DYSLEXIA:
THE EXPERIENCES OF UNIVERSITY STUDENTS WITH DYSLEXIA

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<u>ABSTRACT</u>

This thesis is focused upon and examines the experiences of students with dyslexia in higher education. At the time of the research project started not much was known about the experiences of higher education students with dyslexia. An insight into their lives and experiences with a further overview of their past is evaluated. The participants of this study were undergraduate and postgraduate students studying for a degree in Higher Education and were assessed as dyslexic. The sample consisted of students that were studying in three universities in the city that the research took place. In order for the data to be collected interviews were used, as it would be very difficult to describe experiences and feelings with numbers. The words of the participants were used to support the categories and findings of the study. The students of these particular universities were overall satisfied with the provision and support they were receiving from their institutions although further investigation needs to be done on the attitudes and perceptions of the lecturers with regards to dyslexia.

Στον πατέρα μου

Νικόλαο Μιχαήλ

To my father

Nicolao Michail

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Abbreviations

DDA	Disability Discrimination Act
DfES	Department for Education and Skills
DSA	Disabled Students Allowance
HE	Higher Education
HEI	Higher Education Institution
HESA	Higher Education Statistics Agency
LD	Learning Disabilities/Difficulties
LEA	Local Education Authority
QAA	Quality and Assurance Agency
SENDA	Special Education Needs and Disability Act
SpLD	Specific Learning Difficulties
UCAS	Universities and Colleges Admissions Service

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CHAPTER 1

INTRODUCTION

1.1 Background

It has been more than one hundred years since Dr Kussmaul (1878 cited in Selikowitz, 1998; Beaton, 2004) mentioned the case of an intelligent man who had difficulties in learning to read. He called the problem *word blindness* (wortblindheit).

Furthermore in 1896, Pringle Morgan (cited in Beaton, 2005) introduced in the academic and medical world the first case of what we call nowadays developmental dyslexia or Specific Learning Difficulty (SpLD). It was the case of 14-year-old Percy who, although he was bright and intelligent, could not read even though he had received extensive and persistent training. At the time he used the term 'congenital world-blindness' (Beaton, 2004:3) to describe his difficulty. Since then a diversity of definitions and different points of views have been expressed in order to describe the 'phenomenon' of dyslexia due to the peculiarity of its indications. The term dyslexia has been accredited to Professor Rudolf Berlin (Aaron,Joshi,Gooden,Bentum, 2008). The former is more accepted and used by people with dyslexia and their families (European Dyslexia Association/EDA, 2009), whereas professionals prefer to employ the SpLD term (Riddick, 1996).

The word dyslexia derives from the Greek prefix *'dys'* and the root-word *'lexis'*. The former means 'difficulty' whereas the latter means 'word or language' (Ott, 1997; Hornsby, 1992). It can be best translated as 'difficulty with words'. As mentioned before

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there is not a universal definition for dyslexia. Depending on the professionals' field of study over the years there have been various definitions attempting to identify what dyslexia is.

Dyslexia is mainly associated with language problems such as reading, writing and spelling although people with dyslexia might also experience difficulties with vision, memory and/or orientation.

Several studies have shown that dyslexia, when undiagnosed, can cause a lot of frustration and anxiety in the individuals involved (Riddick, 1996; Edwards, 1994). Dyslexia is a 'hidden' disability (Riddick, 1996) as there are no obvious external signs for people to recognise. It is not like some other disabilities, as for example Down syndrome, or cerebral palsy that people can recognize from the moment they see them. People can get confused and assume different reasons for the children's poor performance in school. That is why, when not diagnosed characterisations like 'stupid', 'thick', and 'lazy' are commonly used to describe students with dyslexia as people, who are not aware about dyslexia, cannot find any other explanation for them not doing well at school. Lack of assessment may result in low self-esteem compared to non-dyslexic students (Miles, 1996; Humphrey, 2002) and lack of appropriate help and support can have long-term effects for people with dyslexia when reaching adulthood (Morgan and Klein, 2000).

1.2 Research Focus

This research study is focused on the experiences of students with dyslexia in higher education. When this project started (1998) not much was published about the experiences of higher education students with dyslexia. There was information available about the

admission of disabled people in higher education and the Disability Discrimination Education Act (DDA) of 1995 placed responsibilities for Further and Higher Education (FE/HE) institutions to publish disability statements. It stated that FE and HE institutions may also include conditions relating to the provision made or to be made with respect to disabled students (DDA, 1995, Part IV, par 30).

 There was limited literature providing information about the voices and experiences of higher education students with dyslexia (see Riddick, Farmer and Sterling, 1997). This study aims to explore in depth and from their own perspectives, the experiences of a small number of students with dyslexia and give them the opportunity to share their life experiences. The research took place in the West Midlands region and the counselling and support services of three higher education institutions were contacted in order to locate students willing to participate in this study. All three institutions were in the same city. This study took place between 1999-2001 and its aim is to try to portray a wider picture of what was happening at that time for university students with dyslexia. By the time the data collection finished the Special Education Needs and Disability Act (SENDA, 2001) was published making unlawful for the institutions to discriminate against a disabled person. SENDA (2001) amended Part IV of the 1995 Disability Discrimination Act and it came into force in September 2002. Now, the Higher Education Institutions (HEIs) by law have to make reasonable adjustments to accommodate disabled people and their needs. They have to be proactive and be prepared for any new students with disabilities that will enrol on any of the programmes they offer.

Depending on the severity of dyslexia students may experience various levels of difficulties that can affect, in some cases, every single aspect of their lives. But how are

these students coping when they decide to go to university? It is a totally new environment for them, especially for those who decide to study away from home, as they no longer have any support mechanisms from family and friends. Entry to Higher Education for young people is often associated with a process of decreasing dependence on the family and increasing personal independence (Parker, 1999: 493). However, the personal independence for students with dyslexia comes with its toll as they have to cope with living in a new environment, the course workload, deadlines, making new friends and social circles and dealing with their finances on their own without any support from family members. They are challenged in both their intellectual and social lives (Farmer, Riddick and Sterling, 2002).

1.3 The Research Questions

Studying for a degree is not a forced decision for any person. The students that took part willingly went to university and they were determined to accomplish their goal. Nevertheless, in order to function effectively in higher education and later in their professional lives the students should be able to:

- Organize themselves personally
- Cope with independent learning and working
- Manage their time effectively
- Read and comprehend complex material accurately and fluently
- Find relevant information from a variety of sources
- Listen, understand and take notes quickly and legibly
- Express ideas verbally and in writing
- Type quickly
- Demonstrate their knowledge and understanding in exams and assessment settings. (McLoughlin, Leather, Stringer, 2002, p.148).

This research project investigates the educational experiences of students with dyslexia currently in Higher Education Institutions (HEI) in order to give voice to that experience. This gave rise to the following research question:

What are the experiences of students with dyslexia currently (1999-2001) in HEIs?

In order to have a better and more holistic picture this research will establish the participants' experiences from primary to secondary and finally in higher education by semi structured interviews. This will allow them the opportunity to express their thoughts and beliefs regarding any difficulties, if any, they have experienced while in education; how they have coped and what kind of support, if any, was available to them. Also, part of the interviews will explore any effects that dyslexia might have had on their self-esteem and social lives.

As mentioned before, semi-structured interviews were used to collect the data. While looking for the best instrument for the data collection the fact that people with dyslexia experience difficulties with reading, writing and spelling (Raymond, 1997; Reid, 1996, 2005) was taken into consideration. Also, another reason for choosing interviews was accounts of people with dyslexia that found very hard and frustrating to express their thoughts in writing (Michail, 1998).

Over the last ten years there has been a marked increase in the numbers of students with dyslexia entering HEIs. Students with dyslexia since 2000/1 form the biggest group of people with disabilities (Appendix). In 2000/1 approximately 32% of disabled Higher Education (HE) students were dyslexic. Until 1999/0 the 'unseen disability' group had the

highest representation in HE (approximately 37%). In 2000/1 the percentage of students with an unseen disability reduced to approximately 30% (HESA, 2005). Reasons for this increase are probably the fact that more students are identified earlier in their lives, receiving suitable adjustments at school and they include their disability in the Universities and Colleges Admissions Service (UCAS) form. Besides, another reason might be the increased incentives offered to students to disclose their impairment (Tinklin, Riddell and Wilson, 2001). Students with dyslexia can apply and get various equipment (computer, scanner, voice recognition programmes) to help them complete their course.

This study will try to investigate and portray a picture of what it was to be a student with dyslexia in higher education at the time this research project took place. It is taken under consideration that due to the small number of students that participated in the project there might be some limitations of conclusions.

1.4 Outline of the study

The thesis consists of six chapters and this is the first. Chapter 2 looks at the literature for a better understanding of the term dyslexia in conjunction with the issues of its definition and labelling. Moreover, it discusses the importance of early identification which is vital in the case of dyslexia as research has shown that adults who were assessed late at life feel resentful for going through life believing they were unintelligent and for losing opportunities for a better education and a brighter future (Morgan and Klein, 2000).

Moreover, chapter 3 deals with the theoretical perspectives that people have adopted over the years in an attempt to explain dyslexia and its causes. It discusses three predominant

theories that are focused on the causal effects of dyslexia: the phonological, the cerebellar and the magnocellular. It also includes the different models of the disability movement that have been developed over the years. The chapter shows that the debate about dyslexia is endless. Is it a condition or is it a disability constructed by our own society? Where a culture is not dependent on the written word dyslexia would not be a 'condition' identified within that culture. Unfortunately, societies and cultures over the years have developed stereotypes about what a typically developed person should do or not. Everyone who does not satisfy the set criteria might be considered 'disabled' or 'abnormal'. People with dyslexia are misunderstood because there are no obvious signs to make it recognisable. It is a hidden disability and only a trained or aware person can notice the difficulties and provide the much-needed help that a dyslexic person craves for. Because of that, there are people with dyslexia who have to endure negative experiences from teachers, parents or friends who from one hand can recognise their potential but on the other hand cannot explain their academic failing .

In addition, the following chapter (4) is focused on the social and emotional difficulties that dyslexia might cause to the individuals. There is no doubt that there are people with dyslexia that go through life without any difficulties and they can cope with their dyslexia. On the other hand, it is unknown the number of undiagnosed individuals who live their lives believing that they are stupid due to certain people who were quick to attach a label to them without considering the devastating effects this might have in their lives. Unanimously, after they are assessed, dyslexic students feel relieved and excited. The label of dyslexia has finally given them the answer to their problems (Riddick, 1996). Academic failure can result in low self-esteem. Research has shown that people with dyslexia have different learning styles compared to non-dyslexic people (Mortimore, 2003). If they are

taught according to their preferred learning style their academic performance and consequently their self-esteem will rise.

Moreover, chapter 5 pays attention to the higher education situation with regard to dyslexia. Since 2001 (SENDA, 2001) academic institutions have to make reasonable adjustments to accommodate students with disabilities and provide suitable support. The Government targets are to widen the participation of students in HE that come from less privileged groups, including students with dyslexia. Certain incentives are offered for both the students and institutions in order to support this. As the number of students increases every year their institutions need to make provisions to assist these individuals to complete their courses successfully. Many institutions have done so by offering help through their learning support services (Singleton report, 1999). Students with dyslexia once formally assessed can apply for the Disabled Students' Allowance (DSA) and with this buy equipment, such as computers, in order to facilitate their studies.

Furthermore, the sixth chapter deals with the questions of research method that arose in this study. Qualitative research was thought the most appropriate method to be used as the participants were asked to share some of their life experiences. These could have not been described with numbers. This project wanted to give the students the chance to talk about their lives and have their voices heard. Semi-structured interviews were used as an instrument to collect the data and the participants were HE students who were officially assessed at some point in their lives and were studying in three universities in the West Midlands area. Their ages varied from 18-38.

The chapters that follow (7-11) describe the outcomes of this research project. Chapter 7 informs us about the participants' profiles and their personal perceptions and feelings about having dyslexia. The majority of the students were quite pleased after their assessment. They consider dyslexia a positive rather than a negative thing in their lives as it has given them the option to be more creative, more determined. Overall, the participants were happy to disclose their dyslexia.

The eighth chapter is focused on the relationships of the participants with their family and friends in connection to dyslexia. Most of the students had family members who suspected they had dyslexia. Their parents were more understanding after they were assessed and tried to help them as much as they could. Also the participants sometimes had to rely on friends to help them with their difficulties.

In addition, the interviewees' difficulties in primary and secondary education as well as the support they received during that time are described in chapter 9. The majority of the participants mention having more difficulties when they were in secondary school. They mentioned difficulties in spelling, reading and during their GCSE and A Level exams. Some of the participants were dissuaded by their teachers from pursuing a place in an HE institution.

Furthermore, the experiences of these students while they were studying in HE are portrayed in chapter 10. Reading and writing were the main problems during their studies. When they were in university the students relied on their computers for correcting their grammar and spelling mistakes as well on their friends and family to proof read their work. Some of the students had support from the learning support services too.

Besides, chapter 11 looks at the current predominant theories in the dyslexia field and different models of disability and compares them with the participants' answers. It also provides an overview of the participants' attitudes towards dyslexia. The study took into consideration Pollak's (2005) and Kurnoff's (2000) work. The students were divided in the following categories: 'students' (connecting dyslexia with intelligence and academic work'; 'patients' (hesitant to disclosure their dyslexia, believe it is their own problem); 'hemispherists' (regard dyslexia as a gift and consider it as a brain difference) and 'pragmatists' (although they employ the support from the learning support services they try to be independent and use their own coping strategies). When the participants were younger (primary and secondary school) the majority of them fell into the 'students' group. After their assessment and as they grew older and started to understand their dyslexia, the participants' views and attitudes regarding dyslexia changed and 'evolved' into 'hemispherists', 'pragmatists' and only one fell into the 'patients' category. Furthermore, the majority of the students that took part in this study believe that dyslexia is part of their personality and identity and they do not consider themselves as disabled.

In the final chapter, chapter 12 includes a more detailed summary of the chapters and presentation of the conclusions that derived from this research project.

1.5 My personal journey to study dyslexia

Ever since I was in the university studying for my first degree the prospect of working with children with special needs seemed very appealing to me. Unfortunately, I did not have the chance to do it until I came to the UK and started my Masters degree. During that time I was placed in a special needs school as part of my course in order to gain more experience in working with children with special needs. The level of the children's disability varied from Mild Learning Difficulties (MLD) to Profound and Multiple Learning Difficulties (PMLD). Although it was a priceless experience, at the time I felt that working with children with severe learning difficulties was not something that I wanted to pursue.

When I arrived in the UK I was aware about dyslexia but had limited knowledge of the subject. I took dyslexia as a module as part of my master degree and the more I studied about it the more interesting and appealing it became. I was especially interested in the emotional and psychological effects that dyslexia might have in people's lives: a hidden disability that could not be treated with drugs. People with dyslexia when having appropriate support are able to ameliorate their lives and improve their skills. People with no learning difficulties sometimes take things like reading and writing for granted and sometimes forget how difficult it can be for others to master these skills. Our society emphasizes the need to get qualifications and specialize in a subject in order to get a better life and career. Children and adults with dyslexia face the possibility that they slip through the net without somebody recognising their particularities and strengths and misinterpret them and lose the chance to have the same opportunities as everybody else in life.

From a smaller research project I did for my master degree (Michail, 1998) I realised that adults with dyslexia, especially the ones who have been diagnosed at a late stage in their life, have been struggling throughout the system all their lives. The individuals I spoke to at the time felt that they had lost a lot of opportunities for a better future, better work, and better life conditions. They believed that if dyslexia was picked up when they were in school and they had support there was no doubt that they would have done better and they would have achieved more in their lives.

One of the people I interviewed at the time was a first year university student that I met through personal contacts. She was not aware about the learning support services in her university and she did not know that she could have asked for support for her essays and stress problems caused by her dyslexia. During the interview she was surprised that although she was in the university for almost a year no one had informed her about the help she was entitled to. I kept in touch with her through friends and every time we talked about her dyslexia she was always telling me how lucky she was having met me and how better things were for her in the university being able to have support from the counselling and learning support services. Probably she was one of the persons that made me start this research. I thought that even if I could help at least one person through this research project it would worth the time and effort.

One of the reasons that I decided that the subjects in this present project would be university students was this already existing interest in dyslexia and adults and the life opportunities that these people might have missed due to late assessment of dyslexia. I believed that with the help of the counselling and learning support services I would be able to find enough people that were willing to talk to me. Besides, I wanted to see how people

with dyslexia cope in an environment like the university and whether the facilities that were provided were enough, or more things needed to be done to improve their lives and making university life more manageable. When this research started there seemed to be limited bibliography about adults with dyslexia. Most of the studies were concentrated on children and their needs. I thought that adults had the right to be heard too.

I need to mention that although dyslexia is recognized 'disability', especially in the beginning of this project, I came across people that were not aware of the term dyslexia and I had to explain to them what dyslexia is. On the other hand, I have met quite a variety of people from different backgrounds that had dyslexia and were really pleased to know that I was doing my project on dyslexia. Their first question to me was 'Are you dyslexic?' When I replied to them that I was not their reaction was very positive and rewarding for me personally. They thought it was good for people to try and improve dyslexic people's lives and help them have a better education than the one they have had because dyslexia was picked up quite late at school or it was picked up when they were already in a working environment.

Talking to all these people who were willing to give me their time and shared their experiences with me is something that I will hold and value for all my life. I have learnt that we should not take anything for granted and that we should not judge a book by its cover. Sometime things are not always what they seem to be. Behind every single person there is a story and by listening to them we can learn valuable lessons about what they go through and maybe we can learn to be more patient and forgiving towards other people.

Over the years perceptions about dyslexia has changed. Rather than considering dyslexia as disability professionals started considering it as a difference (MacKay, 2006; Reid, 2002). As MacKay (2006: 5) says: 'A learning difficulty implies that there is something 'wrong' with the learner, leading to identifing weaknesses rather than celebrating strengths'. People with dyslexia have also strengths not only weaknesses (Davies, 2000). Unfortunately some people tend to focus more on the negative signs of dyslexia rather that the positive ones. People with dyslexia can be creative and successful (Lawrence, 2009). They just need to be taught in a different way (Clarke, 2000). Society has placed people with literacy difficulties in a disadvantaged place (Reid, 2002). There is always an alternative way of thinking, which is to work from the assumption that individual differences are the norm and to identify different ways of reaching the same end point (Grand, n.d: 1). Sherman (2002 cited in Carden, 2007: 7) states that '*while dyslexia is brain-based and life-long, it is amenable to educational intervention … The educational environment can translate a distinct learning difference into a profound learning disability or it can offset neural weaknesses and encourage latent strengths to blossom into competencies and talents'*. Society's beliefs cannot change in a split of a second. Awareness and appropriate training are the ways forward in order to be able to recognize the differences that people with dyslexia have and provide them the much needed help they need to overcome them.

Throughout the thesis the terms 'disability', 'difficulties', 'problems 'and 'condition' are being employed as they are commonly used and associated with dyslexia within the existed literature. Although their use points toward the medical model of disability rather than the social (see chapter 3) it is very thorny not to use them as there are limited alternatives.

1.6 Conclusion

Dyslexia is a disability that it is not obvious to the naked eye and because of that people with dyslexia have been wrongly misunderstood and judged. This research aims to give voice to the experiences of students with dyslexia and through that help to have a better understanding of the lives of people with dyslexia. In order to be able to help and support them their voices need to be heard.

The following chapter presents the debate around the definition of dyslexia and the importance of early identification. It also discusses the issue of labelling and its effects on the person that carries the label.

CHAPTER 2

DYSLEXIA: HISTORY, DEFINITION AND IDENTIFICATION

2.1 Introduction

In this chapter an attempt to portray some of the issues regarding dyslexia will follow. The chapter will begin by looking at the developments of ideas around dyslexia since the first case of dyslexia was recorded. In the process of this chapter we will look at the definitions, identification and the issue of terminology and labelling.

Over the years scientists have tried to define dyslexia. As mentioned before, the definitions vary and depend on the scientific backgrounds of the individual researchers and what they conceptualise as the underlying cause of dyslexia (Ott, 1997). Over the last decades more interest grew about dyslexia or Specific Leaning Disability (SpLD) and more researchers tried to find the causes and effects of it. More than 50 definitions can be found in the literature in an attempt to achieve the right one about dyslexia (Ott, 1997).

Defining any condition is quite important as it can help people to identify any individuals that experience it. Being assessed and identified with any condition can be a very emotional and social experience. Identification is quite closely linked with labelling as any positive assessment of any condition will, as a result, cause a label to be attached to the interested party. Labelling can have positive and negative effects for people. To start with, it gives them a reason for their condition and problems. It can give them the 'power' to ask for specialised help and support. On the other hand, labels can stigmatise people. Research

has shown that even among individuals with disabilities different labels are more accepted than others.

2.2 Defining dyslexia

Since the time the concept of dyslexia was first introduced in the academic and medical world a lot of definitions and different points of views have been expressed in order to describe the phenomenon of dyslexia which has quite a few characteristics. The plethora of the attributes makes the identification and assessment harder and also has caused scepticism for its existence (Elliott, 2008).

Chia (1992 quoted in Ng, 1996: 54) gives three reasons why people are unable to come out with a universally acceptable definition:

1. 'the failure to locate stable correlates of dyslexia,
2. the lack of clarity in the delineation of dyslexia, often resulting in a poor understanding of the relationship between the reading and language, and
3. Too many terms, including the term *dyslexia* as well, have been coined to describe this reading difficulty or disability resulting in an entanglement of synonyms'.

Lyon (1995) claims: 'Despite the significant role that a definition should play in the scientific and clinical understanding of dyslexia, the field has constructed numerous vague, ambiguous, and non-validated descriptions of the disorder' (p. 4). Hammil (1990 gives us 43 definitions (cited in Ott, 1997). The British Dyslexia Association (BDA, 2009a) throughout the years has published ten different definitions.

Another reason for the existence of all these definitions is that professionals employ different assessment procedures and instruments, and that they use different criteria in order to identify their sample. All of these differences can in part be traced back to the

variety of definitions of 'dyslexia' that the researchers have been using (Tonnessen, 1997).

Moreover, there are still major difficulties in giving descriptions, because dyslexia has so

many different aspects; it concerns so many disciplines, each of which has a contribution

to make (Miles, 1995). All that multi-dimension of dyslexia triggered Malatesha and

Dougan (1982) to propose their perspective on the definition debate. They believe that one

of the main reasons for this controversy is the fact that a lot of scientists have not accepted

the possibility that dyslexia is not a single isolated syndrome but a group of disorders. As

Hynd and Cohen (1983 cited in Tonnessen, 1995: 140) said: 'attempting to define dyslexia

can be one of the thorniest problems related to the study of this condition'.

Nowadays, the dispute among the professionals still continues. Rice and Brooks (2004)

cite twenty-eight different definitions of dyslexia written by scholars, institutions or

government bodies over the last forty years. Examining all these different definitions one

cannot but notice that the only element that they all tend to agree as a characteristic of

dyslexia is the reading accuracy deficit; followed by the cognitive impairment (fifteen),

age discrepancy (fourteen), IQ discrepancy (twelve) and spelling fluency accuracy (eleven)

(Table 1).

An analysis of dyslexia definitions

| | | | Behaviour specific to literacy | | | | | | | | |
		Age discrepant	IO discrepant	Reading Accuracy deficit	Reading fluency deficit	Spelling accuracy deficit	Writing deficit	Comprehension deficit	Non-specific behaviour	Cognitive impairment	Intrinsic	Lifelong
Advocates	BDA 1		•	•		•	•		•	•		
	BDA 2			•		•	•		•	•		
	BDA 3								•	•	•	
	BD		•	•				•				
Practitioners	DI		•	•		•	•		•			
	IDA	•	•	•		•	•				•	
	NJCLD	•		•		•	•	•	•	•	•	•
	Orton-Gillingham	•		•		•	•	•		•	•	
	BPS	•	•	•	•	•						
	CDHCN	•		•		•					•	
	Hornsby	•	•	•		•	•					
	Klein	•		•		•	•			•		
Scholars	Fletcher (2002)	•	•	•	•			•				
	Fisher (2002)		•	•							•	
	Grigorenko (2001)	•		•	•					•	•	
	Stein (2001)		•	•						•		
	Snowling (2000)			•					•			
	Snowling et al. (2000)	•	•	•						•		
	Raskind (2000)	•	•	•								
	Cossu (1999)			•								
	Stanovich (1999)			•						•		
	Frith (1999)			•		•	•		•		•	
	Padget (1996)	•		•		•	•	•		•		
	Nicolson (1996)	•		•								
	Stanovich (1996)			•						•	•	
	Badian (1994)			•	•					•	•	
	WFN (1968)	•	•	•						•		
Government	DfES (2002)			•								

Table 1 (Rice and Brooks, 2004: 147)

Sinclair (1995) argues that it is very crucial to have a definition and descriptions of the

problem in order to find the appropriate support and help to ameliorate the difficulties that

people with disabilities face. However, the more precise and accurate the definition and the description of the problem are, the easier it becomes to label children as dyslexic (Tonnessen, 1997) because inadequate definition leads to inappropriate classification (Muskat, 1996: 408). In addition to this, Stanovich (1992) noted that school personnel could use definitions for learning disabilities as a way to allocate school services in order to provide better support to low achieving students. In this way issues of definition become almost inexplicably engaged with issues of access to resources.

Before presenting any definition o*f* dyslexia it is essential to mention that this present study will deal with students that have developmental and not acquired dyslexia. Acquired dyslexia arises as a result of neurological damage, typically during a stroke or brain trauma. People who have acquired dyslexia lose the ability to read and write because of the injury they have had. It can obviously affect anyone at any stage in his/her life. Developmental dyslexia on the other hand connotes a failure in 'normal' development. Acquired dyslexia is a loss of normally developed skills. Developmental dyslexia is a failure in the original acquisition (Vinegrad, 1992: 20).

In the following paragraphs some of the definitions that have been expressed over the years will be analysed to demonstrate the difficulty involved in finding an agreed definition.

In 1968, the World Federation of Neurology (cited in Critchley and Critchley, 1978; Riddick, 1996; Fawcett and Nicolson, 1994) gave a definition of dyslexia that is still widely used:

'A disorder manifested by difficulty in learning to read despite conventional instruction, adequate intelligence, and sociocultural opportunity. It depends on fundamental cognitive disabilities which are frequently of constitutional origin'

Definitions like the above have been criticised a because of their exclusionary criteria (Ott, 1997). They say about what dyslexia is not rather than what it is. As Tonnessen (1997: 81) reports 'originally these groups were excluded on purely *methodological* grounds: one wanted to make sure that the condition being studied was not *caused* by impoverished environment or deficient intelligence'. However, researchers have argued that by excluding these factors the sample of the study would probably be biased as later research has shown that dyslexia occurs in all groups of children no matter their social strata, gender or geographical area (Rutter et al. 1974; Klasen (1972); Naidoo (in Herschel, 1978) all cited in Richardson, 1992: 389; Doyle, 1996; Heaton and Winterson, 1996). Furthermore, Catts (1989) argues that definitions using exclusionary criteria provide a very limited description of the characteristics present in the disorder and therefore the identification of children as dyslexic becomes even harder and more difficult. He points out that if people want to have a sufficient definition of dyslexia by using exclusionary definitions, it is important to add a list of the factors that are known to be present in the disorder. Prior (1996), from her point of view, suggests that sometimes parents and teachers prefer definitions using exclusionary criteria because deep inside them they wish that their child's problem could be only medical and so a medical explanation and cure would be found for it. Unfortunately, things are not as simple as there is no medical-type cure or standard prescription for dyslexia.

Discrepancy definitions are also being used in order to define dyslexia. Discrepancy definitions are based on observable or measurable characteristics of dyslexics. They are

not causal in nature; they do not imply anything about the causes of dyslexia. The discrepancy principle is based on the idea of underachievement; that is, a discrepancy between potential and actual achievement. The assumption is that the child's poor performance in reading and writing is compared with his age and level of intelligence (Riddick, 1996). In the 1970s and 1980s the assumption of the existence of important etiological, neurological and cognitive differences between high-IQ and low-IQ readers continued although there was no empirical evidence to confirm it (Stanovich, 1994). The majority of the definitions were concentrated on the discrepancy between reading and '*cognitive potential*' (Tonnessen, 1995: 143). That happened because it was assumed that poor readers with high aptitude (judged by IQ test performance) were cognitively different from poor readers of low aptitude (Stanovich, 1994). The discrepancy between intelligence quotient (IQ) and performance is widely used in definitions of learning disabilities in general. As Ng (1996) reports, measured IQ is taken as a fundamental construct for defining dyslexia.

On the other hand, there are a lot of people who have criticised discrepancy definitions. Siegel (1992: 619) reports that research has shown that certain cognitive processes of children with learning disabilities with lower IQ scores may not differ from those of children with higher IQ scores. Furthermore, as Riddick (1996: 2) recounts: 'obvious discrepancies between reading and spelling scores tend to diminish as children get older so by adolescence this approach will exclude many children who do have the specific cognitive impairments underlying dyslexia'.

Catts (1989: 53) argues that it is assumed when employing these formulas that IQ and reading achievement are strongly correlated. As a consequence, large discrepancies in

these scores are taken as indicators of dyslexia. In order to show his doubts whether the latter should be taken into account, he presents the findings of Stanovich, Cunningham, and Feeman (1984). In a review of the data from a large number of investigations, they found that the median correlation between IQ and reading ability in grades 1-3 was .45 and in grades 4-8 it was .60. These findings indicate that a large proportion of the variance in reading performance, especially in the early grades, is not accounted for in the general intellectual abilities as measured by standard IQ tests.

Furthermore, another matter that should be taken under consideration when it comes to discrepancy definition is the assessment instruments that are used. Rudel (1985 cited in Catts, 1989: 54) found big differences in the results of two reading tests in the same children. In the first one the mean discrepancy between mental age and reading age was 23.9 months whereas in the second one was 8 months. The former had a limited time for children to respond compared to the latter where the children's answers were not timed.

Miles (2006) believes that by using traditional IQ tests for dyslexics, this draws more on their weaknesses rather than their strengths. The ACID profile (Arithmetic, Coding, Information and Digit Span) commonly used throughout the 1980s as an indicator of dyslexia (Mortimore, 2003; Miles, 2006) has been criticized for its efficiency. Parts of the test rely on mechanisms that dyslexics are not particularly good at. As Miles (2006: 53) points out the Arithmetic subtest 'requires knowledge of times tables', an area that dyslexics might not thrive on, no matter how intelligent they are. Besides, parts of these tests are based on a time limit and there is no extra allowance for people with dyslexia although they might need it to complete them.

Discrepancy definitions, do not take into account the latest findings in the research frontier (phonological, magnocellular and cerebellum), which have been closely linked with dyslexia, and they persist into adulthood (Morgan and Klein, 2000). In addition, dyslexics have problems with reading which are not 'strongly related to IQ' (Snowling, 2006: 2). People with lower IQ have been able to master the reading process. It would also be difficult to apply it to the adult dyslexic that has left school being able to read and write to a satisfactory level. Adults can develop compensatory techniques and although they might be able to read this does not necessarily mean that their dyslexia has disappeared. Adults in higher education or workplace might still need support and special provisions to complete their studies and do their job efficiently (Moody).

Last but not least, in order to use a discrepancy definition there should be at least a two year reading discrepancy between the child and their reading age which means it can not be used for children who are too young, making their identification by these means impossible (Snowling, 2006).

The third way that is commonly used to explain dyslexia is by utilizing descriptive definitions. The BDA and IDA definitions fall into this category.

The IDA (2002) defines dyslexia as:

'Dyslexia is a specific learning disability that is neurological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction. Secondary consequences may include problems in reading comprehension and reduced reading experience that can impede the growth of vocabulary and background knowledge'.

Whereas the BDA (2009) defines dyslexia as:

'Dyslexia is a specific learning difficulty which mainly affects the development of literacy and language related skills.

It is likely to be present at birth and to be lifelong in its effects. It is characterized by difficulties with phonological processing, rapid naming, working memory, processing speed, and the automatic development of skills that may not match up to an individual's other cognitive abilities.

It tends to be resistant to conventional teaching methods, but its effects can be mitigated by appropriately specific intervention, including the application of information technology and supportive counselling'.

Descriptive definitions inform people about the different characteristics and manifestations of dyslexia. They include aspects that are useful and can provide guidance to practitioners in order to help them identify and assess dyslexia. They avoid exclusionary criteria and use more explanatory elements to help individuals understand the term (Elliot and Place, 2004). It is also essential to include the strengths that are related to dyslexia (Reid, 2004). On the other hand, scientists tend not to use these types of definitions as they need much more precise criteria to conduct research (Gaddes and Edgell, 2001). The above definitions can be useful for teachers and other professionals who are involved to a child/adult's education as they give the characteristics that are associated with dyslexia. The teachers can look for these signs and monitor the progress of the child/adult that displays them. If the difficulties are persistent they can ask for further support and request for the individual to be assessed for dyslexia.

In 1998, Bournemouth University suggested as relevant to students with dyslexia in higher education the following descriptive definition:

'Dyslexia manifests itself as an imbalance of skills whereby the dyslexic is unable to commit to paper ideas and information which are commensurate

with their intellectual ability as evidenced by spoken understanding or demonstration'.(Demos project, n.d.)

There is no doubt that there would be quite a few university students who can identify themselves with the above definition as one of the main problems that people with dyslexia face is writing on paper all the ideas they have in their minds (Michail, 1998). Especially as in higher education essay writing and taking exams are required in order to obtain a degree. On the other hand, this definition only focuses mainly on the writing skills of the individuals without taking into consideration the difficulties in reading and comprehension that HE students might experience. In order to be able to '*commit to paper ideas and information'* students need first and foremost to understand what they are reading and do so within a limited period at times (Riddick et al., 1997). Also, it does not provide any information about other characteristics that are associated with dyslexia. On the other hand, how can a lecturer identify a student with dyslexia by just marking his/her work if they do not 'know' the student and if there is not personal contact with him/her.

All this disagreement reveals that dyslexia is a difference with various aspects and interpretations. From all the above the definitions the descriptive ones can be more beneficial for educators and parents as it gives a better understanding of what dyslexia is rather what it is not.

2.4 Identification - Specific Learning Difficulty

Research that has been conducted with children and adults with dyslexia has shown that in the majority of the cases they were diagnosed at quite a late age (Riddick, Farmer and Sterling, 1997; Hughes and Dawson, 1995; Osmond, 1993). All the subjects in these studies wished they had been diagnosed earlier and wanted help and support relevant to their problems. If this had happened their lives would be much easier and happier and a lot of the frustration and anger that they had during their school years would not exist.

The earlier the identification is done the better for the child. Stag (1972 quoted in Fawcett and Nicolson, 1995: 3) claims that with 82 % of children diagnosed in grades 1 and 2 are catching up with their chronological age group, this compared with 46 % in grade 3, and falling to only 10-15 % in grades 5 to 7. Badian (1988 cited in Ott, 1997: 24) also reports that 'when diagnosis of dyslexia was made in the first two grades of school, over 80% of the students could be brought up to their normal classroom work'.

In addition, early identification can be a relief for both the children and their parents. This is due to the fact that dyslexia gives an explanation to both of them for the problems that they or their children are facing. People with dyslexia know deep inside themselves that something is going wrong but they cannot really say what it is. They feel that they are bright and they have capabilities (Kenny, 2002). They know that they work hard and they spend more time than their peers in finishing their work but still the others do better than them and they put half of the effort in than dyslexics do. Children start thinking that they are 'stupid', 'thick' or 'lazy' (Miles, 1993). They hear these words from their teachers or from their peer group and, since they do not have anything else to prove the opposite, after

a while they start thinking that probably the rest are right. Even if someone knows that

he/she is not 'stupid', when he/she hears it a lot of times from different people (teachers,

schoolmates or friends), he/she begins to believe it. *'Everyone told me that I was no good.*

I began to believe them (male, age 26, quoted in Hughes and Dawson, 1995: 183).

Unfortunately, there is a large number of students with dyslexia that suffer or have

suffered during their school years because they are not being treated well by their teachers

and they do not have the help they need to ameliorate their condition. Edwards (1994)

mentions the cases of individuals that have been bullied because dyslexia was not

identified.

Although early identification is of great importance for the future life of the dyslexic child

it does not necessarily happen at all times. One thing that makes early identification

difficult is the belief that a child cannot be diagnosed as dyslexic until about the age of 7

(Riddick, 1996; Fawcett and Nicolson, 1995). This was based on the child's failure to read

at school, as it was only then possible to measure his/her reading age compared to his/her

chronological age. Another problem is deciding how far 'behind' the average the child's

reading, spelling or writing should be before s/he attracts that particular label (Prior, 1996).

It should be mentioned that before a child is diagnosed as dyslexic, the people that carry

out the assessment should exclude any other factors that might cause the child's learning

difficulties. They should check if inadequate or interrupted schooling or any other physical

handicap is the cause for the child's problems (Doyle, 1996; Heaton and Winterson, 1996;

Thomson, 1990). If the child did not have a proper education and did not attend school as

he or she was supposed to, this might be the reason for his/her failing at school and not

being able to cope with the schoolwork (BDA, 2009). In addition, lack of good vision or

some other physical handicap might prevent the child from developing adequate literacy skills (BDA, 2009). All these possible factors might affect the child's literacy and should be taken into consideration and checked before any formal assessment takes place.

2.4.1 Labelling

Labelling has its positive and negative effects or as Solvang (2007) mentions 'bright' and 'dark' sides. One of the positive contributions of labelling is the fact that if the learner's disability is known at school age, an appropriate treatment or a special educational programme can be used for the child's well being (Gallagher, 1976). Furthermore, the label gives the opportunity to the individual to understand his or her problem and to realise that the problems he/she has are not his/her fault (Miles, 1988). A label is reliable if it identifies a learning difference that remains stable across many tests and settings. *It is valid and instructionally useful if children with that label benefit from treatments theoretically compatible with the identified underlying processes more than from other treatments* (Wise & Snyder, 2001: 1*)*. Vinegrad (1992) from his own experience has found that for dyslexics who have been dogged all their lives with epithets such as 'lazy', 'careless' or stupid, labelling has therapeutic effects. The self-image changes and individual feel much better about themselves and can face their problems with more confidence. Solvang (2007) emphasizes the importance of the de-stigmatisation for the individual's self-esteem and confidence. He refers to court cases that took place in Sweden, where dyslexic adults received compensation from their schools due to the lack of diagnosis. The court ruled also in their favour because they were not given the *'possibility of gaining self-confidence from the labelling'* (Solvang, 2007: 85).

> *… Just a call to attention that the plaintiff had a problem she could and should have received help for would have in itself been important to her. This would have given her a sense of safety and knowledge about the problem she faced (cited from court judgement, writer's own translation* (Solvang, 2007:84).

Dowana (1995) in her study of university students with dyslexia reports that most of the students felt better when they knew that dyslexia is the cause of their problems. It was a relief for them. It was a relief to know that they were not mentally retarded. They know that they can ask for help from their schools and universities, especially where the amount of work is large and they have to deal with deadlines and exams. For most of the students labelling has positive effects when it is followed with the appropriate help and support (Barga, 1996). Reid and Kirk (2001) believe that having a label attached to an individual should be a signpost rather than a goal in receiving assistance. The level of support should be connected more with the strengths and weaknesses of the individual and should be adapted to her needs.

Furthermore, Riddick (1996) after a study of children with dyslexia (22 children as sample) and their parents, reports that both parents and their children were quite happy and relieved when they have heard about the child being dyslexic. Some of the mothers questioned felt guilty because they did not manage to understand their child's problem at an earlier age. From the children's responses one can tell that dyslexia gave them the answers to their problems and made them realise that they were not stupid, thick or backwards. As one child said: *'I'm glad I'm called dyslexic rather than lazy'* (Riddick, 1996: 84).

On the other hand, labelling might have a negative effect in the person's life if they get stigmatised from it and others treat him according to the imposed label (Schafer and Olexa, 1971 in Barga, 1996: 416). In schools this can happen via name-calling, accusation and low academic expectations from peers and teachers alike. In addition, Barga (1996) reports that students thought of labelling in a negative way in cases where they were taken apart from their schoolmates in order to receive special help and it was obvious that they got different treatment from others. This happened when students were taken in a very public manner from their classroom to receive assistance for their problem in another room of the building. Before labelling an individual, the people who do it should be very careful and be sure that they do it for the right reasons. In the case of adults with dyslexia, labelling can affect their future and successful employment, as there are employers that might not be very sympathetic to their situation (Reid and Kirk, 2001).

