjustments within education. Sometimes, the term 'dyslexia' is used to cover all learning difficulties/disabilities, either because the majority of students within Higher Education Institutions who claim learning disabilities they are diagnosed with dyslexia or because it is a term that has some 'advantages' (Riddell and Weedon, 2006). Among the 'advantages' of having dyslexia is the access to the Disabled Students Allowance (DSA) which gives students additional funds to pay for the non-medical assistance and any equipments that they need for their studies. At the same time, dyslexic students are covered under the Disability Discrimination Act (DDA) (2005) and are entitled to reasonable adjustments that institutions have to make to accommodate their needs regarding their difficulties. In addition, the more students with dyslexia they get to Higher Education Institutions the more funds the institutions will get in order to assist these students with their additional needs. Therefore, the institutions benefits from attracting dyslexic students who claim DSA (Riddell and Weedon, 2006).

The research project looks into students with learning difficulties, which in this case is a 'category' that includes students with dyslexia, dysgraphia, dyscalculia, dyspraxia and other difficulties which affect students studies. The participant institutions use a different way to 'classify' (for purposes of provisions and adjustments) the disabled students, for example one institution talks about specific learning difficulties, other include everyone under the term dyslexia etc. I will use the term learning difficulties for my research however, I will keep the original terms that each participant (either student or member of staff) chose to use. In addition, the original terms will be used as they appear in quotes from the literature or other sources.

The statistics might show that there are students with learning difficulties who enter Higher Education Institutions, but access to Higher Education does not solve the issues of discrimination and exclusion of disabled students from education. The

solution in order to include students with learning difficulties to education is not simply to allow them access to institutions. Rather the required change is to provide services and help for these students and to make sure that they have the same opportunities as other students without learning difficulties.

In order to achieve equality, the law makes sure that each Higher Education institution provides support and help to students with disabilities, while attempts have been made towards an “*inclusive education*”. Inclusive education means

*“The transformation of a society and its formal institutional arrangements, such as education. This means change in the values, priorities and policies that support and perpetuate practices of exclusion and discrimination.”*(Barton, 1999, p: 58)

Inclusive education was seen as a means to remove barriers, improve outcomes and remove discrimination (Barton, 1999; Lindsay, 2003; Hornby, 1999; Ainscow, 2005; Knight, 1999), while it accepts that the differences that each person has are part of his/her individuality and these differences are normal and acceptable. The aim is to adjust the learning and education to these differences and to find ways to adapt the education to students’ needs and not the other way around. It should not be a case of students who have to adjust and fit to the educational system, and the ‘normal learning processes and standards’ that schools provide (Ainscow, 2005). The universities also have to make any reasonable adjustments in order to accommodate these students and their needs. The success of achieving an inclusive education requires challenging the definitions of learning and teaching and re-thinking the techniques that are used today.

However, there is the problem of the competitive nature of Higher Education Institutions. The changes in the Higher Education sector, after the 1970’s turn to new ways of managing the public sector, including education, led to the discourse of “*new managerialism*” (Deem, Hillyard and Reed, 2007). The new plan of managing academics and academic work, based on the idea of marketisation, resulted in a shift of the focus of Higher Education Institutions away from the purpose of ‘teaching and

learning', towards factors, which do not include disabled students (Deem, Hillyard and Reed, 2007). Based on the idea of marketisation, the performance and the quality of teaching and research levels were frequently 'tested' (Deem, Hillyard and Reed, 2007). The Higher Education Institutions have started competing against each other for more students, among which were students with learning difficulties. However, the concern about students with disabilities in Higher Education does not end with allowing them access to Higher Education. The important issue is to provide and support them throughout their studies in Higher Education. At this point, the need to challenge the teaching and learning procedures, as we knew them until then, becomes apparent.

Later in the dissertation, it will be explained that there is a change in the role that the Disability Support staff plays regarding disability and students with learning difficulties, within Higher Education Institutions. As the Directors will say, the help and support they offered to disabled students used to be "*out of the goodness of their heart*" (Director of DSU c, [Pre-1992]). Whereas, now, after the new law about disability in Higher Education, everything they do is part of the "*mainstream system*" (Director of DSU c, [Pre-1992]). This changing character of Higher Education Institutions regarding policy and provision for students with learning difficulties is explored in this project through the experiences of students and with the help of the official perspective of the institutions. The institutionalisation of disability and that of disabled students, on one hand, increased the number of disabled students who entered Higher Education Institutions. On the other hand, the large number of disabled students in Higher Education increased the time that it is necessary to spend in order to deal with these students, which in turn resulted in losing the 'individual' within the whole. In order to deal with the increased number of students with learning difficulties who have entered Higher Education in a relatively short time, it is easy to ignore the individual needs of students, and to adopt a more general policy which will cover more students. The standardisation of the services, due to bureaucratisation, in a way can be seen as a step towards an inclusive education, where the provision will be in place for everyone who needs it, instead of making students with learning difficulties the special cases who need special measures.

Each university has a different system of ‘categorising’ the students based on the difficulties or disabilities they have. As far as learning difficulties are concerned, three out of the four universities that participated in this research use the term learning difficulties or SpLDs (Specific Learning Difficulties) to include conditions such as dyslexia, dyspraxia, dyscalculia, ADD, ADHD and Asperger’s syndrome. As one of the Directors of DSUs explained, things have changed over time regarding learning difficulties, and while a few years ago under this category there were only students with dyslexia, now students with other conditions are also included (Director of DSU b, [Post-1992]).

One of the universities uses the term dyslexia to cover all kinds of learning difficulties without separating them “...we just classed it as ‘dyslexia’ we don’t break it down really...” (Director of DSU d [Pre-1992]) However, they still offer help for conditions such as dyspraxia, dyscalculia and Asperger’s syndrome and believe that they are learning difficulties; they just do not break down the category when they count the students who are registered. Therefore, whether the categories are broken down or they have been put under one name does not make any difference in these universities as they all accept that the category of learning difficulties includes more than just dyslexia. Sometimes there is the argument that Asperger’s Syndrome is not a learning difficulty but rather that it should be categorised under the “*autism spectrum*” (Director of DSU b, [Post-1992]) category.

Therefore, three institutions break down the learning difficulties into dyslexia, dysgraphia, dyscalculia, dyspraxia etc, whereas one of the old universities uses the category of dyslexia, which includes all students with specific learning difficulties. All of the Directors explained that they only use the categories for purposes of providing support, but they “*don’t tend to put them into boxes*” (Director of DSU b, [Post-1992]). The important thing is that they all offer some sort of support and provision for these students. As will be explained later, the new law makes it clear that there should be some provision for students with learning disabilities.

Apart from the different categories that each university uses to divide students with learning difficulties, they also use different ways of managing the information about students with learning difficulties. Later the differences on managing information, as well as the issue of confidentiality and the ways to separate students with learning

difficulties from other students, without discriminating against them, are all going to be presented and explored in the thesis.

## 1.1 Aims

Changes in Higher Education regarding widening participation for disabled students, combined with the changes in law and anti-discrimination legislation, led to the transformation of support and provision provided for disabled students within Higher Education Institutions. However, little is understood of how the changes are experienced and managed. Therefore, it is necessary to explore the relationship between students with learning difficulties and the support they receive from the Higher Education Institutions. The changes to the provision of disabled students, through the new disability legislation, the effectiveness of the adjustments that institutions have to make to accommodate the students' needs and the issues that have arisen from these new conditions within Higher Education institutions are some of the main research questions that they are going to be explored in this project. Those issues will be seen through the experiences of students from four Higher Education Institutions in the North East region of England, mainly from Durham University. In addition the issues will be explored through the perspective of institutions, via the views of Directors of DSUs from these institutions; and finally, through members of staff from Durham University. The focus will be Durham University; however, the data from the other universities will help to create a better understanding around issues of provision for disabled students.

The study, as far as the student experiences are concerned, focuses on their awareness of the problem, the history of diagnosis of their condition, and the impact that this diagnosis has upon students' engagement with Higher Education. Issues like how the condition affects the individual's sense of identity, stigmatisation and discrimination against students with learning difficulties are explored from in depth interviews with students. Finally, the students' experiences of the support and provision they receive, its effectiveness and their relationship with the institutional support units, are of particular interest of this project. Since it is not only important to allow access to students with disabilities to Higher Education Institutions, but also to provide the support they need in order to study, it is interesting to see how satisfied these students are with their experiences and their interactions with

members of staff and especially the support they receive. Hence, their point of view about provision is of great importance for this project.

In addition, it is interesting to see whether there are differences or similarities between the institutions, due to the turn to marketisation of Higher Education. The marketisation of the Higher Education system, may have increased the number of the students, who enter Higher Education, among which are students with learning difficulties or disabilities. However, it created a tension between the need for widening participation and the quality of services that the institutions provide for students, and more specific, for disabled students. On one hand, there is the marketisation of education, which demands greater number of students to enter Higher Education, while, on the other hand, there is the lack of personalised teaching and learning and lack of personalised services and adjustments, which will meet the requirements of students with learning difficulties. Therefore, it is important to see how the marketisation of education has affected the institutions regarding the services they offer for students with learning difficulties.

From the institutional point of view, in relation to provision for students with learning difficulties, the project explores the role that the Disability Support Units play today and their relation to the students. The changes that the new law has brought to the support that is available nowadays to students with learning difficulties are looked at, through interviews with the Directors of the DSUs as well as some members of staff from one particular institution. In addition, the study explores the reasonable adjustments that the universities have to make in order to accommodate the students with learning difficulties who have been accepted to study. Finally, the formal or informal provision, perception of process, problems and in general, interactions with students with learning difficulties, together with the different ways of managing information about students with learning difficulties, in each university, are seen from the institutions' point of view. The views of the Directors together with the views of members of staff will help to provide a more complete picture regarding support and provision for disabled students in Higher Education, as they represent the official policy of the institutions and will explain the views on disability and Higher Education from their perspective.

It is understandable that there are limitations and boundaries that affect the types of support and the amount of help that institutions can provide for students with disabilities. This project's aim is not to identify and hold accountable the institutions, which do not provide the best support and provision for disabled students. Rather its aim is to give the chance to students and members of staff to express their experiences and points of view on the same issues – provision for students with learning difficulties.

The findings of this project will shed some light on the notion of support and provision in Higher Education. They will give the chance to both the four participant institutions and others more widely, if they wish to use it as a reference, in order to see the views, level of satisfaction and criticism of the students with learning difficulties who studied in their institution. It is possible that some issues, which have arisen from this research, will help to make some changes to the policy that the institutions follow, which will result in better support and provision for the future students with learning difficulties who will study in these institutions.

## 1.2 Numbers

Even though there is a definite increase in the number of students with disabilities in Higher Education, students with disabilities still constitute a minority group within the student population of any Higher Education Institution.

One of the issues regarding the number of disabled students in Higher Education is the fact that monitoring for disability is a relatively recent phenomenon in Higher Education. Significant problems remain, as students do not necessarily declare a disability to the institution. Nevertheless, new laws and legislation offer some reassurance, as to some extent they protect students with disabilities against discrimination caused by their disability. A possible effect of that will be an increase in the number of recorded students with disabilities, which may put some pressure on Higher Education Institutions to improve their services for students with disabilities, if they want more students to enrol. On the other hand, some Higher Education Institutions may see this as an opportunity to expand their ‘market’, in order to include students with disabilities as possible customers for their businesses, since competition is part of the educational institutions (Halsey, Lauder et al., 1997; Deem, Hillyard, et al., 2007).

The numbers of registered students with learning difficulties in each participant Higher Education Institution were collected compared to the total population. Based on the four universities’ official statistics, the following was found.

**Table 2**

<b>Academic Year 2005/2006</b>	<b>University of Durham</b>	<b>University of Newcastle</b>	<b>University of Northumbria</b>	<b>University of Sunderland</b>
<b>Registered students</b>	15314	17784	23355	18384
<b>Students with LDs</b>	600	618	600	300
<b>Percentage of disabled students</b>	3.91%	3.47%	2.57%	1.63%

Table 2 shows the total number of registered students for all four universities, compared to the students who have declared learning difficulties for the academic year 2005-2006. In Table 2 if we add the rest of the registered students with other disabilities to the number of the students with learning difficulties, then the total number of disabled students can reach 1000 or 1500 students.

Based on the official statistics of each university, it is obvious that quite a large percentage of all registered students are also registered with the Disability Support Units. The largest percentage is at the University of Durham, where almost 4% of all students have declared a learning difficulty, as Table 2 shows. The number might rise if we add all students with disabilities and include the students with disabilities who were not registered with the Disability Support Units. For example, based on Durham's University statistics for 2005-2006, among the 15314 total students population there were 1072 students (both undergraduates, postgraduates, full and part timers) who declared a disability, which means that 7% of the total student body declared a disability. The same figure for University of Sunderland, for the same year is 5.3%.

The table shows that while Northumbria University has 9000 students, more than Durham University, the percentage of students with learning difficulties is only around 2.5%, which is almost half of that at Durham. Newcastle University and Sunderland University both have around the same number of students in total but the University of Sunderland has half the number of students with learning difficulties.

The national percentage of *first year UK students* with disabilities in Higher Education in the UK, based on the HESA<sup>4</sup> figures for the year 2005/2006, is 6.12% approximately of the total students' population, while the percentage of those students with disabilities who declared dyslexia is 2.64%. The numbers that are given in Table 2 for all institutions are for *all students* (both UK and overseas domiciled and for all levels of study). However, still the percentage of the students

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<sup>4</sup> The total number of *first year UK domiciled HE students* for the academic year 2005-2006 is 895675. Of them 54830 have declared disabilities and 23655 of disabled students have been 'categorised' by HESA as having dyslexia.

with learning difficulties in Durham University is relatively high, compared to the given national statistics.

The differences in those numbers could have many possible explanations, among which might be the different percentage of students who decided to disclose their learning difficulties to their university or the policy that each university has about accepting students with disabilities. More specifically, based on the statistics from Durham University, the majority of the students who study at the University come from a middle class background (see also Table 5). This gives them the ‘advantage’ of having higher expectations about the support they should get from the institution. At the same time, it is more likely that they are aware, either due to their educational background or due to their families that if they declare the disability they will have access to some sort of support from the institution, which will help them to deal with the high expectations and standards that Durham University has.

**Table 3**

<b>Key statistics for the institutions for the Academic Year 2005-2006</b>				
	University a [Post-1992]	University b [Post-1992]	University c [Pre-1992]	University d [pre-1992]
<b>Number of Disability support staff</b>	5 (full time)	8 (full time)	7 (full and part time and several who are not permanent)	9 (full and part time)
<b>Accepted Home Students</b>	46% Males 54% Females	45.5% Males 54.5% Females	48.6% Males 51.4% Females	50.5% Males 49.5% Females
<b>Group Age Accepted</b>	46.9% (18yrs) 21.5% (19yrs) 8.7% (20yrs)	47.9% (18yrs) 21.4% (19yrs) 7.6% (20yrs)	83.2% (18yrs) 18.2% (19yrs) 3.9 % (20yrs)	60.8% (18yrs) 21.9% (19yrs) 4.9% (20yrs)

Table 3 gives some key figures for all institutions based on available data from UCAS, Universities' statistics and HESA.

Table 3 summarises the key statistics for all four institutions regarding the percentage of males and females participants, and it is obvious that all institutions except of University d [Pre-1992] have a higher percentage of female participants compared to male participants. In addition, it is shown that the two Pre-1992 institutions both have the highest percentage of students in the age group of 18years old, compared to the two Post-1992 institutions where the percentage of 18years old students is almost half of that. The four institutions seem to have the same small differences to the number of disability support staff however; the two institutions did not give the number of disability support staff that included the part time members.

Tables 4 & 5 below are for Durham University only. Table 4 gives a detailed number and percentage of students who declared disabilities in general and dyslexia (label that the university uses for its statistics) in particular, for the academic year 2005-2006. As it is shown, almost 6% of all full time undergraduates have declared a disability and more than half of them declared dyslexia as their form of disability. For postgraduates, the percentage of those who study full time, and have declared a disability, is about 4%. However, if we compare the part time undergraduates to part time postgraduates who declared disabilities we will see that more postgraduates have declared a disability during that academic year.

**Table 4**

<b>Student numbers from Durham University (2005-2006)<sup>5</sup></b>						
		Total	Disability	%	Dyslexia	%
<b>Undergrads</b>	Full time	11426	660	5,78%	377	3,30%
	Part time	86	14	16,28%	3	3,49%
<b>Post grads</b>	Full time	1940	80	4,12%	34	1,75%
	Part time	1706	328	19,23%	18	1,06%

<sup>5</sup> Source: Durham University Statistics available online <http://www.dur.ac.uk/spa/statistics/>

**Table 5**

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**Durham University Statistics (2005-2006)<sup>6</sup>**

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<b>Student Population</b>	11660 UGs (76.2%) 3645 PGs (23.8%)
<b>Home Students Total</b>	13414 (87.7%)
<b>Overseas Students Total</b>	1900 (12.3%)
<b>Socio-economic Background</b>	35% (Non Monitored group) Higher Managerial and Professional Occupational 12% (Non Monitored group) Intermediate Occupations 30% (Non Monitored group) Lower Managerial and Professional Occupational
<b>Students' educational background</b>	35% Independent Schools 32% Comp/Secondary Schools
<b>Students' Entrance qualifications</b>	3867 total new UGs of whom 3350 A Levels (86.6%)
<b>Departmental Staff</b>	1619
<b>Declared Disability</b>	12

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Table 5 above gives key statistics regarding the students and members of staff at Durham University. It is clear that the majority of students are undergraduates and that almost 90% of the total population are classed as Home students. The available data shows that 65% of the students come from Managerial and Professional

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<sup>6</sup> Source: Durham University Statistics available online <http://www.dur.ac.uk/spa/statistics/> and HESA

Occupational background, in addition to 12 % which comes from Intermediate Occupations. 67% of students have previously attended Independent and Comprehensive/Secondary Schools, before they entered university. More specifically, 86.6% of all new undergraduates have A Levels prior to their studies at Durham University. The above statistics are a clear indication of the high standards that Durham University has and the qualifications that the majority of the students who study at Durham University have. Regarding departmental members of staff, Durham University employs 1619 members of staff of whom 12 have declared a disability.

### 1.3 Methods

Semi-structured interviews were used for the data collection. These were combined with the secondary documentary materials (such as journal articles, papers, websites, documents provided by the institutions etc), and helped to draw a more complete picture of the issues of interest. In the end, the sample consisted of 18 students with learning difficulties who studied in the four Higher Education Institutions, 4 interviews with the Directors of the DSUs from these universities and 7 interviews with lecturers and college officers from Durham University only. Interviews with the four Directors of the Disability Support Units, made it possible to see the issues around provision for disabled students, from the perspective of the institutions in general. At the same time, the interviews with members of staff from Durham University, which was the focus of the research, added to the picture of provision for disabled students within Durham University. All interviews with students and members of staff were tape-recorded. The tapes were transcribed verbatim. Ethical issues, such as anonymity and confidentiality, and the validity and the reliability of the research project were all considered carefully during the data collection and analysis of the findings.

As with most of research, there were some limitations and obstacles which had to be considered. Some of them were considered before conducting the research project, while others emerged during the research. In each case, these problems are highlighted in the thesis and explanations, or reasons for dealing with them in the way that was considered appropriate, have been presented throughout the project and especially in the appropriate section in the methodology chapter. Briefly, I will mention that there were problems with ‘accessing’ the students in the first place, and gaining access through the Directors of the Disability Support Units, who are considered the ‘gatekeepers’ for students with learning difficulties or disabilities in general.

## 1.4 Outline

*Chapter 2* explores the social construction of disability and the stigma that is attached to disability and disabled people. The discussion of the two models of disability -the medical and the social model, based on the work of Oliver (1996[a, b]) creates a framework within which more emphasis is given to the analysis of the social model. The emphasis to the social model is because this research is positing itself to see the issues of disability as socially constructed. The social construction of learning difficulties, together with the controversial arguments in favour of and against this idea are discussed in this chapter, given emphasis on the role that the ‘experts’ have played in the creation of the category of learning difficulties. It is argued here that the ‘experts’ who could be the educational psychologists and those who create the tests and assessments, play a key role in the creating of the categories under which a student is disabled or not, with or without learning difficulties. The creation of the categories in which students seem to ‘fit’ in after their diagnosis has a controversial role, as the diagnosis could be seen as both enabling and disabling factor, as it is analysed in this chapter. Goffman’s (1990 [1963]) ideas of stigma and the stigmatised are discussed in extent; while the implications of stigma for people with learning difficulties are also analysed. This chapter ends with the discussion of the implication of the diagnosis of learning difficulties, for parents, teachers and students, together with an analysis of the idea of the ‘*paradox of diagnosis*’, its meaning and its implications for students.

The following chapter (*Chapter3*) discusses the changes in Higher Education Institutions, especially for students with learning difficulties. The key legislation and policy changes are analysed here to show the changes in Higher Education regarding disabilities. Widening participation in Higher Education Institutions, to include more students from the groups which had not traditionally gone to universities (such as students with disabilities), and the idea of an inclusive education, are the focus for this chapter. The important issue in this section is that the changes that Higher Education Institutions make should not be with the mere purpose of allowing access

to disabled students. It is equally, if not more, important to provide for all those disabled students who have gained access to Higher Education. When universities compete with each other to enrol more and more students with disabilities, they should make sure that they offer more and more services and make reasonable adjustments in order for those students to have the same opportunities as other students in Higher Education. The idea of an inclusive education is analysed in this chapter, in order to understand how inclusive education is not about making normal the students with disabilities when they enter school or education. Rather we talk about changing the education in order to include disabled students as well (Barton, 1999).

The last section of this chapter discusses the reasonable adjustments that each university has to make in order to accommodate the needs and the requirements of students with disabilities. Among the issues that arise from this discussion about reasonable adjustments is the need for changes in attitudes within the Higher Education Institutions, as this seems to be the most difficult area that need to change. The arguments of some members of staff about how the reasonable adjustments might threaten the very core of the purpose of education and how the teaching and learning are the main areas that need to change in order to accommodate the needs of students with learning difficulties are discussed in this chapter.

*Chapter 4* details the methodology that was used for this research. A combination of methods was chosen for this study. As the main issues of this research are disability, stigma, labelling and provision for students with learning difficulties, it was considered appropriate to talk directly to students, in order to give them the chance to discuss their experiences and views on those issues. Therefore, the appropriate methods of collecting data and analysing them were chosen, in order to achieve this aim of the study. The ethical dilemmas of doing a research that involves students with learning difficulties, the problems and the difficulties in general that arose during the whole process of the study are discussed in this chapter.

*Chapters 5, 6, 7 & 8* consist of the findings of the data that were collected during this research. More specifically, the first two chapters (*Chapter 5 & 6*) are based on the interviews with the students with learning difficulties, while the last two chapters (7

& 8) explore the views of the Directors of Disability Support Units and that of the members of staff from Durham University.

*Chapter 5* explores the experiences of the students with learning difficulties, starting with their experiences from the diagnosis of their difficulties. The impact that such a diagnosis had on their lives, their choices in Higher Education regarding the institution or the course of study, and the disclosure or not of their difficulties to others are explored in this chapter. The issue of disclosure of the disability is the main concern of students as it was concluded and the level of severity of the students' learning difficulty plays a key role in their decision about the disclosure of their difficulties.

*Chapter 6* focuses on the experiences of students within Higher Education Institutions, as users of the disability support services. The level of awareness of the disability support available for them in each institution, and how this affects their evaluation of the services and the support they receive, is explored here. The majority of the students did not check the disability services prior to the start of their studies. The fact that they then found in place services for them it seems that satisfied them and explains that most of them are satisfied with the available support. Some good and bad experiences that students with learning difficulties have had, either before they entered Higher Education or now that they are students in a Higher Education institution, are explored, giving an indication of how attitudes have changed overtime regarding disabilities, especially after the new disability laws. Again, the severity of the students' difficulties determined the relations they had with members of staff and in general played a role to their satisfaction with the provided services and support.

*Chapter 7* shows the perspective of the institutions of Higher Education. It starts with the views of the Directors of the Disability Support Units who play a key role as gatekeepers for gaining access to both students with disabilities and for students who want to access services. At the same time, the controversy of their role as both employees of the institutions and on the other hand as representatives of students with disabilities is explored in this chapter. Their roles have changed over the years, due to the changes in Higher Education and the new Disability Law. The services they now offer are based on the mainstream system and they are the same for all

students with disabilities. This bureaucratisation of the services on one hand made the job of the Directors of DSUs easier and helped them to persuade, when necessary, the members of staff who were not so willing to help. On the other hand, as it will be discussed in this section and later with the other members of staff, it also created less personalised treatment and services for students.

In addition, the perspectives of lecturers and College Officers from Durham University are explored in this chapter and when necessary they are seen in parallel with the views of the Directors in order to draw a clearer picture of provision from the institutions' point of view. There are some differences between the views of the Directors and members of staff from Durham University, as to whether the lecturers have problems in adjusting their teaching and learning techniques for disabled students. The main concern for the majority of the members of staff is that some services are not useful and are not appropriate for all students with learning difficulties that DSUs ask them to provide those students with. In addition, the issue of how each department and each college defines something as reasonable and how prepared they are to facilitate those adjustments is among the issues that are discussed in this section. The general feeling of this chapter is that despite the undeniable changes in support and provision for disabled students in Higher Education Institutions, the attitudinal barriers are still the main concern for both Directors of DSUs and some members of staff. Especially when we talk about changes regarding learning difficulties, it is more difficult to challenge all those arguments about the teaching and learning than it is to change building to accommodate physical disabilities.

Finally, *Chapter 8* discusses the ways that are used by each institution for managing student information regarding their disabilities. The management of information plays a very important role in the relationships both between Directors-students and other members of staff-students and the difference between protection of students' identities and discrimination can be a very thin line. A way to keep both the students' identities and difficulties as discrete as possible, while at the same time they make sure that students receive the appropriate help and support, without discriminating against them, is a very difficult task. Both the Directors of Disability Support Units and in some cases other members of staff from Durham University who deal with

students with disabilities within the university, mentioned difficulties with handling information and identities of students with disabilities. Each institution uses different methods to handle those sensitive issues of disclosure, and to handle personal information, but the important issue is to see whether they manage to achieve their purpose and the effectiveness that these systems have in students' experiences with the university.

Chapter 9 concludes the thesis and summarises the whole project and the main findings that emerge from the research.

## Background

### 2 Social Construction of Disability and Stigma

#### 2.1 Introduction

Since disability has started to become part of people's consciousness and gained a place within the political agenda (Bowker and Star, 1999 in Albrecht, Seelman, et al., 2001), there has been a growing interest and research on the participation of disabled people in Higher Education and their experiences. (Riddell, Tinklin and Wilson, 2005; Borland and James, 1999; Hurst, 1999; Holloway, 2001) Especially after 1993, when the Further and Higher Educational Act (1992) came into force and encouraged more students with disabilities to enter Higher Education, disability related issues have been of great interest for many researchers. Among the issues which are related to disability and the participation of students with disabilities in Higher Education is the social construction of disabilities, together with the stigmatisation that is caused because of the attachment of the label '*disabilities*'. This chapter, will critically discuss these concepts and will explain how and why it is believed that disabilities are socially constructed and to what extent labelling and stigma affect students with learning difficulties.

The first section of the chapter explores the two models of disability –social and medical– based on the work of Oliver (1996[a]). Both models will be explored; however, more emphasis will be given to the social model as it is considered more relevant for this research. The social model has been one of the most significant intellectual and political developments of the last decades, and transformed the meaning of disability for many people. However, at the same time, it is argued by some that it does not pay the appropriate respect to 'learning difficulties', as it is more about physical and sensory impairments (Chappell, Goodley, et al., 2001; Goodley, 2001; Chappel, 1998). The arguments of both those in favour of and those against the inclusion of learning difficulties in the social model are then explored in

this section. Later in the chapter, the idea that learning disabilities are the creation of 'experts' is discussed because it provides a link, which clearly shows the social construction of disability and learning difficulties and the role that the 'experts' play in the creation of disabilities. The next section will discuss the concepts of stigma and labelling theory, as there is a relation between the use of labels (such as students with disabilities) and the experience of stigmatisation of the students who have had those labels attached. Goffman's (1990 [1963]) ideas of stigma and the stigmatised are discussed, and the implications of stigma for people with learning difficulties are analysed too. The positive and negative effects of the diagnosis of the disability for students, parents and other people are discussed in the third section of the literature review, while the last section looks at the *paradox of diagnosis* of a learning difficulty. This paradox refers to the power of the diagnosis to have two almost controversial roles. On one hand, it is the trigger which leads to label attachment and hence stigmatisation, while at the same time it gives that person the answer to the problems he/she had previously, and allows them access to the so-wanted help and support they need.

## 2.2 Models of Disability

More and more researchers are interested in the subject of disability and people with disabilities but even though people have started talking more about these issues it does not mean that they know what disability is and what their attitude towards disability and people with disabilities should be. First, even the use of the term disability seems to cause some problems as it is often misused instead of handicaps and impairments. Williams (1996) and Zola (1993) argue that there is not an easy way to explain what disability is and to use the term without the risk of misinterpretations. The ‘problem’ starts with the fact that

*“...the language and the categories we use influence both the definition of the problem (define ‘disability’) and the size of the problem as an epistemological phenomenon...” (Williams, 1996, p: 1194)*

For example, mention of the role that the social barriers can play in disability leads to the idea of the social model of disability, while the use of only medical terms in disability’s definition means the acceptance of the medical model. Both definitions can be accepted by some and rejected by others and can still cause arguments over whether or not there is a ‘correct’ term which will actually define disability.

Therefore, before we can even consider talking about disability we have to define what we mean by disability and the difference between disabilities, impairments and handicaps. According to the International Classification of Impairments, Disabilities and Handicaps (ICIDH), published by the World Health Organisation (WHO):

*“An impairment is any loss or abnormality of psychological, physiological or anatomical structure or function”*

While:

*“A disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being”.*

Finally:

*“A handicap is a disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual” (WHO, 1980)*

Within this framework of the definition that WHO gives to disability, which is often characterized as the *“medical model of disability”* or *“individual model of disability”* the problems related to disability are located within the individual. More specifically, according to this approach, a person’s functional limitations, hence impairments, are considered to be the primary cause of any disadvantages he or she experiences (Crow, 1996). This model defines people with disabilities as a group of people whose bodies do not work properly, who do not look or do not act like other people without impairments.

The Union of Physically Impaired Against Segregation (UPIAS) accepts the importance of impairments, but also puts emphasis on the society’s role, and it defines disability as

*“The disadvantage or restriction caused by a contemporary social organization, which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities” (UPIAS, 1974)*

Therefore, based on the UPIAS definition, disabled people are people with impairments who are disabled by barriers in society. This definition takes into account the role that society plays in disabled people's life and it is the UPIAS's distinction between impairment and disability which led Oliver (1996[a]) to write about the idea of the individual and social model of disability.

According to Oliver (1996[a]), there are two models which explain disability: the *individual* and the *social*. The individual model of disability locates the problem of disability in the impaired individual, and sees differences as the direct and inevitable consequences of impairment (Oliver, 1996[a, b]; Chappell, Goodley, et al., 2001). Oliver (1996) described it as "*personal tragedy theory*", which suggests, "*disability is some terrible chance event which occurs at random to unfortunate individuals*" (Oliver, 1996, p: 32)

On the other hand, the social model of disability, based again on Oliver (1996[a]), does not deny the fact that some illnesses can have disabling consequences for people and that they may need medical help. However, the focus of the social model is that society does not provide services and means to accommodate the needs of people with impairments. Therefore, it is a case of social barriers which cause problems to people with disabilities (Oliver, 1996[a, b]). By this, he meant that while seeking the causes of the problem of disability, the social model argues that it is not a case of individuals' limitations or dis-abilities, but rather society's incapacity to provide the appropriate services that people with impairments need. An example of what Oliver (1996[a]) means by the social model of disability is the lack of access to buildings and public transport for people with wheelchairs. According to the social model, the lack of mobility of those people is impairment, but the lack of access to essential facilities is a disability (Oliver, 1996[a]; Harris, 1995).

Its success was that it shifted the debates and responsibilities about disability from "*...biomedically dominated agendas to discourses about politics and citizenship*" (Hughes and Paterson, 1997, p: 325), from disabled people to society's failure to provide for those people. It was not disabled people's bodies that cause them the trouble they had, rather, it was the way that society was organized that caused those problems. At the same time, the social model also had political implications, as it gave rise to a new 'strategy', to remove the social barriers that cause disability.

Accepting the social model of disability means that it is necessary to create a society where there will be less social obstacles to cause problems to people with impairments (Shakespeare and Watson, 2002). The social model also focuses on the fact that the social environment, which is constructed by and in the interest of non-disabled people, defines so-called “*normal*” human activities (Oliver, 1996[a, b]; Chappell, Goodley, et al., 2001; Altman, 2001; Tregaskis, 2004; Abberley, 1998). The onus of responsibility for the difficulties that disabled people have is shifted from the individual with impairment to the restrictions imposed by the construction of the environment and the attitudes of institutions and organisations (Oliver, 1996[a, b])

However, the social model did not receive universal acceptance. It was criticised both by outsiders, primarily by medical professionals and medical sociologists, and from within (from disabled people) (Oliver, 1996 [a]). Those in the medical fields (doctors, medical sociologists etc) argued that the disadvantages that disabled people experience (functional limitations, psychological losses etc) are the result of their impairment. For medical professionals there is a strong connection between illness and disability (body and disability), which means that their job is to treat the body, hence to treat the disability (Oliver, 1996[a]).

On the other hand, even though many disabled people accepted the social model and it gave them the explanation they were seeking, in order to understand their lives (Shakespeare, 1992), it was also criticised by many, even by some of the disabled people who had accepted it in the first place. Those who criticised the social model of disability believed that it does not accept the problem of impairment and is not connected with their experiences of impairment. They said that there are impairments which can cause too much pain, and in these cases, medical interventions can relieve the pain (Shakespeare & Watson, 2002; Shakespeare, 1992; Oliver, 1996[a]).

In respect to this, theorists who support the social model argue that the social model has never suggested that impairment does not count. It is not the intention of the social model to deal with the personal experiences and limitations of the impairments, but rather to talk about the social barriers and obstacles which cause disability, because of the way that society is organised. Furthermore, one model

cannot fully account for human behaviour (Oliver, 1996[a]; Shakespeare & Watson, 2002).

Another criticism against the social model is that it seems to be more about physical and sensory impairments, and it does not pay appropriate respect to learning difficulties (Chappell, Goodley, et al., 2001; Goodley, 2001; Chappel, 1998; Campbell & Oliver, 1996) Even some people with disabilities do not accept the social aspect of learning difficulties. As Simone Aspis writes, “*people with learning difficulties face discrimination in the disability movement*” (Campbell & Oliver, 1996, p: 97). She continues and explains that the lack of acceptance of people with learning difficulties by the rest of disabled people might have been the result of the labels that are attached to people with learning difficulties, such as “*stupid, thick, mental and mad*” (Campbell & Oliver, 1996, p: 97). The disabled people may fear that accepting those with learning difficulties and applying the social model to them will mean that they are the same as people with learning difficulties; hence, they are too the labels that are attached to these people. Therefore, disabled people use only the medical model when they talk about people with learning difficulties, in order to separate themselves from these people (Campbell & Oliver, 1996).

At the same time there are some disabled people who believe that

*“the problems of people with learning difficulties are inherent to their impairments, rather than resulting from issues of access and social barriers”* (Chappell, Goodley, et al., 2001, p: 46).

The problem with learning difficulties seems to be that many people believe that they are “*unchangeable organic impairments*” (Goodley, 2001, p: 211), biological or psychological deficits and, as such, they have nothing to do with social barriers and issues of access. Therefore, they see people with learning difficulties as personal tragedies to whom only the medical model applies.

A further problem with learning difficulties seems to be the false assumption that impairment refers only to the body’s imperfections, when “... *there is nothing*

*intrinsic to the word 'impairment' which suggest physical rather than intellectual imperfection"* (Chappell, 1998, p: 214). However, sometimes in the literature about disability the term "*able-bodied*" is often misused as the opposite of disabled, which is misleading, as disabled does not refer to physical impairments only (Chappell, 1998). Sometimes, even some people with learning difficulties distance themselves from the disabled identity, because they do not have physical impairments (Chappell, Goodley, et al., 2001). They argue that disability is so much connected with wheelchair users and physical impairments, and there is nothing in common with them. This is the reason they prefer the term learning difficulties instead of learning disabilities (Simons, 1992 in Harris, 1995).

Disabled people are those who have been socially excluded and discriminated against because of the impairments and the difficulties they have. Hence, the category of disabled people should include a wider range of definitions and explanations to include individuals who do not necessarily have observable physical impairments, such as learning difficulties, emotional and behavioural difficulties, etc (Barton, 1998 [a]).

Therefore, since impairment is not only about the body then "*... a turn to impairment as a social and political phenomenon necessitates on [sic] inclusion of 'learning difficulties'*" (Goodley, 2001, p: 211). Writers like Barton (1997; 1998 [a, b]; 2002); Chappell, Goodley, et al., (2001); Chappel (1998); Goodley (2001) and Dudley-Marling (2004) proposed that the social model should include learning difficulties. They argue that it is necessary to understand that learning difficulties are a fundamental social, cultural, political, historical and relational phenomenon, rather than an individual's problem. The review of the literature, which will be presented next, shows that learning difficulties can be socially constructed, like other disabilities.

### 2.3 Social Construction of learning difficulties

As was discussed in the previous section, some argue that learning difficulties are not socially constructed and that the individual model should be used when we talk about people with learning difficulties. Here the literature will be used to support this argument and explain why learning difficulties can be socially constructed and that the social model of disability should be used to deal with issues about learning difficulties.

Disabled people claim that they experience social oppression, which is the result of the way that society is organised and treats them. Oppression is a structural concept and is the result of the uneven distribution of both materials resources and opportunities for participation in everyday life activities. Disability, as a form of social oppression and social construction, originated from the discrimination against people because of the impairments they have, but without this being the only form of oppression (Barnes and Mercer, 2003).

In general, the social construction of disability means that social barriers play a major role in the difficulties that people with learning difficulties face in their everyday life. Different complex social interactions, changes and ways of social organisation can lead to disability. For example, learning disabilities became a significant problem only after education's expansion. Before that moment, people who were not educated were not considered a problem, because the way that the society was organised did not require educated people (Shakespeare and Watson, 2002). No one argues that the shift to a more educated society was not an important transformation, or that it happened with the mere purpose of constructing learning difficulties. However, the change in the social structure or way of organisation created a new category of people who are now considered disabled, because they lack the characteristics that society requires everyone to possess now.

Of course, it is not wise to argue that social barriers are the only problems for people with disabilities, because this will mean that the medical model is denied and as has been explained above, only one model cannot explain the experiences of people with disabilities.

Among those writers who propose the idea of the social construction of learning difficulties is Dudley-Marling (2004), who argued that the construction of learning disabilities depends on the complex interaction of people, places, and activities. As he pointed out: “...no student can have LD on his or her own. It takes a complex system of interactions performed in just the right way, at the right time...” (Dudley-Marling, 2004, p: 489) He explains that schools and universities are social institutions created by humans and are designed to fulfil specific social and cultural needs of groups of people. Within these social institutions, some students are identified as having learning difficulties. This distinction, between students with and without learning difficulties, could be seen as the result of the tests and the assessments that are used from schools to test students’ knowledge. These tests have been part of the UK educational system since the 1960s, and arguably have been created by individuals and are based on the social system of the time. These tests assess the students’ performance, while, at the same time, they assess and evaluate the performance of schools and universities. Based on these tests some students will be labelled as below or above average and some will be labelled as having learning difficulties. At the same time, the Performance Indicators, which are going to be discussed later, are tests which assess the institution’s ‘score’ in different aspects, among which is the learning and teaching outcome. All of these tests are created based on the social needs of the time and have to fulfil them. The problem with these tests is that they are standardised and they are the same for every student, regardless of their individual abilities, difficulties or needs. This standardisation of the tests and the system of “*the bell-shaped curve*” (Brueggemann, White, et al., 2001, p: 372) distribution of the results, does not pay the appropriate attention to the individual needs and difficulties of the students.

Considering that schools and universities which issue those tests are socially constructed based on some standards (Dudley-Marling, 2004), it is arguable that those same institutions and groups of people (psychologists, teachers etc), who created the tests in the first place, construct the categories within which they fit the students. As a result, the categories of students with higher, lower, or average intelligence, and the category of these students with learning disabilities, are based on those socially constructed tests. There is the possibility that once those tests are

changed then the categories will change too, and then others will be created or those will be restructured to include or to exclude more students.

*“It is always easy to forget that tests are made, and that they are often made (constructed, manipulated, revised) to produce the ‘normal’ distribution of the bell-shaped curve”* (Brueggemann, White et al., 2001, p: 372)

In order to assess students’ performance and to analyse the tests’ results, sometimes in education the bell-shaped curve is the system that is used. It is assumed that a “*bell-shaped curve*” (Brueggemann, White et al., 2001) which is symmetrical and is a normal distribution, has to represent students’ performance. Within this “*bell-shaped curve*”, students’ performance is compared based on the performance or results of other classmates or other students who took the same test. The highest score is the peak of the curve and anything within the normal distribution area is normal. Any students outside this area of normal performance are considered abnormal and probably have some difficulties. Of course, the problem with the bell shaped curve system is that because someone always has to be the lowest score or the lowest point of the curve, even if that score is quite high, when evaluated against specific performance criteria or standards, it seems bad or not normal. It is apparent that the bell shaped curve system, by definition, creates the categories of normal and not so normal results for students, because it has two ends, the higher and the lower, and the results have to be distributed within those two ends. There is the possibility that the lowest end of the bell shaped curve system, if compared with other results from another bell shaped curve, which represents results from other tests or sets of students, can be found to be quite high or to be the highest score. Therefore, those tests and the results which are represented with the bell shaped curve system cannot be considered as the absolute indication for categorising students as ‘genius’, with ‘learning difficulties’, ‘normal’ or ‘not normal’.

Nevertheless, a series of test and processes like these, which have been specially constructed to evaluate the students’ performance, are used to determine who has

learning difficulties and who is above or below the standards. At the same time, these standards will determine the individual arrangements that the school or Higher Education Institutions will provide to students. The standardisation of the services and the arrangements for disabled students do not pay appropriate respect to the individual needs and difficulties that some students may have. The tests look at the numbers (scores and statistics) and in some cases do not take into consideration the fact that each student learns differently, without this meaning that they have disabilities. Those complex interactions, between schools-tests-students and teachers, label some of them as students with learning difficulties (Dudley-Marling, 2004).

It has become more common in recent years for students after school to go to university to gain higher qualification and degrees. This resulted in an increase in the number of students who have to 'compete' for a place in the university. In consequence, this means that students have to secure the best grades possible during their years at school and especially in GCSEs and A Levels, which are among the entry requirements for university. Both GCSEs and A Level tests have been constructed by the NAA (National Assessment Agency) in order to evaluate the different levels of achievement in learning, for students. The "*typification*" (Berger & Luckmann, 1991 [1966]) embodied in these tests means that they have to be the same for everyone who takes them. In addition, earlier in the school years, further tests and exams (which again have been constructed by either teachers or are based on the National Curriculum Tests), are used to measure or to assess the students' learning levels. Each test is based on the national curriculum and is considered appropriate for the level and the stage that the students are at at the time. According to the QCA (Qualifications and Curriculum Authority) the purpose of the tests is to cover what the child has learnt in the class, over the years, and to give an indication of the student's knowledge and understanding. The results, again based on QCA are going to be evaluated by teachers based on "*their professional judgement...*" (QCA, online, accessed 2008), in order to determine whether the child is at the appropriate level of learning, then the next steps of action are going to be planned.

If a student's results are above or below the standards, then his/her future will be planned accordingly. Even though the QCA claims that the tests results are just a "*snapshot*" of the student's performance, the effects that these results have on

students' plans are well known. The most talented students are encouraged to continue to higher or further education, while the less talented or those students who have been labelled as having 'learning difficulties' are told that they will "*never amount to anybody, that they are limited, stupid, hopeless – in a word, retarded*" (Brueggemann, White, et al., 2001, p: 374)

The use of tests and the assessment of the results by teachers or other professionals who are considered the experts to decide whether the students are normal or have learning difficulties, gives rise to the issue of expertise and the role that it plays in the creation of categories and in particular here the creation of learning difficulties. For this reason, we turn to the role of the experts (such as educational psychologists) in creating the categories of learning difficulties, in the next section.

### 2.3.1 'Expertise' and the creation of learning difficulties

An additional factor that possibly led to the social creation of the category of learning difficulties is the emergence of educational psychology as a form of 'expertise'. Psychology, as well as the rest of the "*psy disciplines*" (e.g. psychiatry, psychotherapy etc) (Rose, 1996) is considered the means that helps people to make sense of themselves and others.

*"...psy experts have achieved a certain privileged position over the past century – for it is psy that claims to understand the inner determinants of human conduct, and psy that thus asserts its ability to provide the appropriate underpinning, in knowledge, judgement, and technique, for the powers of experts of conduct wherever they are to be exercised"* (Rose, 1996, p: 13)

Psychology's 'expertise' refers to the ability of psychology to supply a group of trained and credentialed persons -the psychologists-, who claim that they have the power to manage the personal and interpersonal relations of others. They have the means to control people in social life (Rose, 1996; Danziger, 1990).

Psychologists use their 'expertise' of understanding people's identities and they create categories in order to fit those people, while they construct identities based on these categories. Ian Hacking (1986) described this as "*making up*" of people and explored how this idea affects the way that people understand what an individual is (Hacking, 1986). He argues that each category that is made up has its own history but if we want to explain the creation of categories, we have to think of two vectors.

*"One is the vector of labelling from above, from a community of experts who create a "reality" that some people make their own. Different from this is a vector of the autonomous behaviour of the person so labelled, which presses from below, creating a reality every expert must face"* (Hacking, 1986, p: 234)

Hackings' idea of "*making up*" people was based on Foucault's idea of constitutions of subjects and identity, in which he suggested that we are made into subjects from above (through schools, surveillance and control operating) but also we make ourselves into subjects from below (through the process of communication) (Shakespeare, 1996). A person is disabled because he/she belongs to the category of disability, which in turn was created by the experts in order to fit those people in the first place.

Martin (2004), like Rose (1996), argues that the professionals in "*psy disciplines*", believe that they possess a kind of knowledge of the person and that no one else possesses something similar. Their "*esoteric knowledge and technical capacities*" (Rose, 1996, p: 84) give them the power and the expertise to decide over other peoples' lives and create categories to fit those people (Martin, 2004; Rose, 1996).

This social creation of people and identities, based on the 'expertise' of the "*psy disciplines*", have passed to Education and the categories of students with learning difficulties and disabilities have been created.

