

# **Making sense of dyslexia**

A life history study with dyslexic adults  
mapping meaning-making and its relationship to the development  
of positive self-perceptions and coping skills

Submitted by Ruth Gwernan-Jones, to the University of Exeter as a thesis  
for the degree of Doctor of Philosophy by Research in Education, September 2010.

This thesis is available for Library use on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

This research was funded by ESRC Studentship number PTA-031-2006-0057

For Bill, Edward and Gary,  
without whom I would not have thought of doing this thesis;

and for Alun, Bob, Cheryl and Gert,  
without whose support I would not have finished it.

## ABSTRACT

It has been acknowledged for some time that personal experience, relationship and emotional factors are important aspects of difficulties in learning to read and write; however there is still little research carried out in this area. This thesis explores the way in which eight adults make sense of their difficulties with reading and writing and identification of dyslexia; and their process of developing more positive self-perceptions and coping strategies. The study is guided by standpoint theory, with priority given to participants' perceptions about difficulties in reading and writing rather than to academic and/or practitioner perspectives.

Analysis of interviews is carried out through a life history methodology that identifies discourses of dyslexia in order to situate the way difficulties are understood and addressed. The discourses include four identified by Pollak (2005) and identification of six additional discourses of dyslexia that were present in both the literature review and at least half of the participant interviews. In the analysis, use of these discourses is mapped alongside the life story of each participant using the Model of Vocational Success (MVS) (Gerber *et al.* 1992) as a framework for classifying the development of positive self-perceptions and coping mechanisms.

The participants' life histories reveal that, without identification of dyslexia, difficulties with reading and writing are most often attributed by others such as teachers, peers and/or parents to low intelligence and/or lack of effort. Some participants rejected this understanding and others internalised it. Experience of 'niche' where the participant found themselves to be successful in a specific context best supported the development of positive self-perceptions and coping strategies before identification of dyslexia. Identification of dyslexia provided a means of making sense of difficulties, bolstered self-belief in intelligence, and initiated changes in support and personal motivation which, for the majority of participants, were notably beneficial.

This PhD makes a number of unique contributions to knowledge about dyslexia, particularly through its prioritization of the voice of dyslexic people over professional voices. The identification of six additional discourses of dyslexia contributes to knowledge about the way difficulties with reading and writing can be understood and talked about, and exploration of how these discourses link to the MVS contributes knowledge about the advantages and disadvantages of these discourses to dyslexic people. The discourse 'Hemispherist' (Pollak 2005) was found to offer the most opportunity for dyslexic adults to develop positive self-perceptions and take constructive action to compensate for difficulties.

# TABLE OF CONTENTS

<b>Title page</b>	1
<b>Dedication</b>	2
<b>Abstract</b>	3
<b>Table of Contents</b>	5
<b>List of Tables</b>	8
<b>List of Figures</b>	9
<b>Abbreviations</b>	11
<b>Chapter 1: Introduction</b>	12
Personal introduction	12
The development of the concept of dyslexia	17
<i>Roots in medicine</i>	17
<i>Development of intervention and conceptual approaches</i>	18
Outline of the thesis	22
<b>Chapter 2: Literature Review</b>	23
Introduction	23
Educational and employment outcomes for poor readers	25
Studies on self-perceptions and psychological well-being	27
Research interviewing dyslexic people	32
<i>Perceptions of school experience</i>	34
Humiliation, punishment and trauma	35
Teachers	36
Parents	38
Bullying	39
<i>Perceptions about being identified as dyslexic</i>	40
When dyslexia is not identified	40
Reaction upon identification of dyslexia	41
The need to conceptualise difficulties with reading and writing	43
The label 'dyslexia' means different things in different contexts	46

<i>Ways of understanding dyslexia: discourses</i> .....	48
Patient .....	48
Student .....	50
Hemispherist .....	51
Campaigner .....	51
<i>How positive understanding is achieved</i> .....	52
The Model of Vocational Success.....	53
Early self-perceptions.....	55
Change in self-understanding related to academic context .....	56
Change in self-understanding related to identification of dyslexia .....	56
Change in self-understanding due to experiences of 'niche' .....	57
Change in self-understanding due to parenting a dyslexic child .....	58
Change in self-understanding due to talking to others .....	58
<i>Conclusions from research interviewing dyslexic people</i> .....	59
Methodology of studies.....	60
Conclusion .....	63

**Chapter 3: Methodology** ..... 65

Research design .....	65
<i>Epistemology</i> .....	68
<i>Theoretical perspective</i> .....	69
<i>Research strategy</i> .....	71
Standpoint theory .....	71
Life history.....	74
<i>Method</i> .....	74
Life history research .....	75
<i>Objectivity vs. subjectivity, representation and rigour in life history research</i> .....	76
<i>The life story</i> .....	82
Narrative .....	83
Discourse.....	86
Identity/self.....	90
Impact of time in life and context of interview .....	94
<i>The life history</i> .....	95
Analysing the life story: narrative analysis and analysis of narrative .....	95
Ethical issues involved in re-representing others .....	99
The process of contextualisation .....	100
<i>What's wrong with me?</i> .....	101
<i>Stupid/lazy</i> .....	102
<i>Educational responsibility</i> .....	104
<i>Extra-able</i> .....	105
<i>Show them</i> .....	107
<i>Niche</i> .....	108
<i>The Model of Vocational Success (MVS)</i> .....	109

**Chapter 4: Data Analysis and Discussion**..... 113

The process of interviewing participants .....	113
--	-----

<i>The sample</i> .....	113
<i>The interviews</i> .....	116
The process of analyzing the data .....	120
Adam .....	133
Alice .....	144
Amber .....	152
Bob .....	163
Country Boy .....	175
Elizabeth Kirner .....	185
Pablo Jennings .....	197
<b>Chapter 5: Conclusion</b> .....	209
Comparison of participants' experience with those in the literature review .....	209
Response to research questions.....	211
<i>What's wrong with me?</i> .....	211
<i>DRW=Stupid/lazy</i> .....	213
<i>Dyslexia=Stupid/lazy</i> .....	215
<i>Patient</i> .....	215
<i>Student</i> .....	217
<i>Hemispherist</i> .....	219
<i>Extra-able</i> .....	221
<i>Show them</i> .....	221
<i>Educational responsibility</i> .....	222
<i>Campaigner</i> .....	223
<i>Dyslexia unspecified</i> .....	225
<i>Niche</i> .....	225
Rigour .....	235
Unique contribution .....	238
Future research .....	238
Conclusion .....	239
<b>References</b> .....	240
<b>Appendix 1: Amber</b> .....	248
Transcript from interview 1 .....	249
Transcript from interview 2 .....	269
Transcript from interview 3 .....	281
Timeline .....	292
Summary .....	306
<b>Appendix 2: Letter of consent</b> .....	310
<b>Appendix 3: Ethical consent</b> .....	312

## LIST OF TABLES

<i>Table 2.1. Description of interview studies reviewed</i> .....	33-34
<i>Table 2.2. Description of Pollak's (2005) four discourses of dyslexia</i> .....	49
<i>Table 4.1. Participant information</i> .....	114
<i>Table. 4.2. Description of aspects of the MVS</i> .....	126
<i>Table 4.3. Description of new discourses of dyslexia identified</i> .....	127-128
<i>Table 5.1. Use of discourse by each participant</i> .....	212
<i>Table 5.2. Number of times each discourse links to an aspect of the MVS</i> .....	220
<i>Table 5.3. Examples of criteria for rigour in the thesis</i> .....	237

## LIST OF FIGURES

<i>Figure 2.1. Diagram of Azjen's (1985) 'Theory of Planned Behaviour' (taken from Gwernan-Jones &amp; Burden, 2010)</i> .....	29
<i>Fig 2.2. Gerber et al.'s (1992, p485) diagram of the Model of vocational success</i> .....	55
<i>Fig. 3.1. Diagram of the research framework. The research questions will be answered through a Life history method including analysis of discourses of dyslexia and use of the Model of Vocational Success (Gerber et al., 1992); the methodology of standpoint research; and the theoretical perspective of critical theory, founded upon a social constructionist epistemology</i> .....	67
<i>Fig 3.2. The reciprocal relationships between lived experience, narrative, discourse and identity</i> .....	91
<i>Fig. 3.3. Heron's (1996) 'ways of knowing', a framework for understanding the relationships between pre-verbal and verbal knowledge</i> .....	93
<i>Fig. 3.4. Famous people who are dyslexic, from the British Dyslexia Association website (<a href="http://www.bdadyslexia.org.uk/extra354p.html">http://www.bdadyslexia.org.uk/extra354p.html</a> , accessed March 2005)</i> .....	106
<i>Fig. 4.1a. The circular nature of the process of data analysis in this study</i> .....	121
<i>Fig. 4.1b. Adam's map</i> .....	136
<i>Fig. 4.2. Alice's map</i> .....	146
<i>Fig. 4.3. Amber's map</i> .....	154
<i>Fig. 4.4. Bob's map</i> .....	165
<i>Fig. 4.5. Country Boy's map</i> .....	176
<i>Fig. 4.6. Elizabeth Kirner's map</i> .....	187
<i>Fig. 4.7. Pablo Jennings map</i> .....	199
<i>Fig. 5.1 Number of times each discourse linked to an aspect of the MVS</i> .....	218

*Fig. 5.2 Comparison of the number of times dyslexia discourses vs. non-dyslexia discourse (Niche) links to aspects of the MVS ..... 226*

*Fig. 5.3a/b. Comparison of participants' maps showing patterns of links to the MVS. Before identification of dyslexia links result most often from experiences of niche (represented by the Niche discourse) linking to Goodness of Fit, Social Ecologies and/or the Persistence/Goal Oriented/Desire triad, and these frequently contribute to Understanding. Identification of dyslexia often initiates Recognition, Acceptance, Understanding and/or Learned Creativity, and experiences of niche following identification tend to be interpreted through discourses of dyslexia ..... 228/229*

*Fig. 5.4 Comparison of participants' maps showing the development of discourse. What's wrong with me? and DRW=Stupid/lazy appear in the context of school. The Patient and Student discourses originate with identification of dyslexia, with the Hemispherist discourse following on with development of knowledge about strengths and weaknesses. The remaining 'greenish' discourses occur according to context and experience. Educational responsibility follows realisation that difficulties can be compensated for. The Dyslexia=Stupid/lazy discourse is usually in reference to participants' perceptions of the way the general public views dyslexia ..... 234*

## ABBREVIATIONS

ADD	Attention Deficit Disorder
A-level	Advanced Level General Certificate of Education
ASD	Autistic Spectrum Disorder
AS-level	Advanced Subsidiary Level General Certificate of Education
CSE	Certificate of Secondary Education
DSA	Disabled Student's Allowance
FE	Further Education
fMRI	functional Magnetic Resonance Imaging
GCSE	General Certificate of Secondary Education
HE	Higher Education
LD	Learning Disabilities
LEA	Local Education Authority
MVS	Model of Vocational Success
NVQ	National Vocational Qualification
O-level	General Certificate of Education Ordinary Level
PGCE	Post-Graduate Certificate in Education
SEN	Special Educational Needs
SLI	Specific Language Impairment
SpLD	Specific Learning Difficulty

## CHAPTER 1: INTRODUCTION

*In this chapter I will introduce myself, particularly in relation to my interest in difficulties with reading and writing and dyslexia and the way in which the idea for this thesis developed. I will also give a brief history of the development of the concept of dyslexia, and conclude the chapter with an outline of the thesis.*

### **Personal introduction**

I have a younger brother. He is only 14 months younger than I am, and as children growing up in the Midwestern United States we were constant playmates, fighting and watching out for each other in equal measure. When I started First Grade at age six I was the only child in my class who could read. I remember this well despite having no memories of how I learned; the status and praise given me because of it are the foundations for one the most uniformly successful areas of my life – academia. My brother did not read until he was ten. I also remember this very clearly. My mother bought a small waste bin and filled it with sweets and treats to be given to my brother as inducement for him to practice reading at home and I was jealous. During school years I was puzzled by his Cs and Ds when my report cards held As and Bs; he was certainly my match outside the realm of education including intellectual endeavours, for example to my humiliation (and despite being able to beat most of my other opponents) I could not beat him at chess.