Furthermore, research has shown that dyslexic learners may already be stigmatised by teachers or others professionals due to their poor performance. As Sutcliffe and Simsons (1993) point out, labelling can be stigmatising and in adults can lead to exclusion of individuals from mainstream society. Riddell and Weedon (2006) report that in Scotland although students in higher education were keen on their diagnosis, their lecturers thought that this might be a disguise of laziness. If people in academia 'dismiss' dyslexia, how is it possible for the rest of the population to accept and understand it? How can these lecturers be sympathetic and willing to assist their students if they do not believe in their condition?

People with learning difficulties consider themselves the same as other people and seek to find positive self-concepts (Harris, 1995). Irving (1994), from her own experience of having a disabled brother, raises the issue that unfortunately non-disabled people do not

see the person but his/her disability. People with dyslexia consider themselves as part of the society and feel they have a lot of things to give. Unfortunately, due to the fact that the symptoms of dyslexia are not obvious to the naked eye, some people misjudge them and attach labels to them without even considering the effect that this might have. Nowadays, labels (positive or negative) seem to be an integral part of our lives and although a label can save someone's life (medical), on the other hand socially it can stigmatise the individual.

Gillman, Heyman & Swain (2000) report that when it comes to diagnosing life-threatening diseases usually the diagnosis is appreciated as it gives the chance to the person involved to have the appropriate treatment that can save his/her life. On the other hand, the assessment of other types of syndromes like Downs, autism or schizophrenia may lead to the individual's stigmatisation and exclusion from society. It seems that society has divisive labels with some having a negative concept behind them and others having a positive one. Lakin (1997 cited in Goodley&Moore, 2000: 876) pointed out that:

'Being identified with such labels [as mental retardation] *often prevents people from being 'labelled' with more positive, meaningful, and personally satisfying descriptors, such as 'poet', 'actor' or 'artist'. It has been assumed.. That 'cognitive impairments' – which diagnosticians determine based on performance in vocabulary, memory, math and abstract reasoning – are total impairments, pervasively diminishing everything those so 'afflicted' can do'.*

Dyslexia is a '*hidden, not' evident disability* (Riddick et al, 2002: 91). There are no external signs for someone to 'identify' dyslexia as it might happen with Down's syndrome. Although a book should not be judged by its cover, people with dyslexia, as mentioned before, have been labelled as stupid or lazy due to the mistakes they might have made. What about the talents they might have; their creative mind and expression? Why

cannot people with dyslexia be labelled according to their strengths and abilities? Kenny (2002) a dyslexic herself, from her school experience came to the conclusion that *'the nature of the labels we select to describe individuals depends to a large degree upon the angle from which we choose to focus our lens'* (p.43). Do people always consider the way they perceive individuals with disabilities and whether when they are looking at them what they see first is the person or the disability? People with dyslexia or other disabilities might be a bit different compared to the rest of the population but they might have special abilities and by considering and promoting these abilities might be the first step to try and change the way society perceives them.

For the families of the individuals who have a learning difficulty, putting a label on their condition helped them to deal with the general public and empowered them with an explanation about why their next of kin might behave on a certain way. Besides, the individuals and their families can have access to special support and resources which they would not have had without the diagnosis (Gillman et al 2000). Riddick (2000) enhances the latter by mentioning that many people with dyslexia and their families see the 'dyslexia' label as a positive thing as it allows them to have access to different types of support, to find positive role models (famous dyslexic people), to understand more their problems and find other people with similar difficulties to talk to. In addition, dyslexics need the label, especially in HE, in order to have access to resources that they are entitled to. Without a statement, they cannot claim any allowances. They have to have proof in their hands before claiming anything from the state (Slovang, 2007).

On the other hand, labelling can have traumatic effects on the person's self-esteem and self-concept if taken light heartedly. People have to be very careful before attaching a label to an individual because it is something that stays with them and it is not easy to detach it. In the case of dyslexia it seems that labelling has a positive effect on the person's life, the traumatic experiences and feelings happened before they were assessed. Reading autobiographies of people with dyslexia like Susan Hampshire (1981) or Eileen Simpson (1981) shows there is a very distinctive feeling of relief and contentment for being dyslexic and not 'slow' or 'lazy'.

Green (1998) believes that one of the reason dyslexics have been given inappropriate labels is because they have a different learning style (discussed further in chapter 3).

Labels can be really powerful and affect people's lives. People should use them as a mean to help and support the individuals in need, to assist them accept their difficulties and understand the consequences of their 'condition' (Wise & Snyder, n.d.) . Although social change is important, people with dyslexia need to have a better understanding of what dyslexia is and how it affects their lives. They need to have a sense of identity and accept and comprehend their dyslexia (Fitzgibbon and O'Connor, 2002; Reid and Kirk, 2001). Professionals can help during this journey. They can help heal wounds created in the past and give hope for a much brighter and successful future. People should also try and see the positive side of dyslexia. Davis (1997) sees dyslexia as a gift rather than a disability. Maybe it is time for society to start and try to understand things from a different perspective; focus on the positive side of dyslexia and use the label to emphasize the individual's strengths rather than weaknesses.

2.5 Frequency of dyslexia

The exact number of children or adults that have dyslexia is unknown. This is because of the fact that a lot of children are been assessed at a quite late age and sometimes they develop such good coping strategies that it makes it even harder for their teachers or parents to understand the problems that they have. However, BDA estimates that in the Western world up to 10 per cent of children have some specific problems and about 4 per cent are severely affected (Smith, 1993; Singleton, 1996; BDA, 2009). About two to four percent of the student population have dyslexia (Miles, 1991; Snowling, 1987 cited in Crombie, 1995).

2.6 The case of early identification

Research that has been conducted with dyslexic children and adults has shown that in the majority of the cases they were diagnosed at quite a late age (Riddick, Farmer and Sterling, 1997; Hughes and Dawson, 1995; Osmond, 1993). All the subjects in these studies wished they had been diagnosed earlier and wanted help and support relevant to their problems. If this had happened their lives might have been much easier and happier and a lot of the frustration and anger that they had during their school years would not exist.

The earlier the identification is done the better for the child. Badian (1988) reports that 'when diagnosis of dyslexia was made in the first two grades of school, over 80% of the students could be brought up to their normal classroom work' (cited in Ott, 1997: 24). Stag (1972 quoted in Fawcett and Nicolson, 1995: 3) gives similar percentages. He claims that

82 % of children diagnosed in grades 1 and 2 catch up with their chronological age group, compared with 46 % in grade 3, and falling to only 10-15 % in grades 5 to 7.

Unfortunately, it is possible that there are a number of students with dyslexia that suffer or have suffered during their school years because they are not being treated well by their teachers and they do not have the help they need to ameliorate their condition. In older people with dyslexia (over 40-45 years old) in the days that dyslexia was not widely spread among the general population, those people went through school without knowing why they could not learn the same as their other schoolmates and they reached adulthood with bitter and unpleasant memories of their past (personal contacts).

On the other hand, during the 1950s and 1960s people did not put so much emphasis in their children's education due to economic problems (especially working class parents) and relied more on what the teachers told them (*teachers know best*) (Morgan and Klein, 2000: 18) about their children's progress and abilities and rather than blaming the system for their offspring's failure to read or write they were putting the blame on the child. There is no doubt that since the 1950s people's perceptions and awareness about dyslexia has changed but still nowadays there are adults with dyslexia who are assessed after entering university making it difficult for them to cope with the requirements of their courses and even losing the chance to attend their preferred institution due to lower scores in their A levels exams (personal contact with student support counsellor).

2.7 Conclusion

This chapter focused on a journey that started more than one hundred years ago when Dr Kussmaul recorded the first incident of dyslexia. Ever since, quite a few terms (word blindness, dyslexia, SpLD) have been used to describe it. Although there is not an international definition about dyslexia the BDA and the BPS ones are widely used to help specialists and educators identify children and adults that are at risk or have problems due to dyslexia. The identification, especially an early one is quite important as people with dyslexia have a reason for all the problems and difficulties they might have. The later the identification the worse it is for individuals with dyslexia. Although people can argue that labelling can have negative effects for the individuals in the case of dyslexia it is widely accepted as a positive thing; mainly because it gives an answer to their problems and secondarily because it gives the dyslexic students the right to ask and receive help and support for them.

The importance of early identification informs the research questions about the age the subjects of this particular study were assessed and the effect this had in their personal and family lives. It also brings up the issue of the positive, in the case of dyslexia, feelings that the participants felt after their assessment.

Over the years research has moved towards the causal accounts of dyslexia. In the next chapter a more detailed review of the different approaches by scientists and researchers will follow concentrating on the most recent theories that have been surfaced from researching dyslexia.

CHAPTER 3

NEW TRENDS AND THEORY

3.1 Introduction

This particular chapter pays attention to the latest approaches and theories about dyslexia. It will be focus on the phonological, cerebellar and magnocellular approach as well as any causal accounts that might cause dyslexia. It also contains an overview of the most discussed models regarding the disability movement.

3.2 Models of disability

3.2.1 Medical/ individual deficit model

When people came across individuals experiencing dyslexia related symptoms for the first time they followed a medical approach in their efforts to explain them. As mentioned before, the first description of dyslexia came from Dr Morgan in 1896 that published an article entitled '*A case of congenital word-blindness*'. He described the case of a boy called Percy who spelled his name Precy (Ott, 1997: 6). Hinshelwood (1917) came to similar descriptions. At the time pursuing a medical explanation in order to cure and resolve the individuals' problems seemed to be the best path to follow. Dyslexia seemed at the time to be a neurological condition. Since then scientists that believe in the medical model of dyslexia have explored other possibilities, like the phonological approach, as a cause of dyslexia.

The medical model sees the person's disability as a problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals' (Farrell, 2004: 76). People with disabilities have to adapt to the way the world is and accept the decisions of all the professionals who know better than them about their condition. The model sees people more like outcasts rather than equal members of society. The principal effects of the medical model are obvious in the SEN categorizations. People are labeled according to their abilities and impairments although each category may include more than one condition under the term. The term Specific Learning Disability includes individuals with dyslexia, dyscalculia and dyspraxia. On the other hand, having being diagnosed and 'labeled' the individuals can claim sufficient resources and support in order to get help for their difficulties.

Although the medical model has played an important role in assessing and assisting people with disabilities one cannot discard the importance of these individuals to lead a life like someone with no disabilities. In order to exist as a human being these individuals need more than medical support. They need to be accepted by society and be seen as part of it and enjoy the same rights and provisions as everybody else.

People that have dyslexia can work and do all the things that non-dyslexic people do. By society seeing them as disabled they are deprived the 'privilege' of settling in the community and enjoying their everyday life. Dyslexia is not an illness or a disease than can be cured. So what is the point of treating individuals with dyslexia as patients and why not try to enlighten the society of its existence and improve their lives by accommodating and removing the barriers that prevent dyslexics to accomplish their greatest potential? It is not possible to extinguish any disabilities. Although medical science has reached levels of

being able through DNA analysis to prevent children from carrying some default genes or being born disabled there are always going to be individuals with 'special abilities' in our society and it is our responsibility to accept them and include them in it in the best way we can.

3.2.2 Social Model

During the 70's a new interest group (Union of the Physically Impaired Against Segregation UPIAS) started to make its first steps and advocate the importance of changing peoples and society's mentality towards individuals with disabilities. Over the years the movement became stronger and more people started to regard disability as a social restriction that society placed on people with impairments. This concept opposed to the medical model that was generally accepted at the time and was focused more on the remedy and improvement of the individuals' impairments. Oliver (1990) opposed to the medicalisation of disability asserting that *'disability is a social state and not a medical condition* (p.2)'. On the other hand, he did not renounce the importance of the medical society and all the trained practitioners that have helped and are still helping people with impairments to improve their quality of lives by stabilizing their condition or treating any occurring illnesses. However, doctors may be able to help individuals with their conditions but they cannot make decisions as to how a person with impairments will lead his life and how he feels and experiences his disability.

The social model tried to emphasize the importance of changing the society's attitudes and beliefs about people with impairments rather than trying to change the individuals themselves. It postulates that impairments are transformed into disabilities by the negative

attitudes of society. If people could change and work on altering perceptions about impairments life would be much easier for those who 'suffer' from any kind of disability. Shakespeare and Watson (2002) suggest that this occurs due to the fact that non-disabled people discuss and try to solve the problems disabled people face. Another reason they include is the fact that disability is defined as a problem in our society (Riddick, 2001). People tend to see the impairment rather than the person behind it. The social model does not deny the problem of disability but it is focused more on empowering the individuals and helping them to remove the barriers that have been set by the rest of our society (Shakespeare and Watson, 2002; Oliver, 1990). On the other hand, *a barrier-free utopia* is not viable (Abberley, 1996 cited in Shakespeare and Watson, 2002: 18). No matter how hard the social model advocates try there would always be people with disabilities that cannot lead a 'normal' life and accomplish fulfillment in every aspect of their existence. On the other hand, who is in a position to define what exactly normal is as people have different perspectives and values about life?

People around us, no matter what kinds of impairment have, have the right to choose how they want to live their lives and make the decisions for themselves. Having an impairment does not mean that the individual has fewer rights than someone who does not. It is up to them to talk about their disability and disclose it. Many disabled people do not see themselves as disabled (Shakespeare and Watson, 2002). They live their lives trying not to be affected by any problems that may be caused due to their impairments. Some disabilities are quite obvious to the naked eye some; other like autism and dyslexia are not.

Dyslexia is a hidden, non-evident disability (Riddick et al., 2002), which makes it even more difficult for non-dyslexic people to understand and accept the condition. However,

there are dyslexics that have consciously concealed it, some, as Riddick (article) pointed out, due to fear of rejection but some others because they do not consider dyslexia a problem. They consider it as part of their lives, their existence. It has made them what they are and who they are. They have decided not to use the label of 'dyslexia' in their everyday lives not because of fear of what people might think or do but because they do not see themselves as disabled. After all, as Said (1994 cited in Shakespeare and Watson, 2002: 20) said: *"No one today is purely one thing. Labels like Indian, or woman, or Muslim, or American are no more than starting-points, which if followed into actual experience for only a moment are quickly left behind"*.

3.2.3 Biopsychosocial Model

The biopsychosocial model is seen by some as trying to integrate the medical and social model (Farrell, 2004). Dr Engel believed in a 'holistic' approach to the medical patient looking for a complete and whole evaluation and understanding of the patient and his/her illness (Levy, 2001:1). He emphasized the importance of physician-patient relationship as a tool for the former to gather information in order to help him have a more complete and concrete picture of his patient condition (Eaton, 1980). The patient is both an initiator and collaborator in the process, not merely an object of study. The basic methodological triad for clinical study consists of observation (outer viewing), introspection (inner viewing), and dialogue (interviewing) and these ultimately render the patient's data as scientific **(**Puustinen, Leiman and Viljanen, 2003: 3). Engel's biopsychosocial model was based on the fact that a person's life is affected and shaped by the interactions between biological, psychological and social variables.

Trying to apply Engel's biopsychosocial model in special education is not as easy as it might seem. In order to have a holistic picture of the 'patient's' situation educators need to spend quite some time with the child/adult in need and that requires trained professionals and allocated time and services. As it follows the individual through different disciplines and variables linkages among them are important to be formed. Linkages, however, must be made not only within but also across levels of analysis and systems. For example, exposure and appraisal of stress may vary as a function of personality (individual psychology), socialization (psychological and social) and cultural and socioeconomic factors (Suls and Rothman, 2004: 132). Most of the scientists that have researched and applied the biopsychosocial model are associated with medical related professions. In order to be sure that it can be applied to the educational setting more research needs to be done.

3.2.4 Morton and Frith 3 stage model

Morton and Frith (cited in Frith, 1997, 1999) on their effort to explain dyslexia and its causes came up with the following three-level framework (Figure 1): the biological level, the cognitive level and the behavioural level. In addition, the framework acknowledges the importance of the environment in the life of the individuals and subsequently to the three levels mentioned.
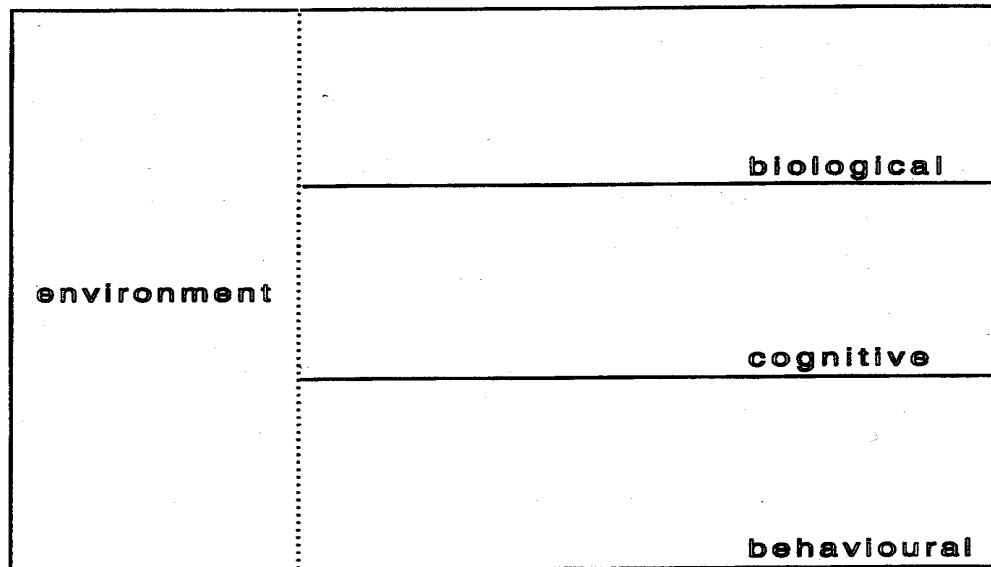
Figure 1. The three-level framework.

(Frith, 1999:193)

Morton and Frith (Frith, 1999) believe that people should not focus only on one of the frameworks in their efforts to define dyslexia. They should try an incorporate a more 'holistic' approach for the causes of dyslexia taking into consideration all the probable factors that may influence it (biological, cognitive and behavioural).

If people want to use the biological factor on its own and regard dyslexia as a syndrome they need to consider the fact that there is such a gap between the behavioural and the biological aspect that the link can be quite fragile. Biological factors in accordance with the environment can influence the brain's development. The cognitive level can work as a bridge between the two (Frith, 1999).

Trying to define dyslexia based on the behavioural level can also create friction, as the biological cause is not brought up. Relying only on tests and observations we cannot have

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a clear picture about the causal effects of dyslexia as the environment (teaching methods, cultural attitudes, socio-economic factors) can influence them and their outcome (Frith, 1997; 1999; Frederickson and Cline, 2002).

Cognitive skills on the other hand, are linked with the behavioural level and the environmental factors, as they cannot be directly observed. Data collected from the behavioural level is used to measure them (Frederickson and Cline, 2002; Frith, 1999). Cognitive theories need to consider both the latest developments in the biological and the behavioural level and act as a bridge that connects them together during this never ending journey of trying to define dyslexia and its causes.

In their model, Morton and Frith lean towards the phonological deficit theory as the link between the two other levels. They believe that an abnormality in the Perisylvian region of the brain causes problems in the phonological system. Paulesu et al. in a brain-imaging experiment found out that dyslexics did not use the insula part of the brain at all compared to non-dyslexic during simple phonological tasks (Frith, 1997). This means that the dyslexic did not use all the potential areas of the language and speech system and as a result they did not perform as well as the non-dyslexic individuals in the phonological tasks.

Another reason that made them support the phonological deficit is the fact that reading and writing is something that needs to be taught and in order to master the skills the individuals need to be able to decode the letters and their sounds (graphemes and phonemes) (Doyle, 2002). In order to be able to read in an alphabetic system the child or adult need to be able to perform the above tasks and only phonology can help them acquire that (Frith, 1999).

On the other hand, the environmental influences are very important during all this procedure. Environmental factors are very important for the remediation of dyslexia. The way that society perceives a disorder can affect the way the individual feels and reacts within it. Western societies consider the acquisition of reading and writing as essential skills in order to develop a prosperous career. . The alphabetic writing system that is used though can be very confusing for someone lacking these important phonological skills. The more complex the writing system is, the more difficult is for people with dyslexia to overcome the hurdles they face (Frith, 1999).English, in particular is considered on of the most difficult languages to learn due to its deep orthography (Townend andWalker, 2006). Assistive technology like personal computers, spellcheckers and other similar devices can be important tools to support people with dyslexia and overcome their difficulties.

Dyslexia is a complicated difficulty that needs to be considered in all three levels if people want to have a better understanding of it. Linking the three-level framework together along with the environmental and cultural factors that influence it is probably the way forward on finding the cause and remediation of dyslexia.

3.3 Phonological Deficit Theory

One of the most prominent theories of the last decades is the phonological deficit one. This theory is based on the belief that people with dyslexia have problems in the phonological processing, irrespective of IQ (Stanovitch and Siegel, 1994 in Snowling, 1998; 2004; Shaywitz and Shaywitz, 2005). Advocates of this theory are focused on the way that 'the brain codes or 'represents' the spoken attributes of the words' (Snowling, 2000: 35).

Phonological skills are quite important skills for a child to obtain in order to be a successful reader and they need to be developed around the age of 5 otherwise the child will have difficulties in reading and learning new words (Fawcett, 2001). Children who are able to manipulate sounds in words are more able readers and make more progress in their reading than the ones that have weaknesses in their phonological skills (Hatcher, 1994; Tijms, 2004). Although speech is 'natural and inherent', reading is 'acquired and taught' (Shaywitz and Shaywitz, 2005: 1301). In order to learn to read people need to understand that letters are representing the sounds of spoken language and that words can be broken into smaller segments (phonemes). A competent reader can segment a written word and then connect each letter to its related sound.

Phonological skills include the ability to break words into segments (onset and rime) and recognising individual sounds (phonemes). Also, include the ability to hear a sound (phoneme) and be able to decode it into the letter that stands for it (grapheme). Children with dyslexia have difficulty in segmenting, detecting, manipulating and coding sounds in words (Doyle, 2002; Shaywitz and Shaywitz, 2005).

Lack of or problems with the above skills can cause difficulties in verbal short memory, non-word repetition, phonological learning, naming (Snowling, 2004). There is evidence to show that children and adults with dyslexia have problems in short-term memory, which results in remembering fewer verbal items than a non-dyslexic of their age (Snowling, 2004, 2000). Verbal material is stored in short-term memory in terms of a speech code (Snowling, 2000). Conrad's work in 1964 showed that people make more mistakes when the letters sound similar (b, c, p, t, v) than they sound dissimilar (f, m, n, s, x) (Snowling,

2000; Miles and Miles, 1999). This suggests that 'when *a stimulus is presented visually its phonological representation is what is memorised'* (Miles and Miles, 1999: 41). It seems that a deficit in the phonological coding restricts the number of verbal items that dyslexics can retain in their memory.

Another observable fact in short-term memory is the 'word length effect' (Baddeley, Thomson and Buchanan, 1975 in Miles and Miles, 1999; Snowling 2000). Subjects were asked to recall lists of short, medium and long words as well as nonwords. It seems that the main problem that dyslexic face considering the above experiment is repeating the nonwords. This is due to the fact that nonwords acquire additional phonological processing and depend more on orthography and phonology mapping than low /frequency ones (Van Vliet, Miozzo, Stern, 2004).

Without a doubt dyslexics experience problems with their phonological representations and this has as effect to restrict their reading abilities. By helping children to improve their phonological skills teachers can assist them to become more confident and competent readers in the future.

3.4 Cerebellar Deficit Theory

Over the last decades, one of the leading hypotheses along with the phonological and magnocellular over the causal effects of dyslexia is the one focused on the cerebellum functions (Nicolson and Fawcett, 1999; 2001). Nicolson and Fawcett (1999) postulate that impairment on the cerebellar proceedings affects the automatisation process, which is vital in acquiring and mastering new skills. In their research, children with dyslexia were tested

along with a control group in balance automaticity and they found differences only under

dual task conditions between the two groups with the dyslexic group having much higher

impairment in balance compared to the control group.

 The cerebellum was mainly associated with the motor skills and coordination although

research from Leiner, Leiner and Dow (1989, 1993) concluded that it is central with the

acquisition of 'language dexterity' (in Nicolson and Fawcett, 1999:163). Besides, Rae,

Lee, Dixon, Blamire, Thompson, Styles, Talcott, Richardson and Stein (1998) report that

reading performance in dyslexia has been improved by anti-motion-sickness medications,

which may be considered 'cerebellar-vestibular stabilisers' (p.1852).

Nicolson and Fawcett (1999, 2001) came with a causal explanation of dyslexia due to

abnormal cerebellar function (Figure 1) linking the difficulties experienced by individuals

with dyslexia. They suggest that problems in writing, spelling and reading can be caused

by direct and indirect cerebellar causation. Mild cerebellar impairment in an infant might

cause problems with muscular control. At a later age his articulation will directly be

affected and as a result the infant will have slower progress in babbling and later talking. If

articulation is less fluent than normal, then one indirect effect is that it takes up more

conscious resources, leaving fewer resources to progress the ensuing sensory feedback

(Nicolson and Fawcett, 2001: 3). This may also indirectly affect the fluency in language

acquisition and therefore directly create problems with the phonological awareness of the

child. In addition, dyslexic children's handwriting can also be directly linked with the

cerebellar impairment hypothesis as in it requires 'precise timing and co-ordination of

diverse muscle groups' (Nicolson and Fawcett, 1999: 171). Brookes and Stirling (2005) in

their research project support Nicolson and Fawcett's findings as they came to similar

conclusions regarding the correlation between reading ability and cerebellar soft signs.
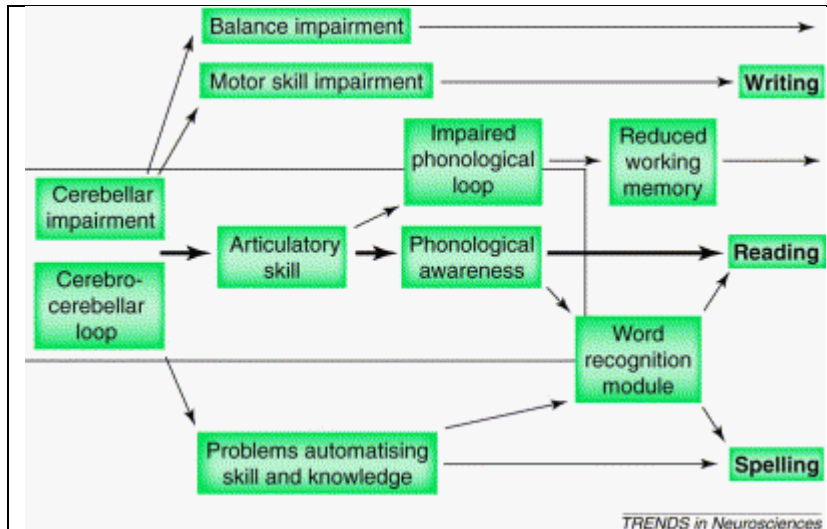
Figure 1   Nicolson and Fawcett 2001: 4)

Apart from these, imaging studies pointed towards a correlation between dyslexia and

irregular cerebellar function. Finch, Nicolson and Fawcett (2002) examined the brains of

four dyslexic adults originally studied by Galaburda et al. and found there were significant

differences in the posterior cerebellar cortex in the dyslexic sample. Both in the posterior

and anterior lobe of the dyslexic brains were more large and fewer Purkinje cells. This has

established a direct neuroanatomical evidence for cerebellar abnormalities in dyslexia.

Although, the sample of this project is quite small (Finch et al., 2002; Bishop, 2002;

Beaton, 2002) mainly due to lack of dyslexic brains available for research, the data that is

presented is quite significant as it is consistent with the cerebellar deficit hypothesis. One

the other hand, more research needs to be done, as the knowledge regarding the brain and

its functions is still limited.

3.5 Magnocellular Theory

Over the last years some scientists have focused their interest in the magnocellular deficit. People without any impairment while they are reading do not look at the text in a steady way. Instead their eyes flicker and they tend to get a wider picture of the written text in front of them. Dyslexics on the other hand, seem to have reduced sensitivity to motion stimuli, which suggests that the visual magnocellular system might be impaired (Stein, 2001).

The visual magnocellular system is the part of the nervous system which allows organisms to see. The magnocellular ganglion cells provide the signals that pass from the eye to the rest of the brain. Some dyslexics have reported visuals symptoms like words becoming wobbly and unstable while they are reading. Stein (2001) believes that these symptoms are caused due to problems in their visual magnocellular system.

The involvement of the cerebellar functions in the magnocellular hypothesis is linked to the fact that some dyslexics experience problems with timing so they may be late or forget appointments (Scott, 2004) and that the cerebellum itself contains magnocells (Reid and Fawcett, 2004). Stein and Walsh (1997) describe a magnocellular temporal processing deficit and suggest that this might be extended to other systems such as vestibular and motor which are functions of the cerebellum.

> *'Dyslexics are notoriously clumsy and uncoordinated, their writing is appalling, their balance is poor, and they show other 'soft' cerebellar signs, such as reach and gaze overshoot, and muscle hypotonia (p. 151)'.*

3.6 Aspects of colour sensitivity – Visual stress

Visual stress or Maeres-Irlen syndrome (MIS) is a concept relatively new in the dyslexia history. Individuals who experience visual stress problems usually complain about sore and tired eyes, headaches and discomfort after reading for a while, sensitivity to excessive light which sometimes results to blurred and wobbly written text (Kriss and Evans, 2005; Grant, 2007; Reid, 2003). Research has showed that the use of coloured overlays or lenses can be beneficial for the individuals that experience any side effects cause by visual stress (Wilkins and Sihra, 2000; Fawcett, 2002;, Singleton and Henderson, 2007).

Wilkins, a pioneer in the field, has proved that the use of coloured overlays or tinted lenses has reduced the symptoms of glaring and eyestrain on individuals that have used them (Fawcett, 200; Kriss and Evans, 2005). He developed the Colorimeter, an instrument that can test the person and help him choose, without the individual knowing, which colour is more beneficial for him.

He also found that coloured overlays can increase the reading speed and are specific and different for each individual (Lightstone et al, 1999; Wilkins, Sihra and Myers, 2005; Kriss and Evans, 2005). Furthermore, Wilkins found that the positive effects of the use of coloured overlays can be also beneficial for children that do not experience any deficit. In one of his studies, 5% of the children that participated improved their reading speed more than 25% by using the coloured overlays (Fawcett, 2002).

Research in adult population has found similar results. Evans and Joseph's (2002) study in university students found that 38% of those who took part showed more than 5%

improvement in reading rate when they used a coloured overlay using the WRRT (Wilkins Rate of Reading Test) criterion. In their sample 89% of the students reported an immediate benefit from coloured overlays.

Grant (2007) also reports a high rate of students with dyslexia that have symptoms of visual stress (75%). In his study 77% of the 100 dyslexics were identified with visual stress. Undoubtedly, the students in his study considered the use of coloured overlays as a positive thing. One student described the use of coloured overlays as *'like a bra: it lifts and separates'* the words (Grant, 2007: 60).

On the other hand, there is some disagreement regarding the prevalence of visual stress within the dyslexic population. Irlen (1995) believes that the occurrence of Maeres- Irlen Syndrome in the non-dyslexic population is 12-14%, whereas her prediction among the dyslexic population in 46%. Unfortunately, Irlen did not provide any data or diagnostic criteria for her results (Kriss and Evans, 2005). Kriss and Evans (2005) found similar results in their non-dyslexic group (12.5%) while their dyslexic group scored only 31%. They postulate that maybe her results were higher if they were based on assessments that took place at the Irlen Institutes.

Furthermore, Singleton and Trotter (2005), in their study in adults with dyslexia, came to the conclusion that people with dyslexia have greater likelihood to develop visual stress although Wilkins believes that dyslexia and stress are completely independent. Kriss and Evans (2005) lean towards Wilkinson's belief too. They postulate that people with dyslexia may experience visual problems but even if these problems are resolved these individuals will probably still experience other difficulties caused by their dyslexia.

Although in their research study children with dyslexia had higher rates of MIS that non dyslexic children their sample was quite small (64 children overall; 32 dyslexic-32 control participants). Singleton and Henderson (2007) believe that in order to understand visual stress people need to take into consideration its link with dyslexia. It is not clear yet whether this link might be causal or not; more research needs to be done.

3.7 Genetics

Thomas (1905 cited in Critchley, 1974, Riddick, 1996; Fisher and Smith, 2001) was probably the first one who published that word blindness often appears in more than one member of a family. Hallgren (1950 cited in Pennington 1989; Ott, 1997) had found the risk to first-degree relatives to be 41 per cent. 88% of the families studied had at least one dyslexic member. Finnucci, Guthrie, Abbey and Childs (1976 cited in Riddick, 1996; Ott, 1997) had similar findings in their research study. 81% of the cases studied contained at least one affected parent. The number of affected children increased when both parents were affected.

Vogler, DeFries and Decker (1985) found the risk to a son of having an affected father in 40 percent and of having an affected mother 35 per cent. For daughters, the risk of dyslexia of having an affected parent of either sex was 17-18 per cent. Dr Hornsby (1992) stated that 88 per cent of the children who attended the Dyslexia Clinic in St Bartholomew's Hospital in London during the 1970's had a positive family history of dyslexia; and often there was a record of more than on child being affected in the family (p. 16).

Fifty per cent of the children that took part in Riddick's (1996) research project were being brought up in families where one parent was thought to have had similar problems as a child. Riddick (1996) mentions that seventeen out of eighteen cases the adult was identified as probably dyslexic after their child was assessed as dyslexic. Two of the mothers were confirmed being dyslexic after formally being assessed following their children's identification.

The above are supported by Grigorenko (2001) who reports that the risk of dyslexia is 8 times higher in children where there is a parental history of reading difficulties. Different studies report that that 25%-60% of the parents of dyslexic children also display reading difficulties. The risk of a child having a reading disability is increased when one of the parents reports similar difficulties (Vogler, DeFries, Decker, 1985). Morgan and Klein (2000) state that familial incidence is mentioned when adults are asked about other family members having similar difficulties to them.

Studies in adolescent twins found modest heritability for reading ability and disability, but significant heritability for spelling ability and disability (Stevenson et al. 1986 in Pennington, 1989: 85). Furthermore, the Colorado Twin Study on identical and non-identical twins reports that the concordance rate for reading problems for identical twins was 70 per cent and 43 per cent for non-identical twins (Riddick, 1996).

On the other hand, researchers claim that not everybody who might have the gene or genes for dyslexia will be affected by it. The environment plays an important role in a person's development. Our brains are not completely formed at birth. On the contrary, our brains are capable of change, growth and development (Hurtford, 1998). The amount of exposure

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children have to text influences their reading abilities. Even someone who does not experience the difficulties a dyslexic person faces, if he does not practice reading he will not learn (Snowling, 2000). The way parents interact with their children influences their growth and development. Olson (2002) emphasizes the importance of the environmental intervention for dyslexia. Although dyslexia cannot be treated with any medication, extra tuition and reinforcement of phonological skills and reading can provide support and improve the skills that the dyslexic person already has (Rose, 2009).

Advantages in genetic research over the last decades have helped researchers to identify genes and chromosomes that are associated with dyslexia (Bates, 2006; Bates et al., 2007; Schulte-Korne et al., 2006; Francks et al., 2002). The human genome consists of over three billion DNA based-pairs (Bates, 2006; Francks et al., 2002). To analyse and identify each gene is a thorny and costly job. Researchers have found another way to trace genes with the help of linkage analysis. Linkage analysis refers to *the analysis of individuals for whom family relations are known* (Franks et al., 2002: 487). Linkage analysis has shown chromosomes 1, 2, 3, 6, 13, 15 and 18 to be related to dyslexia (Franks et al., 2002, Bates, 2006 and Olson, 2002). These chromosomes have been associated with reading ability, phonological awareness, orthographic coding, verbal short-term memory and rapid automatized naming (Olson, 2002, Bates, 2006).

There is still a long way until all the 'mysteries' that surround dyslexia and its manifestations will be unravelled. Genetic research can help professionals have a better understanding of dyslexia and the specific problems that some individuals experience. Although more research needs to be done, in the future genetic research can possibly assist

us detect and identify children at risk at a very early age and therefore give them the change to lead a 'normal' life with minimum costs on their personal and social life.

3.8 Are the theoretical accounts moving together?

Dyslexia or Specific Learning Disability (SpLD) has been under scrutiny for quite a while now. There is so much controversy and disagreement surrounding dyslexia that it seems at times that the scientific and professional world is divided rather than united when it comes to explain and investigate dyslexia.

Nowadays, people's attitudes towards disabilities, including dyslexia, have started to change and people with disabilities have been accepted as equal members of society rather than outcasts. Having a disability does not make anyone less able to contribute to the society. Society, on the other hand, is much more tolerant and helpful towards people with disabilities and dyslexia.

It is not effortless to change attitudes and it takes a long time to persuade communities and make them aware of the diversity of people that live around them. Having difficulties in reading and writing would not have been probably a problem if societies did not place such an important role in the acquisition of reading and writing; if people could get qualifications without having to pass written exams and study complex books; if people were to communicate by using sign language or symbols. It is not impossible to change people's perceptions. It just takes a bit more time and effort and during this time research

is one of the most important 'weapons' that can be used in order to explain the disability and support the people who experience it.

Over the years research has helped people to understand dyslexia and its manifestations. A much clearer picture of what causes and indications of dyslexia has emerged although still there is debate among the researchers considering which approach is the correct one (Fawcett, 2003).

Researchers working on different fields related to dyslexia postulate that their theory is the right one and this sometime has caused some friction among the professionals. Over the last decades, research has informed us about the difficulties that people with dyslexia experience in their everyday lives and in academia (Miles, 2006; Riddick, 1996; Singleton, 1999). Most of the research has being focused on children although a wider interest has developed in dyslexia and its effects on the adult population (Riddick et al., 1997; Morgan and Klein,2000). Karmiloff-Smith (cited in Goswami, 2003) believes that disorders must be studied in early infancy and longitudinally; to explore how alternative developmental pathways might lead to different phenotypical outcomes. On the other hand, people should not disregard the effects that dyslexia has in adults too, especially the ones that were assessed at a late age.

Three main approaches considering the causal factors of dyslexia are the phonological, the magnocellular and the cerebellar. The phonological theory is probably the most predominant one over the last decades (Ramus, 2003) with a considerable number of people supporting it (Snowling, 2001; Ramus, 2001; 2003, Swan and Goswami, 1997). Fawcett (2004:7) believes that '*we are moving towards finding the final pieces of*

information that will help us to understand the enigma of dyslexia'. Although more research needs to be done, there is no doubt the above theories have assisted us expand our knowledge about dyslexia considerably. It will not be easy to reach a theoretical agreement but people should consider that *'there could be three partially overlapping subtypes of dyslexia, each being an independent contribution to reading difficulties: phonological, auditory/visual, and cerebellar'* (Ramus et al. 2003: 844).

White et al. (2006) postulate that although the phonological deficit is unlikely to account for 100 per cent of the dyslexics, it seems that 'it *can be the primary deficit for at least a subset of dyslexics*' (p.250). In contrast sensorimotor theories are these that '*postulate cerebellar or magnocellular origins of dyslexia and so predict impairments of visual, auditory and/or motor function'* (Bishop, 2006:256). In White et al.'s (2006) research study, six participants indicated visual based dyslexia without the presence of a phonological deficit. Although the authors do not dismiss the presence of sensorimotor impairments in dyslexia they postulate that the latter '*does not directly explain the reading disability*' (White et al., 2006: 253).

On the other hand, Goswami (2006) disagrees with White et al.'s (2006) position, as she believes that there may yet be a cognitive deficit to be found that arises '*detached from any neural underpinnings*' (p.259). She highlights the importance of further research that includes larger samples and longitudinal studies in the sensorimotor field.

Researchers currently seem to concentrate and focus their efforts more on the neurobiological basis of dyslexia and how our brain works. Neurobiological research is probably the way forward as there are strong arguments about the existence of different

pathways that can lead us achieving a literate brain. '*The creation of literacy in the brain is not limited to one single pathway' …*We should also take into consideration the environmental and biological barriers that might affect these pathways. (Centre for Educational Research and Innovation (CERI), 2007: 93).

3.9 Conclusion

In this chapter there has been consideration of the different models of disability and the different theoretical accounts that are currently predominant in the field of dyslexia. Is dyslexia a disorder or it is just a socially imposed disability? We live in a society that promotes the importance of qualifications in order to have a better-paid job and a brighter future and reading and writing are significant factors in achieving them. People with dyslexia might have difficulties in the latter but does them make less able to achieve the things a non-dyslexic person can?

When people hear the word 'disabled' their minds usually think about a person in a wheelchair or someone who has severe or profound learning difficulties. As Megan, a dyslexic university student, pointed out: '*I don't like it see when you say that I'm disabled – disability, I think that sounds so bad. I mean I'm not missing any limbs or anything like that. But I suppose really when I think about it, it's so hard every day. You come in, you're like, 'Oh God please don't give me anything to read or write you know, to read out in front of anybody', I would just pass out you know'* (Riddell and Weedon, 2006: 67).