Educational psychologists, based on their expertise, have created different categories, such as learning difficulties, intelligence, and genius etc, in order fit the students into these categories. This categorisation and labelling of the students led, at the end, to the acceptance of this label by the students, who have become students with learning difficulties, genius students etc, because they have been categorised as such. Shereen (2001) explained that in the UK, in the period of 1921-1944, the medical profession together with the psychologists' expertise had the unique responsibility for diagnosing the "*dull and feeble-minded children*", who were still referred to in institutions as patients and were subject to educational and other treatment (Shereen, 2001). Today, educational psychologists are considered the experts who have the ability and, at the same time, the right to identify those who have learning difficulties, and those who are within the normal distribution in education. In essence, who is well educated and receives the standard-normal education and who is not quite normal and has learning disabilities (Martin, 2004; Söder, 1989).

We must not forget, though, that the experts who create the categories of people create as many categories as there are people to fit in. The moment the experts

identify a person who does not fit into the already existing categories, whether these are called 'normal', 'disabled', 'heterosexual', 'homosexual' etc, they can create a new category that will be made to fit these people. Ian Hacking (1986) rightly explains: "*a kind of person came into being at the same time as the kind itself was being invented*" (Hacking, 1986, p: 228). Otherwise, it would be too convenient that people fit so nicely into the existing categories and that the characteristics they possess are exactly those that someone in that category should possess. It is not only cases of disabled people, who fit perfectly into their categories, which have been created for such purposes. Any person, at any given time, belongs to a category which has been created with the purpose of describing the situation and the characteristics of the people who belong to it. Therefore, as Hacking (1986) explains, "*Our selves are to some extent made up by our naming and what that entails*" (Hacking, 1986, p: 236) We become what the categories want us to be in order to fit into them. Having in mind that those categories are socially constructed it is easy to consider disability as a socially constructed problem and to treat it as such.

The medical and psychological 'expertise', as argued above, can create the category of disability, learning difficulties etc and interestingly, the psychologists who create these categories are also those who try to 'fix' the problem of disability using their 'expertise'. They have the 'expertise' to find the solutions and the best ways to normalise the same people that are stigmatised and labelled as disabled, because of the categories that they (psychologists) created.

Brisenden (1986), wanting to show the paradox of the experts' power to write and define disability, argued that sometimes experts' opinion is considered more important regarding disability, compared to the experiences of disabled people. The experts use their power of 'expertise' to persuade others that they have a better understanding of the difficulties and the problems that disabled people face every day, when no one understands disability better than the disabled themselves. Especially medical experts

*"...produce the myths of disability through books, articles, lectures and other forms of sooth-saying and oracle, whilst also having the good fortune to receive a salary for their efforts"* (Brisenden, 1986, p: 20)

Experts are not only the psychologists and the medical professionals. Those who create the tests and assess the results, in either schools or universities, (and based on those tests some students have learning difficulties and others not), can be considered the experts who have the knowledge to categorise people.

Discussing the social construction of disabilities and more specifically learning difficulties, Vlachou (1997) explains that the social construction of learning difficulties starts from within the educational institutions, where “*the use of disabling language, barriers to participation and dignity get legitimated...*” (Vlachou, 1997, in Barton, 1998[a], p: 61) The term special or special needs is an example of the disabled culture, which wants some students to have special needs and to need special provision. The use of terms like these generates and maintains a distance between disabled students and their non-disabled peers within the educational institutions (Barton, 1998[a]). Corbett (1996) argues that the ‘special’, when used for people with learning difficulties or people with disabilities, in general, shows their powerlessness, as traditionally these people have been pictured as not able to protect themselves, to take care of themselves, or cope with everyday life. Therefore, they lack the ‘power’ to deal with their life alone and they have special needs (Corbett, 1996). The disabling and deficit terms which are used every day not only within the educational institutions, are discriminating for students, because they lead to stigmatisation.

However, there is a paradox in the creation of categories, which has to be seen in relation to the paradox of the diagnosis, which will be discussed later in this chapter. The categories that are created by the experts can be seen as both enabling and disabling factors. On one hand, the moment a student ‘fits’ into a category, whether this is ‘dyslexia’, ‘dyspraxia’, ‘learning difficulties’ etc, he or she gains access to support and provision from school or university. The category together with the label that gives to the student, is the key that allows the student to receive any support he/she needs in order to study. On the other hand, these same categories can prevent the students from making some choices regarding Higher Education, or they can lead to discrimination and stigmatisation. As will be discussed next, there is a very strong connection between labelling and stigmatisation. The categories that the experts create and fit the students into can lead to stigma. This ‘paradox’ of the power of the

categories and the diagnosis of disability is going to be discussed analytically next. Before that, it is useful to explore the effects that the use of terms like ‘special schools’, ‘special needs’, ‘learning difficulties’ etc have for those to whom these labels have been attached. The use of labels like these is the main cause of stigmatisation, with significant consequences for their self-esteem and identity.

## 2.4 Stigma and labelling

Labels, such as ‘learning difficulties’, ‘disability’ etc except of being socially created and in some cases misused, can also create stigma to people who have been given these labels. From the moment we use those labels to describe or to refer to people with disabilities or to talk about disability in general, we have to consider the stigma that the labels carry to some extent. Some argue that even the use of terms such as ‘learning disabilities’ is stigmatising for people, as it is seen as something that this person has, a label that is very difficult to get rid of and it is going to be with that person for ever. Theorists such as Goffman (1990 [1963]) and Becker (1963) have pointed out in their work the effects of the categorisation and labelling processes on identity. Based on labelling theory, (from the work of Edwin Lemert [1967] and Howard Becker [1963]) and the study of deviance, a label is not just a simple diagnosis or observation about a person.

A label usually puts that person in a category, which is attached to social meanings. A label can define an individual as a particular kind of person and contains an evaluation of the person to whom it is given. As a result, in cases of diagnosing disabilities, the label of learning difficulties, or physical disabilities, or blindness etc is an action that puts the person in a ‘special category’, making him/her a ‘special person’ (Söder, 1989). In many cases, the ‘sign’ that causes the stigma or the label that leads to stigma is a “*status symbol*” (Goffman, 1990 [1963], p: 59) for this individual and overpowers all the other statuses that the individual has. In cases, where we are talking about students with learning difficulties, the label ‘learning difficulties’ is the first, if not the only characteristic, that others see in this person. The person can also be male or female, mother, daughter, father etc but those statuses are overridden by learning difficulties. Others usually see and respond to that individual in terms of the label, while they tend to assume that the person has the negative characteristics that are normally associated with that label (Söder, 1989). As it was explained before, in reference to the categories within which people ‘perfectly fit in’, people tend to believe that every person who ‘fits’ in that category ‘is’ or

'has' all those characteristics that the category describes and demands them to possess.

The result of the labelling process is very often that of stigmatisation for people who have had a label attached to them. Because people see themselves through the responses of others, soon, they will see themselves as the label that others have attached to them and will eventually behave based on the socially created expectations of others. Lemert (1967) called this "*secondary deviation*", which is different from the primary deviation, as the latter refers to the initial activity of deviance (Lemert, 1967). According to Lemert (1967) the notion of "*secondary deviation*" refers to the change in someone's behaviour due to the label and the characteristics that others have attached to them, with all the consequences that labelling and stigmatisation can have for someone's self-esteem.

Link & Phelan (2001) argued that the misguided impression that stigma is a mark that the stigmatised person has, instead of a term that other people attach to that person, points the finger to the stigmatised. Goffman (1990 [1963]) argues that if someone wants to understand stigma, they have to focus on relationships instead of attributes. An example that better illustrates what Goffman means by this is within the idea of deviance. According to the sociology of deviance, the focus should be shifted from the 'deviant action' to the social reaction that an action like that causes to people. Therefore, an action, behaviour, disability etc is not abnormal, unless people who see it react negatively, which in this case will create a stigma to the person who has disabilities, or is behaved differently from the 'normal' and expected way (Scambler, 1987; Goffman, 1990 [1963]; Kaufman & Johnson, 2004).

One of the problems of labelling is that the label comes to be viewed as an attribute of the individual concerned. Therefore, in cases of students who attend special schools, because they have special needs or learning difficulties, they will have the label of 'special education' with them forever. The identity of having learning disability is something that cannot go away (Beart, 2005). Even if they have learnt to cope with their difficulties, or have found new ways which helped them to overcome their primary learning difficulties, they will always be those who were educated in special schools, hence they have special needs and are disabled. From the moment we call those schools 'special', we give people with learning difficulties another

reason to be labelled and stigmatised. However, even those students who did not go to special schools and attended mainstream schools have their share of stigmatisation and bad memories. Most of the students who participated and were asked to describe their memories from the school years described experiences of shame, abuse and humiliation. Someone who cannot spell and read by the standard age when all normal children learn to spell and write is stupid and lazy and will never achieve anything good in his/her life (Brueggemann, White, et al., 2001; Dudley-Marling, 2004; Ho, 2004). However, as has already been explained, the standard age and the level of achievement that students must have at that age are things that are decided by the 'experts'. Therefore, those standards might change due to social changes and maybe in a few years those students who are now disabled because they do not read or write by a certain age will no longer be disabled, because the standard age may have changed.

The concept of stigma is not something that can easily be defined, as it has been used for many different things (such as stigma and disabilities, employment-unemployment, sexuality etc) and in many disciplines (sociology, psychology, political sciences, anthropology etc) resulting in different definitions in each case (Link and Phelan, 2001). Today there are those who argue that stigma is the attributes that people have while others argue that it is not the attributes that matter rather it is people's interactions with those who have the attributes that lead to stigma. Goffman's (1990 [1963]) theory of stigma points the claim that stigma originally was inflicted, as a mark, on individuals who had misbehaved, or had broken the rules and the values of a particular society. However, in modern societies when we talk about stigma, we do not refer to marks that some people may have that are visible to others. Stigma emerges through the interactions and the encounters in everyday life of people to whom labels have been attached and who have been stigmatised, by the non-stigmatised. During these interactions, individuals are discriminated against due to some attributes that they may possess or because something is known about them, which others may consider as dishonourable, and therefore 'use' it to stigmatise these people (Goffman, 1990 [1963]; Oliver, 1990).

There are three different types of stigma: the "*abominations of the body*", the "*blemishes of individual character*" and "*the tribal stigma*" (Goffman, 1990

[1963]). The first refers to any kind of physical ‘malformations’, ‘irregularities’, ‘distortions’, ‘abnormalities’ or any other term that we use to describe a ‘non-normal’ physical characteristic. The stigma of the character, which is the second type of stigma according to Goffman, is a category which includes everyone with characteristics which show weak will e.g. mentally ill people, homosexuals, criminals, the unemployed etc. Finally, the last type of stigma includes the stigma of nation, race, religion, sex etc that refers to the whole community and not one person alone (Goffman, 1990 [1963]). Each society has its own means and parameters to categorise persons and to identify the characteristics, which are ordinary and normal for the people who are within this society. The social encounters with someone who comes into that particular society are based on the “*virtual social identity*” of that new person, which consists of the characteristics that others give to that person. The characteristics are those which society has pre-determined as ordinary for members and ought to be or expected to be shared by members. Goffman (1990 [1963]) explains that each person also has an “*actual social identity*”, which includes the actual characteristics that someone possesses, regardless of what the particular society that they come across thinks that they should have.

Whenever there is a big gap between the virtual and actual social identity of a person, he/she is stigmatised for the characteristics that they have that should not have been there or that ought to be there and are not. As for the rest of the people, where the virtual and actual social identity has little or no discrepancy at all, these are the normal. This discrepancy between the virtual and the actual social identity can be visible and well known by others and in that case the stigmatised persons are referred to “*discredited persons*” as Goffman (1990 [1963]) explains. In cases where the differences are not known in advance or are not immediately visible by others, then we are talking about “*discreditable persons*”. In the first case the stigmatised individuals have to think about the ways to manage the tension between them and the normal, in each social interaction, while in the second case they have to find the best ways to disclose or hide their differences and the characteristics that make them stigmatised, depending on the case.

By accepting that societies construct the categories and the normal characteristics for people within that particular society, Goffman (1990 [1963]) argues that the stigma

is something that is created and is seen in social interactions or encounters. Of course, this does not mean that when the individual is in his/her own house or environment the disability, or the characteristics that caused the stigma, are not there. The social encounters give rise to the notion of stigma because it is then that the individual has to find ways to hide, disclose, or fake the difficulties in order to avoid, whenever possible, the consequences of the stigma that their condition carries (Oliver, 1990; Goffman, 1990 [1963]). Therefore, a student with learning difficulties can be at home or somewhere else where there is not any teaching and learning involved and this student will have no problem. Whereas in school or at the university, the same student will be stigmatised because he/she is the student with learning difficulties as there the problem is more apparent.

In some cases, there is the possibility that individuals do not know that they have a disability, i.e. they have not been diagnosed yet, but they experience some difficulties, which cause them embarrassment, and in order to 'hide' them they try to avoid social encounter with others.

Of course, sometimes the social encounters can have a different effect on the deviant, depending on the cultural background of the deviant, as there are attributes which for some cultures are not considered stigma, while in others they are.

*“For example, in Tibet, Burma, and Turkey crippled and maimed people are ostracised as ‘lesser human beings’, yet in other societies, for instance in Korea and Afghanistan, they are considered to possess ‘unusual’ culturally valued abilities and are assigned a special superior status”*  
(Scott, 1970 in Scambler, 1987, p: 136).

The attributes or characteristics which cause stigma are those which appear to have a social significance. For example, the colour of eyes does not appear to be a stigma, even though there are differences from person to person and from what is considered the 'normal' eye colour in each country. On the other hand, the colour of skin seems to be the main reason for stigmatisation. This shows that there is somehow a social selection of human differences when it comes to identifying differences that will

matter socially and will lead to stigma. Bearing in mind that the rest of the society makes the selection of the characteristics which count as abnormal and lead to stigmatisation, the notion of social construction of stigma is of relevance here (Green, Davis, et al., 2005).

According to Goffman (1990 [1963]), regardless of whether a person is discredited or discreditable, he/she possesses a characteristic which is unacceptable and non-anticipated, hence 'abnormal', for the rest, who are called the 'normal'. The non-stigmatised people in most cases feel the need to separate themselves from the stigmatised, by using expressions like 'us' and 'them', the 'normal' and the 'abnormal', in order to show that they do not 'possess' or do not share the stigma of the stigmatised people (Link & Phelan, 2001).

As Goffman (1990 [1963]) explained among the people who are not stigmatised but are sympathetic to the stigmatised are the "wise" persons, as he calls them. One type of wise people is those who are related to the stigmatised through a social structure – *"a relationship that leads the wider society to treat both individuals in some respect as one"* (Goffman, 1990 [1963], p: 43). In this category are the family members or friends of the stigmatised, who are 'forced' to share some of the stigma of the stigmatised persons. It does not matter that those people are not stigmatised themselves; the fact that they are related to the stigmatised person is enough for them to obtain some degree of the stigma. Generally, there is a tendency for the stigma 'to spread' from the stigmatised person to the people who are related to him/her; so in these cases, where the stigma is considered something like a disease, which the normal people can 'catch', the relationships with the stigmatised are avoided or terminated, if they exist (Goffman, 1990 [1963], p: 43). Except of the "wise" persons, based on Goffman (1990 [1963]), there is also another category of sympathetic others who are called "*the own*" ones because they share the same problem and through their own experiences they are aware of the difficulties that this person faces. Usually, they *"...share with him the feeling that he is human and 'essentially' normal in spite of appearance and in spite of his own self-doubts"* (Goffman, 1990 [1963], p: 31), while they offer him/her the reassurance that the stigma is normal, as others have it too. At the same time, it gives the stigmatised

person a sense that he/she belongs to a group of sympathetic others who understand him/her and that is somehow a step towards 'normalisation'.

For non-stigmatised people a stigmatised person is "*less human*", therefore, any kind of behaviour towards them is acceptable and the discrimination or the fact that the non-stigmatised try to rationalise their behaviour towards stigmatised people is totally acceptable for normal people. For the rest of the people, who do not share the stigma, the stigmatised persons are not 'worth' the same as themselves. Among highly educated people an uneducated person is less human, an unemployed person is an undesirable companion for the employed people, the working class student does not fit among the upper-class students because he/she is less important compared to them. They want to explain what is wrong with them, what their differences are and why they do not fit in their social structures, even to justify their ill feelings for these people. (Sennett and Cobb, 1972; Goffman, 1990 [1963]) Anyone could argue that any characteristic which is not like the one he/she possesses, is an indication of abnormality. If a person is considered normal, then anything different from that is abnormal. However, this attitude will lead to the extreme cases of racism, sexism and discrimination against others.

The non-stigmatised and normal people have structured categories of people with different types of disability who have specific characteristics and they apply these characteristics to each person who they think falls into this category. Sometimes extra characteristics and extra disabilities are added to each category in order to explain their right to discrimination. Stereotypical ideas about specific stigmatised people are used quite often by the non-stigmatised, just because they have the right to do so (Goffman, 1990 [1963]; Link & Phelan, 2001; Kaufman & Johnson, 2004).

Some non-disabled people's perception about people with disabilities is based on those false stereotypical beliefs which want people with disabilities to be unable to cope with everyday life, be totally dependent on others or society, even when their condition does not require any personal dependency. These stereotypical beliefs together with the disabilist language and terms that not-disabled people use for people with disabilities cause the stigma to the latter and it is discriminating towards disabled people (Barton, 1998 [a]; Corbett, 1996). There is the tendency to attach the same stereotypical ideas that some people have about characteristics that the

stigmatised have to stigmatised people. This results in the creation of fear and uneasiness around people with disabilities or in social situations where people with disabilities are involved (Watson 1998 in Shakespeare, 1998).

There is the tension of duality in non-disabled people's attitudes towards people with disabilities. There is the belief that disabled people are neither healthy nor ill in the eyes of others. Hence others do not know how to treat them in public encounters, which leads to awkwardness and confusion as on one hand the non-disabled think that they have to treat people with disabilities in a special way and particularly favourably because they believe that that is what they need or because they feel sorry for them because of their difficulties. On the other hand, the same people (non-disabled) feel uncomfortable and uneasy around people with disabilities because they do not know what the best way is to treat them and in these cases, they may try to avoid encounters with them (Susman, 1994; Green, Davis, et al., 2005). The lack of disability awareness and sensitivity in our societies are some of the reasons that have made non-disabled people unaware of the best way to behave around people with disabilities. Examples of people's reactions in social encounters with people with disabilities are given in the research of Green, Davis, et al., (2005):

*“Carol (a 68-year-old woman who also has lifelong disabilities as a result of physical impairments), for example, says that when she is among others unfamiliar with the disability experience, “no one really knows what to talk about.” Similarly, Judy (a young adult wheelchair user who also has a hearing impairment) says that in public encounters with others, there is “a hesitance to look me in the eye or to shake my hand because they don’t know how to shake hands with somebody on crutches or in a wheelchair” (Green, Davis, et al., 2005, p: 302).*

In each case, the non-disabled people felt awkward and did not know how to act around the stigmatised. It is interesting that sometimes it is suggested by professionals that disabled people or the stigmatised in general have to pretend and to present a self which is not their true self, but the one that others (non-stigmatised)

expect to see, in order for the non-stigmatised to feel less awkward in their encounters with the stigmatised people. In these cases, the stigmatised should educate other people about their disabilities, help them understand better, even try to pass as 'normal'. However, they should not be too normal (as this will be considered as a denial of the fact that they are different from the rest of the social group), or even accept others' help, even when they do not need it, just because they should not upset those who try to help. The irony in these suggestions by professionals is not that the stigmatised have to adjust their attitudes based on the social encounters and the group of people they are with, but that in many cases this is the only way if the stigmatised want to be accepted by non-stigmatised people (Goffman 1990 [1963]).

A result of the way that the non-stigmatised people treat stigmatised people leads the latter to adopt strategies in order to manage, not the difficulties that their disability has given them, but the stigma that other people attached to them. Goffman (1990 [1963]), while discussing the different ways that the stigmatised use to manage social interactions with the non-stigmatised, draws attention on how to manage relationships with the non-stigmatised in various personal and social situations. With this focus on relationship, Goffman (1990 [1963]) discussed many ways that the stigmatised use to cope with the stigma itself and with social interactions. Examples of such coping strategies include attempting to correct the stigma, devoting efforts to mastering other areas of life, and passing as normal. Individuals faced with stigmatized identities may seek to become 'normal' that is, become like the dominant group using different techniques (Goffman, 1990 [1963]).

In the case of people with learning difficulties, stigma and label have a negative result as they create a status of dependency and incompetence for these people, which have both been seen as something 'bad' by others (Sennett and Cobb, 1972). Söder (1989) criticises the use of labels for people with disabilities and concentrates his critique on three aspects: "*the professionals, the segregation and the standardised routine treatment*". He argues that professionals use their privilege as definition makers to create labels for people with disabilities, which make them dependent on professionals, and other people. It is in their own interest that people continue to be disabled or deviants because then society needs them to treat the deviants. Here, it is obvious again that we are talking about the experts who think

that they have the power and the right to identify who is 'ill' and 'abnormal' and needs their expertise to become 'normal' again. As Barton (1998 [a]) explains

*“people with learning difficulties have experienced some of the most major impositions of professional judgements over their lives, so much so, Ryan and Thomas (1980) argue, that their identity has always been imposed by significant others who claim that such actions are in the interests of these ‘vulnerable’ people”* (Barton, 1998 [a], p: 57).

There has always been the impression that people with learning difficulties need constant support and help from others who can decide and act for them. If this false impression continues to be accepted for students with learning difficulties, then we will end with a culture of dependency between disabled children and professionals (Barton, 1998 [a]). Later, in the review of the literature, this first criticism of Söder (1989) about professionals will be of relevance. The idea of an all-inclusive education system, where there will be no need for professionals, like disability support advisers in universities, because the needs of the disabled students will be taken care of in advance, will be in contrast with the position that professionals have today. Furthermore, in the section where the views of the Directors of the Disability Support Units of each participant university will be examined, the idea of a future where professionals are not needed to provide for students with learning difficulties, will give rise to the notion of dependence between professionals and disabled students.

The second aspect of Söder's critique, regarding labelling, is segregation, which on one hand is not morally correct because it means that society, social groups or social institutions separate people who have some characteristics which are considered abnormal from the mainstream of society and at the same time this separation has a very negative effect on the individual. Labelling students as having 'learning difficulties', or 'special needs' and putting them in 'special schools', away from the mainstream educational system, results in their social restriction and exclusion from particular interactions, contexts and opportunities (Barton, 1998 [a]).

It is known that people who have been hospitalised, been in prison or even students who have attended schools for special needs have to carry the stigma and the label of the institution they have been in for the rest of their lives. This has a profound effect on their life and it is something that they cannot easily hide or change and it is going to be there when they will apply for a job or in any other social interaction where someone will have access to their personal file.

The last negative of the labelling process, according to Söder (1989), originates from the misconception that all people with the same label have to be treated in the same way, regardless of the individual needs and conditions. It is assumed that one standardised routine treatment must be offered to everyone who is blind, in a wheelchair, or has learning difficulties (Söder, 1989).

Frequently, the labels are attached to people with disabilities after the announcement of the outcome of the diagnosis that this person will have. However, in some cases, there is the possibility that the stigmatisation of a person, with the use of discriminative terms, will occur even without a diagnosis, because others will notice the differences that this person has compared to them. In any case, the realisation that a person may have some difficulties will probably lead him/her or someone from the family or school to ask for a diagnosis of the problem, in order to be able to identify what causes these difficulties.

The diagnosis can be both a positive and a negative experience for students, parents and others involved with the student who has been diagnosed with learning difficulties or a disability in general. Later, based on the experiences of both the students and the members of staff, I will show that the process of the diagnosis plays a key role in the understanding and acceptance of the difficulties that these students have. There is a 'paradox' regarding the diagnosis of a learning difficulty or a disability in general.

## 2.5 'Diagnosis' of the disability

As has already been explained above, the labels that are attached to people lead to stigmatization and frequently they have some undesirable effects for the students and their families. However, in some cases, it is possible that the identification of the difficulties that someone faces will have quite a positive effect for that person and his/her family or others in his/her environment.

First of all, the diagnosis and the identification of the difficulties will help parents, teachers and students to understand and explain the cause of the difficulties that they experience. The results from this research showed that most of the students were relieved when they were diagnosed with a specific learning difficulty, as this helped them to understand what was causing all those difficulties they had. At the same time, the diagnosis of the learning difficulties will help both students and parents to find suitable educational plans, which will use the strengths that students have and help in avoiding circumstances which highlight their weaknesses. Nevertheless, the most important reason for students to want to be diagnosed is that the diagnosis establishes their eligibility for legal protection. In order for students to have access to any kind of support and provision, while at school and at the university, they have to have an official diagnosis (from an educational psychologist) (Riddell, Tinklin and Wilson, 2005; Ho 2004). It can be said that the diagnosis is like the golden key which gives them access to the support and the accommodations which are necessary for their studies. At the same time, it covers them under the Disability Discrimination Act (DDA), regarding discrimination and disability rights (Green, Davis, et al., 2005; Craig, Craig, et al., 2002; Cooney, Jahoda, et al., 2006; Ho, 2004).

While a diagnosis of learning disability may provide various benefits and legal protections, there are many reasons why parents and students may still resist learning disability labels. First of all, given the historical oppression of disabled people it is understandable that neither students nor their parents want to carry the label of disabled for the rest of their life, attached to the various, and most of the time wrong, characteristics that a label like that comes with. Even though the diagnosis, may have

a positive effect on students' life, as it helps them to understand their condition better, at the same time it separates them from the 'normal' people as there is the tendency of a separation in almost every society between the 'norms' and the 'disabled' or 'abnormal' (Ho, 2004).

In addition to the weight that such a label carries, we must consider the effect that the diagnosis will have for the student. After the diagnosis, there is the possibility that the focus for other students, tutors and members of staff at university will be the 'disability' and not "*...the real person inside the image of disability...*" (Brisenden, 1986, p: 21). Such a possibility is one that cannot be ignored, as it will have a real effect on the student's everyday interactions with them. Some students without disabilities may believe that their classmates with learning difficulties have achieved what they achieved during university time, either because of the special treatment that they received from tutors or because of other reasons that have nothing to do with the actual abilities that these students may have. Even today, there is this stereotypical idea which places students with learning difficulties at a lower level, and the expectations of them compared to the other classmates are lower too (Dudley-Marling, 2004; Hills, 2007). This is linked to what Bury (1982) explored in the idea that for some people the diagnosis of an illness, and especially that of a chronic illness, is considered as an experience that disrupts "*the structures of everyday life and the forms of knowledge which underpin them*" (Bury, 1982, p: 169). The diagnosis of an illness, impairment or disability challenges and disrupts the experiences and the structures of everyday life, for some people, and it results in changes in the ways that these people see their life and their plans for the future (Bury, 1982). The uncertainty, both in respect to the impact that the diagnosis will have on everyday life, and uncertainty about the behaviour that the person who has been diagnosed has to adopt from now on, causes "*biographical disruption*" (Bury, 1982). The biographical disruptions do not refer only to the difficulties and disruptions that are the result of the disability/difficulty. They also refer to disruptions of everyday life activities, due to "*secondary deviation*" (Lemert, 1967), where someone accepts the characteristics and behaves based on the 'role' that others expect to see from a person with that disability, while they even challenge their abilities to do things.

Another issue with the diagnosis of a disability is that it seems that a hierarchy of impairments exist, which plays a role at the stigma that both the non-stigmatised and the stigmatised will attach to the person that has been diagnosed with a disability. Mark Deal (2003) reviews the literature in order to explore the notion that a hierarchy of impairment exists from both the perspective of non-disabled and disabled people. The hierarchy of impairments means that both non-disabled and disabled people have a different attitude towards different impairments (Tringo, 1970; Janicki, 1970; Harasymiw et al, 1976; Harper, 1999). Based on this notion of a hierarchy of impairments those people who have been diagnosed with impairment or disability, which is one of the least preferred will find it more difficult to be accepted by both non-disabled and disabled people (Deal, 2003)

Different studies (Deal, 2003;Tringo, 1970; Janicki, 1970; Harasymiw et al, 1976; Harper, 1999) showed that there are some impairments and disabilities, which are more accepted by others, either because they are more common or because they are not considered as severe as others are; or are not considered as disturbing for the people's life as other do. Interestingly, this is true for both non-disabled people and disabled people who 'belong' to another 'group' of disability. The stigma for someone whose disability is the least preferred is expected to be 'higher' compared to that of another person who 'belongs' to a more preferred 'category of disability' (Deal, 2003). Therefore, the extra concern for both students and parents regarding the diagnosis of the disability is whether the disability is among those, which are common and hence less stigmatised than others are.

Finally, another negative effect that the label 'learning difficulties' causes to students is that despite the fact that they are now protected under the legislation for disabled people, at the same time the same laws put them under a different or 'special' category, under which everyone is protected by law. By definition, this category shows to others that there is something different about those who fall into that category, so they are not like other 'normal' people. The DDA, which protects students with disabilities from discrimination against them, accepts a person as disabled only if he or she has a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

*“Many cases have fallen because it was deemed by the court that the person did not comply with the definition set out in Part 1 of the DDA”*  
(Riddell, Tinklin and Wilson, 2002).

Despite the negative effects that the use of labels can have for disabled people or the stigmatised in general, it is not an indication that there should be no labels at all. As was argued above, the labels can have a positive effect too and help the person who has the label.

Based on students’ experiences, as they were described to me during the interviews, it seems that there is a contradiction in the results of the diagnosis for students with learning difficulties. This ‘paradox’ of the diagnosis, as I have called it, will be explored next.

## 2.6 The Paradox of the diagnosis

The paradox of the diagnosis lies in the power of the label and diagnosis, sometimes, to make things right. Sometimes it seems that once someone has been given the 'label' of stigmatised person and the differences have been identified, – for example, the person is disabled, black, blind etc- then everything seems to be alright.

On one hand, the diagnosis can be the trigger for the label attachment, with all the negative consequences that the label and stigmatisation can have for that person. On the other hand, it can be the answer to the problems or difficulties that someone had previously (Brueggemann, White, et al., 2001). The relief that follows the diagnosis for some people comes from the shift of responsibility and blame, from them to the disability. It is the confirmation that it is not their fault; they have learning difficulties, which explain their performance, and their difficulties at school. It is not their fault, rather the disability causes the problems they experience.

It is often true that the label becomes the master status for stigmatised people and we cannot see beyond the disability label. In addition, there is the possibility that others, the non-stigmatised, may have a better understanding of the difficulties that the stigmatised person has and this may change their attitudes and behaviours towards them. For example, if a student has learning difficulties and has just found out about it, the diagnosis of the problem may also help the rest of the class to treat this student better, because they now know that it is the disability that causes the problems and the strange behaviour and not the person him/herself. Their classmate, who they thought are not trying enough or are not as good as they are, has been diagnosed with dyslexia, which explains his/her poorer performance in class (Ho, 2004).

However, paradoxically the diagnosis of a learning difficulty, as in the case of dyslexia, can cause contradictory results. With dyslexia there are conflicting opinions about the existence or not of it, which are extended to the argument whether or not it is possible to diagnose dyslexia at all (Rice and Brook, 2004 in Riddell and Weedon, 2006). Research regarding Higher Education (Brueggemann, White, et al.,

2001), has shown that there are still academics who do not accept learning difficulties, like dyslexia as something 'real'. Of course, it is not correct to argue that the opinion expressed by one or some of the academics in a Higher Education institution is necessarily representative of the opinion that the whole institution holds. However, the research presented here showed that the question of whether dyslexia exists today is among those that the Directors of DSUs hear, in some cases, when they deal with certain academics. However, with the exception of one incident the views of the lecturers do not conclude that they do not accept learning difficulties. There are others, on the other hand, who believe that the opinion of those academics who do not believe that dyslexia is a real learning difficulty is not valid and it is the result of the ignorance and lack of knowledge that people have regarding disabilities and dyslexia in particular (Tresman, 2005). Therefore, sometimes the 'label' that comes through the process of the diagnosis does not offer a certain answer for the student. Especially in cases as dyslexia where there is still uncertainty around the existence or not of the appropriate tests to diagnose this learning difficulty. Therefore, the student may end up with a learning difficulty that not everyone accepts it.

In addition, with learning difficulties, there is always the issue of invisibility. People with learning difficulties do not have a visible mark or something that is easily recognisable by others in order to identify them and at the same time to accept them for what they are. It is difficult not to recognise someone who uses a wheelchair and identify him as disabled. However, this is not a case for people with learning difficulties. After the diagnosis they end up with an 'invisible disability' which while on one hand it is easier to hide it from others (and this may be what some students want), at the same time, it is difficult to prove it when they actually need the help of others. In addition, arguably it is much easier in some cases to change or adapt buildings in institutions in order to accommodate the needs of a wheelchair user. However, it is quite a different issue and actually a very difficult one to change the beliefs and the attitudes that some people have about learning difficulties. The most representative example of those issues is the difficulties in changing the teaching and learning techniques in Higher Education in order to accommodate students with learning difficulties (Tinklin, Riddell and Wilson, 2004[a, b])

Consequently, due to the invisibility of the learning difficulties, there are those who argue that people with learning difficulties use their disability as an excuse to either avoid exams or tests during school or at university. Some even argue that the students with learning difficulties, under that label hide the fact that they are actually lazy and they are not working as hard as other students are. Because there is no visible sign that will easily prove the students' difficulties, it is possible for some to argue that people with learning difficulties tend to lie about their difficulties. This has a negative effect on people's self-consciousness, which then affects their behaviour in terms of the disclosure of their difficulties to others (Stage and Milne, 1996).

Therefore, it is important to make somehow visible the unseen disabilities such as learning difficulties in order to allow access to support and provision. However, the way that we will handle this information is very important as it plays a role towards stigmatisation and affects the people's self-consciousness. The appropriate way to handle this information is not to disclose the learning difficulties or disabilities in general without consideration and without trying to respect the privacy of people. On the other hand there should not be a total secrecy around those issues, as it would seem that there is something wrong and that others are ashamed of that expose.

Secrecy is something that especially Simmel (1906) discussed in his work in relation to interactions between people. According to Simmel (1906), secrecy is the condition in which someone tries to hide some aspects of his/her life, while the other person tries to reveal these hidden aspects (Simmel, 1906). As part of the process of interaction between people, it is necessary to know some information about the others with whom we are going to interact. The level of the knowledge we have about others varies between full knowledge and total ignorance. In cases where information is not known about others, or we have an incomplete knowledge of others, we tend to assume such information and create an image about others based on the limited information we have.

During these interactions, secrecy is one way of managing information about others and us and it involves efforts to either reveal to or withhold information from others (Simmel, 1906; Marx & Muschert, 2008). The secret is a central means for information control in society, as it provides 'cover' in cases when the truth is not

desirable to be told, or when a different image is preferable to be presented during social interactions. Of course, it is not possible to know every aspect of others' lives, both because it is not feasible and because there are aspects of our life and others' lives which are meant to be secret. Therefore, through social interactions with others, people chose what aspects of their personality or life they want to reveal depending on the circumstances. Consequently, at times, they want to protect the elements and the 'part of their self' that they do not want to reveal to others. In other cases, during social interactions people emphasise the aspects that they think are 'appropriate' for that particular interaction with others (Simmel, 1906; Ritzer and Goodman, 2003; Marx & Muschert, 2008). Simmel's interest in secrecy focuses on what we learn about social and personal behaviour through secrecy and its meaning for the management of information. According to Simmel, it is very important to understand the social meanings of the hiding, holding, revealing or disclosure of information, for different groups of people and in different conditions and interactions. In each group and each type of interaction, the management of information has a different social function. From Simmel's (1906) concept of secrecy, as a way of managing information, either on the personal or social level, the need for the notion of the "*sociology of information*" (Marx & Muschert, 2008 & 2007) arises. The sociology of information identifies the rules of managing information, while it also clarifies the expected roles that each part, group or individual will play in handling information (Marx & Muschert, 2008; 2007). Later, the ways that institutions use to handle information about students with learning difficulties or in general, disabilities are going to be discussed.

The following chapter will explore the changes that have occurred in Higher Education in the last decades, in relation to disability and disabled peoples' participation. Among the changes that Higher Education Institutions have to make to accommodate students with disabilities are the so-called reasonable adjustments. What this means for universities and tutors, and how prepared they are to make those adjustments, are going to be explored next. The idea of an 'all inclusive' educational system, which will make the mainstream schools and universities accessible to all students despite their abilities, difficulties etc, whilst also ensuring the inclusion of those students within society, are all discussed in the next chapter.

### 3 Changes in Higher Education for Students with Learning Difficulties

#### 3.1 Introduction

The fact that Higher Education Institutions had to make quite a lot of changes in order to accommodate and accept more students from minority groups, one of which is students with learning difficulties, has been of major interest in the last decades. In some cases, these changes/adjustments mean that even the aim and purpose of education has to be re-evaluated in order to include students with learning difficulties and to achieve an inclusive educational environment for every student, regardless of abilities and difficulties. The aim of the changes in Higher Education Institutions is not merely to allow access to students with disabilities, in order to increase their number. It is rather to accommodate these students and to adjust the services that institutions provide, based on the abilities and the individual needs of every student, without discriminating against those with disabilities or difficulties. The turn of the educational system to marketisation and the competition between universities for more students, for better and higher results in Performance Indicators, together with the changes in funding and decision making within Higher Education, are among the changes that have occurred in the last decades. The changes due to marketisation and the competition between Higher Education Institutions have led to a greater number of students who become accepted by the institutions. However, the increase of the students' number resulted in less personalised teaching and learning, as it had to be delivered to a mass number of students. The lack of a more personalised education, on the other hand, led to unavoidable exclusion of groups of students with disabilities and learning difficulties, as their individual needs were almost impossible to be met. Therefore, a tension between the need for widening participation to Higher Education Institutions, a result of the turn to marketisation, while at the same time, meeting the requirements and making the appropriate adjustments for the students with disabilities, was created, due to the turn to marketisation in education. Therefore, the changes resulted in shifting the focus of the Higher Education away

from the its main purposes, which are teaching and learning, towards more market-oriented purposes, like competing and attracting more clients,- students, regardless of whether they were prepared to support and provide for these new students. These changes are going to be explored in this chapter.

### 3.2 Changes in Higher Education

As has been indicated above, Higher Education was not always open for all students and especially for students or even staff with disabilities. Up until the 1990s, disabled students and staff had almost been denied access to most of the Higher Education Institutions (Barnes, 2007; Barnes, 1991). However, a number of changes in the Higher Education system combined with the anti-discrimination legislation led to the inclusion of students with disabilities in Higher Education Institutions. An overview of the history of these changes is given here, to see whether this inclusion has been achieved and what further changes have to be completed in order to allow access and provide services for all students regardless of their abilities or difficulties.

The UK system of Higher Education expanded during the 1960s and 1970s, with the number of universities increasing in the 1960s, in addition to the increase in the money that was invested by the main funding body (University Grant Committee) in the universities. During this period, it was not necessary for undergraduate students to pay any tuition fees, while academics undertook decision-making and management roles only on a temporary basis. The situation changed when in 1979 a Conservative Government was elected, which intended to cut public expenses and “*expose public services and professionals working in them to the discipline of quasi-markets and the regimes of the private-for-profit sector*” (Deem, Hillyard and Reed, 2007, p: 39).

Higher Education Institutions, in the UK, have not been part of the public sector, such as schools and hospitals, and consequently, they retain a significant degree of autonomy in the area of knowledge. However, it can be argued that the “*ideological context and organisational strategy set down by the new managerialism and new public management, respectively*” have an effect on them (Deem, Hillyard and Reed, 2007, p: 1). The ideas of the new managerialism and the new public management aim to restructure the public services. More specifically managerialism is an ideology that considers managing and management as the essentials for any modern political economy that wants to achieve economic progress and development.

The changes in the education system in the UK led to a “*market-oriented system*”, because it encouraged competition between schools, it introduced new types of schools and assigned budgets to schools, based on the number of enrolled students. However, since the new market-oriented system that was adopted in Higher Education differed from the conventional markets in a number of key ways, Le Grand, among other researchers, described the new system as a “*quasi-market*” (Le Grand and Bartlett in West & Pennell, 2002). Changes like the funds that the universities have to locate for student-teaching purposes and the introduction of fees that students have to pay are some of the new “*quasi-market*” conditions in Higher Education. In addition, the competition between the different Higher Education Institutions, in order to attract more students and to achieve excellence in academic achievements, is evidence that Higher Education now operates under “*quasi-market*” conditions. The educational system as it is known today was formed due to these changes and “*quasi-market*” conditions (Le Grand, 1991; West & Pennell, 2002).

In the sector of Higher Education the search for new sources of finance, in order to replace the declining government funding, is one of the reasons that led to the need for new managerialism. In addition, the shift to a mass Higher Education system, and the increased number of new students, made the finding of effective new ways of dealing with them and with the complex organisations-universities an essential part of Higher Education management (Deem, 2001; 1998; Deem & Brehony, 2005; Randle & Brady, 1997).

Therefore, the new plan was to manage academics and academic work based on the idea of marketisation, where the performance and the quality of teaching and research levels were frequently tested. During that period decision-making was the job of the administrators and members of government bodies, rather than academics (Deem, Hillyard and Reed, 2007; West and Pennell, 2002; Barton and Slee, 1999).

Things seemed to change again and led to a new expansion in Higher Education Institutions in the UK from the 1990s onwards, resulting in a further increase in the number of UK universities, students and academics. In 1992, the Further and Higher Education Act brought some changes to the education system, which was divided

into three types of institutions up until then. From 1992, most polytechnics changed their name to university, whilst the colleges of Higher Education changed to university sector colleges (Hurst, 1998). Widening participation in Higher Education, to include groups who have not traditionally gone to university, was a key policy in this regard, and the government (of New Labour in 1997) set a target of 50% of all 18–30 year-olds to enter Higher Education by 2010. Although participation of students from underrepresented groups (like students with disabilities) has increased dramatically in recent years, as the statistics from HESA<sup>7</sup> (2007) showed, the increase in participation is not uniform across all social groups (Leathwood and O’Connell, 2003). This new expansion had some effects for both students and academics. First, students are now required to pay, to some extent, tuition fees, while at the same time big reductions have been introduced, for funds, especially in subjects such as humanities, social sciences and arts. At the same time, academic salaries have relatively declined (Deem, Hillyard and Reed, 2007, Deem, 1998).

The new managerialism and new power management ideologies mean that academics now are assessed based on research publications and students’ evaluation of teaching. In order to achieve this more academics have now resumed management duties on a more permanent basis, compared to the past. Their jobs as managers requires them to monitor the incomes and the expenses of their department, while at the same time they may be asked to find ways to add new funds to the university (Deem, Hillyard and Reed, 2007, Deem, 1998).

The changes in higher Education led to a turn to bureaucratisation of services within Higher Education Institutions as it is now more necessary to have a standardised way of how things work within the institutions, where everything is monitored and everyone has specific duties. This turn to bureaucratisation, which is apparent regarding services and provision for students with disabilities, as it will be shown later through the interviews with members of staff, has both positive and negative effects. For Weber (1978) bureaucratisation is a prime example of the process of

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<sup>7</sup> Indicatively the number of new first year students in HE institutions with disabilities for the academic year 2003/2004 was 45545; the following year (2004/2005) the same number was 49125, while for the year 2005/2006 the number reached 54830 students. (HESA, 2007)

rationalisation at the institutional level. A bureaucratic institution, organisation or society has a defined goal and everyone within this organisation works towards achieving this goal, by eliminating any factor that could possibly threaten this goal. The 'ideal type of bureaucracy' has the following characteristics: functional specialization, clear lines of hierarchical authority, expert training of managers and decision making based on rules and tactics developed to guarantee consistent and effective pursuit of organizational goals. More specifically, the ideal bureaucratic organisations have "*jurisdictional areas*" (Weber, 1978, p: 956) and tasks are distributed based on rules and the specialisation of each bureaucrat in a particular area. Bureaucracy is based on the principle of hierarchy that is a system of super- and subordination where the lower 'officer' follows the rules and orders of the higher ones, while the ideal bureaucrats are given tasks based on their technical knowledge and expertise. The best-trained person and with the highest expertise is selected for the higher job and they are expected to perform in their higher ability, regardless of personal considerations and feelings. As Weber (1978) pointed out business is conducted "*according to calculable rules and without regard for the persons*" (Weber, 1978, p: 975) This 'impersonal' character of bureaucracy and the strict rules that drive bureaucratic organisations caused some concerns to Weber, which have to be considered.

Therefore, even though Weber (1978) considered bureaucratisation as the best form of organisation, and believed that bureaucracy is essential for large-scale industrial societies, he was also aware of the disadvantages that bureaucratisation can have. He was concerned that within bureaucratic societies people will lose themselves because of the specialised routine which they have learnt to follow. Therefore, their freedom and individuality will be lost (Weber, 1978; Calhoun, Gerteis, et al., 2002; Ritzer, 1975; Ritzer and Goodman, 2003). As Weber (1978) argued, the bureaucratisation of modern societies can lead to their depersonalisation. Furthermore, Weber believes that due to highly training of bureaucrats in following rules and making routine operations, rather than taking policy decisions and being the leaders for initiatives, the ideal bureaucrat would not be efficient in crises (Weber, 1978).

The bureaucratisation of services, together with the changes due to marketisation led to the introduction of Performance Indicators, which were produced by the Higher

Education Funding Council for England (HEFCE, 2003), after 1998. Performance Indicators are a range of statistical indicators, intended to offer an objective measure of how a Higher Education institution performs. Some of the areas which are measured are the following: “*non-completion rates for students, outcomes and efficiencies for learning and teaching in universities and colleges, employment for graduates and finally, research output*”. (HEFCE, 2003, p: 1) The purpose of Performance Indicators is to provide reliable information on the nature and performance of the UK Higher Education sector, to allow comparison between individual institutions, where appropriate, to enable institutions to benchmark their own performance, to inform policy developments and finally to contribute to the public accountability of Higher Education (HEFCE, 2003).

The idea of Performance Indicators, which would measure and evaluate the performance (in the areas that have been mentioned) of all Higher Education Institutions, received a mixed reaction by researchers, as it can have both advantages and disadvantages for institutions. First, it is beneficial that the institutions have to produce the reports, which show institutions’ performance in research, teaching, learning, number of graduates etc. It makes it easier for the customers, hence students and parents, to evaluate each institution and decide which one is the best for them. At the same time, the problems start when the Performance Indicators instead of being the measures for judging an institution become the means by which each institution organises and manages itself. In these cases, the institutions may lose sight of their purpose as ‘Higher Education Institutions’, and concentrate only on achieving high scores on performance reports (Barnett, 1988; Elton, 2004; Bird, Cox et al. 2005).