We attended the same university; I studied Psychology and he studied Engineering. He was required to pass a foreign language module to complete his degree. During high school he had taken French, Spanish and German and failed them all, and since I had aced my French classes

throughout he asked me to help him. We sat in his dorm room and I quizzed him on vocabulary using the technique that worked for me – rote memorisation. He couldn't remember the words but I believed he would if we just kept on. I was wrong. Despite being as tenacious as any drill sergeant in my efforts the words remained foreign to him and eventually I became frustrated and resorted to shouting. Not only did the fact that he couldn't remember frustrate me; he was making me look bad. It had been so easy for me to learn and I had thought I could show him how, but I failed miserably. So did he, and he soon left university without his degree.

He has made his life into something he enjoys – he now lives in a log house in the woods and runs the computing side of a printing firm – and I would not want to credit his difficulties learning to read and write with more significance than they deserve. However, my sense of failure at not being able to help him and my puzzlement over his difficulties has stayed with me, as has a sense of injustice. He was denied the injection of self-esteem that academic success has given me despite on all accounts appearing to be an intelligent person. But also, I would warrant that work as an engineer might have made fuller and more satisfying use of his potential. It is not only unjust but also illogical to deny a person a qualification based on a skill unrelated to the job they are qualifying for.

I have started with this story because it is the beginning of my interest in the subject of this thesis. My own experience learning to read and write and its contrast with my brother's are what have made me aware of the potential power that learning to read and write holds in the way a person is perceived by others and the way they perceive themselves. My brother's failure to complete his degree also made me aware of the potentially negative impact difficulties learning to read and write can have on life chances, and its relationship to the way education is structured. Finally, it has made me wish to make a contribution toward righting the injustices I've seen for the dyslexic person in a non-dyslexic world. In this chapter I will continue to tell the story of the part my own experiences play in the writing of this thesis.

My personal experiences represent bias in this thesis because I understand what my participants say to me from the position to which my own experiences have brought me. Therefore the data analysis in this research will involve co-creation between me and those I interview. My personal experiences also represent the authority from which I claim the capability to carry out this research perceptively. These issues will be discussed further in Chapter 3: Methodology, but I would like to set my position in the research from the beginning. Sikes, in her chapter on ethics

and writing life histories, says 'I believe that writing lives is always an auto/biographical process and acknowledging this is, in my view, the first task that ethical researchers must address' (2010, p12).

I am one of an extended family of whom many identify themselves as dyslexic, and my own ability (as well as other family members) to claim a position on a number of other continua of Specific Learning Difficulties (SpLDs) means I belong to the marginalised group I am researching. Thus I am able to relate to the experience of dyslexia well enough to represent dyslexic participants' experiences relevantly. It means my approach is one of 'commitment', 'engagement' and 'solidarity' with dyslexic people; I am 'with the oppressed' (Barnes, 1996, p110). Although I have experience as a practitioner and academic in the field of dyslexia my goal in this thesis is to prioritise dyslexic participants' perspectives over practitioners' and/or academics' perspectives.

At the same time, I do not write this thesis from a position that is generally critical of either practitioners or academics. My failed experience of tutoring my brother and resorting to shouting at him, followed many years later by my experience tutoring other dyslexic learners, means I can relate to the emotions (though I'm sure many better teachers do not resort so quickly to shouting as I did) and quandaries faced by generations of teachers who struggle to teach people who are not learning the way they are taught. I also respect the contribution of other academic researchers in the field of dyslexia, for example in the areas of cognitive psychology and neuropsychology, although their approach in research is quite different to my own. My stance is one that sees scientific/post-positivist approaches to be another valid way of 'telling stories about society or the social world. These methods may be no better or no worse than any other methods; they just tell different kinds of stories' (Denzin & Lincoln, 2003, p15). I believe scientific and interpretative approaches are both valuable means of working on different pieces of the puzzle that is dyslexia.

To continue my experiences with dyslexia requires a hop of ten years and one country. In the years after I completed my Psychology degree I married an Englishman and moved to England, and when my son was six years old he was identified as dyslexic. His difficulties learning to read and write mirrored my brother's, and I was determined to support my son in a way that meant he would not suffer from the reduced life choices my brother had. Identification of dyslexia in my son represented to me the difference between the experiences I saw my brother have and those I hoped my son would have. It was the ticket to understanding what had perplexed me about my brother. I started by reading books about dyslexia written for parents and found myself to be

fascinated, perhaps because of my prior personal experiences and perhaps because of the links to developmental and cognitive psychology which fell into place with the knowledge I had developed in getting my degree. Over the next five years I completed an OCR diploma in SpLD (Dyslexia) while tutoring people with SpLDs, including my son, both privately and in schools. However, my vision of supporting my son did not go completely according to plan.

The information I gathered about dyslexia through reading and my course did not sit easily in the context of schools. My son's teachers and the teachers of pupils I was tutoring were polite and I now realise how unusual it was that I was allowed to tutor in school contexts at all; however I was aware that they did not welcome my comments beyond a perfunctory level. In fact it felt as though we were speaking a different language. On my dyslexia course multi-sensory, structured phonics were returned to repeatedly as a fulcrum point from which to consider addressing difficulties. In schools teachers were sometimes impatient when I brought up use of phonics, sometimes derisive. Multi-sensory principles required an active approach that was not always practical in a school environment. I remember a heavy, wooden chalk board I used to practice large-scale letter writing with a dyspraxic child and the irritation of his teacher as I lugged it across the classroom before and after our lessons.

The theoretical ideas I developed from my course did not always transfer easily to my own teaching situations, either. For example, I remember thinking what an excellent strategy 'using strengths to address weaknesses' was, however when it came to working with pupils, scores from the in-depth psychometric testing I was taught to do initially to establish strengths and weaknesses were so far removed from the learning tasks involved in lessons that applying the knowledge was something of a nonsense. I remember a particular pupil with whom I worked for three years to build up knowledge of phonics. At the end she knew sound—symbol relationships fluently but her reading was still extremely slow and laboured. However, other pupils experienced very good progress, including two who had bad experiences with previous tutors. My son's progress continued and he learned to read and spell, better after he began to receive one-on-one private tuition from a specialist dyslexia tutor, and he has achieved C or above in all his subjects at GCSE. However it has never been a quick or easy process and he has not become a highly accurate or fluent reader or a very good speller, despite his lessons and hours spent working with me. I reluctantly realised it is impossible to tell how much his progress has been due to the extra support and how much would have occurred anyway.

In the final year of my diploma in SpLDs I decided to apply for funding to do a PhD. Initially when I planned its subject I focused on cognitive aspects of dyslexia; however, the professor with whom I made contact to discuss my ideas, Professor Burden, who is now one of my supervisors, was sceptical about the benefits of such research. He was the first person I had met to challenge the dominance of a cognitive approach to dyslexia, asking what its practical implications were. It was not until he began posing me with such questions that I began to make better sense of the inconsistencies I had experienced during my years tutoring. Looking back I began to acknowledge how little cognitive theories had helped me to support my pupils. At the same time I paid more attention to the importance of other factors I had previously been aware of, but had set aside when conceptualising dyslexia, like trust between people – between me, my pupils, pupils’ teachers and pupils’ parents – and the way pupils understood their difficulties. I began to focus on context, attitude and meaning in relation to conceptualising dyslexia.

Over the same period of time that I was cultivating the subject matter for my thesis I completed the final task for my diploma in SpLDs – assessment of an adult who was experiencing difficulties with reading and writing. When I identified the learner, a 63-year old man, Gary<sup>1</sup>, as dyslexic, I watched him begin a process of re-thinking his life and his identity over the next six weeks as I initiated a teaching programme for him. Having been told he was stupid as a child, he re-thought his experiences, replacing an understanding of himself as stupid with an understanding of himself as intelligent but dyslexic. This gave him a framework to understand his experiences in a new way, and also impacted his actions. He showed a new enthusiasm for learning, bought himself a computer and took a computer class in addition to the English class he had been attending. I wondered if Gary’s experiences were common. Did other people who had trouble learning to read and write attribute their difficulties to a lack of intelligence? Was Gary’s process of re-thinking himself something other dyslexic people go through? And, how does having difficulty reading and writing/being dyslexic impact on the way a person understands what it is possible for them to do? Whilst mulling over these questions, they clicked into place as a research project, and I wrote my grant application as a proposal to explore the experience of being dyslexic.

In writing this Introduction, I have become aware that my own story of dyslexia, about my brother and my son, is an example of the importance issues of context, attitude and meaning play in living an experience of dyslexia. What matters to me has to do with relationships, emotions and impact on life choices – loyalty to my brother and jealousy of him, shame because I lost my temper when I

---

<sup>1</sup> All names have been replaced with pseudonyms to protect anonymity and confidentiality.

tutored him; a desire to protect my son. It has been particularly important to me to try to know how to help my son understand himself positively and how to overcome his difficulties. It is knowledge about these kinds of issues that I will be exploring in this thesis.

## **The development of the concept of dyslexia**

I will now give an overview of the concept of dyslexia to provide background information from which to understand the thesis. I will discuss dyslexia's roots in medicine, the development of intervention approaches, the relationship of dyslexia to the disability rights movement and the role cognitive psychology has played in its continuing conceptualisation.

### **Roots in medicine**

The origin of the idea of dyslexia comes from the development of the modular theory of the brain, where specific loss of function can be traced back to damage to specific areas of the brain. In the late 1800s Wernicke (Lanczik & Keil, 1991) and Broca (Dronkers *et al.*, 2007) described loss of speech in patients due to damage to particular areas of the brain. In 1877 Kussmaul described the loss of the ability to read in a patient due to damage to the angular gyrus, which he called 'acquired word blindness' (Critchley, 1970). Pringle-Morgan (1896), a physician to a preparatory school in the South of England, then described an intelligent boy, 'Percy F' that had great difficulty with reading and writing. Pringle-Morgan linked this to the earlier descriptions of acquired word blindness by Kussmaul, but as Percy F had not suffered brain damage, Pringle-Morgan attributed his difficulties to a congenital under-development of the angular gyrus which he called 'congenital word blindness'. At a time similar to Pringle-Morgan, James Kerr, a Medical Officer of Health in Bradford, also used 'congenital word blindness' to describe several children in local schools who had difficulty with reading and writing despite normal intelligence (Pumphrey & Reason, 1991). Though these authors used the term 'word blindness' to refer to difficulty with reading and/or writing, another author, Berlin (1887, cited in Pumphrey & Reason 1991), coined the term 'dyslexia' in conjunction with acquired word blindness.

Thus the origins of dyslexia are embedded within medical practice that conceptualised difficulty learning to read and write with dysfunction of specific areas of the brain. This conceptualisation it is still dominant; Pollak (2005) interviewed 33 students in higher education that had been identified as dyslexic. All 33 discussed dyslexia using medical vocabulary such as 'I've got

something', 'diagnosed' and 'symptoms' (p111). From the beginning dyslexia was conceptualised as an exception to the assumption that a person who is intelligent should be able to learn how to read and write.

## **Development of intervention and conceptual approaches**

Early development of teaching intervention to support dyslexic learners also originated in medical practice. In the 1920s an American psychiatrist named Samuel T Orton (originally a pathologist) and his second wife, June Orton, and Anna Gillingham, with influence from Grace Fernald, worked together to develop instructional methods for people experiencing difficulty learning to read (Hallahan & Mercer, 2001). Samuel Orton theorised that the difficulties resulted from an imbalance in the use of the right and left hemispheres of the brain. He therefore developed strategies to coordinate brain hemispheres known today as the Orton-Gillingham method. It emphasises simultaneous multi-sensory methods, where kinaesthetic-tactile experience of letters' correspondences to spoken sounds is added to visual and auditory ones. It also advocates individual teaching in response to each pupil, led by such information as miscue analysis, where readers' mistakes are analyzed in detail. Though techniques for intervention have been developed and added to since, emphasis on multi-sensory structured phonics still lie at the heart of specialist teaching programmes. Singleton (2008), in his report on specialist dyslexia teaching commissioned on behalf of the recent Rose Report on dyslexia (Rose, 2009), characterises it as multisensory, phonic, structured, cumulative and sequential.