If we lived in a society that it would be acceptable not to be able to read and write probably there would be no mention of dyslexia; people with dyslexia would not have to go through the humiliation and the stigma that comes with the difficulties they face before

their diagnosis. people with dyslexia have proved that they can do anything that a non-dyslexic person can; the difference is they might need a bit more support according to their individual needs to achieve it. If people were more understanding and tolerant towards individuals with 'special abilities' people with dyslexia would be able to accomplish even more.

This chapter has also covered the main theories that are investigating the causal effects of dyslexia (phonological, cerebellar, magnocellular theory). Although there is not a consensus among the professionals about the above theories people can acknowledge their contribution to unravel the mystery of dyslexia.

It also contains an account about the latest developments in the genetics field, which is directly connected with the research questions considering family heritability.

In the next chapter a detailed discussion about the influence of late assessment and the negative perceptions deriving from our society about the 'abilities' of people with dyslexia will follow.

CHAPTER 4

EMOTIONAL AND SOCIAL PERSPECTIVES

4.1 Introduction

People with dyslexia have to overcome quite a few barriers during their lives in order to be able to fulfil their dreams and achieve their targets. The fact that some of them are not assessed at an early age can affect their self-esteem and their self-concept. Once they are assessed research has proved that people with dyslexia learn better once they are taught in their preferred learning style (Mortimore, 2003).

4.1 Social and emotional difficulties

There are not a few cases where people have been labelled because of their behaviour. Especially in the case of dyslexic students negative characterisations (thick, stupid) are widely used when dyslexia has not been diagnosed (Tanner, 2009). This happens because people easily label other people from their reactions instead of trying to think if there is something hidden behind them that makes the latter respond the way they are. This in the long term can cause them a lot of problems in their personal and social life.

4.1.1 Self-esteem

Everybody has an inner picture of his/her strengths and weaknesses, which are being affected from the positive and negative responses he/she receives from the people he/she thinks that are important to him/her (Mosley, 1995). The idea we have about ourselves and the value we ascribe to it is our self-esteem. Self-esteem is created by our experiences and begins to be shaped from the earliest years of our lives (Stenhouse, 1994).

William James (1982 quoted in Griffiths, 1993: 301)) originally proposed that *self-esteem is the ratio of one's success to one's pretensions*. He divided the self into two components, the 'me' and the 'I' (Mussen et all, 1984; Cowie and Pecherek, 1994). The 'me' is the individual's ability to view the self as the sum total of his/her abilities, personal characteristics, qualities and material possessions. The 'I' is the individual's awareness of self as an entity separate from others, of self as unique and distinctive, and of self as having continuity over time (Cowie and Percherek, 1994: 69). The former refers to the individual's process of understanding its role in society, its cultural identity and people's evolution over time, whereas the latter is self-reflective and explains experience, people, objects and behaviour in a subjective manner.

Writing in the context of children William's beliefs were later translated by psychologists into the idea that self-esteem is best understood as *the discrepancy between the 'ideal self' and the 'self-image'* (Griffiths, 1993: 301).

Ideal self is the person's picture of what he/she would like to be or the picture that he/she thinks the others would like him/her to be (Smith, 1998). When the child is growing up and becomes able to understand and value things better,

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he/she gains more awareness of the demands and the standards that society might apply to its members. For example, the higher the person's socio-economic status, the more chances he/she has to be successful and accepted by the society. The child attempts to fulfil these standards in order to be socially accepted and become a respected member of society.

The media is a big influence in forming an ideal self as it provides a lot of images and models of aspiration (Lawrence, 1996). In addition, the family's ideas and the pressure this might pose to the learner could make him/her form an ideal image in his/her mind and try to accomplish this image in order to make his/her family proud of him/herself. The more demands a society might have, the more pressure might be put on a person's shoulders in order to fulfil them; especially when the person is a child as he/she is not mature enough to evaluate his/her strengths and capabilities or to see if the goal that has set in his/her mind is realistic or not. Children look up to their parents and long for their acceptance and approval. Children with dyslexia fear that due to their academic failure they will lose the support and love of their families (Scott, 2003). Without the appropriate help and support children with dyslexia can become part of a vicious circle by feeling guilty and inadequate.

There are people that confuse self-esteem with self-concept (Mussen et al., 1984). The two are not identical. '*Self-concept can be broadly defined as a person's perceptions of him- or herself*' (Shavelon and Bolus, 1982: 3). Self-concept is a set of ideas about one-self that is *descriptive* rather than *judgmental* (Mussen et al., 1984: 356). One can describe some of his/her qualities without trying to categorise them as good or bad whereas when it comes

to self-esteem the person tries to evaluate his/her own abilities comparing them with someone else's. We can see self-concept as an *'umbrella term'* (Lawrence, 1996: 2) because under the self there are three aspects: self-image, ideal self and self-esteem.

Self-concept

Self-image   **Ideal self**

Self-esteem   (Lawrence, 1996: 2)
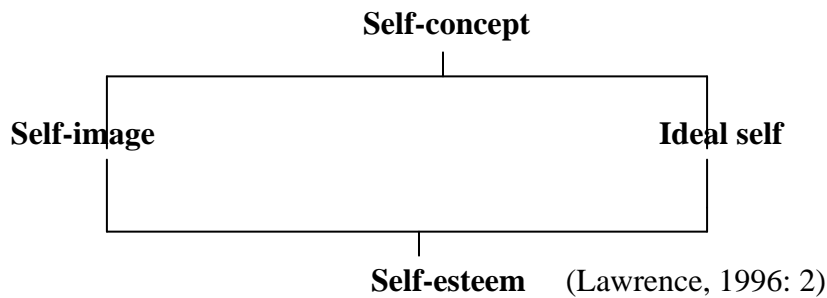
For example, a person by saying his/her occupation (student) reveals something about his/her self-image. At the same time he/she might say he/she is very brave and intelligent and that he/she would like to become a millionaire. This might reveal things about his/her self-esteem whereas the latter reveals his/her ideal self.

Throughout the years a number of definitions have been used to describe self-esteem depending on the psychological knowledge and understanding of each individual (Davies, 1995). Usually, it is defined as *a personal judgement of worth lying along a dimension with 'positive' and 'negative' ends* (Cottle, 1965; cited in Davies and Brember, 1995: 171). Coopersmith (1967: 4) defines self-esteem as:

'The evaluation which the individual makes and customarily maintains with regard to himself – it expresses an attitude of approval or disapproval and indicates the extent to which an individual believes himself to be capable, significant, successful and worthy'.

Lawrence (1981: 246), from his research on children of 8 to 11 years old, defined self-esteem as:*'The child's affective evaluation of the sum total of his or her characteristics both mental and physical'*.

In his research, Lawrence found out that children of that age tended to be concerned about others' opinions in three areas: 1) the opinion of peers, 2) the opinions of teachers and 3) the opinion of parents (Lawrence 1981: 246, Davies, 1995).

Research has also showed that there is a strong and positive correlation between a child's self-esteem and his/her school achievement (Gurney, 1987; Watkins and Dong, 1994). The more children feel good about themselves, the easier they learn and the longer they retain information (White, 1990). The more children have a positive image about themselves, the more chances they have to handle difficult situations in life such us prejudice, failure, solitude, violence, and so forth.

Empirical research conducted by Morgan and Klein (2000) confirms that adults that were not diagnosed early in their lives with dyslexia went through life feeling inadequate, frustrated and angry. Some of the students that took part in their study experienced low-self esteem due to the fact that dyslexia was not picked up when they were young (school) and a feeling of bitterness for the emotional pain that they had to go through. Dale and Taylor (2001) report in their study the feelings of personal failure that adults with dyslexia expressed due to their academic failure. Most of them had negative memories from school as some of them had experienced ridicule and physical punishment due to their difficulties.

Nevertheless, recent research has shown that there is a high percentage of dyslexic adults and young people among offenders. The percentage varies from 31% - 52% depending on the definition criteria, the methods and the age and nature of the individuals that took part (BDA report, 2005; Kirk and Reid, 2004; Morgan and Klein, 2000). Dyslexia if undiagnosed can result in anti-social behaviour as a result of low self-esteem, social exclusion and educational failure (BDA report, 2005; Kirk and Reid 2004).

Kirk and Reid (2004) in their study uncovered that 50% of the young offenders that took part showed at least borderline indicators of dyslexia. Only three of these participants were officially diagnosed with dyslexia. The subjects that had indicators of dyslexia also experienced signs of low self-esteem. Although the participants completed a computerised self-assessment screening test, informal discussions with the offenders revealed '*histories of school refusal, exclusion for disciplinary matters and, in many cases, a bitter dislike of school education*'.

The previous results are supported by the BDA and HM Young Offender Institution Wetherby report (BDA, 2005). In 2005 31% of the young offenders at Wetherby reported to have dyslexia with a further 32% showing borderline symptoms of dyslexia. Their outcomes are similar with comparable studies that have used cognitive tests for data collection.

The previous reports confirm the need for assessing and diagnosing dyslexia early in the individuals' lives. The earlier the screening takes place the better it is for their self-esteem and their future choices.

4.1.2 Self-esteem and Self-concept in Learning Disabilities

Cooley and Ayres (1988) examined the different attributions that students with learning disabilities and normal achievers used in order to explain success and failure. They reported that students with low self-concept, concerning academic performance, were more likely to justify their success due to external factors and their failures due to their lack of ability rather than their lack of effort. Margalit and Zak (1984) report that children with learning disabilities have higher levels of anxiety than do their peers without disabilities (in Gorman, 1999: 73).

Research has been done comparing the self-concept of learning disabled students (LD) and normal achievers (NA). There is no doubt that LD students have lower self- concept scores than NA. However, different studies published throughout the years conclude that children with learning disabilities (LD) might score lower than normal achievers (NA) in their school and academic achievement self-concept but they do not have significant differences when it comes to their global self- concept (Gans, Kenny and Ghany, 2003, Chapman, 1998, Elbaum and Vaughn, 2001). Shavelson and Bolus (1982) report that self-concept can be differentiated from academic achievement.

Kloomok and Cosden (1994) collected data from 72 learners with learning disabilities. Their research used Harter's 'Self-Perception Profile for Learning Disabled Students'. The reason they used this model was because Harter uses a multidimensional model to assess the competence and importance of an individual in a number of domains: *general intellectual ability, scholastic competence, athletic competence, social acceptance, physical acceptance and behavioral conduct (p. 141)*. 67% of the students that took part in their study had positive global self-esteem whereas when it came to the academic self-

concept 85% of the sample reported negative academic self-concept. Harborg (1996) reports that 73% of the LD students that took part in their research had below average academic self-concept. He attributes the differences between LD and NA learners in scholastic competence, regarding his sample, to variables like socio-economic status, intelligence, academic skills and grades rather than other self-concept domains. Scholastic competence was much more important for NA groups rather than LD. LD individuals did not view themselves as academic competent.

In addition, Kloomok and Cosden's (1994) research points in the same direction. Their study sample was divided in three groups: high global/ high academic self-concept, high global/low academic self-concept, and low global/low academic self-concept. The first two groups scored similar on achievement tests with the first group being more confident about their performance in academics. On the other hand, the third group was the one who had the most educational difficulties. The high global/ high academic self-concept group had a more positive image about their competence in other non-academic domains of their lives and they reported they had more support from their friends and family from any other group. The high global/low academic self-concept group reported that they felt quite adequate in their competence in non-academic domains. The low global/low academic self-concept group had a persistent negative image of their competence across all domains. They were the only ones who felt they were doing poorly academically, were not popular among their peers, did not like their appearance, and had problems with their behaviour. The students that took part in this study valued the importance of scholastic competence although they were aware of the problems they were experiencing in school.

Cosden et al. (1999) report that students who rated themselves in a positive way in non-academic domains they also had higher self-esteem. Physical appearance, social acceptance and athletic competence are some of the things that are some of the factors that are quite important and connected with higher self-esteem in LD children (Kloomok and Cosden, 1994).

A quite large part of the research has also been focused on the negative effects that the educational treatment has caused on the emotional and personal lives of children with dyslexia and how much this has affected their self-esteem (Miles, 1996; Riddick, 1996; Edwards, 1994). People have published their auto/biographies trying to make people understand their lives (Kenny, 2002; Simpson, 1981). Humphrey and Mullins (2002) state that children with dyslexia associate intelligence with the ability to read. This means that until they receive adequate help to improve their reading skills it is most probable they would consider themselves as unintelligent and this will affect their self-esteem. Dale and Taylor's (2001) findings come to an agreement with Humphrey and Mullins (2002). Suzanne, one of the participants in their study, believed she was not intelligent when she was at school due to the way she was treated. 'I was told I have to stand on the desk if I didn't spell the word 'away' correctly and I was given three chances to spell the word correctly and failed....I can honestly say I grew up thinking I was thick and stupid, so at secondary school it didn't surprise me that I was bottom of the class really, that's where I belonged (p. 1000)'.

Studies conduct by Morgan and Klein (2000) and Farmer et al. (2002) prove that the majority of their participants felt elated after their assessment. Their self-esteem and self-

concept increased. Knowing that dyslexia was the reason for their difficulties made helped them to have a closure and put all the negative views people had about them in the past.

The majority of the students that go through the educational system without being identified in the early stages start to feel that they are thick, stupid or lazy because usually people perceive them like that. Two university students have said *'It's not hard to believe in people when they say you're thick or you're lazy and your self-esteem drops on the floor'*, *'When people say that [stupid, thick], it really hurts; you believe what people say. When they say to you a lot you believe it'* (Michail, 1998, p.50). Some adults report that having borne the label of 'slow learners' or 'retarded', causing immeasurable damage to their self-esteem (Morgan and Klein, 2000, p.50). As Elaine a adult with dyslexia said: ''It's very hard to come out from doing a whole childhood of being told at school that you're stupid … to become and adult and not think you're stupid' (Dale and Taylor, 2001: 1002).

Andersen, a dyslexic himself, was world famous when he wrote: *'isn't it strange that at the age of 66 I can still suffer and feel those torments of my youth…? In my dreams I am still a school boy and Meisling [his teacher] is rude…'* (Simpson, 1981, p. xiii). Talking to adults with dyslexia (personal informal discussions) quite a few of them remembered the names of their teachers that treated them awfully. They remembered their teachers' negative reactions and some of them the humiliation that they have to experience in front of their peers due to their failure to learn as the rest of the class. On the other hand, they also remembered the names of teachers that treated them fairly and took the time to help them and support them.

When people with dyslexia are assessed they are often very pleased because they know that there is a reason behind their mistakes in their written work, in their inability of coping and remembering things. They can stop blaming themselves for failing. There is an explanation to their answers. They know that they are different and some of them probably knew all their lives, as children can sense from quite young that their way of learning is different to their peers (Barga, 1996). Kenny (2002) describes how much her identification boosted her self-esteem and confidence. *'Almost overnight, my self-perception changed. No longer the B set 'thickie', I found myself suddenly defined as 'gifted'. I cannot begin to explain the positive impact this change had on my confidence and self-esteem. It suited my personality and, in addition, nurtured the skills and abilities that I had. …I think more than anything else this was because (for the short time that I spent there at least –*art college-*) I no longer felt <u>different</u>. It no longer mattered that I was clumsy, forgetful and badly organised. My poor concentration and attention span, my tendency to blurt things out were also no longer a problem – after all, a little eccentricity was to be expected from artistically gifted children. I was just another eccentric, gifted young person, along with all the other gifted young eccentrics, who attended the school with me at that time'*. This describes vividly what it feels like once a person is liberated from the negative presumptions of the past. Having a positive image of themselves can help them improve their self-image and self-esteem. As Davis (1997) says, dyslexia can be seen as a gift and it has a lot of positive aspects that people with dyslexia need to be aware of. The learning difficulties are only one face of dyslexia.

Farmer, Riddick and Sterling (2002) asked university students with dyslexia about the impact their assessment had on their self-esteem. 49% said it raised their self-esteem, 27% said it remained the same and 24% that it lowered their self-esteem. Morgan and Klein

(2000) report that adults who are recently assessed have lower self-esteem than the ones assessed when they were children.

However, the pressure of scholastic competence and the comparison with normally achieving students puts a lot of strain on students with dyslexia and affects their self-esteem. Riddick (1996) mentions in her study that children with dyslexia had, together with reading-retarded children, a poor self-concept especially with poor peer relationships and lack of self-confidence. The children described themselves as disappointed, frustrated, ashamed, fed up, sad, depressed, angry and embarrassed by their difficulties (p. 129).

Another thing that can influence the self-esteem of students with dyslexia is the way the might be treated by their teachers. An unsympathetic teacher telling the student he/she would fail is the last thing a dyslexic student wants and needs, but unfortunately, there are a lot of students with dyslexia that had really bad experiences with teachers. Humphrey (2003) in his study found a lot of children that negative encounters with teachers. *'They shout at you for not doing work; the headmaster didn't believe in dyslexia'* (p.131).

Adults with dyslexia have described how miserable their life was in school because of teachers' lack of support and understanding. Adults with dyslexia seek 'recognition *and* understanding' (Dale and Taylor, 2001).
'I used to get bullied by teachers. They used to call me mental…Yeah, yeah they used to say that I was mental and men in white coats were going to come and take me away' (Morgan and Klein, 2000, p. 51).

This point is further supported by the following testimonials by adults with dyslexia:

' The teachers always seemed to be too busy to give me any extra help – I wanted to do well but I just couldn't get it in the first time' (Aileen in Preston, Hayes and Randall, 1996; p. 54).

'I could never finish copying from the blackboard before it was rubbed off by the teacher, then I got into trouble for not getting it down properly.' (Male, age 33 in Hughes and Dawson, 1995; p.183).

On the other hand, not all the teachers ignore and mistreat their students. There are a lot of good teachers in the schools that are trying their best to support the children with dyslexia and this has a positive effect in their self-esteem. Riddick (1996) talking to the mothers of the children with dyslexia that took part in her study gives examples of teachers that were sympathetic and caring.

'She was so supportive, and she was aware of Mark having problems, and she you know recognised that, and she tried to help us. But apart from that if you ask Mark he'll tell you she was his favourite teacher anyway.'
'She was wonderful, she encouraged him, praised him and rewarded him. She boosted his self-esteem and he progressed a lot with Mrs M. She enjoyed teaching him.' (p.133)

The mothers thought that the teachers who had a better understanding and had formed a good relationship with their children have helped them improve their self-esteem and confidence. Both mothers and children emphasised the importance of giving encouragement and praise as key qualities related to someone being a good teacher.

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Whereas being critical, lacking in understanding, and humiliating the children were some elements that characterised the worst teachers these children had.

How awfully can children be affected by the way their teachers treat them can be probably best described by the following quotation:

'Please convey to teachers in teacher training colleges that being humiliated at school destroys your whole life. If you lose your self-confidence, you are afraid to attempt anything new. It destroys you' (Male, age 50 in Hughes and Dawson, 1995; p.184).

Self- esteem plays an important role in the children's development. It is something that teachers, parents and all the people that surround these children have to work on to help them improve. It is not an easy job but if we want the best for these children we also have to try our best.

4.3 Learning Styles

'I am always ready to learn although I do not always like being taught'.
Winston Churchill

Learning is an important aspect in people's lives. We learn from our experiences, by interacting with our friends and family, by going to school. Education plays an important role in people's lives as we learn to read and write by going to school and later on in our lives we go to college or university to obtain qualifications that can help us have a better quality of life. However, the education system and curriculum is much more focused on performance rather than the learning itself (Reid, 2005). The difference between performance and learning is that the former assesses the individual by his ability to

succeed and achieve in a task whereas the latter helps the learner to improve his thinking and become better in resolving problems. Unfortunately, performance is a very important aspect of our lives. Parents chose schools by their performance tables and students are characterised and occasionally stigmatised by their scores and achievements in tests. Learners with special educational needs can be caught in a spider's web due to their lack of not being as successful as their peers. However, who is to blame for their failure? Is it the lack of knowledge from the learner's side or does the responsibility fall in the educator's hands?

One should bear in mind that not all people learn the same way, even though they might have the same abilities and knowledge. Different people have different learning styles. There are not good or poor students but different.

'*Learning style is the type of strategy used when an individual's cognitive style is applied to a learning situation*' (Mortimore, 2003: 7). The cognitive style refers to the way individuals process any given information whereas the learning style deals with the strategies that each individual employs in order to understand and learn the information (Mortimore, 2003; Reid, 2005). Research has shown that there are more than 100 different instruments that can be employed to identify learning styles (Mortimore, 2003; Reid, 2005; Given and Reid, 2001; Coffield, Moseley, Hall and Ecclestone 2004a). Learning styles can be identified with the use of standardised tests, interviews or observation.

Research has confirmed that if teaching is conducted according to the learners' learning style his performance improves (Doyle, 2002; Mortimeore, 2003; Reid, 2005). Brooks and Weeks (cited in Mortimore, 2003) compared different methods of teaching spelling to

children. They came to the conclusion that once the children were taught according to their cognitive style their spelling improved.

With special reference to dyslexia, Exley (2003) confirms the above position. In her study all the students that took part improved their performance and attainment once their preferred learning style was recognized and they were taught accordingly. The majority had a preference on a visuospatial/kinaesthetic learning style. Reid (2005) believes that students with dyslexia usually process information visually and holistically because they have a right hemisphere learning style. Mortimore (2005) in her study of 117 students found no link between visuo – spatial learning styles and dyslexia. She comments that there is not much information to support the right- hemisphere learning approach as Goswami (2004 cited in Mortimore 2005: 146) suggests that the two hemispheres work together in every cognitive process so far examined, including language and face recognition. On the other hand, Exley's (2003) result cannot be discarded. Her study had only a small number of subjects (8 students) and they showed improvement in their literacy and numeracy. Further research is needed in order to see whether there is a strong connection between dyslexia and visuo – spatial learning.

On the other hand, there is controversy whether the use of learning styles is beneficial to students (Coffield et al, 2004a). This is due to the plethora of different instruments, the validity and reliability of the instruments used and even the usefulness of matching style to teaching approach (Mortimore, 2005). Coffield (2009) reports that although tutors use questionnaires to identify the students' learning styles they tend to forget about them afterwards. He questions their benefits. He believes that tutors should develop a 'flexible repertoire of approaches to learning' (p. 50) rather than settling for just one. Coffield et al. (2004b) suggest that tutors should be cautious before labelling any student. The believe

that ' a reliable and valid instrument which measures learning styles and approaches could be used as a tool to encourage self-development, not only by diagnosing how people learn, but by showing them how to *enhance* their learning' (p.50).

Morgan and Klein (2002) draw the attention that adults with dyslexia need to have a different approach in their teaching and learning. They are much more in need of being taught more practical and relevant skills as their needs differ from the ones of younger individuals. Adults need to fill in application forms, to cope with day-to-day engagements at work and home. Their learning needs to be relevant to their obligations and strengths. Learners should be encouraged to find their own learning style and adapt it to their needs. By understanding the way they learn, individuals can improve their learning and find appropriate methods of achieving that.

This point is further supported by the following comment from a student with dyslexia: *'I make spidergrams. When I get a question, I rewrite it on my own words – why use all these complicated words? I put it in simpler words, then I put answers to the questions that I know already, and sometimes I'm quite shocked by how much I already know'* (Luke in Morgan and Klein, 2002: 166).

Adults with dyslexia feel frustrated because their teaching was not related to their preferred learning style. Although in some cases remedial help was provided at school it had no effects whatsoever due to the fact it was not adjusted to the students' learning style. Morgan and Klein (2002) present the case of Michael who felt that even though he received support at school, it did not assist him to improve his skills as he was taught by conventional methods. Multisensory teaching has proved to be beneficial for students with

dyslexia (Scott, 2004). Conventional methods that focus on overcoming weaknesses are not as effective as the ones that are focused on the learner's strengths.

'I became part of the 'hardcore'. By 'hardcore' I mean we were put there in the first years and were still there in the fifth... The separation of these classes reinforced the stigma of backwardness. If only some thought was given to the needs of the members of these classes, how things could have been different! The question 'Why are not learning?' was never asked. Conventional methods of teaching had failed us, but they were still embodied in these classes: spelling tests, reading aloud, writing out spelling rules. Different people need different strategies to learn - it is just a matter of finding which one'. (Michael in Morgan and Klein, 2002: 158).

Cheminais (2006 cited in Rayner, 2006) writes that effective and successful teachers will:
- Show respect for pupils' individual learning styles and differences.
- Be responsive to pupils' different learning styles.
- Use different levels of tasks and activities.

On the other hand, teachers cannot completely be blamed for failing to recognise and support students according to their learning style. It would be ideal that every student had the immediate support and appropriate help in the classroom but unfortunately it is not possible for the teacher, especially in crowded classrooms, to focus on every child individually and adapt their lessons in order to suit all their students' needs. Limited resources in the classroom, including support staff, make it hard for teachers to concentrate and fulfil everyone's requirements. In a perfect school environment all students should be taught according to their learning style but until more resources, time and support is being

allocated for teachers this would be a utopia. The same can probably apply to university

lecturers where the number of students in a lecture theatre is quite often large.

Nevertheless, this does not mean that teachers and lectures cannot adopt their teaching.

This can happen by talking and listening to their students and assessing the feedback they

give to them. By adopting their teaching to what the students inform them is best for them

and considering their suggestions there is room for improvement.

Are learning styles are essential for students to improve their learning and attainment?

Further empirical research needs to take place in order to be able to answer this question

with confidence. There is controversy in the literature (Coffield et al, 2004a,b; Mortimore

(2005); Exley (2003) showing positive and negative aspects in the use of learning styles.

Maybe the solution could be to 'expose' the students to different types of learning using all

their senses and possible

4.4 Conclusion

People from a young age are concerned about others' opinions in three areas: 1) the

opinion of peers, 2) the opinions of teachers and 3) the opinion of parents (Lawrence 1981:

246, Davies, 1995). Family, teachers and peers and their feed back can affect the way we

perceive ourselves and our self-esteem.

In case of dyslexia research has shown that before they were assessed people with dyslexia

were feeling quite low about themselves and they were started to believe the negative

comments that other people used to describe them (thick, slow). Without an official

assessment they could not explain what was wrong and why compared to their peers they were underachieving no matter how hard they tried.

Dyslexia students associate intelligence with the ability to read (Humphrey and Mullins, 2002). Academic failure can influence their self-esteem and feelings of being unintelligent. Adults report feelings of anger and frustration due to lack of early assessment. They feel that they have missed out in their education and have lost opportunities for a better future (Morgan and Klein 2000).

Research has proved that students with dyslexia learn better when they are taught in their preferred learning style. Successful teachers need to:

- Show respect for pupils' individual learning styles and differences.

- Be responsive to pupils' different learning styles.

- Use different levels of tasks and activities (Cheminais cited in Rayner, 2006).

Dyslexic students with appropriate help and support can accomplish the same things like everybody else. A great example of the things that dyslexic people are capable of is the increase in the number of students with dyslexia that enter Higher Education Institutions every year. Although the incidence of dyslexia in Higher Education is in the region of 1.2% - 1.5% (compared with about 4% in the general population) (Singleton et al., 1999: 81) more and more students every year seek support and identification from their preferred institutions.

This chapter has highlighted the connection between low self-esteem and academic failure and the effects that can have in the life of a dyslexic individual and is linked with the research questions involving the self-esteem of students with dyslexia.

In the next chapter a discussion about the challenges that people with dyslexia face in Higher Education will follow entailing the current framework and the support mechanisms that take place in HEIs across the UK.

CHAPTER 5

HIGHER EDUCATION AND DYSLEXIA

5.1 Introduction

The number of students with dyslexia entering Higher Education Institutes (HEI) increases every year. Dyslexia awareness and government initiatives for the students make more and more students seek support for their difficulties. We cannot be sure of the exact number of students with dyslexia studying for a degree in the UK HEIs as 43% of them are identified after assessment in HE (Singleton et al., 1999).

2.8% of the students studying for a degree during 2006/7 in the UK have dyslexia compared to 0.70% in 1996/7 (HESA). Singleton et al. (1999: 15) believe that the reason for this increase is due to the following:

- Earlier identification and provision for school children with dyslexia.
- Increased support for students with dyslexia within higher education.
- Wider access for mature students.

Since September 2002 HEIs in the UK have to make reasonable adjustments to accommodate people with disabilities (including dyslexia) and their needs.

Students with dyslexia in higher education need an up-to-date assessment in order to prove they have dyslexia. The assessment needs to be carried out by a trained and experienced in

adult assessment psychologist or teacher (Singleton et al., 1999). After the assessment students can apply for the DSA and request support from the learning support services from their universities.

This chapter informs the research questions that are related to the experience of students with dyslexia in Higher Education with particular reference to the assessment and support they receive from their institutions while studying for a degree.

5.2 Dyslexic students in Higher Education

Going to university for every person means the beginning of a new life. It is a totally new environment. The students have to deal with a whole new range of experiences both in their academic and private lives as well. Being away from home, they have to organise their own life and do things without the support of their family and at the same time try to deal with the workload of their studies, keep up with colleagues and study for assignments, deadlines and exams (Gilroy, 1990). Going to university also means moving from any dependence on family, school, and friends that have known the person for a long time to independence. The university is a different education system and atmosphere. It is a semi directed education system (Westwood, 2000). In order to succeed students need to be self-determined and motivated to study. Lecturers will not check on students all the time to see whether they have done the work and the reading they are supposed to do. Students need to be self-disciplined to do the work when they have to.

Being a university student is hard enough but it is even harder if someone has a disability. Coming up to university is a time that students have to confront their disabilities. Students

cannot suspend their disabilities no matter how much they may wish to. They are obliged to do all the things that non-disabled students do but they have to try even harder to overcome any barriers caused by their disabilities in order to succeed in Higher Education (HE) (Borland and James, 1999). Cohn (1998 cited in Heinman and Precel, 2003: 248) described the feelings of a college student with learning difficulties (LD) as follows: "For students with LD it can be a nightmare. When these students enter college they are not only beginning an unexplored and unfamiliar way of life but embarking on a journey that threatens their established motivational drive, need for order, compensatory skills, and social relationships" . However, this does not mean that all students with LD have problems adjusting academically and socially.

When it comes to dyslexia, the exact number of dyslexic students in higher education is not known. One of the main reasons is the fact that a lot of students have not been identified while they were in school. In 1996, the proportion of dyslexic students not identified as dyslexic until reaching higher education system was over 40% (Singleton et al., 2001: 3). Besides, there are students that although they have problems do not ask for special help either because they think that they can cope by themselves (Richardson and Wydell, 2003) or due to fear of being stigmatised as disabled (Tinklin et al. 2001; 2004). In the US, surveys carried out by the American Council of Education on undergraduates have shown that the actual number of undergraduate disabled students is higher than the one reported before entering their institutions (Henderson, 1999 in Richardson and Wydell, 2003).

From 1994 to 1996, the overall number of students entering HEIs in the UK increased from 217,000 to 296,000: a 9% increase. Over the corresponding period, the number of students declaring they have dyslexia on entry to higher education courses increased by 47%, and the incidence of such students increased from 0.74% of all students entering higher education in 1994 to 1.00% in 1996 (Dearing, 1997 in Singleton Report, 1999: 15). Personal unofficial conversations with dyslexia learning support tutors confirm that the number of students with dyslexia in higher education increases every year as well as the number of students being identified as dyslexic after entering university.

Singleton et al. (1999: 15) believe that the reason for this increase is due to the following reasons:

- Earlier identification and provision for school children with dyslexia.
- Increased support for students with dyslexia within higher education.
- Wider access for mature students. Further discussion about the increase of students in higher education will follow.

On the other hand, the statistical information that the HESA provides refers to first year students only. On the other hand, it is not known how many of these students are registered for a one-year course or three years. Also, there is no record informing whether or not some of the students might have dropped out of their courses and have registered for the next academic year to a different course in another department or university. Besides, the HESA does not include in their list any students with dyslexia that are identified after their first year of studies. The data collected is based on the information that the

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Universities and Colleges Admissions Service (UCAS) provide. Whether a student is recorded as having a disability/impairment is based on the student's assessment and the subsequent disclosure of this disability/impairment. As mentioned before, there are students that do not disclose their disability because of fear of not being treated the same as the non-disabled students and fear of not being accepted by the institutions due to their disability. It has to be mentioned that there are students who feel that their disability does not play an important role in their lives and does not affect their abilities to study and they do not believe they need extra help and support in higher education (Nye, 1997). It is most probable that these students will not reveal their disability, as it is not compulsory to do so (Tinklin and Hall, 1999). Therefore, the disability data might not reflect the exact student population. Even if the statistical results of the HESA may not mirror the precise number of students with disabilities in the student population no one can deny the importance of the data collected. There is no doubt that the number of students with disabilities increases every year. They might be underrepresented considering the number of people who have any kind of disabilities (learning, mental or physical) compared to the non-disabled population but the numbers are getting higher every single year especially for people with dyslexia. However, a very important question that should be posed is: *have numbers actually risen or do existing people feel more comfortable at disclosing a disability*? (Vickerman and Blundell, 2010: 23).

5.3 Increase of students with dyslexia in HE

There are quite a few reasons that can explain this increase. One of the most important ones is that the equal opportunity and anti-discrimination legislation encourages the entry of talented but disabled students in higher education (Pumfrey, 1998). Since the 1981 Act

awareness raising has meant that more children are being assessed, statemented and subsequently given trained and structured help in the formative years (Gilroy, 1990: 8). Furthermore, early identification helped students to come to terms with their problems and ask for appropriate help in order to cope with them and succeed in the field that they have chosen. There are a lot of students who find out that they have dyslexia as a result of needing special arrangements for their GCSE or A level exams (Singleton et al., 1999). Therefore, when these students apply for a programme of study in an institution, they will probably include it in their UCAS form in order to be eligible to get the support they need. Tinklin, Riddell and Wilson (2001) believe that the rise in the proportion of disabled students in the student population, especially for dyslexic students is due to the increased incentives for disclosure of impairment.

Another reason is the increase of mature students in education. Over the last years more mature students have entered Higher Education as they have better opportunities to do so. A number of them are dyslexics who were not identified at an earlier age and who dropped school or university because of their poor performance (Jamieson and Morgan, 2008). These mature students probably have 'missed the net' in the past (Gilroy, 1990). Mature students have the chance to enter university via Access courses or other 'non-traditional' routes that can help them accumulate the credits they need to qualify for an entry in higher education without necessarily having to demonstrate the traditional 'A' level competencies (Singleton et al., 1999: 15). The fact that 40% of the student intake is composed of mature students, suggests that the figures for students with dyslexia may be higher, as a large number of intelligent adults in this group did not succeed in early education because their dyslexic difficulties were never identified (Morgan, 1994). A number of dyslexic adults are diagnosed after their children's assessment (Riddick, 1996).

The majority of the students with dyslexia are registered in full-time courses. Only a small numbers of dyslexic students prefer to register for a part-time course. Richardson and Wydell (2003) believe that a plausible reason for the lower representation of students with dyslexia in part-time programmes is that, until recently, the Disabled Students Allowance (DSA) was only available for full-time students. Now students that attend part-time programmes can apply for it (DfES, 2003). Another reason they mention is that people with dyslexia find a focus on written correspondence materials uncongenial (Richardson and Wydell, 2003: 491). This might be true, although this seems to apply more to long-distance learning courses, which rely more on written material than face-to-face contact. Besides, people without disabilities may be in a better position to find employment to support themselves during part-time study (Richardson and Wydell, 2003: 491).

5.4 Widening Participation in Higher Education

Over the recent years the Government has tried to widen participation in Higher Education. In England 43 percent of people between the ages of 18-30 enter HE. The Government's target is to increase the participation in HE towards 50 per cent by 2010 (DfES, 2003). With incentives for both students and HE institutions the Government is hoping to recruit more students from less advantaged backgrounds and ensure their success. These may include disabled people, people from a particular cultural or socio-economic background, or even a particular gender (HE Academy, ICS, 2005). There are four conditions which need to be met if a capable student is to embark on an appropriate higher education course: attainment, aspiration, application and admission (DfES, 2003a: 5). The future candidates have to overcome some barriers that are mainly identified in the

attainment, aspiration and admission process. The admission procedures are generally fair as they are based on merit irrespective of the student's background. In 2000 eighteen per cent of young people coming from a less advantaged background entered higher education in contrast to 48 per cent of people whose families were coming from higher social and economic backgrounds. Also, an 18 year old with a disability or a health problem is 40 per cent as likely to enter Higher Education as an 18 year old without a disability or health problem (Allen and Storan, 2005 in Pavey, 2006: 10). Different programmes (Playing for Success, Excellence in Cities) are running throughout the country in an effort to improve the educational standards and achievements of the students and help them gain a place in the university (DfES, 2003a).

Aspiration and application are by some means connected together. The evidence shows that students who come from the disadvantaged groups are less likely to apply in the older and more established universities (Russell Group) even though they have the appropriate qualifications. The acceptance rates are practically the same for all candidates regardless of their background (DfES, 2003a). Programmes, like the Aimhigher, are trying to raise attainment and aspiration by supporting students from less privileged backgrounds. The Dyslexia Support Network (DSN) is one of the projects funded by the Aimhigher programme (Action on Access, 2005). Every year the three Higher Education Institutions in the network (St Mary's College, Kingston University and Roehampton University) hold a conference to inform potential dyslexic university students and their teachers about the demands of HE, the support available to them and how to access it. Over the first four years that the programme was running the feedback was very positive, as most of the students are not aware about the DSA and the computer software that is available before they enter university (Action on Access, 2005).

The widening participation strategies aim to support the student to reach their potential and experience the benefits of HE. Our society is changing and the employers demand more people with higher education qualifications. Research has shown that graduates with honours degrees earn 64 per cent more than those without a degree. With the new two-year work focused foundation degrees the Government hopes that this figure will drop to 50 per cent. Graduates also are less likely to be unemployed compared with non-graduates (DfES, 2003).

Both students and the country's economy benefit from the expansion of HE. The Government's intention is to make sure that all the students will receive adequate support when they enter HE and the skills that they will acquire are going to be of appropriate quality to meet the needs of the economy and their future employers.

5.5 Graduateness

Over the last decade there has been some controversy considering the concept of 'graduateness'. In 1995 the Higher Education Quality Council's (HEQC) run project on 'graduateness' whose purpose was to *'examine the extend to which agreement exists within the higher education sector on the generic or non-subject-specific qualities expected from graduates. The aim is to identify a set of attributes that could serve as the basis for a threshold standard for all degrees, regardless of field, and thus be used as a bench-mark for comparability of standards at the threshold lever across the HE sector'* (HEQC, 1996, Para. 7).

Over the years scholars and other professionals from different principles have proposed various attributes for those who have successfully completed a degree at a UK university. Bowen lists (1977 in HEQC, 1996) cognitive learning, emotional and moral development and practical competence as some of the qualities that a graduate should have. The Library Association (1996 in Glover et al., 2002: 295) sees graduateness as a set of transferable skills including planning; gathering, selecting, appraising, organising and recording information; communicating and realising results, and evaluating achievements.

Wisdom (1996) tried portraying the student's beliefs on graduateness. 206 students took part in this project and they thought that communication and social skills; planning/organisation; analytical, group working, presentation skills; ability to work form resources; ability to use language precisely were some of the attributes that describe graduateness.

There is no consensus about how we can define graduateness. The reason is that several variables like the growth of students; the new subjects that have been developed, the variety of courses offered in HE are some of the factors that need to be taken under consideration (HEQC, 1996).

Glover et al. (2002) emphasize the direct connection between graduateness and employability. The world of work is changing and many employers are looking for something in addition to a degree and have become more explicit about the skills they seek and more sophisticated in identifying them in their

recruitment procedures (Harvey, 2001). Glover et al. (2002) wanted to investigate the distinction between graduateness and employability and consider the students perceptions about them. In their project the majority of the students that took part were expecting a secure and profitable future from their chosen courses (78%) and only 14% recognised the gains from the wholeness of the university experience (p.303).

Furthermore, in their paper HEQC (1996, Para. 14) mention that '*ancillary qualities that would be expected of a graduate, but which had not previously been regarded as the responsibility of higher education to teach. These ancillary qualities would be likely to include such things as the ability to write in grammatically-acceptable and correctly spelt English (or Welsh), a certain level of numeracy, a range of general knowledge, a basic familiarity with information technology, and so on'*. It also adds: *'there seem to be irresistible arguments that no-one should graduate who lacks such ancillary skills; but there is anecdotal evidence that this can occur'*.