The emergence of Performance Indicators in Higher Education can be usefully interpreted in the light of Michael Power’s (1997) notion of “*audit society*”. As Power (1997) explains, it is difficult to imagine a society where there is no auditing at all, as this requires first, an absolute trust, which is not achievable. On the other hand, a society where there is a constant auditing it is not reasonable and practical. The idea of the “*audit society*” (Power, 1997) means that we have a society where constant checking and verification becomes the extreme case. In these cases, auditing becomes the ruling principle.

Auditing is not merely a matter of a technique and technical experience. Auditing is also a “*cultural issue*” (Power, 1997) and it is based on the communities, societies and institutions we live in or interact with, and the structures that represent our environment. Different societies have required different levels of auditing and different mechanisms for auditing. In some cases, highly structured and formal auditing is necessary, while in some cases appropriate auditing means providing space for individual judgement (Power, 2003).

According to Power (1997) in the early 1990s Britain started using the word audit more often, not only in relation to finance, but also for a variety of contexts, including teaching and learning audit, management audit, medical audit, intellectual property audit and many more. Within education, the audit, either in the form of Performance Indicators, or League Tables or tests and other evaluation mechanisms, has been used, especially since the turn to new managerialism, where auditable standards of performance were required (Power, 1997; 2003). The need for more and better reports, which have been checked by auditors, is something that we see more and more each day, in schools and Higher Education Institutions. Auditing in Higher Education, with the form of Performance Indicators is not something that can easily be criticised as an unnecessary measure. Some standard of performance is necessary in order to provide internal improvements of quality services in institutions. However, it is easy to cross the line between auditing that is productive and aims at improvements within institutions, and the turn to an extreme case of constant auditing, which becomes the main aim within institutions. Consequently, there is a danger that the audit process in universities and schools, using Performance Indicators, instead of being used as a measure of healthy evaluation, which can produce assurance and confidence in the provided services, might turn into an end in itself, if not used wisely. The risk of using Performance Indicators at their extreme can lead Higher Education away from the purposes that it is meant to serve, and turn it into a mere competition to achieve the highest scores between different institutions.

The next section identifies some of the main purposes of Higher Education and discusses how these have to be reconsidered in order to allow access and provide opportunities and services to all students regardless of their abilities.

### 3.2.1 Purposes of Higher Education and democracy

When we talk about the purposes of Higher Education Institutions, we refer to a “*general set of conditions that any institution of higher education has to satisfy in order to warrant the title 'institution of higher education'*” (Barnett, 1988, p: 98). Of course, the specific purposes of a single university, even though they are only applied to that university, should be based on the accepted purposes of all Higher Education Institutions. The idea of a set of purposes for Higher Education Institutions is of importance here because, as is previously discussed, in order to allow access to students with disabilities and learning difficulties in particular to education some changes and adjustments have to be made. In some cases, these changes refer to changes in attitudes and ideas even about the main purposes of Higher Education.

Therefore, having that in mind, Barnett (1988, 1990, 1999, 2000), Bligh, Thomas and McNay, (1999) and Halsey, Lauder, et al., (1997) argue that some of the aspects of Higher Education are the pursuit of knowledge, the gaining of qualifications for a better job, a place to teach and promote ideas such as democracy, equality and individual practical thought. HE can also be seen as a means of social control and even a competitive environment, which seeks to attract new customers every year. Despite the uncertainty regarding the purpose of Higher Education or education in general, its beneficial role for both students and society has been proven throughout the years.

As Halsey, Lauder, et al. (1997) argue, it was in the post war period that education came to assume a key role in the political economy of nations, as it was seen as the main solution which will lead societies to economic growth and social justice. During that time, economic efficiency was dependent on getting the most talented people into the most important and technically demanding jobs, regardless of their social circumstances, as well as extending the periods of formal education in order to prepare the workers for the demanding new industrial jobs. This is something that was a key solution, even in the post-industrial world (Halsey, Lauder, et al., 1997).

It is also known that education was used in the USA as a means to help veterans who returned from WWII to re-adjust to civilian life. More specifically, the GI Bill or the Servicemen's Readjustment Act of 1944, provided tuition, subsistence, books and supplies, equipment, and counselling services for veterans to continue their education in school or college, in order to 're-gain' their citizenship in the society that they had left before WWII (Schugurensky, 1996-2008). Apart from the role of education as a means to 'prepare' the workers for their new skills in the industrial societies, and also teach them the new ways of modern technologies, education, during this period, was also seen as contributing to the foundations of democracy. The veterans had to find again their role within the society, which had changed a lot since they left, and education helped them to re-gain the citizenship they needed in order to feel members of the same society as other Americans again. The harmonious coexistence between the veterans who had just come back with the rest of the society, which had moved forward in the mean time, was promoting a democratic society.

Dewey argues: "*a democracy is more than a form of government; it is primarily a mode of associated living, a conjoint communicated experience*" (Dewey, 1916, p: 101 in Halsey, Lauder, et al., 1997, p: 4). Those who supported this argument, believed that in order to 'teach' democracy, through education, they had to establish a common school. The common school was designed to provide greater equality of opportunity, as it was the same for all students despite their background, ethnicity, gender, abilities and social class. The equality of treatment that this common school was teaching to students was the best example of democratic life (Halsey, Lauder, et al., 1997). It was not only during the post war period that education promoted democracy. Even now, it is a common belief that Higher Education is "*Shaping a democratic and civilised society*" (Bligh, Thomas and McNay, 1999, p: 9).

British society is diverse and a multi-cultural one it is essential its citizens know how to live all together and interact with each other in order to make their society a civilised and democratic one. This is achievable only if people know how to take responsibilities for their actions, respect the rights and the beliefs of others, know how to present and support their arguments without assaulting others, respect everyone in the society even if he/she belongs to a minority group and treat everyone

the same way and with the same respect. These concepts, which are necessary for a civilised and democratic society, can be gained through Higher Education. So it is within the role of Higher Education to develop these ideas and concepts and to pass them onto new citizens (students) (Bligh, Thomas and McNay, 1999; Halsey, Lauder, et al., 1997).

Ideas such as democracy and respect for difference are essential for a society which wants to fight social exclusion and discrimination against disabled people while at the same time they will help in the process of disability awareness training. However, the turn of Education (and Higher Education) to marketisation, as was explained above, creates a tension between the aim of providing knowledge for democracy and knowledge for the economy. More specifically, the marketisation of education, and the “*quasi-market*” (Le Grand in West & Pennell, 2002) conditions which have formed Higher Education, are in tension with the promotion of democracy, rather they encourage the knowledge of the market-oriented systems that is apparent in every activity of education. Students and institutions have to compete in order for the former to gain access to better institutions, while the latter try to attract more clients for their businesses. Therefore, the idea of democracy in education, which is based on the freedom and the equality of opportunities for everyone, has been replaced by a curriculum that aims to create competitive individuals who will have market behaviour (Brown, Halsey, et al., 1997; Hickman, 1998; Hickman & Alexander, 1998; Fott, 1998)

Among the aims of Higher Education is to gain credentials for employment. It is well known that an educated person, with a Higher Education degree has more opportunities to find a better job. A person who has developed the ability to use the knowledge, which has been gained through the educational system has all the requirements to find a better job, compared to someone who does not have a Higher Education degree. Students know very well that a degree from a Higher Education institution is required, in order to have a better-paid and more prominent job, regardless of whether they have already decided what kind of job they want to pursue (Brown and Scace, 1994).

Higher Education is the means which both creates and fills demand for expertise in work places. There are occupations for which only a degree from a Higher Education

institution can give someone the chance to work there, like medicine (Bligh, Thomas and McNay, 1999).

In addition to these aims of Higher Education, the views of those who argue that it can also be used as a means of social control have to be mentioned. Therefore, on one hand we have democracy and even socialisation for people who choose to go to Higher Education but on the other hand, there is the fear of social control, the effects that the marketisation and the competition between institutions can have on students and the extent to which students develop individual thoughts through Higher Education.

Today, there is the element of market competition to Education institutions and in a sense each institution acts as a small or medium sized business with students and parents as the business's customers (Bligh, Thomas and McNay, 1999; Halsey, Lauder, et al., 1997; Barnett, 1990). This competition between institutions can have both a positive and a negative outcome as on one hand, it can mean a rise in educational standards, improvements in services, provision, teaching quality etc for students, while on the other hand, it can mean that the main focus of the Higher Education Institutions shifts from students' interests to university-business financial interests. Those who believe that the marketisation of education does not promote democracy argue that

*"...in that (the marketisation of education) knowledge is not only structured to be economically productive but itself becomes wholly a commodity under market conditions..."* (Halsey, Lauder, et al., 1997, p: 23)

When students are educated within the competitive environment of Higher Education Institutions they learn to be competitive and attempt to gain personal advantage in the competition for job opportunities, which some may argue is not a good example of democracy or something that the Higher Education Institutions should want to promote (Brown and Scase, 1994). On the other hand, some would argue that fostering competition is exactly what would stimulate a healthy democracy in which the most able occupy the most important posts, which is what a meritocracy requires

doing. Similarly, there are many people in Higher Education who see their job as promoting academic elites and given that, failure of the weakest is an essential component. The impact that the economic recession has affects the instrumental orientations to university life. In addition to that, there is the concern regarding the extent to which students develop independent and individual thought through Higher Education, under the ‘influences’ of privately funded research and the market’s demands (Halsey, Lauder, et al., 1997; Barnett, 1990; Brown and Scase, 1994).

Having seen that there is a complexity regarding the aims and purposes of Higher Education, it is difficult not to question the real reasons behind the interest that institutions show in students with disabilities. As is going to be argued below it is not a case of just allowing access to students with disabilities to Higher Education; it is also important to provide services and to adjust the institution’s functions around the individual needs of each and every student with disabilities who is accepted. The aim of Higher Education Institutions should not be only to increase the number of their ‘clients – students’. Rather they should be focusing their efforts on providing the necessary means for an inclusive educational system, which is going to be helpful for all students, no matter their abilities or difficulties.

Before we continue with the idea of an inclusive education, it is necessary to see the key changes in disability law in Higher Education that led to more disabled students entering Higher Education Institutions. At the same time, for the purpose of this project the policy that Durham University follows regarding students with disabilities is analysed here.

### 3.3 Disability Law changes and Durham's University disability policy

As it has already been mentioned, there are many changes in law and legislation regarding disability in general and in Higher Education more specifically. Among the most important legislation changes is the Further and Higher education Act (1992) which aimed to widening participation of underrepresented groups of students in Higher Education, among which are disabled students. At the same time, it introduced, through the Higher Education Funding Councils, funding to institutions in order to improve provision for these groups of students. In addition, the Disability Discrimination Act (1995, 2005) as it was amended after the Special Educational Needs and Disability Act (2001), is the most important law that protects and provides support to disabled students in Higher Education, by making unlawful to discriminate against them because of the disability. Furthermore, it gives guidance to institutions about the adjustments that have to be made in order to provide support to disabled students. Based on the new DDA (2005) institutions have to publish disability statements, which will include the policy that the institution follows regarding provision for disabled students. The policy that Durham University follows regarding students with disabilities is discussed next.

All of the above legislation changes, which will be analysed here, could be seen as the result of the political implications that the social model of disability had, as it gave rise to new strategies, to remove the social barriers that cause disability. The social model of disability, and its gradual acceptance through the changes in law and legislation, focuses on the creation of a society where there will be no more social obstacles to cause problems to people with impairments (Shakespeare and Watson, 2002).

Up until 1993, when the Further and Higher Education Act (1992) came into force, Higher Education was not largely accessible to disabled people, either staff or students. At the same time any adjustments that were made were “*at the good will of staff and students*” (Riddell, Tinklin and Wilson, 2004, p: 13) Among the changes that occurred after the Further and Higher Education Act (1992) was the widening

participation of groups who were underrepresented until then into Higher Education institutions. One of the minority groups were disabled students. The Further and Higher Education Act (1992), replaced the *Universities Funding Council*, which distribute funds provided by central government to universities for the provision of education and the undertaking of research, by the *Higher Education Funding Council for England*, the *Higher Education Funding Council for Wales* and the *Scottish Higher Education Funding Council*. The national funding councils established by this Act would now offer initiative funding to institutions in order to improve the provision they offered to disabled students. For example, in England a number of special initiatives have improved rates of participation and also the quality of policies and provision (Hurt,1999). However, in Scotland the funding was distributed more evenly across the different institutions. The premium funding which was introduced in 1999-2000 in England and 2000-2001 in Scotland, was paid on the basis of the number of students within each institution who claims Disabled Students Allowance (DSA). Therefore, now the level of funding depends on both the institutional level and the disabled students' level within each institution (Riddell, Tinklin and Wilson, 2004).

DSA contributes to the extra costs disabled students may have to pay as a direct result of their disability, mental-health condition or specific learning difficulty. The allowances can help with the cost of having a non-medical helper, items of specialist equipment (i.e. computer equipments, tape-recorders etc), travel and other course-related costs. It is paid directly to students, and it is based on the outcome of an assessment of needs that disabled students undertake, in order to determine the support they require (Skill: National Bureau of Students with Disabilities, 2007).

The introduction of premium funding based on the number of students with disabilities can be considered a positive development as it gives motives to institutions to include these students to their main body of students, which is not something that they used to do prior to Disability Discrimination Act (DDA, 1995 & 2005) when the access to these students and also disabled members of staff was limited, if not restricted. However, the relation of the amount of premium funding to the number of students who declare disabilities, it could be seen as a motive for institutions to attract disabled students not only because they want them to be part of

their system but also because of the funds that these students will bring (through the premium funding from HEFCEs). HEFCEs publish statistics including the number of disabled students at each institution in order to compare the participation of disabled students in each Higher Education institution (Riddell, Tinklin and Wilson, 2002). Institutions compete with each other for more students, higher and better results in performance indicators and general for a better place among the whole of universities as this will show that the institution is considerate towards disabled students, which is something that might attract more disabled students in the future.

In order for institutions to be headed towards anti-discrimination against disabled students, the Quality Assurance Agency (QAA) for Higher Education with its Code of Practice for disabled students, aims to help higher education institutions to meet their responsibilities for the assurance of academic standards and quality regarding disabled students. This Code of Practice emphasises that

*“... Accessible and appropriate provision is not 'additional', but a core element of the overall service that an institution makes available... Institutions should be able to address individual cases effectively and also manage their provision in a way that develops an inclusive culture.”* (QAA of HE, 2010, p: 4)

Clearly, it is essential institutions to see the adjustments and the provision for disabled students not as something that they have to react on it after it is requested by disabled students, but as a central part of their policy and practice. Institutions must act proactively in regards to provision for disabled students and to take care of the individual needs of disabled students as a proof of their steps towards an inclusive culture. (QAA of HE, 2010)

In addition to do the above, the most important Act which placed requirements on employers and service providers not to discriminate against disabled people is the Disability Discrimination Act (DDA) 1995, which however did not originally include requirements for the provision of education. Part 4 of the DDA (1995) placed some requirements to post-16 education funding bodies to publish disability

statements indicating the institution's policy, provision and future plans for disabled students; however, it did not include the requirements to institutions not to discriminate against disabled students (Disability Rights Commission, 2002).

Later, this Act has been significantly amended by the Special Educational Needs and Disability Act (SENDA) (2001), and for the first time it includes measurements which prohibit disability discrimination in the Post-16 education sector. The new DDA (2005) now gives disabled people rights in the areas of: employment; education; access to goods, facilities and services, including larger private clubs and land-based transport services; buying or renting land or property, including making it easier for disabled people to rent property and for tenants to make disability-related adaptations and finally, functions of public bodies, for example issuing of licenses. The Act requires public bodies to promote equality of opportunity for disabled people. (Disability Rights Commission, 2002; Directgov)

The SENDA (2001), which came into force in 2002, establishes legal rights for disabled students in pre- and post-16 education (Further and Higher Education institutions and sixth form colleges, in England, Wales and Scotland). Based on SENDA (2001) it is unlawful for responsible bodies to treat a disabled person "*less favorably*" than a non-disabled person, for a reason that refers to the person's disability. Discrimination against disabled students can also take place by failing to make a "*reasonable adjustment*" when they are placed at a substantial disadvantage compared to other people for a reason relating to their disability (Disability Rights Commission, 2002).

The new Part 4 of the DDA (2005) gives some advice to post-16 education providers in order to avoid discrimination against disabled students who want to access education, while at the same time it describes the duties that each responsible body within this sector has for the provision of the services for the disabled students. (Disability Rights Commission, 2002) However, there are some areas which are not completely clear in that Act and could be considered as conditions which potentially weaken the Act's impact depending on how they are interpreted by each institution. These sections are mainly regarding reasonable adjustments and the way that they are explained in the Act leaves some space for different interpretations from one institution to another. For example, while the DDA (2005) gives some guidance on

reasonable adjustments for disabled students, at the same time the Act, in limited circumstances, permits institutions to justify treating a disabled person less favourably than other people. Among these circumstances is the need of the institution to maintain academic and other prescribed standards. If an institution believes that the less favourable treatment of a disabled student results from institution's attempt to maintain academic standards then the discrimination is justifiable (Disability Rights Commission, 2002). It is not claimed that the Act intentionally allows institutions to discriminate against disabled students under certain circumstances, but that it leaves space for some institutions to justify their discrimination towards disabled students under the excuse of maintaining academic standards, which are set by each institution and therefore, they should be changed and reviewed accordingly to the students needs. The right practice should be institutions to find ways that allow for disabled students to be assessed whether they meet these academic standards in different ways and conditions that are not discriminatory for them but rather they meet their abilities or difficulties. The issue regarding what could be considered reasonable adjustment from each institution and how each institution defines and presents some adjustments as reasonable or not, is going to be explored in more details later in the chapter.

Another issue within DDA (1995) which accepted some critique (Gooding, 2000) is the definition of disabled people that is given in the DDA, which defines a disabled person as someone who has a physical or mental impairment, which has an effect on his or her ability to carry out normal day-to-day activities. And even though the physical or mental impairment can include sensory and hidden impairments (like mental health problems, learning difficulties, dyslexia, diabetes etc) many cases have fallen because court was not persuaded that the person actually meets the terms of the definition as it was given in the Act (Gooding, 2000).

The DDA (1995) as amended by SENDA (2001) required institutions to publish disability statements, indicating policy, provision and future plans for meeting disabled students requirements. More specifically, documents which refer explicitly to the university's provision for disabled students include, according to Holloway (2001), the *Disability Statement*, the *Teaching and Learning Strategy* and the *Teaching and Learning Guidelines* (Holloway, 2001). The first sets out the current

policy and provision in accordance with HEFCs. While the other two direct departments to undertake reviews in order to identify the requirements of disabled students, based on current and previous students views, which will then determine the plans that have to be put in place in order to meet the students' requirements (Holloway, 2001).

The DDA (1995) is designed to ensure that a proactive, and not a reactive approach, is taken by universities to accommodate students who have a disability. This means that universities have to anticipate the adjustments that are necessary in order to accommodate specific needs of disabled students. Those adjustments have to be made before the students' arrival (Fraser, 2005).

The National Committee of Inquiry to Education (1997) suggested,

*“The ‘normalisation’ of disability implies that universities should be encouraged to generate a culture and environment where disability is not regarded as a problem”* (Robertson & Hillman, 1997[c], p: 1).

The National Committee Inquiry suggests that changes are required, in order for disability not to be seen as a problem. At the same time, the notion of ‘normalisation’ that it uses is problematic. The process of normalisation, as it is explained by the National Committee of Inquiry, suggests that if the universities/institutions manage to create an environment where people have disability awareness and sensitivity towards disabled students, then disability will not be seen any more as a problem, which needs a solution. Disability awareness means that Higher Education Institutions have to understand the need for some changes in the structural, organisational, relational and financial conditions that they operate in, in order to establish a barrier-free environment for students with disabilities. A barrier-free environment is a learning environment, which is open to students' individual needs, regardless of disability and circumstances. Disability as a concept covers a multitude of different cases and special needs, and to some extent, it is understandable that universities cannot cover every aspect of it. However, disability sensitivity, which means that others accept the complexity of the issue and

treat disabled students with respect, is something that is necessary within every institution (Robertson and Hillman, 1997 [a, b, c]; Chappell, 1992, 1997).

However, this idea of ‘normalising’ disability first implies that there is something wrong with the students with disabilities that has to be fixed and to be made normal. The aim of the changes should not be to make the students with disabilities and in general the stigmatised ‘normal’. Rather the aim is to change the social conditions that create the stigma and the deviance in the first place, so that there will be no need to normalise the disabled students. In addition, the ‘*normalisation*’ principle continues to the notion of the professionals and the ‘experts’ who have the power to ‘normalise’ the students with disabilities. The dependency between the professional experts and the students with disabilities, does not change, though it actually should be removed in order to achieve a more inclusive educational environment. Therefore, there is an argument for changes to be made, but not towards the ‘*normalisation*’ of disability, but rather towards the elimination of the social barriers that create disability in the first place (Chappell, 1997, 1992; Oliver, 1994).

In order to achieve this elimination of the social barriers, some steps forward are the policies and the plans that institutions must put in place for students with disabilities. More specific Durham University, which is the main interest in this project publishes on their website a list of all policies that are available in this institution. Among them is the “*Diversity and Equality Policy*”, which is divided into 12 sections among which is the “*Policy Statement on Promoting Disability Equality*” and an Annex (1) about “*Equal opportunities in Teaching and Learning*” (University of Durham, 2009). Based on the “*Policy Statement on Promoting Disability Equality*” (University of Durham, 2009) the institution is committed to eliminate any discrimination against disabled students and to promote equality of opportunity between disabled and non-disabled students. At the same time the institution must promote positive attitudes and encourage disabled people to participate in University of Durham, while it takes any necessary steps to take into consideration the needs of disabled people. In order now to meet those targets, as DDA (2005) requires it to do so, the University of Durham has published a “*Single Equality Scheme*” (University of Durham, 2007), which illustrates the university’s commitment to promoting diversity and quality of opportunity for both members of staff and students. Within

the “*Single Equality Scheme*” is included the “*Disability Equality Scheme*” (Annex B) which explains in details the plan that the University of Durham will follow in order to attain the requirements that DDA (2005) has set for disabled students. The action plan takes into consideration the views of disabled students and members of staff and their recommendations and explains how the plan was set out and the actions that have already been completed (University of Durham, 2007). The social model of disability is accepted and adopted when designing, monitoring and managing university’s built environment or service delivery. In addition, based on the “*Disability Equality Scheme*” the university “*will work with the social model as the basis for development activities to improve the access to and success of disabled people*” (University of Durham, 2007, p: 28)

Durham University Service for Students with Disabilities (DUSSD). DUSSD supports and offers help to students with “*a recognised disability, a specific learning difference (SpLD), a medical condition and a mental health problem*” (University of Durham, 2010a). DUSSD works closely with departments and colleges in order to ensure that both disabled students and staff can get the appropriate support they need. In order to succeed in that Durham University since 2008, has also been committed to a development of a Departmental Disability Representative (DDR) network. DDRs are the point of contact within each department for members of staff and disabled students regarding disability issues. They are members of staff who take this role and are the advisers for disability issues and the mediators for disabled students between the department and DUSSD. Usually, their role within the department gives them the chance to better advice the institution and more specifically DUSSD on how they have to reasonably adjust the services and the provision in order to accommodate the needs of the students within their departments. DUSSD offers a list with the names and contact information for the DDRs on their website for each department and gives the chance to students and other members of staff who have disability related issues to access a familiar face within their department in order to find the help they need (University of Durham, 2010a)

In addition, the website of DUSSD offers information about disability policy, issues of confidentiality, funding information for disabled students and how to access that,

guidelines on how to register to DUSSD and what is the process that they will follow after the registration, and of course a list with the services there are available within the institution for students or members of staff regarding disabilities. (University of Durham, 2010a)

Based on information from DUSSD for the academic year 2005-2006, the following table shows the breakdown of disabilities of the students who were registered with DUSSD that year.

<i>Dyslexia/Specific Learning Difficulty</i>	<i>ME (or CFS)</i>
<i>Dyspraxia</i>	<i>IBS/Crohn's/coeliac disease</i>
<i>Dyscalculia</i>	<i>Multiple Sclerosis</i>
<i>Other learning/literacy problems</i>	<i>Cystic Fibrosis</i>
<i>Attention Deficit Disorder</i>	<i>Severe migraines</i>
<i>Asperger's Syndrome</i>	<i>Colour Blind</i>
<i>Speech/Communication problems</i>	<i>Raynaud's Syndrome</i>
<i>Irlen Syndrome</i>	<i>Other medical conditions causing study problems</i>
<i>Visual-impairment</i>	<i>Mental Health problems</i>
<i>Hearing-impairment</i>	<i>Eating Disorder</i>
<i>Joint problems (not mainly mobility)</i>	<i>Obsessive Compulsive Disorder</i>
<i>Mobility problems</i>	<i>Unspecified Disabilities</i>
<i>Cerebral Palsy</i>	

Of course there are also other disabilities which can affect the students' ability to study and DUSSD gives online a sample list with conditions that students may present with as a guide for members of staff making clear that there are other numerous conditions that someone could declare as disability (University of Durham, 2010b)

So having seen the changes in the disability law, it is useful to see explore the idea of the inclusive education and see whether it is feasible to achieve an all-inclusive educational system for all students.

### 3.4 Inclusive Education

The idea of the inclusive educational system, which is “*the education of all children, which necessitates serious changes, both in terms of society and its economic social conditions and relations...*” (Barton, 1998 [a], p: 60) is going to be discussed next. Inclusive education is an issue which has been the central point of discussion in recent years and especially since the “*Salamanca Statement*” (UNESCO, 1994), as the ideal educational system which will fight discrimination and the exclusion of students with disabilities. UNESCO’s World Conference on Special Needs Education, held in Salamanca, Spain, in 1994, made it clear that the future direction of the special needs field lies in the efforts to ensure that all children receive basic education (Ainscow, 1997; 2005; Lindsay, 2003; Hornby, 1999). In many countries, the Salamanca Statement was used to create strategies that will support movements towards inclusive schooling for students with special needs. Based on the Salamanca Statement every child with his/her unique characteristics, interests, abilities and needs has the right to education. Each school and educational institution should take into consideration those needs and accommodate them within the mainstream schools (UNESCO, 1994). The inclusive schools which will make every arrangement possible to educate all children including those with disabilities and disadvantages as a result of their needs will not only achieve the education of all children but at the same time will develop the concept of inclusion within society. Inclusive schools help to minimize attitudes which lead to discrimination against disabled people or people with differences; in general, they lead to inclusive societies (UNESCO, 1994; Barton, 1999; Farrell, 2001).

As has already been discussed in a previous section, one of the purposes of Higher Education is to promote democracy, which in turn will lead to better societies, without discrimination against minority groups and with respect and understanding for each person, despite their needs, abilities or other differences. An inclusive educational system arguably aims at, and at the same time is based on, that same idea of democracy through education. Inclusive schools and Higher Education Institutions, promote the basic ideas of a democratic society, which will lead to

inclusive education. Therefore, there is a link between democracy and inclusive education, which should not be ignored.

Inclusive education was seen as a means to remove barriers, improve outcomes and remove discrimination (Barton, 1999, 1998[a, b]; Lindsay, 2003; Hornby, 1999; Ainscow, 2005; Knight, 1999). Barton makes it clear that

*“Inclusive education is not integration and is not concerned with the assimilation or accommodation of discriminated groups or individuals within existing socio-economic conditions and relations. It is not about making people as ‘normal’ as possible.... It is ultimately about the transformation of a society and its formal institutional arrangements, such as education. This means change in the values, priorities and policies that support and perpetuate practices of exclusion and discrimination.”*  
(Barton, 1999, p: 58)

Inclusive education accepts that the differences that each person has are part of his/her individuality and these differences are normal and acceptable. The aim is to adjust the learning and education to these differences and to find ways to adapt education to students’ needs and not the other way around. There should not be a case of students who have to adjust and fit to the educational system and the normal learning processes and standards that schools provide (Ainscow, 2005).

Inclusive education is beneficial not only for students with disabilities and learning difficulties but also for all students. First, it is going to teach all students to accept and respect the differences and the abilities of others and this will have positive results for society in general. As Barton (1999) argues, *“education has a part to play in combating injustice and discrimination both within and outside the educational system...”* (Barton, 1999, p: 59) The way that the curriculum is structured, together with the teaching and learning techniques and the physical structures of schools and institutions, all constitute the barriers that have to be challenged and changed, in order to achieve an educational environment suitable for all students, regardless of abilities and disabilities. These barriers, whether physical,

social, economic or even attitudinal, have to be challenged and removed both from within schools and Higher Education Institutions, but also from the wider society (outside of the educational institutions) in general, in order to see the benefits to the whole of society (Barton, 1996, 1998 [a, b], 2002).

Still, the previous turn to marketisation affected the educational system in recent years, as has been discussed earlier, gave rise to ideas of competition and selection processes, which lead to inequalities and discriminatory attitudes within education. The competition between educational institutions together with the use of any means possible in order to select the 'best' students for each university or educational institution, not only promotes inequalities between students and discriminates against students with disabilities and learning difficulties, but also leads to the exclusion of specific groups of students. This of course should not be the aim and the purpose of educational institutions (Barton and Slee, 1999). The competition between universities for students may have increased the number of students who entered Higher Education. In some cases, it might even have been a step towards better provision and services for students, in order to attract them. However, it also led to discrimination and unequal treatment of those students who chose from the beginning to disclose their difficulties or disabilities (Barton and Slee, 1999; Barton, 1998 [b]).

The inclusive educational system, which will fight all these discriminatory attitudes and will remove the barriers that keep disabled students outside Higher Education, could not avoid criticism by some. Those who criticize inclusive education believe that inclusion is not a realistic goal for special education and that the theories and policies are quite far from the actual practices of an inclusive education (Hornby, 1999; Farrell, 2001).

The concept of inclusion is related to the social model of disability, which wants full access to all areas of independent living, including of course education and employment. As well as the inclusive schooling and the changes that have to be made at the primary and secondary levels of education, the same adjustments have to be made in Higher Education to achieve inclusion. Again, the transition and the changes cannot be achieved without cooperation between students, academic

teaching staff, government and Higher Education administration (Barton and Slee, 1999; Fernie and Henning, 2006).

Therefore, the idea of inclusive education together with the reasonable adjustments for students with disabilities and learning difficulties requires us to challenge our definitions of learning and teaching and to re-think the techniques that are used today, when we have a more standardised and less inclusive education. Practices such as providing lecture notes and having in place support and provision for all, not only for students with learning difficulties, together with statements which will explain the help available for students for each university are among those changes and reasonable adjustments which are required in order to have an inclusive educational environment in Higher Education Institutions. To what extent Higher Education Institutions are willing to change in order to accommodate the needs of students with disabilities and what they mean by accommodations and adjustments compared to what individual students need are some of the issues that are going to be discussed based on the answers from the interviews with students with learning difficulties.

The challenges of making those reasonable adjustments, in order to accommodate students with disabilities and especially those with learning difficulties, and the tension between the turn to marketisation in Higher Education and the inclusiveness that the institutions want to provide are discussed next.

### 3.5 Higher Education and reasonable adjustments

The reasonable adjustments that Higher Education Institutions have to make are not obtained without a struggle. Since Higher Education Institutions are consisted of quite a large number of members of staff who obviously might have different knowledge and understanding of disability awareness and sensitivity, it is assumed that, the persuasion process for everyone within a Higher Education Institutions would not be an easy task. In addition, the competitive nature of the universities to achieve higher scores in Performance Indicators, may take the focus away from the purpose of teaching and learning towards other aspects that do not include disabled students. As was explained above, the increase in the number of students could lead to a more standardised and less personalised education, where the needs of disabled students cannot always be met (Riddell & Weedon, 2006).

Dyslexic students and students with learning difficulties in general can pose particular challenges to the idea of absolute standards in Higher Education. This could be because they challenge the traditional forms of assessment that are used by institutions to assess students' work. In these cases, "*the onus lies with the institution to find new forms of assessment which will no longer penalise students with learning difficulties*" (Riddell & Weedon, 2006, p: 58).

On the other hand, Stage and Milne (1996), writing about students with learning disabilities at a college level, argued that it is not always within the priorities of professors to identify students with learning disabilities and modify their teaching techniques in order to accommodate those students. There are those tutors and lecturers who argue that since learning is the primary scope of the university and students with learning difficulties are not good at that, then there is nothing to be done. However, learning in Higher Education refers to "*a state of mind over and above conventional recipe or factual learning*" (Barnett, 1990, p: 149). It is not just a case of listening to the lecturer and writing down notes and essays. It is a case of understanding what students have learned, to conceptualise the knowledge they received and even to criticize what they have been taught, instead of just accepting it as a fact.

Based on this it could be argued that with reasonable adjustments students with learning difficulties can achieve learning in Higher Education. Reasonable adjustments, on one hand, are what the law requires from the universities to provide for students with disabilities, but on the other hand, what each institution understands or defines as reasonable is another matter. In addition, the extent to which each university is prepared to apply those adjustments is something that is open to discussion. Research by Wolfendale and Corbett (1996) noted that new universities were more used to teaching non-traditional students than pre-92 universities. Whereas traditional universities had to establish learning support services to meet the needs of the expanded student population, these were often already in place in new universities (Wolfendale and Corbett in Riddell, Tinklin and Wilson, 2002). Research by Riddell, Tinklin and Wilson (2005) showed that even though some progress has been made in most of the participant institutions regarding administration, examinations and assessments and student support, the area with the least progress made and the need for significant changes was teaching and learning.

Teaching and learning is an area which many believe is the most problematic, as it is considered the main purpose of Higher Education. It is believed that if the existing learning and teaching approaches are to change, there is the risk of ‘losing’ the standards that the institutions have set for all students. Some people would argue that the entry of disabled students into Higher Education challenges these standards as they have argued that the assessments and the teaching and learning techniques are discriminatory against students with learning difficulties. Therefore, the institutions have to change the teaching and learning techniques they use, while at the same time they have to keep the fairness for other students (Riddell & Weedon, 2006).

Any changes or adjustments to this area will mean re-examining the ‘standards’ of Higher Education and its scope. Brueggemann, White, et al., (2001) argue that

*“Reasonable accommodation for LD means questioning our definition of intelligence and questioning how integral certain teaching and testing methods truly are to Higher Education”* (Brueggemann, White, et al., 2001, p: 372).

Academics, among their excuses for finding it difficult to provide extra help for disabled students, argue that there is an increased pressure from universities for publications and research, which does not leave much time for adjustments. In addition, they do not want to provide their lecture notes in advance because the students they will not attend their lectures, or because they do not use lecture notes for their teaching. Others have claimed that providing more help to some students would be a discrimination against the other students who will not have this extra help. At the same time, concerns about the effects of lowering the standards for some students was mentioned together with the lack of training in order to deal with students with disabilities (Riddell, Tinklin and Wilson, 2005, 2002; Stage and Milne, 1996).

Of course, the overt intentions of the disability laws, which universities have to follow, are to provide equality of opportunities for disabled students. However, some argue that although the DDA, which protects the disabled students from discrimination and asks for reasonable adjustments to be made, by universities to accommodate disabled students, explains what a reasonable adjustment could be, it also gives some parameters under which something is reasonable (Riddell, Tinklin and Wilson, 2005, 2002). The parameters that have to be considered by institutions before any changes could be made to accommodate disabled students include the need to maintain academic and other prescribed standards; the financial resources available; the cost of taking a particular step; its practicability; health and safety requirements; and the relevant interests of other people, including other students. If any of the above factors/parameters are considered that are to be in jeopardy then the institution may discriminate against disabled students without this been considered are acting unlawfully (Riddell and Wilson, 2006, p: 59).

These parameters could be misunderstood and interpreted by universities in different ways. For example, universities have to take into consideration the need to maintain the academic standards before they make any adjustments. Already some researches (Riddell, Tinklin and Wilson, 2005, 2002; Stage and Milne, 1996) have shown that tutors consider providing more help and support to disabled students an act of lowering the standards and clearly this is not something that they are prepared to do.

The undeniable turn of Higher Education towards an increasingly competitive big business, and the fact that they encourage disabled students to apply, means that disabled students are more likely to respond if provision is good and the institution earns a positive reputation in this respect. However, provision and special adjustments are not easily made or applied to universities for reasons that have been outlined above. Maybe the lack of funding, workload etc is the reason for not being able to provide the appropriate services and provision for disabled students. However, it causes even more concern that the lack of disability awareness and appropriate services for dealing with disabled students' needs are the real problems (Riddell, Tinklin and Wilson, 2005, 2002; Stage and Milne, 1996; Barnett 1990). Until now, within the university, disability has been perceived as a problem of individual students who, as a result, are often unable to access course information via the available systems. This perception reflects the medical model of disability (Oliver, 1990), which constructs disability in individual terms influenced by concepts of normality, as defined by current thinking. The acceptance of the social model of disability and a broader interpretation of disability are the key elements which should lead to possible improvements in disabled people's life within Higher Education Institutions (Holloway, 2001; Barnett, 1990).

As Stage and Milne (1996) explained, students with learning difficulties want to go to Higher Education because either everyone else goes too, other members of their family go too or want them to do so or even because they want to have prestigious job later in their life. In addition to these reasons, studying at university is potentially empowering for disabled students, as well as, for other students. Higher Education offers everyone opportunities to obtain knowledge, develop social skills and experience empowerment, through the gaining of qualifications and the learning process in general (Hurst, 1996).

Next a discussion about the idea of the 'old and new school' lecturers, which refers to their attitudes regarding teaching and learning and the adjustments that have to be done for students with learning difficulties, is going to be explored, though the current literature. As it will be shown later, this argument about lecturers is something that was mentioned by almost all of the Directors of the DSUs, which makes it an interesting issue to mention.

### 3.6 Old and New school teachers and existence of dyslexia

Related to the arguments about challenging the teaching and learning techniques in order to accommodate disabled students, which some argue that would change the purpose of education (Riddell & Weedon, 2006), is the issue about the so-called old and new school teachers. This issue was apparent from the interviews with both students and members of staff (particularly the Directors of DSUs) By that, we mean that some lecturers seem to be more prepared to adjust their teaching and learning techniques and attitudes to accommodate students with disabilities, while others find it more difficult. Of course, this is not only regarding the attitudes of lecturers but it rather could be seen in other members of staff's attitudes towards disabilities. In addition, there are some debates regarding what dyslexia is and whether actually all those students who are diagnosed with dyslexia are actually dyslexic. These issues will be explored here through the literature, while later in the thesis will be seen through the interviews with students and members of staff.

Research (Tinklin, Riddell and Wilson, 2004[a, b]) shows that senior managers in Higher Education Institutions agreed that during recent years Higher Education has seen many changes, such as reductions in funding, an increase in workloads due to the expansion in student numbers and the pressure to publish performance indicators. Also among the changes is the introduction of premium funding on the basis of the number of students from under-represented groups, such as working-class background, disabled students, students from ethnic minorities etc, who are accepted in each institution. The amendments to the DDA in order to widen access to disabled students and the need for new policies which will provide help and support for those students also added pressure to institutions and their managers. The same research shows that there are signs of progress for those students and especially for students with disabilities, but among the areas where more difficulties were reported by students was the teaching and learning. This area includes the changes in attitudes and the ways that lecturers use to teach disabled students in Higher Education Institutions (Tinklin, Riddell and Wilson, 2004[a, b]).

The lecturers who follow the “*old school*” teacher’s example, who do not adjust their teaching methods and practices in order to accommodate the needs of students with disabilities, explain that it is not their job to provide extra support and help for those students. Furthermore, they believe that any adjustments for disabled students may be seen as unfavourable treatment for the rest of the class, or that if they give the lecture notes in advance then students will not attend classes. Moreover, some say that the university requires them to maximise their efforts in research and that it is the research that matters more than teaching, therefore, any emphasis should be towards better research and not better teaching techniques. The Research Assessment Exercise (RAE) puts extra pressure on Higher Education Institutions and lecturers to lean towards research more than teaching, in order for the university to gain more funds (Tinklin, Riddell and Wilson, 2004[a, b]; Riddell, Tinklin et al. 2005; Borland and James, 1999). The emphasis on research and the ‘distance’ from teaching can be seen as one of the consequences of the changes that the New Managerialism and the turn towards marketisation, have brought to Higher Education. The shift in interest in Higher Education from learning and teaching, towards higher scores in Performance Indicators, gaining funding for research, and in general, meeting all the requirements for a better business, does not allow lecturers and other members of staff to concentrate on students’ needs. (Bligh, Thomas and McNay, 1999; Halsey, Lauder, et al., 1997; Deem, Hillyard and Reed, 2007; Barnett, 1990)

Related to the issue of the unwillingness of some lecturers to provide support and help for those students who may need it is another issue regarding the arguments by some around learning difficulties and more specific regarding dyslexia. Reviews on dyslexia by Rice and Brooks (2004) concluded that “... *the condition was poorly defined and methods for judging the outcome of ‘treatments’ were unreliable*” (Riddell, and Weedon, 2006, p: 63) The main debate about dyslexia is the effectiveness of the methods that are used to define it, as well as the definition that different organisations give to dyslexia. For example the British Dyslexia Association and the Dyslexia Institute give definitions based on physiological differences, whilst the British Psychological Society adopts a more inclusive definition, which has been criticised because it does not clearly separates people with generic learning difficulties from those with dyslexia. Therefore, it seems that there

are still concerns about the best and more accurate definition of dyslexia, whether it is caused by single or multiple factors and how the educational system should be adjusted to accommodate the increased numbers of students who are dyslexics. (Riddell, and Weedon, 2006)

Through the interviews with both students and members of staff we will see whether these debates and concerns regarding learning difficulties and dyslexia in Higher Education that are mentioned in the literature are actually among the issues that these people are going to mention.

The chapters that will follow will explore the practice of an all inclusive educational system, through the lens of students with learning difficulties and members of staff. As will be shown, it is quite a different matter to advertise the adjustments that universities are prepared to make in order to attract more students with difficulties, and a different issue when attempts are made to achieve those adjustments in everyday activities between students and members of staff

## **Methods**

### **4 Methods**

#### **4.1 Introduction**

This chapter aims to give an outline of the methodology and the methods that were used for the completion of this research. The study involved students (N=18) with different learning difficulties, including dyslexia, Asperger's syndrome, dyspraxia, dyscalculia, dysgraphia, Obsessive Compulsive Disorder (OCD) and agoraphobia from four universities in the North East of England (Durham, Newcastle, Northumbria and Sunderland). In addition, interviews with the Directors of the Disability Support Units from these institutions, as well as members of staff from Durham University are also included in the study.

The first section of the chapter justifies the choice of qualitative methodology for this research study. A combination of methods was used for the collection of the data, such as semi-structured interviews and review of the literature. Here, the reasons that these methods were considered appropriate for the research are explored. Finally, the process of data analysis for the research is described, and some of the problems and limitations of the project are identified.

## 4.2 Methodology

The choice of qualitative methodology lies in the nature of the research problem. As the project attempts to understand the experiences of students with learning difficulties and the problems they are facing while studying in Higher Education Institutions because of their difficulties, the best way of achieving that is through qualitative methods such as in depth interviews.

Qualitative research is the approach that aims to interpret and analyse the culture, behaviour and lives of humans in society. It achieves that by taking as a point of origin and as the main interest the views of those same people who are studied, so it produces findings, which come from 'real-world settings' and not laboratory constructed tests (Bryman, 1988; Strauss and Corbin, 1998; Patton, 2002). Because it has its philosophical groundings within the interpretative paradigm supporters of qualitative methodology argue that the world cannot be simply explained by using the same techniques as those in natural sciences. The social world is more complex and researchers need to have in mind the influence and the role that humans play in social worlds. Humans are conscious beings, aware of what is going on in a social situation and capable of making choices about how to act. Therefore, for the supporters of interpretative sociology, the task of the researcher is to discover and understand the various systems of meanings that we, as actors, use to make sense of, and play our part, in the social world (McNeill, 1990).

As the main issues of this research are disability, stigma, labelling and provision for students with learning difficulties, it was considered appropriate to talk directly to students, in order to give them the chance to discuss their experiences and views on those issues. The research deals with topics that are considered quite sensitive as they have an effect on students' identity and life and, as such, they have to be treated with the appropriate methods in order to understand them.

The characteristics that are essential for research like this are openness, flexibility and communication, which are all found within qualitative methodology. Because there were no pre-determined hypotheses to be tested, qualitative methodology, as grounded theory, benefits from the fact that there is a potential for an approach that

is not constrained by scope or orientation. The areas of study were chosen and then the data ‘determined’ the relevant theories, which helped with the interpretation of the experiences and views of students with learning difficulties. With qualitative methodology, there is the flexibility to change some aspects of the research and even the methods of data collection when this is considered appropriate for the benefits of the research.

The communication between researcher and subject is also a very important element for qualitative research. The relationship itself is important, as the subject defines the scope and flow of the research to an equal extent (Bryman, 1988). With the interview the interviewer has the chance to observe the body language of the interviewee, the facial expressions and the pauses or silences that have a significant importance for the interpretation and the understanding of the reality that the interviewee tries to define.

Of course, it is very important for the researcher to be careful enough not to dictate to participants what he or she wants to hear from them, because the researcher may get the desired results but these may not be the true. On the other hand, it is good for the participants to have a general idea of what is expected of them, as this helps them to concentrate on the subject of the project. Even though this is true, it is sometimes quite useful to leave the interviewee to “...*ramble and move away from the designated areas in the researcher’s mind...*” (Measor in Bryman, 1988, p: 46) as this will reveal issues and topics which interest the interviewee. However, usually the success of interviewing depends largely upon the ability of the interviewer to maintain a constructive relationship with the participant, while ensuring that the information needed to meet all the aims of the project is collected (Bailey, 1987; Bryman, 1988; Seale, 2004).

### 4.3 Methods

As the aim is to explore and discuss the experiences and the views of both students with learning difficulties and the perspectives of members of staff on provision for these students within Higher Education, qualitative methods served the purpose of this project better than any other method.

According to Weber's *Verstehen* sociology, sociologists have the ability to understand the social phenomena, not simply by intuition, sympathetic participation or empathy.

*“To him, verstehen involved doing systematic and rigorous research rather than simply getting a feeling for a text or social phenomena. In other words, for Weber (1921/1928) verstehen was a rational procedure of study”* (Ritzer, 2003, p: 114).

The main research methods associated with qualitative research are i) ethnography/participant observation; ii) qualitative interviewing; iii) focus groups; iv) language based approaches to the collection of qualitative data, such as discourse and conversation analysis and v) the collection and qualitative analysis of texts and documents. It is also possible in qualitative research to combine more than one research method, for example, researchers employing ethnography or participant observation frequently conduct qualitative interviews (Bryman, 2004; Silverman, 2004; Silverman 2005).