Though the idea of dyslexia has been around since the late 1800s, it became a topical issue during the 1970s. In 1970 in the UK a law was passed (the 1970 Education (Handicapped Children) Act) that gave every child, disabled or not, the right to be educated. This shifted responsibility for disabled children from social services to education. Awareness also developed at the time that there were a number of children in schools who did not have sufficient difficulties to warrant special schooling, but nonetheless had difficulties that required different kinds of support. In response to these changes in structure and awareness, the Department of Education commissioned a report to investigate the situation of educational needs for children in special and mainstream schools, the Warnock Report (1978), and in response to it the 1981 Education Act was passed which initiated the idea of Special Educational Needs (SEN), SpLDs and statements of SEN, the document required to secure funding for support from Local Education Authorities (LEAs).

During this time legislation and policy-making regarding education increased, and Corbett and Norwich (1997) cite this as a signpost of political/social change. One of the changes involved issues of rights for children and parents, for example the Warnock report and 1981 Education Act recognised the rights of parents to be involved in decisions about their child's education, and the right for children to be included in mainstream education. Before the 1970s special schools were non-political caring services similar in approach to medical practice. Afterward, special schools became more similar to mainstream schools, with a focus on educational goals. The field of specialist education became politicised as parental choice-making introduced a 'market economy' where schools became competitors. In direct contradiction to the recommendations of the Warnock Report, the importance of professional assessment for disability and the need for categorisation increased as LEAs depended on professional opinion to make decisions about funding allocation from restricted budgets. The involvement of parents in SEN decision-making set up a situation where funding went to parents who were most able to fight for it, exacerbating already-present class inequalities.

The disability movement began at much the same time, making public individual disabled peoples' experiences of disadvantage within and resulting from attendance at special schools, which challenged professional hegemony. Before the disability movement, and still, currently, disability is primarily conceptualised as a problem that originates within the disabled person. The perspective is medical, asserting a biological cause that prevents normal function, and is from the perspective of professionals about passive 'patients'. This perspective justifies segregation and marginalisation of disabled people on the basis that they are less worthy than a non-disabled person. The disability movement works to challenge the medical perspective by arguing that disability results from social barriers constructed against those with impairment. This latter idea is the crux of the social model of disability, developed in the 1980s and 1990s (Barnes, 1991, Finkelstein, 1980, Oliver, 1990), based on a manifesto written by The Union of the Physically Impaired Against Segregation (UPIAS, 1976).

In light of these developments, it is not surprising to learn that many of the dyslexia charities in operation today were founded during the 1970s, and those founded earlier experienced upsurges in membership of parents during the 1970s and 80s. The aim of these charities was to advocate on the behalf of dyslexic children, supporting parents to challenge schools by affirming the intelligence of their children and placing blame for their child's difficulties on teaching method rather than the child. Although approaches to teaching dyslexic children such as the Orton-

Gillingham method had been around for decades, use was associated more with the independent sector than state schooling. In addition, a focus on phonics was not at all popular in the 1970s and 1980s when the whole language movement swept through teaching.

The whole word movement focuses on the importance of meaning in learning to read and deplores the meaningless-ness of phonics. Frank Smith (1978, 1985) writes,

*'there is very little we can learn about reading without reading – and in this context I am referring specifically to reading written words in sequences and settings where they make sense. I am not referring to drills and exercises with letters, syllables, nonsense words, or even words when they are in sequences and situations where they have no purpose and make no sense. Children do not need nonsense in order to learn to read; they need to read (p125).*

This approach to literacy acquisition was more than a method, it was a belief system that liberated teachers, as is shown in the following passage written in response to a paper (Heymsfeld, 1989) declaring the need to combine skills-based teaching with the whole language approach,

*For a generation of reading specialists and teachers who have been educated as technicians ... whole language is much more than an alternative to basals. It is not a reading methodology at all, it is a philosophy of curriculum ... Whole language redefines ... the teacher as a professional decision-maker ... Heymsfeld is not alone in recognising the energy and innovative genius these empowered teachers are generating. It is not the psycholinguistic gurus but the teachers who have created the whole language movement (Goodman, 1989, p69-70).*

The attitudes inherent in the whole language approach were a common context in which challenges were made by parents to teach their children differently – using a structured, multi-sensory phonics approach. A common response was to reject such suggestions on many grounds. Dyslexia was not (nor is it now) a neutral term in Education. Although I have not been able to find the specific origins of the definition of dyslexia as 'the middle-class name for stupid', the fact that the parents most likely to be concerned about their child's education and so challenging teachers in this way were in all probability middle-class, and that schools historically known for successfully educating dyslexic children were fee-paying, like Millfield School in Somerset, give a reasonable explanation for it. Other reasons to reject specialist teaching include full rejection of the concept of dyslexia as un-proven, and lack of resources (Griffiths *et al.*, 2004, Riddick, 1996).

Definition is also an area of controversy in dyslexia. Rice with Brooks (2004) reviewed 28 definitions of dyslexia and found that the only criterion in common (in 27/28 definitions) was

reading deficit. The other most common criteria were a discrepancy in age between literacy skills of those identified as dyslexic and their peers (in 14/28 definitions), discrepancy between IQ and attainment in literacy skills (in 11/28 definitions) and presence of cognitive impairment (in 14/28 definitions). These four criteria serve well as example of a tendency by non-dyslexic people to turn dyslexic people into problem subjects, *e.g.* what exactly is wrong with them? I will not enter into debate over defining characteristics of dyslexia in this thesis because such a focus is in opposition to my intent. This thesis is not concerned with aetiology or measureable deficit; rather it is concerned with the way people make sense of the experience of having difficulty reading and writing. Dyslexia is an important part of the thesis because, as has already been mentioned and will be shown, it is one of the only ways a person can make sense of such difficulties without resorting to negative self-attributions. For the purposes of my thesis then, the criteria for participants' inclusion in my study are experience of difficulties with reading and writing and self-identification as dyslexic.

Cognitive research into reading acquisition exploded from the 1980s, and this added a new dimension to the question of dyslexia. A huge amount of research has been carried out in this area, with many dead ends. However, a strong association is found between children struggling to learn to read and spell and problems with the ability to distinguish and manipulate the individual sounds in words – 'phonological awareness'. It is now theorised that this difficulty prevents children from developing sound—symbol correspondences; they find it difficult to learn the alphabetic code. The relationship between difficulty learning to read and write and problems with phonological awareness has been documented to the extent that Vellutino *et al.* (2004), in their review of 40 years of cognitive and neuropsychological research in dyslexia, conclude 'word identification due, in most cases, to more basic deficits in alphabetic coding is the basic cause of difficulties in learning to read' (p 2). In this way cognitive science provides a theoretical basis for the use of structured phonics in teaching dyslexic children to read, because such programmes explicitly and carefully teach the manipulation of sounds in words verbally (phonological awareness training), and the connection between spoken sounds and written letters (phonics). Without such explicit instruction dyslexic children are not able to internalise the sound-symbol correspondences that make accurate reading possible.

The cognitive theory sounds straightforward – perhaps that was why I was drawn to it during my diploma in SpLDs – however as I found during my years tutoring dyslexic people, the reality is not. The cognitive approach is narrow, and there are numerous questions that remain unanswered.

What accounts for the complexity of symptoms represented by those finding it difficult to learn to read and write? Why do many (estimated at 25-40%) dyslexic children not respond well to structured phonic programmes? A structured phonics approach also does not take anything but method of teaching into account, and any teacher knows that method is only one, small piece of the puzzle. A structured phonics approach also does not address issues of personhood in its theorising, and as was shown by all the participants in this study, the method by which they were taught to read is much less important to them than the attitudes others expressed to them about their difficulties with reading. I do not wish to dismiss the role of cognitive psychology or multi-sensory, structured phonics; I acknowledge their importance. However, I will be looking at a different aspect of dyslexia in this thesis which I believe to be more important because it has been so little recognised; that of the experience of living it.

## **Outline of the thesis**

Having introduced myself and my perspective on dyslexia as well as the issue of dyslexia, I will now introduce the research project. In the next chapter I will carry out a literature review that focuses on interviews with dyslexic people, as this is the kind of research that is able to contribute knowledge about life experiences. I also describe my choice of focus in the thesis based on the findings of the literature review; I will be identifying use of discourses of dyslexia in participant's interviews, and exploring relationships between use of discourse and a theoretical framework developed by Gerber *et al.* (1992) called the Model of Vocational Success (MVS). This framework conceptualises the way attitudes, understanding and action work together to support a dyslexic person to understand themselves and their difficulties more positively, and be able to act in a way that helps them cope with their difficulties. In Chapter three I describe and justify my choice of methodology in exploring the experience of dyslexia through standpoint theory and life history, as well as describing the process of the research. Chapter four is comprised by the life histories of the seven participants in this study, each with a visual representation of their analysis of use of discourse and the way it relates to aspects of the MVS, which I call a participant map. Finally, in Chapter five I conclude the study by drawing together the life histories and describing patterns related to discourse and the MVS identified in the participants. I also discuss the rigour of the study, the unique contribution it makes and make recommendations for future research.

## CHAPTER 2: LITERATURE REVIEW

*In this literature review I will examine research that explores the experience of being dyslexic. The nature of my criteria for interviewing someone for this thesis – that they have experienced difficulty with reading and writing and identify themselves as dyslexic – indicates that research concerned either with the experience of difficulties learning to read and write and/or a person’s experience of identifying as dyslexic is relevant. Therefore I will include in the review research interviewing dyslexic people, studies that use surveys to probe what it feels like to be dyslexic, for example with regards to identity and levels of self-esteem, anxiety and depression, and studies on outcomes for dyslexic people in terms of educational qualifications, employment and other measures of ‘success’.*

### **Introduction**

One of the complications of reviewing this literature has been that of nomenclature. There are a number of terms that are used to denote a person with difficulties reading and writing that differ slightly in focus. I will use the term ‘poor readers’ to refer to individuals in studies that focus on difficulties with reading and writing because poor reading is the most common denominator in such studies. For studies that research dyslexia I will refer to individuals as dyslexic. It is still possible, however, that some participants in research reviewed here will be people who have neither experienced difficulties learning to read and write nor identify themselves as dyslexic, particularly within the research carried out in America on those with Learning Disabilities (LD) and research carried out in the UK on those with SpLDs, because of the wider nature of these categories; they include a number of subgroups, for example, dyscalculia and dyspraxia, inclusion

of which is based on the distinction of difficulty in a specific area rather than general difficulties. However, because dyslexic-type difficulties are the most common type of difficulty in both LD and SpLD, it is reasonable to include such studies.

In the 1980s, as discussed in the Introduction, awareness began to grow about the individual experience of disability. Calls for research that sought the experience of individuals in addition to the viewpoints of professionals became more common throughout the field of disability, and this was true in the field of dyslexia as well. For example, the federal Interagency Committee on Learning Disabilities (1987) recommended that more attention should be paid to the social and emotional aspects of learning. Similarly, in 1988, the British Psychological Society commissioned a national inquiry into current theory, practice and policies relating to Specific Learning Difficulties in the UK (Pumfrey & Reason, 1991). One of their key recommendations was that 'Specific learning difficulties be examined in the context of personal experiences and interpersonal relationships, recognizing the emotional impact of a prolonged struggle with literacy' (p276). Previous to these calls for research very little was done to explore emotional and social aspects of dyslexia, and what research was carried out tended to adopt a professional view rather than the disabled person's view. For this reason I will give only a broad outline of this earlier work, drawing on others' literature review (Edwards, 1994, Gerber & Reiff, 1991, Riddick *et al.*, 1997, Riddick *et al.*, 1999) to summarise research carried out before 1990.

Since 1990 there have been a number of studies carried out both in and outside the UK on social and emotional aspects of dyslexia. However, in comparison to the amount of other kinds of research relating to dyslexia, this focus of study is still rare. A recent search on EBSCO (Gwernan-Jones, 2009) for research papers on 'dyslexia' published during 2007 and 2008 returned 48 papers, 80% of which related to cognitive or neuro-psychology, 12% of which studied intervention within schools, and only 8% of which explored the experience of being dyslexic. This is an area that is still under-researched.

The purpose of this literature review will be to organise information from studies that have already taken place in order to set my own study in context. At the time of writing this literature review, I had already carried out interviews and done preliminary analysis for the thesis. I have therefore used this literature review to inform choice of the focus of the more in-depth analysis, so that my thesis builds on and/or fills a gap in existing literature. I also intend to evaluate the methodologies other researchers have used in the field.