If such proposal were applied it would directly affect all the students with dyslexia. Does this mean that people with dyslexia will be not permitted to enter higher education? The proposal contradicts the rights for equal opportunities for people with disabilities and SENDA (2001). Learning support tutors have been employed to support the students in need. Until now some HEIs have refused access for people with dyslexia only to medically related courses and programmes of teacher training (Singleton et al., 1999). We should also take into consideration the effect something like that might

have in a dyslexic person's self-esteem. How can we persuade a student with dyslexia that he is part of the society and at the same time we 'reject' him due to the fact that his literacy difficulties. Laycock, (2001 cited in Pollak, 2005: 149) has observed: 'in terms of the social model of disability, I have always regarded the brain functions associated with dyslexia as part of a perfectly normal variation in the population, but the English language as a social factor 'disabling' dyslexics in much the same way as stairs inhibit those in wheelchairs'.

Singleton et al. (1999) report that although students with dyslexia achieve lower proportion of 'good' (first class and upper second class) degrees compared with other groups; there is still a considerable number of them that do obtain 'good' degrees. We should also take into consideration the positive aspects of dyslexia and how much individuals with dyslexia have contributed in our society.

5.6 Support for Students with Disabilities

'When disabled people enter higher education they are taking up an opportunity to increase their knowledge, to develop their social skills, to obtain good qualifications and to expose themselves to debate and discussion. It is an important experience for empowerment' (Hurst, 1996:141).

The empowerment potential is not something easily achieved by students with disabilities, as they have to overcome quite a few barriers in order to succeed while they are studying for a degree. Obtaining a degree will give these students better opportunities to get a better

job and therefore earn more money. This is something that will affect their lives long term (Fuller, Healey, Bradley and Hall, 2004).

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Students with disabilities require, depending on the degree of their difficulties, support to overcome any rising problems caused by their disability. 44% of the students that took part in the Fuller et al.'s study (2004) reported having barriers connected to their disability. Until recently institutions in the UK did not have any legal obligations to make special arrangement to accommodate students with disabilities. The Disability Discrimination Act of 1995 excludes institutes of higher education. However, Part IV 2001 places more responsibilities on the councils requiring higher education institutions to publish disability statements and include conditions relating to the provision made or to be made with respect to the disabled (DDA, 1995). The Quality Assurance Agency (QAA) (1999: 1) code of practice published guidelines for higher education institutions in order 'to ensure that students with disabilities have access to a learning experience comparable to their peers'. In 2001 The Special Education Needs and Disability Act (SENDA), revised in 2005, makes it unlawful for the body responsible to discriminate against a disabled person. It amended part IV of the DDA 1995 and it came into force in September 2002. The HEIs have to make reasonable adjustments to accommodate disabled people and their needs. They have to be proactive and be prepared for any new students with disabilities that will enrol in any of the programmes they offer.

Tinklin, Riddell, and Wilson (2001) reported that:

- All institutions have a Disability Statement.
- Arrangements are largely in place for addressing disabled students' needs in examination.

- The majority of institutions have application and admission procedures relating to the needs of disabled students in place.

- 95% on institutions in England and Wales and all institutions in Scotland have a disability officer. This is a part-time post in some institutions and a relatively new post in most English/Welsh HEIs (p. 3)

On the other hand, Tinklin et al. (2004) reported that few institutions claim to be 'prepared in advance' for disabled students although there are signs that things are moving forward towards the needs of individual students as most institutions include in their policies provisions for disabled students in relation to teaching, learning, informing and raising awareness among the institutions' employees. Riddell et al. (2005) stated that English universities were better equipped and had more employees in their students support services mainly due to Government funding. The majority of the institutions though delegate the provision of support for students with disabilities to departmental level (Holloway, 2001). This frustrates the students, as there are not clear guidelines in place and each department may respond differently. Holloway (2001) also adds that departments receive disability as a problem affecting individual students and therefore requires individual response (p. 609). Riddell et al. (2005) postulate that departmental autonomy makes the support and provision for disabled students harder to be achieved. The following remarks from a senior management at an English university can describe the tension produced due to that:

'We got to the stage where each department had to have someone to look after women, someone to look after overseas students, somebody to look after disabled students and someone to look after mature students. In small departments, together with the requirement to fill out performance forms for the QAA and the RAE, it was producing real

aggro…We have been thinking about having one person in each department who has a sort of conglomerate portfolio for all the waifs and strays' (Riddell et al., 2005: 69).

All this tension does not help the disabled students and results into unrealistic expectations that the departments cannot deliver. It also means that students with disabilities are left uncertain over who is responsible to help them and make reasonable adjustments to their needs.

Hurst (1996 in Richardson and Wydell, 2003) suggested 'that students with disabilities were thorough in their preliminary research and applied only to those institutions which had the facilities they needed and where there was strong chance they would be offered a place'. Riddell et al. (2005) confirm this. They reported that institutions that publicised the support they offered for students with disabilities, for example mental health disabilities had much higher numbers of students disclosing this disability.

Tinklin et al. (2003 in Fuller et al. 2004: 458) rightly suggest hat ' until institutions consult their disabled students directly they will remain ignorant of the difficulties and barriers faced by disabled students as they go about their daily business'. More research that includes the students' experiences needed in order to improve the rapidly changes of HE and provide the reasonable adjustments to facilitate their learning. It is important to consult the students themselves and listen to their voices (Riddell et al., 2004; Vickerman and Blundell, 2010).

5.6.1 Support for Students with Dyslexia

The National Working Party (Singleton et al., 1999) reported that almost three quarters of the HEIs that took part in their project had some kind of provision for students with dyslexia. A little more than half of all the institutions had a dyslexia-trained tutor offering support for the students with dyslexia. New universities seem to have better facilities than the traditional ones. 57% compared to 27% had a dyslexia-trained tutor. In the case of colleges offering higher education course the tutors were employed by the institution, whereas in the case of universities, only half of these professional were employed by the institutions. The rest were employed on a consultancy basis. 40% of all the universities were offering *specialist-counselling* facilities for students with dyslexia (Singleton et al., 1999: 44). New universities seem to provide more services to students with dyslexia than the traditional ones. The National Working Party (Singleton et al., 1999) believe that this is occurring because new universities have slightly more students with dyslexia (1.31% opposed to 0.95%) and last but not least new universities were more successful in bids for funding from the HEFCE to support special initiatives to widen access for students with disabilities.

Students with dyslexia have the right to ask for extra time during their exams. The National Working Party (Singleton et al., 1999) report that almost all the institutions that took part in their study (195 in total) allow extra time for students with dyslexia in written exams. The time is usually ten to fifteen minutes extra per hour. New universities tend to allow students more additional time than the traditional ones (fifteen minutes opposed to ten).

Apart from that, special arrangements in examinations for students with dyslexia are taking place in the majority of the HEIs including use of an amanuensis, a reader or a word processor (Singleton et al., 1999). New universities were also more disposed to allow students to tape-record their answers in examinations or take an oral examination rather than a written one. Some universities even allow rest breaks, use of separate rooms for dyslexic students and use of electronic spellcheckers during examinations

5.7 Assessment in HE

As mentioned before, the precise number of students with dyslexia attending higher education is not known as not all the students want to disclose their dyslexia in their UCAS form and there are many cases that are not aware of being dyslexic before entering university. The Working party report that during the survey they conducted 43% of the dyslexic student population was assessed after entering university (Singleton et al., 1999). Riddell and Weedon (2006) state that although there are students with dyslexia that do not agree with the disability term still the number of students that seek diagnosis after entering HE is on the increase. Singleton et al. (1999) estimate that an average university can expect from 60 to 100 new students each year to come forward claiming dyslexia related difficulties. The latter consists of students that need to be reassessed because their previous assessment might have been more than two years old as well as students that were never diagnosed in the past (this includes students that realised they had dyslexia after their first year in the institution).

In the majority of the cases the HEIs are covering the cost of the assessment. The National Working Party (Singleton et al., 1999) state that 60% of the assessments were funded by the institutions and only in 10% of the cases the students had to pay themselves. The majority of the HEIs performed a screening assessment before students were referred for full psychological assessment. Half of the HEIs administer their own internal assessment whereas professionals outside the institution assess the remainder. The cost of the assessment can vary from £150 - £300 (Singleton et al., 2001).

An educational or other qualified psychologist and specialist teachers are qualified to certify the assessment (Gilroy, 1990; Hurst, 1996; Jamieson and Morgan, 2008). The assessment can be carried out either at an independent assessment centre, or at the students' college or university. Singleton et al. (1999) report that assessment in HE should be carried out only by trained professionals who have experience of adult assessment. They suggest the following five professional bodies as the most suitable in assessing HE students:

1. Chartered Psychologists with current Practising Certificate.
2. Educational Psychologists employed by an LEA or who are members of the Association of Educational Psychologists.
3. Qualified Clinical or Occupational Psychologists.
4. Experienced teachers with a qualification from a professional training course involving assessment of adults with dyslexia, and who have demonstrated competencies in psychometric testing.
5. Psychologists or persons in related professions who have substantial experience in the assessment of dyslexia in adults and who have demonstrated competencies in psychometric testing (Singleton et al., 1999: 94).

From September 2007, specialist teachers need to have a practising certificate issued by an approved professional body in order to conduct assessments (Jamieson and Morgan, 2008:12). Although this does not apply for HE; as in order to be eligible for Disabled Student's Allowance (DSA) the students need to have a full dyslexia assessment by a psychologist (Meehan, 2010).

It is essential for both the student with dyslexia and the HEI to have an up-to-date assessment. First and foremost due to the need to confirm that the student actually has dyslexia. Also, institutions need as much information as they can about:

- The severity of the student's current difficulties.

- How those difficulties are likely to affect their particular studies.

- What support would therefore be appropriate

- What examination arrangements would be fair (Singleton et al., 1999: 82).

Gathering all this information is beneficial both for the student and the institution. Students, especially the ones who were not identified before, have finally an explanation for their difficulties. Moreover, they can ask for special provisions during the length of their course and their exams (extra time, use of a laptop, use of a tape recorder during the lectures). On the other hand, the university can support the individuals' needs in accordance with their course requirements although *not all difficulties can be foreseen* (Singleton et al., 1999: 84), as it is almost impossible for learning support tutors and the people that conduct the assessment to be familiar with every single course that an institution can offer.

Students that have been diagnosed before entering university and have

declared their dyslexia in their UCAS forms need to be re-assessed if their

assessment took place before the age of sixteen or if their assessment is more

than ten years old (Jamieson and Morgan, 2008). They need an up-to-date

assessment if they want to apply for the DSA and have their dyslexia

recognized by their institution. Previous assessments though can be quite

useful as the assessor can have a better picture of the individual's history of the

problem (Singleton et al., 1999).

5.8 Disabled Student's Allowance - DSA

Once they are formally assessed by a qualified and experienced professional students with

dyslexia can apply for the DSA. The DSAs are not paid as a set amount. Money is

allocated depending on the needs of each individual. It is offered to both full-time and

part-time students. The rates of allowances for 2003/2004 were as follows.

For full-time undergraduate students:
- Specialist equipment allowance - up to £4.460 for the whole of your course.
- Non-medical helpers allowance - up to £11.280 a year.
- General Disabled Students' Allowance - up to £1.490 a year.
- Reasonable spending on **extra** travel costs.

For part-time undergraduate students:
- Specialist equipment allowance - up to £4.460 for the whole of your course.
- Non-medical helpers allowance - **as a percentage** of the full-time rate, according to the workload of a part-time course.
- General Disabled Students' Allowance **as a percentage** of the full-time rate in the same way as the non-medical helper's allowance, to a maximum of £1.115 per year

- Reasonable spending on **extra** travel costs. (DfES, 2003: 18)

The DSA gives the chance for dyslexic students to buy equipment that is useful for their studies such as computers or any other device that is necessary for their work to complete their course. In addition, extra money can be given to those who need extra help outside the school time and need to attend special sessions to improve their skills (Pumfrey, 1998). Apart from these, the students can use the DSA money to have one-to one learning support, use someone to take notes for them in the lecture theatre. The DSA is not means tested and all students that are eligible for it can receive it regardless their financial background.

Filling in the forms for the DSA is not an easy task for students with dyslexia they might found it difficult to do so. Norton (2007) quotes some of the students' answers regarding the DSA. Student A said: *'The [DSA] forms are quite difficult… you needed someone to read it…'*. Student D also commented: *'…a lot of students might not actually bother with it because it is so hard to fill it in'* (Norton, 2007: 50). The students need support to complete the forms and receive the DSA.

Fortunately for the students, the student support services usually help students to complete the forms and apply for the DSA. 99% of the institutions that participated in the National Working Party's study declared that they assisted students with their applications for the DSA (Singleton et al., 1999). On the other hand, they were not in a position to know how many of these applications were successful, as many students did not inform their institutions about the final outcome of their applications. Institutions were not content with the DSA system considering students with dyslexia because of: 'inconsistencies between LEAs, the time-consuming nature of DSA application, the fact that the DSA does not

cover the cost of initial assessment and the fact that various categories of students are

excluded from the DSA at the present time' (Singleton et al., 1999: 45).

5.9 Conclusion

The nature of HE is rapidly changing. The Government wants to attract more people into

entering HE, especially from less advantaged groups. New routes that make access in HE

accessible have been set in place and incentives are offered to the students as well as the

institutions to make this possible. With the new programmes the Government expects to

raise the participation of students aged between 18-30 from 43 to 50 percent by 2010. All

these changes are happening in accordance with the needs of the industry and the

economy. Employers need more skilled and specialised individuals that can help the

economy and make it stronger. The Government's intention is not to make HE a third

compulsory stage of the education system but rather to strengthen the quality of the entire

education system and its institutions in order to support and promote the growing economy

and social needs of society (DIUS, 2007).

On the other hand, the Government contradicts itself if the proposals in the

HEQC (1996, Para14.) paper about the qualities of a graduate are applied

where people that have difficulties in their writing and numeracy skills should

not graduate. Students with dyslexia have proved that they can be successful in

their courses given the appropriate support. Besides, if the proposal comes into

action it will be at odds with the equal rights and opportunities that students

with disabilities should have.

Dyslexic graduates can be an asset for the growing economy and people can use their skills and special abilities to do so. University life can be challenging for these students but with appropriate support they can overcome the barriers created by their dyslexia. Once they are officially assessed by a trained and experienced specialist they can apply for the DSA and acquire equipment than can enhance and facilitate their learning. Nowadays, both full-time and part-time students can apply for the DSA and receive it irrespectively of their financial situation.

Following a discussion of the literature in the areas of qualitative research methods, the following chapter shows how these are brought together in a detailed discussion about the present research project and the methods that were used in order to collect and analyse the data.

CHAPTER 6

METHODOLOGY

6.1 Introduction

Over the last decades there has been an increase in interest in trying to find what dyslexia is and where it comes from. A lot of researchers have focused their research on children and the effects dyslexia has in their lives. When this research project started there was limited information about students with dyslexia in higher education. This project aims to listen to higher education students speak about their lives and the problems they have to conquer in order to complete their courses.

This present study will try to take a look at the experiences of dyslexic students in higher education. It took place between 1999-2001 and its aim was to portray a wider picture of the situation at the time with regard to university students with dyslexia. After the completion of the data collection the Special Education Needs and Disability Act (SENDA) came into force making it unlawful for the institutions to discriminate against a disabled person. The HEIs have to make reasonable adjustments to accommodate people with disabilities and their needs. They have to be proactive and prepared for any new students with disabilities applying and being accepted to any of the programmes of study they offer. Although, the SENDA came into force in September 2002, the three institutions which the participants of this study attended, had already appointed counsellors and provided dyslexia support in their learning support services for students with dyslexia.

They were dealing with any assessment needed, helping students complete their DSA forms and trying to give them any extra support they required.

Entry to Higher Education is a milestone for any student as it is the beginning of a more independent personal life (Parker, 1999). The independence from their family is starting to increase and new horizons are unfolding in front of them. For students with no disability achieving independence is more tangible. Students with dyslexia have to work harder in order to accomplish it. Although they are granted access to higher education with the same standards and assessment routines, they may need much more help and guidance than the non-dyslexic students to complete their chosen programmes of study. Students with dyslexia are challenged to compete in a world that was not designed for them and they have to comply with its rules and requirements.

6.2 Developing the research questions

As mentioned before the main research question is: What are the experiences of students with dyslexia currently (1999-2001) in HEI?

In order to be able to answer to the main research question the following sub-questions will be considered:

- How do these students cope with the new challenges they face while they are studying for a degree?
- How proactive were their universities at the time of the research study?

- How aware were the students about any special arrangements and other support mechanisms taking place in their institutions?

- How do they feel that lecturers respond to their needs?

The QAA identifies that:

With the completion of their degrees, students with dyslexia will have to be able to:

'… have developed an understanding of a complex body of knowledge, some of it at the current boundaries of an academic discipline. Through this, the graduate will have developed analytical techniques and problem-solving skills that can be applied in many types of employment. The graduate will be able to evaluate evidence, arguments and assumptions, to reach sound judgements, and to communicate effectively

An Honours graduate should have the qualities needed for employment in situations requiring the exercise of personal responsibility, and decision-making in complex and unpredictable circumstances' (QAA, 2001).

All courses will require students to be independent, be able to look for information in the library or using the internet, to follow and keep deadlines and discuss and expand ideas either in writing or with others (Farmer et al., 2002). However, students with dyslexia will find it harder to cope and deal with the above requirements without any help and support.

In order to help students with dyslexia it would be useful to have a background about their lives and previous experiences. This gives rise to further questions for research:

- Did dyslexia have any effects on their self-esteem?

- How did they feel about having to live with dyslexia?

- Have they looked for any support from close relatives or friends?

- What was the reaction of their teachers in school?

- Was there any effect on their social lives?

A further question considers how late assessment can result in low self-esteem and school 'failure', if these students do not have suitable support for their problems. In the educational system the problems augment when these students continue their studies, as the workload gets more and more difficult to comprehend. Students felt much better knowing they have dyslexia as it proves they were not, as mentioned before, 'stupid' or 'lazy', words that sometimes people used to call them (Farmer et al., 2002). Once these students realise and accept their condition they manage to find ways to improve their skills. This happens either by asking help from others (friends, family or professionals) or by trying themselves to study harder in order to catch up with the rest of their group.

By dealing with all the above questions, I will try to portray any difficulties that dyslexic university students might face and find ways by listening to their voices to improve the standards and support available to them; with the intention of giving them the chance to enjoy their life in university and benefit from equal opportunities in learning.

What is the experience of students with dyslexia in Higher Education? What are their problems, if any, their coping strategies and what kind of support is

there for them in the university setting? This is considered in the light of the

smaller questions mentioned before.

In the following pages the research method instruments and the data collection

process will be examined.

6.3 Qualitative Research

Deciding which research method to follow in order to gather data is one of the

hardest decisions in terms of research. Knowing that the participants of this

study were students with dyslexia and the questions asked involved moments

of their personal everyday lives meant that their answers would be lengthy and

quite descriptive.

I wanted people to share with me moments from their lives; to have their voices heard. I

intended to examine how they coped with dyslexia and how dyslexia has affected them

during their lives. Qualitative research gave me the opportunity to explore these questions,

as it can be focused on views and beliefs.

As Denzin and Lincoln (1994: 2) said:

'Qualitative research is multi-method in its focus, involving an interpretive, naturalistic

approach to its subject matter. This means that qualitative researchers study things in

their natural settings, attempting to make sense of, or interpret, phenomena in terms of the

meaning people bring to them'.

Qualitative researchers are interested in *meaning* (Merriam, 1988 in Creswell, 1994: 15). They study a social setting to understand the meaning of participants' lives in the participants' own terms. They want to investigate how people make sense of their lives, experiences and how they shape their world. They try to have a more personal relationship with the participants and try to understand people as a whole. They see people as human beings that can think and learn, have an awareness of themselves and their past and possess motives and reasons (Newman, 1994). People are not just instruments analysed by reducing the data to numbers. Qualitative researchers go beyond the details of everyday life and try to see what is behind this. They take the information they need directly from the people that are involved and listen to the different emphases they give them. Each person conceives differently the same or similar situations and the way each person interprets the world has his/her own signature. This is a way of providing individual insight into a situation (Einser, 1998). Quantitative researchers, on the other hand, aggregate large numbers of people without communicating face to face with them (Janesick, 1994).

The data gathered with the qualitative paradigm is most of the times descriptive. When we talk about personal experiences it is not easy to present them with numbers and we cannot ask people to limit their responses to a one-to-five scale. Quantitative research involves numbers and counting. Quantitative data are enumerated as variable values and then statistically tested (LeCompte and Preissle, 1993 in Vierra, Pollock and Golez, 1998: 120). Qualitative researchers prefer to use their participants' words and use *thick descriptions* (Gall et al., 1996) to present the results of their study avoiding the need to present series of statistical tables and analysis (Armstrong, 1987). Data are analysed as closely as possible to the form in which they were recorded or transcribed. During the time data are collected,

qualitative researchers pay attention to everything that is happening around them and the way the participants of the research behave. Every single detail counts and might give precious information to their study.

Furthermore, in qualitative research the researcher builds his/her theory and depending on the finding, s/he may differentiate his/her original question and form it relative to the direction the study takes. This inductive procedure means that theory is built from data or is grounded in data (Newman, 1996). With grounded theory, generalisations emerge out of data themselves and not prior to data collection. In quantitative research, researchers specify the variables they are about to investigate before beginning their study.

This present study did not set up any variables before it started. There were some specific areas that were to be studied but most of the categories and the conclusions were drawn after the data were collected and all the needed information was gathered.

Another reason that influenced my decision to use the qualitative approach in this present study was the fact that at present, the main body of evidence on the social and emotional concomitants of dyslexia comes from personal accounts and life histories (Riddick, 1996: 33). Most of the people that had done research on the social and emotional problems of dyslexia have used qualitative methods of research such as interviews, case studies or observation techniques to gather their data. Riddick (1996) interviewed some of the children and their parents that attended the Dyslexia Institute. Edwards (1994: 152) chose

the case study approach because she wanted to look at each person as a whole and try to discover what particular elements in his career helped him to cope with his difficulties better. She used a 'free interview' where she let the children speak freely about the problems they had and with participant observation she gave additional insight to the study. Furthermore, Miles and Varma (1995) and Preston, Hayes and Randall (1996) have used case study approaches also. The former wanted the public to become aware of the stresses that dyslexics experience and encourage techniques that can help for these stresses to be avoided. The latter wanted to describe the problems of students with dyslexia in higher education and give an individual holistic existence to the problem in order to help people who are dealing with these students to have a better understanding of their problems. Moreover, looking at the relevant literature one will find a lot of published personal accounts and biographies of dyslexic people. Susan Hampshire (1981) is one of the most famous biographies published in the United Kingdom. Other examples of personal accounts are the ones of Faludy and Faludy (1996) and Innes (1991) where dyslexic students and their parents describe their struggle to cope with the problems dyslexia has caused them.

6.3.1 Life History

 Plummer (1983 cited in Cohen and Manion, 1994: 59) suggests that 'the life history is frequently a full-length book about one person's life in his or her own words'. (Denzin (1990: 29) believes that a life is lived on two levels, the *surface* and the *deep*. The former refers to the person's everyday routines and things, and habits whereas the latter refers to the moral, sacred, inner self. This inner self is something that other people rarely have the chance to see. Nevertheless, people's descriptions about their lives can sometimes reveal

the inner self and let us see what is behind the picture they show to most people. Lewis (1961, cited in Bryman, 1988: 48) used the life history method in his effort to study members of the Sánchez family and their experiences in a Mexican slum. He tried to ask as many questions as possible and cover various subjects about the way they live, their traditions, their dreams and fears and to have a better understanding of their everyday lives. This present study too will ask subjects to share their life experiences and use the information in order to have a better understanding of their lives.

 It is not easy for people to expose moments of their lives especially if these moments might have had a negative impact at their existence. On the other hand, people may find it easier to speak about their feelings to a stranger rather than to a friend as the former has more possibilities not to use this information against them at a certain time.

 In this present study I will try to focus on analysing some important times of dyslexic students' lives as far as their education and personal lives are concerned: moments, people, and places in their lives that played an important role in the building of better self-esteem and to a better understanding and accepting the problem that they have. Sometimes, things that might not seem serious or little details from a person's life that might not be taken into account can result in changing this person's life in a positive or negative way, depending on the circumstances.

 This study considers whether or not external factors such as environment, family, or school have affected these dyslexic students' lives and if so, to what extent they do that and what effects this has in their lives. Karl Marx (cited in Denzin, 1999: 93) observed, men and women "make their own history, but not… under conditions they have chosen for themselves; rather on terms immediately existing, given and handed down to them'. This

can also apply to people living with dyslexia. They make their own history but their dyslexia affects it. Dyslexia is an integral part of their lives, their own personal histories.

A 'life history' or 'personal history' is a written account of a person's life based on spoken conversations and interviews (Denzin, 1990: 40). It can describe a life or a part of a life as an account from the person in question. It is a narration to which each individual can add his own experiences and describe things that he thinks are important to mention. In its expanded form the life history may concern the collective life of a group, organisation, or community. It can give fruitful information about the habits, the dilemmas, the mentality, or the fears certain groups of people have. Life histories give us a flavour about other people's lives described by them and that is something that makes them more interesting and worthy to read.

6.4 Data Collection

Since the present study deals with the life experiences of dyslexic students, the best way to collect the data was by letting them speak for themselves and listening to them describing their problems with their own words and expressions.

6.4.1 Interviews

The research instrument that was used for the data collection was interviews. Interviewing is the most applied technique for conducting systematic social inquiry. Almost 90 per cent of all social science investigations use interviews (Briggs, 1986). Most of the scientists

consider interviews as their 'windows on the world' (Hyman et al., 1975 cited in Holstein and Gubrium, 1997: 113).

The most important reason for choosing interviews for this research project data collection was the fact that the interviewees had dyslexia. Although questionnaires could have been an alternative method to use to collect data it did not feel appropriate as people with dyslexia, depending on how severe their dyslexia is, usually have difficulties with reading, writing, or spelling. Using a questionnaire where persons with such learning difficulties are expected to write their answers on a piece of paper, probably would put a lot of pressure on them and cause them a lot of anxiety something that this research would not like to do for ethical reasons. Besides, a lot of people with dyslexia have such handwriting problems that it is really difficult to understand what they write and what they want to say. Probably people that deal with students with dyslexia on a daily basis would be able to understand their handwriting. Unfortunately, since I did not have such experience I could not consider and risk asking the participants to write down their answers. Apart from legibility, a lot of people with dyslexia have difficulties in expressing their thoughts on paper. They have the ideas in their minds but do not find it easy to write them down. Participating in smaller research project, a twenty-year old university student described how *'…all the ideas were in my head at once and I couldn't get them down on paper fast enough, so I had to stop, basically I had to start to think and just be more organised about my thoughts and just get them down quickly and get a diagram and then to plan them more organised'* (Michail, 1998: 20). My intention was not to make the participants feel uncomfortable or embarrassed at any time. I wanted to save them any awkwardness by asking them to reply in writing. Besides, I did not know in advance, due to confidentiality

reasons, whether their dyslexia was severe or not and how well they could express themselves in writing.

Hughes and Dawson (1995) in a similar piece of research used questionnaires to collect their data. The participants of the study were adults who were attending, or had attended, the Winchester Dyslexia Institute. However, the administration of this questionnaire was unusual as the questions were tape-recorded and the respondents were provided with tape recorders and headphones to record their answers. At the same time, tutor support was available in case someone needed some help. Unfortunately, although it was considered in the beginning, my research study did not have the funds or the access to such equipment to do something similar and use such a type of questionnaire.

Riddick (1996) in her research on dyslexic students and their families used interviews to collect the information she needed. The same happened with Edwards (1994) who used interviews as his main instrument for collecting his data. Interviewing gives researchers the opportunity to converse and interact with the interviewee. They can observe their body language and their behaviour. They can clarify questions and ask them to expand their answers. It is a more 'human' way to collect data rather than answer an impersonal questionnaire.

Undoubtedly, using questionnaires for collecting data has advantages. The sample can be bigger and the time required collecting the data is usually much less than for interviewing people. On the other hand, interviews are more *user-friendly* (Tall, 1997). People find it more interesting to talk rather than fill in a questionnaire. They have the freedom to ask for clarifications in case they do not understand something. The interviewer has the

opportunity to probe and prompt whenever she thinks that this will give her more fruitful information about her research (Brown and Dowling, 1998). During the interview, especially when the respondents feel comfortable, *"respondents may reveal feelings, beliefs, and private doubts that contradict or conflict 'what everyone thinks', including sentiments that break the dominant feeling rules.… In other cases, interviewers will discover the anxiety, ambivalence, and uncertainty that lie behind respondents' conformity"* (Kleinman et al. 1994 in Miller and Glassner, 1997: 104). In the process of interviewing, the reactions of the respondents and their body language can give clues about how they feel and whether they lie, or they try to hide something (Robson, 1993). Moreover, the interviewer has a greater opportunity to evaluate the respondents' non-verbal manifestations of his attitude (Gorden, 1975). This formed part of the information gathered.

Best and Kahn (1998: 320) suggest that the interview is in a sense an oral questionnaire. Instead of writing the response the subjects or interviewees give the needed information orally or face-to-face. On the other hand, Gorden (1975: 75) believes that a questionnaire is an *extension* of the interview in the sense that in a questionnaire the respondent reads the questions, while in an interview the interviewee asks the questions orally. At a certain point all the above may be right but questionnaires cannot replicate the face-to-face interaction between the interviewer and the interviewee. Both parties have to be active. 'Respondents are not so much repositories of knowledge – as they are constructors of knowledge in collaboration with interviewers' (Holstein and Gubrium, 1997: 114).

 The research interview is *'a two-person conversation initiated by the interviewer for the specific purpose of obtaining research-relevant information, and focused by him on*

content specified by research objectives of systematic description, prediction, or

explanation' (Cannell and Kahn, 1968 in Cohen and Manion, 1994: 271). At the time of

the interview the interviewer can see what is 'inside a person's mind' (Tuckman, 1972).

After that it is the interviewer's duty to try and present the information obtained as

accurately as possible.

Last but not the least; one other reason that this research study used interviews for its data

collection is that of *improved response rates* (Oppenheim, 1992). Interviews compared

with postal questionnaires often have a better response rate. Jackson and Rothney (cited in

Borg and Gall, 1989: 447) conducted research in high school students using both

interviews and questionnaires. The response they got for the interviews they did was 98

percent compared to 83 percent of the mailed questionnaires. One other aspect that was

given consideration was the fact that the respondents were asked to give information about

their lives and personal problems that they faced. These types of questions could not be

answered on a one-to-five scale as is usually used in scaled questionnaires. This would

limit their freedom to express their opinions and the information needed would not be

gained.

 Riddick, Farmer and Sterling (1997) in their research on the problems students with

dyslexia face used both questionnaires and interviews. A written essay was asked too in

order to identify some of the errors people with dyslexia make while writing. The

questionnaires were used in order to compare the answers the dyslexic students gave with

the ones of the control group whereas in the interviews only the students with dyslexia

took part. Riddick et al. hoped that interviews will help them '*try to get to the core of*

people's lived experience' (Josselson and Lieblich, 1993 quoted in Riddick, Farmer and Sterling, 1997: vii).

6.4.1.1 Interview Structure

 The interview that was used in this research was semi-structured (Appendix 1). A set of questions was prepared in advance in order to cover the topics that needed to be studied but at the same time there was flexibility for the researcher to modify the questions, change them or omit some of them during the interview depending on the interviewee's answers.

I, wherever possible, tried not to use long and complicated questions in order not to confuse the interviewees. Ialso tried to avoid leading questions in order to give the opportunity to the interviewees to reply freely and explain everything with their own words and expressions. Besides, like that, the interviewees would not be affected by the ideas of the researcher. I did not want to give them any kind of structured or alternative answers in order not to prejudice them and direct them into saying something that would not portray their own perspective.

 All the interview questions were open-ended. Open-ended questions have a number of advantages. First of all, they are flexible as they allow interviewers to probe so that they may go into more depth if   they choose, or to clear up any misunderstanding. Besides, they allow interviewers to make a truer assessment of what the respondent really believes as theycan ask for verification of the interviewee's answers (Cohen and Manion, 1994). One of the disadvantages of open-ended questions is that by giving the opportunity to the

respondents to answer spontaneously, data would be more difficult to analyse and categorize. However, it was decided to use open-ended questions because it is better to hear what other people want to say instead of leading them to ready-made answers that might not represent their thoughts and beliefs. Besides, closed questions might be very restricting as they might have 'yes' or 'no' as given answer.

Moreover, most of the interview questions were direct ones although I was aware that in some cases direct questions might cause a respondent to become cautious or guarded and give less-than-honest answers (Tuckman, 1972). I decided to use direct questions relying on the interviewees' goodwill to reply as honestly as they could. Furthermore, as this present study is dealing with people's feelings and difficulties , non-specific questions would not be so appropriate as the main reason for this research is to get to the heart of the problem instead of going around it and not facing it directly.

6.4.2 Sampling

The present research study took place in a large city in the West Midlands. Fourteen students took part and all of them were born in England. At the time the present project took place they were studying for an undergraduate or postgraduate degree in one of the three universities in this specific city. Their ages varied from 18 – 38 years old. All of them had been formally assessed as having Specific Learning Difficulty (SpLD)/ Dyslexia at a certain point in their lives. The age that they were diagnosed as dyslexic was not taken into consideration in selecting the sample to participate in this research study.

Before I started collecting the data I was hoping that I would be able to acquire a large sample of participants (30) from the three universities. The counselling services of the three universities were contacted and they helped me come into contact with the learning support services of each university. The learning support staff were very helpful and agreed to inform the students that they had on their lists about my project either via e-mail, letter or face to face. I could not have any direct contact beforehand with any of the students unless they contacted me or agreed for the learning support services to give me their details due to confidentiality reasons. Unfortunately, the response rate was low. After that, my target was to talk to as many people as I could have access to, hoping that I would have at least 10 students. In the end, the interviews I could use were only fourteen although more people were interviewed. Among the interviews, two had to be discarded as the quality of the recording was very poor and it was impossible to transcribe them. Although the tape-recorder was placed quite near the interviewees in these two particular interviews it was not possible to understand their answers during the transcription. One interviewee informed me that he was not assessed as having dyslexia yet; he was waiting for his official assessment and he came to talk to me hoping that I could tell him whether he was dyslexic or not. Nevertheless, I conducted the interview and I explained to him that I was neither qualified nor experienced to come to such conclusion and I reassured him that he was very helpful and I was really appreciative for taking the time and the effort to talk to me. One last interview was discarded because the participant was 50 years old and the age gap between her and the other participants was quite large. Although, further education students were to take part in this study, the original sample of the F.E. students did not give the depth of information needed. In the end, the final sample consisted of 14 H.E. students, aged between 18-40.

As mentioned before, in the beginning of this study I thought that it would be interesting if further education college students were taking part in the research too. I had already some experience, as a volunteer in an adult education learning centre, working with adults with dyslexia and I wanted to see whether they had similar problems or not and how someone faces the problems that he has because of his dyslexia at a younger age.

After further consideration, college students did not participate. The reasons for their non-participation is that before I started my interviews I decided that a pilot study would be useful in order to check if the interview questions were easily understood and answered and to check if I needed to change anything in the interview schedule. In this pilot study four college and one university student took part. The interview with the university student had no problems in terms of understanding the questions and I believe that the interviewee was honest and open with me in replying to my questions.

On the other hand, college students were very reluctant to talk to me. Although I reassured them that everything that they would tell me would be confidential they gave me the feeling that they were very reserved and uncomfortable in answering the questions. Most of their replies were monosyllabic. They did not seem willing to cooperate with me in expanding on their answers. Furthermore, one of the college students although he willingly accepted to talk to me, he was not sincere in his answers and the information given considering the severity of his dyslexia. He described a very moderate case of dyslexia whereas he was quite severely dyslexic. The only reason I learned the truth about the severity of his condition is because I had an informal chat with his college learning support tutor and she described a completely different picture considering his language problems. Apart from that, college students gave me the impression that taking part and talking to me

was more like a 'game' to them as they seemed to take the whole procedure very light-heartedly and amusingly. This probably was due to their age (16-18).

In the beginning of the study, there was no limit as to the age of the participants. After discussion with my supervisor, we decided that any students older than forty years old should not be considered, as it would have been such a significant generation gap between them and the younger students. Besides, there would be a lot of differences to the way the older students were educated. As a result one interview with a student who was fifty years old was not used in this project.

In order to acquire an adequate sample, the learning support units of each institution were contacted. The counsellor dealing with the dyslexic students in each university contacted the students and due to the confidentiality record no information was given to me. In two of the universities the counsellors e-mailed the students in their mailing lists informing them about the study and asking them to participate. My contact details and e-mail was attached to the e-mails asking the students to respond directly to her. One of the universities asked me to provide a letter with stamped envelopes and she sent the letters to the students (see appendix). Unfortunately, the response from the students was much smaller than anticipated. One of the reasons might be that the students with dyslexia were not interested in participating in the project. Another reason, as one of the participants highlighted, might be that they forgot to reply to the e-mails or letter sent to them. Dyslexia can also affect people's memory. Besides, one of the support tutors was surprised to hear that a number of students that have told her that they wanted to take part in this study did not contact me. It is not possible to know whether they forgot or they changed

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their minds. Last but not least, two of the participants were found through personal contacts.

Before each interview started, I introduced myself and explained to the participants the aim and the reason for conducting this study and I asked permission to record the interviews. I promised them that their personal details would be kept confidential. I also explained to them that they could ask any questions they needed during the interview in case they did not understand any of my questions. The tape recorder was placed as closely as possible to the interviewees in order to achieve better sound quality. I made sure I was not holding the tape recorder as I did not want the participants to feel uncomfortable.

6.4.3 Recording Data

As mentioned before, a tape recorder was used during each interview to record the conversations. Although it takes a lot of time to transcribe the recorded data, tape recording speeds up the interview process, as there is no need for extensive note taking (Gall, Borg and Gall, 1996). Taking notes can sometimes distract the interviewer's attention and does not enable very much eye contact with the interviewee. Besides, if the interviewer wants to join the conversation too it is easier to record the interview rather than stop every few minutes or seconds to write down what the participants says. This can create an awkward situation between the researcher and the participant (Fielding and Thomas, 2001). It can also result in missing non-verbal signs or not paying the appropriate attention to the respondents' words and therefore data might be lost. Besides, tape recording helps most by providing a full record of what has been said during the interview (Glesne and Peshkin, 1992). No matter how good memory people have it is almost

impossible to remember every conversation verbatim. Silverman (2001: 162) presents

three clear advantages that tapes and transcripts have compared with other kinds of

qualitative data:

1. Tapes are public records.
2. Tapes can be replayed and transcripts improved.
3. Tapes preserve sequence of talk.

Tapes can be replayed and researchers have the advantage of returning to their data in the

original form as often as they wish (Silverman, 2000). Besides, the researcher can have

access to the whole conversation that has taken place and go back to it as many times

needed.

Another reason that the interviews were tape-recorded was the fact that English is not my

mother tongue, and I believed that by using a tape recorder I would not lose any data that

in the later stages of this research project might become significant.

On the other hand, tape recording also has its negative aspects. Transcribing the interviews

is a laborious and time-consuming process (Fielding and Thomas, 2001). Depending on

the length of the interview it can take from two to six hours to transcribe an hour of

interview. I transcribed the interviews of this project and depending on the length of each

interview the transcription took from two to ten hours. Another fact that influenced the

time of the transcriptions was the quality of the recording. Although all the interviews took

place indoors they did not have the same-recorded quality. In order to make sure the

interviews were transcribed correctly the services of a professional audio-typist were also

used. The reasons for this were to double check the responses and correct any language

mistakes that I may have made.

6.5 Ethics in Research

 Every research study should give great importance to the ethical problems that might come up during the process of data collection. The researcher should respect the subjects that take part in the study and try to protect their right to privacy by keeping their identity secret from the public eye (Bulmer, 2001; Christians, 2003). In cases where questionnaires are used for collecting the data the anonymity of the persons is somehow guaranteed as in most of the cases they can return them without having to write any personal information. When it comes to face-to-face interviews the researcher gets to know in person the subjects as he/she has personal contact with them. In this case the researcher should try and protect the participants of the study by promising them confidentiality (Cohen and Manion, 1994). Fontana and Frey (1994) report that there is a growing number of researchers who believe that much of traditional interviewing is unethical, whether wittingly or unwittingly, as some of the techniques and tactics of interviewing can sometimes manipulate the respondents while treating them as objects or numbers rather than individual human beings. Baumrind (1964 cited in Cohen and Manion, 1994: 363) notes the possible failure on the researcher's part to show gratitude for the subject's participation in the study is a result of the researcher trying to keep his/her objectivity. This can be avoided by trying to spend some time after the interview with the participants and thank them for their participation, reassure them that they did well, they were quite helpful and what they said has given quite important information in the research study. The participants of a study are sometimes not quite confident whether the things they said are important

and they need the reassurance that talking with the researcher helped him/her

with his/her study. It is up to the researcher to make the study participants feel

comfortable and not to press them to say things that they do not want to say.