#### 4.3.1 Interviews

Because of issues of confidentiality and sensitivity about the identity and the issues, which are discussed with the students, the Directors of the four Disability Support Units and the lecturers and college officers from Durham University, qualitative research methods and specifically interviews were considered as the best choice for this research. Having in mind the fact that the students' participants have specific learning difficulties, which in some cases include writing and spelling difficulties, it was unrealistic to ask them to fill in questionnaires and elaborate on their views and feelings. Therefore, for practical reasons semi-structured interviews were chosen in order to give each student the chance to express their feelings and thoughts on the problems and the experiences they have in their everyday interactions within the community of their institution.

Interviewing is so common in the social sciences that it is quite often considered 'the' method of social science. For some researchers who use qualitative methodology, the open-ended interview is considered the best method as it gives them "...the opportunity for an authentic gaze into the soul of another..." (Atkinson and Silverman, 1997, p: 305). However, this claim of authentic-personal experiences of people through interviews has been challenged by some other researchers who are concerned with the widespread adoption of the interview as the preferred method of qualitative research. They argue that in the contemporary society where we live interviews do not always offer the authenticity that the researcher wants to show. Atkinson and Silverman (1997) argue that

*"...qualitative research often seeks merely to elicit personal narratives of experience or confessional revelations. It is congruent with the dominant forms of the interview society that the predominant technology of social research is the interview"* (Atkinson and Silverman, 1997, p: 309).

Atkinson and Silverman (1997) argue that in the contemporary interview society that we live in the interview is becoming a personal confession and that some researchers imply that people's experiences are individually meaningful and authentic, but as they say this is not always a case (Atkinson and Silverman, 1997; Silverman, 2001).

Those who support the use of interviews in social science research argue that with interviews, in contrast to questionnaires, the researcher has the chance to ask the participants to elaborate on answers that they gave. In addition, based on participants' answers they have the chance to learn about topics which may be important but the researcher did not think about when she/he was preparing the semi-structured interview guide.

Clarifying the meaning of what they have said is another important part of the interview. Given that this method (interview) places a high value upon determining the meaning and interpretations which people have of the world, it is a matter of the greatest importance to get these right. One technique for ensuring validity is termed respondent validation, which means checking your interpretations with the person who gave the response (Robson, 1993; May 2001).

There are different styles of interviews such as 'unstructured interviews', semi-structured interviews' or structured interviews. For this research, the semi-structured interviews were considered the most appropriate method of data collection for the following reasons: first of all, semi-structured interviews give the researcher flexibility and offer freedom to follow up on any leads or on interesting responses that the interviewee gives. At the same time semi-structure interviews give some kind of structure, which is absent in unstructured interviews, because in cases like these where the issues of interest are considered sensitive there is the possibility that there might be moments of silence or very short responses to particular questions. Therefore, there is the need of some kind of structure which will help both the interviewer and the interviewees to overcome these moments and to go on with other aspects of the research subject. At the same time,

*“open-ended questions often do not facilitate people with learning disabilities in speaking fluently, because they usually give very short answers and wait for the next question”* (McCarthy, 1998, p: 140).

Therefore, the semi-structure interviews were considered the most appropriate method of data collection, and were used in order to get the information that was necessary, while at the same time, gave the chance to participants to elaborate on issues, identify others that participants considered interesting to mention and also it allowed for more in-depth discussion.

The choice of interviews, and more specific of semi-structured interviews was also based on the fact that the major participants were students with learning difficulties. In some cases the nature of the disabilities could include difficulties with writing and spelling, which made it unpractical to ask participants to fill in questionnaires and elaborate their views on forms and reports as there was the possibility to make them feel uncomfortable about their writing or spelling mistakes.

At the same time, the semi-structured interviews were also used for the interviews with the Directors of Support Units, the lecturers and the college officers. They were also useful as they gave the participants the chance to elaborate on their views, or to mention issues, which they thought, are important and they had to be mentioned regarding the issues of students with learning difficulties.

#### 4.3.2 Validity, Reliability and Ethics in qualitative research

Validity and reliability are among the key research concepts in social research. A number of qualitative researchers (Altheide and Johnson, 1998; Leininger, 1994 etc) argue that terms like ‘validity and reliability’ are more appropriate in quantitative rather than qualitative research (Morse, Barrett et al., 2002). Guba and Lincoln, in the 1980s, substituted these two terms with ‘trustworthiness’, which, they explained, consists of four aspects, which were *credibility, transferability, dependability and confirmability* (Morse, Barrett, et al, 2002 p: 2). When we talk about reliability-trustworthiness in qualitative research, we refer to the ‘quality’ of the research. A good qualitative study aims to help people understand the phenomena, situations and behaviours that are studied. Therefore, the concept of quality in qualitative study aims to ‘*generate understanding*’ (Stenbacka, 2001 in Golafshani, 2003).

Guba and Lincoln (1981) recommended that the specific strategies such as “*negative cases, per debriefing, prolonged engagement and persistent observation, audit trails and member checks*” (Morse, Barrett, et al, 2002, p: 5) have to be used to ensure trustworthiness in qualitative research. Others like Silverman (2001) and Seale (1999) argue that reliability in qualitative research is achieved with “*low-inference descriptors*” (Silverman, 2001, p: 226). As far as interviews are concerned, this ‘low-inference descriptors’, which ensures reliability, can be achieved by

*“Tape recording all face to face interviews, carefully transcribing these tapes to the needs of reliable analysis and presenting long extracts of data in your research report...”* (Silverman, 2001, p: 230).

Following the work of Kahn and Cannell (1983), Moser and Kalton (1983) suggest that there are three necessary conditions for the successful completion of interviews: *accessibility, cognition and motivation*. Accessibility refers to whether or not the respondent has access to the information that the researcher wants to learn about. There are many reasons why the respondents may not reveal the information that the

researcher requires, such as personal, political, ethical reasons, which prevent the interviewee from answering the questions. The second necessary condition is cognition, which means the equal understanding between the interviewee and the interviewer about what is expected, and what their roles are during the interview. As it was discussed above, it is important for the interviewee to have a fair understanding of what the subject of the research project is and what the interviewer expects from his participation. Without this, the person being interviewed may feel uncomfortable and this affects the resulting data. For this reason, clarification is not only a practical, but also an ethical and theoretical consideration. Finally, a necessary condition for a successful interview is for the interviewer to motivate the participants and encourage them by making them feel that their participation is vital for the project. In order to do this the interviewer needs to maintain an interest during the whole interview (May, 2001).

Together with validity and the reliability, *ethics* is something that is quite important in both social research and interviews in particular. Ethics refers to the decisions and promises that have to be mutually accepted and agreed by interviewers and interviewees in order to avoid problems like uneasiness, awkwardness, discomfort and ethical dilemmas during or at the end of the interview.

As with all social research and research projects in general, the consideration of ethical issues is a fundamental part of the whole research process and has to be taken under serious consideration. More care should be taken when the research is “*socially sensitive*”, which means that there are social consequences for both the participants (in this case the students with learning difficulties) and for the whole class of people that are represented by this research (disabled students). (Sieber and Stanley, 1988).

This particular research, where participants are students with learning disabilities, could be considered “*socially sensitive*” (Sieber and Stanley, 1988) as it is possible the attempts of ‘levelling the field’ for students with learning difficulties, (by providing support and provision within higher education) to be seen by some as an attempt to give disabled students an advantage over students without disabilities. The later will have consequences on the way that others see and treat students with learning disabilities. Therefore,

*“... research methods associated with sensitive research among people with learning disabilities need to be carefully selected so as to be ethically appropriate and unobtrusive”* (Tuffrey-Wijne, et al, 2008, p: 187)

It is true that the last years advances in the social position of people with learning disabilities have led to more and more researches that concerning issues in the lives of these people to actually include people with learning disabilities as participants. (Stalker, 1998; Gilbert, 2004) However, the fact that now there are numerous researches that involve people with learning disabilities, does not necessarily mean that all the potential difficulties involved in seeking people’s views have been resolved. Researchers have to consider all the ethical issues before planning and conducting a sensitive research which involves people with learning disabilities. Among the ethical issues which have to be taken into consideration for research with participants with learning disabilities are “*consent, confidentiality and anonymity*” (Sieber and Stanley, 1988; McCarthy, 1998; Swain et al, 1998; Lewis and Porter, 2004; Tuffrey-Wijne, et al, 2008). The interviewer has to ensure that the participants understand what the research is about and its purposes. For this reason the interviewer-researcher has to make sure at the beginning of the interview, or even before the participant agrees to participate, that the interviewee has a clear understanding of the nature of the research, and the main aims and objectives of the research, in order to give a knowingly consent when he/she will be asked for. Especially with participants who have learning disabilities, the researcher has to explain the purpose of the research as better as possible without of course this implying that the researcher patronises people with learning disabilities, as if they could not understand the nature of the research in which they are asked to participate. However, in some cases, it might be possible that the severity of the learning difficulty creates additional difficulties to the participant to fully understand the context of the research and the purpose, or what it is expected from him/her.

Depending on the case, it is quite useful the researcher to have a few informal meeting with the participants before the actual interview in order the participant to get to know the researcher. However, for ethical reasons this attempt for familiarity

should not create false expectations for friendship beyond the research period. (Rogers, 1999 in Gilbert, 2004)

In addition, since the participants are people with learning difficulties the researcher should consider those when preparing materials for the participants. Alternative formats of any materials that are given or need to be used from participants should be prepared, in order to help them to have full access to that material (Rogers, 1999 in Gilbert, 2004)

At the same time the researcher not only in cases of interviewing people with learning difficulties but in all cases, ought to make as clear as possible the role that he or she has in relation to the body that does the research. For example if in a case like this dissertation the researcher is a student this should be clear so that the participants should not conclude that the researcher works or represents the disability unit or the university. This knowledge will help participants to open up when are asked to evaluate and assess the services they receive from university.

Here it is essential to mention the role of the gatekeepers who in some cases is mistaken as the people who will make the decision about the consent or not of people with learning disabilities (Sieber and Stanley, 1988; McCarthy, 1998; Swain et al, 1998; Lewis and Porter, 2004; Tuffrey-Wijne, et al, 2008). The gatekeepers, who could block access to potential participation in research for people with learning disabilities, could be their parents, organisations, professionals or support workers etc, or as in the case of this particular research the Disability Support Units (DSUs) of each university the participant students belonged to. It is important to have the consent of people with learning disabilities and their agreement to participate because they have understood and agreed on the purpose of the research and not to allow the gatekeepers to make that decision for them. The gatekeepers have their own views and opinions about the value of the research and who should or could be allowed to participate. However, this should not allow them to make the final decision about the participation or not of people with learning disabilities. As it will be explained later there were some issues with gaining access to students with learning disabilities because of the role that the DSUs played and that affected the final number of participant students for this research project. Overall, the knowingly consent of participants is an ethical issue which plays an important role in research

especially when the research involves people with learning disabilities and touches sensitive topics as their experiences.

In addition, other ethical issues which are important for social research is *confidentiality and anonymity*. When the research is based on asking people with learning disabilities to share their personal experiences and their views of the services they are offered, then it is necessary for the researcher to ensure that the issues of confidentiality and anonymity of the participants are taken care of. It is essential that the researcher has taken all measures to ensure confidentiality and anonymity of the participants, during the whole process of the research and not just to offer reassurances of confidentiality and anonymity without been sure that he/she can keep these promises. In some cases it might be the nature of the disability within the specific sample of participants that can lead to identification of the participant. For example, if there is only one student with agoraphobia within a specific department and the department is named within the research, even if the researcher does not identify the participant the fact that the department is known and that there is only one case of student within it, makes is automatically identifiable the participant, which breaks the promise for confidentiality and anonymity of participants. Even though this is just an example and did not happen in this research, in some cases it was necessary to alter some of the personal details of the participants in order to protect their identities. However, the details that I changed, such as the participants' sex or year of study, they are only minor details which did not play a key role to the analysis of the cases or did not alter the findings. Therefore, it is important for the researcher to take every necessary steps during the whole process of collecting and analysing data, and even writing of the report, in order to protect the confidentiality and anonymity that it was promised to participants (Rolph, 1998; Gilbert, 2004; Lewis and Porter, 2004; McCarthy, 1998) Especially, in cases where the participants are people with learning disabilities where there is still the issues of "*shame and stigma attached to having a learning disability*" (Rolph, 1998, p: 135) the ethical issues of anonymity and confidentiality have to be taken into special consideration by the researcher/interviewer, in order to protect the identities and the lives of these people.

#### 4.3.3 Data collection – population and interview guide

The research used a combination of research methods. Of particular importance was the use of semi-structured interviews, the results of which informed a dialogue with the wider literature. I also used written documents, such as journal articles, websites, documents from the universities etc, as secondary literature in order to gain a wider and more complete view of the issues around provision for students with learning difficulties in Higher Education.

At the beginning, the study aimed to see the differences and similarities between four well-known institutions in the North East area of England (Durham, Newcastle, Northumbria and Sunderland) given that in the literature the significance of the binary divide was emphasized (Williams, 1992; Tinklin, Riddell, et al. 2004 [a, b]). The most important role for the selection of the institutions for this research was the fact that two of the universities are so-called ‘old universities’ [Pre-1992] (Newcastle and Durham), while the other two are ‘new universities’ [Post-1992], such an approach suggested itself as a useful strategy. However, since the recruitment was unequal across institutions students from the four institutions was not equally distributed, as the majority of the students were from Durham University, it seemed reasonable to concentrate at this institution. Of course, the data collected from the other institutions have been used as well, as they provided an over-arching framework which discusses support and provision within North East universities.

Therefore, the final population of the research was students with learning difficulties who study in one of the four pre-chosen universities, who were self-selected by responding to a general invitation to participate by either e-mail or a letter, which were both circulated by the disability units in each university. In addition, four interviews with the Directors of the Disability Support Units from each university were added to give the point of view of the universities on issues around services and provision for students with learning difficulties. The focus at Durham University led to additional interviews with members of staff from colleges and lecturers from different departments in order to have a better picture of the provision for students with learning difficulties in that particular institution.

From the population, only students with learning difficulties were considered, which means that students with physical or mental or other disabilities were excluded from the research. Only the students registered with the support services of the university could be contacted and also those who were not registered but had visited the support units and had picked up the leaflet that was there had the chance to be participants. In some cases, in order to find more participants I contacted some departments from the Universities of Newcastle and Durham and the administrators agreed to send the e-mail to all their students because they could not identify only the students with learning difficulties. In the end, the sample consisted of 18 students from the four universities, but they are not equally divided between the universities. The first table below shows the number of participants from each university. While the next table shows the participant members of staff from each institution (Directors of DSUs, college officers and lecturers). Institutions were first divided into New Universities; hence post-92 institutions and Old Universities (pre-92 institutions) and their names were coded using letters. The same coded system was applied to Directors of each institution where each Director was coded with the same letter as the institution he/she represents. For the members of staff who are from Durham University their names were also replaced by letters. Table 3<sup>8</sup> summarizes the background information for participant students. As it shows there are 10 males and 8 females' participants, while the majority of them were in their early 20s. Also the majority of the participants studied full-time and they were on their last (3<sup>rd</sup>) year of their studies. Thirteen out of the eighteen participant students disclosed dyslexia as their learning difficulty and six of them also mentioned another disability in addition to dyslexia.

Participant students from each institution

	<b>University of Durham</b>	<b>University of Newcastle</b>	<b>University of Northumbria</b>	<b>University of Sunderland</b>
<b>Number of participants</b>	13	1	1	3

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<sup>8</sup> Appendix 1

### Identification codes for members of staff and institutions

<b>Members of staff</b>	<b>Institution</b>
Director of DSU a	Post-1992 a
Director of DSU b	Post-1992 b
Director of DSU c	Pre-1992 a
Director of DSU d	Pre-1992 b
Disability Officer	Durham University
College Officer a	Durham University
College Officer b	Durham University
College Officer c	Durham University
Lecturer a	Durham University
Lecturer b	Durham University
Lecturer c	Durham University
Lecturer d	Durham University

For the semi-structured interviews that I used both for the interviews with the students, for the Directors of the Support units, the lecturers and college officers, I was particularly interested in the process at work with respect to the experience of the students themselves and the institutional contexts in which they worked.

The semi-structured interviews enabled each student to give an account of the aspects of their experience, which they considered relevant and important to themselves. Thus, the amount of information gathered about any one aspect of student experiences was variable, but all data is important and can be seen to be significant in its individuality (Abrams, 1982; Cuff, Sharrock and Francis, 1998; Ritzer, 2003).

The interview questions, for the students, were divided into six sections: a) biographical and general questions, b) questions about the condition and diagnosis of the learning difficulty, c) their experiences from school or prior to Higher Education (if they had been diagnosed earlier in their life), d) their experiences while in a Higher Education institution; their decision to go to Higher Education, the choice of course, university etc, e) questions regarding their interactions with the Disability Support Unit, the level of satisfaction with the services and provision etc. Finally,

there were questions regarding their relations with tutors, classmates and other members of staff from the university in relation to their difficulties.

Students' views and thoughts after the diagnosis were of particular interest, in order to see if the paradox of the diagnosis that the literature describes is something that applies in these cases. The majority of the interview questions were concentrated on their experiences from their university (including the support unit, tutors, classmates, other members of staff etc). At the beginning of each interview, some introductory questions were asked about the participants' studies, their choice of the university and the course, in order to develop a more friendly relationship with the respondents. They had to feel comfortable and relaxed about the interview.

In cases of the interviews with the members of staff from the institutions, the questions aimed to explore the University's official policy about provision and support for students with learning difficulties. The procedures that they follow, in order to help students to identify their difficulties, were explained in detail, while at the same time the available support and services for students were explored. An extensive part of the interviews with the Directors of Support Units was about their role in Higher Education institutions as Directors of Disability Support Units and the difficulties and the problems that their job involves. Issues like 'definitions' of learning difficulties for each university, reasonable adjustments and means to accommodate students' requests were explored together with their general experiences with students with learning difficulties.

At the beginning of the research I needed to collect some statistical data in order to see the number of registered students with learning difficulties in each university, the total number of registered students with disabilities and the total student population at the year of study. I collected the data from the Director of the Support Services from each university or from the official statistics that each university publishes either online or in printed documents. There are differences regarding the population of each institution (both in terms of total students population and in students with disabilities), as the statistics that have been given earlier in this report indicated.

The very first contact with the support services at each university was through the universities' websites. I found the website for each university and from there the e-

mails and the contact details either for the Director of the Support Services or for the Dyslexia Advisor. I sent them an e-mail<sup>9</sup> explaining the main research interests for my research and asking for an appointment to discuss the ways they could help me to contact students. After the first meeting, where I explained what my research was looking into and what I was asking of them, we decided to either send an e-mail to students or in one case to leave a leaflet<sup>10</sup> which explained the research and was asking participants to contact me at the reception within the Support Services Unit. In regards to lecturers and college officers from Durham University, I either sent the same e-mail to the appropriate persons within almost all departments and colleges (such as departmental or collegian secretarial staff) or I personally visited most of the departments and colleges, which did not replay to the initial e-mail, in order to help me to identify the most suitable person who could speak to me about provision for students with learning difficulties within that particular department or college.

After the initial e-mails to all disabled students who were registered with the services that had been sent by the Directors of DSUs, the participant students contacted me via e-mails in order to either ask more questions about the research or to arrange the meeting for the interview. The meeting arrangements were made through e-mails in order to find a suitable time and place for the interview. I explained to all students that I will go and meet them at their institution, at a place which I tried to make sure that it would be as quiet as possible. Therefore, in most cases I had asked the DSUs to arrange a room for us to use in their building, as it was a familiar place within the university for these students and there were rooms which could be quiet and suitable for an undisruptive interview. In some cases I was meeting the students in study rooms in university's library or in a meeting room within their college or I had arranged to go to their department, in order to make sure that the place where the interviews would take place would be quiet so that I could tape record the interviews. Usually the interviews were last anything between 45 min to 1h30min.

At the beginning of each interview I explained again the purpose of my research, even though the e-mail and the previous communications were as explicit as

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<sup>9</sup> See Attachment A

<sup>10</sup> See Attachment B

possible about the nature of the research and its purpose, the main subject of study etc. I made sure at the beginning of each interview that the participants knew that the interview was confidential and that the anonymity of the participants would be kept throughout the process of writing the report. I explained that I will put numbers in all interviewees and that the recordings will not be used by anyone else except of me and for the purpose of writing my PhD report. I also added that the interviewees' identities and contact details would be kept concealed even after the PhD thesis report and that not even my supervisors could see the participants' names and details. I felt that it was important to make that clear as the research was part of a PhD thesis and therefore I was also a student-researcher who had to report back to a member of staff (in that case supervisor) within an institution. It was also explained that they could withdraw from the study at any point if they felt that it was uncomfortable for them to participate, even at the end of the interview. After this short explanation of the procedures and after asking again whether they agreed to participate, the interview was conducted. Students were not offered to get a transcript of their interview as the process of finding participants and getting the interviews done and transcribing the interviews was a long procedure and by the time all that would have done some of the participants might have already finished their studies and would left the institutions.

The same procedures implied and for the participant Directors of the DSUs, the lecturers and the College Officers who participated in the research. After the initial agreement via e-mails to participate, I went to their offices to meet them and we had the interview done after they had been explained the purpose of the research and the issues of anonymity about the college/school/department they work in. Again, I used letters in order to identify and separate each Director/college officer/lecturer and letters to separate the institutions they are in. Most members of staff who participated asked for a copy of the findings/final report after the whole process of the PhD would be completed. Only one participant member of staff insisted on seeing the transcript of the interview as soon as I had completed it. After I sent it she commented on something that she thought was not so clear as it had been said on the interview, therefore, she explained it again asking if it was to be used this part for the final report to reflect what she was actually meant.

#### 4.4 Data Analysis

All interviews with students and members of staff were tape-recorded. The tapes were transcribed verbatim.

Comparative analysis was used as the main method of analysis. Using comparative analysis in research means that the researcher always starts with a case and then tries to find more cases, in order to 'test' the original hypothesis (Silverman, 2005; Strauss and Corbin, 1998). The purpose of the constant comparative method of analysis is to generate theory more systematically, not only with the help of the data that have been gathered during the research but also with the help of theoretical sampling, in cases where there is no other case through the research to compare it with it (Strauss and Glaser, 1967). The fact that there is no other case to compare this 'new' and 'unique' case with does not make it less important or less significant than the rest.

The data that were collected from the students' interviews were constantly compared with each other, within each of the general 'categories' of interest, based on the interview guide. More emphasis was given to the questions regarding their experiences during their school years (for those who were diagnosed early in their life), the support they receive from the university, their satisfaction with the support and provision. In addition, questions on how was the process of the diagnosis for those who were diagnosed when they entered Higher Education, their relationship with their tutors and classmates or other members of staff who knew about their difficulties etc were included in interviews. Finding similarities and differences among the different students' cases was the main aim of the comparison.

The data from the interviews with the Directors of Support Units as well as the other members of staff from Durham University, were also analysed by comparative analysis, in relation to both the answers they gave and those of the students. When the available data was permitting it difference or similarities between the institutions were identified, while at the same time when appropriate the members' of staff answers' were analysed and were compared with those of the students. This second comparative analysis aimed to explore the differences or similarities between the two

different perspectives: official university policy and students' views on the same issues. Finally, when appropriate quite extensive quotes from all the collected interviews were used to demonstrate the issues that were considered important.

Even though in some cases general conclusions were made regarding the majority of students or the departments/colleges, at the same time all cases were assessed individually and if an important issue arose just from one student's case or from a few, they were also outlined and analysed.

#### 4.5 Problems and limitations of the research

The interviews gave a great deal of information which could not have been collected with any other method. However, there are some problems which arise from the use of qualitative methods and more specifically from the use of interviews, and they are related to the very nature of this research.

Quantitative researchers sometimes criticise qualitative research as being too subjective. They usually mean that qualitative findings rely too much on the researcher's often-unsystematic views about what is significant and important, and upon the close personal relationships that the researcher frequently strikes up with the people studied.

The lack of repeatability of a qualitative study, which may affect the validity of the research and its findings, is considered among the limitations of the qualitative methodology. Therefore, the lack of repeatability, alone, in a qualitative study, cannot be seen as a weakness in the choice of qualitative methodology (Bryman, 2004).

The lack of standardization that it implies inevitably raises concerns about reliability. Biases are difficult to rule out. There are ways to deal with these problems but they call for a degree of professionalism, which does not come easily. Nevertheless, although the interview is in no sense a soft option as a data-gathering technique, it has the potential of providing rich and highly illuminating material. In addition to this, other things which are considered as disadvantages of using interviews as a research method are the time that an interview requires for preparation, and then for the actual interview sessions. The actual interview session will obviously vary in length. Anything under half an hour is unlikely to be valuable; anything going much over an hour may be making unreasonable demands on busy interviewees, and could have the effect of reducing the number of persons willing to participate, which may in turn lead to biases in the sample that you achieve. When an interviewer asks for participants and gives information about the length of the interview, it is important to be as specific as possible about the actual length of the interview. Also all interviews require careful preparation, which takes time. Arrangements to visit;

securing necessary permissions, confirming arrangements, rescheduling appointments to cover absences and crises, these need more time. Notes need to be written up; tapes, if used, require whole transcription. As with all the other techniques, time planning is a crucial skill of successful enquiry in the real world (Colin, 1993).

During this research there were some obstacles which made the whole process more difficult but at the same time show some of the issues which are related to the fact that the participants are students and also had learning difficulties. First, I did not have access to the students directly because of confidentiality issues, as the support services did not have the permission to give out the students' contact details without asking them first. Therefore, I had to go to the Director of each Support Unit and ask their permission and their help to contact students with learning difficulties. Initially, I sent a letter<sup>11</sup> to the Directors of DSUs explaining the research I wanted to conduct and asking for their help to contact students. The Support Services in each university were the gatekeepers of the participants for this research and this brought about some difficulties, which are explained below. The only contact I had with students was after they had received the e-mail about my research and had decided to contact me themselves. After their initial e-mail, where they said that they wanted to participate in my research, I knew their names and contact details and we were communicating in order to arrange the meeting for the interview.

The issue with the support services in universities is that they are your first contact and sometimes the first cause of your problems regarding access, because they can give you access or refuse access to you to participants. In my case one of the support units did not agree to send the e-mail which was asking for participants to students, as the Director of the Support Services said, they do not want students with learning difficulties to be contacted too much for research purposes. They believe that it is not convenient for them to receive regular e-mails of this kind. In addition, it was mentioned that they had their own students (from their university) who wanted to interview students with learning difficulties as part of their course, so they did not want to 'bother' students with learning difficulties with many e-mails. This problem

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<sup>11</sup> Attachment A

with access raises the issues around students with disabilities who are regularly the subject of research and their availability. In each case, it is the university and more specifically the Support Services which will decide whether those students will be contacted for research purposes. The support services are like the gatekeepers for these students. For different reasons each time, as in order to protect them from the researchers or because they want to have exclusive access of them, for the students from their university the DSUs keep disabled students away from researchers. As Lee (1993); Stalker (1998) and Lewis and Porter (2004) explain there is a serious concern with gaining access to people with learning difficulties as organisations, professionals, support workers or a third party could block or allow access to these people. The gatekeepers play a key role in decision making about the participation of people with learning difficulties in research. As Tuffrey-Wijne et al. (2008), while talking about doing research with people with learning disabilities, points out

*“Researchers would do well to take the time-consuming task of gaining access to participants when planning their studies. Sufficient time should be allocated to the process of finding people willing to participate, gaining the confidence of staff, explaining the study, meeting the participant and gaining consent”* (Tuffrey-Wijne et al. 2008, p: 187)

It could take quite a long time to ‘pass’ through the gatekeepers and persuade them that the research you want to undertake is valued and will benefit either them (as organisation, professional body etc) or the people with learning difficulties that are the main interest of the research. The difficulty is that gatekeepers have their own views about the value of the research which could influence their decision to allow or not access to people with learning difficulties and directly affect the number of participant people, as it happened in this particular research.

Also, another reason for denying access to students with learning difficulties could be because support services might patronise these students, as if they are not capable of knowing if they want to participate in research, hence they do not give them the choice to decide whether they want to be included in research studies. Therefore, the

researcher has to have the Support Services' approval in order to contact students with disabilities. Of course, there are the undeniable issues of ethical considerations, as they have been mentioned above, which have to be kept in mind when research is taking place and this includes people with disabilities. However, I would suggest that it could be considered 'unethical' for the support services to decide whether the students will participate in a study, without even asking them if they want to, only on the basis of their opinion about whether the students are over contacted for research purposes.

In case of the university which did not send the e-mail to students the decision was made for them. In that particular case, I created a 'leaflet'<sup>12</sup>, which explained the research I wanted to do, and asked students who wanted to participate to contact me. Many students were excluded from the research, as the letter that I had left at the reception for them to pick up, meant that only those who visited the support services would have the chance to find out about the research. This solution was not very proactive, as not many students visit the centre on an everyday basis. As the research showed, most of those who were interviewed said that they only visit the support centre once or twice a semester, if they need something which cannot be arranged over the phone. Therefore, the number of students with learning difficulties who were going to visit the support centres during the period that the leaflet was there was expected to be limited.

In order to overcome the problems with access of participant students and to increase the chances of participation, I decided to contact three departments from the universities of Newcastle and Durham in order to ask the administrators to send an e-mail to all of their students and inform them about the research. The e-mail was sent to all students regardless of having disclosed disabilities or not the members of staff said that they could not identify and separate the students with disabilities. The choice of the departments and the institutions that were selected was mainly on the basis of some contacts that either myself or my supervisors had with some members of staff on that particular departments and universities. This approach had some

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<sup>12</sup> Attachment B

results but again was not very proactive as the total final number of participant students proved to be limited.

One of the Directors of the Support Services, during the interview and while we were discussing the access problems for these students, said that they were planning to have a special question for the new students from the new academic year, which would ask them if they wanted to be contacted for research purposes by e-mails or by post. This would give them the chance to have a list of those students who agreed to be contacted if anyone wants them to participate in research. As an idea, I found this approach very useful for both students and potential researchers, as it would first, give the chance to students to decide themselves about their participation or not on similar researches. At the same time, it would reduce the time that takes for researchers to persuade the gatekeepers in institutions about their research and finally access the students. At the same time if the number of students who wish to participate in research is quite high, it would probably mean that the potential researcher would probably have quite high number of participants in contrast to sending e-mails to all students who have or have are not expressed interest for such research participation and waiting their response. I would think that something like that would be a very good practice especially for the particular institution, which denied access to students with disabilities on the ground of their views and opinions about contacted students.

The problem with access to students was very important in this research, as it resulted in changing the original aim of the project. As it has been explained earlier, the lack of participants and their concentration mainly within one institutions only led to the need to change the focus of the research towards this institution instead of seeing the differences between the four institutions as it was aimed to do..

As is known, sociologists in carrying out their work inevitably face ethical and sometimes legal dilemmas, which arise out of competing obligations and conflicts of interest. Social research is a process which involves researchers and respondents, and which is based on mutual trust and cooperation as well as on promises, and well-accepted conventions and expectations (Sarantakos, 1993).

Ethical issues of anonymity, confidentiality, consent and privacy were considered during this research. Both the e-mail and the leaflet that I had prepared for students made it clear that the interviews were anonymous and confidential and that they were informal. It also explained that there were no obligations for students who wanted to ask any questions about the nature of the research to participate after they had found out about the research. In this way I wanted to make sure that students knew in advance that the interviews were actually discussions about their experiences and that if at any time they did not feel comfortable they did not have to continue with that. The initial e-mail which was used to contact participant students was made clear that I was a PhD student myself from Durham University, and that meant that I do not represent or do the research on behalf of the Disability Unit or the university in general. With this I was hoping to make students understand that they could talk to me freely about their experiences and give an honest assessment and evaluation of the services they receive from their institutions, something that should not be easy in case the researcher was representing the institution.

Before each interview I explained to students again that the interview was anonymous, which means that I would not use their names in the final report and also no one would know their identity except for me. I asked their permission to use a tape recorder for the interview, while the verbatim transcribe of the interviews aimed to ensure that the views of the participants would not misunderstood or altered. Before the interview I outlined again the main aims of the research and asked them if they understand the research and whether they wanted to continue with the interview, reminding that they could stop at any time if they did not feel comfortable with the interview, even after the completion of the interview.

## Findings

### 5 Experiences of students with learning difficulties of Higher Education

#### 5.1 Introduction

The previous chapters have explored the existing literature around issues like social construction of disability, stigma, labelling, and the impact of diagnosis for disabled people and more specifically for students with learning difficulties. The changes in Higher Education, towards a more inclusive educational environment, with the help of reasonable adjustments, were explored through a review of the existing literature. Consequently, the qualitative research approach that has been chosen, requires exploring these issues from the perspectives of the students who participated in this project, in order to see whether their experiences differ or not from these that the literature discussed.

More specifically, the first of the two chapters of the students' interviews (Chapter 5) explores their views on how they experienced their learning difficulties and the impact that the diagnosis had on their life and their self-esteem. The 'paradox' of the diagnosis, as has been described in the literature, was obvious in the cases of some students. In some cases, the diagnosis, and the attachment of the label of learning difficulties, meant that students are now stigmatized as disabled students, which came as a surprise, especially for those who were diagnosed later in their life, and it changed their sense of self-esteem quite a lot. On the other hand, for other students, paradoxically, the diagnosis, and consequently the label of learning difficulties, was the answer they were previously seeking, in order to explain the difficulties they experienced. Therefore, the diagnosis actually helped them to explain the difficulties they had and even gain access to the help they needed. The extent to which the students' difficulties affected their future choices in life in relation to continuing to Higher Education or the choice of the university and course are examined here,

based on students' answers to relevant questions. Finally, the issue of disclosure of the learning difficulties that students have is explored here, and it seems that again the students had a mixed feeling about it. Some, especially those with mild difficulties, did not consider it important to mention their disability when they applied to university or to other students and members of staff. However, some students with more than one learning difficulty, were not equally open about their difficulties, as they based their openness on how common their difficulties are considered to be. All of the cases will be explored in this chapter.

## 5.2 Diagnosis: labels and identity work

### 5.2.1 Diagnosis explained their difficulties

As explained above, in the literature, the diagnosis which identifies some form of learning difficulty is one of the important moments in a student's life. The interviews with the 18 students showed the variation that the impact of the diagnosis had on each student's life. Some of the students felt that something really 'bad' and unfortunate had happened to them, while others felt that the diagnosis was the answer to the questions they had had up until then, and that finally their difficulties had been explained. Even though it seemed that the majority of students felt relieved when the diagnosis showed that they had learning difficulties, there were individual cases both from those who felt relieved and those who were not so 'happy' with the diagnosis, in order to understand the real feelings that students had towards the diagnosis of their learning difficulties.

Starting with those who felt that the diagnosis was a positive experience and gave them the answer to the problems and difficulties they had until that moment, one interviewee, who has dyslexia, explained that "...*the school never picked it up and that was blindingly obviously...*" (I<sub>1</sub>, M, 22, OUa, Dysl).

His feeling after the diagnosis was more of a relief as he said:

*"I was quite relieved actually because throughout my school I wasn't sure and once I found out that was the reason why I was so bad, I could have said 'that's why'; cause I didn't know...There is a certain views (sic) on dyslexia at my school. I remember being in an English class, and some who knew they were dyslexic said to the teacher 'I am dyslexic' and the teacher just laughed at him and said 'you can't be dyslexic you are in a grammar school'. They reckon that it is slightly higher education than the state schools; you have to pass a test to get in, so if you've passed this test you can't be dyslexic"* (I<sub>1</sub>, M, 22, OUa, Dysl).

The fact that the school was not able to understand that this student had dyslexia, even though, as he said, his performance made it clear that he had some difficulties, caused anger and frustration to that student. It is significant that during his interview he emphasised quite a few times that the school was not able to identify that he is dyslexic. Even though the diagnosis was a good experience for that student as he felt relieved at the same time, there is some kind of need to blame someone else for the difficulties the student had, in this case the school is to blame. The emphasis on the fault of others is apparent from the mention of the lack of ability of the school to identify the problem. In addition, the impression that the students in a grammar school cannot have learning difficulties, because they passed through tests before they entered school, shows a stereotypical idea about the kind of students who go to different kinds of school. It seems that this teacher stereotypically believes that grammar schools accept only students from a higher class, who do not have learning difficulties, in contrast to state schools, where students are from a different class, where it is normal to have learning difficulties. Even the fact that the teacher laughs when another student mentioned dyslexia makes a really bad impression on the interviewee and maybe even made him think twice about revealing to that teacher that apparently he also had learning difficulties.

Another student when she was talking about her school years, even though she was not diagnosed until she came to the university, commented on the school's inability to identify that she had dyslexia and dyscalculia:

*“In high school, I always did really well except in maths....In my Year 9 report, they wrote that ‘she refused to believe mathematical concepts’. But because I did so well in other things, I mean my writing was always terrible because of dyslexia and things like that, but they didn’t know that, but because I did well in all other things they didn’t think that there was anything wrong. They thought that I was just being difficult...” (I<sub>17</sub>, F, 22, OUa, Dysl&Dysc).*

The lack of teachers' ability to recognise that this student had problems due to dyslexia and dyscalculia almost automatically led to the conclusion that the student was difficult, which automatically implies that there is something wrong with the student or that the student's performance was his/her fault. In a case, the label 'stupid' was used by a teacher to describe a student, as the student explained.

*"...However, I was told by my English teacher 'you are not dyspraxic, you are stupid' when I was 14-15 so that put me off in English and History which actually those [sic] were my strong subjects"* (I<sub>5</sub>, F, 21, OUa, Dysp).

Similarly, other students explained that because they had been labelled as 'slow' or 'lazy' by their teachers, prior to the diagnosis of the learning difficulty that caused them problems. They doubted themselves about their performances, even though they could not accept that it was their fault. These students explained that the labels that their teachers or classmates used when they were referring to them caused them really unpleasant experiences and at some point they changed their own self-image as they used to see themselves as those labels (Interviewees 8, 9 & 11). In these cases, students accepted label imposed on them and changed the way they see themselves (Lemert, 1967). Consequently, the diagnosis for these students came as the so much wanted answer, which changed the way they used to view themselves and, in addition, it improved their self-esteem, as it was not their fault any more, it was the learning difficulty which was causing them these problems. The paradox of the diagnosis is apparent here, because even though the diagnosis gives students the label of learning difficulties, which causes them stigma, at the same time, it gives them a sense of relief that it is someone else's fault and not their own.

In some cases, the diagnosis was the process that helped some students towards normalisation, because they feel that they needed the medical term to explain the difficulties they had and to put them into a known category of people. An example of such a case is a student who was diagnosed with agoraphobia who said:

*“I was very relieved knowing what it was. Very very relieved actually because before I was just called it ‘my freakiness’ so it was nice to have a proper medical name and understand it a bit more and know that there are other people like that as well with that condition” (I<sub>2</sub>, F, 19, OUa, Agor).*

For this student, the diagnosis was the confirmation that she was normal. She feared that there was something wrong with her, but the diagnosis removed the responsibility from her to something else, which in that case was the disability, the agoraphobia. It helped her to accept that it was not her *“fault”* or her *“freakiness”* as she used to call her panic attacks, but it was the fact that she had agoraphobia that was causing all those problems. It is interesting that the medical explanation of the difficulties helps some people to accept and understand their perceived problems. The fact that her problems had a name, in that case agoraphobia, and that there were other people with the same problems, was, paradoxically, the confirmation that she was normal. As Goffman (1990 [1963]) explained, usually the realisation that a person possesses a stigma can cause some uneasiness. At the same time, the realisation that a stigmatised person belongs to a group, which consists of *“sympathetic others”*, can help in the process of normalisation.

A similar case, where the diagnosis came as a very positive experience because it confirmed that there is a professional explanation of the difficulties that the student had, was described by a student who has been diagnosed with dyslexia and dyscalculia. In this case, even though the student said *“I knew that there was something wrong...”* (I<sub>17</sub>, F, 22, OUa, Dysl& Dyc) because of the difficulties that she had, especially with maths, the diagnosis did not come early in her school years. Actually, she was diagnosed when she first came to university, where she did her research on the internet about dyslexia and dyscalculia and she realised that she may have something similar. The fact that she did her own research and she was actively seeking a diagnosis and an explanation for her difficulties is something that emphasises her need to solve the mystery behind her difficulties and to give a proper medical label to her problems (Interviewee 17).

Once more, in that case, the official diagnosis helped this student to understand what was causing all those problems that she described earlier in her interview when she was talking about her school years. Her comment is fascinating “...it was like actually say that there *was* something wrong, so that was good...” (I<sub>17</sub>, F, 22, OUa, Dysl& Dysc) as it shows clearly that the diagnosis was the so much wanted answer to her worries that there may be something wrong that she did not know for sure before. As a result, now, she knew that “*the something wrong*” had a name and it was officially identified as dyslexia and dyscalculia, therefore she was normal.

Apart from the fact that this student had the so much wanted explanation for her problems and she was able finally to give a name to her difficulties, it is of importance to see the role that the official name of the diagnosis played here. As has been explained in the literature the professionals and the experts (in cases of learning difficulties we are talking about the educational psychologists) offer their expertise and they create the names and categories within which they fit students. Therefore, some students end up having dyslexia, others dyscalculia, dyspraxia etc. These categories, together with the experts who have created them in the first place, both create stigma due to the characteristics that the labels used are attached with. However, interestingly, the professionals’ categorisation and the name given led to a feeling of relief that this student felt after the diagnosis. The fact that the student had a professional name given to the difficulties previously experienced was enough to reassure the student that everything was alright from now on. We could say that this is another example of there being a relationship of dependency between professionals and ‘clients-patients’. The students need the experts opinion about their difficulties in order to accept the diagnosis and at the same time the professionals need the students as ‘clients-patients’, in order to establish the significance of their job. Here Goffman’s idea of “*sympathetic others*” is of relevance (Goffman, 1990 [1963]). The sense of normalisation that the student felt at the end redirects us to the notion of sympathetic others, who have similar conditions to the stigmatised and hence, they all feel part of a group and that helps them towards a normalisation.

However, the process of the diagnosis of the learning difficulties is not always and for every student a positive experience which helped them to understand their problems. For some students, it was accompanied by bad experiences and it changed

their whole image and self-esteem. Some examples of these cases will be shown next.

### 5.2.2 When the diagnosis causes additional problems to students

As indicated before, the majority of students expressed a feeling of relief when they found out that there was nothing ‘wrong’ with them, when it was actually a case of a learning difficulty which was causing the problems they had. It is interesting that the sense of relief came because of the bad experiences they had before the diagnosis, where they had been blamed for their poor performance at school. However, there are also those students who did not feel the same ‘relief’ after the diagnosis of their difficulties. These students felt that something bad had happened to them and their main feeling was anger and disbelief, either because they did not get the diagnosis earlier in their life, or because they could not believe that they were actually disabled.

In the previous section, one of the cases that was mentioned was that of a student who was frustrated because the school was not able to identify that the difficulties he had were the result of learning difficulties (Interviewee 1). While the student was relieved that finally there was a diagnosis for his problems, at the same time he felt anger against the school that failed to diagnose it at the right time. A similar case is mentioned by another student who was not diagnosed until he was in the second year of his PhD. In this case, the university, rather than the school, failed to identify that the difficulties a student had were the result of dyslexia. The student was in the second year of a PhD when he was first diagnosed with dyslexia.

*“...I was in my second year of my PhD and I was submitting an upgrade report for my PhD and one of the lecturers who read it, she thought I was dyslexic. She dealt with a lot of students in ... (name of the university) and she thought I was dyslexic just from my work...” (I<sub>3</sub>, M, 28, OUa, Dysl).*

The first reaction to the idea that he may have dyslexia, as this tutor had suggested, was disbelief, as was explained:

*“Well, I didn’t think that I was going to be dyslexic, mainly because I’d got through so far. I mean I am in my second year of my PhD, why now?” (I<sub>3</sub>, M, 28, OUa, Dysl).*

When I asked this student about the feelings after the diagnosis, he explained that it was amazing that no one had so far had realised from the work that he did in the last 7 years at the same university that he had dyslexia.

*“I felt that I had always struggled with certain things and I thought that this is part of life. This is what I was taught when I was little; it was like this is very hard but you have to get on with it and this has happened for so long...By being in my second year of my PhD I actually wasn’t sure what was going to happen, how this will [sic] affect me or anything particularly because I was: ‘I have a degree, I have an MA, I’ve got GCSEs, I am in my second year of my PhD...’ I was quite concerned that I hadn’t been diagnosed and that really did worry me and if that had happened to other people as well because this to me signifies that actually I have been to universities for 7 years and nobody noticed, nobody said anything to me. I was actually angry about it...” (I<sub>3</sub>, M, 28, OUa, Dysl).*

The student was taught and grew up with the idea that the struggles that you may have in school are part of how life is, as life can be tough for some people. He learned that you have to try hard in order to achieve anything at school or in life in general and based on that belief he managed to go through the schooling years and also the university years up until the moment that someone else told him that these struggles were the result of dyslexia. The first reaction of disbelief is so ‘natural’ and normal for anyone who managed for so long to overcome any difficulties that they may have because of a learning disability. It is even harder and more challenging for someone who for so many years thought that they did not have any disability, one

day to learn that actually the difficulties are not part of everyday life but rather that they are the result of a learning difficulty and that from now on that person is categorised as disabled.

Consequently, the shift in this student's identity from 'non-disabled' to 'disabled', from 'non-stigmatised' to 'stigmatised', caused some sort of confusion and mixed feelings as it is not easy both to accept the disability and the possible stigma that a disability carries and furthermore to manage the new identity that the diagnosis brought to light. The disbelief in the diagnosis was followed by concern about how the life and the identity of the student is going to change and the concern led to anger towards the system that was unable to identify the disability earlier.

Reflecting on how this student felt when was diagnosed he also added at the end that it is quite hard to explain his feelings as they were mixed. On the one hand, he was angry that he had not been diagnosed earlier in university's years, but on the other hand the fact that he managed to get to the state where he was, even without any help regarding dyslexia support, is an achievement in itself,

*"...but it is quite hard to evaluate how I am feeling about that. I feel that the thing that I have my degree doesn't actually represent how much work I've put in and I think it is my self-esteem that is more damaged than actually the grades you've got because to me it was that how much I worked is not reflected back. I didn't have allowance, I didn't have extra time, I didn't have help, I didn't have dyslexia tuition, I didn't even have any software to help me and I feel that's... I suppose to me doesn't reflect that, but saying that...I am going to have a PhD so this, in a lot of ways, for me, this is a very positive thing personally" (I<sub>3</sub>, M, 28, OUa, Dysl).*

The effort and the hard work that a dyslexic student or a student with learning difficulties puts into his/her studies most of the time is not reflected in their work or their marks unless they have support and help like proof reading services and a dyslexia tutor to help them improve their skills. Therefore, as this student explained his degree does not reflect the hard work, he put into it, and it is not only his marks

that suffered, his self-esteem was affected too. Still, having achieved all that without any support or special help for dyslexia is remarkable.