## **Educational and employment outcomes for poor readers**

A good deal of the research carried out before 1990 followed children who experienced difficulties in education into adulthood, to examine educational and employment outcomes. Representing the whole population of those with difficulties reading and writing was then (and still is) a problem. For example, before 1975 in the United States, when Public Law 94-142 (Education of All Handicapped Children Act) was passed, schools had no legal obligation to educate disabled children. With the new law, new categories of disability became prominent as the educational system began to identify problems children had in school, but, before this such difficulties went for the most part unnoticed. A similar process evolved in the UK as described in the Introduction. Therefore, pre-1975 research tends to represent only the most severely disabled children. As mentioned before, the older studies also approach disability from a professional perspective instead of seeking the disabled person's perspective, narrowing results as to scope and subject. The question of who is being studied varies not only according to diagnostic criteria as discussed above, but also according to context, for example many of the studies were carried out in specialist institutions that tended to cater primarily for particular socio-economic groups. This means that study results cannot be combined as if they are researching equivalent situations. They can, however, offer relevant information as long as it is understood that the results are specific only to the particular groups studied, rather than representing the adult outcomes of all children who had difficulties learning to read and write in school.

Amongst the studies carried out prior to 1990, many report adults for whom childhood reading difficulties persisted into adulthood (Balow & Bloomquist, 1965, Buchanan & Wolf, 1986, Hardy, 1968) with some studies looking for and finding positive correlation between educational psychometric test scores from childhood and those in adulthood (Frauenheim, 1978, Silver & Hagin, 1964). In other words, the difficulties children experienced with reading in school they experienced to a similar degree in adulthood. In addition to the persistence of reading difficulties, spatial and temporal organisational difficulties have also been shown to persist (Silver & Hagin, 1964). A number of studies indicated that low-achievement careers predominate as outcomes for children who experienced difficulty reading in school (Carter, 1964, Preston & Yarrington, 1967, Rackham, 1972, Silver & Hagin, 1964) and adult employment was depressed in comparison to that predicted on the basis of parental jobs and IQ (Abbot & Frank, 1975).

Though most of these early studies found poor outcomes, there are some studies that report the potential for positive outcomes. Some studies sought out professional adults who had experienced difficulty with reading and writing as children, thereby demonstrating that high-achievement careers were possible (Gottfredson *et al.*, 1983, Gottfredson *et al.*, 1984). Aspects of intervention and socio-economic background became a matter of interest, as it was found that differences in these areas were linked to different outcomes. Some studies suggested that supportive intervention could have a positive impact (Abbot & Frank, 1975, Rawson, 1968, Rogan & Hartman, 1976, Silver & Hagin, 1985). Such support tended to be available only from private institutions so primarily those from wealthier families had access. Silver and Hagin's study looking at learning disabled children of affluent parents (1985) found much better outcomes than their earlier study which had been carried out with children from deprived backgrounds (1964). More positive outcomes were also attributed to lower levels of severity of difficulties (Rogan and Hartman 1976).

Maughan (1995), highlighting the biased nature of outcome studies following small groups of pupils from specialist schools into adulthood (such as those above), carried out a literature review combining results from such studies with the outcomes of poor readers based on longitudinal research that was as representative as possible, for example by looking at cohort studies (*e.g.* Ekinsmyth & Bynner, 1994, Maughan *et al.*, 1994, ALBSU, 1987, Yule, 1973). Her review therefore offers a more representative guide to general outcomes for children who struggled with reading in school.

Maughan's literature review concurred with the research that suggested that reading problems persist into adulthood. Reading for pleasure was found to be rare amongst adults, and many did not read for information. However, this finding was qualified by the possibility of improvement in comprehension between childhood and adulthood, though reading speed remained depressed. Improvement in comprehension and accuracy continued over adulthood for those adults who remained in contexts that involved consistent exposure to texts, for example in education. Another interesting qualification in Maughan's review is that the extent of reading improvement between childhood and adulthood did not seem to be related to parental socio-economic status, but rather level of severity of difficulties and general intelligence. In contrast, parental socio-economic status played an important role in educational attainment, with those from higher socio-economic backgrounds attaining higher qualifications (though taking longer to achieve them than peers, and seeking higher qualifications that involved less reading and writing compared to peers). Those from lower socio-economic backgrounds were more likely to leave school without

qualifications, and those who did complete qualifications were more likely to go through vocational training and apprenticeships as opposed to formal education. This finding was repeated in MacDonald's (2009) more recent study.

Occupational outcomes were also linked to parental socio-economic status, presumably because of the close links between levels of educational qualifications and employment status. However, Maughan's review also noted the important role played by motivational aspects in regard to occupational outcomes, because poor readers tended to have fewer and less ambitious plans for the future. She proposes two interpretations from the literature; 1) a lack of ability to plan, with a tendency to give up in the face of adversity (McCall *et al.*, 1992), or 2) a positive coping strategy, where adults avoid situations where they are likely to sustain damage to self-esteem (Oka & Paris, 1987).

In summary, although difficulty with reading in school often results in negative outcomes such as difficulty with reading in adulthood, lack of educational qualifications and lower status occupational outcomes, this does not have to be the case. The studies reviewed here suggest that high quality intervention in school, higher socio-economic background, lower levels of severity of difficulties and motivational orientation all can play an ameliorating role.

## **Studies on self-perceptions and psychological well-being**

Self-perceptions and psychological well-being tend to be measured psychometrically, primarily through surveys, and are an aspect of the experience of being dyslexic that will not be looked at specifically in my research. Although understanding how having dyslexic-type difficulties can impact self-perceptions and psychological well-being will be helpful in making sense of the life histories of the participants in my study, there will be no assessment of my participants in relation to this topic. For this reason, rather than reviewing at length the substantial body of work in this area, I will instead base most of my information on a recent literature review on this subject carried out by Burden (2008).

From a social constructionist perspective, we come to understand who we are and how valuable we are according to the status of the roles we fulfill in society, and the attitudes that others express towards us. Self-perceptions associated with dyslexic-type difficulties therefore often develop within an educational context, where difficulties with reading and writing first become

apparent. A child will come to understand how successful they are by comparing what they can do to what their peers can do, and in response to attitudes expressed toward them by significant others, such as peers and teachers. Intuitively one would guess that a child who experiences difficulties learning to read and write would understand themselves to be less able than peers who learn literacy easily. Particularly because of the central role reading and writing play in most aspects of school, and the prolonged nature of the school years, intuitively one might also predict that such negative self-perceptions could impact a child fundamentally. Like the variation in outcomes discussed above, though, the studies reviewed here suggest the extent to which negative self-perceptions develop is variable according to a number of environmental factors. This variability is an issue I will focus on because of its potential to offer insight into the processes involved in developing positive self-perceptions despite difficulties with reading and writing.

The reason self-perceptions are particularly important beyond their impact on well-being, is because of the relationship between self-perceptions and action. Azjen (1985) offers one theoretical construct that models this relationship in his 'Theory of Planned Behaviour' (see Figure 2.1). A person develops attitudes in a context of normative beliefs, and these alongside the person's perception of the control they have work together to bring about behaviour. Stanovich's 'Matthew effect' (1986) demonstrates one working out of this relationship, where a child who picks up reading quickly is heaped with praise and enjoys reading, then reads more and learns to read even better, whereas a child who struggles with reading begins to associate it with negative experiences as others correct and are disappointed in him or her; that child avoids reading as much as possible, and falls further and further behind. Here the normative beliefs involve the importance of reading; the attitudes developed might be 'I'm good at reading' by the child who enjoys it and 'I don't like reading' or possibly 'I can't read' by the child who has difficulty. The resultant behaviour of both children then compounds their initial experiences. It is this relationship between experience, perception and action in which I am particularly interested. Azjen is not the only researcher developing models conceptualising it; in the next section I will discuss one developed in response to a large-scale research project with adults with LD (Gerber *et al.*, 1992) which will be used in the analysis in this study.

In this section of the review I will be looking at studies of self-concept and self-esteem. Theories relating to self-concept have developed over the span of years in which research described here was carried out, and require some explanation. 'Self-concept' refers to the way a person perceives themselves, and now is understood to consist of multiple dimensions, with the possibility of a

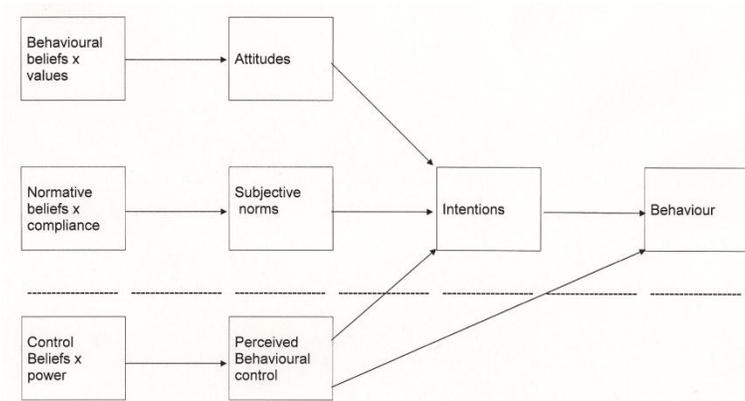


Figure 2.1. Diagram of Azjen's (1985) 'Theory of Planned Behaviour' (taken from Gwernan-Jones & Burden, 2010).

person holding different self-concepts in regard to different contexts of life, for example academic, sport, social, physical (Harter, 1996, Hattie & Marsh, 1996). 'General' or 'global' self-concept refers to a general evaluation of self (Harter & Pike, 1984). Self-esteem refers to the way a person feels about their self-concepts (Burden, 2008). Especially in earlier research self-concept was regarded as unitary; self-esteem, self-concept and/or self-perception can currently be used synonymously or distinctly by different authors (Zelege, 2004). Despite the development and clarification of such terms, consistent use between researchers is still undependable. Such lack of clarity no doubt contributes to contradictions reported below in research findings.

A number of studies looking specifically at poor readers found they have lower self-concept than peers (Fairhurst & Pumfrey, 1992, Gjessing & Karlsen, 1989, Huntington & Bender, 1993, Lawrence, 1971, Lawrence, 1985, Lewandowski & Arcangelo, 1994, Riddick, 1996, Rosenthal, 1973, Saracoglu *et al.*, 1989, Thomson & Hartley, 1980); however this finding requires qualification. The difference in self-concept as related to peers refers primarily to *academic* self-concept (Chapman, 1988, Grolnick & Ryan, 1990, Montgomery, 1994, Prout *et al.*, 1992, Zelege, 2004), whereas global self-concept tends to be equivalent (Chapman, 1988, Zelege, 2004). Therefore it appears that the correlation between poor reading and lower self-concept usually remains specific to an academic context rather than encompassing global self-perceptions.

As Burden (2008) comments, for dyslexic children to have low academic self-concept is hardly surprising and can be seen to reflect a child's realistic assessment of their performance in relation to their peers in school. On the other hand, a child will take into account many other factors when establishing perceptions of global self-concept, such as strength in other areas, and therefore

overall they are less likely to differ from peers. The relationship between academic self-concept and academic self-esteem is one that is more interesting. Many studies suggest that poor readers do in fact suffer from low academic self-esteem as children, which can continue into adulthood (Fairhurst & Pumfrey, 1992, Gerber & Reiff, 1991, Gjessing & Karlsen, 1989, Humphrey, 2002, Lewandowski & Arcangelo, 1994). Context, however, is suggested as a potential contributor to self-esteem, with those in specialist schools having higher academic self-esteem due to more favourable comparison with peers (Humphrey, 2002) and improved environment (Thomson, 1990), and those leaving school for employment are likely to see improvement as they no longer cope primarily with academic demands (Riddick *et al.*, 1999). Some studies show it is possible for a child to have lower academic self-concept than their peers, whilst having equivalent academic self-esteem (*e.g.* Frederickson & Jacobs, 2001) – they may realise they are less able to read and write than their peers, but they do not necessarily have to feel bad about their difficulties.