After all no researcher has the right to suppress the participant's personality for

his/her own benefit.

Before each interview started I emphasized the fact that the participant's name will be not

be revealed in the written form of the thesis. All the participants gave their consent and

they were happy to take part in the study. The informed consent of the participants was not

given in writing, as is required in medical experiments (Bulmer, 2001). The participants

had contacted me of their own free will through the letters and e-mails that were sent to

them via their learning support services. A brief summary of the project was given to the

participants and they were given the chance to pose any questions they wanted before the

start of the interview. One of the questions that almost all the participants asked was

whether I was dyslexic myself. They did not give the impression they were annoyed or

disappointed by the fact that I was not dyslexic. On the contrary, they thought that is was a

positive thing rather than a negative to do research on dyslexia although I was not dyslexic

myself.

When someone is conducting a research project they should have in mind 'the need to

strike a balance between society's desire, on the one hand, to expose the hidden processes

at work in modern society and, on the other, to protect the privacy of the individuals and

groups and to recognise that there are private spheres into which the social scientist may

not, and perhaps should not, penetrate' (Barnes, 1979 in Bulmer, 2001: 49). I believe that

this present study did not offend any of the participants and respected their privacy and uniqueness.

6.6 Data analysis

The process of qualitative data analysis is fundamentally a nonmathematical analytical procedure that involves examining the meaning of people's worlds and actions (Maycut and Morehouse, 1994). Although our lives are full of experiences we are aware that each individual might have a different understanding of a certain situation. People can react in a different way under the same circumstances and give different meanings to other persons' responses. Nobody can really predict the exact way that people might respond in any given situation. The qualitative researcher is attempting to examine these meanings and behaviours and capture how people interpret the world around them. The qualitative researcher is trying to find patterns within the participants' words and present them for others to inspect while at the same time staying as close to the construction of the world as the participants originally experienced it (Maycut and Morehouse, 1994).

6.6.1 Interview Data Analysis

The data collected from the interviews was first transcribed verbatim and recorded using a word processor. After the transcriptions, a hard copy of the interviews was produced in order for the gathered data to be carefully read. During the first reading of the interviews each transcript was examined carefully enabling the researcher to obtain a wider picture of the interviews. Further readings took place in order to start and develop categories deriving

from the data. According to Gillham (2000: 59) 'categories' are simply

headings – a first stage in tidily presenting the range of data the interviews

have thrown up. In themselves those headings do not amount to much: the

substance and meaning comes with the use of direct quotations categorized in

this way but displaying the range and character of the response.

The creation of the categories was based on the *open coding* process (Strauss

and Corbin, 1990 cited in Mertens, 1998: 352). This part of the analysis

pertains specifically to naming and categorizing phenomena through close

examination of data. The data are broken down into discrete parts, closely

examined, compared for similarities and differences. Tesch (1990) describes

the procedure of reading the data and then dividing it into smaller more

meaningful segments as de-contextualisation. The data were carefully and

meaningfully checked and any themes and topics deriving from the data were

put together. The data analysis process was inductive (Mertems, 1998; Maycut

and Morehouse, 1994). Initially, common categories were drawn following the

initial research questions and topics. For example one general category would

be coping strategies. Under this category, sub-themes and concepts related to it

were formed.

Once the general categories and sub-topics were chosen, they were transferred

along with all the data records to a computer programme suitable for

qualitative data analysis (NVivo). Theory building and code-and- retrieve

software programmes help manage the data and manage and interrogate the

researcher ideas (Lewis, 2001). Document handling is much easier as NVivo

gives the researcher the chance to highlight, underline, mark and manoeuvre text in multiple fonts (Richards, 2002). Nodes are used for coding and they represent ideas that can be linked to mark up passages in documents. Nodes give the researcher the opportunity to work through the concepts from general to specific (Crowley, Harre andTagg, 2002). The management of data using software like this is easier to handle as the researcher can use the programme to code the interview and at the same time include all his notes, reports and conclusions (Richards, 2002). All the important aspects of the project can be kept together.

Once all the interviews and data records were inserted in the programme, the process of re-contextualization commenced (Tesch, 1990). During this procedure all the categorised data was printed out and read to identify similar concepts and topics deriving from the data. During this process the existing categories were checked and connections and differences between themes were identified. Also, further subcategories were created forming the several topics explored in this present study.

With the completion and formation of the themes and sub-themes that derived from the gathered data the process of the interpretation and discussion of the data began.

6.7 Validity and Reliability

6.7.1 Validity

Over the last decades the terms validity and reliability in qualitative research have been a subject of debate among the scientific community (Silverman, 2000, 2001; Denzin and Lincoln, 1998; Morse, Barrett, Mayan, Olson and Spiers, 2002). Professionals have also used alternative terms like trustworthiness, credibility, goodness and authenticity (Morse et al, 2002; Bailey 1996; Whittemore, Chase and Mandle, 2001) in order to describe validity and reliability in qualitative inquiry.

'An account is valid or true if it represents accurately those features of the phenomena that is intended to describe, explain or categorize' (Hammersley, 1992 cited in Denzin and Lincoln, 1998: 288). What makes a research project valid? Polkinghorne (1988 quoted in Bailey, 1996: 189) believes that validity in qualitative research should be understood as verisimilitude, *'results that have the appearance of truth and reality and that are well grounded and supported'*. Sandelowski and Barroso (2002 cited in Rolfe, 2006) postulate the report itself is the only site that is being evaluated in research projects – qualitative or quantitative. People assess every study depending in what is written in the report accompanying it. I want to believe that this study represents the experiences of university students with dyslexia and gives an insight into their lives and attitudes.

Although the sample of this study is not a large one (14 students) one cannot underestimate the importance of their narratives. 'The rationale for conducting in-depth interviews is that people involved in a phenomenon may have insights that would not otherwise be available

to the researcher, and it is the quality of the insight that is important, rather than the number of respondents that share it (Wainwright, 1997 cited in Pyett, 2003: 1174). I also believe that the participants' answers were truthful and sincere, as they were not forced by any means to take part in this study. On the contrary, they praised this attempt to portray their experiences and believed that people can learn and be helped by them.

The interviews took place in the participants' preferred location in an attempt to make them as comfortable as they could be. Before each interview a brief conversation with each individual took place in order to create a rapport between the researcher and the interviewee and make them feel at ease. The anonymity of the respondents and the reasons for conducting this study were presented in the beginning of each interview and the participants were informed to feel free to ask for clarifications in case they did not understand any of the questions or anything else due to my accent (Greek). During the interviews I tried to keep the conversation as friendly as I could without jeopardizing the integrity of the study. 'For some purposes, it is necessary to generate a kind of conversation in which the 'respondent' feels at ease. In other words, the distinctively human element in the interview is necessary to 'its' validity. The more the interviewer becomes rational, calculating, and detached, the less likely the interview is to be perceived as a friendly transaction, and the more calculated the response also is likely to be' (Kitwood, 1977 in Cohen et al., 2007: 153).

The participants that took part in this study were selected using the same criteria – had been officially assessed, were studying for a higher education degree. In order to make sure the above criteria were met, and the sample was reliable, the learning support services

of three universities were contacted and helped me to get in touch with the willing

individuals who eventually formed the sample of this study.

6.7.2 Reliability

 'Reliability refers to the degree of consistency with which instances are assigned on the

same category by different observers or by the same observer on different occasions'

(Hammersley, 1992 cited in Silverman, 2001: 225). In order to make this present study

reliable, another step that I took towards it was to make sure that all the interview

questions were formed as clearly as they could be and tried to keep the same sequence of

questions in every interview (Oppenheim, 1992 quoted in Cohen Manion and Morrison,

2007). Also, leading questions were avoided (Cohen, et al., 2007), as I did not want to

direct the participants' answers. The purpose of this study was to examine and understand

their attitudes and experiences, not to confirm any knowledge that I already had by reading

literature about dyslexia. During the interview I tried to respect the participants' feelings

and attitudes and be as objective as I could.

Apart from that, the interviews, as mentioned before, were tape-recorded and

transcribed verbatim firstly by myself and afterwards by a professional

transcriber in an attempt to have an accurate and detailed account of the

participants' experiences. Sacks (1984 cited in Perakyla, 1997: 203)

emphasizes the importance of using tape recorded materials:

'It was not from any large interest in language or from some theoretical

formulation of what should be studied that I started with tape-recorded

conversation, but simply because I could get my hands on it and I could study it again and again, and also, consequentially, because others could look at what I had studied and make of it what they could, if, for example, they wanted to be able to disagree with me'.

By tape-recording the interviews I could concentrate and pay attention to the participants' answers and I was able to clarify any comments that I did not understand. Moreover, the transcripts provided the utmost needed quotes that are used in the analysis of this project (Silverman, 2001). I believe that the selective narratives portray clearly the thoughts and beliefs of the participants and they give us a better understanding of their lived experiences.

During the collection of the data and while conducting the interviews I tried to be as objective as I could be towards the participants and the views expressed. I was biased to a certain extend by the information that I had already acquired by reading literature relevant to dyslexia but I tried when I was talking to the interviewees to stop thinking about what I already knew and I concentrated on what my participants had to say. I believe it is not possible for any person to be 100 per cent objective as we all have our experiences and beliefs and our personalities are being formed due to them.

In order to make sure that the data was interpreted correctly authentic quotes, taken from the interviews, were used to support the findings.

6.8 Conclusion

When I started this research project my intention was to help and support university students with dyslexia and to have their voices heard. The aim of this study was to explore the lives and experiences of dyslexic student studying in HEIs in the UK. The students were studying in three universities in the West Midlands County. The research took place between 1999 and 2001.
The Learning Support services of the three universities were employed in order to approach the students. The learning support tutors contacted the students and gave them my details. I had to wait for the students to get in touch with me as for confidentiality reasons the learning support tutors could not give me their details.

Due to the fact that I had to deal with people's lives and experiences qualitative research was considered the best method for the data collection. I did not want to limit the participants' responses to one-to-five scale and it would be impossible to present their experiences in numbers. Besides, this study wanted to look at the students' perspective. Previous research projects on the social and emotional problems with dyslexia have used qualitative methods of research to collect their data (Riddick et al., 1997; Riddick, 1996; Osmond, 1993).

Interviews were used for the data collection, as I did not want to make the participants feel uncomfortable in case they were experiencing difficulties in their writing due to dyslexia. Apart from this, interviews are more user-

friendly and during the interview you can interact with the participants; facilitate their thoughts, observe their body language. Interviews also have a better response rate compared to questionnaires. The use of questionnaires would limit the participants' freedom to express their opinions and give adequate information about their lives and experiences.

The interviews took place in the participant's preferred place (residence, university library) and open-ended questions were used. A tape recorder was used to record them, as English is not my mother tongue and I did not want to distract the interviews while keeping notes. All the participants were informed about the purpose of the study and they were reassured about their anonymity.

In the following chapters the data collected from the interviews will be presented and the process of analyzing and presenting the results will start.

CHAPTER 7

OUTCOMES OF THE RESEARCH: BEING DYSLEXIC

7.1 Introduction

The aim of this present study was to explore the lives and experiences of students with dyslexia in Higher Education. How they coped and what kind of difficulties they had, if any, during their studies? Were their universities providing them any support?

The first part of the results gives the reader some information about the participants and their course of study. It also examines the age they were assessed as dyslexic and their feelings and attitudes towards it.

7.2 Participants' profiles

All the persons that took part in this research project were undergraduate and postgraduate students in three different universities in one of the biggest cities in the West Midlands area. Five of them were studying at university A at the time that this study took place, five at university B and four at university C. Out of the fourteen people that participated in this study four were mature students and two of them were postgraduates (Table 1).

Table 1				
Name	University	Degree in	Age	Age Assessed
Anna	B	Social Worker	33	32
Camilla	A	Nursing	38	37
Gloria	A	Nursing	19	17
Kacy	A	Art	38	36
Kara	A	Drama	21	11
Karen	A	Computer Science	22	16
Lana	C	Psychology	30	29
Larissa	B	Visual Communications	21	11
Mac	C	Psychology and Sociology	21	19
Rachael	B	Sociology and Law	20	17
Ralph	A	Biochemistry	20	16
Sabrina	A	Master in Engineering	26	17
Carla	C	Mechanical Engineering	23	8
Darius	C	Business and Economics	18	11

(Table 1)

Brief portraits with a description of the participants' age, the subject they were studying,

the year they were assessed as well as the year they were in the university at the time the

interviews took place will be given to in order to introduce them and indicate the initial impression which they made on the interviewer.

Kara, Ralph, Sabrina, Gloria, Karen, Camilla and Kacy were all studying in the University A.

Kara was 21 years old and a Dance and Drama student in her final year in the university. Kara is a very determined young lady and she managed to get a 2:2 in her degree. Her next step would be to go and continue her studies in London.

Ralph was 20 years old and he was in his final year studying Biochemistry. He got a third in his degree and he was quite disappointed by this. Nevertheless he said his ambition would be to have a career in the media and become a successful radio producer.

Karen was 22 years old and was studying for a Masters degree in science. Karen was very confident as a person despite her dyslexia. She was looking forward to finishing her degree, moving on to Scotland and start her career.

Mac was 21 years old and he was in his first year of studying for a degree in Psychology and Sociology. Michael was determined to succeed in life despite the difficulties he was facing due to dyslexia.

Lana was 30 years old and she was studying part time Psychology. Lana had a lot of difficulties throughout her life but she was determined to do well in her studies and She was thinking of applying for a PhD after the completion of her degree.

Rachael was 20 years old and she was in her first year studying Sociology and Law. She was the only participant whose family could not accept the fact she had dyslexia. She was identified as dyslexic when she entered university.

Anna was 33 years old she was in her first year of studying to become a social worker. Anna is a mother of two children and not too confident about being dyslexic. She was identified as dyslexic quite shortly before the interview took place. Due to her difficulties, lack of support and her late assessment she had failed her first year.

Kacy was 38 years old and she was studying part time for an Art degree. Kacy was also working as a musician and she was a member in a band. She was amazed by the support students with dyslexia had compared to when she was at school. One of her ambitions was to write a book.

Camilla was 38 years old and she was in her second year studying to become a nurse. Camilla is a very creative person and she already had a degree in design. She was trying hard to overcome her difficulties and complete her degree.

Sabrina was 26 years old and she was studying for a master's degree in science. Sabrina is a very outgoing person and very friendly. She was determined not to let dyslexia stop her finding a good job and having a good life.

Larissa was 21 years old and she was in her second year studying for a degree in visual communications. She was quite confident and positive about having dyslexia.

Darius was 18 years old and he was in his first year studying for a degree in business and economics. Although he had to change career orientation because of his dyslexia, he wanted to become a doctor, he was very confident and determined that he will succeed in life.

Carla was 23 years old and she has just finished her degree in Mechanical Engineering. she was very confident about being dyslexic and she considered dyslexia as a positive factor in her life.

None of the participants was working full time at the time that the interviews took place. Larissa, Sabrina and Kacy were working part time to have some extra money to support themselves. Lana was getting money from the government as she tried so many times to find a job but because of her dyslexia she could not cope. Besides, she finds it difficult to study and work at the same time.

7.3 Age assessed as dyslexic

the age that the students were identified as dyslexic varies depending on the individual. The younger students were assessed at an earlier age compared to the mature students (8 years old the youngest and 37 years old the oldest). Carla, Kara, Karen, Mac, Gloria, Rachael, Ralph, Sabrina and Larissa were assessed at the age of 8,11, 16, 19, 17, 19, 17, 11 respectively compared to Anna, Camilla, Kacy and Lana who were assessed at the age of 32, 37, 36 and 29. All the mature students were assessed after their entry in the university whereas the younger students with the exception of Rachael and Mac, who sought

assessment while on their first year in the university, found out that they were dyslexics when they were at school.

As mentioned before the age and as well as the reasons that prompted the participants' diagnosis vary. The younger students were 'lucky' somebody spotted their difficulties when they were at school. Kara and Sabrina were one the youngest who found out they were dyslexic at the age of 11. Kara *"… I took an examination to my secondary school and they found out that I was really dyslexic."* Sabrina on the other hand was tested because of her brother's dyslexia; *"to begin with they did not know why I was little behind I think and it was because my brother was found to be dyslexic that I was tested…"*

The rest of the younger group found out about their dyslexia when they were about to take their A level or GSCE exams.

Ralph*: "…It was my A level English teacher after about a month or so of doing the course she put me up for the test because she thought I might be dyslexic. And I was."*

Larissa: *"I found out, I was at college and one of my teachers thought I was dyslexic. And I said: no, I do not think so. And I went for the test and they said I was so…"*

Rachael and Mac on the other hand, were the only younger participants that were assessed when they went to the university at the age of twenty although they had problems in school. Rachael said she knew that something was wrong with the way she was reading things but she kept it quiet because *"I just didn't want to be different. I just wanted to be like everyone else."* She only decided to go for an assessment due to the workload in her course. She was *"struggling a lot"* so she *"had the test"*. Rachael is definitely not the only

girl who went through school and by being good and quiet managed to finish school without anyone noticing her problems. Males and females deal with different ways when it comes to the emotional consequences of school failure. Girls when they face school failure tend to be shyer and have a reduced self-esteem and confidence. They are more likely to avoid taking part in school activities and avoid being noticed (Zabell and Everatt, 2000). Males tend not to show their feelings as much as females and have more troublesome behaviour. This is why teachers tend to rate them more disruptive and more inattentive than their female peers on tasks involving language. Hurford (1998) believes that when facing problems at schools girls tend to be more withdrawn that the boys and try not to get any attention.

Mac on the other hand, had a suspicion that he might be dyslexic from the early age of 8-9 years old but he was never diagnosed properly although his teachers thought that he might be dyslexic. He decided too to ask for help and to go for the assessment when he went to the university because *"the work is harder"* and he had difficulties in getting through it. Mac and Rachael are not the only people with dyslexia that they could feel that something was wrong with the way they learnt but they could not exactly attribute their academic failure to anything. Riddick et al (1997) in their book quote stories of students with dyslexia where they also mentioned the feeling of being different and knowing deep inside them that they were not stupid contrary to what people were saying to them.

Considering the mature student group different reasons apply for not being assessed when they were younger. They attribute their lack of assessment to the lack of awareness about dyslexia when they were at school. As Kacy mentioned, now things are different from the past. There is more awareness and more help for people with dyslexia than there was some

years ago. She was really impressed by the help one of her fellow students had when she was at school. *"There's a girl on the course who is also dyslexic from Nottingham and she's been to a special school and everything was recognized, she had special help, special ways of putting things down. I mean she's a younger student. I am a mature student. I can't believe the help that is available."* Another dyslexic mature student in another study also mentioned: *"in the early 60's there was no such thing as dyslexia. We were called the old fashion stigma like dumps, stupid, slow"* (Michail, 1998). Camilla too was diagnosed as dyslexic at the age of 37, and that was because she was falling behind with her work in the university. When she was at school *"the classroom in those days it is quite big; a lot more pupils and dyslexia testing wasn't done too often"*.

Apart from that, another problem for mature students is the financial aspect of the assessment, especially for the ones who study part-time. The cost of an assessment can be quite dear and although most of the universities pay for the student's assessment there are cases that the individual has to fund it. The prices can vary conditional on the area where the test is carried out. In the London area prices range from £235 - £315 depending whether it is a full or review assessment. In areas outside London somebody can pay slightly less (£260) to be diagnosed (The Dyslexia Institute, 2002). A lot of mature students do not have the money either because they have families to support or because they are out of work and do not have the extra money that they need to pay to be assessed. Lana was trying for four years to get properly assessed. *"Nobody assessed me. All they do…not the proper assessment like semi-assessment and go: oh, we don't understand it. You come out with a funny one. Nobody'd do that. It was like go here, go there, go there. Who was going to pay for this? And I couldn't afford 250 for it, an assessment myself. So, eventually, the unemployment service agreed to send me. But they send me somewhere else*

for a semi test and then I had to wait another year to go and take the test. So, it took quite a long time". The rest of the students that were diagnosed while in university though did not have any problems as the university paid for their assessment.

7.4 Labelling

Some of the participants have been labelled negatively due to their late assessment (Dale and Taylor, 2001). Fawcett (1995) points towards all these alternative labels like stupid, not very bright, lazy, a late developer, or even worse case scenario aggressive, uncooperative or difficult that might be attached to the children if they are not labelled as dyslexic because of the reluctance of some people to use the dyslexia label. The former labelling might cause much more trouble, as it does not offer any solutions whereas if these children are correctly identified as dyslexic, they are given the chance to get some help and overcome their difficulties. Scott (2004: 31) reports that labels like: 'maladjusted', 'retarded', 'disturbed', 'brain injured', 'handicapped' and 'backward' were one of the aspects of dyslexia that made people with dyslexia and counsellors that he interviewed for her book the most angry.

Labelling can have positive and negative effects on the individuals. One of the positive things is that people understand better their past experiences and this can help them improve their self-image (Riddick et al. 1997). It can also help the individual to have access to resources and improve their lives at school/university, as their teachers/lecturers might be more understanding and helpful. While studying in the university students can apply for DSA and use the label for their own benefit (Hammond and Hercules, 2007).

On the other hand, there is always the stigma that comes with any label and there are always going to be people that might try to humiliate and put people down because of it. Also, tutors might be affected and give lower grades (Riddick et al., 1997). Nevertheless, none can ignore the relief that the individuals feel, in particular the ones with dyslexia, knowing that they are no longer unintelligent and there is a reason behind their lack of academic success.

Kenny (2002) believes that '*it is no so much issues, such as labels and special education, that might be the concern, but rather the quality and meaning attached to them*' (p.49). From her own experience she considers that the label that is attached to an individual '*depends to a large degree upon the angle from which we choose to focus our lenses*. She suggests that rather than focusing on the term 'learning disability' people should characterise a child who might have a learning disability (e.g. dyslexia) as exceptionally good at something else (e.g. art or dance). The author suggests we might use a term like '*kinetically gifted*' (p.43) instead if someone is good at dance.

The students that took part in this study had similar experiences and were wrongly labelled not according to their problems but according to what other people thought they were. Gloria although she had problems at school she did not think of asking for any help because she thought she was '*stupid' and slow'*. 'Thick' and 'slow' were labels attached to 50% of the cases that took part in Riddick's (1996) research project. Twenty five per cent of the children were labelled as lazy by their schools.

When teachers are labelling someone lazy they can probably understand that the individual is intelligent and they contribute this academic failure to lack of effort rather than trying to

investigate whether something else is behind the student's failure (learning difficulty). Whether it is lack of training on the teachers' behalf or lack of school resources to spot dyslexia more research needs to be done on the reasons why students fall through the net without being properly assessed. Woods (2007) investigated the access arrangements to GCSE examinations for students with special educational needs. Eighty per cent of the teachers that took part in his study considered the existing system unmanageable. Lack of availability of a 'specialist' assessor due to limited school recourses, lack of teachers' non-contact time to prepare the appropriate documentation and the non-identification or low prioritisation of 'borderline' students are some of the reasons that the teachers gave for the unmanageability of the system (p. 91). If the system itself does not help the educators diagnose the students in need no wonder why there are still individuals that miss out.

 Lana, due to her high IQ, was put in the top groups in her school. Because of her dyslexia she ended up being confused and not being able to keep up with the upper group. *"But no, because I was clever and they decided I didn't understand. They thought I was lazy or whatever."* Her teachers at school called her parents once and told them: *"your daughter is going to fail. She is very lazy. She doesn't do anything. It's not that she doesn't have the ability, she doesn't bother and the main problem is that she never turns up to school."* Lana refused to go to school when she was younger and she would to anything in order to accomplish that.

Kacy had similar feelings about school. She hated school and did not want to go.
'I hated school completely but they said I was just lazy and I'm not lazy at all.
I'm more hyper than anything.'

Mac was the only person that went to a low achievers school so "*it was just natural*" for him not to do well, as there were not a lot of expectations of the pupils' performance. Apart from that, he changed schools quite a few times and not attending a specific school for a long period made people think that he was just lazy so "*there was no need to do any tests*."

The impression from this group of students with dyslexia is that when they went to school after a certain point they started to understand that something was wrong with the way they learned things. However, they did not get an explanation about their problems and started believing what other people said to them; hence they went through their lives thinking that they were probably thick or stupid. Kara when she was younger '*used to think she was really stupid'*.

Dodd (1995) reports the case of Margaret and describes her relief and happiness to find out that she was dyslexic. When Margaret found out about her dyslexia she said to her mother: '*I'm not thick, am I mum? I'm dyslexic'* (p.2). For young Margaret it was a realisation that she had a special 'problem' and she was looking forward to having some help to overcome her ifficulties. Miles (1996) mentions a letter from a mother addressed to him. Susan (her daughter) was diagnosed when she was nine. Soon after her assessment her daughter started to regain her confidence and become the lively and happy child she was until the age of 5 or 6.

What can somebody say or do for these people who for so many years thought badly about themselves? Who can give them back the confidence they probably have lost and the things they might have done if things were different? Adults with dyslexia feel cheated and

frustrated for all the things they missed because they were not assessed when they were still at school (Morgan and Klein, 2000). It is very difficult for a normally developed individual to understand and feel how someone with dyslexia feels. For some people with dyslexia the label have a positive effect on them (Riddick, 2010) whereas there are some that might not found the label useful (Tanner, 2009). It is very important for people to remember first and foremost to care for the person not the label (Hammond and Hercules, 2007).

7.5 Being dyslexic. A gift or a curse?

All the subjects that participated in this research project were asked to describe their feeling about being dyslexic and whether they would like to change the fact that they are dyslexics. Surprisingly most of them they would not like to change their dyslexia and if they could would probably only change some of the negative elements that dyslexia has caused in their lives. Only one participant was negative about being dyslexic and would like not to have been one. The rest of the participants did not think that dyslexia was a totally harmful thing in their lives. On the contrary, most of them thought that although dyslexia might have caused them quite a few problems in their lives at the same time, it gave them a lot of positive things too. This confirms the point made by Scott (2004). She once did an exercise in guided imagery with a group of ten to thirteen year-old children with dyslexia. She asked them what they would exchange from the things they owned for anything they wanted. In her surprise only two out of over thirty children that were in the group wanted to give up their dyslexia. I have to admit that I was surprised too. By reading the literature I had the impression that people with dyslexia would like to get rid of it given the chance. How wrong I was.

There might be people who might try to link the rejection of the dyslexic label by the person himself, with the confidence and the acceptance of his 'condition'. From this research it is not easy to come to such conclusions, as half of the subjects were diagnosed quite recently (six months to one and a half years) from the moment they were interviewed and only one seemed not to have accepted her condition and was not able to find something positive coming out of it. Morgan and Klein (2000) confirm that perceptions of self-esteem are likely to be lower among recently diagnosed adults.

In all the subjects the identification of dyslexia was something, if I'm allowed to say, of a godsend. It was like having an answer to their prayers about their problems and their difficulties. Being dyslexic gave them the freedom to be themselves and not to try to hide their mistakes, for example in reading or writing, from others. By knowing they have dyslexia, it gave them the confidence they were missing to do things and helped them to be more determined with the things that they were doing.

Farmer, Riddick & Sterling (2002) reported similar findings. In their research project, they asked students from two universities whether being assessed as dyslexic changed the way they saw themselves. The majority of the students (45 students 63%) said yes and only 26 said no (37%). There was a very small percentage that did not have any recollection of the initial impact of the assessment as they were assessed at an early age and they had grown up with the idea. 87 per cent of the students who declared that their identification changed the way they see themselves mentioned the changes as positive, whereas only as small percentage (6.5%) talked about negative changes in their perception.

Rachael faces the fact that she is dyslexic and gets on with it but *she doesn't feel less confident than she did when she was younger. She feels more confident.'* Without doubt,

being dyslexic these students did not have, do not have and will not have an easy life. All of the participants have their ups and downs because they have to try harder and work more than anyone else who does not have dyslexia but in the end most of them could find something encouraging coming out of all this effort and feel really good and proud about themselves.

As Kara described:

'You feel a bit hard done by sometimes. You just think it's very frustrating. It's very annoying that other people can just stand and read a book, read a play in an hour or two, it takes you three days to understand, to let it go in, seep in. But it hasn't affected my character, I wouldn't say because it's just sometimes it gets to you but that's only when you're tired and stressed and like try and do an essay and you can't quite get that word.' Kara thinks that if she weren't dyslexic she would be a bit more confident with what she does (drama student) but *'then again for my own dyslexia it makes me more enthusiastic and like determined to do something instead.'* She feels so much happier because she has tried hard to accomplish her target.

Camilla too, she gets frustrated now and again but other than that she does not feel bad about her dyslexia. Considering this, she would not like to change her dyslexia because: *'my brain's very, very creative so if I wasn't dyslexic I wouldn't be creative. I think differently. I can think in pictures and construct ideas and, in my head, so that I see things in my head. I can use my brain in different way, because of dyslexia I create in other ways.'*

Ralph feels indifferent about being dyslexic. On one hand he would like to change his dyslexia because sometimes it causes him trouble, but on the other hand he thinks too that

dyslexia makes his brain work and think differently and tries to find alternative ways of doing things, which is something good from his point of view. *'Just getting stuff wrong or it's getting like in my driving test, the guy asked me to turn right and I'm right: just goooo. And I was like: that was left and I was like: oh, sorry... Certainly not for any reasons with any stigma attached to me or anything like that. Just to possibly... I wouldn't make so many mistakes and be confused sometimes but then also I think it's almost healthy in a way because it made me, made my brain think other ways of doing stuff, to get round problems. Like even before if I knew I actually had dyslexia I was compensating for little things and God, I can't remember any examples but I'd do stuff slightly differently or make up my own ways and just sort of keeps your brain active when you're quite young I think and if your brain is growing and you're creating more diverse sort of pathways and you have to think more about something.'*

For Gloria being dyslexic is not something that she would like to change as *'in a way, it's not good to have dyslexia but it gives you a reason, if you feel you can't manage something, whereas if you were perfect, what reason have you got to give for not being able to do something?'*

Larissa and Sabrina feel fine about being dyslexic. As they said they were born like that and it is fine for them to be like that. They are dyslexics. It is the only thing they have experienced so they cannot tell any difference how it is not to be dyslexic. As Sabrina said: *'I like everything I've done so far and doing things rather you want to say I'd change my different talents but I am the way I am. I am dyslexic. I view the world the way I do see it. I can really change it. I don't.'*

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The issue about how a dyslexic's brain functions is something that Lana raises in her interview too. Lana does not mind being dyslexic, what she does mind is the assumptions other people make about the side effects of being dyslexic. *'I don't think being dyslexic is half as bad, it has some wonderful advantages, I can think things nobody else can even imagine thinking. I can do things that other people can't imagine doing. But the easiest is that people take for granted that is supposed to be easy and normal and straightforward, I can't do, and that to me and the side effects stops it a lot.'* Lana would like to get rid some of the negative effects dyslexia has on her and if she could change something in her life it would not be her dyslexia but to be diagnosed when '*she was very small and sent to maybe a proper dyslexia school, not an ordinary school where they would have known how to deal with her and where they would have known how to support her and then her life would have been very, very different'*. Humphrey (2002) found that children with dyslexia that were attending units for pupils with SpLD had higher self-esteem for reading ability, writing ability, English ability neatness and popularity than the ones that were attending a mainstream classroom.

Most of the participants, despite the problems that they face, considered dyslexia to be a gift after all as it gives them the chance to do things that other people would need much more time and effort to do. It somehow balances the effort they need to make in order to succeed in doing things that 'ordinary' people like me or any other non-dyslexic person takes for granted; like reading a book, finding your way around campus, following instructions or being able to understand certain questions without paraphrasing them. People with dyslexia can be more creative. As Karen said: '*She* (her mother) *like me thinks of it as a gift in that I can perceive different things in a different way and, fair enough, I can't write very well, my spelling is appalling but, you know for example, with computer*

science I can often visualise the programmes I'm writing quite, I can kind of visualise the way that the programme is going and how the programme construction in a very mental, visual way in my own head and I don't know, I don't think I, we; I've not talked any people that can do that, they perceive it differently. …I've been told that architects can, dyslexic architects, can sometimes see the drawing in terms of their own building in a kind of three dimensional way in their heads. It's kind like that with me and my programmes, again, I don't know if that's dyslexia but, if it is, it's a gift rather than a disability'.

It can be very disheartening for individuals with dyslexia to look at their friends doing simple things instantly without much effort whereas they might spend hours trying to figure out what they need to do On the other hand, everyone has strengths and weaknesses. People should take the example of these students and concentrate on the positive things that dyslexia might 'offer'. Things like creative (West 1997) and lateral thinking or visual perceptiveness (Loncraine, n.d.)

7.6 Feelings after assessment

Most of the subjects gave the impression that they had high self-esteem about themselves and they were quite confident. In terms of confidence I wanted to see whether dyslexia has affected their relationships with other people and how open the interviewees were about the fact they had dyslexia to other people (friends, colleagues, lecturers). Apart from this, I wanted to see how willing these students were to discuss their own difficulties and how talkative they were when they had to express their feelings or remember things from the past that might have had negative influences in their lives.

The interviews show that respondents that have accepted the fact they have dyslexia were more talkative compared to those that have not. Most of the participants were quite open to discussion about their difficulties and they did not hesitate to talk about them or to tell other people that they were dyslexics. Among the participants it appears that age is not something that can be taken as a factor in being more confident, as confidence seemed to have more to do with the person's character and personality and the experiences this person has rather than the chronological age.

Without a doubt, for all the subjects their self-esteem changed after being diagnosed as dyslexic. Before that some did not think highly about themselves and they recall that they were quite shy about discussing their problems and asking for help. Some of them, such as Rachael and Lana, were self-conscious and they knew that something was wrong with the way they were learning things but still they could not get any help either because they were afraid to ask, as they did not want to appear to be different from others. Because of their high intelligence, people thought that they did not have any problem and were just lazy as experienced by Gloria or Kara. Most of the participants were confused in the early years of their lives about not being able to do things their schoolmates did. This made them feel embarrassed or frustrated and most of them lacked confidence. Things got better though when dyslexia came out in the open. All the subjects felt relieved on one hand because of it but on the other hand for some of them it was difficult to accept it. Kacy, when she first heard she was dyslexic, felt embarrassed because she was quite 'old' (36) at the time of her assessment and as she said: *'I suppose everybody expects that you can write'*. Dyslexic children from a young age have associated being able to read with intelligence (Humphrey and Mullin, 2002). Also, in western societies the written word is quite powerful and adults with dyslexia are surrounded by print, taking for granted that

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people are literate – menus, signs, instruction booklets and timetables – and evidence of literacy demands in society are steadily increasing (Wolff and Lundberg 2003 in Tanner 2009: 1). Now, two years after her assessment Kacy has a different opinion about that. *'It did (concern me that I was dyslexic) at first and in fact when the report came through saying I have a reading age of like a 12 year-old and a spelling of a 14 year-old or whatever. But then they said you have an IQ of 100 and something. Which is good. I think that upset me at first but then I don't see it as an embarrassment now. I actually see it as a gift because I wouldn't be doing probably the things that I'm doing'.* `For Kacy it was her age that made her feel uncomfortable. People expect adults to be able to read and write without any problems. She was worried more about what other people will think rather than the dyslexia label itself. The label gave her the confidence to accept herself and see the positive things of dyslexia.

None of the subjects denies the fact that their dyslexia has affected their lives, not only in terms of education but at a personal level too. Disappointment and frustration were some of the feelings that the subjects reported, especially when they were younger, because of other people's expectations from them and from the way they treated them. Tanner (2009) reports the feelings of frustration and powerlessness that adults with dyslexia experience due to the lack of understanding from their teachers and peers.

Some of the participants had to go through hard times when they did their GSCEs or A levels as their teachers discouraged them from trying to go to university and do things to improve their lives. Kara describes this: *'all my life has been affected by dyslexia. You know, in prep school I was meant to be stupid and then went to a school I was told I probably wouldn't get very many GSCEs and I used to get 10 GCSEs and then in my next*

school to do my A levels I was told: 'You really shouldn't do A levels'. I didn't think I would do very well. I then got 4 A levels. Once I'd done my A levels I was told you can't go to university. You just haven't got it, can't do it. You're dyslexic and hold you back in every way and I said 'Bugger you' and now I've finished. I've got my degree and I feel like I've achieved something but, it's been a struggle definitely.' Kara was not the only respondent that was disheartened in her efforts to do better in her life. Jenny, one of the students that took part in the Riddick et al., (1997) research project, speaks briefly on her negative experience of her teachers. Diagnosed at the age of 15, her teachers did not encourage her to do some GCSE subjects, and she believed they did so because they thought she was slow and incapable. She does not think that they took her dyslexia into account.

Sabrina and Larissa as well agree that dyslexia has affected their lives but they both come to the point where they realise that this disability made them stronger and more determined as they wanted to prove they could accomplish their targets and their aims.

Sabrina said: *'there are parts where it's been affected a lot I think when I've been upset by it and not knowing what it is and how to deal with it and got cross with it. My mum said I came home one day and I was screaming my head of why I couldn't read, read as fast as everyone else. And I still have, up to recently; I hadn't read a book cover to cover. I did A level Literature because I wanted to prove that I could still, I wasn't stupid at writing and doing this and that...'*

Determination is a common theme among people with dyslexia. Although people let them down and sometimes consider them unintelligent, people with dyslexia do not give up!

They persevere and succeed even though the odds might be against them. Scott (2004: 217) when asking her dyslexic clients what dyslexia has given them usually they reply: 'their ability to struggle, cope, survive and 'stay in there''. Persistence and stubbornness are considered assets among successful dyslexics (Reiff et all, 1997 in Alexander-Passe, 2006). Students with dyslexia are determined to prove to people that they are not quitters and can achieve and accomplish their dreams. Morrison (2006) talks about Attia, a dyslexic student, who was humiliated by her teacher when she was in second grade. Her teacher's behaviour made her determined to prove to people that she can succeed and complete her course with the minimum help she can have. The thought of her fellow students laughing at her 'feeds' her stubbornness.

Lynda believes that her life has been affected positively and negatively by being dyslexic and it not being recognised. *'Negatively because I came out of school with only one GSCE and not being able to do the work and not going to school. But positively because I think it's made me a stronger person and just to get with things and find ways of dealing with it myself.'*

From the experience of the interviewees it appears that one of the problems dyslexic people face before being assessed is that they do not know how to cope with their difficulties and they feel incompetent. Simple things can be a struggle to them.

Rachael and Anna believe that dyslexia affected their confidence. Now they seem more confident than they were in the past but still they were not very articulate about their feelings and they described everything by using the minimum amount of words that they could. Probably this had to do with their personality as they looked like being quite

reserved and not very extroverted persons. Besides, the fact that they did not know me might be one reason for not wanting to share their feelings with me

Lana is one of the participants, for whom it seems that her life is being affected most and still is by her dyslexia. She seems to have had the most difficult childhood and she is still having problems in her everyday life because of that. None of the rest of the participants said or maybe admitted having so many problems in their lives. In Lana's own words:

'My life has been affected by my dyslexia a lot. Everywhere possible. Relationships, friendships, trusting people. Certain situations I had to have a psychotherapist when I was small because I was causing so many problems at home but they thought it was me and then they decided it wasn't me, that I was clever and all sort of stupid things. Not getting proper treatment because people missed these certain things that you do and then they decide that you fall into this category and to treat you as being in this category and that carries on all the way through your life. I left school I had terrible nightmares with jobs, dropped out of college. I had one job after another. I find it very difficult in a work situation cause I don't understand the politics basically all that sort of stuff and it gets very confusing and I tend to get very isolated. Every part of your life. I've had accidents all the time. You avoid going to very public places where lots of people are there cause you can't understand what is going on. You get confused. You make mistakes; they say you're stupid, everybody laughs at you and they talk about you behind your back and think you're weird and all sort of stuff. You avoid going to new places cause you're going to get lost, you don't know where to go, you don't know how to get there. You miss appointments cause you muddle up your times. You name it.'

Lana's life unfortunately is one of many. Tanner (2009) in her study describes the negative effects that unconscious assumptions from non-disabled people have in individuals with dyslexia. Rocco (n.d.) also expresses his concern about the impact that our choices, as a society has in individuals with disabilities. People tend to not see how their choices or actions might affect other human beings. In his article he uses a quote from a lady with an invisible disability (autoimmune disorder) that could describe someone with dyslexia: 'If

you look at me you see a normal person…because that's nothing that looks abnormal. ...
sometimes it's very difficult to make people understand that yes there is something really
wrong, because there are no signs of it on the outside (p. 134)'.