It is understandable that the more years someone spends at university or in education, in general, the more chances he/she has to identify what causes the difficulties they have and to have a proper diagnosis. However, there are students who left school after compulsory education and did not continue to Higher Education or did not have good performance at school due to learning difficulties, which were not diagnosed early enough in order for the students to receive the appropriate support and help. On one hand, the longer the students stay in education the more opportunities they have to be diagnosed. On the other hand, it is not always possible to stay longer and continue their studies when they have not identified the source of their problems in order to get support which will help them to continue and study further in Higher Education. In this case, the student managed to spend 7 years in Higher Education before he was finally diagnosed with dyslexia.

Another reason why the diagnosis of a learning difficulty was not something that some students accepted easily or with a relief was because they were diagnosed with a difficulty which is not considered as common as dyslexia for example. I will mention here two examples of students who were diagnosed with dyslexia and OCD (Obsessive Compulsive Disorder) the first and the second with dyscalculia and dyspraxia. Both of them said that they were more open and they find it easier to accept that they have dyslexia and dyscalculia respectively, but they did not feel the same about the OCD and dyspraxia diagnosis.

The first student believes that the fact that OCD is “... *rare or it’s not something well recognised, something like dyslexia...*” (I<sub>6</sub>, M, 33, OUa, Dysl&OCD) makes him less open about it compared to how open he is about his dyslexia when it comes to telling friends, classmates and tutors. Similarly the other student, when she was asked to explain how she felt when she was diagnosed with dyscalculia and dyspraxia, said:

*“...the dyscalculia element, it was quite a relief. Because you know, I’ve always suspected that and I’ve always had low maths grades.... The dyspraxia thing, I was a bit more surprised because a lot of the stuff you read*

*about on the internet they are for people with very very severe cases; because they are obviously the ones that are diagnosed. And I do sort of look and say 'yeah, I recognise some of them', but I didn't actually think I had it to the degree where I get diagnosed with"* (I<sub>13</sub>, F, 20, OUa, Dysp&Dysc).

This student in order to have a better understanding of dyspraxia looked into the available information on the internet. Her views on dyspraxia were influenced by what was written on the internet, which referred mainly to the more severe cases, and this "...was a mistake because it has a lot of over the edge descriptions of what it is..." (I<sub>13</sub>, F, 20, OUa, Dysp&Dysc). The way that dyspraxia was described on the internet had a negative influence on that student, and as she explained,

*"...the self-esteem was damaged, because now I just contextualise everything in terms of 'I am a dyspraxic'; and sort of everything I do is 'does this conclude that I am dyspraxic or not?' and it's not a very healthy state to be in....Now I would question my ability to carry out things which I would have done before"* (I<sub>13</sub>, F, 20, OUa, Dysp&Dysc)

This student's self-esteem and self-image changed after the diagnosis. The low self-esteem and self-questioning of her abilities were not only the result of the negative and extreme examples that were given to describe what dyspraxia means. Moreover, after the diagnosis her perspectives on things and tasks that she used to be able to do changed too. She was challenging everything in relation to dyspraxia and she was wondering if tasks that she can or cannot achieve were related to the fact that she is dyspraxic. The student was influenced by the wrong impressions and misconceptions about what a person with this disability is capable of doing. As has been suggested before, there is the tendency to assume that the people with learning difficulties are not able to live their lives by themselves, are dependent on others, and in general are not able to carry out everyday activities. Therefore, this student, by accepting the examples and the definitions she found on the internet, also accepted the label imposed on her (Lemert, 1967), because of these false characteristics and lack of

abilities that presumably a person with this learning difficulty may experience, based on the assumptions of others.

It is clear from the above examples that the students' self-image and self-esteem is vulnerable especially to negative comments or references which are related to the learning difficulties they have been diagnosed with. As has been discussed above sometimes it is possible that once the label of a disability has been attached to a person, then this person will become that label. The label, in this case the learning difficulty, can become the master status, and the stigmatised person will start to be the label and even the self-identity of that person can change accordingly.

These students, also, mentioned the additional “*stigma*” of having a learning difficulty which is not one of the so-called common learning difficulties. As they said, they were more open and they find it easier to understand and accept one of their difficulties compared to the other, which was not as common.

Clearly, here we see that the impact of the diagnosis on each student is not the same. It can be both the ‘so much wanted answer’ that explains all the difficulties and lifts the fault and blame off the students’ shoulders, while, on the other hand, it can be the trigger for life changes, which are not always good for the students’ self esteem and identity.

The student who had been diagnosed with dyspraxia and dyscalculia (Interviewee, 13) gave a very good example of how the diagnosis can be both a negative and positive experience for students. She clearly shows that the ‘paradox of diagnosis’, which can be the reality in some students’ life, affected her and surely she is not the only one who have experienced it. She said:

*“The diagnosis is a wonderful thing because it means that you’ve got an explanation for difficulties but when it’s leading you to question things in your life, then it’s not so great”* (I<sub>13</sub>, F, 20, OUa, Dysp&Dysc).

Based on the cases of students who have been explored and discussed here, we could say that there are two main categories into which we could separate the students’

experiences. On one hand, there are those students who either directly or indirectly accepted the “*secondary deviation*” (Lemert, 1967) because at some point they saw themselves as the label that others had attached to them. Eventually, they ended up behaving according to the socially created expectations of others, and based on the characteristics that others expected to see from people with these kinds of difficulty. The acceptance of the secondary deviation led to either change in their choices (even if they were indirect) and even their expectations and their self-image.

On the other hand, there are those students who saw the diagnosis of their learning difficulties, as a “*biographical disruption*” (Bury, 1980). This notion was apparent in cases where students described how they started challenging their abilities to continue normal everyday activities that they used to do until that moment.

### 5.3 Learning difficulties within the family and diagnosis

Among the participant students, there were also some cases where the students knew that either they had some sort of learning difficulty earlier in their life, at pre-school age or when they were at school. Some of them had the advantage that their parents, sisters or brothers had similar difficulties and had already been diagnosed with learning difficulties or just knew more about learning difficulties and could help them to overcome theirs. In cases like these, it is the issues of acceptance and adjustment that are the main concerns for students rather than the “*moral damage and spoiled identities*” as Goffman (1990 [1963]) argues. In these cases there is the issue of “*familiarity*” and they are among their “*own*” and the “*wise*” ones, who understand and support the stigmatised as they are both categories of sympathetic others (Goffman, 1990 [1963]).

A distinctive example is of a student who has dyspraxia, dyslexia and Asperger’s syndrome (Interviewee 18). He was diagnosed at quite a young age because his brother was also dyslexic and with Asperger’s Syndrome, so the symptoms were quite well known to his family. Therefore, the diagnosis was easier than in cases where no one else has something similar in the family.

For another student with dysgraphia the diagnosis did not cause any surprise to him as it was something known among his family.

*“It didn’t really bother me; my sister was diagnosed also at a very young age. I had similar symptoms but not as severe as my sister who has dyslexia and so it didn’t really surprise me a lot. It seems to be in my family; my dad has something similar to ours, so it didn’t really bother me I just realized that I have something, something that I have to work on...”* (I4, M, 18, OUa, Dysg).

The same student said that because his sister had dyslexia too, he knew about the support and the provision that the university is obliged to give to students with learning difficulties,

*“I knew that there was some (support) from my sister’s old university. She was at (name of university) and I knew that there is support available from the universities and there would be some support wherever I went” (I<sub>4</sub>, M, 18, OUa, Dysg).*

The impact that primarily the family but also friends have in the process of the diagnosis and the way that the person will learn to deal with the issue of learning difficulties is very important. Parents who either have a learning difficulty or because of their occupation can help their children with the difficulties they have due to learning disabilities play an important part in the child’s process of accepting and understanding the problems. For example, a student with learning difficulties who has a relative who works as an editor for a magazine found it very useful that this person could proof read her work, instead of giving it to someone else in the disability support unit. As she explained:

*“...I get tired quickly and it takes time to go through material and I am very bad checking my own work for the reason that I just said. Normally, (the person’s name) has to read; she is an editor for a magazine, and she does a fairly good job. She doesn’t look at the context obviously but just that it makes sense and I find that very useful...” (I<sub>5</sub>, F, 21, OUa, Dysp).*

She also added that

*“My (relative’s name) picked up that, fortunately she was studying psychology and she went to her lecturer who was an educational*

*psychologist and I was tested and I was found as dyspraxic” (I<sub>5</sub>, F, 21, OUa, Dysp).*

The support that she receives from her family is very important and very helpful for her as she made clear when I asked her how helpful she finds the support she receives from the DSU in her university,

*“...probably with the help of (name of the family member) or other people I would be able to do it even if the university didn’t give me that much, but obviously I needed things like extra time and some stuff like that” (I<sub>5</sub>, F, 21, OUa, Dysp).*

The above examples all show that somehow it is easier for students who have other members of their family with learning difficulties to accept the diagnosis and deal with the difficulties they have. Furthermore, we could say that they seem less concerned about their difficulties and the fact that they are among the “*sympathetic others*” (Goffman, 1990 [1963]), seems to help them to accept the difficulties they have and to adapt more easily to these changes.

However, there were examples of students where the diagnosis was not early in their lives and this caused them anger and frustration, because they believed that the school or the university should have picked it up; there is a case of a student who was diagnosed later in her life and her comment is worth mentioning. As she explained

*“Now that I am older, I understand the nature of my learning difficulties and it’s not something to be stigmatised and it’s not that you are not intelligent and other things that I would probably wouldn’t understand if I was younger and it would have damaged my self-esteem” (I<sub>13</sub>, F, 20, OUa, Dysp&Dysec).*

For the student the fact that she was older when she was diagnosed helped her see some things about her learning difficulties differently and maybe in a more mature way than what she would have done if she was much younger.

The interviews with the 18 participant students showed that there are two ways to see the diagnosis of a learning difficulty. Some of the students saw the diagnosis as the confirmation that the difficulties they experience are not their fault and there is an explanation for their problems. On the other hand, some saw the diagnosis as a bad thing that happened to them and changed their life and their self-esteem. The finding from the research supported the literature about the "*paradox of the diagnosis*". Maybe for the majority of the participant students the diagnosis was not a bad experience; on the contrary, it was the explanation and the point from where they were no longer 'slow' or 'lazy' but they have some difficulties which affect their performance at school. The previous bad experiences made the diagnosis of the learning difficulties more of a good thing in their life, and helped them understand and explain to themselves and others why they had struggled until that moment. The diagnosis was seen by some students as a process towards normalisation, as it proved that there is nothing wrong with them; they have difficulties, which have a name and there are others with the same difficulties as they experience them, hence they are normal.

Still, there were students who struggled to accept the diagnosis and it had a negative impact on their self-esteem and the way they see and do things in their life. These students experienced a "*biographical disruption*" (Bury, 1982) which were the result of the diagnosis of their difficulties. Some of them started challenging their abilities to do everyday things which they considered normal and easily done, and now they doubt their ability to do them. In some cases the notion of the "*secondary deviation*" (Lemert, 1967) was apparent, because the students accepted and started behaving based on the expectations of others. For those students, where another member of family had similar difficulties, the diagnosis was less of a surprise than for those who did not know anything about it. Members of family and friends play a very important part in the life of students with learning difficulties, as the interviews showed, and their support and help is something very much appreciated by students.

## 5.4 Students' choices and learning difficulties

### 5.4.1 Choice of university and course

It is arguable that one part that a learning difficulty can affect is the students' ability to obtain knowledge depending on the severity of the learning difficulty and the form of the disability (for example dyscalculia causes additional problems with maths). Therefore, apart from the effect that the diagnosis had on those students' life, we have to see what impact their difficulties had, if any, on their choice of university and the course of study or even their decision to continue their studies after school at a Higher Education institution.

Based on students' responses two categories have become apparent. On one hand, we have those students who did not base their decisions about university or course on their learning difficulties. On the other hand, for a few students, the difficulties played some role in their decisions. A few examples of both categories of students' responses, regarding the choices they made in relation to their difficulties, will be mentioned here.

For the majority of students, the learning difficulty did not play a key role in their choice of the university. This is understandable for the four students who were diagnosed with learning difficulties while they were at the university. But also the fourteen students who were diagnosed earlier and knew about their difficulties before they applied to the university of their choice did not base their decision *primarily* on the fact that they have learning difficulties, but rather on the university's reputation or location.

A few students said that even though they knew that they had some sort of learning difficulties, this did not put them off going to a Higher Education institution, because for them it was just a case of working "... *a little bit harder really...*" (I<sub>4</sub>, M, 18, OUa, Dysg) or in some cases their difficulties made them "...*more determined*" (I<sub>9</sub>, F, 19, OUa, Dysl). They also explained that the learning difficulty is something that they knew they would have all their life and they treat it as something that they have

to work with and accept that if they try hard they will manage to achieve whatever they were planning on doing (Interviewee 4 & 9). Accepting that learning difficulties are something that you have forever and it is not going to go away later in your life is something that those students understood and took in a positive way. For these students learning difficulties mean that they have to accept them as part of their life, and try to work with them, rather than to let learning difficulties to determine their decisions about plans. Possibly, some of the students who did not decide whether they would go to Higher Education based on their learning difficulties, and who considered learning difficulties as something that is going to be with them forever, do not consider learning difficulties as a salient identity which will determine their life. The fact that they have learning difficulties does not necessarily mean that this is the first and only part of their identity that they put forward and they base their decisions on that. Among other explanations for this are the emotional impact that a label, like that of learning difficulties can have, together with the stigma that this label attaches to everyone who ‘carries’ it (Beart, 2005).

For another student, Higher Education seemed like “...*the next natural step to go from A levels to university*” (I<sub>18</sub>, M, 20, NUa, Dysl&Dysp&AsperS); while for another his parents were the main reason that persuaded him to go on and apply to a Higher Education institution.

*“...my parents have always told me that education is very important and one of the most important things is to go to Higher Education and all that stuff will affect the rest of your life; so, I always knew that I had to go on and go to university... I just knew it was a good university; has a good reputation so, that’s the reason I came here”* (I<sub>8</sub>, M, 19, OUa, mDysg&smem).

The parents’ influence is obvious here as their opinion about the importance of university for the child’s future had an impact on the child’s choice of what to do after school.

All of the answers made it clear that these students wanted to go to university and despite their difficulties they wanted to try to go as high up the educational ‘ladder’

as they could. They knew that they had to work harder than the rest of the students but this did not put them off their decision to achieve a degree from a Higher Education Institution.

However, this was not the case for everyone. Some students were more concerned about the impact that the learning difficulty may have on their studies. Despite that, they decided to apply to a Higher Education Institution. Of course, someone could argue that there are not so many alternatives for a student who has just finished High school and has some A levels, other than to go to Higher Education. Among the reasons that motivated students to go to a Higher Education institution after school, the lack of choice and the lack of alternatives have to be considered as possible explanations. Some of these examples, where students were more concerned about the impact that their learning difficulty may have on their studies, are given here.

One student with agoraphobia gives an example of her worries and the effects that the learning difficulty will have, once at the university:

*“I was kind of worried how it would be and I came on an open day I spoke to one of the lecturers in my department and I said that sometimes I feel uncomfortable in a full room and she said that the classes are really small, it is a very small department and the lectures are really small. I think that my biggest lecture is about 16 people, which is nothing compared to something like physics...so that was quite reassuring but I didn't really think about it too much because I didn't want to sort of base my decision on that so...” (I<sub>2</sub>, F, 19, OUa, Agor).*

Even though this student actually went to the university of her choice, she had to make clear beforehand that the lecture rooms would not be packed with students because this would mean that she would not be able to attend due to her condition. Therefore, in that case, the difficulty played a role in this student's decision but fortunately, there was a solution to her worries and that did not put her off her course.

Another student with dyspraxia mentioned that even though she was sure that she wanted to continue to Higher Education she had to make a decision, regarding the course of study, based on the previous experiences she had from school, which put her off her “*strong*” subjects, so she ended up doing something else:

*“...I actually went to (she mentions a university) and I did Economics and Computer science, mathematical subjects, because these were subjects where, although I wasn’t as naturally good as other subjects... I faced fewer problems expressing myself; and it was only really when I sort of started doing essays I found that OK they weren’t my best plan but...Actually I was better in things like philosophy and politics but you know from the age of 11 to 15 I was told that I was rubbish at them. I always wanted to do it, but it took me a little bit longer...”* (I5, F, 21, OUa, Dysp).

For this girl, the learning difficulty had an effect on her decision on the course of studies, but as she explained it was not entirely the difficulties she had that caused the problems but rather the impact that her teachers’ comments had on her which made her choose a course that actually she did not like a lot. In this case, it was not the objective difficulties that someone with a learning difficulty may have, but the subjective perceptions that others have towards students with learning difficulties that caused the problem. Below I will show with more examples how previous bad experiences, especially from school years, have an effect on students’ decisions and self-image.

The students’ responses showed that the majority of them did not base their decisions about going to Higher Education or choose the universities and courses upon the fact that they were diagnosed with a learning difficulty. Among the possible explanations for that behaviour could be that for those students the disability is not the master status which controls their choices and decisions or maybe their conditions were not so severe as to prevent them from making those choices. These students have a learning difficulty; however, it seems that they have managed, in different ways in each case, to control the extent to which this ‘status’ will influence their life choices. This is not always easy as it is not uncommon for the disability to

become the master status for some disabled people, either because of the nature of the disability (especially when it is a severe case, or when it is a visible disability) or because of how others treat them once they know about their difficulties.

Another factor that has to be considered here is that the majority of the participant students were from the University of Durham. It is well known that most of the students who go to Durham University come from a middle-class background<sup>13</sup>, which can affect their views and expectations about the university, the courses and the services they will get. Therefore, it is quite possible that the choice of going to Higher Education for studies after school, for students from middle class families, was “...*the next natural step*” (I<sub>18</sub>, M, 20, NUa, Dysl&Dysp&AsperS). Therefore, since most of the sample consisted of students from Durham University, it is quite understandable that the majority of the participant students did not base their decisions about going to Higher Education and choosing the university and courses upon the fact that they have some learning difficulties.

Learning difficulties may be the ‘kind of disability’ that will be with them forever, as it is not going to go away with time, even though it is also an unseen disability, but still, its effects can be minimised with the appropriate help and support. These students did not consider their difficulties as the driving force that would determine their choices regarding university and studies. Of course, this cannot be true for all conditions, as there are disabilities which can affect people’s identity and therefore play a key role in their decisions and choices, but for the majority of these students this was not the case.

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<sup>13</sup> Based on statistical data from University of Durham for the year 2008-2009, 3409 students (34.96%) of the total 9750 students (non-monitored grouping) come from Higher Managerial and Professional Occupations background. 1183 students (12.13%) are from Intermediate Occupations backgrounds, while 2916 (29.9%) of students come from Lower Managerial and Professional Occupational background. Therefore, clearly the majority of the students from Durham University are from higher and middle-class socio-economic backgrounds.

#### 5.4.2 Bad previous experiences and choices

It has been shown above that the choice of university was not based on the difficulties each student had, but it is interesting that most of the students, who were studying sciences said that they chose the courses because they knew that they would not have any essays or too much written work to do. One student with dyslexia said that

*“... I am not a very good writer so that’s one of the reasons why I chose science, especially engineering, where you don’t have any essays to write; if I had to do English I would suffer possibly” (I<sub>1</sub>, M, 22, OUa, Dysl).*

Almost all of the science students mentioned that their decision about the course was related to the difficulties they had when they were still at school, where they had a poor performance in subjects like English, history etc, while they were better at maths, chemistry and science subjects. Therefore, even if they did not choose the course directly because of their difficulties, they had already made that choice at school, because of the difficulties they had then. A few of them made their choice purely based on the university’s reputation or the course’s reputation. One particular student with Asperger’s Syndrome said that he chose the university because it was close to his family home, where he wanted to live (Interviewee 11). It is understandable that there are difficulties which have an impact to students’ university life and are not directly related to the teaching and learning process of the university.

Therefore, there is some relation between the choice of subject and the difficulties which some students experienced while they were at school. This is related to the fact that past educational and social experiences can continue to shape a disabled student’s self-image. However, the majority of the students said that their disabilities did not play a direct or key role in their choices. As has been discussed in the

literature, disabled students have the same motivations for going to Higher Education as other students without disabilities. Consequently, it is reasonable to assume that these students, despite their difficulties, have strong motivations and even support from their families, in order to overcome their difficulties and to let them have as little impact on their choices as possible.

However, bad experiences from school, such as being called “*stupid*” (I<sub>5</sub>, F, 21, OUa, Dysp) or incidents of bullying regarding their learning difficulties, can very much leave a mark on a student’s life. The fact that students did mention the bad experiences they had at school even when they had been asked about their experiences now that they were at university seems to be related to the impact that these previous bad experiences can have on someone’s life. All of the students who had been diagnosed while they were still at school mentioned some bad experiences from teachers or classmates who treated them unequally because they knew that they had some sort of learning difficulties. A student who has dyspraxia gave an example of bad previous experiences and she was diagnosed when she was 14 years old. She said that before she was 16 (when she changed school), she was only receiving extra time for exams and she was using a computer but, as she explained, “*the teachers were very hostile about it...*” (I<sub>5</sub>, F, 21, OUa, Dysp) and that made her unwilling to use the computer, which in fact was part of the support she was receiving for her difficulties. Other examples of bad previous experiences while at school mentioned by students who had been put off some subjects because the teacher told them that they were not good enough at them, despite the fact that the students had been diagnosed with a learning difficulty, which explained the difficulties they had in these subjects. The use of labels by teachers and lack of ability to diagnose a learning difficulty were also mentioned by students as examples of problems they had while at school (Interviewees 5, 8 & 18).

It is only natural for people (not only students with learning difficulties), to try to avoid any subjects, activities or situations which will reveal a weakness of their character, while at the same time, they try to engage in areas where they perform better. However, in cases of students with learning difficulties it seems that to a significant extent they try to avoid the subjects which show their ‘weaknesses’ more. These attempts result in excluding them from following their interests and ending up

doing something that is not their best choice but in which they had better chances to succeed.

Undeniably, previous life experiences, either good or bad, can have an effect on students' life. However, all those students who mentioned previous bad experiences said that they had not experienced any similar bad behaviour from classmates and tutors while they were at the university. A student with dysgraphia mentioned:

*“...you know that there are always people who make jokes about it at school those who make jokes “Oh, you get extra time that is why you do this (say that you have dysgraphia)”...but it is always people who just didn't mind...all that was back at school not at the university” (I<sub>4</sub>, M, 18, OUa, Dysg).*

Among other possible explanations for this behaviour could be the fact that the majority of students within universities are more mature than schoolchildren and they understand and respect the individual needs of others better, and they are not as judgemental as younger students are. I have already mentioned above an example of a student with learning difficulties who said that even for her the diagnosis now that she is older is better understood and accepted than if it had come earlier when she was younger (Interviewee 13). Therefore, it is possible that the perspective of people regarding disabilities changes due to previous experiences from the schooling system regarding disabilities, and as they are older and more mature, their attitudes change. In addition, the attempts at better disability awareness within the Higher Education Institutions make it easier for students with learning difficulties or other disabilities to have better experiences than those they had while at school. At the same time, the tutors know, because they have been informed by the DSUs, that they have to act in accordance with the law, which wants them to treat those students equally and not less favourably, compared to other students. This has an effect of making the lives of students with learning difficulties 'easier'.

Therefore, it is clear from these examples that the past experiences with teachers who did not believe that those students with learning difficulties would succeed in their life and that they did not have dyslexia, dyspraxia etc. but were “*stupid*” (I<sub>5</sub>, F,

21, OUA, Dysp) or did not try hard enough, had a profound effect on students' future choices. As had previously been argued, the diagnosis for those students was the proof that they were not lazy or stupid. The diagnosis gave them the reason (the name of the disability/learning difficulty) that was causing them the difficulties.

The last example is from a student with dyspraxia, who had been put off her favourite subjects at school after an incident she had with her schoolteacher. The student was told that she should avoid History and English, which in fact were her favourite subjects. Her English teacher did not believe that the student's poor performance was due to dyspraxia but the result of the student being "*stupid*". This incident had an effect on what course this student chose when she applied to Higher Education and this 'compulsory' choice affected her studies. Of course, here the change in life choices is not a direct effect of the diagnosis of a learning difficulty, but still is the result of the problems that a student had due to a learning difficulty. The student had to find ways to avoid these subjects, which showed that she was 'weak' or not as good as other students and at the same time to adapt to the new label that she had been attached to. In the literature review, it was explained that the label in some cases could become the master status of a person that it is attached to and this can have negative results in his/her identity and self-image (Söder, 1989). It is possible in some cases when a label is attached to a person that the person will 'act' based on the attached label, either by accepting the label or by trying to hide the stigma at any cost. In these cases, we have the "*secondary deviation*" (Lemert, 1967), where the person acts based on the expectations of others who have given them that label. The previous example from the interviews with the students showed that the label that the teacher used for that student resulted in leading the student, later in her life, to avoid the courses that would make the 'label' apparent, even though her personal preferences were towards these subjects.

The effect that the label of learning difficulties has for students might determine the students' decision to disclose the difficulties that they have. The next section discusses students' decisions to disclose their learning difficulties either to the university, when they applied, or to students and members of staff.

## 5.5 Disclosure of disability

Another issue, which seems to be of importance regarding students with learning difficulties, is that of disclosure. Each student has to decide whether he/she will 'reveal' the difficulties he/she has, both to the university (through the application process) and also to tutors, friends and classmates.

There were various answers to the question about whether they mentioned on their application form that they have learning difficulties. With the exception of four students who were diagnosed after they had been accepted by the university, other students who had been diagnosed earlier in their life in the majority said that they had mentioned their learning difficulties when they applied. Still among them, there were those who did not mention that had a learning difficulty, even though they had been diagnosed while at school. Some of those who did not mention anything about the difficulties they have on their application explained that they did so because they only had a mild form of learning difficulty, such as mild dyslexia, so they did not consider it 'important' to mention it. A student with mild dyslexia, who does not use any of the services for students with learning difficulties, explained that "*...because my dyslexia is mild really, I didn't care, I didn't need extra assistance so...*" (I<sub>12</sub>, F, 20, OUa, mDysl). Two more students with mild dyslexia, who did not feel that it was important to mention that on their application, even though they were receiving support from the DSU (Interviewee 7 & 10), gave the same answer.

This research concluded that the 'level' (mild or severe cases) of the disability plays a key role in the students' decision of disclosure. The degree of the disability, and the 'severity' of the learning difficulty, is important as it determines the attitude and the response that the student will have towards his/her learning difficulty. As has already been suggested, even the type of learning difficulty the students have been diagnosed with plays a significant role in students' reaction to the diagnosis. Students with more common learning difficulties, like dyslexia, said that they found it easier to accept it and understand their difficulties, compared to some other difficulties, which were considered less common and known. Here, it is apparent that

the degree of the disability, whether the learning difficulty is ‘mild’ or ‘severe’, changes the way that the students react to it. It seems that students with mild dyslexia, for example, do not consider it significant to mention it when they apply to university. Probably, they also do not consider that learning difficulties is an important ‘part’ of their identity, it does not have a master status for them, and therefore, they do not mention it initially.

Those who said they have learning difficulties on their application also commented that they are quite open about their difficulties and do not try to hide them from others. The answer that a student with dysgraphia gave when I asked him about the subject of disclosure is significant. He said

*“...it didn’t really bother me, I just realized that I have something, something that I have to work on.” and “Yeah, I don’t make any effort to hide it” (I<sub>4</sub>, M, 18, OUa, Dysg).*

Another student with dyspraxia said that she is really open about her difficulties and actually she even have invented an easy term to explain what dyspraxia is, when she is asked by her friends:

*“When I was asked by my friends to explain it I came up with something simple...well dyslexia is a problem with taking information in and dyspraxia is a problem with getting it out” (I<sub>5</sub>, F, 21, OUa, Dysp).*

Her attitude shows that she has accepted that she has some difficulties but this does not mean that she is not intelligent or as good as other students. During her interview, her attitude made it clear that she is a very confident person who ‘has something’ rather than ‘a person who is the disability’. I noticed a similar attitude towards learning difficulties when I was talking to a more mature student who has dyslexia and obsessive compulsive disorder (OCD). He seemed to be quite open about his dyslexia and the difficulties that this causes him but a little bit more

‘concerned’ about OCD. Not that he is hiding the fact that he has OCD, but he is not as open about it as he is with dyslexia.

*“...I am quite open about it, less open about OCD, I think...I don’t know whether it’s rare or it’s not something well recognised something like dyslexia, so I am quite open about my dyslexia..” (I<sub>6</sub>, M, 33, OUa, Dysl&OCD).*

Behaviour like this is understandable, as dyslexia seems to be one of the ‘most common’ learning difficulties, especially within the educational environment. On the other hand, conditions like Asperger’s syndrome, OCD and mental health problems are not reported by students as often. Of course, this does not mean that there are not students with those difficulties but the number of students with dyslexia in each of the universities where I did the research was much higher than any other ‘category’ of learning difficulties. It is as if some conditions are more acceptable than others are. Dyslexia seems to be more common among students so more people are familiar with the difficulties that dyslexics may have. It seems that some conditions or some disabilities are considered less well-known compared to others. Dyslexia for example may not be understood by everyone and accepted by all, as the literature showed and also students and staff argued about it, but it is in general more recognisable than other disabilities, such as OCD or Asperger’s Syndrome, especially in education. At the same time the lack of awareness regarding these disabilities causes stigma because it is the unknown factor that triggers the discrimination and hence the stigma. Therefore, the public awareness regarding some disabilities defines the level of stigma that there is around these disabilities, while the public acceptance on the other hand, of some disabilities, makes people with these disabilities more or less open about their difficulties, compared to those with other disabilities. Deal’s (2003) idea of the existence of hierarchy of impairments is apparent here, as it seems that there are more common and less common disabilities which in essence determine the level of stigma that a person with this disability has.

Now, in cases where students wanted to inform their supervisor and friends about their difficulties the results are clearer. Most of those who were open about it on their application were also open to their supervisors, friends and other members of staff. However, some of them did not personally go and tell their supervisor or tutors about their difficulties because they had been told that the DSUs would inform the department and/or their supervisor and members of staff. It is interesting that all of them had mentioned it to some close friends and classmates and mentioned that they do not hesitate to ask for the help of friends and classmates if they needed it. All of the students mentioned that their classmates were supportive, especially in cases where students were asking for notes. In addition, one student said that when he was in a group and was reading something that he could not understand then he would just say to someone: *“can you explain this in English, in words that I can understand? And they will do it”* (I<sub>1</sub>, M, 22, OUa, Dysl).

I have to make clear here that in order for students to receive any kind of support or help from the university they have to tell everyone of interest about their disability. In the case of the students in Higher Education, the persons of interest are the DSUs Officers, who will write the appropriate reports and do the assessments, which will qualify the students for the support. The lecturers and some members of staff within the departments also have to be aware, together with the librarians in case students need their help. Most of those people are going to be informed through the DSU in each university, but, as I have already indicated, it is also useful for students to inform these persons about the difficulties they have. Therefore, they need the report from the DSUs, which will be like the assessment and will explain what support they require, and by using this report, they can ‘prove’ that they need help for their studies. However, it was made clear by the DSUs that unless students specifically require it, the DSUs will not notify anyone about their difficulties, either within or outside the university. The DSUs ask for written permission from students to inform whoever they think needs to know about the students’ difficulties. Even in cases where the parents had to be informed signed permission from the student had to be in place. As a Disability Support Adviser explained

*“...we don't even acknowledge we know the student unless we've got the written permission from the student which specifically says that I am allowed to speak to the parents, because otherwise we don't do that” (DSU a [Post-1992])*

It could be a case of confidentiality issues regarding who is informed about a student's diagnosis, but at the same time the total secrecy that the DSUs keep regarding these cases makes it more difficult for these students to feel 'normal' if they think that they have something horrible, a stigma, that no one can know about. I am not arguing that it is easy to say that you have a disability or difficulty. However, the big secrecy that the university wants to keep, where they do not even acknowledge that they know the student, as the DSU Officer said, seems somehow to cause the student or the 'stigmatised' shame if they say that they know him/her.

Issues of disclosure are of major importance mainly for two reasons. First, as has been discussed in the literature, the disclosure of a disability can lead to stigmatisation and the use of labels with the negative consequences for students' life. At the same time, the disclosure could have positive effects and benefits for students. Among the positive effects is the access to support and provision and protection under the disability law. On the other hand, the negative effects of disclosure, like stigma and discrimination, cannot be ignored. The research showed that one of the students' main concerns after they have finished their course, according to DSU advisers, is whether they have to disclose their disability to the potential employers. In addition, it is very important to mention that a common concern for tutors who have been asked to write a reference for a student with learning difficulties is the disclosure of the students' disability. For the reason that, they do not know what effects the mention of the students' learning difficulty will have on students' employability. There is always the concern that the employers may not be so 'enlightened' about disabilities. Therefore, in these cases the label of learning difficulties in someone's reference letter is not something that will help the applicant. Students with learning difficulties or disabilities, with the help of the DSUs and the provision they receive, while in the university environment, are somehow protected and taken care of. Then they finish school and try to find a job,

and the issue of disclosure or not of their learning difficulties once again arises and now they do not have the support of the DSUs. Of course, they still have the law that protects them against discrimination, but the search for a job is a different challenge to applying for a course in a university. Lack of disability awareness can be more of an issue in the general population than within the Higher Education environment, and the employers might not be always as willing or as prepared as a university can be to accommodate employees with learning difficulties. Therefore, the issue of letting the employers know about the employee's disabilities or not is quite an important concern for students.

When it comes to the issue of disclose whether in the application form to the university or to their tutors and classmate, there is a variety of opinions that were expressed during the research. Some students seemed more open about their difficulties, while others did not consider their disability quite severe enough in order to mention it to others, or they were less open about some difficulties compared to others. It is not easy to decide whether the best action is to disclose the disability or not as this can have both negative and positive effects, which in each case have to be considered. Deal, (2003) argued that there is a hierarchy in impairments and disabilities and this results in some disabilities being more accepted and more 'preferred' compared to some others, both from non-disabled people, like employers, and from disabled people from another group. The public awareness about disabilities and especially of some forms of learning disabilities, like for example dyslexia, plays a key role in the decision of the person who has a learning difficulty, whether to disclose the disability or not. Even for dyslexia, which is considered the most common learning difficulty it is sometimes considered a cause of stigma for students and parents and causes concerns whether or not it is good to be diagnosed and disclose the dyslexia. Therefore, it is understandable that it is not easy for disabled people to decide whether they will disclose their difficulties, when they are going to apply for a job, or apply for a degree in Higher Education.

The next chapter sees students as 'users' of the Disability Support Services which are available for them at their universities, in order to explore their experiences, weather good or bad, from their interactions with the members of staff within the Disability Support Services and at the university in general. Their satisfaction with

the services they receive, and any issues and concerns that they may have regarding the support they receive, will be explored next.

## 6 Students as ‘users’ of disability support services

### 6.1 Introduction

The previous chapter explored the students’ experiences with the diagnosis of the difficulties, the role that the learning difficulties played in their decisions about going to Higher Education and the subject of study, and discussed the issues around the disclosure of disabilities.

Here, this chapter sees students as the users of the Disability Support Services, which are available to them through the university they attend. The interviews with the 18 participant students gave an idea of the relationship the students have with the members of staff within the DSUs, but also with other members of staff, and classmates, within the university. The majority of the students who knew that they had a learning difficulty when they applied to university were not aware of the services that are available for them from the university. The first contact with the DSUs is usually either through other friends who have already registered with the DSUs or through the leaflets that the universities give out at the beginning of the academic year. For those students who had declared their disability when they applied the process of enrolment with the DSUs was easier, because the DSUs contacted them prior of the start of their studies to sort out the support they needed. The lack of awareness regarding the services and the support in place for them has to be considered when their satisfaction with the received services is of interest. Someone who does not expect to receive any help at all from the university for his/her learning difficulties is expected to be quite pleased and satisfied when they receive some services in the end. Of course, this does not mean that the services they receive are not of good standard; however, the students’ expectations were not high, as the majority did not know about these services. In order to draw a picture around the support that students with learning difficulties receive at the university, and to show how satisfied the students are from their interactions with DSUs and the

services they receive, some examples are given, from both bad and good experiences that they had.

## 6.2 Students' awareness of disability support services in Higher Education

The previous chapter showed that for the majority of the students with learning difficulties who participated in the research and who knew about their difficulties when they entered Higher Education Institutions, their difficulties did not play a key role in their decisions regarding the choice of university or course or even whether they would continue to Higher Education. As this section explores the experiences of students as service users at their universities and their interactions with the DSUs, it is also useful to see how informed they were about the existence of services and provision for students with learning difficulties at their chosen universities.

The analysis showed that none of the students had checked the services in advance, and only a few of them knew that the university is obliged by law to be prepared and to provide support for students with learning difficulties. Those who knew or suspected that they might get some sort of help had heard about it from friends who had already started their studies or other members of their family who either were students themselves or just happened to know about it. A student with dysgraphia said:

*“I knew that there was some (support) from my sister’s old university. She was at (university’s name) and I knew that there is support available from the universities and there would be some support wherever I went” (I4, M, 18, OUa, Dysg)*

Another student said that it was his mother who mentioned that there must be some support services for students with learning difficulties and therefore, he decided to go and visit them (Interviewee 18).

A girl with mild dyslexia said

*“I think that I was aware of that, but I didn’t actually make a contact with them, because my condition is quite mild and so in the background...but one of my friends who is registered with the services, the Disability services, she contacted them anyway, so I’ve tried too” (I<sub>12</sub>, F, 20, OUa, mDysl).*

Again, here the influence and the help that family and friends play in students’ life, is important, as it can be the informal and the first form of help that the students with learning difficulties have when they enter Higher Education.

Once more, it is obvious here that the level of the severity of the difficulties plays a role in students’ decisions. The students with mild conditions did not consider it important to contact the university and ask about the services for students with learning difficulties. For other students with more severe learning difficulties, such as the case of Interviewee 2, the learning difficulties required her to go and ask for help during her first weeks in university. This student, who has agoraphobia, she explained:

*“...when we got here in the fresher’s week, we had to do some articulation and I was very worried thinking about it...so I spoke to my senior tutor and I think she go (sic) and talked to the disabilities people, so she sent me...so I went to see them” (I<sub>2</sub>, F, 19, OUa, Agor).*

Therefore, it is apparent that the level of the difficulty that the student has been diagnosed with plays a role in their decision to seek support, or disclose their difficulties, or to search well in advance about the available services.

For other students, the first contact with the DSUs in their university was after they had started their course or in the *Fresher’s week*, as the first week of the academic year is called, when the orientation for new students is taking place. As the Directors of the DSUs explained, and some students (Interviewee 8) mentioned, it is a common strategy to approach all students (as they cannot identify those with

difficulties, unless they go and register with them) and to give them leaflets about the services that the institution provides for disabled students. The leaflets include information about the services for students with disabilities and learning difficulties and the procedures they have to follow, if they want to get the support from the university.

The other possible way for students to have their first contact with the DSU services at their university was through an e-mail or a letter, directly from the DSU. This method is only possible in cases where the students knew that they had some sort of learning difficulty before they applied to the university and they had declared on their application that they have a disability. Therefore, in these cases, the DSUs had the student's contact details from their application form and they could contact them in advance. An example of such a case was with a student who has dysgraphia, who said:

*“...yes, I put it down on my UCAS form (that I have dysgraphia) and the DSU, the support department, they contacted me...I think they contacted me once before I came to ...and then I got in contact when I came here as well...”* (I4, M, 18, OUa, Dysg)

From the students' interviews, it was clear that the majority of them did not know about the services that each university offers for students with learning difficulties. This is either because they did not have a formal diagnosis until they had already entered the university or in the cases of those who had an early diagnosis, they just did not consider it important to check for the services in advance. Again, here we could consider that among the possible explanations is that the disability for these students may not be a master status, which affects their decisions.

However, at the same time we have to think of the students and the universities in terms of 'customers' and 'organisations' that offer some sort of services. In this case, the customers should be more informed regarding what services are on offer and how to demand these services because it is their right to use them. Their lack of awareness regarding the services that they can get from the university is going to

affect their experiences, directly and indirectly, with the universities and the DSUs. If the students knew in advance about the services that are available for them and had been informed, well in advance, about the processes that they have to follow in order to access these services, then the whole process of registration with the services could have been easier for them. In addition, it could have been done before the beginning of their studies, so that everything could have been in place for them. This could have solved one of the problems that students mentioned regarding their experiences with DSUs, which is the long delays in assessments time, and the making of appointments with DSUs. However, in some cases, the Directors of DSUs mentioned that sometimes students do not register with the services until they actually need something from them, but the process that they have to follow can take weeks to be completed until the DSUs are able to offer the support the students want.

Furthermore, another issue, which emerged from the analysis of the students' responses was that their expectations were not as high as they should have been if they knew that it is their right to receive support from the institutions. It is understandable that if the 'customers' do not know what they can expect or what their rights are then if anything is given to them it will be considered as something really good and the 'customers' will probably be satisfied with it. However, if their expectations were higher or if they knew well that it is their right to receive help, then anything less would be considered unacceptable and if the quality of the services was not satisfactory they could have complained.

Despite the lack of awareness regarding the support and services provided by the university, it is important to see the experiences that these students had once they accessed the support while at the university.

### 6.3 How valuable is the support from the DSUs

This section analyses how the students valued the support and the quality of the services that they actually received once they registered with the DSUs. If they did not know in advance that they would get some sort of help and provision from the university of their choice, and then they get it when they arrive at the university, it is understandable that those students feel really privileged and satisfied about the support they received. When someone has minimal expectations about the provision that they will receive, then any amount of help or provision will seem like something very satisfying and, as it was unexpected, it will be received as something positive. Therefore, it was normal that the majority of students said that overall they are satisfied with the provision, the services and the support they receive from the DSUs at their university.

The interviews with the students showed that when students were asked to express their satisfaction about the DSUs and the services they received, they justified it with examples of personalised treatment. Those who said that they were satisfied with the services mentioned examples of good communication with the DSU officers, their personal tutors and members of staff within the DSUs, while at the same time they valued the fact that their personal needs were met by the institution. Some examples from students' experiences will be given here to show what students justify as satisfactory services from the DSUs.

Among the positive comments that students made regarding DSUs' officers are about the good communication between them.

*“...they always kept me up to date and they informed me about how my concession was going on. So, like my limited experience with them had been, sort of, when things were going really wrong and I needed them to sort of come and help me and I think they've been really good at doing that” (I<sub>5</sub>, F, 21, OUa, Dysp).*

*“In terms of the DUS, I am very happy and my supervisor he’s been really fantastic, so I am very happy actually like the institution provides so much support...”* (I<sub>3</sub>, M, 28, OUa, Dysl)

Emphasis is given to good communication about personal issues, like sorting out the exam arrangements and concessions, and good personal relationship with the tutors in the DSUs, when they need their help.

*“I have a good dyslexia tutor and what she does is she helps me with all sorts of things. Let’s say that I’ve got problems with this or we go through my work and she does what I want to do basically. It does work as an assistant...”* (I<sub>3</sub>, M, 28, OUa, Dysl)

The importance of being able to have a personal communication with the DSUs officers/advisers, whenever they feel that they need their help, is something that was emphasised by students.

*“I think that if I’ve needed anything, I just go there and anybody can help. I’ve been there before and they’ve been brilliant. I have no problems with them at all”* (I<sub>1</sub>, M, 22, OUa, Dysl)

*“Very satisfied...they (DSU) said that before the exams if you want to come and talk to me that is fine...they made my options very open to me and I’ve never felt pressure and I think that everybody is very accommodated so very satisfied”* (I<sub>5</sub>, F, 21, OUa, Dysp)

Of the essence, for these students, is the feeling of comfort that they feel with the officers within the DSUs:

*“...They are very reassuring; they are quite nice people, very easy to reach. Sometimes I feel very uncomfortable discussing this thing with people but they are very sort of reassuring and very, you know, very understanding and good. I think it runs very well actually, they seem quite efficient in doing stuff...”* (I<sub>2</sub>, F, 19, OUa, Agor)

It is essential for these students to be able to go to the DSUs and find someone who is able to deal with their enquiry and understand their problems. It is difficult, and at the same time uncomfortable, for some students to talk about their difficulties to others. Therefore, it is important that the people within the DSUs are as reassuring and understanding as possible, in order to make more students feel that in times of need there is a friendly person to whom they can talk about their difficulties and their struggles with the studies. This is something that is important for all students because sometimes they can feel stress and pressure during the academic year, especially before exam periods, but it is a bigger issue for students with learning difficulties as understandably they may have more struggles with their studies.

All of the examples showed that the students' satisfaction with the support they get from the DSUs comes from receiving personalised treatment, either in the form of good personal communication with advisers, good relationships with dyslexia tutors or even the fact that they can see a friendly face when they need someone's help. It is apparent from their interviews that they do not want the standardised treatment, which lacks the personal touch and is the same for everyone, regardless of needs and difficulties.

As noted above, it is understandable for students to be satisfied with the support that they receive when they actually did not expect any support at all. In addition, it is understandable that when they were told that they would receive xyz support and they actually get it in the end, then they will be quite satisfied with that help. The law requires that the universities provide a disability statement, where it is explained what they can provide for students with specific disabilities. Therefore, if the university decides the kind of support that it will provide and 'advertises' it to

students-customers, then there is no question of students not being satisfied with that support, because they received exactly what they were promised.

However, the issue here is who defines the support that the DSU will provide and how the marketisation and bureaucratisation of the services affect the quality of the support that is provided to the students. It has already been discussed the law required that the institutions make reasonable adjustments in order to accommodate the needs of the students with learning difficulties. However, it is up to each university to define the adjustments that are considered reasonable and this can cause problems or misunderstanding between students and DSU Officers. At the same time, the standardisation of the services, due to the bureaucratisation of the disability support, creates a tension between the support the institutions provide and the support that the students value as satisfactory.

Some of the problems that students experienced when they were asked to value the services they receive from the DSUs are going to be explored next.