This perspective, that the way the child understands their difficulties can have an impact on feelings, motivation and self-efficacy, is a promising, though surprisingly neglected, area for further research. Children whose difficulties go unexplained are inclined to attribute them to a lack of intelligence, and lose motivation (McNulty, 2003, Palombo, 2001, Riddick, 1996, Riddick, 2000), whereas explanation of difficulties can result in improved coping abilities (Davenport, 1991). Burden (2008) emphasises the relationship between educational and parental support and the potential for change to academic self-concept as well as self-esteem. If a child is supported to learn to cope with educational demands their academic self-concept is likely to improve, whereas in environments that are not supportive children's academic self-concept is likely to dwindle further. In his study of 50 dyslexic boys in a specialist secondary school (2005), Burden found that though on entry the boys' academic self-concept was lower than non-dyslexic pupils, boys who attended the school longer had higher academic self-concept, and the academic self-concept of those in their final year was equivalent to a mainstream standardised sample. He also analyzed the boys' feelings of self-efficacy, learned helplessness and locus of control. He found strong feelings of self-efficacy (the boys expressed confidence in their ability to achieve); low levels of learned helplessness (88% did not exhibit learned helplessness and 12% did, a level lower than previous research would have predicted) and an internal locus of control (the boys believed their own hard work was responsible for academic improvement). Interview studies have much to contribute toward deeper understanding of survey findings relating to self-perceptions; with further evidence from semi-structured interviews with his participants, Burden attributes the development of these positive self-perceptions to the gain of control over what school they attended and the

environment of the school which fostered incremental notions of intelligence and a sense of belonging (see below for further discussion).

Burden's literature review (Burden, 2008) reveals little research that supports the concern that dyslexia is associated with social difficulties and/or behavioural difficulties of any protracted length. Though some studies indicate correlation between dyslexia and social/behavioural difficulties (Balow & Bloomquist, 1965, Bynner & Ekinsmyth, 1994, Hardy, 1968, Saunders & Barker, 1972, ALBSU, 1987, Yule, 1973), others indicate little difference between poor readers and peers (e.g. Abbot & Frank, 1975, Edgington, 1975, Gottfredson *et al.*, 1983, Gottfredson *et al.*, 1984, Hinton & Knights, 1971). This contradiction is untangled somewhat by studies that suggest social/behavioural difficulties decrease with maturity (Boetsh *et al.*, 1996, Burden, 2005, Ingesson, 2007, Spreen, 1987) and may be linked to co-occurring difficulties rather than dyslexia (Durrant *et al.*, 1990).

In terms of psychological well-being in adults, Maughan's (1995) review reports mixed findings. Some studies show little relationship between a history of poor reading and psychiatric disorder after middle childhood (Maughan *et al.*, 1985, McGee *et al.*, 1992, Rutter *et al.*, 1976), others show that poor readers are more likely to experience new disorders from their mid to late teens (Bruck, 1985, Huntington & Bender, 1993, Kellam *et al.*, 1983, McGee *et al.*, 1992). Though these are contradictory findings, the latter studies show significant but not large differences between poor and mainstream readers. The situation may be well-represented by a study carried out by Riddick *et al.* (1999), where standardised inventories of anxiety levels given to dyslexic students at university showed no statistically significant differences to a control group, but self-reports of anxiety detailed higher levels than controls. This variability suggests again that environmental factors play an important role.

In conclusion, poor readers do not seem to differ significantly in global self-concept from mainstream peers. However, both academic self-concept and academic self-esteem are often significantly lower. Though social and/or behavioural difficulties are correlated with poor reading especially in younger children, this seems to be a temporary link that dissipates with maturity, or is due to co-occurring difficulties. Research probing adult psychological well-being has returned mixed results, but even studies that find poor readers experience higher levels of psychological disorder as adults do not show levels greatly larger than controls. That academic self-concept and academic self-esteem are influenced by environmental factors is a promising area for research and

intervention. What links are there between the environment and the development of self-perceptions? In what way do a person's understandings of their difficulties interact with their developing self-perceptions? Studies that seek more in-depth perceptions of dyslexic children and adults are likely to contribute toward answering these questions, and it is to this type of study I now turn.

## **Research interviewing dyslexic people**

As discussed in the introduction, research that examines the experience and emotions involved in being dyslexic is relatively rare. Most of the research carried out and the writing done about dyslexia is from a professional perspective, whether the viewpoint of an educational psychologist, teacher, or cognitive psychologist. But what is the dyslexic person's perspective? Dyslexia is not the only disability in which professional perspectives are dominant; rather this is the 'status quo'. Academic Michael Oliver, a wheelchair user, writes about his experience of beginning to read academic literature about disability,

*When I began to read some of the things that able-bodied academics, researchers and professionals had written about disability, I was staggered at how little it related to my own experience of disability or indeed, of most other disabled people I had come to know. Over the next few years it gradually began to dawn on me that if disabled people left it to others to write about disability, we would inevitably end up with inaccurate and distorted accounts of our experiences and inappropriate service provision and professional practices based upon these inaccuracies and distortion (1996, p9).*

Do inaccuracies and distortions skew provision and professional practice in the area of dyslexia? Interview as a method offers a valuable means to view dyslexia from a dyslexic person's perspective. The interview studies reviewed here all include open ended questions to some extent in their design, giving the dyslexic person the chance to direct the topic, potentially to areas outside those of professional priority, so this review begins to answer this question.

The interview studies reviewed here address a number of common themes. These are:

- Perceptions of school experience,
- perceptions about being identified as dyslexic,
- different ways dyslexic people understand dyslexia and

- the manner in which dyslexic people come to understand themselves and/or dyslexic-type difficulties positively.

I have chosen to structure this part of the review by following these themes rather than discussing each study individually, because by doing so I will be developing conceptualisation of the experience of being dyslexic in a new way. However, to support the reader in understanding what studies are being discussed, I provide a list of the studies reviewed alongside a summary of each one in Table 2.1.

Study	Description
MacDonald 2009	Paper written from PhD thesis. Semi-structured interviews with 13 participants from a possible 77 to establish a sample most likely to represent diverse social backgrounds. Analysis was based on the social model of disability to uncover social barriers. Barriers were found within education and employment that affected all the participants, however those from working class backgrounds experienced more severe barriers, in the form of less access to private intervention during school years and less access to technological support in adult years (UK)
Armstrong & Humphrey 2009	Semi-structured interviews/focus groups with 20 dyslexic FE students. Focus on response to identification as dyslexic. The authors developed the psycho-social 'resistance-accommodation' model in response to the data (UK)
Ingesson 2007	Semi-structured interviews with 75 dyslexic teenagers and adults centred on well-being, educational achievement, self-esteem, peer relations and belief in the future. The majority experienced distress and failure during the first 6 years but as they grew older difficulties became limited to areas demanding reading and writing (Sweden)
Burden 2005	Surveys/semi-structured interviews with 50 dyslexic boys from a specialist secondary school. Surveys look at academic self-concept, learned helplessness, locus of control and depression, results of which were more positive than previous studies would have suggested they would be. Interviews put scores into context. Also identified metaphor of dyslexia as a barrier to learning (UK)
Pollak 2005	Book written from PhD thesis. Life history interviews with 33 dyslexic adults in HE, Pollak described 4 discourses about dyslexia based on the interviews ( <i>Patient, Student, Hemispherist and Campaigner</i> , see Table 2.2) (UK)
McNulty 2003	Semi-structured interviews with 12 dyslexic adults. McNulty wrote a 'collective narrative' in response to the interviews which tells the story of the experience of being dyslexic. The main plot involved contending with the awareness that 'something is wrong with me'. (USA)
Dale & Taylor 2001	Personal learning journals and focus groups with 7 dyslexic FE students, with a focus on how the adults made sense of dyslexia. Problems and benefits of recognition/labeling and non-recognition of dyslexia are discussed in public and personal contexts (UK)
Hellendoorn & Ruijsenaars 2000	Semi-structured interviews with 27 dyslexic adults. Interview categories were assigned ordinal or nominal scales and statistically analyzed as well as being qualitatively analyzed. Many remembered school negatively but had positive experiences of family support. Social and emotional problems were self-reported but also the perception of being persevering and responsible (The Netherlands)

Study	Description
Riddick et al 1997	Semi-structured interviews with 16 dyslexic HE students. The authors also carried out surveys of self-esteem and anxiety with these students as well as matched non-dyslexic students, reported in Riddick <i>et al.</i> 1999. The purpose was to communicate the interview results as life stories, rather than carrying out systematic analysis (UK)
Riddick 1996	Semi-structured interviews with 22 children (8-14 years) and their mothers (separately), as well as specialist tutors. Sample chosen to be as representative as possible of the pupils currently being tutored by the Durham or Newcastle branches of The Dyslexia Institute. Interviews focused on the process of being identified as dyslexic and the experience of living with dyslexia including social and emotional consequences. The conclusion and recommendations focus on the need to change negative attitudes and increase awareness of dyslexia in teaching practitioners and the general public (UK)
Hughes & Dawson 1995	Questionnaire and semi-structured interviews about school experiences with 47 dyslexic adults, many of whom recalled their schooldays negatively and reported long-lasting negative effects (UK)
Rawson 1995	Primarily an outcome study based on the lives of 56 boys all of whom attended the same private school in America during the 1930s and 40s. Twenty were identified there as dyslexic and were supported with the Orton-Gillingham method. The men were all followed up in the 1970s and 1990s, when interviews were carried out and their educational and employment outcomes compared. No statistical differences between groups (USA)
Edwards 1994	Semi-structured interviews with 8 teenage dyslexic boys. Main finding was presence of emotional suffering (UK)
Gerber <i>et al.</i> 1992	Causal comparative design (start with an effect – here success – and search for possible causes). Semi-structured interviews were carried out with 71 learning disabled adults matched into 2 groups based on a number of factors, broadly described as ‘highly successful’ and ‘moderately successful’. Developed the ‘model of vocational success’ (see Figure 2.2) on the basis of the interviews, one aspect of which is reframing (USA)
Gerber and Reiff 1991	Ethnographic study of 9 dyslexic adults ages 22-56 using semi-structured interviews. Sample chosen according to levels of ‘adjustment’ (vocation and qualifications) into high, med, low, then assessed according to social and emotional adjustment. Found the group with best social and emotional adjustment were those in the ‘medium’ group (USA)

Table 2.1. Description of interview studies reviewed.

## Perceptions of school experience

In the interview studies with dyslexic people reviewed here, descriptions of negative experiences of school are common. Though it is likely most people have some negative memories of school, these are notable for the intensity of the negative emotion involved. Indeed, some researchers have named negative experience and emotions in relation to school for dyslexic people the main finding of their study (*e.g.* Edwards, 1994) or make this the focus of their study (*e.g.* Hughes & Dawson, 1995). Other authors, while acknowledging that for many dyslexic children school is difficult, focus their studies on trying to understand how dyslexic people come to make sense of their experiences in a way that addresses both positive and negative emotions (*e.g.* Armstrong & Humphrey, 2009, Burden, 2005).

Some studies reviewed here looked at the proportions of participants who remembered overall negative, neutral and/or positive experiences of school, a helpful guide to obtaining an overall picture of the incidence of intense, negative emotion. Of the 27 dyslexic adults interviewed by Hellendoorn & Ruijsenaars (2000), eight (30%) had negative experiences, eleven (40%) had mixed experiences and eight (30%) had positive experiences. Of 54 dyslexic adults interviewed by Hughes & Dawson (1995), just over half (54%) said they 'mostly disliked school'. Of sixteen dyslexic students in higher education interviewed in the study by Riddick *et al.* (1997), only three (19%) reported overall positive experiences. Though none of these studies claim to be representative of the whole population of dyslexic people, they suggest that from one third to one half of dyslexic adults may remember school in primarily negative terms.

### **Humiliation, punishment and trauma**

Many dyslexic participants share stories that involve feeling humiliated in school (Dale & Taylor, 2001, Edwards, 1994), in particular in relation to being made to read out loud in front of the class (Gerber *et al.*, 1992, Hellendoorn & Ruijsenaars, 2000, Hughes & Dawson, 1995, McNulty, 2003, Riddick, 1996, Singer, 2005). Other commonly described humiliating experiences involve repeatedly taking longer than peers to complete work and/or being punished for taking longer, for example by being held in at break. In some instances the humiliation was not only because public attention was brought to the participants' reading and writing difficulties, but also involved the teacher ridiculing the pupil, as in this recollection by a participant; 'Miss Y is the worst teacher I have known. Can you imagine, she often started reading lessons by saying, "Let's listen to A [read] and have a good laugh". If I ever came across her, I could still kill her for what she did to me' (Hellendoorn & Ruijsenaars, 2000, p233). Being ridiculed by a teacher was a common experience in the study by Hughes & Dawson (1995); two-thirds of the participants reported that 'teachers showed me up in front of the class' (p182). Recollections of dyslexic adults who were in school before the 1990s sometimes involve physical punishment (Dale & Taylor, 2001, Edwards, 1994, Hughes & Dawson, 1995); 'My headmistress in primary school used to think I was being lazy and awkward so she would hit me to try to get me to read even though I couldn't' (Hughes & Dawson, 1995, p183).