7.7 Disclosure of Dyslexia

Dyslexia as mentioned before has no obvious external signs like other disabilities
(e.g.Down syndrome) therefore people may misinterpret the dyslexic person's behaviour
and difficulties. It is not easy for people with disabilities to acknowledge the problems they
experience (McLoughlin et al., 2002). On the other hand, it is vital for people with
dyslexia to inform their colleagues and friends about their dyslexia in order to avoid
misunderstandings and awkward situations. Unfortunately, not all people with dyslexia are
willing to disclosure their dyslexia. McLoughlin et al., (2002) believe that before people
with dyslexia try to explain to others about their difficulties they need to know their
strengths and weaknesses. They should be able to describe any manifestations caused by
dyslexia and how they are affected by it.

In this present study the majority of the participants were willing to disclose their dyslexia.
Anna was probably the only individual who appeared introverted and not willing to talk
about her problems. Lack of confidence dominated her answers. She seemed reluctant to
approach other people, as *'when you see someone else that hasn't got that problem, you
feel disabled to that person, that hasn't got that problem'*. She was the only person very
hesitant to tell people apart from her family that she had dyslexia. As she admitted, she has
told only one person on her course about her dyslexia and she was about to tell another one
but she changed her mind, as she did not think *'it's any use going around telling people'*.

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Besides, one of the reasons that she does not like to talk about her being dyslexic is that she thinks '*that other people might not understand* (her problems) *and you cannot relax'*. There are always going to be individuals who will not understand dyslexia so McLoughlin et al., (2002) advise that people with dyslexia should inform only the individuals that need to know and even then they should disclose only what is necessary.

In contrast to Anna, Lana and Gloria, Karen, Kara and Ralph are quite open to telling people that they have dyslexia. Gloria, Kara and Ralph will let people know if it comes up in a conversation; they will not hide it. Kara is completely open about it '*because if people can understand me better then they might be able to help other people as well and they kind of understand when I ask them 'what this word say? You know, they know it's not just me doing stupid or...'* Lana also believes that by telling people it will enable them to understand why she is doing certain things, but it is not so easy for non-dyslexic people to understand all the time. Lana thinks that '*being so forward about it*, *they (people) tend to think us weird as well. But I don't think totally as a negative thing.'* Ralph too thinks that by telling people '*it rationalises my dyslexia tendency.'*

Mac has let some people know but he does not '*go around broadcasting that I have dyslexia.'* His friends back home do not know, as they do not see his work so there is no need to let them know. In the university he has mentioned it to some people and he thinks it was very funny because… '*I've told one guy and he said to me: where were you at the exam? And I said, I was in a different room, why is that? I said oh, I have dyslexia and he turned around and said, oh, I didn't know that. And I said I do not have it on my forehead'*.

Apart from Lana-who as mentioned before seems to be more affected than anyone else in this study by her dyslexia- the rest of the participants did not have any negative reactions or experiences from their friendly environment before and after they realised they were dyslexic. None of the subjects reports any name-calling from their fellow students in their early school years. It was more the idea they had of themselves in their minds of what they friends might think of them rather than their friends' reactions that had made them less confident in the past. It was more the fear of being rejected because of the problems they were facing and their inclination to hide their weaknesses that made people, such as Rachael, less confident to approach other people and ask them for their help.

7.8 Conclusion

The participants of this study welcomed the label of dyslexia as an explanation to their problems. Some of the mature students noticed a big difference since the days they were at school and they were impressed with the help and support that nowadays-younger students, once they are diagnosed, receive at school and university.

Surprisingly the majority of the interviewees, given the chance, would not like to discard their dyslexia. They have moments that they feel frustrated and they know that they have to work twice as hard as their peers but on the other hand dyslexia makes them creative and makes their brain work differently and visualize things in a way that people without dyslexia cannot. They see and accept dyslexia for the positive things it offers them. They perceive it more as a gift rather than a disability. The majority of the participants were also willing to disclose their dyslexia to friends and colleagues. They believe that by letting people know they can understand and accept them more and they also raise awareness about dyslexia.

The following chapter deals with the family environment and how the participants' friends

and families reacted to the problems caused by their dyslexia.

CHAPTER 8

DYSLEXIA AND FAMILY

8.1 Introduction

This chapter explores the relationships between the participants and their families. How their parents reacted before and after their assessment and with what they tried to do to help and support their children's difficulties. It also explores the notion that dyslexia runs in the families.

8.2 Reactions at home

Not all the families experienced the same reactions when they were told about their child being dyslexic. The responses varied from family to family. Some of the families, like Kacy's, accepted it very easily; some others, like Camilla's, are still trying to come to terms with it.

Almost all the participants with the exception of Camilla and Anna said that their families were not surprised by the fact they had dyslexia. The participants said that their families knew that something was wrong. On the other hand, one might think if the parents knew that something was wrong why did they not try to do something about it. Dood (1995) speaks about parents' inability to help their children because of their lack of knowledge

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about dyslexia. She believes that parents are left alone to battle for their kids' lives and problems. Besides, parents sometimes are thought to be overprotective and teachers sometimes dismiss their worries as not valid. Unfortunately, it was not possible to have access and talk to parents because the participants of this study did not stay with their families any more either because their families lived in another city or because they had their own families and lived with them.

Camilla said that although she has told her family about her dyslexia they were *'just starting to accept it'*. Her explanation for that was that although they knew that she had problems with her memory they did not do something when she was younger. When she was at school dyslexia was not something that people would do a lot of things about. Now as she says *'it is different'*. Camilla reasons quite a few times in her answers the fact that when she went to school dyslexia was not picked up as much as it is now. This comparison seems to be constantly in her mind and maybe it gives her a reason to understand why she did not have enough help from her school of her family. For her, people, including her family, were not aware of the dyslexia problem and that is why she did not have the response she should have had to her problems. The lack of people's awareness when it came to dyslexia quite a few years ago is something that Kacy too emphasizes in her interview. She was really impressed by the help and support that one of her younger fellow students in her course had received throughout her school years. Because of the awareness people have now compared to 15 – 20 years ago when Kacy went to school, her friend was identified at an early age, she attended a specialist school, had extra help and assistance. Nowadays, Kacy believes that dyslexic students receive so much care compared to the ones of her generation, as then only a very small percentage of people were aware of the

existence of dyslexia and only a limited amount received the appropriate help for their individual needs.

Sabrina, also, was the only participant whose mother was quite upset with the school because they did not pick it up earlier. The reason her mother got upset was because she could tell that her daughter was quite intelligent. She knew that something was wrong with her and that she did not achieve the things she was meant to achieve. The school said that her daughter: *'was fine'*. Her mother did not rest upon the things the school told her about her daughter's difficulties. She tried her best to find the cause of her problems. If it were not for her mother Sabrina probably would not have been assessed at that age.

Parents a lot of times have faced rejection and they had to try hard in order for their kids to be assessed. Some have been characterised as overprotective in their attempts to draw the attention to their children's problems. Stories of mothers having to fight the school authorities in order to have their kids assessed are not rare. This battle is even more important for parents that are dyslexic themselves and they are trying to protect their children from going through the same negative experiences they had to tolerate during their own schooling. Helen, a dyslexic herself, no matter what she did to have her daughter assessed she come across a negative encounter with her daughter's school who tried to do whatever they could to reassure her that her child did not have any problems and compared to other children in her class her reading was much better. Therefore, she did not need any extra help. Her daughter's school believed that '*her spelling will come when she is ready*' (Morgan and Klein, 2000, p.89).

Jenny's parents, on the other hand, set their minds at rest after her school told them that there is nothing to worry about their daughter's difficulties at the age of 6. Her teachers

said 'it will come' (Riddick et al. 1997, p.131). They believed the school and this caused a lot of suffering to Jenny, as she struggled most of the time in her school.

A family that did not react in a positive way was Lana's. In the beginning they thought it was their daughter's '*excuse of being lazy and not being able to do certain things'*. Lana still does not believe that her family fully understands her problem and what dyslexia means. On the other hand, Lana's mum thinks that '*she should be the one needing help for having gone through all the hell of bringing her up'*. Lana admits she had a very difficult childhood and she was a very complicated child who would do everything in order to avoid going to school; even pretend she was sick. She reached a point that she could even fool doctors by pretending to be ill.

'I could be ill and nobody would know what was wrong with me and I had mumps twice. The doctor didn't spot the cotton wool because I shifted it around. They knew I was making half of it up but they couldn't figure out quite what.'

Most of the participants' parents accepted their children's dyslexia. All the participants said that their parents knew that something was wrong because they knew their children better than anyone else and they could understand their high intelligence. On the other hand, something did not fit with their children's achievements and the things they were capable of doing. For most of the participants' families it was a relief to know their children had dyslexia because this explained their children's problems and the difficulties they had throughout the years.

8.2.1 Support from Families

In terms of support from the families the participants of the study had different experiences. Some of the families were supportive and understanding, some others were not either because it is hard for the parents to understand the effects that dyslexia might have in a person's life or because as Kara said: *'I think they (parents) can (understand) to a certain extent but unless you have dyslexia yourself and experience it, there are different types of dyslexia but obviously someone who isn't dyslexic can't quite understand why your brain does these things. You can understand on a superficial level but not quite what's inside you when you write it down'*.

Anna's parents tried to help her as much as they could by buying her books to help her with her reading but it did not work very well. For her it was the best they could do at that time since she was not diagnosed and besides, *'they did not know how the way the system work, they just sent us to school and that was it really'*. She believes that she would have had more help and support from them if they knew how school operates.

Morgan and Klein (2000) interviewed three generations of a family; Karen, her daughter Isobel and her grandson Lee. Isobel and Lee are dyslexics. Lee was diagnosed at the age of 6. Through these interviews they wanted to see whether Isobel, an undiagnosed dyslexic child, and Lee had any similarities or differences in their childhood experiences. Lee when he spoke about his dyslexia found a lot of positive things to say about it. He believes that being dyslexic makes him special in a way that nobody else is. He could point out the things that he is good at like sports (football, tennis) or being a good talker. He has managed not to let his problems in his reading and writing lower his self-esteem and he

managed on any given occasion during the interview to point out his strengths. He receives extra help with his English and he is quite happy going to school. Lee was lucky because his mother's problems made her seek help for him quite early in his childhood.

Isobel on the other hand had struggled during childhood. Nobody seemed to understand what was the reason that had caused her all the problems. After leaving school she worked in an architect's office, who happened to have a dyslexic son and he suggested that Isobel might be dyslexic as he recognised some of the dyslexia symptoms in her. Isobel did not look into it further as she became pregnant. She was finally diagnosed as dyslexic at the age of 24 when she decided she wanted to improve her academic skills and she was attending an access course to go to university. Isobel pointed out how good her social skills were when she was a child but the way her teacher treated her was dissimilar to her son. Her behaviour, especially in the secondary school, deteriorated and she would do anything given the chance to misbehave. At some point in her secondary school Isobel was punished and prevented from attending an art course, although she was very good at it, because of her bad behaviour. Isobel does not blame her family for her problems. She believes that they just did not realise her potential. Her mother, Karen, was not aware of dyslexia. Her main concern was for her children to be happy and if they did not do well at school, she did not think that pushing any pressure on them would do them any good. Karen had relatives in their family that they did not succeed academically so she considered Isobel's failure as something that was inherited from them. She did as much as she could to help her though as she did not consider that her daughter was 'thick'.

'I'd teach her to spell 'would' and 'could' and two weeks later, she'd leave out 'u's and she'd mix up 'b's and d's ; I never could understand why she couldn't learn...I tried and

when she couldn't I thought, well I'll leave it because a lot of my husband's family are not very bright and one side of my family are not very bright; some can't read or write. Because of that I felt that it must be the genes that Isobel has picked up from them, so why to push her and make her unhappy' (Morgan and Klein (2000: 87).

Karen believed that although her daughter was not able to succeed academically she would be successful accomplishing her goals because of her determination. Karen also admitted that she had different expectations for her two daughters future, which were based more on their personality rather than their academic abilities (Morgan and Klein, 2000).

8.2.2 Mothers versus fathers

Kara, Karen and Ralph believe that their parents, especially mothers, can understand them more now when they are getting stressed about their work. Karen's mum herself has done a lot of personal reading about dyslexia and its effects in order to support her daughter and to help her to have a better understanding of her problems. Karen does not consider dyslexia as a disability. Her mum gets very irritated when dyslexia is called a disability because both of them think of it *'as a gift in that Karen can perceive different things in a different way'*.

On the other hand, Lana's parents are not supportive at all. They always took her reactions as *'attention seeking'* she tried to explain to them but it seemed that they do not understand her problems. She does not blame them somehow because she admits that she was a very difficult child and probably some of the things she was doing were a way to get their

attention. Her doctors have told her parents that they *'have to rule her with an iron rod or she will rule you'*. Her relationship with her family has deteriorated through out the years.

Mac and Rachel too have families that do not understand them and so they do not get much support from them. Mac thinks that they cannot understand his problems because he *'can speak perfectly well and to a higher standard'* but his writing does not match his speech. So his parents cannot comprehend the fact that although he does not have any problems in analysing something perfectly well orally he might fail in his exams. Mac, from his side, he has tried to explain to them but at the end of the day he considers dyslexia as *'his own problem or issue'*. His parents have told him what is on offer after that he thinks it is up to him to do what he wants and to deal with his difficulties.

Rachel, on the other hand faces different problems to Mac. She comes from an Asian family and for her family being dyslexic *'is like devalue for the whole family'*. Dyslexia is something that her parents do not want other people to know. They tell her that it is not something that she should be ashamed about but then again from their behaviour she knows *'they are not happy with it'*. They might try to understand her problems but deep inside her Rachel knows they did not like her being dyslexic. They are also opposed to having her younger brother tested because they believe he does not need to, as he is not dyslexic.

From the answers that the participants gave, mothers seem to be more supportive than fathers. With the exception of Darius, who was the only one who asked his dad for help with his proofreading in all the other participants the mothers were the ones who supported them the most before and after they assessment. Mothers are usually more close to their

children and spend more time with their children either because the fathers are working longer hours or working away from home. We also have to consider that in some families there is no father figure in the house. Bungener and McCormack (1994) give more reasons for the father's absence. First, it is the overprotective mother who marginalizes the father. Second, with disability, there is normal separation and individuation between mother and child. Both these situations can result in a cutting-off, or excluding of, the father (in Scott, 2004: 139)

Apart from these, mothers are usually more patient and they are more involved with their child's education and development. Some mothers also do not work and as they stay at home they are the ones that usually are dealing with the children and checking if they have done their homework or learning their spellings or timetables.

Riddick (1998) interviewed only the mothers of the children that took part in her study as a) mothers were the ones who brought their children to the Dyslexia Institute and b) because the fathers of the children although they were concerned about them, they did not have a lot of day to day involvement when it came to issues surrounding their children's dyslexia.

Ralph's dad gets very upset when his son is driving and he is having problems with his orientation. As Ralph said: *'my father gets annoyed when I could claim dyslexia when I do something wrong. It's not my fault, I'm dyslexic! He goes like: yeah, right. Like diplomatic immunity!'* His father blames his mother for his son's dyslexia because it runs in her family. Karen, also, believes that her father cannot understand her dyslexia and she does not have any recollection of him talking about it. The mother was the parent that mainly

the participants mentioned in helping them. It has to be said that some participants, like Gloria, believe, although not assessed, that their fathers have dyslexia too. Further discussion about this subject will follow.

It also seems that parents like Karen's, Sabrina's, Carla's, Darius's, tried to do the best they could with the means they had and tried to read and study about their children's problems in order to help them the best they could. Carla and Darius attended a boarding school and one of the reasons their families have chosen the particular schools was because they knew that their children would have additional help tailored to their personal needs and difficulties.

 Throughout the years there have been quite a few publications for parents, students and carers that are willing to learn more and understand more about dyslexia. Tips for better spelling, remembering things, how to help improve their children's self esteem, information about getting help from organisations and anything that the parents might think would be appropriate for the severity of the difficulties their off spring deal with (Temple, 1998, Blight, 1985, McNicholas and McEntee, 1991, Chivers, 2001, Smith, 1995).

8.3 Relatives with dyslexia

The majority of the people that took place in this study (11 out of 14) mentioned having at least one member in their family with difficulties similar to the ones they had. Only a handful of them were officially assessed. The rest of them, especially parents, the participants suspect that they have dyslexia although they have not been formally

identified. It is quite common for people with dyslexia to suspect somebody from their family having dyslexia after they have been identified themselves (Riddick, 1996; Scott, 2004).

Three students mentioned one of their parents experiencing problems similar to then. Nevertheless, none of them has been formally assessed. Fifty percent (50%) of the children that took part in Riddick's (1998) research study were bought up in families where at least one parent was thought to have had similar problems as a child. Some of the mothers admitted that some of the symptoms that their children experienced because of their dyslexia reminded them of their husbands' or their own difficulties throughout their school years.

The rest of the participants revealed one of their siblings as having dyslexia and the majority of them were assessed too. Ralph and Karen are the only ones who seem to have a strong family history of dyslexia as more than one of their close relatives has been assessed as dyslexic.

Anna thinks that her brother might be dyslexic although she cannot be quite sure as he moved schools and at his second school he did not have any special treatment for the problems he was facing and he was never assessed. She, also, has three children, a daughter and two sons, and she suspects that her two boys might be dyslexic too as they are very good in maths but they have difficulties with their spelling. She did not consider asking to have them assessed despite the problems she had herself faced for not being assessed because she believe that *'if they have it is in a very low percentage'*. This somehow contradicts Morgan and Klein's (2000) belief that once a person is assessed in

adulthood he can have a significant impact on helping the next generation gain access to resources and support (p.76). Anna is not very confident about her dyslexia and probably that is the reason why she does not seek any help for her own children. Mothers who have successfully dealt with their dyslexia, whose family was there for them to help them and support them, are more likely to be able to cope with having a child with dyslexia. (Beresford, 1994). On the other hand, maternal vulnerability can transmit risk to her child. This can happen through transmission of psychological characteristics such as 'low self-esteem, learned maladaptive coping behaviour or poor ability to form attachments' (Bifulco, Moran, Ball, Baines, Bunn, Cavagin, 2002: 1083). It has to be mentioned that there is no implication that Anna is not a good and caring mother to her children. Bifulco et al. (2002) in their study found a very small percentage of vulnerable mothers were responsible for poor parenting behaviour themselves.

Camilla believes that her mum has dyslexia but she was never assessed. Her mother has similar problems to her, not being able to spell and write very well but Camilla thinks *'she does not realise it'*. The age factor comes back again. Camilla reasons it is due to her mother's age. In the old days dyslexia was not something that teachers or parents would consider as a problem for their children failure at school.

West (1997) in his book mentions the case of Nobelist Bajuj Benacerrat whose dyslexia was not recognised in the 1920s. He had to work really hard throughout his life to accomplish everything he has managed to do. When he noticed his daughter first and his grandson later making the same mistakes and having the same difficulties as him he realised that the difficulties he was facing were not 'unique' as he thought (p. 63).

Karen and her family believe that her dyslexia comes from her granddad. When they look back at his letters they can see it. Her mother is dyslexic but she was never formally tested but all the signs are there: *'spelling appalling, she capitalised randomly'*. Her brother is also dyslexic and her uncle, her mother's brother. Karen too as Camilla reasons the fact that her uncle did not have any support during his school years because he went to school in the 1950s and 60s.

Rachel suspects that her younger brother is dyslexic too but because of her parents' refusal of his being assessed, she cannot prove it. He makes similar mistakes to hers. In Rachel's case, as mentioned before, we cannot be certain of what makes them be so negative with their children's dyslexia. It can be a cultural thing or it just can be a shock for having a child with a disability. Rachel's family might be going through a bereavement period. It is not easy for parents to accept that their child, no matter how smart, outgoing or gifted they might be; the thought of having any kind of disability can be devastating for the parents (Scott, 2004). All the parents dream about having the perfect child. Research has shown that families that have a child with a learning disability are at risk for physical, emotional and/or social stress compared to the ones with 'normal' children (Lardieri, Blacher, Swanson, 2000). In their research Lardieri et al. (2000) concluded that parents, especially the ones with children with behavioural problems, are concerned and stressed about their children's future and about the ways they themselves can cope with their children's problems and needs as well as trying to keep up with the rest of their family and their personal lives too. Moreover, if the problem for Rachel's family is cultural any generalisations cannot be made, as, Rachel is the only participant with an Asian background.

Mac too, thinks that his sister is dyslexic but he is not sure as *'she hasn't done any GCSEs, no A levels. She kind of fell out of school'*. Ralph believes that his mother is dyslexic too although she is not assessed she has the same sort of symptoms as him. He also has two cousins, from his mother's family, that he thinks are dyslexic too. Gloria believes that her dad and her little brother have dyslexia. She believes one of the reasons her dad has dyslexia is because *'he didn't get any GCSEs apart from maths'*. Darius too suspects that his dad and brother are both dyslexics because of the mistakes they are making; but none of them has been formally assessed.

Sabrina's brother is formally assessed as being dyslexic and last but not least Carla has a younger sister who recently was assessed as being dyslexic. Being assessed themselves helped their siblings being identified at a younger age.

From the participants of this research it looks like the ones who had relatives in the family already being assessed had much more support than the rest of the group. The parents who were aware about dyslexia were much more supportive and understanding. They have tried their best to make their children have a positive image about dyslexia and focus more in the positive things that dyslexia offers them (e.g. creativity) rather than the negative effects it has in their everyday lives. They have worked hard to improve their children's confidence and make them feel good about themselves. Maternal warmth is very important for and beneficial for a dyslexic child. It seems to empower the dyslexic child and help him to be more positive (Scott, 2004).

8.4 Relationships with friends

No major problems are reported in relationships with their friends. People seem to be more judgemental when they were not informed about the subjects' condition. After being informed usually they tried to help their dyslexic friends when they needed them and seemed more sympathetic with their difficulties. Karen mentions that some of their friends wished they were dyslexic too when they saw her getting a computer and some other equipment from her LEA to help her with her work at the university. Ralph recalls some arguing with his friends when he should not have done on things that are not of great importance like: '*it might be on TV when someone was laying on their back and I had a five minute argument with my house mates to say: no, no, no they were on their front!*' Dyslexia has not caused him any problems with his friends. Apparently because his dyslexia is quite moderate as he describes it, his best friend did not believe him when he was diagnosed. He thought he '*was scamming the system.*' Most of the subjects confront their friends, maybe not straightaway but as long as they accept their disability they are more open to make other people aware of what their problems are and where they originally derive from.

Lana as mentioned above, experienced and is still experiencing a lot of negative remarks and behaviour from friends in her environment. It appears that the people that surround her seem incompetent to understand to full extent her abilities and disabilities and because of that she gets a lot of negative remarks for the things she is doing. Most of her life she seems to mingle with people that criticize her more than praise her for the things she is doing and for the effort she is putting into succeeding in them. It is difficult for her to build relationships according to her because she is dyslexic. She is quite confident about being

dyslexic. As she says: *that would not bother me (being accepted as dyslexic from others) cause either accept or not I'm quite harsh about it'* Her problem is that she is afraid of being hurt by people that do not understand her and the way her mind works. She said: *'I'm scared of being hurt a lot because I've been in the past because I know that people do not understand things and they tend to get confused and things like that…And avoid situations there is a lot of people because I know that I'm not going to understand. I cannot follow. If it is a lot going on like in a pub there's a lot of noises, there's a lot of people. I would get totally lost and I'll sit down like a complete idiot cause they'll be talking and this and that and I'm like eh?? Or I'll, I've got that habit of misunderstanding and talking people literally and that doesn't fit with people's expectations of me.'* Her experiences have made her very hesitant in letting people in but once '*she lets somebody in and they are ok but very few people are like that*.'

The rest of the subjects did not express any problems with their social and emotional lives. Larissa has a lot of friends that have high IQ and they belong in a group of people with similar abilities. She never felt out of place hanging out with them even when she did not know about her dyslexia and she did not think highly about herself. Dyslexia did not stop the rest of the subjects from being sociable and having lots of friends. Ralph jokes about his dyslexia with his friends and a lot of times he is the one that initiates the jokes. Kacy does not think that her dyslexia has affected her relationships with her friends. She likes writing letters to people and she was and she is doing that although she has problems with writing. She did not mention any negative comments from her friends although as she says: '… *everyone that gets a letter has to decipher it before they read it*'.

Most of the subjects are quite confident in telling people that they are dyslexic. They might have been hesitant in the beginning but once they have accepted it they were more open to let other people know about their difficulties. Anna is still having problems in telling people but the time she realised she was dyslexic was quite near the interview and I believes that she is still in the process of accepting it herself. It is not easy to confront other people with something if one has not come to terms with it first.

8.5 Conclusion

Most of the participants' families knew before they were assessed that something was wrong with their children. They could see their intelligence and their potential but could not understand why their offspring were failing at school. The majority of the parents understood their children's problems and some of them even tried to help them by buying books. The mature students report that they did not have much help from their families but they believe that this happened due to lack of awareness about dyslexia when they went to school. Two participants reported no support from their families; one due to her disturbing behaviour (her parents believed that they are the ones who need support for all the trouble she has caused as a child); the other due to the family's cultural beliefs about disability.

After they were assessed 11 out of 14 interviewees could recognise symptoms related to dyslexia in close family members. They could see their parents and siblings making the same orthographic mistakes as them. The largest part of the participants had to rely on their mothers to help them with their difficulties. Probably because mothers tend to spend more time with their children when they were younger while fathers work more and long hours.

Chapter 9 will examine the difficulties the subjects of this study had to face while they were in school (primary and secondary). It will take a closer look to their coping strategies and their survival techniques, as many of them were not aware of their dyslexia at the time.

CHAPTER 9

SCHOLASTIC EXPERIENCES OF DYSLEXIA

9.1 Introduction

All of the participants went through primary school without being assessed for dyslexia. The mature students that took part were assessed when they were much older which meant they finished school without knowing they had dyslexia. How this affected their school performance will be presented in this chapter as well as the support they had, if any, from their schools.

9.2 Difficulties and Dyslexia

9.2.1 Experiences of HE students with dyslexia in school (primary and secondary)

Almost half of the participants were identified while they were at school. Unfortunately, it did not happen the first couple of years. The youngest person who was assessed was Carla and that was at the age of 8. Due to the fact they were identified late, this resulted in them having a lot of difficulties attending school and dealing with the everyday homework that they had to do. The problems they faced and the severity of them varied from person to person. It seems that most of the students' problems started to emerge when they reached secondary school and they had to face a more difficult and demanding programme.

Greca and Stone (1990) in their research study comparing learning disabled and non learning disabled children, conclude that girls with learning disabilities could be

distinguished from other low achievers by their lower perceptions of self-worth, higher ratings of anxiety-withdrawal, and lower ratings of behaviour problems. Their results concur with Spreen's (1987 cited in Riddick, 1996: 46) study. He reports that learning-disabled girls are particularly vulnerable to adjustments and that especially in adolescence problems of withdrawal were common. Furthermore, different research studies have suggested that children with learning difficulties have lower self-esteem compared to children with no learning difficulties because of their academic failure. Humphrey (2002) reports that students with dyslexia in a mainstream environment make unfair comparisons between themselves and their mainstreams peers and they feel more isolated and excluded. This comes in contrast with students with dyslexia attending SpLD units who feel more relaxed and more loved and wanted. Heyman (1990) in her research study among 87 children with learning disabilities in a New York public school (3rd to 6th Grade) suggests that self-perception of the learning disability may have an effect on academic self-concept and self-esteem, which in turn may influence achievement. Cosden et al. (1999) also report that students who had higher tested cognitive abilities and academic achievement felt better about their disability.

9.2.2 Exams

GCSEs and A Levels are something that most of the students remember because it is one of the milestones in a student's life and their future depends on how well they will do in them.

Camilla and Larissa came out of school with only one GSCE. The only GCSE Larissa passed was Geography *'and it was a C'* and she *'failed the rest of her* exams'. Kara was

told not even to try taking the exams. Sabrina did not have extra time in her GSCE exams because she was not diagnosed and the problems went on when she had her A levels mock exams. *'…On my A levels, when I got my paper out you could tell that I knew what I was talking about but it did not make any sense whatsoever.'* She remembered some of her teachers saying that *'this girl got some problems'* but nothing was done on their part. If it was not for her brother's assessment there is a big possibility she would not have been assessed. Gloria and Mac also suspect their father and sister respectively of being dyslexic by reason of their failure to pass their GCSE exams.

Miles and Varma (1995) report that GSCE examinations might cause quite a lot of stress to students long before the actual examinations take place. One additional cause of stress is the abolition of the 100% coursework option in English (p.50). A lot of students were put off because of that. Riddick et al. (1997) in their research talked to university students about their experiences in school. Some of these students described their GCSE examinations:

'Six attempts to get a GCSE. I moved up one grade to a 'C' every step on the way' (Sean, p.105).

'…I did my GCSEs with no extra time, and no help. I got five 'C's and three 'D's' (Caroline, p. 93).

9.2.3 Reading, Writing and Spelling Difficulties

Another problem frequently mentioned at an earlier stage concerns students' failure to read, write and most importantly to spell. It is quite common for dyslexics to skip words, add words or make up words when they are reading (Nosek, 1997). Riddick (1995) found

that children with dyslexia are far more concerned about their writing and spelling problems rather than their reading by the age of 10. The older they get the more concerned they are about the accuracy of their work. Spelling is supposed to be the biggest difficulty students with dyslexia face (Klein, 1993). Everatt (1997) found that there is a marked difference in spelling ability between individuals with dyslexia and non-dyslexic ones. The former produced a greater number of errors than the latter. Deno et al. (1982 cited in Riddick, Farmer and Sterling, 1997: 9) reported that students with learning difficulties make two to four times the number of spelling errors made by students who do not have any learning difficulty in their written work.

Without a doubt English is not an easy language to learn and having a learning difficulty makes it even harder to master the language and express freely without having the concern of making mistakes all the time. An anonymous person wrote the following poem in an effort to illustrate the difficulties that people with dyslexia face because of some 'abnormalities' in the English language. Spelling of words that come automatically to someone who does not have any learning difficulties may confuse an individual with dyslexia and make him/her wonder about the correct spelling.

The Craziest Language

We'll begin with a box, and the plural is boxes;
But the plural of ox should be oxen, not oxes.
Then the fowl is a goose, but two are called geese,
Yet the plural of moose should never be meese.
…………………………………………….
We speak of a brother and also of brethren,
But though we say mother, we never say methren.
Then the masculine pronouns are he, his, and him.
But imagine the feminine, she, shis, and shim.
So English, I fancy you will agree,
Is the craziest language you ever did see.   *(Nosek, 1997: 169)*

For Camilla, Kara, Karen, Ralph, Darius and Carla spelling was one of their main problems in school. Camilla's spelling and writing was very messy in school. Kara and Karen describe their spelling as *'appalling'*. Ralph got into arguments with people because he *'thought I was right and I'd only realise afterwards that I was completely wrong and it takes about five minutes and it suddenly it will click and I was like: Oh my God, noooo!!'* Ralph used to write capital letters in essays when they should not have been. Darius always put letters the wrong way round. *'B's and D's and C's and D's'*. Darius feels insecure about his spelling. If he has to write a cheque and wants to be sure that it will not 'bounce', he writes the correct amount of money on his computer and then he copies it from the computers' monitor. People that have dyslexia usually confuse letters in their reading and writing such as b with d, p with q or n with u. They may also have problems with numbers in maths or in science, such as 6 with 9 or 3 with 5. Depending on the severity, dyslexic people might reverse the letters or the numbers they are reading, omit words that are in the text or create others that might not exist in the text, and so forth (Lewis and Howell-Jones, 1995).

Reading was a struggle for Larissa. She did not want to read aloud because she *'could not read'*. Her goal is to manage one day to read a book from cover to cover. She is sometimes jealous of people for being able to read. Reading aloud is probably one of the worst 'nightmares' for a person with dyslexia.

Carla could not really read or write at eight years old, which was the time she was diagnosed. She believes that *'I did not have the right teaching method of teaching; my short-term memory is very bad, very, very bad. I've had to learn to develop my short-term memory, techniques to enhance memory in to long term. I had to learn, I was given special teaching, I had to learn from scratch. I had to learn about grammar and English. I had missed all that; I just hadn't really noticed that so I had to learn that from scratch and how to remember my spelling'*. Kacy too was not able to read properly until she was 14 years old. She believes that at about that age she managed to read a book from cover to cover for the first time. She was very embarrassed about not being able to read at an age where all her schoolmates were fluent in reading.

Other problems some of the students that took part in this study remembered were reading comprehension and making notes, coping from the board. Gloria found it hard to keep notes and at the same time to understand what her teachers were trying to explain. Mac describes his problems at school as *'not understanding anything. There were questions put to me and I wouldn't understand them'*. Rachel had *'to listen to something three or four time'* until she understood what people wanted to say or were asking her to do.

Anna was the only person who specifically said that confidence was one of her problems in school. The lack of confidence, as mentioned before, seems to be her most important negative aspect that dyslexia has caused her from an early age.

9.2.4 Avoiding School

Thomson (1987) explains bad behaviour as one way for children with dyslexia to gain attention. Behaving rudely or by causing trouble in the classroom is a way of expressing themselves and they 'succeed' in gaining some attention, even if it is negative, from their peers, teachers or family. Thomson also comments that another reaction is to withdraw from school. The child might cause no trouble but will try not to be noticed in the classroom and avoid any participation. People usually get to notice the child's failure during assessment time where inability to pass tests becomes obvious. Miles and Varma (1995) report cases of school refusal and bad behaviour as a result of school pressure and wrong treatment from teachers. In Edwards' (1994) study, truancy and school refusal occurred in seven out of eight cases that participated. For two of the boys truancy and school refusal started as early as infants' school, for five of them it happened repeatedly whilst at primary school and it was habitual at secondary level. Two of her participants, William and Mark, said:

'This is when I really started trying to miss school (primary school). *About a year before this, I started acting ill and trying to miss the bus, but my mum always knew when I was faking and always made me go, even when I was ill,'cos she never knew if I was faking or not! Missing the bus never worked, because my dad threatened to make me walk, and it was a long way!'* (William, p.103)

'I used to hang on the banisters at home, when sussed out as not sick. Mum had to get Dad out of work. (I got hit). They didn't know what to do. Ripped blazer, everything. I went to a

doctor and got hypnotized, for fear of school. Small green tablets they put me on. (I used to eat cat's food to be sick.) Three or four times I went. Really scared. Dad joked, snapped me out of it…if I had tests, even at junior school, I'd put my hand down my throat to chuck up, or a cotton-wool sandwich… I used to wag to every time we had a test at school – save me being bottom of the class. Feels like you're empty inside, but it goes.' (Mark, p.94)

Kacy played truant a lot mainly in an attempt not to take any tests and similar things. Rachel recollects only one case, when she was about twelve, that she did not go to school because *'I thought I was really thick so I didn't go to school for five weeks cause I just couldn't cope with it. …I couldn't understand the work'*. Lana appears to be the participant of this study who had the most problems in school. She was experiencing almost all the symptoms associated with dyslexia. She started by refusing to go to school and doing her utmost to achieve it. *'I used to do everything I could not to go to school. I remember being in my bed in my bedroom hanging on to the leg of the bed until the bed got jammed in the doorway, which is where I stayed until I could be pealed off the bed. I remember screaming being dragged down the road, dropping things on my legs, dropping things on my arms so I could do break my arms so I would not have to go to school…If I could have poisons to make myself ill I would have taken them not to go to school. School was hell'*. Kacy and Rachel admitted trying to avoid going to school but their cases were not as severe as Lana's.

In addition to problems with reading, writing and spelling, Lana was accident-prone, had serious problems with orientation, and had problems communicating with her schoolmates. *'...when I was younger I had problems with reading. I couldn't spell at all. I couldn't remember timetables. I used to write my letters back front. I did not understand what punctuation was between infant and junior school. Handwriting, my teachers used to shake my handwriting. And completely just didn't know what was going on cause sometimes I'd seem really clever and other times I seemed really stupid. I was accident-*

prone; I'd fall over and have accidents all the time. I did not really get on with the other

children. I got bullied.'

What she has found also very frustrating was people's attitude towards her. At school

because of her high intelligence, when IQ tested, her teachers used to put her in the top

groups and then she *'worked her way back down again'*. She was often called out in front

of the class: *'where does the apostrophe go in this?'* Her memories from school are only

negative. Throughout her interview Lana had only negative comments about her school

experience. She tried to make an effort to go to school and to attend her classes in the last

two years because of her A levels but still she could not cope and her attendance was not

good.

Telling right from left was another difficulty pointed out. Organisation, bad memory and

co-ordination problems were also mentioned but in a very small proportion. As Karen said:

… and it never kind of fitted together (her problems) *until I got diagnosed and then*

suddenly went, Oh!).

9.3 Support mechanisms in school

9.3.1 Personal coping strategies

As all the subjects were diagnosed after being at school for some time, they had to find

their own ways to cope with their difficulties. It seems that when it comes to coping

strategies all the students concentrate more on the period when they were at secondary

school rather than primary school. This is probably because of the workload students have

in secondary school. Primary school years seem to be easier to cope with and the students mentioned some problems but mainly they were concerned about secondary school. One other reason might be that secondary school is more competitive too and the stress of the exams and performance made them most likely more aware about their problems. Especially for those who were not diagnosed before entering secondary school things were not easy at all.

Gloria when she was at school did not think she had a problem to ask for more help. She thought that there is no point in asking for help, as she believed that she was stupid and slow. She would sometimes ask her teachers to slow down or repeat what they were saying when she was taking notes but that was only when she understood what they were talking about because she found it very hard to write down things from the blackboard and listen to what the teacher was saying. After she was diagnosed she was given an hour a week with a special teacher to help her cope something Gloria found very useful.

Karen and Kara did quite a lot of work on their own, trying to improve their weaknesses by practising their spelling and writing at home. They would devour lots of their free time at home in trying to find ways to make their weak points much stronger and overcome them if possible.
'My spelling I was just, I was trying to teach myself to write again which worked to a large extend' (Karen).

'I did more reading myself and I tried to fiddle with the essays, did lots of essay plans, had spider diagrams to try really get the right stuff for the essays and structure it properly…' (Kara).

Camilla, Kacy and Lana on the other hand were the opposite of the above-mentioned. They would try to avoid going to school or being picked for certain activities in the classroom. *'Playing truant'* as Kacy says. Lana would do anything to avoid school as mentioned before. She could make herself ill. As she said: *'if I could have poisons to make myself ill I would have taken them not to go to school'.* The same pattern followed Lana throughout her school years. When she was in secondary school she *'had welfare officers round her house so often really, it was unbelievable!'* When she was older Lana learned to use her strengths to avoid going to lessons. She is extremely good at talking her way out of any situation so when she was at school she made the most out of it. She used it with teachers in order to achieve whatever she wanted to. She said: *'I could waffle my way round a teacher. To be able to avoid going to chemistry for a year and a half and actually going to the teacher and saying: I'm not coming to your class because of this, this and this'. And they know that you are at the top by being there, is quite an achievement'.*

Camilla would try to avoid being picked by the teacher to do anything she felt she was not good at. Because she was self-conscious about her problems with reading she would try and find a spot in the classroom where the teacher would not ask her do any reading at all. *'I just tried not to get chosen to read: you know, because they (teachers) only choose if you sit near the front…I used to like sit at the back'.* Camilla would compensate for her weaknesses by being good in things she liked, like maths and creative things. She can make and build anything. So for Camilla failing in reading was balanced by succeeding in other subjects.

Kacy and Camilla would ask other people to help them too. They would ask them how to spell words or if they could write up things for them. Another strategy Kacy would use is to use pictures in her mind. She would try to match pictures to the things she was taught just to remember them. It was easier for her to remember by visualising the picture in her mind.

Mac does not remember having any coping strategies at school. The only thing he remembers is that there was a period he did not do any academic work at all. At some point he was transferred to a school '*that were all pupils who were not going to make it at school'*. It was something like a unit and people did not have lots of expectations from the students. It was easier for him not to do any work, as there was not any pressure from staff. He was considered a low achiever and his progress was similar to the expectations people had for him.

Anna did not do anything more to improve on the sections where she had problems. She just does not know how she coped. She could not remember anything that she would do to go through the school years. As she said:

'*At school I just coped by myself. I'd had no help, no support with that but I just coped by myself…Obviously now I'm older I see just slipped through the net and nobody really took any interest to say 'well help her with her spelling problem' and see if I coped*.'

Darius is one of the few students, including Mac, who thinks that dyslexia is his own problem and he has to cope with it and tries to be as independent as he can. He worked

hard on his own trying to improve his skills. One of the things he did, and still does, is to read his essays backwards once he has written them.