#### 6.4 Bad experiences with DSUs

However, despite the general satisfaction that most students expressed with the support they receive from the DSUs, there were some individuals who were not so pleased with the services that the university offered them, whose opinions are equally important as other cases and some of these examples will be outlined here. A student with mild dyslexia and problems with short-term memory, who had some rather bad incidents, twice, with the receptionists in one of the DSUs, gives one such example. The first time it was when she first visited the DSU:

*“Well, when I first went there it was the same two receptionists and I felt a little bit like...they think I’m dumb...and they know more than me really, but when I ask them questions they never know the answers, or they didn’t want to tell me. They always say, “Oh, it doesn’t matter”. Like I rang up the other day to find out about my case because something has been changed and they say, “Oh, it doesn’t matter, it’s fine”... and I just wanted to know. I wasn’t ringing to complain or anything, just I would like to know what’s going on. So, I get really angry, because I’m always having to demand it and say ‘I need to see somebody’” (I<sub>8</sub>, M, 19, OUa, mDysg&smem)*

The next incident was later when she had some problems with her equipment and she needed a new laptop and a report to explain why she qualified for a new one:

*“...So, I get for the new laptop and I got sent another report with that, from another lady. But a different lady didn’t know that she sent me the report, so, for a good length of 10 minutes I was arguing with... and we were nearly shouting at each other because she was saying: “no, this is a new report” and I was saying “but I’ve already got that report”, and she just wouldn’t believe me. Until I came back a few days later saying, “Look, this is the*

*report". So, there was a bit of a mix ups a few times and I do feel that because...I feel like they see us as dumb and that I am kind of lying to try and get all the free stuff. So, it is a bit difficult to make them believe me really...they just seem so disorganised and so...Nobody knows what another person is doing and they do treat you like they don't really care. You are just another person that goes and see them really...and they are doing YOU a favour. They do seem to have this idea..." (I8, M, 19, OUA, mDysg&smem)*

In cases like this, there is always the problem of the perception of someone without the stigma towards someone with the stigma. The non-stigmatised person has an impression about the stigmatised person, which in most cases is wrong and does not represent the stigmatised person, and based on that idea they treat the stigmatised person accordingly, regardless of the individuality of each person. Based on the statement of this student, the people within the DSU acted as if the student was trying to use the disability to gain more than what she should. The student with learning difficulties felt that she was being treated unfavourably by the member of staff within the DSU, because of the idea that the staff had about the student, due to the learning difficulties.

Another issue that arises from the statement of that student could be the standardised treatment that in some cases it offered towards students with learning difficulties. The student felt that she had been treated as if she was just another student among the hundreds they see every day. It is true that the marketisation of Higher Education and the competition between institutions has led to an increase in the number of disabled students who enter Higher Education. Therefore, a more standardised approach and more bureaucratised services have been applied to students with disabilities, in order to deal with their increased number, while at the same time the law requires the same treatment for everyone with disabilities in order to eliminate discrimination. However, within this approach there is the possibility of losing the individual within the whole, trying to offer a standardised treatment for everyone. This case is one example of the standardised treatment, that the DSUs might have been forced to offer, in order to handle the increased number of students with disabilities and to comply with the new disability law. In addition, from the

interactions that this student had with the DSU, she felt that the officers' opinion is that their job is a charity, and not to make sure that the students receive everything according to their rights. It may sometimes feel like an act of charity but it definitely is not. It is the law that gives these people the right to ask for or demand the help and support that they need. Of course, this one incident, as described by this student, does not mean that all members of staff within DSUs treat students like that. However, at the same time, an incident like that should not be ignored.

Another student who participated complained about the way that a DSU officer handled her request not to mention to her department that she has dyslexia and dyscalculia. The student had specifically requested that her department knows nothing about her difficulties because as she explained

*“I want to apply to (...) (another course) after this course, but basically, I didn't want my department to think ‘oh, there is something wrong with her, I don't want to write her a reference for (...) (the new course)’ and I wanted nothing to be passed onto my department and they (the support unit) knew this. They knew it so much because I made sure that they absolutely knew it...”* (I<sub>17</sub>, F, 22, OUa, Dysl& Dyc).

However, for some reason, which was not clear to her, the DSU officer who was dealing with her case, considered it appropriate to inform the department about this student. This case, which is a matter of confidentiality between the student and the DSU officers, also reflects the issues of stigma that students with learning difficulties are facing. The student feared that if her department knew about her difficulties then this might affect her chances of having a good reference and even her chance to apply for another course after the one she was studying. She considered her difficulties an obstacle for her plans, not because she did not have the abilities due to her difficulties to do whatever she wanted to do next (which it may be the case, but we cannot be sure), but due to the stigma that she thinks her difficulties carry. She feared also that the label of dyslexia and dyscalculia in her file would affect the way others may treat her.

Similar to the previous case, it is once more an issue of perceptions that the non-stigmatised are seen to have regarding stigmatised persons. If someone sees the labels 'dyslexia and dyscalculia' on a student's file, it is possible, if he/she does not have any disability awareness, to reject or treat that student according to the idea that he/she has about what dyslexia and dyscalculia are and not based on the actual abilities of the student. It is usual for people to focus on the negative (in this case disability is considered a negative characteristic) instead of the individual's abilities and the things that they can do with them, which in turn results in stigma and discrimination.

A possible explanation for the officer's decision to inform the department could be the fact that the university has a routine process that is used to deal with all students with disabilities and it might not be prepared to handle individual cases and requests. This routine treatment, which is the result of the bureaucratisation of the disability services, makes it easier to provide the same treatment for everyone, and it helps with the increased workload. At the same time, it might be the case where, as next will be explored in more details, if one within the university knows about a disabled student (officially from the student's UCAS form) then it is assumed that everyone within the university who has to know knows about that and it is public record. However, again it seems to be difficult to separate each case and to see each case differently and make exceptions for special request of secrecy within the different departments and sections of the university. The standardised treatment means that all students will be treated in a same way, as this will help officers to deal with the increased number of students with disabilities.

Despite that standardised treatment, which in some cases could be seen as understandable, there is the possibility here that some DSU officers think that they know what the best is for students who visit the DSU, which results in treating them like children who do not know themselves what is the best for them. The next chapter will discuss the role of the DSUs officers and will explore whether they are the 'experts' regarding disabilities, as they claim to be.

One student identified the bureaucracy in the institution and mentioned it as one of the things that he does not like about the institution and the services.

*“I was a little disappointed with the bureaucracy, which is not part of the DUSSD process, they have to sort out who’s going to send out my dyslexia report. Especially as more graduates are coming through, I think that that’s the only problem that the university, itself, has to sort it out in a major way, as the graduate school couldn’t have given me any advice, which I was very disappointed with” (I<sub>3</sub>, M, 28, OUa, Dysl).*

Finally, a student with dyslexia and OCD gave a third example of bad experiences with the members of staff within the DSUs. This student said that he had to visit the DSU at his university many times, in order to get the report which would allow him access to the services for students with learning difficulties. As he said, even though he had been diagnosed with dyslexia and OCD earlier in his life and had sent the assessment papers as soon as possible to the DSU in order to register there, no one contacted him. So he said:

*“I think ...I had to be practical. I had to seek an appointment, nobody came to me and says ‘Dear, Mr (his name) we’ve received your assessment, we would like to make an appointment to see you on this and this day’. It wasn’t like that at all I had to...I had to find out... I just looked for some of the advisers and I picked up some of the advisers and I went to see them, and then the ball started rolling. I mean whether it’s a good thing or a bad thing...with the services here you’ve got to be quite proactive, you’ve got to, otherwise nobody will come to you...” (I<sub>6</sub>, M, 33, OUa, Dysl&OCD)*

It is worth mentioning, that this student said that he thinks that someone has to be proactive in order to get the help and the support he needs from the DSUs, but what about the cases of students whose difficulties are related to communication skills, like Asperger’s Syndrome, and prevent them from being proactive. How will these students be able to access the so-much needed provision if they cannot *go around* and demand the support? The same student later said that he thinks the problems he had with the DSU were due to lack of staff *“I think they probably are under*

*resourced, I think they need more people, but that's not my problem. It's their... ” (I<sub>6</sub>, M, 33, OUa, Dysl&OCD), and because the officer who was dealing with his case works only on a part-time basis:*

*“... I think probably because she's part-time, probably cause she's not know as much as somebody who's full-time. So, you get the impression sometimes “oh, God what does she know?” She really knows what she's doing, she's done that now which is the main part of her job, but I think in terms of getting anything done, I'd probably lay more on (other staff) and I would do this...” (I<sub>6</sub>, M, 33, OUa, Dysl&OCD)*

Interestingly, later during the interview in response to a rephrased question regarding the same issue of their opinion about the overall provision even those students who had positive experiences with DSUs made some comments about the services, which need to be mentioned here, as they are interesting. Among other complaints that students had about the university was the long waiting list and the big delay in assessment results, in order for students to receive the report from DSUs which would allow them to have access to support and provision. In one particular case, a student who I spoke to, just before the Christmas break, said that he was still waiting for the report. I contacted him after two months and he was still waiting for a proper report from the DSU. He was receiving some sort of help during this period but not the full provision he could get after the DSU had sorted out the assessment report. I have to mention that it is not only the people within the DSUs who cause the delays to students. There are other agencies like the local LEAs and some professionals-experts who are involved in those processes, and who are not directly employed by the university and are not directly part of the DSUs teams, but whose participation is necessary for the preparation of the report which will allow access to provision for the students. Probably the students only see that the university has to prepare the reports and that might explain some complaints about the long delays that were mentioned regarding the DSUs. They might not know that other parts are involved

and they can cause delays and this might cause misunderstanding between students and DSUs.

I have already mentioned the case of a student who was diagnosed after being at the university for 7 years, but no one was able to understand that she had learning difficulties. The student decided to mention her case to the Educational Welfare Officer at her university and as she said:

*“...I was actually angry about it and I went to see the Educational Welfare Officer about it because I thought that this is something that the university had to do but they don't. I am getting a letter from the Dean said that actually they are not considering looking into giving any of the staff training, which disappointed me because I thought was something that... I wasn't criticising the university, it is just a thing that happened and could be prevented” (I<sub>3</sub>, M, 28, OUa, Dysl)*

The university appears not to have considered it important to take any action to train the staff in order to prevent similar cases in the future. I do not claim here that this is the case in every university regarding the matter, but the official answer that this university gave to the student's concern about the issue, is interesting. The next chapter will show the issues of provision for students with learning difficulties from the universities' perspective and especially from the point of view of the Directors of the DSUs, where the aim is to see another aspect of the same subject.

#### 6.4.1 Students' relationship with members of staff and tutors

It is interesting to see the students' relationship with lecturers and other members of staff except of this that they have with DSUs. Few students mentioned some problems they had with other members of staff, especially tutors, within the university environment. One of the most common problems, was the unwillingness of tutors, lecturers or members of staff to help them regarding support for their difficulties. The same problem has been mentioned by all Directors of the DSUs, however, the data from the lecturers, even if they are not representative of the whole population of lecturers from Durham University, they did not conclude on lack of disability awareness or lack of sensitivity, as it would be shown next. The support advisers see this problem more often when they try to persuade members of staff about the adjustments they have to make. There are several possible factors which may lead to the above problems, among which are the lack of disability sensitivity and awareness, within the educational environment, and the lack of understanding and acceptance of the 'unseen' disabilities. In addition, there is the issue of what each university and each tutor means by adjustments, especially regarding the teaching process and techniques that are used. For example, the request in advance for lecture notes by students with learning difficulties may seem like a very helpful technique, or adjustment for them. At the same time, it gives rise to the issue of students not attending classes because they already have the notes and this it comes in contrast with one of the very purposes of Higher Education. Higher Education does not want students to repeat what the lecturers already have said in their lectures; students have to develop critical thought and to work in order to win in this *individual competition* that education seems to be. But again students with learning difficulties, for example students with dyslexia, by 'definition', have problems with notes taking, which means that they have a disadvantage compared to other students who might find it easier to take notes during the lecture.

There are researches which show that there are some lecturers whose opinion regarding disabilities, and especially learning difficulties, is that it is not within their

job requirements to work extra in order to accommodate disabled students by providing notes, different formats of lecture notes etc. (Brueggemann, White, et al., 2001; Dudley-Marling, 2004). It has already been discussed that some lecturers argue that the main scope of education is for students to learn. Therefore, since students with learning difficulties are not ‘good’ at that, then there is nothing to be done for them, by lecturers or the university (Stage & Milne, 1996; Brueggemann, White, et al., 2001).

Among the other excuses, or arguments that lecturers use, is that the special adjustments for students with learning difficulties may seem like unfair treatment towards other students who cannot ask for lecture notes, or extra time in exams, because they do not have the ‘excuse’ of the learning difficulty (Stage & Milne, 1996; Brueggemann, White, et al., 2001; Dudley-Marling, 2004).

However, we have to keep in mind that not all lecturers or members of staff are the same and hence there are those who are helpful and those who are not so understanding of the difficulties students may have. An example of some tutors who are not as ‘accommodating’ as others regarding students with learning difficulties was given by a student who has mild dyslexia from her personal experiences with some of her lecturers:

*“I think some of them (lecturers) are more experienced lecturers like they know how to accommodate people, so they give people enough time to write notes down...but I found a couple of the lecturers I’ve got, they just keep going, keep going and you can’t keep with notes taking, which is hard...”* (I<sub>12</sub>, F, 20, OUa, mDysl)

Issues and concerns around these issues will be also raised below when the Directors of DSUs will mention them among the problems they face in their work. There, examples of lecturers’ arguments regarding reasonable adjustments and provision for students with learning difficulties will be presented, in order to show the extent of the problem. However, the views of lecturers and members of staff from colleges

from Durham University, will also give their perspective of the issues arise here next.

The findings of this research showed that most of the students who had mentioned to their supervisors or other lecturers that they have learning difficulties said that they did not have any significant problems with them, especially after they had explained to them that they had some sort of learning difficulty. Most of the lecturers were happy to help by giving notes in advance or by encouraging them to go and see them if they needed anything or if they wanted an extension on essays. A student with dyslexia says about her tutor from the department:

*“...he’s actually phenomenally..., he’s been great. He realised that if I am sending my work and it hasn’t been proof read and he tends to look onto my ideas instead of my grammar, which might be appalling...he is really helpful”*  
(I<sub>3</sub>, M, 28, OUa, Dysl)

The opinion of another student, even though he did not mention to his tutor that he was dyslexic, regarding his tutor’s reaction to this information is interesting:

*“I think probably her opinion would change because most people do from my opinion maybe just understand a bit more rather than do anything major to be different. If you do hand in or writing something down and your English is poor it just understands rather than just go ‘what is that’”* (I<sub>1</sub>, M, 22, OUa, Dysl)

On the other hand, the Directors of the DSUs mentioned the attitude of members of staff as one of their main problems. There are several possible explanations for the discrepancy between the students’ opinion about the tutors’ attitude and that of the DSUs’ Officers. One possible explanation is that the DSUs’ officers manage, in most cases, to persuade members of staff that the law requires them to accommodate the students’ needs, whether they agree with this or not. This has as a possible result,

that students go and see those lecturers and actually receive the help they need from them, which helps them to form a better opinion about those lecturers. In addition, there is the case of lecturers who as human beings are sensitive to individual demands for help and regardless of the law they are willing to offer their help whenever possible. This leads to another possible explanation, which some lecturers that I have spoken to express. As they explained, it is a different case to respond to an individual student's request or 'demands' for help with notes, books, extensions etc. and a different case when the DSUs 'demand' lecturers' cooperation. The interviews with the lecturers from the university of Durham showed that the majority of the lecturers do not have any problem to provide support to students with disabilities and to comply with the majority of the adjustments that DUSSD recommends. Those who mentioned some issues with for example providing lecture notes in advance they said that it is not just them but their whole departments' policy. However, they added that they would make any other possible adjustment to help students.

A student when I asked her if she had informed her lecturers about her difficulties, explained that even though they had received a note from the DSU which informed them about the needs of this student she said "*...but I don't think that it does any harm to put...a face to a name*" (I<sub>5</sub>, F, 21, OUa, Dysp). She explained that she believed it is more personal and that makes it easier for lecturers to respond to the student that requires their help, instead of only receiving a plain note from the DSU, which is more of a list of students' names than individuals who ask for help. Another student said that even though the DSU already informed the lecturers "*...if I haven't had the lecturer before then I am taking the copy with me to show it as well...*" (I<sub>18</sub>, M, 20, NUa, Dysl&Dysp&AsperS)

Even though it seems that it is both useful and quite practical for students to inform their lecturers about their problems (despite the effort of the DSUs to inform the lecturers in advance about those students), there is still the issue about how proactive the students have to be. However, it is arguable whether the personal difficulties of the students allow them to be as proactive as the situation requires. It is not always easy for students to be as proactive as is needed in order to access the support they require. It is possible that their difficulties prevent them from doing something like

that, as is the case of students with Asperger's Syndrome, who have trouble in communicating with others. It is quite difficult for these students to be proactive and actually go and see the lecturers and ask them for help or support.

It is useful now to see, in the next two chapters, the opinions of the four Directors of the DSUs from each university, and that of the lecturers and College Officers from Durham University, who in each case they offer the official point of view of each institution. Their views on the issues that have already been discussed through the interviews with the students will form a clearer picture of the general issue of provision for students with learning difficulties in higher education.

## 7 Provision for students from the institutions' perspectives

### 7.1 Introduction

The two previous chapters showed the issues around learning difficulties from the perspective of students (with LDs) based on their personal experiences. The next two chapters will see the issues of learning difficulties and provision of Higher Education, from the perspective of the institutions, through the views of the Directors of the DSUs, as well as that of the lecturers and College Officers from Durham University.

The interviews with the four Directors of the DSUs, who are in charge of the services and the provision that universities offer to students with disabilities in general, including learning difficulties, as well as physical disabilities, and other forms of disabilities, helped to see the issues around provision for students with learning difficulties from the perspective of the institutions. In addition to the Director of DSU from Durham, the focus of the research at Durham University made it necessary to include the views of some lecturers and College Officers, who offered their perspective on the issue of provision for students with learning difficulties for that particular institution. Information from the universities' web pages and available leaflets were also used, when necessary, to draw a picture around those issues

This chapter starts with the role that Directors of the DSUs have within the university. The new law brought several changes to the disability issues in Higher Education Institutions and at the same time, it changed the role that Directors have now. The Directors explained that among their roles is to be the "*gatekeepers*" who manage the relation between students with disabilities, members of staff and even external organisations or individuals, such as researchers or other people who need to contact the students. It is only through Directors of DSUs that someone can have any communication with the students with disabilities. Therefore, they are also the "*mediators*" and the persons who are going to "*advocate*" for disabled students in Higher Education Institutions, as the Directors pointed out (Director of DSUs, b &

d). The complexity of their role lies in the inherent tension that there is in their post, as they have been employed by institutions to accommodate the needs and requirements of students. They have to find a balance between their employers' interests and the students that they have to support. Of course, they now have the law to help them succeed in that as the new disability law makes sure that the students with learning difficulties receive the help and support they need from institutions and they are not discriminated against within Higher Education. The support they provide for students with disabilities used to be "*out of the goodness of their heart*" (Director of DSU c, [Pre-1992]), whereas now, it is part of the mainstream system and part of the bureaucratisation of the disability in Higher Education. The turn to the bureaucratisation of disability and the consequences of this turn for both students and members of staff are explored in this chapter.

Even though their role is easier, as they explained, due to the new disability law, at the same time, they still face quite a few difficulties when it comes to persuading some members of staff about new adjustments and changes they have to make to accommodate students with disabilities. Among the problems as the Directors of the DSUs explained is that they have some members of staff (the so-called "*old school*" lecturers [Director of DSU a, [Post-1992]) who still argue about the existence of dyslexia or learning difficulties. The way that some members of staff act upon the new adjustments that they have to make in order to accommodate the students with learning difficulties can be explored through the framework of Weber's (1978) "*formal and substantive rationality*". According to Weber, formal rationality means that people calculate the best way to deal with each case or difficulty, and the calculations are based on universally accepted laws, rules and regulations. Substantive rationality, on the other hand, directly orders action into patterns through groups of values. (Ritzer and Goodman, 2003, p: 132) The uneasiness around people with disabilities, as Goffman (1990 [1963]) explored it, is another common argument that the Directors have to deal with when they try to persuade members of staff about the adjustments that have to be made in order to accommodate the needs of students with learning difficulties. Generally, issues on disabilities seem to be getting better after the new DDA but still their role is to manage the tension between students with learning difficulties and institutions.

## 7.2 How the Directors of DSUs see their role within Higher Education

The Directors of the DSUs hold a key position within each university because they are the gatekeepers who manage to some extent the relationships between students and lecturers or the university as a whole. The Directors' job, as gatekeepers, is to determine whether the students with learning difficulties will get the support and the provision they need in order to successfully study in Higher Education. They control the access to support and in a sense they exercise their power by controlling the students' access to the institutions' support. At the same time, they are the gatekeepers between the students and any researchers who want to contact them. The Directors are the first contact for everyone who wants to talk to or interview the students with disabilities. In order to conduct this research their approval was necessary before I was even allowed to contact the students in order to explain the purpose of the project and ask for their participation. Therefore, their role as the gatekeepers is quite important and this gives them the 'power' to control access to services and support (Broadhead & Rist, 1976; Corra & Willer, 2002).

Furthermore, they are the managers whose job is to balance the tensions between students with disabilities and Higher Education Institutions in order to accommodate the needs of students without compromising the 'standards' that the institutions have set. They also promote awareness and understanding of dyslexia and other specific learning difficulties by providing information regarding specific learning difficulties, while supporting staff development initiatives. Overall, they are the mediators between students with learning difficulties or disabilities in general and Higher Education Institutions. The Directors of DSUs are there for both students who need help and access to support and, in addition, for members of staff who need help in their dealings with the students with learning difficulties. Paradoxically, they act and work both for students and for the institution and this tension in their role was obvious in many cases during the interviews, and is going to be explored next in this chapter.

The role of the Directors as managers of the disability units has changed in recent years due to changes in the disability law, which clarifies the rights of students with disabilities within Higher Education and the adjustments that universities have to make to accommodate the needs of students. The Directors explained that even though the workload has increased due to the increase in the number of students who register with the services, their job seems to be easier because they have the law to use, in cases where persuasion is needed in order to help students with learning difficulties. Their role includes responsibilities such as assessments for students' disabilities, support and help after the assessment, liaison with departments and services, which in turn will help the students, coordination with lecturers and tutors to accommodate students' needs and many more. The Directors described their role as a demanding job, which plays a key role in the whole provision for students with disabilities.

*“...it is our job to enable them to attend and study effectively the university and hopefully gain a degree; that means that... from start to finish we see students who are due to come to the university. So, we advise them and give them guidance on what technology they need and what is available within the university; on how to get the support that they need...Our job, basically, is to facilitate students to study in their best possible way they can and demonstrate the potential and graduate; that's my job. If they graduate and they are happy and they've done their best and have reached their potential, then I am happy” (Director of DSU a [Pre-1992])*

Keeping students 'happy', which means giving them all the support they need and helping them to overcome their difficulties and eventually succeed and get the degree they want, is something that is not easily achieved. The students' needs could change over time, different needs can become apparent, or some may have been met and no further action is necessary. Every time the needs have to be assessed and met, when possible. Therefore, in order to do that the Directors have to make sure that different departments and members of staff who are going to be in contact with the

students with learning difficulties are aware of the needs and of the adjustments that have to be made, in order to accommodate students' needs (Director of DSU c, [Pre-1992]) . Members of staff have to know about the difficulties that each student faces, providing that they are informed about the difficulties that each student with a certain learning difficulty experiences, in order to make the appropriate adjustments to accommodate these students. Therefore, the role of the Directors is to inform members of staff about the identity of the students with learning difficulties. This task is not a simple one, as there are issues of confidentiality and the appropriate management of information about the students is required. Both issues are very important and the next chapter will explore in detail the ways that Directors use to manage the students' information and making sure that the appropriate persons are informed about the identity and the needs of the students with learning difficulties.

The Directors are in charge of a larger team that as a whole is responsible for the provision and support of students with disabilities. Their job does not end with administration duties and management of budgets and funds. Some of the Directors still work as disability advisers and dyslexia tutors. They have one-on-one meetings with students, while at the same time, they “...*make sure that the university complies with disability legislation and that (sic) types of things*” (Director of DSU b, [Post-1992]). Most importantly, their role is to be there for students with disabilities whenever and for whatever reason they may need their help.

*“... basically, we're the person's first point of contact, for disabled students, and we believe that we advocate for them quite a lot of times. We also do quite a lot of staff training, disability awareness, deaf awareness, dyslexia awareness and so on”* (Director of DSU b, [Post-1992])

This Director (of DSU b, [Post-1992]) claims that their job is to “*advocate*” for students with disabilities and it is something that they have to do “*quite a lot of times*” (Director of DSU b, [Post-1992]). By that the Directors seem to mean that they help and support students with learning difficulties and their job is to make sure that everyone else within the university, like members of staff, knows what they

should do to accommodate the needs of these students. At the same time, it can be interpreted as saying that students with learning difficulties are not capable of doing some things by themselves. They cannot advocate for themselves when it comes to issues of support and provision for their difficulties and hence they need others, in this case the Directors of DSUs, to advocate for them. The ‘stereotypical’ belief that disabled people are unable to cope with everyday activities, and they constantly need others to advocate for them and to ‘defend’ these “*vulnerable people*” (Ryan & Thomas, 1980 in Barton, 1998 [a]) is still apparent. This idea of the dependency of disabled people exists regardless of whether the difficulties that the person experiences prevent him/her from doing everyday life activities (Watson, 1998; Shakespeare, 1998; Sennett and Cobb, 1972). Some students mentioned in their interviews that in some cases they did feel that the DSUs patronise them and treat them like children who do not understand and who cannot do some things by themselves, and they need others to do things for them, because they have learning difficulties (I<sub>8</sub>, M, 19, OUa, mDysg&smem).

In this case, the Director’s (Directors of DSU b, [Pre-1992]) argument about advocacy can be seen as that they play the role of the person who will handle the situation and will solve the problems of the students with learning difficulties. At the same time, it seems as if they are the experts who know how to manage difficult situations between the students with learning difficulties and other members of staff. Their expertise on the needs of students with learning difficulties allows them to advocate for these students. Not that the Directors of DSUs and the whole DSU cannot be considered as the mediators who link together students and university, but they should not be seen as the protectors of the students with learning difficulties, who cannot do things by themselves. In fact, it is the law that protects the students’ rights and protects them from discrimination.

All the procedures and the support that the DSUs offer have to be according to the Disability Discrimination Act (DDA), the legislation which protects students with disabilities, in order to avoid possible misunderstandings regarding what can be offered or not. The bureaucratisation of the disability and the services, after the changes in the Disability law, means that there are standard services that have to be provided by each institution for disabled students and in some cases the individual

needs of the students cannot be met, because they are not covered under the typical treatment.

*“...Well obviously managing a large team and make sure that obviously some procedures are followed and comply with the DDA and that university is compliant with DDA, that’s what we are working towards. And we also...it’s not just supporting students with difficulties but also members of staff to help them support students. So it’s not just the students’ point of...it’s just across the university”* (Director of DSU d, [Pre-1992])

The role of the Directors and at the same time the role of the whole DSU within each university is a complex one. They are the first contact for both students with disabilities and staff who deal with students with disabilities, and at the same time, they represent both the university and the students. By saying that, I mean that the DSUs are the university’s representatives regarding the official policy about students with disabilities, while at the same time they represent students with disabilities when there is the need to deal with their issues within the university. As the Directors explained, and from information available through the universities’ websites, their job is not only related to disabled students but academic staff too and actually in two ways. On one hand, it is their responsibility to train the staff, to explain the situation for each student and to make sure that everyone within the university follows the rules and regulations, while at the same time they offer services for disabled members of staff too. Therefore, they play quite an important organisational-managerial role within the institution-university regarding any issues related to disabilities. Based on the law, the disability regulations and the university policy they manage the relationships between students and staff or students and the university in general, making sure that each side plays its role according to those rules.

Understandably, it is not an easy task to manage the conflict between the interests of students with learning difficulties and the interests of their employer, hence the university. It is common to have to play the mediators between the interest of the

students and these of the university. In order to release the tension between the two sides (students - university) the Directors of the DSUs have the help and support of the law. The law makes clear the rights and the obligations of each side (university-students), in relation to the disability issues and it is the mediator which can be used to solve any kind of conflict of interests between students with learning difficulties and the university. The Directors of DSUs can and should refer at all times to the Disability law in order to be fair to both students and the institutions and to use it as a means of persuasion for anyone, whether a student with learning difficulties or member of staff, who raises an issue of discrimination.

### 7.2.1 How Directors' roles changed with the new Disability Law

Understandably, the role of the Directors of the DSUs has changed, especially since the new law about disability in Higher Education came into force. The Directors said that their role is easier now, as they do not have to fight as much in order to achieve something. They can now use the law, which will persuade almost everyone to comply with the new requirements. According to the new DDA and the Special Educational Needs Act (SENDA 2001), it is unlawful to discriminate against people with disabilities in education. It is the duty of the institution to anticipate the needs of a student with disabilities and to accommodate them by making reasonable adjustments. Therefore, the DSU officers ensure that everyone follows the new rules and regulations. There are cases, which will follow below in this chapter, where some members of staff are not so keen to support the students with learning difficulties. In these cases, the DSU officers can use the law as a reference and persuade members of staff to do whatever is possible to accommodate students with disabilities. At the same time, the law can be used as a reference for students who claim unfair treatment and discrimination against them, due to their difficulties, or who in some cases request unreasonable support and treatment. In these cases, the law will be used to prove that they do not have 'unlimited' rights within Higher Education Institutions and that there are laws which explain what they could ask for from the institutions.

The changes in the law and the new regulations that each university have to follow, in order to accommodate the needs of students with learning difficulties, who may come to study to university, as the Directors of the DSUs explained, have made their role and their job easier. However, the new law enforcement did not mean an immediate change in people's attitude towards disability and discrimination. As was explained in the literature, the new law, which requires changes in order to accommodate the needs of students with learning difficulties, requires challenging the teaching and learning techniques that have been used until now. However, the fact that the universities had to change their policy and the members of staff had to

adjust their teaching techniques, based on the new law, did not come automatically. Directors of DSUs argue that in some cases they have to struggle to persuade members of staff, who have to make some changes in their teaching techniques in order to anticipate the possible needs of students with learning difficulties.

The response of members of staff to the new changes should be explored through the lens of the framework of Weber's "*formal and substantive rationality*" (Weber, 1978). In this case, the formal changes in the legislation regarding disability have a substantive result, which is the improvement in disability awareness. However, the important outcome here is that those who follow the legal changes do not necessarily do so for the substantive reason of wanting to have a better understanding of disability and take it more seriously. They may think that this may be the only way to avoid prosecution under the new law, and this is formal rationality because it occurs with reference to the laws.

The Directors' role is extended to members of staff, because they have to support staff in such a way that it will make the changes in their job (like providing lecture notes in a different format, change the way they deliver the lecture etc) easier and this will benefit both members of staff and students. Again, as the Director of one of the institutions will explain next, the law serves to persuade even the most 'difficult' who will not take the changes seriously and will try to avoid the role that they have to play for these changes to come into force. The new law will help Directors, students and members of staff to understand what role each person plays in Higher Education Institutions, regarding disability awareness. The nature of the services that the institutions provide to students with learning difficulties, has changed due to the new disability legislation.

*"As the law became more precise as to what we did have to be like, I suppose I had to make sure that the university took on board that. And it no longer had to do it out of the goodness of its heart. We had to do it because it was the legal requirement to do so. So the law changed and made my role easier in some respects ... now I just say 'look this is what problems they (students) have and these are the sort of support systems that will help them' and they*

(lecturers) *try and comply with that and if they can't they brought it into us. So I think there are all these changes for us...all attitude I suppose...but it's also become more of...it's all sort of in terms of strategic and university policy and university strategy. So we are part of the system, part of the mainstream system, rather than...sort of I don't know... a luxury service... The university is obliged to do something and therefore, we are taken notice of in the mainstream system, which helps. It does make my own job a lot easier*" (Director of DSU c, [Pre-1992])

This quote shows the shift of the provision that the services offer to students with disabilities, from something that was "*out of the goodness of their heart*" (Director of DSU c, [Pre-1992]) to something which is part of the "*mainstream system*". The bureaucratisation of the services for students with disabilities in Higher Education leads to a more generalised policy, which is common for the institutions and is based on the new law. The DSUs do not want to provide special services for students with disabilities, but rather to provide the same services that the other students receive through the mainstream university system. Their job is no longer an act of charity or welfare but rather they should be seen as service providers, which is part of the mainstream system and policy that the university has for all students who study there.

Because of the bureaucratisation of the services for students with disabilities, providing support for disabled students is not an act of charity any more, as it used to be. Students with disabilities used to be seen as vulnerable people who needed pity and compassion from the non-disabled, who could give them whatever they considered best for them, regardless of their individual needs. There is now a more general policy, which has to be followed by each university, which is based on the new disability law. This bureaucratisation of the services can be beneficial for both students, who receive the services they need, and at the same time for DSUs because they can now rely on the law to do their job, which make it easier, as they said.

However, we have to consider the disadvantages that bureaucratisation could have for services, which previously had a more charitable character. Weber's "*ideal type*

*of bureaucracy*” considers bureaucratisation the best form of organisation; however, he was also concerned that the bureaucratisation of modern societies can lead to their depersonalisation. This notion of depersonalisation is relevant to the services that Higher Education provides for students with learning difficulties. Considering the characteristics of a bureaucratic organisation and the changes in Higher Education due to the bureaucratisation of the services, they provide for disabled students, it is possible to argue that bureaucratisation could lead to an ‘impersonal’ kind of services, where everything is based on the law and is the same for everyone, regardless of individual needs and requirements. Therefore, now that the services have been institutionalised and bureaucratized and are the same for every institution and every student with learning difficulties, it is easier for service providers to lose sight of the individuals’ needs and to concentrate only to a more general policy or plan that they have to follow for everyone. The institutionalisation and bureaucratization of the disability in Higher Education resulted in services, which are organised according to a “*typification*” (Berger & Luckmann, 1991 [1966]) of the disabled students. This means that the services that are provided for disabled students are standardised and are the same for every disabled student. Within this typification of the services, individual needs and requirements could be somehow forgotten since all individuals have to be treated and be provided with the same services.

In addition, the bureaucratisation of disability services resulted in an increase in the number of disabled students who require the services from the institutions. Therefore, the disability support advisers have to spend less time with each student in order to manage the increase in the workload. Consequently, the limited time they spend with each student does not leave much space for dealing with the ‘individual’ needs of the students and a more generalised policy is followed, which is the same for every student with learning difficulties. Consequently, in order to avoid the disadvantages of bureaucratisation and to challenge it, a more personalised treatment and character of the provided services is necessary. In order to achieve that, it is important to keep some of the previous characteristics of the services, which were out of the goodness of the institutions’ hearts, and had a more individual character. The services should of course be the same for all disabled students so that there is no

discrimination against some groups of disabled students, however, the individual needs of students with disabilities should be taken care of, in order not to lose sight of the individual within the whole. As the lecturer at Durham University mentioned earlier, it is not just a case of giving for example extra time for exams to every student with learning difficulties. the severity of the learning difficulty has to be assessed and the extra time that is allowed has to reflect that severity, in order the measure/provision to be adequate for every individual student with learning difficulty.

However, arguably the new law and regulations aim to ensure that disabled students receive the same treatment, services and support that other students receive from the university. In order to achieve this adjustments have to be made by institutions. The DSU, in each university, is now organised based on the law's requirements regarding disabilities, and they have already made some adjustments in order to accommodate students with disabilities. Each university is now more prepared to accept and accommodate the needs of students with learning difficulties, and the whole DSU works towards this goal, where the university will provide as much help and support as possible to make the university a more friendly 'environment' for students with disabilities.

Despite the help that the new law offers to Directors of DSUs it is still important to point out the uncertainty that there is in their role due to the uncertainty of the existence of disabilities and more specifically of learning difficulties. The social construction of learning difficulties together with the ambiguity around the definitions and the existence of dyslexia and learning difficulties in general, between the 'experts' who create the labels and those with the label, make the role of the Directors even more controversial. On one hand, learning difficulties is something that not everyone accepts as a real problem within Higher Education as it is an unseen disability. On the other hand, Directors have to try to find solutions and ways to provide support for those students who have learning difficulties, while persuading those who are reluctant to make reasonable adjustments. Here in the next section these issues and how the Directors solve this problem are going to be explored and discussed.

### 7.2.2 The Directors' role in the future

As has been said, the role of the Directors within the Higher Education Institutions is a complex one and we could even say that they act as mediators between students and the university. The changes in the disability law and the idea of an inclusive education, which have already been discussed in a previous chapter, led to changes in the Directors' role. Actually two of the Directors of the DSUs (Director of DSU b and d) hoped that in the future their role would not to be as necessary as it is now. However, they do not think that something like that will happen in the near future. Maybe after 10-20 years, or, as one of them joked about it, "*I hope that won't actually happen until I finish paying my mortgage*" (Director of DSU b, [Post-1992]).

Even though the Director of the DSU mentioned it as a joke, we have to consider the possibility of a future where there will be no need for disability advisers, or disability support units, either within Higher Education or in general. In that case, there will be some disadvantages for all those who work in the services and whose work is to provide services and support for students. If an all-inclusive learning environment, as the Director of the DSU wished for, actually happens then what will happen to those people who work now in the DSUs?

Arguably, there is a dependency between DSU officers and students with disabilities. As was shown above, the conception that the disabled people are unable to cope by themselves, they are in constant need of help and support from others and they are in fact dependent on others, is still active within the literature of disability (Watson, 1998; Shakespeare, 1998; Sennett and Cobb, 1972). Without the students *in need* the DSUs have no reason to exist, while at the same time without the DSUs the students cannot access the support they need. Directors hope for an educational environment where everything is in place and every need of students has been taken care of before the students come to institutions, while the students with learning difficulties want a society without the social barriers which disabled them and made them in need of mediators, advocates and disability support advisers. However, these two groups of

people in a way need one another, because without the disability advisers the students cannot access the services they need, and without the disabled students, the Directors have no job. As Söder (1989) argues, it is in the professionals own interest that people continue to be disabled or deviants because then society needs them to 'treat' the deviants. The professionals, the experts in disabilities, the Directors and everyone else who interacts with people with disabilities are only necessary because there are disabled people. Paradoxically, disabled people are disabled by those same professionals and experts, and the social barriers that exist in the society. The dependency between these groups is obvious in the institutions.

We live in a society where disability service providers, educational psychologists, dyslexia advisers etc are all part of the system, and in one or another way they play a role within that society. Therefore, when we wish for an all-inclusive educational system it is necessary to think all those who work for disabled students. An all-inclusive educational environment means that there will be no need for disability advisers, educational psychologists, dyslexia advisers to help people with dyslexia and many other employees working on provision for students with disabilities. Is it possible and even desirable to achieve an all-inclusive educational system, where those 'experts' will be unnecessary and these members of the society will have no place? Despite the paradox of the issue, and despite the hopes and the wishes of everyone, an 'all inclusive educational environment' means an educational environment where all the needs of the students have already been taken care of, in advance, instead of looking into individual cases and make them special cases. An environment like this is something that may seem like the ideal situation and maybe in the first instance we all may wish for it, but in reality it is something that is not feasible and at the same time, if it happens, it will change the whole idea of support and provision as it is now known.

*“What I would like to see, what I am looking for, is an inclusive learning environment. And I always say, whenever I do training sessions with staff, outside the services, I wish in an ideal world you wouldn't need a disability support, because everything would be so inclusive, that you will not need us... In a real inclusive environment, all that would be anticipated and instead of*

*me having to go to a course and say, “you need to make your exam papers available in large print”, they would already do that. Do you see what I mean? They would have anticipated that, rather than react to individuals, they would have anticipated it and plan such to include everybody”* (Director of DSU b, [Post-1992])

The Director describes *an ideal world*, which is the all-inclusive educational environment. However, the wish for a future where the DSUs will not be necessary is more like a hope that in the future those with disabilities, whether physical or mental or learning difficulties, will be treated equally to others and will not be considered as a group which has to be treated differently because there is something wrong with them. Now, the institutions make the required adjustments only when students with learning difficulties enrol at the university or register with the DSUs. The Director, however, wished for a future where each university would take into consideration the needs of disabled students when they plan their policy or organise the way their *businesses* are going to work, and would anticipate those needs well in advance, regardless of whether there are disabled students enrolled in the institution. The educational environment in Higher Education will be structured and prepared in such a way that there will be no need to treat some students differently because the services and everything will be in place whether there are students who need and use them or not. Therefore, students with disabilities will not be seen as the clients who need more services or extra help, because the university will be prepared and organised in such a way that those services will be standard issue for everyone and proof of good practice.

However, the idea of an all-inclusive education, as was described in the literature, is not something that you can just wish for and happens. In order to achieve inclusive education the way that Higher Education Institutions are organised has to be challenged and the teaching and learning techniques have to be redefined. The argument here should be whether the Directors of the DSUs can be the leaders who will make the necessary organisational changes towards a more inclusive educational environment. Among Weber's (1978) concerns about the disadvantages of bureaucratisation was that in crises the highly bureaucratic 'experts' might not be

good leaders as they are used to following rules and laws in order to achieve their goals, rather than making policy decisions and taking initiatives. In a changing environment, therefore, it might be that under the bureaucratisation of the services and the demand for the same services for every student, the Directors of DSUs cannot lead Higher Education towards a more inclusive educational environment. Despite this, a leadership towards an all-inclusive educational system will automatically mean the end of their job. Their role may be to represent the students with disabilities within the university, but at the same time, it is arguable whether they have the authority to proceed with all the changes and the arrangements that have to be made, in order to achieve inclusion for students with learning difficulties. The changes in attitudes towards disability are more difficult to achieve compared to changes in buildings and teaching techniques.

As the Directors explained, there are still problems, which make their job necessary, despite the fact that the law helps them to do their work more easily. The changes in the Disability law and the bureaucratisation of the services, may have changed the form of the services from charity like services to more standardised ones, which are beneficial for students, and this makes the job of the Directors easier. However, at the same time, this bureaucratisation led to depersonalisation of the services. The individual needs of students are not always met and the Directors do not have the authority to be the leaders towards an all inclusive education, as it is the law and the bureaucratisation that determines the changes.

All four Directors pointed out some problems when they were asked if there was anything that they wished to change. This fact alone could mean that things may be better since the new law came into force, but still bad attitudes, which were mentioned as the main problem for two of the universities, are not something that you could easily change. The problem with the bad attitudes, which refers to the argument that dyslexia does not exist, and the unwillingness of some academics to help students with learning difficulties, is going to be analysed in the next section.

### 7.3 Institutions' point of view about provision for students with LDs

#### 7.3.1 Lecturers' views

Having seen the changes in the role of the Directors of Disability Support Units above, it would be useful to see the views of lecturers and some College Officers from Durham University, in order to have a more clear view of the institutions' opinions about provision for disabled students. Four lecturers from different departments and three College Officers from an equal number of colleges from Durham University helped to see the issues of provision and support for students with learning difficulties within Durham University. Their views combined with those of the students themselves in order to have a more complete picture regarding these issues at Durham University. Some of the issues that members of staff have identified are seen and if appropriate are contrasted with the views of the Director of DSUs in order to see how different parts of institutions and even different institutions see those same issues.

First, regarding the adjustments that each department has to make in order to accommodate the needs of students with disabilities and more specific that of students with learning difficulties, the four departments seem to have different responses to what DUSSD recommends. One of the lecturers (Lecturer a) points out:

*“...We treat every individual as an individual case. All of our handouts are in DUO and in large text if they need it and they can put a background coloured text, which is good for dyslexia students as well. We encourage everyone in the department to produce handouts with a font, which is very easy to read for example Arial size 12 font, which is the minimum”* (Lecturer a)

As this lecturer explains, even though they treat each student as an individual case, which means that they will try to see and provide help for every individual based on his/her needs, at the same time the department follows some general practices, which they think are good for all students. The lecture notes are available online for every student and good teaching practices such as using a font and format that will

accommodate also students with dyslexia for example is something that the whole department does. Here, it seems that this department follows a more proactive approach, regarding provision for disabled students. The department tries to prepare in advance and to change, whenever possible, the teaching practices that it follows for students. Therefore, the department is more prepared and it is possible that in most cases these techniques would cover most of students' with learning difficulties needs. If these adjustments are not enough, then as the same lecturer (a) said if they have a particular request from one student regarding specific adjustments that the student may ask, then they will contact DUSSD and based on the individual circumstances they would follow the advice that DUSSD will give them regarding this particular kind of disability.

However, the other three departments even though have mentioned that they will do their best to accommodate the needs of students with disabilities and they also have some good teaching practices in place for everyone, they seem not to agree always with what DUSSD suggests as reasonable for these students. More specifically, lecturer (d) when was asked about the adjustments that DUSSD recommends said :

*“We have a main generic issue about that. DUSSD always says that in the case of most disabilities they frequently put in the report that it's helpful for the students to have lecture notes or slides in advance of the lecture. And it's actually our department's policy that we don't do that or certainly that we don't enforce that staff should to do that if requested. There are various opinions of members of staff on that. One of the main issues of staff is that they often updating things until the evening before the lecture and some staff indeed they don't have lecture notes, it might be that they just stand and talk, where of course most nowadays they would have power points or some short of handouts at least.”* (Lecturer d)

As it is explained here, this department's policy is not to provide students (not even students with learning difficulties) lecture notes in advance. The reasoning in that is that members of staff do not agree that this is feasible for them, as most of them

either do not use notes in general or they finish their lecture notes the night before the lecture, hence they cannot put them online in advance for students. One of the lecturers (lecturer d) explains that the department have requested DUSSD to alter the way they write the reports so that it is not discriminatory that they do not provide the lecture notes.

*“That’s one issue, and we would actually get DUSSD to agree to modify the report to say 'where possible' department to share the notes. As we did have issues because of the phrasing that DUSSD's report got. Students were expecting that these things were their right and often they've approached staff with very much words like 'I suppose to get that, why I don't get it?'. It was a little bit confrontational so we thought of trying and best avoid that.”*

(Lecturer d)

The department asked and probably persuaded DUSSD to change the way the requirement of giving lecture notes in advance is phrased in their reports, so that it is only applicable “*where possible*” (Lecturer d), so that students cannot argue that they should get that. Here with the example that this department gives about this rephrase of the requirement so that it is not obligatory to make the adjustment, it is relevant the issue that has been discussed in the literature about the circumstances under which an institution can justify the less favourable treatment to disabled students without this been considered discrimination. (Disability Rights Commission, 2002)

In addition, the main issue with reasonable adjustments is how each institution, department etc understands and justifies something as reasonable.

*“...in terms of the legislation about reasonable adjustments itself it's problematic because what's reasonable to one person isn't reasonable to another person. So sometimes, this requires discussion and maybe some compromise on both sides. A lot of that comes down to the understanding of where the issues are on both sides so that students can see it from the*

*learning and teaching perspective and we can see it from their perspective with the disabilities they are facing.” (Lecturer d)*

This lecturer believes that there should be compromises from both sides (students with disabilities and lecturers-institutions) in order to find a common place where there will not be any discrimination against the students, while at the same time there will not be unreasonable requirements from lecturers. On one hand, the important thing is to find a common place and an area where everyone is ‘happy’ in the sense that both students and the institutions are getting what it is necessary in each case. On the other hand, the fact that everyone defines differently what is reasonable and what is not, and on that base the institutions can claim that something is not reasonable and hence they should not be obliged to do it, leaves a grey area regarding adjustments for disabled students. Even the law (DDA, 2005) as it has been explained is not completely clear about what is reasonable and what can be considered unreasonable and not been provided. Therefore, it is arguable here that an educational environment closer to the ‘inclusive environment’ where many things are in place for everyone so that there is not a discrimination against some students, is something that could partially solve these issues.