Some participants say that negative experiences such as those described above affect them so deeply the emotions linger on into their adult lives. They describe themselves as being left with a permanent scar or feeling traumatised (Edwards, 1994, Gerber *et al.*, 1996, Hughes & Dawson, 1995, McNulty, 2003). McNulty (2003), who is a psychotherapist, writes that while these

descriptions do not meet a clinical diagnosis of trauma because they do not involve threat of death, they do resonate with trauma as described by Khan (1974; cited in McNulty, 2003). In Khan's *cumulative trauma*, a child is not adequately protected from a recurring threat. McNulty proposes that the participants who describe their experiences as trauma were failed by the significant adults in their lives (including parents and/or teachers), who did not protect them from gross misunderstandings about the nature of dyslexia. These misunderstandings 'publically call into question fundamental qualities of the self, such as work ethic, emotional state, or intelligence, and lead to intense feelings of shame and humiliation' (McNulty, 2003, p377).

Though the numbers of participants who expressed these feelings are higher than is desired since any such experiences are unacceptable, the participants who felt traumatised were in the minority. Also, many pupils who were humiliated and/or punished did not internalise these experiences to the same extent as those who felt traumatised. This is likely to do with the degree and frequency of negative experiences, but as was suggested above and will be discussed in greater detail in later sections, the way a person understands themselves and/or dyslexia can have a significant impact on how such experiences are interpreted.

## Teachers

Teachers are undoubtedly important people in the lives of dyslexic schoolchildren, and both teachers who helped and teachers who hindered play a part in interviews with dyslexic people. The three dyslexic students in higher education who said their school experiences were primarily positive in the study by Riddick *et al.* (1997) stated that their teachers had acknowledged they were dyslexic, were sensitive to their needs and had provided helpful intervention. A participant from Hellendoorn & Ruijsenaars (2000) said 'I will never forget Mr X. When he came in my life, something changed, because he really understood. He at least gave me credit for the hard work I did, even though I still could not read' (p233). In contrast, other participants spoke of teachers who treated them as if they were unintelligent and/or lazy (Edwards, 1994, Gerber & Reiff, 1991, Hellendoorn & Ruijsenaars, 2000, Hughes & Dawson, 1995, Riddick, 1996). Other teachers refused to accept participants were dyslexic and/or provide any accommodation and/or taught them inappropriately (Dale & Taylor, 2001, Hellendoorn & Ruijsenaars, 2000, Riddick *et al.*, 1997), for example by giving remedial lessons to older children using literacy acquisition materials designed for infants. The teachers remembered most negatively were those mentioned above who humiliated dyslexic pupils in front of their peers for their difficulties.

Many dyslexic people in the studies reviewed here were negative about the mainstream teachers they had had in school, in terms of their teachers' attitudes toward dyslexic-type difficulties, knowledge about dyslexia and intervention for dyslexic difficulties. However, pupils who had attended specialist schools were more likely to report positive experiences. In Hellendoorn & Ruijsenaars' (2000) study, fifteen participants received extra support from an elementary school teacher, but eleven of the participants said the help was inappropriate. In contrast, support received from 26 specialists (psychologists, orthopedagogues, teachers from special schools, licensed remedial teachers, speech therapists and psychomotor therapists) were judged generally favourable. Although only four of eleven participants in special schools rated their time there positively, those who were positive said it was because they felt understood by teachers, whereas those who had a negative or ambivalent time there cited bullying, feeling stigmatised because of attending a special rather than mainstream school or losing old friends as reasons rather than citing negative experiences with teachers. MacDonald's (2009) study is similar in that his participants reported that additional support in state education was not as effective as specialist fee-paid support. In Burden (2005), of 50 dyslexic boys, 62% said the teachers at their mainstream schools had not understood their feelings, whereas at their specialist school only 4% felt the teachers did not understand their difficulties. These studies suggest that additional training and experience with special educational needs for teachers has a positive impact on the school experiences of dyslexic pupils.

In the studies by Riddick (1995) and Riddick *et al.* (1997) the authors explicitly discuss the attitudes of mainstream teachers about dyslexia. They warn against judging previous eras within education by means of today's knowledge of dyslexia, which is relatively recently developed. They point out that laziness is actually a logical judgment to make about a pupil who is verbally able but produces a very poor quality of written work. They also set negative perspectives about dyslexia in a historical context by citing the ideological struggle of the previous decades surrounding dyslexia in education, for example understanding dyslexia as the 'middle class name for stupid'. For a teacher in this context, the open accommodation of dyslexia can mean professional risk. Finally, they make the point that appropriate intervention was beyond these schools' financial position, and that robust evaluation of specialist methods was then, and is still, limited. However, the authors also counter these mediating comments by stating that damage is inevitably done by any use of humiliation and ridicule on vulnerable pupils as a means of control in the classroom.

## Parents

The large majority of parents in the literature reviewed here were supportive to their dyslexic children, and it is clear that this support was significant in how able the child was to address their difficulties. In Burden's (2005) study, of 50 dyslexic boys interviewed 84% said their mothers understood their feelings and 68% said their fathers did. Of the 27 participants in Hellendoorn & Ruijsenaars' (2000) study, 22 spoke of support from their parents and how important a part it played in their sense of well-being. In this latter study, there was a significant correlation between level of support from parents, acceptance for being dyslexic, feeling less disabled, having fewer problems, having better coping skills and having higher levels of educational qualifications. A number of authors emphasise the important role parents play in helping their children make sense of dyslexia, particularly in relation to difficulties prior to the identification of dyslexia, when it is not clear what is going on, as well as following identification (Burden, 2005, Griffiths *et al.*, 2004, Ingesson, 2007). In Riddick's (1996) study, 80% of 22 children said their mother was the primary person to explain dyslexia to them. Hellendoorn & Ruijsenaars (2000) concluded, 'the most powerful sources of help were not the educators, but the parents. Their support, as well as the present relationship with them, seemed most conducive to mental health' (p237).

It is common for dyslexic participants to describe their parents being required to 'fight' to gain acknowledgement and support for their children in school. Many parents, if teachers were not forthcoming with assessment and intervention to address their child's difficulties, initiated private assessment and tutoring themselves, and sometimes moved the child to a specialist private school (Burden, 2005, Griffiths *et al.*, 2004, Hellendoorn & Ruijsenaars, 2000, Norwich *et al.*, 2005), with some mothers seeking information about dyslexia to the extent that they became relative 'specialists' themselves (Griffiths *et al.*, 2004).

A minority of parents were not supportive of dyslexic children. Riddick *et al.*'s (1997) study categorises unsupportive parents as 1) parents with children in school before information about dyslexia was readily available, who did not understand the nature of their child's difficulties; 2) parents unwilling to challenge the authority of teachers and 3) parents with lower levels of education. Another study by Riddick (1996) however, found that in a group of 22 children receiving tutor support from The Dyslexia Institute, ten of the children were from working class backgrounds and twelve from middle-class backgrounds, demonstrating that many parents with lower educational qualifications pursue support for their dyslexic children. However, in

MacDonald's (2009) study it was only the children from middle-class backgrounds whose parents paid for additional specialist tuition.

## **Bullying**

According to Olweus (1998, cited in Ingesson, 2007), about 10% of children in the general school population are bullied. Studies represented here made varying reports of the prevalence of bullying due to dyslexic difficulties, from very little bullying in Burden's (2005) study of 50 dyslexic boys in a specialist secondary school, to 100% in Edwards' (1994) small-scale study of eight dyslexic boys, also in a specialist secondary school. Other studies report prevalence of between 25 and 50% (Hughes & Dawson, 1995, Ingesson, 2007, Riddick, 1996, Singer, 2005). Whether a person experiences bullying or not is important to their self-perception and social well-being; in Ingesson's (2007) study, there was a significant correlation between being bullied, low self-esteem and poor peer relationships.

The discrepancy between reports could be due to a number of factors. Small sample sizes, for example in Edwards (1994), could mean the boys all simply happened to have been bullied, but this is not generally representative of being dyslexic. Differences in school ethos may play a role; Swan (1985, cited in Riddick, 1996) showed that the attitudes of teachers within a school impact the attitudes of the children, so schools in which teachers were particularly negative toward dyslexia could have resulted in higher levels of bullying. This is corroborated in Singer (2005) where visible indicators of dyslexia made a child more vulnerable to bullying, so teachers' exposure of dyslexic children to ridicule increased the likelihood that they would be bullied. Also, the bullying experienced by some of the participants may have been unrelated to their dyslexia. Finally, discrepancies may result from differences in interview question format. In a study by Singer (2005), 85% of sixty nine to twelve year-olds in her study said they had been teased about dyslexic difficulties, whereas 25% said they were regularly teased and/or bullied. In other words, it is probable that the great majority of children have been teased at one time or another, while different numbers will have been exposed to frequent bullying; interview questions may not have been equivalent in what they defined as teasing and/or bullying. Despite these qualifications, because in most of these studies the incidence of bullying was higher than 10%, it appears that dyslexic children are at higher risk of being bullied than general mainstream children.

## **Perceptions about being identified as dyslexic**

Whether or not to identify children as dyslexic is another potential area of conflict between parents and schools. Labeling, or assigning a category of disability to a child, is on the whole viewed negatively within Education. According to Coles (1987, 1989, cited in Pumfrey and Reason, 1991), labeling focuses attention on within-child aspects of difficulties and encourages a tendency to ignore social and political aspects. It also stigmatises the child, attaching any negative perceptions of disability to them (Szasz, 1961, Becker, 1963, Lemert, 1967, Goffman, 1968, cited in Riddick 2000). In the Warnock Report (1978) statutory categories of learning disability were done away with, and replaced with a single category, 'special educational needs'. The purpose of this was to combat a tendency to view a child according to knowledge of the label assigned to him or her, rather than observing, analyzing, and responding specifically to the needs of the child. Thus identifying a child as 'dyslexic' within schools is something many teachers are still reluctant to do. In contrast, parents can have the perception that with a different kind of specialist teaching, their dyslexic child will be able to learn to read and write, and identification of dyslexia is understood as a key step in that journey (Augur, 1981). For some, having their child identified as dyslexic can be a symbol of hope for a way forward, and therefore many have pursued identification of dyslexia and specialist teaching with determination. I have touched upon the perspectives of both teachers and parents and the inherent potential for conflict in their views about labeling; now I will turn to the experiences of dyslexic people on being identified as 'dyslexic'.

### **When dyslexia is not identified**

Many of the participants interviewed in the studies included here were not identified as dyslexic whilst they were at school, and many others were identified relatively late in their school careers. In Ingesson's (2007) study of 75 teenagers and young adults the average age of diagnosis was twelve years of age; this study is quite up-to-date, so pupils are still often not identified until secondary school. Older participants may not have heard the term dyslexia until well into adulthood, 'when I went to school it certainly didn't exist dyslexia, it wasn't even a word that was in the dictionary' (Dale & Taylor 2001, p1002). Having difficulties with reading and writing in school without identification of dyslexia is therefore a common experience for dyslexic participants.

A comment repeated by many dyslexic people when interviewed is that they were aware that they were different from their peers before they were identified as being dyslexic (Burden, 2005,

Hellendoorn & Ruijsenaars, 2000, Ingesson, 2007, McNulty, 2003, Pollak, 2005). Burden (2005) writes about the 50 dyslexic boys in his study; 'Many of the boys' earliest memories of school were of feeling confused and frustrated at their inability to master tasks that others, often with less evident abilities, seemed able to manage quite easily' (p42). The conclusions reached by younger dyslexic children often involved the understanding that 'there is something wrong with me' (Hellendoorn & Ruijsenaars, 2000, Ingesson, 2007). Some said they decided they must be unintelligent and/or lazy (Dale & Taylor, 2001, Ingesson, 2007, McNulty, 2003); others said they felt as though they didn't belong (Burden, 2005, Dale & Taylor, 2001).