'One of the difficulties that I had is that I was reading it how I expected it to be instead of what it actually was so I wasn't recognising spelling mistakes. By reading it backwards it meant I had to read every single word and I would have to look it up and concentrate and recognise the spelling'. (Darius)

When he was younger he also had a spelling book where he used to transfer the words that his teachers would notice he had written wrong in his essays. His mother was helping him to learn the correct spelling of the words.

One sentence that the subjects of this present study used to say when asked how they coped with their dyslexia at school was: *'I don't know, I just did'*. This was especially for people like Ralph, whose dyslexia is quite moderate. He believes that because he did not really know that he had problems, he coped with it without realising it. When he was confusing right from left he had to think which hand he writes with and he had his answer. Ralph also would concentrate and try harder with his schoolwork.

9.3.2 Support from School

People like Camilla and Anna did not have any support from their school when they were younger. The reason is most likely because they were not diagnosed as dyslexics at that time. And as Camilla quite often states in her interview dyslexia was not one of the things that were quite acknowledged at the time she went to school.

Kacy and Lana did not have much help in school either. Kacy had some extra English tuition when she was doing her O levels. She found it very useful from a grammar point of view and it helped her understand how to put things together. When she was doing her O levels she knew there was a problem because:

'… When I did my O level English, I'd written the whole essay and come to the end and read it back and there was words backwards and all over the place…'

Kacy is amazed about the help dyslexic students now receive and about the wider recognition and the services that are given to them.

Lana said *'I wouldn't have known where to look for or…nobody understood waste of time.'* Lana's refusal to go to school and her high intelligence made people believe that she was lazy rather than having any other problems. Even her own parents thought that she was a trouble maker and nobody seemed to be concerned about her progress and her continuous attempts to avoid school.

Sabrina and Darius, on the other hand, had some extra support from school. Darius believes that he got the support that he had because his parents took him to a private school and because they were paying money for his education he had more attention from the teachers and the school. He also mentioned that there were a few other people in his year with dyslexia or other learning difficulties and they used to have extra English lessons while their peers were taught a third language.

Sabrina had some support for her spelling and she received extra lessons to help her improve it while she was in school. Although she thinks it was enough for the time it did

not continue throughout her secondary education. It was something she was pleased to happen because she did not want to be different to other children. She did not want to be alienated from other pupils by going to special lessons. The fact she had a spelling computer with her helped her through her secondary years. She could cover her problem by using the spelling computer. It has to be mentioned that she was appreciative to have extra time when she took her A levels as this extra time helped her calm down and do her exams without any panic.

Carla was another student who had extra help in school but that was after the first eight years of her life. The reason was that due to the fact her father was in the army and she had to change schools every two years so people did not realise she was dyslexic. They thought she was *'deaf or something'*. When she went to a steady school people there realised she was not stupid; she was actually intelligent and she just did not know how to learn properly. She considers herself lucky to be in a small boarding school with only 100 students in the whole school. There she was given one to one teaching and extra English lessons. Unfortunately, when she moved schools at the age of twelve she did not have any extra help really until she reached the age to take her A levels, where she was given extra time for her exams.

Ralph too did not have any support when he was at school. He got extra time in his exams after he was diagnosed, but before that it seems that it did not affect him that much as he considers his dyslexia quite moderate. He was fortunate enough to find a teacher when he was doing his A levels who spotted his problems and she put him up to be assessed since she thought he might be dyslexic and she was proved right.

Gloria had an hour a week with a special teacher to help her with her problems but that was after she was diagnosed. She had much more support after her assessment. She believes that it was not enough to solve things but *'…it was enough so that I felt that I could get on with what I was doing and get through my A levels.'* Before that people thought that she was *'a bit slow'* or *'a troublemaker'*. She believes that she had more support because it made more sense to people rather than when she was not diagnosed.

Mac was probably the only person who believes that his teachers were not interested in his and his fellow students' progress, especially when he reached the age of 14/15, because they would leave school the following year so they were not expecting anything really from them. Some help was given with the schoolwork although for him it was not sufficient but on the other hand he could not afford to have any extra private tutorials. When he was 15 years old, went to a school '*where people,* as he said*, were kind of like: you have till 15 and you leave school and then you are not going to be a problem here. But where are you going? So at the age of 15 I'm like: I should be in my second year of doing my GCSE but I am not. So I'm like, so then I was at this school and everybody in my class was like, not doing anything, I was like working towards GSCEs. So then I left that school and I did my GCSEs in a year.'* It was Mac's own determination and his desire to have a better future and accomplish something in his life that made him work hard to succeed. Unfortunately, out of seven GCSEs that he did he only passed five, his highest mark was D in English.

9.4 Conclusion

The participants of this study had to go through school without most of them knowing they were dyslexic. Their difficulties were mainly in reading, writing and spelling. Some remedial support was offered to them but they believe it was not sufficient enough to help them cope with their schools demands. Some of the interviewees assume that they coped without even realising that they were doing it. One of the students was pleased for not receiving any extra support in secondary school because she did not want to be different to her peers. School avoidance was another way to cope for some of the students. These students believed that it was better not to go to school as they felt that no one understood their difficulties. By not going to school they avoided the humiliation of their teachers for the mistakes they were making.

A levels and GSCEs are a landmark for students that want to continue their education and enter university. The participants of this study struggled with them and at the same time they had to face unsupportive teachers who rather than encourage them they were putting them down. For some of the participants though a positive thing came out during their preparation for their A levels and GCSEs. They were lucky enough to be spotted by some of their teachers who helped them and identified their dyslexia.

Fortunately all the students managed to succeed in their exams and they were offered a place in the university. The next chapter focuses on their experiences in Higher Education. Are things better now? Are they still facing their problems? Do their universities offer them any extra help and support? In chapter 10 the participants describe their difficulties and how they cope with these.

CHAPTER 10

DYSLEXIA IN HIGHER EDUCATION

10.1 Introduction

University life is a start of a new life and a brighter future. Students stop being dependent

on their families and they have to face everyday life on their own. Universities expect their

students to be independent and work on their own in order to complete their assignments

and pass their exams. For students with dyslexia achieving independence is not easy as

they have to cope with their course demands and at the same time they have to find ways

to manage their dyslexia difficulties.

10.2 Problems caused by dyslexia in the university

University is a very important step for everybody. Most of the students, with the exception

of Rachel, stayed away from home so they did not have any help from their families with

their new environment. Going to university for dyslexic students can be a struggle in the

beginning or for some cases throughout the whole duration of the course. The workload is

much more compared to their schoolwork. Everybody expects them to submit everything

on time and manage the given deadlines. The degree and the amount of academic

difficulties depends again on the severity of the problem and how determined each

individual is to overcome the obstacles and the different university requirements. Some

people, like Carla and Darius, try to use the minimum help given to them. Carla did not

want to even have extra time in her exams because as she said she did not want to be treated differently. Darius too, believes that he can cope with university life. He considers dyslexia as his own problem that he has to cope with and try to do things the best he can. Both Carla and Darius have not asked for any allowance for books or computer equipment although they are entitled to. They did not want to be different from anyone else and they are quite confident that they can cope with the difficulties caused by their dyslexia on their own.

Unfortunately, not everybody is like them. Most of the students mention reading as one of their main problems at university. The amount of time needed on their part to read a page is much more compared to the time their peers spend. Riddick et al (1995) examine automaticity in dyslexic children and concluded that if skills take around 100 hours to master, it would take a dyslexic child around 1000 hours (10 times as long) to reach the same level (p. 26).

Kacy states, *'it takes me twice as long to read and research for the art history'*. Lana says, *'…it takes a very long time to read. I can read something and it is like, have I read this? Brand new – but I've read it. And I read stuff and it doesn't go in. I don't know what it says or I make up words. I read what I expect to read rather what's there'*.

Carla points out that at university they give you too much information that you have to read and understand in a very short space of time, something that she finds very difficult to do in that limited time because as she says, *'to learn something, I have to go deep into it, I can't do surface learning of things, I have to understand it. I have to understand why it works, especially engineering and physics and maths…I can do maths when I get into it*

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but it takes me a long time and it takes much longer to do everything. So I've always been behind in everything'. Riddick et al. (1995) state that looking at the psychologists' reports on many of the students that took part in their study; these students have slower than average writing and reading speeds. Carla is one of the best students in her course. She knows that if she has the time to do something, her course work will be a very good piece of work. Unfortunately, sometimes she has to hand in work that is not of good quality because of the lack of time. Not being able to organise her time and taking so much time compared with her friends to complete an essay, she has to rush in order not to miss the deadlines given by her professors.

Another problem a lot of the participants in this study faced during university is their inability to express their thoughts in written form. Essay writing is one thing directly influenced by this. As Carla states, *'...I have all the information, I've done all the research and then it's how to put it on the paper? How do you get it out of your head and onto the paper? Once it's gone it's all right but some of the time I've had to get someone to help me to start. Especially with a big report'.* Larissa has been given a personal tutor to help her with essay writing. At the time the interview took place she had seen her tutor once and she was hoping for good future co-operation with him. The inability to express his thoughts on paper has taken its toll on Mac too. Because he can speak perfectly well and can express his points and ideas verbally to a higher standard, his poor written performance confuse people. He can write but his writing does not match what he speaks. The highest mark he recollects having in an assignment was 54%. He got this mark because his lecturer thought it was a good assignment although he did not understand all of it but he did not downgrade him because he could see that Mac knew something of it. Mac was really pleased by this approach because he did not react as other people who have read

his work usually do: *'ok you don't make your point clear there, you're very not clear and you're not structured and not very good'*. Gloria has to read her essays all the time while she is writing them to be sure she is writing the correct things. She states, *'essay writing is another difficulty but the way to get through it is just hard slog'*. Riddick et al. (1997) report cases of dyslexic students who have chosen courses that require minimum written work. The participants of this study did not mention something similar. They had chosen their degrees because they were interested in the subject they were studying.

Miles and Varma (1995) reveal that the examination period for a dyslexic student can be really stressful because dyslexics find the pressure of writing, working against time and reading carefully very tiring.

Exams also seem to be another major problem for the majority of the students; examinations are influenced by the students' lack of ability to express their thoughts on paper and by their reading difficulties. Carla gets stressed because of the time limit and as a result she gets frustrated and she cannot write anything down. Darius and Ralph have to take multiple-choice exams which both for different reasons find it hard. Darius says: *'multiple choice actually I find one of the hardest because they've got so much big chunks of writing and I read the writing how I expect it to be rather than what it is...'* Ralph on the other hand finds very confusing the double negative in the questions asked. He states, *'if it says: which of these is not a not not sort of thing, like three nots in the question and you've got two answers and you got like, one Friday not and the other said not as well. You obviously know that someone is in the wrong; someone is in the right but, you have to keep your head round all the things sand that's really a pain...'*.

Lana finds very exhausting the fact that she has to take a four-hour exam without any break to rest her mind. She believes that without any time off even for a couple of minutes the extra time cannot be used as she gets very tired from the constant effort she is making to concentrate.

Note taking is another difficulty, which all the dyslexic participants in this study face. It is really hard to concentrate to write something during their lectures and listen to the lecturer at the same time. Miles (1995) states that because of the structure of the courses, a lot of lectures may be given at speed. So students have to be quick and write down their notes if they want to keep up with the information given. Rapid reading and writing can tire the eyes and the brain. Dyslexic students often can do that for only a short period of time. As a consequence they end up with bad quality notes, or because of the speed they are writing they cannot read their handwriting and they end up very stressed and frustrated.

 A tape recorder that might seem a solution is not always easy to be used as the person who handles the recorder has to be very close to the lecturer in order to have a clear recording of the lecture. Besides, sometimes the number of students in lecture theatres is quite big and the background noise they make might affects the recording and creates problems with the transcription. There are also lecturers who are not very willing to allow their lectures to be recorded. Anna finds it '*embarrassing not being able to write down what you want to say and the fact that you might get the spelling wrong'*. She says, *'you want to write down certain words but you know you don't want to write it because it might be wrong on paper and someone looks at it and can go: that is not how you spell it and you get embarrassment'*. Rachel could not keep up with the lectures because '*everything was going too fast. I was writing notes and my handwriting was a mess, I couldn't understand*

my handwriting'. Darius too has problems reading his notes because of his terrible handwriting. But Darius does not have problems with note taking in all his courses. Some of his lecture notes can be found on the university's intranet or Internet. So in effect he does not have to write any notes because the lecturers put the notes up before each lecture so the students can print them off. Therefore, he can print out the notes and later in the lecture theatre he *'can scribble notes on'*.

Another difficulty dyslexic students face in university is finding books in the library, finding their way around the campus and lecture theatres. Riddick et al. (1997) report that participants in their study complained that library staff were not very helpful and sympathetic with them when they asked for their help.

At university, Lana and Ralph mention having problems with orientation and finding their way around campus. Ralph's case is minor compared to Lana's as she has ended up in the wrong bus and going to the wrong direction quite a few times due to her failure to read the correct bus numbers or the correct signs.

10.3 Survival Techniques

10.3.1 Computers

All the students that participated in this present study pointed out that computers are one of the most useful things they have to cope with their problems caused by dyslexia.

Computers can help them with their spelling and correct most of the mistakes that they make while they are writing their essays and assignments. It has to be mentioned that

sometimes word processors do not correct all the mistakes people make while they are writing, as they cannot spot words that are spelt correctly but are used in the wrong context. As McLoughlin, Leather and Stringer (2002) point out, spellcheckers and grammars checkers unfortunately will miss words that are spelled correctly but inappropriately placed and they do not correct homophones. This is definitely a problem that all people that are using word processors have come up against. I for example, although I am not dyslexic, due to the fact that English is not my mother tongue, rely a lot on the spelling and grammar checks of the computer to correct any words that have been misspelled. There are numerous times when I realised that instead of 'beginning' I had written 'begging' or instead of 'sort' I had written 'short'. The computer did not mark the latter words as wrong because they are written correctly and computers have not the ability to clarify the context the word is used in.

For people like Carla computers are a vital piece of equipment in her life as a student. Her handwriting is not very neat so she writes everything on her computer. Darius too because of his spelling problems relies on his computer to find the correct spelling. Even if he wants to write a cheque he will first write the amount of money in his computer and then he will transfer it onto the cheque to be sure he has spelt everything accurately.

Very few of the participants were using voice recognition programmes to help them with their essay writing. Kacy was offered the choice to use a voice recognition programme but still by the time the interview took place she has not tried yet. She believes that it would be good for her '*if you can Dictaphone even your ideas down first and them sort them out.*' She thinks that this would help her with her organisation and help her not to panic about the things she has to do. Darius, on the other hand, did not find it very helpful to use a

programme like that. When he had his assessment he tested out the software package but he did not get on with it. The reason was that he is quite softly spoken and he found it hard to use, as you have to train the programme recognising your voice. Another problem that Darius noticed was the following:

' I taught myself to touch type so I can type quicker than I can speak and by the time it recognises and you go back over it, it takes a long time.'

Lana is probably the only student who found Via Voice very useful. The only problem she seems to have when using a computer is when she tries to scan books into it. She finds it time consuming and when she finally manages to do there are always little problems coming out.

'…And then you finally get it in and you don't notice that it's done something funny with some of the words. Like: it flipped and it's changed a word or changed a letter and when you transfer it into Word and it changes the text type or you've got three columns because it's got a photocopy of something of a newspaper and there's three different columns and it's joint them all together and you can't unmuddle that. You've got no chance. Or, it deleted a picture out of it or all the text is big here, small there, half print here and it's just very confusing. Or you've done too many pages in one go before you've gone to save it so it saves half a page and so you think it saved more and you haven't. Or you think you've got a whole chapter there and three quarters of it is unreadable and so, it gets so very, very, very frustrating.' Lana is the only person who mentioned using a scanner to help with her coursework out of all the participants.

Moreover, almost all the students that took part in this present study have bought their computers with money that the LEAs have given to them after they had their assessment.

Most of them would not be able to afford to buy the software and the computers without this financial support. Darius's computer cost £2000. Kara's almost the same amount of money. Lana had to fight for quite a few years to get a computer because she was a part-time student. One of the reasons, as Lana said, was that in the past part-time students were not entitled to get any grants for equipments like this.

10.3.2 Proofreading

Proofreading concerns the detection and correction of errors in text and generally concerns superficial aspects of writing such as spelling, grammar and punctuation (Farmer, Riddick and Sterling, 2002: 45).

Mac, Darius, Carla, Gloria, Rachel and Kara mentioned using friends and family to proofread their essays and assignments. Gloria will ask her mother go through her essays when she is at home and correct any grammar and spelling mistakes whereas when she is in university she relies on her friends. Since all the above students do not live with their families any more they rely more on their friends help to proofread their work. Carla always gets people to proofread her work and *'juggle it all around'*. She can use her computer to correct most of her spelling mistakes but by proofreading she wants to make sure the grammar is correct too.

Anna and Lana's tutors help them with their work. They are the ones to whom those two students usually turn for help. Lana is not only using her tutor for proofreading but also to help her organise the structure of her essays and put her thoughts into paper. Lana said: *'…I've got fifteen answers in my head and they are right, and I've got to work out which*

one to give them and I don't know which one to give them. So I'm trying to put all 15

answers down at one and then going off on a tangent because I've thought this wonderful

idea and I've connected this up to that and I'm loads of stuff but all they (lecturers) want

is; prove to us that you understand this text, but that's taken for granted, and I'm always

taking forg ranted what the people know. I'm making these leaps and I think other people

can make them and they can't…. I'm doing essays and it's like I'm doing a PhD instead of

a degree.'

10.4 Other Strategies

10.4.1 Note Taking

Note taking in lectures is a frequent problem students with dyslexia have to face. It is a

very complex skill for dyslexic people because it places a heavy load on working memory.

It is affected by a significant number of factors including listening comprehension,

processing information, and organising and recording notes in a legible and fluent fashion

(McLoughlin et al, 2002: 164). Other variables include how confident the student is in his

ability to take notes, his spelling skills and his knowledge about the subject he is being

taught (McLoughlin et al, 2002). In addition, one should not forget the fact that a lot of

students with dyslexia cannot read the notes they have written because of their poor

handwriting skills. Darius and Rachel have a great difficulty reading their notes because

they cannot understand what they have written during the lecture. Darius was not able to

keep up with the rest of his group in one of his subjects as his lecturer did not give them

any handouts in advance so he could make any extra notes on them. Riddell et al. (2005)

reported that although access to lecture's notes in electronic format was one for the most

common adjustments required by students, lecturers were very unlikely to comply with this. Some of the reasons the lecturer gave were:

- *Lecture notes were their intellectual property and did not wan to be reproduced without their permission.*
- *Lecturers did not use written notes, preferred to lecture spontaneously using a variety of sources.*
- *If notes were available, students will not come to lectures* (Riddell et al., 2005: 93).

They also reported that younger lecturers were more likely to use IT than the older ones and more content to share their notes too.

Mac and Kacy have someone who takes notes for them during their lectures. Their universities have made the arrangements for them to have these facilities. The DSA offers an allowance up to £10.250 per year for Non-Medical Personal Helper. This can pay for sessions with a specialist tutor, a personal note taker, proof-reader or anything else that each individual might need during his full-time or part-time studies in the university (Heaton and Mitchell, 2001).

In addition, another variable is the way the materials in each lecture are presented. If the lecturer gives some handouts in advance or puts his lecture notes on the Internet or intranet, as some of Darius's lectures do, it is easier for the student with dyslexia to take notes during the lecture. This definitely makes students less worried as they can have the lecturer's notes in advance and it is easier to write on them. But not all lecturers do that. Kacy mentioned that although she was supposed to be given lecture notes on a CD-Rom or on paper she never received them. She does not know the reason why it did not happen. She believes it is something to do with the lecturers. Gloria had similar problems with her lecturers. Some of her lecturers are kind enough to give her handouts as it is difficult for

her, especially if they talk very fast and look at their overheads, to do both at the same time. Some of Gloria's lecturers instead of giving her handouts, although she has asked them to, have given her a summary sheet of the lecture. Gloria thinks that it is not enough and has tried on some occasions to explain that to some of her lecturers but it has not worked.

Gloria and Kara have to rely n their friend notes. Gloria said:

'…If I haven't got it down, I can take some people's notes and then from their notes and some books, put it all together and make sense. I mean because I listen to the lecture I can usually understand it better than the people that are sat and writing so I understand from their notes and then I understand from the books'.

Anna and Kacy suggested a dictaphone as another way to try and keep lecture notes. Anna although she had one had not used it yet to tell the researcher if she found it useful or not. Kacy on the other hand had used it in the past, before acquiring a note taker, but she did not find it very practical. She said: '*the first time I have used a Dictaphone it was a small one and it did not pick up. So you had to put it right down by the person who was talking. As they (lecturers) are walking around it does not pick up everything. It is not as easy really as it could be*'. She got another one with a much better microphone so she can put it at the front. But she realised that it took her '*almost three times the time that it takes just to take notes in the lecture*'. This happened because she had to listen to the tape, stop it, write it down and start again. Kacy is more than happy now that she has somebody taking all the notes for her.

Kara believes that having a Dictaphone in lectures is very useful because when she hears the lecture again *'it becomes more into my brain and it's sort of understand it more'*. The latest versions of Dictaphones are digital ones. The advantage of this is that students can 'mark' point in the recording so they can go back and listen to them quicker when they need to (Du Pre, Gilroy and Miles (2008). Students can also download their recording in their computer.

10.4.2 Personal coping strategies

The students in this present study have embraced some other techniques to make their lives at the university less effortful. All these methods depend on the severity of the problems that dyslexia has caused them over the years.

Carla tries to write everything down and keep notes of the things that she has to do. Her dyslexia affects her memory and she always makes sure she does not *'make appointments without writing things down'*. An adult with dyslexia, I have met in a meeting that a group to support students with dyslexia had organized, mentioned the importance of the use of a Dictaphone for people whose memory has affected by dyslexia. It is something that everybody can easily operate. The person who is using it can record all the meetings and arrangements he/she has to do every day, or record an appointment so that he/she does not forget it. Kacy thinks that Dictaphones are helpful even when you need to write an assignment because *'you can Dictaphone your ideas down first and then sort them out. …It's just the organisation'*.

Kacy finds it useful to make use of mind maps to organise her thoughts and to write her essays. She believes that mind maps or spider grams are *'a really good way of organising'*.

She said: *'that's the problem with doing like essays, everything comes out so fast and I can't, this does not work in co-ordination, to be able to organise your ideas before you start writing down'*.

Kara finds spider diagrams useful too. Whenever she has problems organising her essays she usually goes to the student support office in her university and meets the person in charge to help students with dyslexia. There, they help her to do a spider diagram and *'sort of extract the information from you and they will write it down on the sheet and you put points and it will be in the proper order it's good to write'*.

All the students mentioned having extra time in their exams at the university with the exemption of Carla. Although she was entitled to have extra time she did not ask for it. She did not want to be different to everyone else and if she asked for extra time she would have to go to different time exams to everyone else and that was something that she did not want to do.

'I didn't ask (extra time)*. I could have done, I just didn't. I just felt like I'd leaned on it, my dyslexia, I do not know why, I'd just got this thing about not being different from everybody else. I don't want to be different anymore. I've always had longer time… I just didn't want to be different any more. In some ways I suppose with dyslexia you just don't want to be different. You are different bur you don't want to be'* (Carla).

It has to be mentioned that Carla although she also knew that she could get financial support from the DSA to buy her computer she did not use this benefit to buy it. Her family bought it for her. She was also offered help from the student support office of her

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university but she did not accept any. She looked at the things that they offered her but *'it was too much to bother'*.

10.5 Coping with dyslexia now

Almost all the participants, with the exception of Anna, agreed that they now could cope with the problems caused by being dyslexic much better than they did in the past. Anna, as mentioned before, is the only student that said that it is '*about the same*' to cope with her dyslexia now than it was before. There is more help available to them and more awareness about dyslexia and that has made them more confident and more relaxed to ask for help from other people and not to try and hide their problems. Kacy believes it is a lot easier now. For her *'it's not being afraid to ask for the help because the help is there'*. Gloria thinks that the support she was given has made things easier for her.

Kara agrees that is easier now for her to cope with the problems that dyslexia has caused her over the years as: '*I learnt to just accept it rather than always questioning it and I think that from gaining a degree and from my A levels and things like that I really turns: yes, I'm dyslexic but I can still do that everyone else can do. And you just got to remember that'*.

Darius too believes that he has managed to learn how to deal with dyslexia and he knows, as he grows older, that dyslexia will be there but he will learn to compensate for it more. He is trying to understand what dyslexia is. He knows that he is not lazy or stupid and he is aware of his abilities and how to work things through. Darius is trying to be as independent as he can. Although he was offered help from the student support office of his university he has not contacted them. He is concentrating more on the advantages that

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dyslexia has given to him. He feels that dyslexia gives you some skills, which other people do not have. He is quite good at lateral thinking and at visualizing things, problems, areas and his communication skills are better than most of the people that he knows. He used to hate being dyslexic when he was younger but he will not waste his time any more worrying about it or feeling sorry about himself. He wanted to be a doctor but dyslexia prevented him from accomplishing his dream. However, he has chosen a different profession now and he is doing really well. As he said, he is one of the few, if not the only one, in his year that managed to save money and make a profit out of them. He was really pleased with himself. Darius has learnt over the years to concentrate on his skills and try to improve on the things he is not as good at by putting in a lot of effort and without relying on other people to accomplish his goals.

Carla is also trying to be as independent as she can. She believes that dyslexia is something that you can overcome. You can learn to use it as a gift rather than a *'crutch'*. You should give up thinking *'I'm dyslexic I can't do anything'*. Now, she knows what to expect and she is prepared to face any problems that may happen. Carla is laughing at her mistakes, listening to herself when she is speaking and when she gets things round the wrong way, she finds it quite funny.

Lana can cope better now because throughout the years she has developed various strategies to handle her problems. She has managed to develop ways of distracting people so that they do not ask her questions that she may not be able to answer. She can talk her way around things and manage to hide some of her weaknesses.

Sabrina and Ralph regard age as another reason for being able to cope more easily with their problems. Ralph thinks that because he is getting older he is getting more experienced in every aspect of his life, so that makes him better at handling situations that may occur. He also added that a lot of things that he is doing are subconscious. For example if he is compensating in a way, he does not really notice he is doing it and he is attributing it to him being more experienced as he is getting older.

Mac, on one hand, believes that it is easier to cope with his problems now but on the other hand, he is worried what the future will hold for him. Although he is grown up the challenges are much greater now and going to school and college was much easier than attending university. People require more things at university and he believes that his whole future is influenced by how well he will do in his studies. He cannot do as much as he is expected to do. He gets tired after the lectures and he cannot concentrate on his studies as much as he would like to. It is more worrying for him too, because it involves, as he says, money and his time and he knows that he is not up to his best aptitude. He is concerned that the results that he gets from his tests and exams will never represent his abilities and his qualities.

10.6 Educational system and support

When this research project took place and although the SENDA (2001) had not come into full force yet, all three universities had specialised dyslexia tutors in their learning support teams. In their study, in Scottish universities, Riddell et al. (2005) report that almost all the institutions that took part had structures in place for the provision of disabled students.

They state that currently the main focus of the universities is to provide individual support for the students rather than a more fundamental institutional change.

All the students overall were content with the support they were receiving from their universities but they felt, especially the ones who were assessed after entering university that they were let down by the education system when they were younger. Anna said that the education system, for the first time in her life, is in the process of assisting her with the difficulties she has because of her dyslexia. The other mature students shared similar feeling to hers.

Anna, Camilla and Kacy (mature students), feel that the educational system is helping them now but did not in the past. Camilla wishes that she had been diagnosed a lot earlier so she did not have to go through all the painful process of not knowing what is wrong with her and struggling through her schooling. Kacy, now a mature student, believes that lack of awareness about dyslexia and its symptoms in the past prevented her from doing better in her life. Now she is quite pleased with the support that she gets but wishes as does Camilla, to have been diagnosed when younger.

Lana, on the other hand, feels let down by the whole education system. She would like *'to get a bomb and get all of the educational system together and blow them up!'* She was the only one who felt like this as she had experienced prejudice and rejection from her educators before she entered university.

Mac too, feels that he was let down in the past as he was placed in a 'special needs school' due to his difficulties. He does not think that *'if you have a problem you should be put in*

an institution where everybody is the same and they are non-hopefuls'. Students that took part in Tanner's (2009) study expressed similar conduct. Some of them we placed in 'special classes' with students who had intellectual disabilities (p. 790). Mac managed to be where he is now because of his own determination. He wants to continue his studies after he graduates in order to be able to find a better job. When he looks back at his other friends from school some of them did not go to college after school and as a consequence they never managed to have enough qualifications to find a better job and have a better future than the one their teachers thought they would have. He feels that all these people were deprived of a better quality of life because they did not have any support when they mostly needed it most and they had nobody to believe in them and their abilities. In Mac's school his teachers thought that the students would fail in the future, so they did not think to encourage them to follow different directions in their lives and focus on the things they were good at.

Kara feels a little bit disappointed with the support she had from the university when she first started her degree. She thinks that there is not enough information for students with dyslexia that start university. She believes things should be more organised and your department or somebody else from the university should be appointed to approach students with dyslexia and inform them about the help that is available. Vickerman and Blundell (2009) report that of the *'75% of the students that have declared a disability on their university applications, 47.6% indicated that they had not been contacted prior to the commencement of their course by either academic or welfare services staff*'. Although, Kara had declared her dyslexia she was not approached by anyone. She learned at the end of her first year that help was available for her from one of her friends. If HE institutions expect people to declare their disabilities, they should have set systems in place to

approach them, if not before they commence their course, surely after and inform them about the services that are available for them. Kara passed her first year without any support but if she failed who was to blame for that?

Ralph and Gloria are pleased with the things that were offered to them. The existing laws have helped them buy a computer and have access to benefits. Ralph finds it very useful that he gets £150.00 per year to buy his books (DSA). Gloria believes that if she did not have all this support she would not be able to do all the things that she does now.

Sadie postulates that the educational system has not helped her, although individuals who were working in the educational system did. Reyna is quite happy with the fact that she had the dyslexia test and was diagnosed, but she is not happy with the fact that nobody talked to her after her assessment about the things she believes she needs. There was a meeting after her assessment in which she wishes she were present in order to discuss with the committee about her needs and decide with them what it was essential for her to have; not them making decisions without listening to her first.

Overall the students were content with the support they were receiving from their universities but not from lack of support when they were younger.

10.7 Conclusion

The participants of this study did not have a trouble free life in university. Their difficulties could not disappear and they had to adapt their lives according to them. Only two participants declined their allowance for books and computer equipment, as they did

not want to be different to their peers. The rest of the participants were able to acquire a personal computer and support from learning support centres in their universities. Although spelling was considered as one of the biggest difficulties in primary and secondary school it seems a secondary problem in university. The main difficulty in the university is reading as the lecturers expect students to read large amounts of text within a limited period. Now all the students are using computers to write their essays and do their course work and rely a lot on the grammar and spell checkers in their computers. Although spellcheckers cannot recognize and correct all the mistakes they still save a lot of time and effort on the students' behalf.

Students rely a lot on friends and family to help them with proofreading. Some of them have support from their tutors in order to write their essays. The participants of this study found spider grams and mind maps useful to gather the information needed for their work. Putting their thoughts in a paper can create difficulties as they have the information in their minds but putting them on paper is not as easy as it appears.

A limited number of the participants use voice recognition programmes. The feedback they gave varies and although some individuals consider them useful some find it hard to use them, as you have to train the programme to recognise your voice.

Dictaphones were also used by the interviewees as a way to record the lectures and avoid note taking. Some of the students found it very difficult to concentrate on the lecture and keep notes at the same time. Dictaphones give them the chance to listen to the lecture again in their own time.

Nowadays the lives of the participants are much better than they were in the past. Their experiences with dyslexia have taught them valuable lessons and have helped them to improve their coping strategies. They are older, more mature and they have people around them that recognise their dyslexia and are willing to help them.

In chapter 11 presents the attitudes and perceptions of the participants regarding their dyslexia in connection with the current prominent theories in the field of dyslexia and the different models of disability.

CHAPTER 11

DYSLEXIA AND MODELS OF DISABILITY

11.1 Introduction

Dyslexia was originally defined based on the medical models of disability (Riddick, 2001). Over the years and with the growth of the social model of disability the field of dyslexia started to change and people started perceiving dyslexia more as a difference rather than a disability (MacKay, 2005; Reid, 2003) and considering the impact that society has on individuals regarding labelling and stigmatization (Riddick, 2001; MacDonald, 2009). 'Dyslexia has come to be socially and historically constructed as specific learning difficulty, with the implicit assumption that the learner is of a normal intelligence (Rose, 2009) with a particular explanation for a neurological or brain dysfunction which is affecting literacy development' (Soler, 2009: 46). The following chapter will look at the participants' responses and compare them with the current prominent theories and models of disability surrounding dyslexia.

11.2 Discourses of dyslexia

'The meaning of learning disabilities is tied closely to the meaning of schooling' (Dudley-Marling, 2001 cited in Reid and Valle, 2004: 466). Looking at the various definitions about dyslexia (BPS, 1999; BDA, 2007; Rose, 2009) all of them are connected with the learning process and opportunities that the individuals might have had. Societies as

mentioned before put great emphasis on the written word and the acquisition of qualifications in order for people to have a prosperous future. Looking at the answers of the participants these points are confirmed. All the participants have connected dyslexia with learning and more specifically the ability to read and write. Over the years they compared themselves to their peers and could understand, especially before their assessment, that they were 'different' to them. Research literature (Reid and Valle, 2004) compares normal and abnormal learners; able and disabled. But who are the people who define what normal is? In the past, while I was in Greece, I was interested in learning sign language. During this experience I met hearing-impaired people who refused to 'talk' to typically developed individuals as they thought that the sign language was part of their culture not the 'speaking' one. For them I was the 'outsider', I was not the 'normal' one. Padden (2000) describes that the use of sign language distinguishes the Deaf from the English speaking culture. Sign language belongs to the Deaf people. Some Deaf people might choose to use speech but within the Deaf community, speaking is not a preferable mode of communication (Padden, 2000). Although it is difficult to draw generalisations by this experience; it shows that the idea of normalcy can be very subjective. Riddell et al. (2001, 2005) postulate that many people with disabilities reject the labels that society have assigned them, 'preferring to see themselves as having a physical impairment or as not being disabled at all' (Riddell et al., 2005:130). Riddell et al (2005) state that although students with dyslexia in HE willingly categorise themselves in the disability group, as it is the only way for them to receive support; they do not consider themselves as disabled. One participant in their study said: *'I don't see myself as disabled. I ask myself the question, 'Has it stopped me from doing anything?' and the answer is 'No'* (Sheena cited in Riddell et al., 2005: 137).

Over the years different models have been developed in the dyslexia field and most of the debate about dyslexia is affected by them. Pollak (2005: 110) presents them as:

- The medical model – dyslexia as a biological defect
- The IQ/attainment discrepancy model – dyslexia defined by scholastic achievement
- The brain specialisation model – dyslexia as a group of strengths and weaknesses
- The syndrome model – dyslexia as a pattern of difficulties, usually found together.

Based on what the participants in his research said, he divided them in the following categories: 'patients' (medical model), 'hemispherists' (brain specialisation model), 'students' (IQ/attainment discrepancy model), 'syndromists' (syndrome model) and 'campaigners' (a new category that derived from the participants' answers) (Pollak, 2005). Kurnoff (2000: 231-2) in a similar research project in the US presents four categories which derived from the students' responses; 'Conventionalists' (work closely with learning support teams without creating personal strategies), 'Low profilers' (do not disclosure their disability, do not ask for special accommodations, do not associate with learning support teams), 'Independents'(use personalised coping strategies, ask for special accommodations on an informal basis) and 'pragmatists'(try to have a balance between special accommodations and personalised coping strategies).

On the other hand, Nosek (1997) in her study divided adults with dyslexia into three categories: the 'candid dyslexic' (aware of their dyslexia and openly discloses it), the 'closet dyslexic' (conceals their dyslexia through denial, shame and fear) and the 'confused dyslexic' (not aware about being dyslexic, struggles though school and life).

Looking closely at the above categories one can notice similarities among them. Pollak (2005) states that Kurnoff's participants can all be clustered as 'students' as they '*all seem to regard dyslexia as entirely an academic matter*' (p. 138). Some of her 'pragmatists'

resemble the 'and the 'independents' resemble the 'campaigners' (Pollak, 2005). Nosek (1997) on the other hand, classifies adults according to their willingness to disclose their dyslexia. Her 'closet dyslexic' bears a resemblance to the 'patients' and 'low profilers'. There are no 'confused dyslexics' as all the participants in Kurnoff and Pollak's studies are aware of their dyslexia and have been formally assessed for it.

While trying to analyse the participants' adaptations of dyslexia all of the above categories were considered. Reading the students' narratives gave a better picture about the way they portrayed and adopted dyslexia in their lives. The categories selected correspond to the participants' responses throughout the interviews and I believe they best describe the interviewees' answers and attitudes towards dyslexia.

11.3 Participants' adaptations of dyslexia

Looking at the above categories and comparing them with the responses of the participants of this present study, the following categories have been derived: 'students' (have connected dyslexia with intelligence); 'patients' (believe that dyslexia is their own problem and are hesitant in revealing it to other people, mainly on a need to know basis); 'hemispherists' (see dyslexia more as brain difference and as a positive entity in their lives. They also see dyslexia as a group of strengths and weaknesses and 'pragmatists' (use the support from the learning support offices but at the same time try to be independent by using their own coping strategies too).

11.3.1 'Students'

Undoubtedly, all but one of the participants, when they describe their primary and secondary school experiences, fall in the 'student' group as all of them at some point in their interview reported connections between intelligence and their scholastic achievements. This was mainly due them not being identified as dyslexic and their teachers' approaches to their difficulties.

Camilla's teacher thought she was just very slow. She surmises that in her school days the support that you received had to do with the parents' involvement in their child's schooling. If the parents did not realize that there was a problem and put some pressure on the school to help their child, usually nothing would be done. Macdonald (2009) believes that people with dyslexia have been given negative labels by their teachers about their intelligence due to their literacy levels.

'Well the soul-destroying experience of knowing that you've put effort into a piece of work and all you got back was a line through every 2nd and 3rd word. And the teacher hasn't actually read what you've written, but had just marked your spelling, it was soul-destroying. And you know, it leads you not to want to make any effort... I think because they did not understand, they thought I must be lazy, it must be you... the assumption was it was my fault' (Christopher) (Macdonald, 2009: 354).

Carla's teachers realized that she was not stupid or deaf when she was diagnosed. They became conscious that she was intelligent; she just did not know how to learn properly. Catherine's not dismissive but most of them (teachers) *'did not bother too much at all really'*. She believes that either they saw it as a condition, which affects people mentally, or they did not really understand it.

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In her Australian research study in university students with dyslexia Tanner (2009) shows similar responses from her participants. '*I was classed as very dumb at school by my teachers and was overlooked and forgotten about*' (Student D). '*Just because we could not read they thought we were dumb*' (Student N) (p. 790). Some of the students felt that they were let down by the school system whereas some others felt that they failed the system as they were not good enough. Tanner (2009) also reports students with dyslexia were placed into special education units or 'special classes' (p.791) because their teachers misunderstood the link between dyslexia and intelligence. Fitzgibbon and O'Connor (2002) state that it is quite common for adults with dyslexia to report negative feedback from teachers during their childhood. This though can have long term effects in their self-esteem and might cause psychological disorders during adulthood.

12.3.2 'Pragmatists'

Growing older and being aware of their dyslexia most of the 'students', although they still connect dyslexia with their academic work and progress, have altered their view regarding their dyslexia to 'hemispherists', 'pragmatists' and 'patients'. All the interviewees still experienced difficulties in their studies while in university and they had mainly connected dyslexia with academic performance, with the exemption of one who reported having difficulties in her social life due to dyslexia. On the other hand, they do not connect their performance with intelligence. All the students were aware that they could do better if dyslexia was not present but being in the university they had adopted a different way of thinking and seeing their dyslexia.