Another issue that arguably has been mentioned by all four lecturers is that the feeling that the lecturers or the departments in general have is that DUSSD gives a very standardised allowance to all students with learning difficulties and more particular dyslexia. As it has been mentioned in the literature the typification of the services due to the bureaucratisation leads to less personalised treatment where the individual needs of students with disabilities can be lost in the process.

When I asked one of the lecturers whether there are other members of staff within his department who do not believe that learning difficulties or dyslexia exists and they should do all these adjustments for these students he said:

*“Not that they don’t believe per se... We’ve got a member of staff within the department who says that not all dyslexic are actually dyslexic.... A comment, which actually goes back to DUSSD, is that ‘if you are dyslexic you get 25%*

*extra time'. It doesn't matter if you are mild dyslexic, severe dyslexic, you get 25 %. So if you have mild dyslexia you get 25 % and it's enough. If you have more severe dyslexia you get again 25% but that maybe is not enough."*  
(Lecturer b)

This lecturer identifies a problem that has also been mentioned both in the literature and from participant students, which is the standardised treatment that it is offered from DSUs, regardless sometimes from the individual needs of students. The bureaucratisation of the services and the need to deal with as many students as possible in the least of time, it led to a system, which provides standard allowances to all students with learning difficulties and in some cases the allowances are either not enough or they are not needed and do not offer any help at all. The severity of the learning difficulties and the different form of learning difficulties has to be taken into consideration when the institution provides support for students. There are differences in the needs of a student with mild dyslexia to those of the student with more severe case of learning difficulties. At the same time, the use of a special calculation from someone with dyscalculia most probably does not offer any help to a student with dysgraphia. Therefore, a personalised treatment where the individual needs of students are met and the realisation that not everyone with learning difficulties has the same needs and does not need the same treatment, is of essence.

*"This is a comment from the department 'once you get the dyslexia title everybody gets the same'. But there are grads of dyslexics we have mild, we have severe dyslexia but they get exactly the same."* (Lecturer b)

Another lecturer emphasised that it is important the university not only to put up facilities but also to make sure that all facilities are appropriate (Lecturer c) He gave an example that is about the wheelchair users, which however shows the point that he made about how appropriate the services and the facilities that are offered should be. Therefore, he mentioned that in his department they have put ramps for wheelchair users in order to allow them access to upper levels of the departments

where the lecture theatres are. However, after certain complain from users they calculated that a wheelchair user needs 25 min to go from the entrance of the department to the lecture theatre with these ramps (Lecturer c). Inevitably, this is not something that can be done every day from students because they have to spend almost an hour to go in and out of the lecture theatre. Therefore, the point is that the university's or the DUSSD's role does not end by just putting ramps for wheelchair users or by providing 25 % extra time to all dyslexic students regardless of the end result. They have to make sure that the adjustments are first useable by students and that they are actually what students needs in order not to be discriminated. There is no point in giving resources, which are not appropriate and are not the ones the students need just because they are the standard treatment that all students with disabilities should receive.

Four out of the five lecturers said that their department does not have any problems with members of staff who do not comply with the new DDA (2005) law regarding adjustments for disabled students. As one of the lecturers pointed out:

*“I think even prior to that staff was always willing to help... I don't think we had people who we had to go and tell 'look we've got to do this because it's required by law'. You know the staff is generally kind and they don't wish students to be disadvantaged by any disability.”* (Lecturer d)

The other lecturers reported this sense of a generally helpful and responsive to students' requirements members of staff too. However, the Directors' opinion is contradicted to that of the majority of the participant lecturers. Directors have mentioned that sometimes one of the main problems they face when dealing with academics who do not want to follow the legal requirements regarding students with disabilities is related to whether dyslexia in particular actually exists.

*“...if we're talking about dyslexia in particular, we have lecturers who think that a lot of students use dyslexia as an excuse for not working. And some*

*students do use dyslexia as an excuse for not working, but it's very few, very-very few and far between. We have psychologists, lecturers on psychology who don't agree...that dyslexia is as problematic as what it is...*" (Director of DSU a, [Post-1992])

The literature showed that when psychologists argue about the existence and the misuse of the term dyslexia to cover poor reading performances, it is not a case of ignorance or lack of disability awareness, but issues related to the “*styles of reasoning*” (Hacking, 2002) that they use to ‘classify’ the different problems or disabilities that people may have. For them dyslexia does not exist as a different ‘category’ but it is just a reading disability.

The Director from another university also added about this issue:

*“...They still argue about that (if dyslexia exists). You can make as much awareness training available as you can but...we found dyslexia is slightly easier now to take on board and students don't have those problems to go through... that process that dyslexic students had to go through 5 years ago. There is still a little element cause of all students these days they don't spell so well, so they are getting messed with that. I think the difficulty is they are not quite sure how to deal with it rather than take it on board, which is a different issue.... In a sense, they have to know, and if they don't, they have to explain why they haven't... I think the difficulty is we send our report, obviously onto department and some departments are so much better and make sure all their staff has the right information. And I think that's where the whole...that's the 'black' area. Some departments are relatively good...”*  
(Director of DSU c, [Pre-1992])

This Director of DSU believes that things have changed for dyslexic students in the last couple of years, and now it is more of a case of lecturers who do not know how to deal with those students, rather than that they do not believe that dyslexia exists.

When lecturers do not know how to deal with students with learning difficulties, then the need for training regarding disabilities within the university is essential. Learning difficulties are hidden disabilities and are not visible to others, which in essence as the literature discussed has additional difficulties, compared to some other visible disabilities. For this reason, the DSUs have to send reports to departments in order to inform the lecturers and other members of staff about the students who have learning difficulties. How the departments will handle these reports and whether the lecturers know how to deal with the difficulties that these students may have is still a problematic area within the institutions.

Another Director of a DSU said, about the difficulties that she faces regarding the lecturers' attitude towards the provision for students with disabilities, that it is a case of some lecturers who believe that those students should not be in Higher Education Institutions in the first place, if they need help with exams or notes etc. The fact that they need some sort of help makes them automatically 'unsuitable' for future jobs, hence, there is no place for them in HE, as there is no point in studying.

*“Attitudes have changed and improved dramatically over the last 5 years, but there are still some people who perhaps, don't feel it's their job to produce materials in an alternative format, who don't even believe that dyslexia exists, who don't believe that dyslexic students can become effective professionals, so they shouldn't be on courses...“If they need...if a student needs a scripting in exams how are they gonna function in the work place?” These are the sort of arguments we are getting all the time, and so we have to argue with that all the time. That's probably the main area, that's the main area of difficulty” (Director of DSU b, [Post-1992])*

Here, the Director's comment points to the idea that was explored in the literature, of how the disabled people are 'less human' than the non-disabled. Non-disabled people believe that the disabled are not 'value' as non-disabled people and they have no place in mainstream education or in society in general (Sennett and Cobb, 1972; Goffman (1990 [1963])). This opinion may sound 'old fashioned' or unreal in our day

where there is some disability awareness which ‘teaches’ respect for people with disabilities.

Nevertheless, this Director explains that this is something that she hears a lot, as a common argument from those who are not in favour of providing help and support for students with disabilities. The fact that some students need support in order to study in Higher Education means that they should not be there in the first place. Besides, as those in favour of this argument say, even if the students with learning difficulties manage to finish the university and get a degree, they have little or no chance of becoming ‘effective professionals’, therefore, there is no reason for them to be in Education. The students have already been stigmatised and discriminated against, merely on the grounds of having been diagnosed with learning difficulties. The issue here could also be seen through the idea of the perceptions that the non-stigmatised have towards stigmatised, as well as the standardised beliefs for the characteristics that all people in the same groups should share. It is assumed that since these students have learning difficulties they all lack the abilities to succeed and to achieve a higher degree in education.

Fortunately, things have changed in recent years, probably with the help of the new legislation for students with disabilities in Higher Education. However, as the Director of DSU b explains,

*“I think that there is still a lot of what I would call ‘attitudinal barriers’... It’s the attitude now that we need to get over. But it is improving ...”*  
(Director of DSU b, [Post-1992])

Changing the ‘attitudinal barriers’ is the most difficult part of the job of the Directors, because it is easier to change buildings and physical barriers than to change people’s attitudes. Apart from the ‘barriers’ that exist for students with learning difficulties and disabilities in general, like the lack of access to Higher Education, because of the standardized test that leads to the creation of categories of ‘learning difficulties’, there are the ‘attitudinal’ barriers, which in some cases can be the most difficult to change, compared to the rest. ‘Attitudinal barriers’ are the

beliefs and the attitudes that non-disabled people hold about those with disabilities. These ‘barriers’ can be the result of either fear about the ‘unknown of the disability’, ignorance about what a disabled person may ‘look like’, misunderstanding and lack of awareness in general about disability. In general the uneasiness around disabled and stigmatised people, as Goffman (1990 [1963]) explained, is something that cannot be changed easily. There is a great deal of challenging of the ‘beliefs’ and the misconceptions about the disabled people, in order to manage this tension. Regardless of the origin of these attitudes, the result is discrimination and unfair attitudes against people with disabilities. Most of the times, it is easier to change a building, allowing access to wheelchair users, to provide lecture notes in a different format for students with learning difficulties or blind learners, rather than to change peoples’ attitudes towards disabled people. In order to change attitudes, you have to persuade people about learning difficulties, to make them understand that the students with learning difficulties have the same right to be there as other students and their difficulties can be overcome if the appropriate support and provision is in place. It is necessary to raise the level of disability awareness, in order for the non-disabled to accept that it is their responsibility and their obligation to comply with the law and the university’s policy, in order to help and support these students.

Directors of DSUs considered among the attitudinal barriers the views of some lecturers who one Director (a, [Pre-1992]) called them the “*old school*” lecturers. The Director said “... *you have the other lecturers who come in the class, deliver their lecture and go; and that’s what we call the “old school”*” (Director of DSU a, [Post-1992]). The lecturers who ‘fall’ under the first category are those who do not consider it within their responsibilities, and their job descriptions, to do anything more than just deliver the lecture and leave. Consequently, for those lecturers the task of producing lecture notes or lecture materials in an alternative format for students with disabilities, or providing extra help or support for students with disabilities, is not something that they consider doing without the ‘pressure’ from the DSUs and the ‘persuasion’ of the law. The issue that has been discussed in the literature about the need for changes in attitudes and the need to challenge the teaching and learning techniques that are used in institutions is of relevance here. The old school teachers as this Director called those lecturers believe that changing

the teaching and learning in Higher Education Institutions would mean that we challenge the core of the purpose of Education. And it is these attitudes and these beliefs that need to change in order to have Higher Educational institutions which are not discriminate against disabled students.

Of course, not all lecturers are the same and we should not have a standardised opinion about all lecturers. There are also on the other hand, those lecturers who will try to help and will provide any possible help for students with disabilities. Either those lecturers seem to have a better understanding of the changing character of provision in higher education for disabled students, or they share more disability awareness, compared to the other lecturers.

*“...Sometimes we have lecturers who are so proactive and they send students over. Sometimes they send students over that shouldn't be sent over to be assessed and screened for dyslexia, but you know I would rather have all or none...And they are very proactive and they ring us and they say 'I think I've got a problem with this student. They have a difficulty doing this and taking notes... what do you think?'...”* (Director of DSU a, [Post-1992])

However, except of the issues that have been addressed above about the lecturers, the Director's comment reveals two additional issues, which have to be discussed here. First, the Director distinguishes the lecturers' attitudes, towards disabilities, into two categories. This has to be seen through the context of “*typification*” (Berger & Luckmann, 1991 [1966]). Here, the Director uses some standard assumptions about the lecturers and creates two categories. They assume that the lecturers have to be divided and categorised based on their attitudes towards disability awareness and hence, two categories of lecturers have been created, the ‘old and new school teachers’.

From this quote, the impression that the Directors have the expertise to identify the students who have learning difficulties, compared to those who do not have learning difficulties, is created. The Director implies that the lecturers, or at least some of the lecturers, are not able to identify these students with learning difficulties, and they

tend to send everyone they think may have difficulties to DSUs, in order for the Directors to make the distinctions. The Director here claims to have an ability and the expertise to distinguish disabled from non disabled students, and this makes them the ‘experts’ who have the power to label and separate students based on their difficulties. Again, here the dependency between the Directors and the students and between the Directors and other members of staff is apparent. Both students with learning difficulties and members of staff are dependent on the Directors’ expertise to identify those who are in need and those who do not need any help. In addition, the Directors use their position to claim that they have the expertise to decide and correctly identify the students who need their help, compared to lecturers who do not possess this knowledge. Therefore, even the lecturers who are not in the category of the “*old school*” teachers, and who have a more proactive attitude towards disabilities and students with learning difficulties lack the expertise to identify correctly the students who need the disability support. Therefore, on one hand, there are the lecturers who do not consider it necessary to provide help and support for the disabled students and on the other hand, there are those lecturers who want to help, but they lack the ability to distinguish the students who need support. In both cases, the Directors and the DSU advisers are needed and are the experts who will guide the lecturers and will help the students with learning difficulties to access the support they need. Presumably, both lecturers and students with learning difficulties depend on the help and expertise of the Directors and their teams

Only one lecturer mentioned that a student reported a discrimination against him from a lecturer. As the lecturer (Lecturer c) explained the student had learning difficulties and the member of staff who was an *older lecturer* refused to assess the students in a different way that would not be discriminating because of the difficulties that the student had. The older lecturer (the fact that the lecturer was older was emphasised by the interviewed Lecturer c)

*“...insisted that the student had to be tested in a same way as the rest of the students and had no conception of learning difficulties what so ever and the whole incident didn’t go well.”* (Lecturer c)

The student ended up leaving university after the incident. The lecturer in that department explained this happened only once (during the last 10 years he works in that department), and most of the time the members of staff are “*turned around*” (Lecturer c) and are persuaded about the adjustments that have to be done either from DUSSD or from the Departmental Disability Representative. Except of that one incident that the lecturer mentioned there were not more examples of the other lecturers about issues with some members of staff who do not cooperate and do not help students with learning difficulties. Of course since the sample from lecturers is not representative of the whole population of lecturers in these institutions, there is the possibility that in other departments might be some members of staff who are closer to what is described by Directors as ‘old school teachers’.

Overall, what was emphasised by all lecturers was that they generally do not have any problem to help, when possible, the students with learning difficulties and other disabilities in general. When they receive the reports from DUSSD about the difficulties that their students have they try to follow the recommendations and if necessary they will refer to DUSSD for further help and support.

Lecturers and Directors both referred to the undeniable progress in provision for disabled students in Higher Education Institutions. As Directors said, it is rather helpful that some lecturers or members of staff contact the DSUs regarding students’ difficulties, because the DSU officers cannot know all the cases of students, unless the students have declared a disability. With the help of the lecturers who contact the DSU when they have concerns about some students, the DSU can identify and assess the students’ difficulties and see if they need help or not. Of course, sometimes the lecturers may misread the ‘signs’ of learning difficulties and they might contact the DSU when there is no need, but it is better to do that rather than just do the lecture and ignore any difficulties the students may have.

As one of the Directors of a DSU added, sometimes it is a case of sensitivity or disability awareness among the academics and members of staff in general, which can make a difference. In her case, the Vice-Chancellor for Staff and Students’

Affairs is a person who takes disability quite seriously and he ‘uses’ his position to promote disability awareness within the university.

*“...the other thing that I haven’t said is to have disability issues taken seriously at the highest level, within the university. We are quite fortunate here in as much as our deputy, Vice-Chancellor for Staff and Students’ Affairs, he does take disability issues very seriously, and that’s at the top level and that’s improving things all the time...”* (Director of DSU b, [Post-1992])

It is always helpful to have ‘allies’ in key positions within the university who have disability awareness, because they can help and ‘use’ their position to make things easier for students with disabilities. As the Director of the DSU mentioned in their university (b) their deputy takes disability issues very seriously and that results in some improvements in matters regarding disabilities.

The same Director, when she was talking about the issue of disability awareness, mentioned the difference that she observed in lecturers’ attitude towards seen and unseen disabilities. The problem with the unseen disabilities, as that Director explained, and was seen through the review of the literature (Stage and Milne, 1996; Brueggemann, White, et al., 2001; Dudley-Marling, 2004), is that those people do not have a visible ‘sign’ which will ‘identify’ them. This makes the ‘job’ of the lecturers who try to identify those who need help more difficult. Again here, the Directors of the DSUs show their expertise in identifying and distinguishing the students with learning difficulties, in contrast to lecturers who lack the ability to identify these students due to lack of visible signs. Here, the Director shows another aspect of their job, which is to make ‘visible’ the students with the ‘invisible’ disabilities. On one hand, there are the students with learning difficulties whose disabilities are ‘unseen’. The invisibility of their difficulties, in a way, ‘helps’ them to avoid the stigma that the disclosure of their difficulties will bring to them, while at the same time, it prevents them from receiving the support they need, as the lecturers cannot easily identify them. On the other hand, there are the Directors, who protect

the identities of the students, and as will be discussed in the next chapter, they have specific ways to ‘manage the sensitive information’ about these students, while at the same time, they are the ‘experts’ who can identify the ‘invisible’ students and make them ‘visible’ to the lecturers. The whole issue of ‘making these students visible’ to others, while at the same time keeping their identities secret, and the management of that kind of information about these students, are all going to be discussed in detail in the next chapter. In general, the ‘invisibility’ of the difficulties that students with learning difficulties experience should not be used as an excuse for not supporting them.

Even though the general feeling from lecturers was that there are no particular problems with students with learning difficulties or disabilities in general, the majority of the lecturers said that they believe that there is a line, which should not be crossed regarding how much support and extra help it could be offered to students. As one of the lecturers (d) explained:

*“...we have to be careful the support we offer to give them similar capabilities to other students. We don't take them way beyond giving them that extra help that makes it easier to them than other students...It's about knowing where to draw the line...”* (Lecturer d)

As other lecturers pointed out the aim is to give any necessary means to the students with learning difficulties in order to compensate for their difficulties, however this does not mean that “*we will do the work for them*” (Lecturer a) against other students’ interests. As an example, this lecturer mentioned:

*“I can think of an example of a student with dyslexia again from previous years where he had a problem with a particular subject and even though he had an one to one sessions with a postgraduate he was kept pushing for more and more, at a point where you think that it is the postgraduate who does all the work for him....It still needs to be the student's work and we make clear*

*that we can help so that the students don't have any disadvantage due to lack of understanding. But once we feel that everything is in place then we would stop. Sometimes they cannot understand that it is actually them that they have to do all the work.” (Lecturer a)*

We do not argue here that all students take advantage of the support of help it has been offered to them; however, there is a possibility that some students may feel that they could take advantage of that help.

### 7.3.2 College Officers' views

In addition to the views of the lecturers from different departments, it is useful to see the views regarding provision for students with learning difficulties or disabilities in general, of some of the College Officers. The three Colleges that participated in this project they might be different in size regarding students' number, however, they all share the same awareness and sensitivity regarding the needs of students with disabilities.

All three colleges explained that even though they do not have an academic role, however, they support students with disabilities and/or learning difficulties and help them in every possible aspect in order to eliminate any difficulties that could affect the students' academic progress. Therefore, as the college officers said they are informed either through DUSSD or via the students' applications to the colleges, about the students who require additional support due to any disability. So they make sure that the adjustments that DUSSD recommends when possible are taken care of even before the students are starting their academic year. Mainly the adjustments regarding students with learning difficulties would be on the basis of having, when necessary special software on common computers, so that students with dyslexia for example could use them. Of course, mainly all the software, computers, equipments etc students' get them from DUSSD through the DSA. However, colleges try to make sure that there is some equipment, which could be useful to students and could be used if necessary.

One of the college officers (a) explained that their college is prepared to offer some resources on students' arrival even if they have not been assessed yet by DUSSD in order to identify whether the student has a learning difficulty or any disability indeed.

*“...even before they have been assessed I will see if we could help them on arrival with resources. We have tape recorders in college and we have*

*laptops in college. We make no assessment and we don't give any recognition that this is what it is considered to be reasonable adjustment. We simply do it for new students when they arrive so they kind of feel confident that they are not going to be left behind, if they wish; but it's their choice whether that's any help for them or not.”* (College Officer a)

This seems very helpful for students and very thoughtful of the college to offer some resources to students who have said that they have some difficulties. It shows that in this case the college acts proactively and has some kind of help in place for students until they have been formally assessed from DUSSD. Of course these students are encouraged to contact DUSSD and been assessed in order to find out whether they have any learning difficulties. Once the support from DUSSD and the DSA is in place the equipments are all returned to college in case another student needs them.

Another College Officer (b) explained that mainly the UK students are eligible for DSA, which will provide them with all the necessary equipment and any kind of support they need. However

*“If there was something that they couldn't get through DSA, which would be unusual, but if there was, the college would look at it and certainly if DUSSD would recommend it we would certainly look into that.”* (College Officer, b)

It is apparent that the Colleges take into serious consideration the needs of students with disabilities and learning difficulties and they take every possible measure to help and support the students in order to overcome their difficulties that may affect their studies.

All College Officers mentioned that once they have the students' applications, and they see that a student declared a disability or difficulty then they will try to arrange a meeting with these students at the beginning of their year. They will then discuss with them what the college could do to accommodate these students until their report

from DUSSD is in ready and everything is sorted out for their studies. (College Officer c)

It seems that all colleges have a very good cooperation with DUSSD, as all College Officers mentioned that they keep taking guidance from DUSSD on how to deal with students' needs and how best to support them during their years of study. In addition, there is a very good cooperation between the colleges at Durham University with regular meetings between College Officers. So if there is a particular issue that come up that College Officers felt it might affect also other colleges or if they want to see how other colleges dealt with issues on certain circumstances then they will have a meeting and will discuss them on those meetings. (College Officer c)

One other topic that was discussed with College Officers and next will be explored through the interviews of the Directors of DSUs, was the issue of managing students' information. By that, I mean the instances where some students who have learning difficulties or disabilities might request from their colleges not to mention that to other members of staff within the University or more often to their department. All of the College Officers explained that it is not something that is common. However, when in cases of students who do not want the department to know, the college will have to explain that once a student discloses a disability to any employee, within the institution, then it is considered that the institution knows. (College Officer a)

Most of the cases as another officer explained students call and

*“...query whether they should put it up in their application, and we used to have to reassure students that it doesn't count against you because there is an admissions procedure and there is clear guidance that disability isn't taken into account. But I do understand students with for example medical problems who they don't want to put it in, because of course it doesn't count against you but equally, people seen it, so I can't say that one person can't see it and think.... I mean it's human nature, people can see it and it's up to the individual to make the decision. But legally as an institution it shouldn't make any difference in the admissions' procedure...”* (College Officer b)

The stigma that a disability can cause to students and the fear of rejection because of the difficulties is something that sometimes affects students. However, as this officer explains and as it has been discussed in the literature it is against the law to discriminate students based on their disabilities.

Sometimes as it was mentioned (College Officers c and a) and as it will be seen next through the Directors of DSUs, the main concern of students regarding their disabilities is whether they should mention it to potential employers. College Officer (c) explains that quite often she has to advise students on that matter and she does understand that students sometimes feel 'unprotected' outside of the university's environment.

Overall from the perspectives of both lecturers and college Officers, it is concluded that the majority of the members of staff at Durham University are willing to help and support students with learning difficulties and disabilities in general. The main issues which have arisen here are some concerns about how each department interprets and justifies an adjustment as reasonable and how in some cases they could avoid doing an adjustment on the grounds of the teaching and learning policy that it is followed. In addition, the issue that was mentioned from lecturers regarding the standardised treatment that they feel that they give to all students with learning difficulties, regardless of the severity and the level of the difficulties that each student has, is important. As it has been mentioned before in the literature and through the interviews of the students, they prefer a more personalised treatment and services and they value more the personal treatment from the DSUs. There are still some attitudinal barriers which have to change, but the findings of the research showed that in general things seem to get better with the persuasion of the law and the disability awareness that exists in Higher Education.

The next chapter will show the methods that the Directors use in practice in order to manage the information they have about the identities of the so labelled 'students with learning difficulties' within the institutions. The 'paradox' of Directors who try to treat these students equally to other students, while at the same time they use techniques in order to separate them and to make their 'invisible' disability 'visible' to everyone, together with two different ways that are used to separate students with learning difficulties, are going to be discussed next.

## 8 Management of information within Higher Education Institutions

### 8.1 Introduction

Among the roles of the Directors of the DSUs is to manage the information about the difficulties that students have, while, at the same time, they have to make sure that they do not discriminate against these students by stigmatising them or making their difficulties apparent to everyone. It is very important both for students and for the university, as an institution, to find a way to manage information. The disclosure of the disability, as has been examined through the interviews with the participant students, but also through the literature, is among the main concerns for both students and members of staff within Higher Education Institutions. Through the disclosure students gain access to support and help, while at the same time, they are attached with the label and the stigma of the disability that they have just disclosed. Therefore, in order to balance the effects of the disclosure of the disability, and to make it a more positive experience for students, one important step is to find a correct and appropriate way to manage the revelation of the difficulties or disabilities that the students experience. It is of equal importance, if not of greater, the correct management of this information about a student's difficulties from the institutions. Total secrecy, even though it may seem to protect students' identity, at the same time, is not the best practice for managing information in organisations or institutions like universities. The total secrecy shows that there is something bad, unacceptable, or abnormal that must be kept secret and the institutions have to protect, not the secret itself, but the rest of the world from this secret.

The notion of “*sociology of information*” (Simmel, 1906; Marx & Muschert, 2007; 2008) is of importance here, as it is central for examining the management of information about students within the institutions. On one hand, Directors have to respect the privacy of each student, while on the other hand, they have to allow access to students information to all those who have to know about each case. In

essence, they have to find ways to make ‘visible’ to those who need to know the students with the ‘invisible’ disabilities, while at the same time they have to protect those students’ identities from stigma and discrimination, after the disclosure of their identities. Without this information, they cannot provide the appropriate support and provision for the students with learning difficulties. One of the characteristics of learning difficulty that distinct it from other disabilities is the fact that it is an unseen disability and that makes it difficult to be identified by others. Therefore, it is problematic for Directors to make visible the invisible disability without discriminating against the students. The sensitive issue of disclosure of the disability has already been seen from the perspective of students, but here the management of the sensitive information about disabled students will be explored from the perspective of the university, through the Directors of DSUs and the Disability Officer from Durham University. Some aspects of the issue have been discussed previously through members of staff from Durham University.

This chapter examines issues, which were identified by the Directors of DSUs from each university and the Disability Officer from Durham University, related to ways that are used for managing students’ information within the Higher Education Institutions. Here the two ways to manage the information about the students with learning difficulties are going to be explored as examples of the ways that universities categorize students. The consequences and the effectiveness of those systems, for students, will be seen in the last section.

## 8.2 Management of students' information in institutions, making 'visible' the 'invisible' disability

The disclosure of disability as it has been concluded from the views of students and was discussed earlier is an issue that plays a quite important role is one of the most sensitive issues that both students and universities have to manage in the appropriate, confidential way, in order to avoid discrimination. When students inform the university and more specifically the DSUs that they have learning difficulties, they expect that this information will be treated as confidential and discreet and will be revealed only to the people who must be informed. The first technique that the institutions use to inform the tutors/lecturers about the identity of the students with learning difficulties and the needs that those students have is the "*support memo*".

The "*students' support memo*" (Directors of DSU a and b, [Post-1992]) or "*teaching and learning memo*" (Director of DSU d, [Pre-1992]) is within the standard support that students with learning difficulties receive. It is sent to lecturers and it "...*outlines all the areas of difficulty, how their difficulties affect their ability to study and what support they need to have*" (Director of DSU a, [Post-1992]).

This memo may include all the necessary information for students with learning difficulties; however, whether this technique will work depends on many factors, among which is the willingness or unwillingness of tutors and lecturers to co-operate and comply with the requests of this memo and the extent to which they have easy access to this memo. One of the lecturers (Lecturer b) explained that this information is within the students' files, which the lecturers do not have everyday access to. Therefore, this memo in itself does not solve the problem of the management of information about the students with learning difficulties. Arguably, it works like a suggestion card and at the same time, as a plan that has to be followed, as it specifies the adjustments that by law have to be done in order to accommodate the needs of the students with learning difficulties.

The use of this support memo, which aims to inform lecturers about the required changes and adjustments they have to make by law, for these students, is a step towards a learning environment with more disability awareness. Whether the

lecturers will see it as a helpful aid for them and for the students, as it explains what has to be done, or as something that forces them to do extra work and arrange extra help for these students, is a different matter. So far from the information that has been gathered by participants (both students and members of staff) it seems that both opinions are correct. There are those lecturers who use it as a guide to see what they can do to help and support the students and there are those who think they are not obliged to act on it. Maybe the case is that due to confidentiality issues the lecturers cannot always access this information about students. Only when there is a specific issue about the student's assessment, such as when the student is about to fail the module or something similar, which will require a decision by the examiners' board, will the lecturers be informed by the school that this student has a learning difficulty. Therefore, in these cases it may not be that lecturers do not act on learning difficulties but they may not even know about the students' difficulties. The previous chapter showed that all departments take into serious consideration the adjustments that DUSSD suggests for students with learning difficulties. However, one department (among the participants) requested DUSSD to change the way that the support memos (reports) are written so that it is clearly stated that the adjustments are done "*where possible*" (Lecturer d) from lecturers and departments. Of course, this one example does not mean that lecturers do not comply with the reasonable adjustments that are required for students with disabilities, but it shows that the support memo is just a step towards provision for these students and does not solve the problem.

However, Durham University has a system where in each department there is a Departmental Disability Representative (DDR), as it was explained earlier in the thesis. The DDRs have access to that memo as it was explained by the other three lecturers (Lecturers a, c, d) and the disability officer, therefore, they will inform either the appropriate lecturers or members of staff about the students who need additional adjustments or they will take care with DUSSD's and department's help to make any necessary adjustment for these students. However as it is shown here it is not certain that all members of staff (especially lecturers) will see this memo and will know what adjustments have to be made for a student, unless the student or the DDR informs them.

This problem, in some respect, is confirmed by the Director of the DSU (c, [Pre-1992]), who explains, “...*some departments are so much better and make sure all their staff has the right information*” (Director of DSU c, [Pre-1992]). The Directors send the support memo to departments and then the departments have to make sure that all their staff who are involved with students with learning difficulties, and who have to know how to deal with each case, are informed. However, if the departments are not well organised and they do not distribute the information to their staff, then students may face difficulties because they act themselves, like going and informing lecturers about their difficulties, while at the same time, members of staff can argue that they were not informed about the students and what they had to do. In these cases, the problem comes back to the issue of students’ proactive character whether or not they will go and inform the lecturers about the difficulties they have and the things that they require help with.

As the disability officer from Durham University and all Directors of DSUs explained, this memo is something that the university cannot send to anyone unless the students themselves either sign or make it explicitly clear that want this to be sent to departments.

*“Once the draft (of the report) is ready it’s send to students electronically for the student to give permission to send it out. Usually, when the student comes (in the DSU) we ask them to fill in a registration form and to sign that they are happy for information of disabilities to be shared if necessary with either the department or the university...”* (Disability Officer)

This means that for confidential issues and concerns, the university cannot send it without the approval of the student. However, what happens in cases where the student needs help with specific elements of his/her course, but at the same time, does not want the department to be informed about the difficulties he/she has? What can the university do in that case? Moreover, how can lecturers know that this student, who is about to fail due to what seems like poor work, has a learning difficulty and requires further help and support? As has been explained before, the

disclosure or the revelation of a learning difficulty, even though it means that this person will be stigmatised at the same time, is the only way that allows access to the support and help that the students need.

One of the Directors, in order to show the extent of their commitment to respect the privacy of the students, by keeping their identities hidden, unless the students give their permission, said that

*“We don’t even acknowledge we know the student unless we’ve got the written permission from the student, which specifically says that I am allowed to speak to the parents because otherwise we don’t do that”*  
(Director of DSU a, [Post-1992]).

This statement, which may seem an ‘extreme measure’, can be interpreted in two ways. On one hand, the Director wanted to show that the university respects the privacy of the student and his/her determination to keep a ‘secret’, the disability, even from the parents, who are close to the student and in a way they either already know about their child or they have the ‘right’ to be informed. However, on the other hand, it gives the sense that the university ‘denies’ the knowledge of the existence of these students. In a way, it looks as if the university tries to hide the students with learning difficulties from the rest of the world and they have nothing to do with these students, they do not know these students.

Certainly, issues of confidentiality have to be considered here. The university is obliged under the Data Protection Act (1998) and the Disability Discrimination Act (2001) not to disclose or misuse any personal data that they have gathered regarding students’ disabilities. From the moment the student informs the institution about his/her disability, the university has to conduct an agreement as to how this information is going to be treated. If the student asks for confidentiality then the university has to make sure that the confidentiality is kept regarding this information, specifying to what extent some aspects of the disability would be disclosed. For example, if the student asks for confidentiality, but still needs access to the services and there is a need for some reasonable adjustments, then some people within the

university or the Disability Support Unit have to be informed, in order to offer the support and services to students. Universities, like any other organisation, institution etc, have to be very careful how to control the information that they gather about students, and how to handle sensitive personal data, such as disability related information, in order to avoid breaking the laws of DPA and confidentiality.

Keeping the confidentiality that the law and the norms of the interaction with students requirements is one aspect of the management of the information about students with learning difficulties. However, the other aspect is the notion of total *secrecy* around disability issues, which has to be taken into consideration, as well as the *sociology of information* as it was discussed in the literature (Simmel, 1906; Marx & Muschert, 2008, 2007). The extreme of the total secrecy that the institutions claim that they keep about students with disabilities may seem like, once the disability is revealed, it will cause embarrassment to the university or the student, or that there is something ‘wrong’ with students with disabilities, which has to be kept secret in order to ‘protect’ the society from it.

Therefore, it is necessary for the management of information about students with disabilities to be arranged in such a way that both protects students’ identities and does not stigmatise them, while at the same time it complies with the confidentiality law and the Data Protection Act (DPA) (1998).

One aspect of the management of information and the issues of confidentiality between the institution and the students is the conflict in the way that the given information has to be managed. As the Directors of the institution explain the students, after they have been given the assessment report, which identifies the learning difficulties they have been diagnosed with, have to think whether they want to let members of staff know about it or not. If they decide to ‘hide’ their difficulties, then the university is obliged by confidentiality issues to do so.

*“But on the other hand, if they have put it on the UCAS form, it’s public information. The university has the official report; therefore, it is our job to make sure that they do know. That’s where there is a conflict. We are obliged, under the new law, to send and make sure that everybody in the*

*university knows, as soon as they have informed the university. If they come to us as an individual and ask us not to mention that information we are banned from passing that information...so...there is a terrible conflict there”*  
(Director of DSU c, [Pre-1992])

Therefore, it is clear here that there is a conflict in managing the information, students provide. Once the disability is mentioned on the application, then it is not personal information any more, rather it is public information, and as such, it can be ‘treated’ in a different manner. The law determines in this case the management of the information and it requires that everyone of interest becomes aware of the student’s identity. The reasons that make students prefer not to disclose their disability could be related to stigma, as the impact that an attached label of a disability can have on students’ self-esteem and self-image is well-known, as it is attached to characteristics which can stigmatise them forever. In addition, it is possible that students may have mentioned that they have disabilities when they applied to the institution, but they do not see ‘learning difficulties’ as a salient identity which they have to accept and to be known as ‘having’, therefore, they do not reveal it. (Beart, 2005; Goffman, 1990 [1959]; Sennett and Cobb, 1972; Link & Phelan, 2001; Kaufman & Johnson, 2004; Watson, 1998 in Shakespeare, 1998) Nevertheless, this is not the only document that can be used as a reference for the legal requirements and reasonable adjustments that have to be put in place for disabled students.

The new law covers and protects students with disabilities within the Higher Education Institutions, but its implementation within each institution is not something that can be taken for granted. The important issue is the extent to which the law is actually put into practice on a day-to-day basis and activities within the institutions, and that is the focus of this research. Students with learning difficulties have already demonstrated fitness to succeed in Higher Education by the fact that they managed, despite their difficulties (personally and socially constructed), to finish all the necessary steps, which led them to Higher Education, as did other students without disabilities. Therefore, they have every right to be there and to

receive all the necessary help and support that they require in order to end up with the degree of their choice.

As has been outlined in the literature review learning difficulties have the distinct characteristic of being ‘unseen’ disabilities, as students with learning difficulties do not have visible sign to identify them among other students. This invisibility of learning difficulties can help students to hide the stigma that their difficulties cause however, there is still the problem of the unseen disabilities. The problem with the unseen disabilities is that they cannot easily be identified and this causes concerns and problems when it comes to providing support for these students.

The DSUs have to find ways to make ‘visible’ the invisible learning difficulties in order to allow access to these students to support and provision. However, by making that there is the fear of stigmatising the students and causing more problems to the ones they already have to overcome. Therefore, in order to ‘eliminate’ or minimise the stigmatisation of the students, through making ‘visible’ their identity, the institutions need to find an appropriate way to manage and handle the sensitive information about the students, which will allow them access to services they need. The written permission that allows the institution to inform others about students’ disabilities is the only evidence of students’ disability. Unless there is this written permission, it is as if the students had never mentioned or never accepted that they have learning difficulties. However, the implication of this action has to be considered, regarding stigmatisation. This paper makes the difficulties that students have ‘visible’ to others, and this can lead to stigma and even discrimination against the students. From the students’ point of view, one way to manage the stigma of having learning difficulties is to “hide” it, in order to “pass” as “normal” (Goffman, 1990 [1963]). By allowing the institution to use the information about their difficulties, they, in a way, accept that identity, and they can now have access to the support they want.

The difference between seen and unseen disabilities is that it is easier to identify who has disability and may (or may not) need your help. It is difficult not to see if someone is in a wheelchair or if someone uses a white cane. After having identified the disabled person, it is easier to offer help and see if they need it or not.

*“I think most people would...sympathise, is not the correct word, but empathise with the needs of a visible disabled person, and so if it is a wheelchair user, or if it is a guide dog, or if someone is using British Sign Language, it’s visible and they can see that. It’s the unseen disabilities that they find difficult, because, and this comes back to what I was saying about inclusion, if you are relying on being about to tell by looking to somebody that they need some support, that’s not going to work; because the majority of our disabled students, don’t have visible disabilities. They have specific learning difficulties, they have mental health issues, they might have medical conditions...They don’t have the label. So, instead of trying to work out which are the disabled students, make it all-inclusive and it is a lot easier all around” (Director of DSU b, [Post-1992])*

In cases of dyslexia or learning difficulties, which are unseen disabilities, it is not easy to identify the person who may need help. Students at universities are judged and evaluated based on their academic performance, but as this Director explains, it is easier for academics to empathise with students with visible disabilities and they may not necessarily judge them better or worse due to their visible disability, but they can definitely identify them and offer help. On the other hand, with learning difficulties or other unseen disabilities the academics cannot identify these students just by looking at them, and unless the students identify themselves or lecturers be are informed about the students by the DSUs, then it is impossible to know who has a learning difficulty. This may affect the lecturers’ judgment of the students’ performance. Not being perceived as disabled might be of benefit for the students as they avoid being labelled, but on the other hand, a lack of awareness from classmates or members of staff can only be added to the difficulties that the student faces. They might not want to disclose or consider themselves disabled, thereby, not accessing funding and resources that they are entitled to. However, one of the major problems faced by students who have hidden disabilities is that often other people do not believe them. They are told that they do not look as if they are disabled, they do not have the ‘signs’ that disabled people have. Hidden disabilities can also cause

difficulties because of the attitude of others due to fear or ignorance – the attitudinal barriers that have already been mentioned. People fear anything that they do not know or understand or anything that they cannot see, which may explain the uneasiness of lecturers around students with unseen disabilities. However, the ‘solution’ of an all-inclusive environment, that the Director suggests, as the easiest way of dealing with students with unseen disabilities, is not always the best practice. Moreover, it should not be considered as the ‘panacea’ that will make everything better. The idea of an all-inclusive education is not to ‘hide’ the identities of students with disabilities against other students. It is not about avoiding dealing with disabled students. The inclusive educational system is about providing, in advance, the same opportunities and making the necessary adjustments so that disabled students are not discriminated against.

Therefore, due to the invisibility of the learning difficulties, lecturers can argue that they are not sure who needs their help or how to identify the students with dyslexia or learning difficulties among other students. There is also the issue of uneasiness around people with disabilities, as Goffman (1990 [1963]) explained when he was talking about the stigmatized and the attitudes towards them by the un-stigmatized. It is the job of the Directors of the DSUs and their staff to ‘train’ other staff and teach them about disability awareness and their responsibilities towards students with disabilities. Members of staff have to know how to deal with students with difficulties and what support they have to provide under the university policy, and the disability law. On the other hand, they should be careful not to treat disabled students too differently from non-disabled as this could also be considered as a form of stigmatisation or discrimination, because of the change in attitude. However, it is necessary to understand and accept others regardless of their difficulties or differences and no matter how visible or invisible these differences are to other people.

*“...with visible disabilities we can get people onboard pretty quickly, but sometimes they are quite frightened, especially if they haven’t dealt with, for example, with a physically disabled student before. And so they are a little bit worried. It’s a case of building-supporting them I think, so they feel confident to talk to the student direct. Another part of our role is to support non*

*disability service staff in their work with disabled students, because obviously we don't want all of them to come to us, we want them to work directly with the student. But that can be, especially if it's someone with quite significant physical disability or essential impairment or communication problem, sometimes people lack confidence "oh, can I say that to them?" they are coming sometimes for reassurance to us" (Director of DSU b, [Post-1992])*

The Director emphasises here that lecturers feel 'frightened' or 'worried' when they have to deal with students who have disabilities for the first time. Their fear is especially apparent when they deal with unseen disabilities, because as was explained above, it is more difficult to identify the students with unseen or hidden disabilities and the lack of confidence makes their interactions with these students more problematic. In these cases, the role of the Directors is to help lecturers and members of staff to learn how to deal with students with learning difficulties and their enquiries. It is common for some lecturers or non-academic staff not to have dealt with students with disabilities before. Therefore, in order to help them deal with the students' inquires effectively, the DSUs encourage them to contact DSUs and ask for support and advice. Durham University with the Departmental Disability Representatives (DDR)s who are the first point of contact for both students and lecturers within each department regarding issues with disabilities, tries to solve some of these issues. Either the DDRs have some form of disability awareness from personal interest or because they have been in regular contact with DUSSD and they, in most of the cases, offer help to any member of staff who needs additional help on who to deal with disability's issues. (Disability officer).

Another 'paradox' regarding management of information between students' identities and institutions is that while the institutions claim to make every effort to hide the identities of these students, all four universities have separate arrangements for exams, assessment times etc for these students. When a student with dyslexia, for example, has been granted exam concessions, this means that he or she will not take the exams in the same room with the rest of the class but in a separate room together

with all the other students who for similar reasons have exam concessions. Students with dyslexia usually have 25% extra time for every hour of the exam time that other students have, which is another reason that makes them take the exams in separate rooms from the rest of the class. Therefore, even if the class or the lecturer did not know before that this student had a disability, the fact that during exams he or she is not in the same room with the others almost immediately means that this student has some disability and has been granted an exam concession. As has been argued, these arrangements can cause bigger stigma than the disability itself (Johnson and Fox, 2003 in Ho, 2004).

One of the lecturers from Durham University mentioned that issue as one of the students' concerns regarding adjustments that they are offered to them:

*“One thing that is apparent is that dyslexia students they do not want to be separated like that... They want to be in the same room with other students because a lot of them they prefer other students to be unaware of their disability which is a problem as we offer them to sit in a place where they won't be disturbed and sometimes they don't want that...”* (Lecturer a)

From the participant institutions two ways of managing information about students became apparent and they will be discussed next in order to see their effectiveness for students.

### 8.3 Ways to manage information about students with learning difficulties

Previously, in the literature review, the effects of the categorization of people with disabilities and the stigma that this action has on them were explored in detail. Here this section will discuss two ways of managing information, while some comments from students will show how effective the students think these systems are both for their primary purpose (to help students) and for their self-identity.

Apart from the special arrangements during exams for students with learning difficulties, the universities also have other ways to separate these students and their work from other students. The Director of one of the universities that I spoke to explained that they use a system with *stickers* in order to separate the work of students with learning difficulties. In addition, the same institution has a programme, a special course (*Get Sussed*), only for students with learning difficulties in order to help them with skills like writing, spelling etc. These two different ways can be seen as two approaches or two solutions to the same problem - that of helping students with learning difficulties. However, the main point about these two approaches is again the conflict in the role that they play for students with learning difficulties.

On one hand, institutions claim to do everything possible to protect students' identity regarding their disabilities, and they claim reasons of confidentiality and secrecy about the students' identities. However, on the other hand, they use methods of controlling the information they get about students' identity, which do exactly the opposite. The use of labels, stickers, special courses etc are all solutions which cause stigma and even discrimination against students with learning difficulties, as they are used with the purpose of clearly marking and separating the students' work from that of other members of the university population. At the same time, these methods or solutions that are used here, can be seen as a means of '*normalisation*', especially the course, as it suggests that with this course the university or the DSUs will fix the problems the students with learning difficulties have. Both solutions will be evaluated based on the students' comments to see whether they succeed in their purpose of helping students with learning difficulties.

### 8.3.1 Stickers

It has been explained before that learning difficulties is an ‘invisible’ disability, where those with learning difficulties do not have a visible sign to identify them as disabled, and this can make it more difficult for others and especially lecturers to identify and empathise with students who may need more help. On the other hand, this may be beneficial for some students who do not want to be labelled as disabled. Here we see that despite the invisibility of learning difficulties, the institutions use visible signs for students with learning difficulties in order to identify them and to make them ‘stand out from the crowd’ of other students.

It is as if we need the visible sign of disability in order to accept and not discriminate against those with learning difficulties, otherwise it is difficult to provide support and provision for these students and to treat their work in respect to their difficulties. However, this idea comes totally in contrast to the theories of labelling and stigma, where the attachment of labels and signs constitutes an act of discrimination against those who have been labelled and it should be avoided in order to avoid the stigma that the attachment of a visible sign can cause to students.