Another common experience reported by dyslexic participants was being told or treated as though they were unintelligent or lazy by teachers (Dale & Taylor, 2001, Hellendoorn & Ruijsenaars, 2000, MacDonald, 2009, McNulty, 2003, Pollak, 2005, Riddick, 1996, Riddick *et al.*, 1997). Riddick (2000) writes that the assumption behind a reluctance to label within education is that if no formal labeling takes place, the child will be free from any associated stigma. However, she argues that dyslexic children are often subject to stigma from being 'informally labeled as lazy, careless or stupid' (p661) before being given a formal label of dyslexia. MacDonald characterizes the attribution of lack of intelligence and/or lack of diligence to a social barrier 'where blame seems to fall on the pupils' ability rather than teaching methods' (p354). Dale & Taylor (2001) characterize not being identified as dyslexic in school as equivalent to failure in school, because the dyslexic person is not able to overcome their difficulties nor make sense of them.

### **Reaction upon identification of dyslexia**

The way participants described their responses to being identified as dyslexic vary considerably, and include feeling relieved, ambivalent, 'not bothered', not being able to remember it at all, and ashamed and/or angry. Those who feel 'relieved' understand it as 'I'm not stupid or lazy after all' (Riddick *et al.*, 1997) whereas those who feel ashamed understand it as a within-person problem, a public, formal verdict of 'there's something wrong with me'. Characterizing reaction to identification as only one thing in itself can be misleading. Pollak (2005) describes a participants' reaction,

*... she found [identification] 'really shocking'. She recalled having three simultaneous emotional responses: relief that she had not been pronounced unintelligent, gladness that her difficulties had been recognized and dismay that she had low reading and spelling ages (p100-1).*

McNulty (2003) linked his participants' reaction to identification to the way assessment was carried out, and to the way dyslexia was explained to the person being assessed. Depending on how dyslexia is explained and how others respond to identification, it can mean the person is affirmed with potential for adaptation and support, or can further add to trauma.

Some researchers document reaction to identification as a process (Armstrong & Humphrey, 2009, Dale & Taylor, 2001, Pollak, 2005, Riddick, 1996) where even an initial negative response may develop to more positive perceptions. 'Sophie' is interviewed at age thirteen and again at sixteen;

[age thirteen:] *When I found out I was really upset because I thought it was incurable like. Like if you were a bit slow, you think "Oh well, I can do this and then I'll catch up" But when I found out like, everyone was saying "Oh I thought you'd be happy", but I wasn't, I was shocked (Riddick, 1996, p145).*

[age sixteen:] *Interviewer: How do you feel about the label now? Does it help you understand or do you resent it for making you feel different?*

*Sophie: Yes it does, it helps me. Because there's things about it and stuff you can relate to, and that makes you feel a bit better that there's someone out there going through the same thing (Riddick, 1996, p146).*

Ingesson's (2007) study showed improved self-perceptions over the course of school experience, with primarily negative self-perceptions in elementary and middle school, until in secondary school over 70% of the young people interviewed viewed themselves positively. She attributes this in part to a process of 'identification and gradual acknowledgement of the dyslexic difficulties' (p584), and surmises that regardless of initial responses to identification, it becomes positive with time. Identification of dyslexia enables the child to make sense of the difficulties which previously may have been understood in ways negative to the self. It is also often the precursor to improved intervention. Even if mainstream schools did not change the support they offered when a child was identified as dyslexic, support and understanding increased from family members (Hellendoorn & Ruijssenaars, 2000). A conclusion authors came to repeatedly in the interview studies is that early identification of dyslexia is helpful.

A study with a slightly different reason for this conclusion was carried out recently with twenty college students. It looked specifically at the experience of being labeled dyslexic (Armstrong & Humphrey, 2009). On the basis of their interviews the authors developed what they call 'the Resistance—Accommodation Model'. It represents a person's willingness to identify as dyslexic

along a continuum, from complete resistance or refusal at one end to complete acceptance on the other. The participants who were most resistant to identifying themselves as dyslexic were those who had not been assessed as dyslexic or referred to as dyslexic at all in the past, whereas those who had understood previously that they were dyslexic were comfortable accommodating 'dyslexic' in their identity. The authors suggest that because identity becomes more fixed during adolescence, the older a person is when dyslexia is identified, the more difficult it becomes to assimilate it. They found resistance to identifying as dyslexic to be a risk factor to positive outcomes; the participants who accommodated a dyslexic identity were more motivated to study, more willing to receive learning support and did better in their studies. The authors therefore concluded that early identification is important for positive outcomes.

### **The need to conceptualise difficulties with reading and writing**

The discussion above suggests that young people need a way to understand why they might be different from peers in learning to read and write. Otherwise they are prone to conceptualise their difficulties in terms of negative, within-self factors such as being unintelligent or lazy. From the interview studies reviewed here, it can be concluded that teachers also need a way to conceptualise difficulties with reading and writing, or they come to the same kind of conclusions. In creating one category of disability, 'special educational needs', the Warnock Report (1978) meant to encourage teachers and specialists to focus on each individual child's needs rather than assuming difficulties related to a category of disability identified. However, children's difficulties need to be linked to bodies of knowledge with which teachers are familiar (Riddick 2000). As she points out, 'In some cases teachers stated quite clearly that they did not believe in the concept of dyslexia so in having no intention of looking for specific within child factors and their interaction with the educational environment they inevitably made incorrect attributions of negative environmental factors at home or within child factors, such as slowness or laziness' (p656). Riddick (2001) continues by speculating that it may be particularly important to label non-evident disabilities (disabilities that do not have an obvious physical manifestation) in order to prevent inaccurate or negative attributions.

Some authors argue that the term dyslexia is used to identify a subset of those with reading difficulties who deserve special treatment, and that identification of some children as dyslexic can create a situation of discrimination for the dyslexic subset of children to the detriment of the remaining children who have difficulties reading and writing but are not identified as dyslexic

(Elliott & Gibbs, 2008). Certainly the research represented here rarely describes adequate provision provided within mainstream schools even after a 'fight' from parents; rather, such provision is more often provided by parents privately after support is not found within mainstream schools. If anything, the accounts from dyslexic adults would argue they are discriminated against in mainstream schools in response to identification of dyslexia.

Elliott & Gibbs (2008) also discuss dyslexia as a socially defined construct. Before the late 1800s, being literate was a characteristic of the powerful elite, and universal literacy considered dangerous. In the late 1800s this reversed, and now absence of universal literacy is considered dangerous (Cook-Gumpertz, 2006, cited in Elliott & Gibbs, 2008). Because children are not always literate when leaving school, and schools are judged according to levels of literacy in their students (for example through league tables of exam results in the UK), it is therefore in schools' interests to perpetuate a situation where teaching such children is outside their level of expertise (Goody & Watts, 1968, cited in Elliott & Gibbs, 2008). Universal literacy would in fact challenge the status of those already established as successful, and 'there remains a paradoxical but self-serving need to maintain a group who remain "illiterate"' (Elliott & Gibbs 2008, p486). MacDonald (2009), in his interview studies comparing dyslexic participants from lower and middle classes, found that all experienced discrimination in education and employment due to dyslexia, but that for working class participants the discrimination was more severe because they did not have access to specialist tuition and enabling technology.

Such arguments provide one way to situate the parent-school conflicts described thus far in the interviews. The government and Education community, despite making promises to 'eradicate illiteracy' (Makay, 2007, cited in Elliott & Gibbs, 2008), in fact resist change. Parents, on the other hand, are motivated to make sure their child does not end up a member of the disadvantaged 'illiterate'. Dyslexia from this perspective can be seen as a movement against the educational system, first made by parents, then taken up by dyslexic people in asserting themselves as not belonging to the 'illiterate' category. Specialist schools, especially private ones, can be seen to be outside the educational institution and therefore more free to adopt effective regimes. Teachers, from this perspective, are in as difficult a position as their dyslexic pupils as they are employed to carry out the purposes of the institution.

A number of dyslexic participants stated that 'stupid' represents the way they perceive the public understands dyslexia. In this way understanding having difficulty with reading and writing as a lack

of intelligence is generalized to dyslexia. For example, Sophie, in commenting on the ethos of her school regarding dyslexia, said 'Well people think you're stupid to be quite honest, that's the whole attitude of it' (Riddick 1996, p146). Armstrong & Humphrey (2008) conclude that participants who resist identifying as dyslexic do so because they equate 'dyslexia' with 'stupid'. They write, 'Anthon's logic is: "teachers say I am stupid; dyslexia = stupid; therefore I am not dyslexic"' (p99). Humphrey & Mullins (2003) carried out a survey with 188 children aged 8 to 15, 61 of whom had been identified as dyslexic. The dyslexic children showed a significantly higher correlation between their constructs of 'good at reading' and 'intelligent' than non-dyslexic children, suggesting that children who have been identified as dyslexic, more than non-dyslexic children, equate the ability to read with being intelligent. As stated above, many participants perceived difficulties with reading and writing to be a sign of a lack of intelligence, as well as reporting that teachers and peers made this assumption. As Armstrong & Humphrey (2008) so aptly show, it is a simple matter to replace 'difficulties with reading & writing' with 'dyslexia' and thus end up with the understanding that 'dyslexia' = 'stupid'.

Armstrong & Humphrey (2008) further suggest that understanding dyslexia as 'stupid' requires Anthon to distance himself from academic work in order to protect his self-esteem. Anthon comments that academic study has 'never been my thing', and that he has 'never been bothered' about it (p99) – and suggest that his motivation to work at school is compromised by his understanding. Such responses can, however, be interpreted in different ways. That such an attitude is negative can be said to resonate with non-disabled attitudes toward disability, where it is assumed that because a person is unable to do what most people do, their lives must be ones less valuable (Morris 1991). It is also possible to affirm Anthon's perspective – academic work does not have to be 'everyone's thing' – and view his choice to eventually leave the course as one that is in fact better for him because it is more sensible in 'fit' to his strengths and weaknesses (Oka & Paris 1987). Gerber et al. 1992 also emphasise 'goodness of fit', equating it with self-understanding and positive action. Dale & Taylor (2001) discuss a student, Suzanne, who decides after she finishes an access course that she does not want to continue on to a degree. This decision is judged to be positive by the authors because she makes the decision based on the inadequacy of the support offered by the educational institution rather than giving inadequacy on her part as a reason. Armstrong & Humphrey (2008) also state this possibility when they write " 'investing in the alternative' can be a psychologically healthy process" (p 100).

Research by Dweck (1999) contributes further to showing that the way a person understands intelligence impacts their motivation to work hard. She proposes two understandings of intelligence; 1) an entity theory, where intelligence is something a person is born with and remains fixed throughout ones' life, and 2) an incremental theory, where intelligence is something that can be cultivated by learning, and increased through effort. Those with an entity view of intelligence shy away from challenge, because they may find it difficult and look unintelligent. Those with an incremental view of intelligence seek learning opportunities and work hard. By surveying pupils on the transition from elementary to middle school to identify those with entity vs. incremental views of intelligence, it was possible to predict their performance in the context of the greater challenge of middle school. Those with entity beliefs declined in class standing, whereas those with incremental beliefs improved (Henderson & Dweck 1990).

It can be argued that the dyslexic children who understand themselves as unintelligent, or the teacher and/or peers who are reported as calling them unintelligent, hold entity views of intelligence. The child has difficulties with reading and writing and is therefore unintelligent, and there is an unspoken sense that *there is nothing that can be done about it*. That these children are 'unintelligent' even by an entity view of intelligence is probably untrue. But perhaps more importantly, an incremental view of intelligence gives a child a conceptualisation of intelligence that empowers them. Views about intelligence can be changed from entity to incremental via teaching on the subject (Dweck 1999), and therefore individual teachers and/or the overall attitude of the school toward intelligence can play a positive role. Two authors of interview studies reviewed here commented that the schools in their study provided an ethos commensurate with incremental views of intelligence, and that this supported the positive outcomes of the dyslexic pupils who attended there (Burden 2005; Rawson 1995). Considering the close link shown by the research reviewed here between negative assumptions about intelligence and difficulties with reading and writing, attitudes toward intelligence in schools is a key issue for the support of more positive experiences of school, healthier self-perceptions and stronger motivation to work for dyslexic children.