The pragmatists while in university were aware of the different environment and its new requirements. In school Anna reckons, especially when you are not aware of having dyslexia, you do not know what is happening and *'you just go with the flow'*. In the university, students knew that help was available from the university's learning support team and all the students have asked for special accommodations (extra time in their exams, use of IT). On the other hand, at university students are supposed to be more independent and do their own reading and learning with as little help as possible (Gloria). Primary and secondary school was a friendlier and more personal environment for the participants. Because of this the participants got to know their teachers for quite a few years and thus developed a more personal relationship with them (Kara, Gloria, Ralph and Rachel). In the university, due to the large number of classes, unless the students pursue a personal relationship with their lecturers (Mac and Carla) interactions are more impersonal. Rachel postulates that lecturers *'sort of keep themselves to themselves and they do not interact with students'*. On the other hand, lecturers have less time to interact with students; things are more formal (booking tutorials) (Kara, Gloria). Riddell et al. (2005) report that although there are some lecturers that are willing to help and support their students; some others consider these requests as an 'additional burden, distracting attention from more important aspects of their word such as research' (p.640). Also, there were lecturers that thought that making accommodations for these students might be considered as disadvantaging others. Some of the participants in Griffin and Pollak's (2009) study described unsympathetic comments from their lecturers who believed that learning difficulties were used as an excused to obtain special arrangements (extra time in exams, extensions for coursework).

Carla believes that although things are different at university, you can always find people willing to help you when you ask for their help. Not all the lecturers are helpful, but everything has to do with the individual. She considers herself very lucky in studying subjects where the numbers of students in the lecture theatre is quite small (30-40 in her class). In a case like this you can have one-to-one time with your lecturers and ask for extra explanations if needed. Vickerman and Blundell (2010) report that the positive experiences of people with disabilities in HE depend on 'the attitudes, experience and personal knowledge of particular members of staff, rather than institutional policies and provision' (p.29).

The pragmatists are aware of their difficulties. They are also aware of their course requirements and the work they need to do in order to graduate. They are using the help that the learning support teams in their universities offer but at the same time pragmatists are using their own coping strategies. They are determined to succeed and prove wrong the one who doubted them in the past. One of the students that took part in Kurnoff's (2000) study said: *'The worst trap you can fall into is questioning yourself, your intelligence, your self-worth. Dyslexia is not going to stop you from doing what you want. The only thing that can stop you is who you are deep inside – your fear of trying, your fear of succeeding'* (p. 295).

11.3.3 'Hemispherists'

The 'Hemispherists' in this study perceive dyslexia more as a gift rather than a disability They see dyslexia as a positive entity in their lives as it has given them the chance to understand concepts in a different way than non-dyslexic individuals do. 'Hemispherists'

accept that people with dyslexia have both strengths and weaknesses (Pollak, 2005). They believe dyslexia to be more of a difference rather than disability. They believe that people with dyslexia are more creative than non-dyslexic people (Lana, Gloria and Karen). Anna would not change her dyslexia as she thinks it is what makes her creative. *'No No, because my brain's very, very creative so if I wasn't dyslexic I wouldn't be creative' (Anna).*

Lawrence (2009) states that professionals should be careful when discussing creativity and success with their students with dyslexia as there is no research evidence that all students with dyslexia might have these characteristics. Grant (2001) believes 'that there is one unifying factor running through the accounts of people who are creatively successful, it is this capacity for hard work'.

Reading life stories from people with dyslexia most of them will acknowledge that they work much harder than their peers in order to succeed (Riddick et al., 1997). This persistent work habit and determination that characterises a lot of people with dyslexia might be the key for creative endeavours (Grant, 2001). Ehardt (2008) states that people with dyslexia show three-dimensional (3D) understanding which makes them able to *'hold an actual picture of an image, literally seeing the 'big picture'* (p. 364). He believes that because their three-dimensional ability is very strong this might prevent the ability to process information in other ways.

Lana said: *'The only way I can describe my brain, this might sound strange; is like having 2 brains, one's here, in there,(uses hands to show) and there's a tiny little connection between the one is in the air and the my brain. My brain just sits and watches it. And this brain out here does all the work. ... But it enables you to do things and other people go: oh my God! How did you do that? And you can't explain how you do it. It's just, it happens. You come up suddenly with a certain idea and people can't work it how you got there cause it's 3 miles down the road and it's going to get them 5 years to get to where you are. But they're not the problem with doing a degree as well because I've got 15 answers in my head and they are all right, and I've got to work out which one to give them and I don't know which one to give them. So I'm trying to put all 15 answers down at once and then*

going off on a tangent because I've thought this wonderful idea and I've connected this up to that and I'm loads of stuff but all they want is; prove to us that you understand this text, but, that's taken for granted, and I'm always taking for granted what the people know. I'm making these leaps and I think other people can make them and they can't.'

Research has shown that people with dyslexia have developed visual competencies (O'Keefe, 2008). West (Adelman, 2005) believes that people will dyslexia might have an advantage over non-dyslexic people due to their visualisation skills. Advances in technology and the use of computers might be the opportunity for people with dyslexia to demonstrate the areas that are skilful and 'use' dyslexia to their advantage. Are people with dyslexia slow readers or out of the box thinkers? (The Yale Centre of Dyslexia & Creativity, 2009).

"They (referring to dyslexics) may have had difficulty learning from books and lectures, but with future changes they may find themselves far better adapted to learning from simulations of reality as education and testing programs begin to emphasize interactive computer simulation over the verbal description of reality traditionally provided in books and lectures… In the near future, creative visual thinkers with some learning difficulties might very well find themselves far better adapted to certain fundamental changes."
(Woolsey, Kim and Curtis, 2004 cited in O'Keefe, 2008).

11.3.4 'Patients'

Only one participant fits in the 'patients' category (Anna.) She sees dyslexia as her own problem. She has told only one person in her class that she has dyslexia. She is hesitant in telling people because: 'when you see someone else that hasn't got that problem, you feel disabled to that person, that hasn't got that problem'. She was the only participant to use the word disabled to

describe herself. She feels more relaxed when she is with other people with dyslexia 'because they're sharing the same thinking as myself even though it comes in different ways'. Pollack (2005) states that the 'patients' in his research had doubts about their intellectual ability and from their answers it was apparent that they believed that dyslexia was a personal defect.

Anna is using the words 'problems', treatment' and 'low confidence' quite often during her interview. As mentioned before, Anna was assessed as dyslexic quite recently before the interview took place and maybe she did not 'absorb' the dyslexia label yet. She expressed difficulties with her memory but she said: *I do not think that's dyslexic I think that's doing too much.*

12.4 Social versus medical model of disability and dyslexia

Disability is not only a personal characteristic but a societal characteristic too (Reid and Valle, 2004). According to the social model of disability, individuals might have impairments but these can be transformed into disabilities by the negative perceptions of society (Riddick, 2001). The individual deficit model of disability says *'that the disabled person must try to overcome their disability by some means or other in order to join in the mainstream'* (Coleridge, n.d.: 28). The problem lies with the individual and they are at fault. The social model of disability has an opposite view. It says *'even though a person has an impairment that cannot be changed, she or he is still of equal intrinsic worth'* (Coleridge, n.d.: 28). Society needs to change and make adjustments in order to include people with disabilities as equal members of it.

There is no doubt that people with disabilities have faced, and still in some cases, face prejudice but they have lawful rights for equal chances in life as a non-disabled person. It has to be mentioned though that sometimes the disability itself can sometimes be a barrier and not all the difficulties that a disabled person might face derive from society's attitudes (Coleridge, n.d.). Also, there are disabled people, who might have constraints on the type or amount of work they might be able to do due to their impairments (Shakespeare, 2008).

Due to a text-based information society (Macdonald (2009) and the negative connotation attached to being 'illiterate' (Riddick, 2001: 224) people with dyslexia have faced discrimination and dyslexia has become a major difficulty.

Non-disabled people when they see a disabled person tend to focus more on his/her disabilities rather than his/her capabilities. Gardner and Macklem (n.d) state that once people are labelled as disabled '*their other abilities are apt to be overlooked*'.

Society can sometimes have a tendency to set up certain characteristics of what those with disabilities can and cannot do. One of the results of these characterisations is that some who become labelled 'disabled' are excluded from the workforce as their capabilities are not recognised by an able bodied society as adding to the value of that society, particularly within an economic framework (Tregaskis 2000).

As mentioned before, our society has given labels to people and although this has its positives, as they can address their problems and look for appropriate treatment and support, on the other hand it has made people become a part of, a 'minority' group. They have to comply with the rules that people without disabilities have set (Camilleri, 1999)

and they have to fight to be able to lead a 'normal' life as the rest of the world. Although labels have positive attributes, they can also stigmatise individuals. In the case of dyslexia though, labelling can have a positive effect for people with dyslexia as it can prevent negative attributes towards them (Riddick, 2001).

People with disabilities sometimes avoid contact with their peers in an attempt to prevent prejudice and discrimination against them (Jahoda and Markova, 2004; Camilleri, 1999). Onley and Brockelman (2003) report that even people who face disabilities have some stereotypes about which disabilities are more acceptable by society. 'Acquired physical disabilities were at the top of the hierarchy, followed by congenital impairment, then cognitive (such as learning disabilities) then developmental and finally psychiatric disabilities' (Onley and Brockelman, 2003: 48).

Dyslexia is a 'hidden' disability (Riddick, 2002). People with dyslexia have faced prejudice and discrimination especially before their assessment. Their academic failure was regarded as their own responsibility or as poor 'intellect' by their teachers (Macdonald, 2009: 354). Adults with dyslexia in Collinson and Penketh's (2010) study report cases of teachers who had treated then unfairly because their work did not match their verbal and practical participation in the class. Mike, one of their participants said: *'I was the class fool I didn't want to be there. In chemistry when we were writing reports other people would write 3 pages – there was mine- the teacher held mine up, I think he thought 'he knows it but he can't be bothered'* (Collinson and Penketh, 2010:12)

Lack of awareness has resulted in people being bullied and traumatised for something that was not their fault but they were made to believe it was. Perceptions of how they should

behave and react have made people facing disabilities believe that they are 'the problem' (Tregaskis, 2000).

All but one of the participants of this study though, did not believe that they are 'the problem'. They do not see themselves as disabled. They perceive dyslexia as part of their personality and identity. It is an indispensable part of them that they would not like to change. As Larissa said: '*I feel fine about it (Being dyslexic). I mean, it's what I've always been*'. The fact that the participants of this study did not want their dyslexia to go away can be considered as a sign of 'dyslexic pride' (Burden and Burdett (2005). They argue that the former can happen when people with disabilities consider *themselves capable of success* (p. 102) in the domain that is important to them. Professor Gosling (2007) believes that people with dyslexia, especially academic staff with dyslexia, should not try and hide it. They should take pride of it. He has dyslexia and he considers that the world needs both people with dyslexia and modals thinkers. With mutual respect both sides can collaborate and create a fruitful partnership.

Most of the participants at some point in their lives had come across people that were negatively disposed towards them. They were referred to derogatively and there were times that these students believed these notions. It has to be said that none of the participants spoke ill of them for having this opinion. The participants consider that people's lack of knowledge about dyslexia and the problems caused due to this, is making them suppose people with dyslexia are less intelligent. Research in adults with dyslexia confirms the above (Tanner, 2009; Dale and Taylor, 2001).Adults with dyslexia, especially during their childhood felt that they were not intelligent. Dale and Taylor (2001) refer that

stereotypes such as '*students with disabilities are in some ways slower or less able as learners'* (p. 1006) should be challenged and diminished.

In order to improve the lives of people with dyslexia it is important to know what society's perceptions about dyslexia are. Part of this research study focused on the personal encounters that the particular students had with non-disabled persons. It does not indicate that all non-disabled people have the same attitudes and behaviour towards people with dyslexia.

Social awareness was the first thing that most of the participants thought needed to be done in order to improve the lives of people with dyslexia; showing how they have connected their previous negative experiences with pessimistic perceptions from society. Society promotes the written word. People's lives are surrounded by print (labels, street signs, menus) (Tanner, 2009). People with dyslexia have to confront their difficulties on a daily basis. In her study, some of the participants admitted using excuses like *'had forgotten their glasses'* (p. 792) in order to avoid admitting their difficulties. Macdonald (2009) believes people with dyslexia that develop good coping strategies experience fewer restrictions by society. One of the participants in his study revealed: *'I reckon that dyslexia is about coping strategies... If you've got coping strategies then that's what you need to get through in society'* (p. 356).

Kara believes that if there was a way to show people that there are other people that are having problems they would probably be more understanding and helpful towards their difficulties. She experienced bullying while in school due to her difficulties. Darius used to *'get a lot of stick about getting extra time in the exams'*. He postulates that people in

general do not understand. He thinks that there is not enough information available for people; although he doubts that people would care enough to read the information that was available. Bullying, especially in the early school years, is something that students with dyslexia have endured (Edwards, 1994). Ingesson (2007) reports that almost a third of the participants that took part in his study (75 participants, aged 14-25) had experienced bullying and teasing from their peers due to their difficulties. For the majority of the interviewees though dyslexia did not affect their relationships with their friends. All the participants in this study were happy with their friends and their support.

Western societies consider the ability to read and write as a very important skill to have. On the other hand, if these societies who expect high levels of literacy and education fail to make adjustments to support the individuals who might experience difficulties in literacy this can 'undermine a society's claim to fairness and humanity' (Shakespeare, 2007: 13). People assume, especially when someone reaches adulthood, that he or she will be able to read and write without any problems. The lack of awareness of the side effects that dyslexia can cause can create a lot of misunderstanding and prejudice.

From people's questions like *'what is it like? Can you not read?'* Karen came to the conclusion that people speculate that dyslexia has to do with people who cannot read. *'They never realize that dyslexia actually is under a wide umbrella'*. Dyslexia is mainly associated with difficulties in literacy. Kerr (2009) in a small scale research that involved twelve Adult Basic Education (ABE) providers found that they had related the term dyslexia with 'difficulty in literacy' (p. 280). Also, reading narratives of individuals with dyslexia their main difficulties they mention are linked with literacy (Dale and Taylor, 2001; Macdonald, 2009).

The fact that people may not knowingly have come across any people with dyslexia is another reason that increases their negative attitudes. Research has shown that people who have a background in disability and have frequent contact with disabled people have more positive and favourable attitudes towards them (Tervo, et al., 2004; Tervo, et al., 2002). Lana surmises that because the general public do not come across many people that have dyslexia, they cannot understand. Beer (n.d) reports in her survey that 90% of the people with hidden disabilities, whom she interviewed for her survey, were socially dissatisfied with the way the non-disabled park and DNR employees behaved towards them. She believes that one of the reasons was that these employees tend to associate the idea of disability with visual cues (e.g. wheelchair). People are less understanding because non-evident disabilities do not comply with the idea of disability in their minds. Non disabled people take issues or features that are supposed to be easy and 'normal' and straightforward to them (e.g. instructions) for granted but they cannot realise that people with dyslexia might struggle with them. People's lack of understanding reflects on Lana's relationships because: *'I have to build a model to interact with non dyslexics but that makes it quite hard because it's always one way and it's lot of effort and it's like, everything that you do becomes so tiring and so energy consuming'*. Lana finds it very difficult to be in public places as the noise can distract her. Also, she has difficulties understanding when people are teasing her or non-verbal cues.

Carla postulates that people should try not to judge people by *'who they are or what they say they are or anything like that'*. They should give people a chance to prove what they are really worth before they come to quick conclusions. As she said: *'you never know until you get to know someone, how someone is'*. Riddick (2003) state that trainee teachers,

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when applying for training courses did not revealed their dyslexia due to previous negative experiences. As well as this, Macdonald (2009) reports that adults with dyslexia who declared their literacy difficulties to potential employers were dismissed automatically.

A common theme that derived from the answers of the participants is the perception that people with dyslexia are stupid. Adults with dyslexia in Macdonald's (2009) study in order to overcome stigma tried to establish themselves as intelligent within their working environment before their dyslexia was revealed. One participant said: *'...there are certain people who can't handle misuse of words. So if you use a word incorrectly then you are an idiot, you're completely rejected'*. Ralph believes that: *a prejudice view would be somebody who can't spell and I think maybe some people think it's like that, it's a form of stupidity or something'*. Sabrina thinks that people will treat you differently when they hear you are dyslexic. Trainee teachers (Riddick, 2003) reported people receiving negative attitudes towards them when they declared their dyslexia. Emma was *'rejected everywhere she applied for early years. Told it was because she was dyslexic'* (p. 396). Although Riddick's sample was small (6 participants) it shows the discrimination against teachers with dyslexia. Their competence from their employers was measured with their ability to spell correctly regardless of their other skills and competencies.

But the fact that dyslexia is getting *'commoner'* makes people more aware and more relaxed about the disability. Sabrina finds that in university things are better because people seem to be more alert about dyslexia.

Part of the increasing awareness of dyslexia can be put down to its portrayal in the media. Although in the past portrayals of dyslexia in the media have not been as positive as they

could be (Qureshi, 2009), this attitude is changing as time passes as some media begin to celebrate individuals with dyslexia who have found success (BBC, 2009).

Kacy believes because of the media exposure people see the problem that you have, the challenges and the problems. People are starting to understand their difficulties and try to help them as much as they can. Rod believes that nowadays '*most people are pretty cool with it*'. Kacy reckons that '*dyslexia does not have the same image that it did have years ago whereas people think you are thick*'. Recent research investigating trainee teachers' attitudes towards dyslexia has shown that these students are starting their careers '*with a positive set of behavioural beliefs and values about dyslexia and reformulated normative attitudes*' (Gwernan-Jones and Burden (2010: 80). Although these students had positive attitudes towards dyslexia about 40% were uncertain about methods on how to support children with dyslexia. 90% of the participants felt that there should be more training given to teachers about dyslexia.

Last but not least, something that Darius, Mac and other people with dyslexia have said has to be mentioned. They all said that unless somebody has dyslexia himself, he could not really understand what a person with dyslexia goes through. Palfreman-Kay (1998) report that students with disabilities form quite strong communities since they are sharing similar experiences. If somebody has not experienced the difficulties and all the consequences that they face, they can never fully empathize with the person whose life is affected by these problems. Also, Dale and Taylor (2009) report that adults with dyslexia feel more relaxed in a supportive environment, where all participants had the same difficulties. Anna believes that other students with dyslexia can comprehend her problems better than a non-dyslexic student. The BDA (2010) has started a mentoring scheme where they try and

bring together adults with dyslexia in order to share experiences and coping strategies. They believe that a scheme like this will help individuals raise their self-esteem and show that *dyslexia does not have to be a barrier.*

12.4 Conclusion

Over the years people with dyslexia were stigmatized by society due to their difficulties and lack of awareness. People with dyslexia could understand that they were different from their peers but without any support and help, they had to go through life believing the negative connotations attributed to them; believing it was their fault they could not learn and succeed academically.

The social model of disability was the beginning of a new era for people with disabilities. To a degree it was the society who was causing their disabilities, not them. People tend to focus more on the disabilities rather than the abilities of people with impairments. In case of dyslexia, most of the literature is about the difficulties people with dyslexia face and the best ways to support them rather than what people with dyslexia are good at and how they can use their abilities to contribute in society.

The participants of this research study feel that dyslexia is more of an ability rather than a disability. Dyslexia is part of their lives and it has made them who they are. Although, living with dyslexia can be a struggle at times as societies put great emphasis in acquisition of literacy, the majority of the participants in this study feel that they are not disabled. They feel that non-dyslexic people are not aware of the characteristics of dyslexia and as a result some might perceive them as stupid. Although media exposure and government

initiatives have helped to raise the awareness of dyslexia over the recent years some of the participants believe there is still some prejudice towards people who have literacy difficulties.

Over the years different theories and models have developed in the dyslexia field. Depending on their life experiences the participants of this study expressed their views regarding the way they portray dyslexia. Dyslexia is mainly associated with academic competence and literacy acquisition. Although their difficulties continued when they reached adulthood and entered the university most of the students were conscious of the demands of the university life and were determined not to let dyslexia affect their lives and their successful completion of their degrees. Only one student perceived dyslexia as a disability. The rest have accepted it and were working together with the learning support teams in order to improve their skills and overcome their difficulties.

In the next chapter a summary of the project and the results that derived from the data will be presented as well as recommendations for future research.

CHAPTER 12

CONCLUSIONS

12.1 Introduction

The purpose of this study was to investigate the lives and experiences of a group of HE students with dyslexia and have their voices heard. The data collected from the interviews gives an insight into these students' lives and helps answer the research questions of this study. What were the experiences of HE students with dyslexia while studying for a degree? How did they cope with the challenges they faced and what provision they received? How dyslexia affected their lives? The study is also trying to illuminate the difficulties these students face and the strategies they have used over the years in order to overcome them.

12.2 Answering the Research Questions

Over the years dyslexia has caused controversy among professionals who question its existence. Personally I believe in the existence of dyslexia and I consider it more of a social problem rather than a medical one. Western societies consider reading and writing as some of the most important skills people should have if they want to be able to have adequate qualifications; have a better job; earn more money. Also, Government initiatives encourage people to further their studies and enter university. The difficulties that people with dyslexia face, if unrecognised, can become a barrier and prevent them from achieving their goals.

People with dyslexia may have to face rejection and humiliation from their friends and teachers because they make mistakes. People are not as forgiving as they could be. Research has shown that students with dyslexia have negative connotation like: 'slow', 'unintelligent' or 'lazy' attributed to them because they do not match up to the standards that society has set for 'normal' people and they cannot learn the way the rest of their peers do. Does this make them less equal than the rest of the population? People with dyslexia have the potential to accomplish anything that a non-dyslexic person can. They might need a bit more help and support in the way but they can definitely conquer their difficulties and succeed.

When this research project began (1998) most of the research available was related to children. There was not much literature for adults and especially adults studying for a degree in Higher Education. I had almost no experience of working with people with dyslexia but I thought that dyslexia as a 'disability' was very interesting? as it did not have the characteristics that someone expects from a disability, some obvious signs that can help you identify it, such as Down syndrome or other severe learning difficulties have. It was a hidden disability that could cause a lot of frustration and disappointment to people that had it if they were not properly assessed.

With this study I wanted to explore the experiences of a group of students with dyslexia studying in Higher Education, to listen to their voices and try to understand their situation and the difficulties they had to face, if any, caused by their dyslexia. By listening to the student's perspectives this study has presented a picture of what was happening at that time for a group of university students that had dyslexia.

The project highlights certain areas that can be investigated such as more research on the lecturer's attitudes towards dyslexia, more practical sessions within the university environment to advance the students' skills as well as more clear guidelines for a whole institutional approach to dyslexia.

12.3 The experiences of HE students with dyslexia

12.3.1 University life

Studying for a degree is the beginning of a new era. Students leave the security of their homes and start being independent. They have to deal with deadlines, reading and writing essays and they have to control and manage their time in order to succeed. How do students with dyslexia cope with these new challenges? What kind of support do they receive from their institutions? What else needs to be considered? Listening to the students' voices is the best source of information for non-disabled people to understand what they are going through in an effort to make provisions for these students, and to help them fulfil their potential and treat them as equal members of the society.

Overall the participants had positive experiences while in the university. It is imperative to note that at this stage of their lives all of them were assessed as dyslexic. They were aware that it was not their fault they had difficulties with their learning. Some of them were still coming into terms with the label of dyslexia as their assessment was quite recent. Overall, they had accepted the dyslexia as a label as it gave them the reason for their academic underachievement in the past. For the mature students this was more challenging to accept as society expects that when people reach adulthood they should have acquired literacy skills and be fluent at it.

Thirteen out of fourteen of the students did not see dyslexia as a disability. They were focusing on the positive things that dyslexia had offered them: the creative thinking, the ability to visualise things in a different way, the determination and the strength to work hard. Dyslexia was part of their lives. They were born with it and they had embraced it in their lives. Living with dyslexia can be difficult at times but all the students were determined not to let dyslexia stop them from succeeding.

The students had received more negative comments and prejudice before they were assessed as a result of their difficulties. People put them down and this resulted in them feeling insecure and not confident. The participants reported that after their assessment their self-esteem and confidence improved and increased. The older they grew and started learning and understanding what dyslexia is the better their self-esteem became. Most of the students were more confident now than when they were in school. Only one student (Kate) said that she was not very delighted after her assessment but it had to do more about what people would think about her being in her mid thirties and not being able to read, rather than the label of dyslexia itself. Also, only one thought dyslexia as a disability and as a problem. Anna was coming to terms with her assessment and her difficulties. Her late diagnosis had resulted in her failing her first year as she had no support for her difficulties. She felt hesitant about revealing her dyslexia, as she was concerned about people's reactions and prejudice.

Overall, the interviewees were happy to disclose their dyslexia. Some were more confident and there was no issue to whom they disclosed their dyslexia; some did it in a need to know basis (lecturers, close friends). The former believed that by letting people know they

raise the awareness about dyslexia and therefore people can be more understanding and supportive towards them. They thought that although non-dyslexic individuals do not empathize all the time it is better to be informed about dyslexia as it can give them an insight into a dyslexic student's difficulties. The latter informed only the people they thought they need to know because they did not want to be penalised (lower marking) due to their difficulties.

When they were younger all participants had connected dyslexia with intelligence. They thought that their academic underachievement was because they were not intelligent. This perception was imposed on them primarily by their teachers' attitudes towards them and the experienced they had mixing with non-disabled people. When the majority of them were assessed during their GCSEs and A levels they had experienced negative attitudes from their teachers who were not aware of the manifestations of dyslexia and did not understand why these students could not progress the same as their peers. Few of the participants dealt with unsympathetic teachers who discouraged them going to the university because of their literacy difficulties. Determination was the one thing that made them continue working hard, not giving up and the drive to prove to the people who doubted them that they were wrong. In some cases the negative responses received from their teachers rather acted as a driving force for these students to succeed. Fortunately none of the participant expressed any negative attitudes from their lectures regarding their dyslexia. They believe that their lecturers might not understand their difficulties but they attribute this to lack of training and awareness of dyslexia.

Now that the participants are in the university they do not associate dyslexia with intelligence. They feel that they are intelligent and, as mentioned before, they focus on the

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strengths of dyslexia rather than the weaknesses. Some of them believe that people with

dyslexia have a different way of thinking. They are aware of their difficulties and work,

when necessary, with their learning support tutors. They are conscious about the demands

of their courses and that they need to work twice as hard as their peers to complete their

degree.

12.3.2 Difficulties and Provision in HE

All three universities had specialised staff to support their students with dyslexia. The

participants knew there was support available and it was up to them to utilise the facilities

offered to them. The majority of them were taking advantages of the special arrangements

that were in place for them in order to support them with the workload and their exams.

Some of the students use the services to help them with their essay writing and

organisation. Two of the participants have people keeping notes for them in the lecture

theatre. Only two students did not want to use the extra time they were entitled to, as they

did not want to be different from their peers. The learning support tutors have also helped

all the participants who were willing to receive the DSA and helped them fill in their

application forms.

Although, the students had a positive opinion about the learning support teams in their

universities their views of the academic staff varied. Looking at their narratives it became

obvious that although their universities were catering for their individual needs, there was

not a coherent institutional policy regarding provision and staff consistency. Even though

some members of staff were quite helpful and supportive by providing notes in advance;

however, not all them met these terms. There were cases that although the students were

promised that there would be notes available to them before the lectures this did not happen and they did not know to whom they should turn to assist them.

Furthermore, the interviewees believe that there should be a better organisation system within the university in order to inform the students of what they are entitled to. There seem to be some confusion among the students about who is supposed to inform their lecturers about their dyslexia. They did not know whether they had to do it or their tutors from the learning support services. Due to confidentiality records, the learning support tutors need the permission of the students to inform their tutors or lecturers. The students seem not to be informed about this. Besides, some were puzzled by the fact that in some universities students could be examined orally and their universities did not offer them the option. The group of students that took part in this project were not certain whether the former could apply to them.

There are no national guidelines of what a 'reasonable adjustment' is. The Demos project (Demos, 2009) was maybe one of the few initiatives that were set to help academic staff with their disabled students and it included some examples of 'reasonable adjustments'. Unfortunately, because it was a project funded by the Higher Education Funding Council it only ran for three years (2000-2003). How many academics though were aware and still are aware about its existence is not known. The Government has requested universities be more proactive but it is up to the universities to decide what these special arrangements will be. Oral exams can be considered a reasonable adjustment for students who have difficulties expressing their thoughts in paper but it is not available to all students with dyslexia. Some universities follow this initiative and others do not. Some universities use special stickers during their exams to identify students with dyslexia in order not to be

penalised due to their spelling mistakes. These options were not available in the three universities that the research took place. Who decides and defines what a reasonable adjustment is? What was the reason that made some universities to follow the former initiatives before the SENDA was introduced? It appears that there is no consistency between higher education institutions regarding the provision of students with dyslexia. Were the participants of this study entitled to oral exams? If the answer is yes why they were not given the option? The participants felt that a better network needs to be set in HE to inform lecturers about their students with dyslexia and ways to facilitate a more positive learning experience for dyslexic students. Also, it is imperative for the students to know all the options that are available to them. All three universities had learning support tutors to assist their students with dyslexia but, as mentioned before, rather than a whole institution approach the support was focused on the individual's needs.

While studying at the university, the students that took part in this study had to cope with the difficulties caused by their dyslexia. Time management is not one of these students' best attributes. It takes so much more time to read and comprehend the materials required for their course work. They need to work twice as hard as their non-disabled colleagues to be able to submit their work by the given deadlines. They feel disappointed at having to rush their work to comply with the deadlines. The majority of the participants in this study felt that dyslexia was preventing them from showing their potential as they had difficulties expressing their thoughts in paper. They felt their assessments were marked lower because their writing skills were not up to standards. Not being able to express their thoughts in paper was probably the main concern of the students..

Taking notes was also a struggle for them as they found it very hard to simultaneously listen and keep notes during their lectures. Their handwriting also made taking notes even harder. Some of them could not understand what they had written. The majority of the students expressed their disappointment at not being able to have the lecture notes in advance. Some of the participants tried to use a tape recorder during the lecture. This gave both positive and negative feedback. The positive thing is that the students could listen to the lectures as many times as they wanted to. On the other hand, trying to write down notes by listening to the tape can be time consuming. Also if the tape recorder is not placed close to the lecturer the quality of the recording can be quite poor. There were also lecturers who were not very keen on having their lectures recorded.

Exams are another barrier that students with dyslexia have to conquer. Although they are entitled extra time some of the students found it very hard to be able to concentrate without any breaks in between. Besides, another difficulty is the fact that the students misread the questions and understand different things. This leads them to answer the questions incorrectly and therefore get lower marks.

12.3.3 Education system - School and University

Overall, the students were much happier with the education system and the way they were treated after they were identified as dyslexic. However, they believe that there is not enough awareness in the departments where they were studying about dyslexia. They postulate that if there was a whole university approach and there were seminars for staff to inform them about the complexity of dyslexia they would be much more sympathetic to their needs.

The students who were identified after entering university felt bitter and let down by the educational system due to the opportunities they believe they have lost in the past and for going through life without knowing what was wrong with them. The mature students were pleasantly surprised with the support that students with dyslexia receive nowadays compared to when they were in school. They believed that dyslexia is more 'common' these days than it was in the past. They were also content with the support network that was in place for them by their universities.

School life was not effortless for these individuals and most of them went through school without any support. The students that were assessed during school reported having some support but their approaches towards it varied. Some found it beneficial but others did not agree with it as they did not want to be different from their peers and attend 'special classes'. Two of the students attended private schools and they reported better provision and support. They also felt that being in a small class (20 students) was helpful as the teacher could spend more time with them and support them.

The difficulties that the students experienced during school continued when they were in the university. Note-taking was a difficulty that the students had both in school and university. In the university though some were taking advantage of the DSA allowance and they had note-takers helping them. While in school none of the participants reported any provision for these difficulties. The support available was focused mainly on their literacy difficulties (spelling).

In school most of the difficulties focused on writing and spelling correctly. While in university this seem to be not as crucial as when they were younger as all the students were using computers to write their essays and were relying on the inbuilt spell-checkers to correct their mistakes. Reading was much more of an issue for the students when in university as they had to read large volumes of text as part of their studies within a specific time frame. While in school reading did not seem to be of great importance. The students' narratives concentrated mainly on their helplessness to read aloud and the fact they could not read as well as their peers.

12.3.2 Dyslexia, family and social life

Most of the families were not surprised that their children had dyslexia. They could feel that something was 'wrong' with their children because they could tell that their children were intelligent. Unfortunately, very few acted on it. The mature students believe that people's awareness about dyslexia when they were at school was limited both from parents and educators. Some of the parents tried to help their children by buying books, sending them to seminars and supporting them themselves as much as they could. The older students contributed the lack of support from their parents to their lack of knowledge of dyslexia and the trust they had in their children's teachers to know best; therefore if their child was failing it was because the child did not try hard enough. Their approach was leaning towards the medical model of disability that blames the individual for their difficulties. It was up to the students to overcome their difficulties. Lack of appropriate teaching or recognition of their disability was not an issue at the time.

Mothers seem to have a predominant role in the participants' lives as they relied a lot on them for support when they were younger. Usually mothers are more patient than fathers and usually work fewer hours than their partners. Some of the participants believe that their parents, especially their fathers, did not get involved in their schooling because they are dyslexics themselves; although they were never officially diagnosed.

The majority of the students mentioned having at least one relative with dyslexia. They could recognize patterns of their mistakes in close family members. The parents of the students who were aware of dyslexia beforehand were much more understanding and supportive compared to the ones who first heard about dyslexia when their children were diagnosed. Their children were much more confident and open to discuss and disclose their dyslexia. The parents that were knowledgeable about dyslexia tried to expand their children's knowledge and help them to regard dyslexia as a difference rather than a disability and concentrate on the positive things that it has to offer them; not only the weaknesses.

Regarding the participants' social network, they reported that their friends were quite understanding and sympathetic about their dyslexia and they were willing to help them out if they needed their support. In the university the participants had to rely more on their friends for support as they lived away from their families. They would ask their friends to help them with proofreading their essays. While they were at school their parents were the ones who helped them with their difficulties when needed. The students were aware of the demands of their courses and they were trying to be and work independently as much as they could.

Only one participant express having difficulties in her social life because of her dyslexia. Everybody else was quite content with their lives and friends. One student mentioned that his friends were 'jealous' because he obtained all his computer equipment for free. The majority of the students were happy to disclosure their dyslexia to their friends.

12.3 Reflections about the study

Since this research study started there have been quite a few developments in the dyslexia studies field. People have started considering dyslexia more as a difference rather than as a disability. Research has also begun to focus more on students with dyslexia in HE. During the course of this research I have learnt how important it is to listen to the voices of the students with dyslexia if educators want to improve their teaching and provision for these students. Dyslexia is a non evident disability and people sometimes are quick to judge people with dyslexia due to their literacy difficulties. Society places great emphasis in the written world and as a result people with dyslexia face barriers because of their difficulties. One cannot completely understand what a person with dyslexia faces until they have experienced it themselves. Unfortunately this is not something that can be accomplished by a non-dyslexic person.

I have learnt that teachers should be more patient and try and adopt their teaching to the needs of their students. As educators, we should be more flexible, be open to changes and pay more attention to the children who are 'different'. Their 'disabilities' can be turned into abilities with the appropriate help and support.

While I was collecting my data I was surprised to hear that the students who took part in this study did not want their dyslexia to go away. As a non-disabled person, I thought that

they would quickly dismiss dyslexia and if given the chance they would want to 'get rid of it'. On the contrary, the participants of this study had embraced their dyslexia and they were focusing on the positive aspects of it rather than the negative. They did not consider themselves as disabled, although 'officially' they have accepted the label as it is the only way to receive extra support in HE.

If I had the chance to do this project again I would try and have a larger number of participants and also include the opinions of the learning support tutors. If changes need to be done the learning support tutors should be considered as they are the ones who set everything in place for the students with dyslexia in HE. The larger the sample the more strength the narratives of the participants would have although I believe that even though this research study had only fourteen participants their experiences are very important and their narratives were adept in giving an insight into their world.

12.4 The way forward

The number of the students in HE increases every year and with the governments' widening participation agenda even more will apply for a place at university. Universities should be prepared to accommodate all the new students and their needs. Good practice should start from school and consequently continue in the HE sector. Schools should be prepared and aware about the needs and particularities of students with dyslexia and adopt their curriculum and teaching in order to include their needs. Schools should try and be more dyslexia friendly where teachers fully understand the needs of children with dyslexia. This should include clear guidelines about the identification and assessment of students at risk of dyslexia. Teachers should receive adequate training to be in position to identify the

students in need. Appropriate support should follow in order to assist the students and improve their skills. Specialist teachers should be in every school in order to support not only the children but the staff in school that might need support with their learners with dyslexia. A dyslexia friendly environment will also help increase the children's self-esteem and self-concept.

Schools and parents should work closely together trying to find ways to advance the children's learning. Collaboration between parents and teachers is very important. Teachers should inform the parents about the techniques and strategies they use in the classroom and encourage them to follow them at home in order to support their children.

Universities need to be more proactive and inform their staff about dyslexia. Dyslexia training should become compulsory in the HE institutions. The number of students with dyslexia increases every year and therefore academic staff should be aware of their difficulties and be informed of strategies that can help and support these students. Besides, more initiatives should be given to lecturers to try and make amendments to their teaching methods and styles. Lecturers should also be given time to prepare their lecture notes and publish them on the Internet in advance. Marking guidelines should be clear and students with dyslexia should not be penalised because of their spelling. When marking a dyslexic student's work, lecturers should concentrate more on the context and the ideas presented rather than the spelling and the grammatical mistakes. Lecturers should encourage their students to give them feedback on how they can improve their practice and work together creating an inclusive environment that would benefit not only the students with dyslexia but their fellow students too.

Furthermore, universities should try and contact the students with dyslexia when they enrol and inform them about the facilities available to them. Clear guidelines of what the students are entitled should be put in place. Students with dyslexia should be aware of all the options available to them and they should be left to decide whether they want any special arrangements or not.

The sample of this study is not big enough to make generalisations. More research needs to be done that will include a larger sample of students. The voices of the students need to be heard. By listening to the students, universities can adopt their policies and programmes and create a much friendlier environment for students with dyslexia.

Additionally, research on the teachers and lecturers opinions about dyslexia would be useful. The people that teach dyslexic individuals should also be heard. People need to know their opinions too and listen to their recommendations if they want to improve the lives of the students with dyslexia. Before any changes take place, their side needs to be considered.

The number of mature students increases every year too. Many of them have dyslexia. It would be interesting to further investigate their lives and their experiences in HE and see whether dyslexia was the reason they went to university at a late age. Besides, some of the mature students in addition to their working on getting a HE degree also have their own families and some of their children might have dyslexia too. How do they cope with these? How do they manage to organize their family lives and at the same time study for a HE degree? How do they support their children in school?

Last but not least further research into people's attitudes towards dyslexia would help into shedding some light about the awareness of dyslexia. There is no doubt that dyslexia is much more recognised and people are more aware of it. Government initiatives and the media have contributed to raise awareness about dyslexia. Famous people that have succeeded regardless their difficulties have been a positive role model for people with dyslexia. But what do non-dyslexic people know about the manifestations of dyslexia? Do they consider it another disability? How do non-dyslexic people perceive dyslexia? It is not an effortless task to try and change society's perception about disabilities. The fact that dyslexia is a non evident disability can make this effort even harder. If people want to remove the barriers that prohibit people with dyslexia to have equal opportunities, they should try to change the way society perceives and reacts towards people with disabilities. Public awareness is very important as dyslexia being a non evident disability does not have any obvious sign for people to recognise it. By listening to the voices of people with dyslexia and making them heard people will be able to have an insight into their lives and sympathise with the things that they go through and the effort the put in order to be able to function and accomplish their goals.

People with dyslexia do not need society to feel sorry for them. They need and want to be equal and active members in it. They have the abilities to perform in a high level if they are asked to. Society should 'take advantage' of their strengths and build on them by creating and inclusive environment where having a disability will not be a barrier. In order to mainstream disability societies should work along with people with disabilities, listen to them and try to incorporate their suggestions.

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APPENDIX

Interview schedule

1st part - Personal Information

Name, occupation, age of the interviewee.

2nd part – Dyslexia during school years

Age that dyslexia was diagnosed.

Problems that dyslexia has caused to the interviewee during his school years.

How he/she coped with the problems (if existed).

What was his/her teachers' attitude?

Did s/he have any support in school and what kind of support?

3rd part – Dyslexia and personal relationships

Does the interviewee think that dyslexia was an obstacle to start a relationship? (Friends)

What were the problems in creating a relationship?

4th part – Dyslexia and family

What was the family's attitude to dyslexia?

Did dyslexia cause any problems inside the family?

If yes, how did that affect the interviewee at his personal life and at his school life?

5th part – Dyslexia in HE

What kind of problems did s/he face in HE?

Is any support available?

Does s/he employ the facilities of the learning support services?

In university does s/he have a better treatment from his/her lecturers compared to his/her teachers at school?

6th part - Life Overview

Looking back at his/her life, what the interviewee thinks about it?

Would s/he like to change something in his/her life? (dyslexia)

Does s/he think that the educational system has helped him/her to overcome his/her problems?

If not, what s/he thinks it should be done in order for students with dyslexia to have more help and support?

Does s/he have any regrets for having dyslexia?