As far as using different ways to separate students with learning difficulties is concerned, the opinions of the Directors were not unanimous. One of the Directors of the DSUs said that their university actually uses a system with stickers which say ‘SpLDs’ on top and are yellow and are given to their students and they have to use them every time they are handing in an essay or the exam papers. This way the lecturer or the examiner will know that this student has a learning difficulty and will have that in mind when marking the work of this student.

*“So, when they hand in a piece of work they put a sticker in front and that reminds the lecturer that they have a SpLD and that there are certain criteria that they need to take into consideration when they are marking them. Exam papers again you put a sticker in your exam paper then again, if it’s possible the same rules are taken into consideration; because we have so many students with SpLDs and the lecturers forget which students have and which*

*students haven't so that's just a visual reminder for them*" (Director of DSU a, [Post-1992])

This Director of DSU is the same one who said that they do not even acknowledge that they know the student unless they have written permission by them to do so. However, here paradoxically she claims that the students have to use a visible mark, a sticker, in order for lecturers to identify them and mark their work based on certain criteria for students with learning difficulties. How does this sticker 'protect' the identity of the student and how ethically correct is the system that uses a sign that is visible to everyone to separate these students? The total secrecy that they claim to keep unless they have the written permission of the students in order to disclose their disability seems to contradict totally with this system with the visible yellow stickers. In addition the system with the stickers is only 'useful' in marking essays and exam papers, and does not offer any support or help during lectures, for example, or seminars when there is the possibility for students with learning difficulties might require some help.

The other issue with handing in essays and exam papers is that the universities usually require students to write their anonymous code instead of their name, which is not helpful in cases of students with learning difficulties, as even if the lecturer knows the students' name, he or she cannot identify the student's paper without it. Even when the students use the sticker and the anonymous code, the sticker does not explain what kind of learning difficulties this student has in order for the lecturer or the examiner to be able to understand the difficulties the student had regarding this piece of work or exam paper. It is a different case when you have dyscalculia and you hand in a maths based assignment and very different if you have to write an essay where you will not use any maths equations etc. Therefore, the sticker alone does not necessarily help or solve the problem with students with learning difficulties and it does not necessarily help lecturers when they mark students' work, because they cannot know exactly what the difficulties of this particular student are.

At the same time, and having said that, it is arguable that the lecturers do not always know what to do when they see a sticker or when they know that a student with learning difficulties writes this piece of work. It has to be clear either by rules and

regulations by the university or the DSUs what exactly they have to do when they have to mark the work of a student who uses a sticker, in order to treat these cases equally to others and not less favourably. There is also the issue of whether the provision for marking differently the work of disabled students is a necessary action once they already receive extra help compared to other students. Though the research concluded that at least in the case of one of the universities, the lecturers knew that the university's policy says: once the support for these students is there, (either in the form of extra time, exam concession, dyslexia tuition etc.) then there is no need to make special provision in marking. This would be to go too far and give a double advantage to students with disabilities compared to other students.

When I asked the Director of the DSU of the university that uses stickers if there are cases of students who did not find this system with the stickers correct and they protested about its use, because it makes them seem different or separated from the others, for example during exam times, she said:

*“Right, if it is a case of an exam, then if a student has extra time then they will either be in the same hall with everybody else, and have the time added at the end, or they will be in a separate room. So, regardless, if a student has extra time in exam then other students they would know why they weren't there, so that may not be a problem. The yellow stickers, the only time that people would be aware that they have to put the stickers on, is when they look over their shoulder, because they hand it in in the lecture and it's only the lecturers who see the work. You can put it on at the last minute. I've never had a student not use the stickers. Some forget to use the stickers and then they go back over and ten minutes later put the stickers on. But I've never had this arise when they have not used the stickers. NEVER” (Director of DSU a, [Post-1992])*

Therefore, if no matter what, the students' identities will not be kept secret (either because they have to sit the exams in a separate room, stay longer or because of the yellow sticker) then how does the university show its concern about confidentiality issues and privacy of the students' identity? The system with the stickers may be used as a solution for the marking problem, which is to separate the essays and exams of

students with learning difficulties, in order to provide the special treatment that they may need. It can also help lecturers to identify the students that have learning difficulties and judge their work accordingly. However, it does not avoid the problem of revealing the students' identity to everyone who sees the stickers, and does not avoid the stigma and the discrimination that an act like that will result in.

The university claims that it cannot acknowledge that it knows the student with learning difficulties without their permission, but it has a distinctive way to separate them and most importantly identify them to other class members or lecturers. Of course, someone could argue that students have the right to refuse the use of this sticker or that the anonymous code does not identify the student to everyone else, unless they know the students code. However, unless students decide to use the stickers, it automatically means that there is no way that their needs and difficulties will be addressed and will be taken into consideration when their work is marked. Consequently, it is not so much a case of choice whether they will use the sticker, but more of a one-way road if they want to pass the exams.

At the same time, while the Director of the DSU said that she never had a student who said that s/he does not want to use the stickers due to fear, stigma and embarrassment, she additionally said that there are those who forget to use them and go back later to put them on their work. It is possible that some of them go back when no one else is waiting to hand in an essay and therefore they can put the sticker on when no one is there to '*look over their shoulder.*' (Director of DSU a) Other evidence which shows that actually there are students who do not agree so much with the sticker system is the case of a student who said when I asked him how he feels with this system:

*"...first year I was a bit itchy about it because I mean I am this kind of person...I mean I am not a very open person, I don't like to sort of feel any different from everybody else and obviously with this kind of thing, I think the yellow stickers stand out a bit. So, the first year I was a bit sort of I wanted to hand my essays in and I didn't want to be anybody else around. When this year, I mean I am used to it now and I am not bothered about it, I mean when I hand essays in there's been people from the course whom I know and talk to and they've been asking what this is and I stood and explain it to them so it is*

*a bit more relaxed than what I was in the first year”* (I<sub>18</sub>, M, 20, NUa, Dysl&Dysp&AsperS)

Especially for the first year students, who have a difficult year as it takes time for everyone to adapt to the new university environment, get used to the new rules and regulations, and meet new people, the system with the stickers seems like another thing to worry about.

Apart from the stickers, which as I said emphasise the marking of essays and exam papers of students with learning difficulties, and aim to make it easier for markers to identify that the student who handed in this work has learning difficulties, there is another arrangement, which emphasises learning and it is called ‘Get Sussed’. Next, the effectiveness of this learning aid is assessed based on the experiences of both students and the Director of the DSU of the university that uses this system.

### 8.3.2 Get Sussed

The same university has another system, which aims to give a learning aid to students with learning difficulties. It is a course where students with learning difficulties can gain credits by completing some modules, which are exclusively available to students with dyslexia. The system is called Get Sussed (Director of DSU a [Post-1992]) and it includes modules about

*“... Essay writing, effective note taking and it is a module you can actually...it’s in... It’s self-taught, you work through the programmes and the book, and if the students need a hand with them, they can get a hand with them. We used to have a module, only one module, 20 credits, which was only for students with dyslexia”* (Director of DSU a, [Post-1992])

The Director of the DSU explained how it works and how students gain the credits for this module. She said that it did not run in the year of the actual research, because they decided to revise it but in general, this is how it worked:

*“Basically students can put in, it’s 20 credits. Contact time was 3 hours every week during term time and it was basically taught as people with dyslexia liked to be taught and benefited from being taught. So it was multi-sensory and we covered subjects such as essay writing skills, organisational skills, time management, visual techniques and everything was done in a multi sensory way. So, everything that had to do with studying was in there and as you were learning and learn to improve your study skill you were actually able to keep all that on file and have the credit at the end of the year... it was an elective module, if they wanted to study it they could and then if they didn’t then they didn’t”* (Director of DSU a, [Post-1992])

We have to pay attention to her comment that the module was taught *“as people with dyslexia liked to be taught and benefited from being taught...”* (Director of DSU a,

[Post-1992]) This quote may be interpreted as showing some kind of expertise again from the Director's perspective, as they are the experts who know how the students with learning difficulties want to be taught. In addition, it shows some kind of patronising attitude towards students with learning difficulties. It is as if students with learning difficulties need a specific way of teaching and learning, which is only possible through this course and there lies the effectiveness of the course.

The students who attended the class commented on how they feel about it and how effective they think these classes are. Their views will help to conclude whether the Director actually could claim that they know how the students with learning difficulties liked to be taught. One student who attended the course commented:

*"...it felt kind of patronising and very sort of 'this is how you do this thing' kind of thing even though I mean you know how to do those things they are talking about. So it was a bit too patronising and a bit slow and a bit rubbish...it wasn't exam based, it was based on the book; it was more or less if you did everything in and you did the presentation, you've passed. That was the good side of it, the bad side of it is that it was really really... to me it felt really patronising and not on the level we should have been, it felt like we were back to primary school. So it was a bit silly..." (I<sub>18</sub>, M, 20, NUa, Dysl&Dysp&AsperS)*

It seems that students with dyslexia felt that there is some kind of discrimination or patronising behaviour against them; as if they are not capable of understanding when they are taught in the 'normal' way. The student felt that the modules were delivered in a way that would be appropriate for students in primary school, and not students in Higher Education Institutions. Bearing in mind that despite the difficulties that these students have, they are at Higher Education Institutions and this by itself shows that they already have the basic skill of essay writing, taking notes etc, it is questionable why the university choose to deliver this course in such a way. Another student who participated in this module felt the same way. *"The problem with that was the way it was delivered and the style of it..." (I<sub>14</sub>, F, 21, NUa, Dysl)*

The students who commented on the module both had dyslexia and other learning difficulties and both detected some problems with the way that the module was taught. On the other hand, the Director explained that this course “*it was basically taught as people with dyslexia liked to be taught and benefited from being taught*” (Director of DSU a, [Post-1992]). If it was specifically constructed to help students with dyslexia but the students found it at a lower level of what they would have found useful for them, then what is the point of something like that? Of course, it is possible that other students who attended this class may have found it useful and might have helped them. However, from the data that collected in this project we cannot conclude that this course was totally accepted by students.

The dissatisfaction with the way that the course was delivered may also explain the drop in the level of attendance towards the end of the year, as the Director of the DSU explains below. The university probably understood that the module had to be revised before it was re-entered the next year as a module for students with dyslexia.

The attendance on this module was very good at the beginning of the module but it was getting ‘average’ later.

*“Yes, yes it was nearly always full. It was average...if you look in how many students there are in population then there could have been more, but it was always always the start of the year full, and you would have one or two drop outs by the end, of the year”* (Director of DSU a, [Post-1992])

Now, as for the other three universities, they do not use any similar system to separate the students with learning difficulties from other students. One of the Directors said about the usefulness of a system like that:

*“...any attempt to separate the exam papers is...that it seems like levelling the playing field...Anything is seen as giving, like differentiation marking that happens at some universities is...this university takes that as another step of giving them an advantage and we don’t have that”* (Director of DSU b, [Post-1992])

This university believes that it is not fair and ethical at the same time to treat these students in a different way to the rest, in exams, from the moment that these students already have extra time, which is what they need, based on the assessment they had. Therefore, any attempt to separate them and help them any further will be like giving them an advantage, which is not fair for the rest. Another Director of DSU from a university where they do not use stickers or any other method to separate the students added:

*“...If they obviously had a concession for extra time either for an assessed work during term so their essays obviously, as they had agreed, will hand in later, then in the sense this is different. And exams if they have extra time, they obviously had a concession. Hopefully that should mean that it’s a mediate for the difficulty, have extra reading time or someone to proof read or...But no. We don’t have any system where we use stickers. I know a lot of students don’t mind telling they are dyslexic and don’t have problem being identified as being dyslexic. If they are concerned that they might be discriminated against because of that, we would encourage them to use the mitigating circumstances. We regard it as better. We don’t use stickers” (Director of DSU c, [Pre-1992])*

This university believes as well that the extra time for exams and the agreed extensions on essay hand in times are enough for the students with learning difficulties and are according to what was agreed with them after the assessment of their needs. Therefore, they do not consider another way to separate those students from the rest of the university necessary. A similar opinion was expressed by the third Director of DSU whose university does not use any system to separate the students’ essays or exam papers.

*“No, we don’t have...They do have that extra time in exams and those papers are separated. So you know if anybody...the extra time is only for dyslexia students. So we don’t do that. So if they are given the extra time and support*

*we don't think that it's necessary to give them any further concessions on the marking" (Director of DSU d, [Pre-1992])*

There is an obvious difference in the ways that each university chose, in order to separate the work of students with learning difficulties. At the same time the two different systems that have been described (yellow stickers and Get Sussed) have been used as possible solutions to organisational problems that institutions have regarding how to 'make visible' to lecturers students with learning difficulties and how to help students with learning difficulties in the learning process.

The first system that uses stickers to inform the lecturers that the assessment or the exam paper that they are marking is from a student with learning difficulties, is a more direct approach, which makes it easier for others to see and identify the student with learning difficulties. The problem with that method is that as well as the lecturers other students or members of staff who work in the department, but are not lecturers, can see the sticker on the students' papers and can identify this student when the papers are handed in. Therefore, if the student wants to keep secret the fact that s/he has learning difficulties from others within the school (not lecturers) then this sticker is not helpful at all.

On the other hand, the course Get Sussed may seem like an easy and helpful way for students with dyslexia to gain credits and skills that will help them with their studies, but students said that the way it was taught made them feel patronised. This system does not use a visible sign to separate the students with learning difficulties, so it may be less stigmatising for students, but the fact that it was taught in a way that made students feel "... *like we were back to primary school*" (I<sub>18</sub>, M, 20, NUa, Dysl&Dysp&AsperS) causes discrimination against them.

From the discussion about the managing of information about students within institutions, it is concluded that each part (students and DSUs) have to play a specific role when handling this information, otherwise, the rule of protecting the students' identities from discrimination while providing support, cannot be met. Maybe the fact that only one of the four universities uses a distinctive system to separate the work of students with learning difficulties, while the other three Directors claim that they find a similar system 'discriminatory' and 'unfair', in itself shows that there are still

concerns about the effectiveness and the 'protection' of the students' identity,  
regarding systems like that.

# Conclusions

## 9 Conclusion

The aims of this research as they were identified at the beginning of the thesis were to explore the relationship between students with learning difficulties and the available provision that exists for them through Higher Education Institutions. Since there are changes in the Disability Law, which resulted in changes in the support and the provision for disabled students, it was important to see the effect of those changes in Higher Education Institutions. In addition, the effectiveness of the adjustments that the new Disability Law has introduced and the issues that all those changes have created, were the main interests of this research and have been addressed. Furthermore, the marketisation of education which certainly aimed to widening participation to Higher Education for groups of students who did not use to have access to Higher Education, among which are students with disabilities, created a tension to the services and the support that the institutions offer to disabled students.

In order the research to explore these aims and to discuss the issues of interest, it employed interviews with students with learning difficulties from four Higher Education Institutions. Since the main purpose of the research was to explore the provision for students with learning difficulties it was considered appropriate to talk to disabled students directly, which gave them the chance to talk about their own experiences. The research has explored the provision for students with learning difficulties at Durham University mainly; however, the collected data from the other three institutions in the North East Region of England were used to show a more general picture around the issues of support and provision of students with disabilities and learning difficulties in particular. Even though the results are not representative of the whole population of students with learning difficulties from Higher Education Institutions, the issues which have been identified and addressed here can help to see the relationship between students-institutions and provision.

In addition, the research aimed also to see the same issues through the perspective of the institutions, and for that reason, it also included interviews with Directors of

Disability Support Units from four Higher Education Institutions and members of staff (lecturers and college officers) from Durham University in particular.

Through the interviews with students with learning difficulties, it was concluded that the diagnosis of their difficulties it might had different effects for each student; however, it was an important moment in their life. For some it was the answer they wanted in order to explain their difficulties and allowed them access to the services for their difficulties. For others who accepted the “*secondary deviation*” it caused “*biographical disruptions*”. However, for the majority of the students their difficulties did not affect their choices of continuing to Higher Education, their course of study and the institution they wanted to attend.

However, the research concluded that the disclosure of their difficulties and of their learning difficulty in particular is a great concern for students. The findings concluded that the severity of their disability and the level of the learning difficulty students have plays a key role whether they will disclose their difficulties or not. The students who had mild dyslexia for example did not consider it important to mention it to members of staff, while others with more severe cases of dyslexia or other difficulties had concerns whether they would reveal their difficulties at the university. The hierarchy of the impairments as it was discussed in the literature was apparent in many cases in students’ interviews as for some difficulties is was easier for students to disclose them compared to some others.

In addition, the interviews with the students in relation to how they value the services they receive from Higher Education Institutions and how satisfied they are identified another important issue, which is the standardised treatment that they believe that they receive. Even though the students said that they are satisfied with the services they receive, they all valued the personal treatment that in occasions they receive from the Disability Support Units. This shows that students want a more personalised approach from DSUs and adjustments, which would be specific for their needs and not the same for everyone.

The main findings from the interviews with the Directors of DSUs and that of the members of staff from Durham University identified that the bureaucratisation and the institutionalisation of the services, which in a way is the result of the marketisation of education, led to a less personalised services and more standardised treatment for all

disabled students. This on one hand it may have some advantages for example for the workload of the DSUs, as it is now easier to provide support for more students, however, it could also lead to losing the individual within the whole. Among the main conclusion from the institutions' perspective was that if an all-inclusive education is to be pursued, the marketisation of education and the bureaucratisation of the services that institutions provide to students have to be replaced with more personalised treatment and more emphasis to the individual needs of students. The students have already shown through their interviews that the personalised services are the ones that they value and they want from the institutions.

Furthermore, the interviews with the lecturers and college officers from Durham University, as well as, the views of the Directors of the DSUs, were combined with that of students. Despite the progress that everyone sees in Higher Education Institutions regarding disability awareness, the main conclusion is that it seems easier to make adjustments to buildings in order to accommodate wheelchair users, for example, rather than change the attitudes of some people regarding learning difficulties. The invisibility of learning difficulties, which causes some additional problems to those who try to persuade others about the need for support, together with the attitudinal barriers that need to be overcome, in order to change teaching and learning practices in education, for disabled students, are the main concerns for both students and members of staff.

The results from both students' views and members of staff, combined with the literature helped to identify three main tensions: the 'paradox of the diagnosis', the tension between bureaucratisation and the need of more personalised services for students, and finally, between marketisation of education and knowledge for democracy. Those tensions are summarised here in order to emphasise the conclusions of the research.

This 'paradox' of the diagnosis is the first of the three main tensions that were identified from the findings of this research. The tension of labelling and stereotyping lies in the ability of the label to be both the trigger for stigmatisation and at the same time, the answer that the disabled person seeks in order to explain the difficulties he/she experiences.

The review of the literature showed that Higher Education was not always open to disabled students and staff (Barnes, 2007; Barnes, 1991). However, since 1993, when the Further and Higher Educational Act (1992) came into force, an increase in the number of students who entered Higher Education Institutions has occurred. The aim of the Act was widening participation in Higher Education to include groups who did not traditionally continue into Higher Education, such as students with disabilities.

A clear shift in interest towards disability and the experiences of students with disability in education occurred in recent decades. At the beginning, the problems of the students in Higher Education were seen only as individual and medical difficulties. However, the social aspects of disability, as UPIAS (1974) explained gave rise to the notion of the 'social model' of disability (Oliver, 1996[a]). Despite the emphasis that has been given to the social model of disability it also accepted some criticism both from within and from outside. The criticism from within, i.e. from people with disabilities, was about the lack of social model to take into consideration the impairments and the problems they can cause to disabled people (Shakespeare & Watson, 2002; Shakespeare, 1992; Oliver, 1996[a]). People with learning difficulties pointed out that the social model does not pay the appropriate respect to learning difficulties, as it is more about physical impairments (Chappell, Goodley & Lawthom, 2001; Goodley, 2001; Chappel, 1998; Campbell & Oliver, 1996). On the other hand, the criticism from outside came from those medical professionals (like medical sociologists, doctors, psychologists etc) who supported the idea that the problems of disabled people are the result of their impairments (Oliver, 1996 [a, b]). Therefore, as their job is to fix the body and the body causes the problems of the people with disabilities, by taking care of the impairments, they can fix the disability too.

The social model emphasises the need for disabled people's participation in decision-making, which means that people with disabilities need to have their say in decision making about their rights and the ways that their needs will be met. Legislators can benefit from disabled people's input and experiences as people with disabilities know better what they need and how things could change in order to accommodate their needs. It has to be clear that in some cases the professionals are not the 'experts' to deal with disabled people neither should they be allowed to use their power over disabled people in order to control their lives and to make decisions for them (Oliver, 1996[a]). Sometimes experts' opinion is considered more important regarding

disability, compared to the experiences of disabled people. The experts use their power of expertise to persuade others that they have a better understanding of the difficulties and the problems that disabled people face every day, when no one understands disability better than the disabled themselves (Brisenden, 1986, p: 20).

Professionals such as educational psychologists, medical professionals, legislators etc create categories in order to fit in people with different abilities characteristics and label based on these categories that they have created. The social construction of disabilities and the labels that are given by the experts to people with disabilities can lead to discrimination against disabled people and more importantly to stigmatisation. Both these issues (labelling and stigma) have been explored in the literature review, while their implications were analysed through the interviews with both students and Directors of DSUs. With labels such as ‘learning difficulties’, ‘disability’ etc there is always the possibility that they will become the master status for the individual to whom the label has been attached and others could only see the label instead of the person. Sometimes, disabled people accept the label and the stigma that the label gives them and start behaving based on the expectations and the characteristics of the label. This is called “*secondary deviation*” (Lemert, 1967) and the interviews with the students revealed that there are some cases where actually the students at some point believed and accepted the “*secondary deviation*” and started to challenge their abilities and their life, based on the expectations of others (Interviewees 8, 9 & 11).

However, the label can have a contradictory result from that of stigmatisation. The label, which comes after the diagnosis of the disabilities, gives the so-wanted explanation of all the difficulties that people had before the diagnosis (Brueggemann, White, et al., 2001). At the same time, it allows access to all the services, support and help that the disabled people need, which they could not access without the official diagnosis of their difficulties.

This tension became apparent in many cases through the interviews with the students. The research concluded that for some students, the diagnosis was quite a positive experience and provided them with a sense of relief as it explained the difficulties and the struggles they had had until that moment. The diagnosis gave a “*proper medical name*”, as one student (I<sub>2</sub>, F, 19, OUa, Agor) explained, to the difficulties they had and reassured them that the problems they had experienced in the past were not their fault. The diagnosis for some students was the process they had to follow in order to

achieve the normalization they wanted. The identification of the disability, helped them to feel that they were part of a group of people who had the same difficulties as them and they had “*sympathetic others*” (Goffman, 1990 [1963]), to help them feel ‘normal’. The bad previous experiences that some students had before they were diagnosed with learning difficulties made the diagnosis more of a good thing in their life, as it helped them understand and explain to themselves and others why they had struggled until that moment.

However, the labelling process that was the result of the diagnosis can also lead to stigmatisation and the consequences that this could have. Among the participant students, some explained that the diagnosis of the learning difficulties was not a very positive experience for them. The diagnosis came as a surprise, especially for those who were diagnosed later in their life and it changed their sense of self-esteem considerably. The shift from a non-disabled person to a disabled one and from non-stigmatised to stigmatized it caused many concerns to these students, as it changed their life and especially their self-esteem. In some cases, the notion of the “*biographical disruption*” (Bury, 1982) was apparent, as students found that the diagnosis disrupted their everyday life activities and they started to challenge their ability to complete everyday activities, as they used to do before the diagnosis. The findings of the research also confirmed the theory of the existence of a “*hierarchy of impairments*” (Deal, 2003). There are impairments, which are considered more common, and more accepted than others are. Therefore, those people who have been diagnosed with impairment or disability, which is one of the least preferred, find it more difficult to be accepted by both non-disabled and disabled people. Students with multiple learning difficulties, who participated in the research, expressed a different level of concern about one form of learning difficulty, compared to the others they had been diagnosed with. For example, a student with dyslexia and OCD (I<sub>6</sub>, M, 33, OUa, Dysl&OCD) explained that he is more open and finds it easier to accept the dyslexia, compared to the OCD. He considers that dyslexia is a more common disability, more people know about it and hence it is easier to be open about dyslexia. On the other hand, he is less open about OCD as it is not considered as common (I<sub>6</sub>, M, 33, OUa, Dysl&OCD). The level of public awareness about disabilities and the level of public acceptance of forms of disabilities play a key role in these cases, as the lack of knowledge about some disabilities causes greater uneasiness and stigma,

compared to some more known disabilities. Finally, the findings of this research showed that for those students where another member of family had similar difficulties the diagnosis was less of a surprise than for those who did not know anything about it. Members of family and friends play a very important part in the life of students with learning difficulties, as the interviews showed, and their support and help is something very much appreciated by students.

The second tension, which became apparent from the finding of this research, is between the personalised treatment that the students prefer and the bureaucratisation of disability services within Higher Education Institutions. The majority of the students who knew that they had a learning difficulty when they applied to university were not aware of the services that are available for them from the institution. None of the students actively checked with the university to see the kind of support and services that they offer for students with learning difficulties. Only a few of them had heard before, from friends and members of the family, that the universities are obliged by law to provide some support. The lack of awareness about the services can be explained because the majority of the students, as was discussed in their interviews, did not consider their difficulties a master status which would affect their choices. Consequently, they did not consider it necessary to check the services that are available for students with learning difficulties, and when they actually received the support, they were quite pleased and satisfied with what they got.

Despite the lack of awareness about the existence of provision for students with learning difficulties at the university, they chose before they applied to it, the students who participated in this research registered with the DSUs in order to get some help and support for their difficulties. Therefore, when they were asked about their experiences with the DSUs and the members of staff at the university in general, they gave a variety of answers. All of the students who were satisfied with the DSUs, when they were asked to explain and give examples of their satisfaction mentioned examples, which showed that they valued the 'personalised treatment' they were getting from the DSUs. They put emphasis on the personal relationships they had with the DSUs advisers, their personal dyslexia tutors or members of staff within the DSUs. The positive comments about the DSUs were related to the way they feel when they need the help of the DSUs advisers. The students mentioned that they like the fact that they feel comfortable talking with the advisers, which is important for them

in order to 'open up' and discuss their difficulties and concerns. In addition, students liked the fact that they can find a friendly face in the DSUs that can they trust and be reassured by that person that most of the time their problems can easily be solved. Therefore, the research concluded that students value the personalised treatment they would like to get from the DSUs. They do not want the standardised and bureaucratised treatment, which is the same for everyone with learning difficulties. They want a more direct contact with the DSUs. Therefore, students valued and defined as satisfactory treatment when they were treated as persons, instead of a group of people, where everyone will get the same treatment and the same support, regardless of their individual needs.

The changes of disability law within Higher Education and the general changes in Higher Education, due to new managerialism, the introduction of Performance Indicators and the demands for reasonable adjustments, altered the form of support that is offered to students with disabilities. The interviews with the Directors of the DSUs pointed out that the services institutions used to give to students with disabilities were "*out of the goodness of their heart*" (Director of DSU c, [Pre-1992]). This means that they had a charitable character, where it was not determined by law what they have to offer, therefore, the institutions were offering whatever they considered appropriate, or they were not even obliged to offer any support at all. The interviews with the four Directors of the DSUs, discussed the changes in their role within Higher Education, due to the bureaucratisation of the services and the general changes in education. Directors play the role of the gatekeepers, who control the access to both students and services, they are the mediators and they advocate for students. All of these aspects of their role are quite complex and the complexity comes from the inherent tension that their role has. This tension comes from the fact that they have been employed by the institutions to protect the interests and rights of both the institution and the students. They have to be the mediators who will find a way to accommodate the students in a way that will not contradict the institutions' interests. Of course, the bureaucratisation of the services and the law help them towards this aim, as it is used as a reference for persuading the institution and the students about the role that each side plays in every situation.

The bureaucratisation of disability services in education has changed the character of the services. This change on one hand is beneficial for both students and DSUs, as it

is no longer based on the good will of Directors of DSUs and institutions whether they will provide support to the students with disabilities. There are laws which define the support that has to be in place for disabled students, which makes the job of Directors of DSUs easier. On the other hand, the bureaucratisation of the services has led to their depersonalisations, as it does not pay the appropriate attention to the individual needs of the students, which in many cases are forgotten due to the standardisation that is followed in service provision.

In addition to that, the information collected from the lecturers and College Officers from Durham University, showed that their views are close to that of students, in a sense that they expressed their belief that the adjustments that the DSUs ask them or the departments to do are very much standardised. Of course, as they said some of the adjustments are just good teaching practices and should be done for every student, however, the majority of students with dyslexia for example, regardless of the severity of their difficulties, they will all get 25 % extra time in exams. The lecturers argued that this is much standardised treatment and in some cases either it is not enough for some students, or it is more than what some other students would require. The lecturers pointed out that the university should not only provide facilities, so that it seems that it complies with the new disability law and regulations. There should be evaluation of the facilities to make sure that they are actually useable from students who need them.

The turn of education towards marketisation and the bureaucratisation of the services resulted in an increase in the number of disabled students who enter Higher Education. This increase led to a more standardised and less personalised education, where the needs of disabled students cannot always be met (Riddell & Weedon, 2006). In addition, the more students with disabilities in Higher Education there are the less time the DSUs advisers have to spend on each student. Therefore, in order to manage the number of students, both the services and the teaching and learning techniques have become less personalised and more typical-standard for all students, regardless of individual needs and difficulties. This “*typification*” (Berger & Luckmann, 1991 [1966]) of the services, due to bureaucratisation resulted in missing the individual within the whole.

Even though the majority of the students expressed a general satisfaction with the services they receive from the institutions, there were some complaints about the

DSUs and other members of staff. The students' complaints can be seen as related to the bureaucratisation of the disability services. One complaint (I<sub>8</sub>, M, 19, OUa, mDysg&smem) was against the stereotypical, standardised treatment and the perception that all students with learning difficulties are the same, therefore the non-disabled people have to treat them in a certain way. Other problems which were mentioned by students were related to the long time of waiting for sorting out the support they could have access to, or the waiting time for assessment of their needs. Clearly, this is related to the increased number of students with disabilities who enter Higher Education, which increases the workload of the DSUs. The last complaint in relation to staff from the DSUs was a case of violation of the confidentiality that should exist between the students and the DSUs advisers. The student made it clear that out of fear for the stigma and the impression that others would have once they knew about her difficulties, she did not want anyone else, except for the DSU adviser to know about her difficulties. However, the adviser considered it appropriate to inform the department, which is against the confidentiality that they promise to students. Maybe the standardised treatment for such cases overpowered the individual needs and requirements of the student. Also there is the possibility that since the law says that once an employee of the institutions knows about the disability or if it is in the students' UCAS form, then it is public record and it is considered that everyone who has to know about it within the institution knows.

In other cases, students mentioned that they have to be quite proactive in order to get the support they need from some lecturers. Even though the DSUs inform the lecturers about the students who have learning difficulties, it is better, as students said to be proactive and go themselves and introduce themselves to lecturers in order to "*put a face to the name*" (I<sub>5</sub>, F, 21, OUa, Dysp). Once more, the need for personalised treatment is emphasised by students. The lecturers have to see the person that needs help instead of just a name on a list or a group of disabled students who need extra help. However, it is not always easy for students with learning difficulties to be proactive. In some conditions, like Asperger's syndrome, this is one of the main concerns and if the student has to be proactive in order to get the help he/she needs, then this is going to be a big problem for them. Lecturers from Durham University argued that usually they are informed from the DDRs about the students who need additional support and the kind of adjustments that have to be made for those

students. However, it is different to have a personal contact with the students who need their help than just have a list with names that is not so personal.

Related to the bureaucratisation of the services, the changing character of Higher Education due to the turn to marketisation is the tension, which was concluded from the findings of this research, between marketisation and the promotion of democratic knowledge. As was discussed in the literature, one of the aims of education is to teach democracy to students in order to use this knowledge in the wider society and in their everyday activities with other members of society. However, the change of Education's character towards a more market-oriented system, where students learn to compete for access to education and services, while institutions compete for students-clients and higher place in evaluation scores, does not promote democracy any more, rather it teaches students market behaviour (Brown, Halsey, et al., 1997; Hickman, 1998; Hickman & Alexander, 1998; Fott, 1998)

Related to the last two tensions are the issues of inclusive education and reasonable adjustments, which were both discussed and analysed not only through the literature but also through the interviews with students and members of staff. The research concluded that even though the law calls for reasonable adjustments in order to accommodate the needs of students with disabilities in Higher Education, at the same time it sets some factors that have to be taken into consideration by the institutions, in order for an adjustment to be reasonable. If any of these factors is not met, then the institutions can avoid the adjustments, without that action being considered unlawful and discriminatory (Riddell and Weedon, 2006). Having in mind that one of the factors is to “*maintain academic and other prescribed standards*” (Riddell and Weedon, 2006, p: 59) it is easily assumed that changes in teaching and learning techniques can be made difficult, as academics still argue that providing for students with learning difficulties is against the standards of Higher Education. Therefore, there is the problem of defining what each university and each tutor means by reasonable adjustments, especially regarding the teaching process and techniques that are used. The data from the interviews with the lecturers and the College Officers from Durham University showed that there are cases where each department or college defines slightly different whether an adjustment is reasonable or not. In these cases, the official policy of Durham University (as it was expressed by the Director of DSU and the disability officer) is that the departments have to discuss the adjustments

with the student, in order to find and provide an alternative form of support or adjustment.

An extension of the law's requirement for making reasonable adjustments, for students with disabilities, is the idea of an all-inclusive educational environment, where the adjustments to meet the students' need will have already been taken care of as a standard procedure, and not only in cases where students need those adjustments. The idea of an inclusive education is not about making adjustments in order to include the students who have been discriminated against by the existing policies and practices. It is rather about changing the existing policies and transforming the social structures and institutional arrangements, in such a way that it will include these students (Barton, 1999). Making reasonable adjustments for students with learning difficulties or for disabled students in general might be considered as a step towards inclusive education, however, at the same time, it perpetuates discrimination. An inclusive education means that everything will be in place for all students regardless of their abilities and disabilities, and there will be no need for more adjustments, because the adjustments mean that there is the need to distinguish or to provide special treatment to the students who need these adjustments from other students. Therefore, the policy of reasonable adjustments it might try to level the field for students with disabilities, but actually put them in the category of those who need adjustments and special treatment.

The inclusive educational system was discussed with the Directors, and even though, all of them mentioned that they believe that an all-inclusive education is something that should happen, they do not believe that it is going to happen soon. An all-inclusive education system will mean that there will be no need for disability advisers to provide support for students, educational psychologists to assess and make the diagnosis of learning difficulties and other professionals whose job is to support and help the students with disabilities. However, all those professionals, advisers, supporters etc who now work because there are students in need of support, are dependants of the students and they are part of our society. If we could achieve an all-inclusive educational environment then what would happen to all these people? Furthermore, an all inclusive education, which will have everything in place in advance for students with disabilities, regardless of their needs, could also mean that the individual needs of students may not be met, or are lost in the wholeness of the

inclusive educational environment. At the moment, some of the adjustments that are made for students with learning difficulties, like giving them more time during exams, or having them take the exams in a different room from the rest of the class, could be considered discriminatory. Students with learning difficulties who have been isolated and singled out by the other students, feel bigger stigma (Ho, 2004). However, the inclusive education, which would eliminate the discrimination and protect students from standing out from the crowd, may also lead to standardised techniques, which would be the same for every student, with or without disabilities, without paying much attention to individual needs, which may not be met by the inclusive educational system.

However, the idea of an inclusive education is not something that you can wish for and will automatically happen. Barriers, whether physical, social, economic or even attitudinal, have to be challenged and removed both from within schools and Higher Education Institutions, but also from the wider society (outside of the educational institutions) in general, in order to see the benefits to the whole of the society (Barton, 1996, 1998 [a, b], 2002).

As Tregaskis (2004) argues, in order to challenge the exclusion of disabled people from the society, it is necessary to act both at the individual and at the professional level. As individuals, we have to learn how to act and to take into account the needs of others; while the professionals (policy makers, legislators etc) have to make sure that new changes will be introduced in order to include the needs of disabled people. It may seem that the whole society has to change in order to achieve the inclusion of disabled people, and this may not be very realistic and especially not something that can be done immediately; but small changes can make a big difference. Starting from the schools and the universities, not only disabled people will have to learn to demand and know their rights but also non-disabled people will have to learn how to act and what they can do to challenge the exclusion of disabled people in the society (Tregaskis, 2004).

However, the attitudinal barriers, which refer to attitudes and beliefs that the non-disabled people hold about those with disabilities, cannot be as easily changed as physical barriers. As the Directors pointed out, they still face quite a few difficulties, when it comes to persuading some members of staff about the new adjustments and changes they have to make to accommodate students with disabilities. Among the

problems, as the Directors of the DSUs explained, is that they have some members of staff (the so-called “*old school*” lecturers), who still argue about the existence of dyslexia or learning difficulties. Generally, things seem to have got better after the new DDA but still their role is to manage the tension between students with learning difficulties and institutions. There are several possible factors, which may lead to the above problems, among which is the lack of understanding and acceptance of the unseen disabilities. People with learning difficulties after diagnosis end up with an invisible disability, which on one hand, makes it easier for them to hide it from others and avoid the stigma, on the other hand, it is more difficult to prove it when they need help and support. It is easier for a lecturer to empathise with the students with visible disabilities, compared to the learning difficulties, which are unseen and unless the student identifies him/herself or the lecturer is informed about the difficulties that the students have, then they cannot offer help and support. At the same time, there is the issue of uneasiness and fear (Goffman (1990 [1963]) around people with unknown, or unseen difficulties, therefore, lecturers may lack the understanding about what to do and how to act around students with unseen difficulties.

The disclosure of learning difficulties and the management of the information about students’ difficulties were also discussed with both students and members of staff. The research, revealed a variety of opinions that were expressed during the interviews with the students. Some students seemed more open about their difficulties, while others did not consider their disability quite severe enough in order to mention it to others. Interestingly, those with mild forms of learning difficulties, like for example mild dyslexia, did not consider it important to mention that they have learning difficulties, even though later they visited the DSUs and make use of some of the facilities and support for students with learning difficulties. The “*hierarchy of the impairments*” (Deal, 2003) and the commonality of the difficulties played a key role in disclosing the difficulties of students. The students with the more common difficulties were more open about them and had no problem informing lecturers and other classmates, about their difficulties.

However, the issue of the disclosure of the disability for students with learning difficulties is not merely upon the decision to reveal it to lecturers and classmates. An important aspect of the disclosure, as it was with the diagnosis, is that it allows access to the services and support these students need. Unless students decide to be

diagnosed and hence given a label of learning difficulties, they cannot access the support they need. Similarly, if the students decide to hide their difficulties from the university and the lecturers, then they lose the right to access all the support they can get from the institution. Therefore, even though the disclosure of the difficulties may seem like a choice, in practice it is a more complicated issue. In addition, the Directors as well as the members of staff from Durham University mentioned that students are concerned whether they have to disclose their difficulties when they leave the university and try to find employment. Lecturers wonder whether they have to mention the learning difficulties when they are asked to write a reference for a student. The level of public awareness about disabilities is important here, as arguably within the Higher Education Institutions, the students have the Directors of DSUs, who in a way protect the students against discrimination. However, the level of sensitivity and awareness of the potential employers is another matter. There is always the law that protects the disabled people against discrimination both in the educational and the work place environment, but the education environment is more prepared to accommodate the needs of students with disabilities. The label of learning difficulties could affect the employer's decision about the potential employee and the stigma that this label carries is a real concern for both students and members of staff. Therefore, the question of disclosure of disability is not easy to answer, without taking into consideration both the positive and the negative effects that this action may have.

Consequently, the correct management of student information by institutions, based on the research findings, is an important issue for both students and Directors of DSUs. Of great importance is the correct management of students' identities, in order to both give them the support they need, while at the same time protecting them from discrimination. Among the differences of learning difficulties, compared to other disabilities, is that learning difficulties are not visible to others. The lack of a visible sign, which will easily identify the person with learning difficulties, on one hand, can be seen as an advantage as it does not automatically stigmatise the person, on the other hand, it is also difficult to allow access to that person to necessary services and support. Therefore, there is the tension in the role of Directors of DSUs of making visible the invisible students with learning difficulties, without stigmatising them and discriminating against them. Only one of the four participant universities uses two

different ways to manage student information. The first system uses a yellow sticker to separate the essays and exams of students with learning difficulties and the other is more of a learning aid for dyslexic students. The research concluded that both systems, while they aim to help students with learning difficulties, they also had some negative consequences for students. The first one does not protect students' identities from others who do not need to know about it, as it gives a visible sign of an invisible disability, without effectively protecting their identities from those who do not need to know about the students' identities. At the same time, the course for dyslexic students was taught in a way that was not considered appropriate by some students who attended it, and probably for that reason it was revised in the year of the research, in order to make it more appropriate for students with learning difficulties.

Despite the fact that the collected data could not be considered as representative of the whole students' with learning difficulties population in Higher Education, the findings from the project could add to the existing literature regarding provision for disabled students in Higher Education. Following the research findings, it would be interesting to conduct a further research, in order to investigate some of the issues, which became apparent in more detail. A future research, which will involve more institutions in UK and will include more students with learning difficulties, will allow for more generalised results, which could be considered more representative of the students' population. In addition, the unequal distribution of students among the four institutions, which resulting in focusing at Durham University mainly, once resolved could allow a research, which will compare the four institutions on the ground that two are Pre-1992 institutions while the other two are new ones [Post-1992]. A new research that finds and discusses similarities or differences within the framework of the binary system of institutions, would probably identifies very interesting issues. A similar study can be conducted but it should include more regions of England, in order to have a better sample of Higher Education Institutions.

The main limitation of the research was the limited sample, which was the result of problems with gaining access to students with learning difficulties. The initial way of contacting them through the Directors of DSUs proved problematic, due to issues of confidentiality and even in one case due to the unwillingness of the university to trouble the students by participating in another study. The alternative option for contacting them which was chosen, through leaflets that I left at the DSU help desk,

did not prove very helpful, as the interviews with the students showed that students do not visit the DSUs often. Therefore, a good solution for gaining access to students, as one of the Directors of one of the DSUs suggested, is for the institutions to create a list with the e-mails of students who have already been asked, during enrolment, if they wish to participate in future researches and they have agreed to do so.

## 10 Attachment A

Dear Sir/Madame,

my name is Polyxeni Vouroutzidou. I am a postgraduate student from the University of Durham and I am doing a PhD in Sociology of learning disabilities.

My project hopes to focus on the provision and the services, which are available from four well established UK institutions (University of Durham, University of Newcastle upon Tyne, University of Sunderland and Northumbria University), for students with learning disabilities/difficulties. It will be a comparative project between these four Universities, which will explore the extent of support and the effectiveness of the provision provided from institutions to students with learning disabilities.

Students' experiences from their interactions with the Disability Units in each university and the views of members of staff who work in the Disability Units will be explored and analysed in order to see the issue of provision for disabled students from each possible angle.

For this project, the participation of students with learning disabilities who study either full or part-time, at any level and any discipline, and are either home or foreign students, and also the help from members of staff who work within the Disability Units or deal with these students, are essential. Therefore, it is necessary the number of students and members of staff who will participate to be as great as possible.

For these reasons, I would like to ask for your help and support and your co-operation with me for the completion of this research.

I would be grateful if an appointment could be arranged for me to come and talk to you about the research that I am undertaking. Of course, I will be prepared to feed back the findings of the research in order to contribute to the enhancement of the important services that you provide, if you want.

If there is anything about the research that you would like to ask, please do not hesitate to ask me.

Thank you very much for your help and cooperation,

Polyxeni Vouroutzidou  
University of Durham  
32 Old Elvet,  
Durham, DH1 3HN

## 11 Attachment B

Dear Student

I am Xenia Vouroutzidou, a PhD student from University of Durham and I am doing research on students with learning difficulties who are studying at your University as well as other universities in the area. The research aims to explore the experiences of students in relation to the provision, the available services and the support you receive from your university regarding your abilities and difficulties.

If you would like to meet with me to discuss your experiences, I will be happy to arrange it with you. The information given will be confidential and the meeting will be informal, however the interview will be tape recorded so that I can ensure I am not missing any information and I will arrange for the interviews to take place at your university.

If you would like further information or have any questions about my project, please contact me by email or on one of the telephone numbers listed below.

I would like to thank you in advance for any help you are willing to give me.

Regards,

Xenia

## 12 Appendix 1

Table 3 Background information for participant students

No	Gender M / F	Age	New University (NU) / Old University (OU)	Full/Part- time studies	Under/Post graduate	School/Department	Year of study	Disability
1	M	22	OUa	F/T	Undergraduate	Engineering	2 <sup>nd</sup>	Dyslexia
2	F	19	OUa	F/T	Undergraduate	Classics & Ancient History	2 <sup>nd</sup>	Agoraphobia
3	F	28	OUa	F/T	Postgraduate	Anthropology	3 <sup>rd</sup>	Dyslexia
4	M	18	OUa	F/T	Undergraduate	Natural Sciences	1 <sup>st</sup>	Dysgraphia
5	F	21	OUa	F/T	Undergraduate	Politics & Economics	2 <sup>nd</sup>	Dyspraxia
6	M	33	OUa	F/T	Undergraduate	Natural Sciences	3 <sup>rd</sup>	Dyslexia & OCD
7	M	19	OUb	F/T	Undergraduate	Electrical & Electronic Engineering	1 <sup>st</sup>	Dyslexia
8	F	19	OUa	F/T	Undergraduate	Sociology	3 <sup>rd</sup>	Mild dyslexia & short memory problems
9	F	19	OUa	F/T	Undergraduate	Sociology	1 <sup>st</sup>	Dyslexia
10	M	20	OUa	F/T	Undergraduate	Biology	3 <sup>rd</sup>	Mild dyslexia

<b>11</b>	M	40	NUb	P/T	Undergraduate	History of Art	5 <sup>th</sup>	Aspergers Syndrome
<b>12</b>	F	20	OUa	F/T	Undergraduate	Sociology	3 <sup>rd</sup>	Mild dyslexia
<b>13</b>	F	20	OUa	F/T	Undergraduate	Sociology	3 <sup>rd</sup>	Dyspraxia & Dyscalculia
<b>14</b>	F	21	NUa	F/T	Undergraduate	History	2 <sup>nd</sup>	Dyslexia
<b>15</b>	M	20	NUa	F/T	Undergraduate	Engineering	2 <sup>nd</sup>	Dyslexia
<b>16</b>	F	26	OUa	F/T	Postgraduate	Sociology	1 <sup>st</sup>	Dyslexia & dyspraxia
<b>17</b>	F	22	OUa	P/T	Undergraduate	Biological & Biomedical Science	3 <sup>rd</sup>	Dyslexia & Dyscalculia
<b>18</b>	M	20	NUa	F/T	Undergraduate	Art Design, Media & Culture	3 <sup>rd</sup>	Severe Dyslexia, Dyspraxia & Aspergers Syndrome

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