### **The label 'dyslexia' means different things in different contexts**

Riddick (2000) makes the point that labels can be perceived differently in different contexts, and that for dyslexia there is a personal and public level. On a personal level being identified as dyslexic has the potential for a number of positive outcomes, for example:

- Positive impact on self-understanding,
- initiation of change to action in terms of intervention,
- potentially offers a person a sense of 'challenge', where new understanding gives hope and acts as a spur, and may also initiate personal assertiveness (Riddick *et al.*, 1997) and
- attention brought to coping strategies.

On the other hand, a number of participants spoke of negative aspects in relation to the public sphere relating to stigma:

- Public association of dyslexia with incompetence and/or unintelligence,
- the possibility of being pitied (Hellendoorn & Ruijsenaars, 2000),
- the possibility of being discriminated against if at work (Hellendoorn & Ruijsenaars, 2000, MacDonald, 2009),
- having dyslexia dismissed as 'no such thing' (Riddick *et al.*, 1997),
- Reason for jokes, ridicule (Dale & Taylor, 2001, Hellendoorn & Ruijsenaars, 2000, Riddick *et al.*, 1997) and
- the possibility of being misunderstood, for example many see it as solely a problem in spelling (Dale & Taylor, 2001).

For some or all of these reasons, many dyslexic participants said they were careful to whom they disclosed they were dyslexic, and emphasised that the ethos of each public environment played an important role in their decision.

There are also personal aspects of the label that can be negative and public aspects of the label that can be positive. On a personal level, some may use the label dyslexia as an excuse to stop trying, a reason to avoid challenge or take an easier path in life (Riddick *et al.*, 1997). On a public level, the identification of dyslexia can lead to greater support within education, especially in higher education. Some participants, despite finding themselves in an environment negative to dyslexia, choose to disclose their disability anyway on the basis that those who are not aware of dyslexia are in fact the uneducated ones (Riddick 2000). Thus, it is clearly not possible to state that dyslexia as a label is positive or negative even within a personal vs. public realm; there are both benefits and disadvantages to it that vary by context and attitude. Despite the real possibility of

stigma associated with public acknowledgement of dyslexia, many people choose to adopt it. The personal/public aspects of the label mean that a person can manage the use of the label so that they benefit from its ability to support positive self-perceptions while controlling the potential for the label to prompt negative public reactions through careful decisions about disclosure.

## **Ways of understanding dyslexia: Discourses**

Pollak (2005) focused his PhD thesis on identifying discourses of dyslexia in interviews with 33 dyslexic students attending university. He defines a discourse of dyslexia as 'the values, beliefs and power relations associated with the concept' (p109), and identified four within his study, *Patient*, *Student*, *Hemispherist* and *Campaigner*. He does not suggest that a person understands dyslexia in only one way, on the contrary, the same person may speak about dyslexia differently according to context or even mood. However, he proposes that it is often possible to identify a dominant way of understanding dyslexia that characterises a person's perspectives. This too may change over time. Pollak tentatively links the discourses to characteristically negative and/or positive responses in participants; however, it would be easy to oversimplify such links. Each discourse, in the same way the label of dyslexia can be seen to be positive and/or negative according to context and attitude, has the potential to have both positive and/or negative elements (see Table 2.2).

### **Patient**

The most prevalent discourse of dyslexia Pollak identified was one he dubbed *Patient*. The *Patient* discourse of dyslexia involves the perception that dyslexia is a problem within a person, a skills deficit with biological/neurological/cognitive origins. Pollak called it *Patient* because he placed its origins in the medical model of disability. The medical model views disability primarily as a problem within the disabled person. It has similarities to Wolfendale's client perspective described above, because in the medical model powerful professionals make choices for passive, needy patients. This kind of conceptualisation justifies the marginalisation of disabled people, because it asserts that a biological cause prevents disabled people from functioning normally within society. Pollak attributes the prevalence of medical conceptualisations in relation to dyslexia to the fact that historically almost all those involved in the early description of dyslexia were medical professionals.

<b>Discourse of dyslexia</b>	<b>Origins and Characteristics</b>	<b>Potential positive impact</b>	<b>Potential negative impact</b>
<b>Patient</b>	Origins: Medical model of disability, where origin of problem is within the disabled person. Pollak's study found that explanations by educational psychologists, teachers, parents and the media are primarily from the Patient discourse, and all participants at times used this discourse. Prevalence makes truly positive self-perceptions difficult. Characteristics: Difficulties are understood to be a neurological/cognitive deficit.	Provides a specific reason for difficulties that is different than Stupid/lazy. Can combat the attribution of laziness.	Can still be understood to mean Stupid/lazy, is understood as an innate deficit so may involve negative self-perceptions, negative emotion, lack of motivation, avoidance of schoolwork
<b>Student</b>	Origins: Discrepancy definition of dyslexia, where dyslexia is identified when there is a discrepancy between standardised scores on attainment tests and IQ scores. This discourse falls within a medical model of disability. Characteristics: Difficulties are understood to be of neurological/cognitive origin, however intelligence is affirmed. Dyslexia is understood to be a difficulty related to the realm of academia only, and this discourse often involves description of study skills to compensate for difficulties	Affirms intelligence, which increases motivation to work and develop study skills/compensatory measures. Compartmentalises dyslexia.	Stress over amount of time and effort needed for schoolwork. Anxiety over future difficulties with reading/writing in employment. Potential for some negative self-perceptions, negative affect
<b>Hemispherist</b>	Origins: Orton (1928) proposed dyslexia to be related to unusual brain hemisphere development. Some links to a social model of disability, where the origin of disability is understood to be in society, but also acceptance of neurological and/or cognitive differences, linking to a medical model. Characteristics: Understanding dyslexia as a difference not a disability, awareness of strengths as well as weaknesses, often related to right-brain strengths and left-brain weaknesses. Tendency to seek HE courses that involve non-linear-text-based assessment such as portfolios and verbal exams. Awareness of metacognition such as learning styles and lecturer styles which are helpful.	Self-acceptance, positive self-perceptions, assertiveness, awareness of ones' strengths and weaknesses, and application of this knowledge to life circumstances.	Understanding dyslexia as a difference rather than disability can perpetuate the 'us' 'them' discrimination involved in understanding disability only in negative terms because it denies disability
<b>Campaigner</b>	Origins: The civil rights aspects of the Social model of disability. Characteristics: Focus on the 'right to be educated', with a belief that dyslexic people need to campaign together to secure rights	Willingness to educate others about dyslexia. Supports positive self-perceptions and understanding.	Characteristically 'angry'/aggressive, frustration at lack of cooperation from the educational system for academic support

Table 2.2. Description of Pollak's (2005) four discourses of dyslexia.

All 33 of Pollak's participants spoke at times of dyslexia through a *Patient* discourse. This may have only involved using cognitive terms such as 'short-term memory' or medical terms such as 'diagnosis' or 'symptoms' when talking about dyslexia. What participants were exposed to about dyslexia, in the form of media, educational psychologist reports, and understanding from teachers, parents and peers, was most often in the form of a deficiency perspective. Though Pollak identified *Hemispherist* and *Campaigner* discourses as being better able to support positive understanding of dyslexia than other discourses, even those who understood dyslexia in these latter discourses struggled to construct a consistently positive identity as dyslexic because of the prevalence of the discourse of dyslexia as individual deficiency.

For some participants, the sense of dyslexia as a problem within themselves went deeper. Nine of the 33 participants primarily spoke about dyslexia from a patient discourse, and these were the participants with poorest self-image for whom understanding themselves as dyslexic meant understanding themselves to be intrinsically deficient. Some of them believed they were unintelligent and expected themselves to fail when applying to university, and then expected to fail during exams. Social withdrawal and lack of confidence characterises these participants.

## **Student**

The *Student* discourse of dyslexia involves understanding dyslexia as a phenomenon that only impacts academic life. Pollak named this discourse *Student* because he identified the origin of this discourse to be the IQ/attainment discrepancy model, where dyslexia is defined by a difference between results from standardised academic attainment tests and IQ tests. With twelve of 33 participants primarily speaking about dyslexia from this perspective, it was the most commonly used discourse in Pollak's study.

The *Student* group of participants understood dyslexia as a problem with reading, spelling and/or writing, and although many of the other participants referred to difficulties in these areas, those for whom the *Student* discourse was primary all commented that dyslexia was only relevant to areas of their lives involving academia. Pollak characterises these participants as understanding themselves as intelligent, despite being aware of their academic difficulties. Though keen awareness of difficulties impacted academic self-concept negatively, confidence in their own intelligence meant these participants were motivated to learn study skills to overcome difficulties. Also, this understanding of dyslexia supported the compartmentalisation of dyslexia, enabling motivated pursuit outside the academic realm. However, Pollak notes

that some participants were prone to feeling stressed by their course workloads, and concerned about how they would cope with reading and writing tasks in the workplace.

### **Hemispherist**

The *Hemispherist* discourse of dyslexia involves understanding dyslexia as a difference in learning style, and does not view it only as a problem, but rather describes its impact through both strengths and weaknesses. Pollak named it *Hemispherist* because this understanding was often expressed through the idea that different sides of the brain are involved with different kinds of activities, for example the left brain specialises in language and linear logic, and the right brain specialises in spatial, holistic thinking. Most highlighted right brain strengths and left brain weaknesses. Some of these students identified with famous dyslexic people, for example those well known in architecture or arts.

Seven of 33 participants primarily understood dyslexia in *Hemispherist* terms, and the majority of these were mature students. The mature participants in Dale & Taylor's study (2001) were also more likely to be aware of their strengths, and this led them to challenge previous understandings of dyslexia as a problem within themselves.

It was common in this group for students to choose their undergraduate course because it offered alternative means of assessment, such as portfolios or verbal reports. Pollak linked this discourse to the work of Gerber *et al.* (1992, 1996) and the idea of reframing, noting that *Hemispherists* tended to be further on in this process than *Patients* and *Students*.

### **Campaigner**

This discourse was identified from the interviews with participants, rather than arising from models of dyslexia Pollak identified in the literature. Four of the students experienced dyslexia as a political struggle, and were involved in forming dyslexia support groups or campaigning to increase awareness of dyslexia, or for rights. This discourse is situated firmly within the social model of disability where disability is understood as arising from structures within society rather than from problems within people. Pollak identified links in this discourse to the idea that the strengths often associated with being dyslexic may actually give dyslexic people an advantage as our culture moves away from textual information to more visual forms (West, 1997, Davis, 2001). Some of the participants felt the structure of the university system – for example in expecting linear written word with particular styles of grammar and spelling – were infringing on their right to be educated. Pollak characterised this discourse as angry because in this discourse there was a tendency to fight to secure perceived rights, such as higher marks.

All four of these students demonstrated aspects of the other three discourses. However they were the only ones to describe political aspects of being dyslexic. Their understanding of themselves as intelligent is expanded to include the right to academic success and the need for solidarity amongst dyslexic people to campaign for these rights. Pollak describes the most positive way of understanding dyslexia in his study as coming from a campaigner, 'I don't think I really think of [dyslexia] as impinging on [the rest of my life]. I tend to take the positive view that it gives me a different perception' (Pollak 2005, p136).

## **How positive self-understanding is achieved**

Research about dyslexia, as discussed at the beginning of this chapter, is largely involved in identifying cognitive and/or neuropsychological deficits and evaluating intervention. Focus on these areas to the exclusion of others leaves researchers and practitioners blind to other aspects that are fundamental to attaining better outcomes for dyslexic people. The way people come to terms with their difficulties is such an area. A number of studies reviewed here demonstrate that many people develop positive self-perceptions related to being dyslexic, and that this supports better well-being and/or educational/employment outcomes (Armstrong & Humphrey, 2009, Burden, 2005, Gerber *et al.*, 1992, Gerber & Reiff, 1991, Gerber *et al.*, 1996, Hellendoorn & Ruijssenaars, 2000, Ingesson, 2007, McNulty, 2003, Pollak, 2005).

In this section I will look at how research interviewing dyslexic people has begun to clarify the processes by which positive self-perceptions develop. A model which gives a framework to the development of positive self-perceptions and which also sets this process in a larger context of the relationship between internal understandings and external action, called the 'Model of vocational success' (MVS) (Gerber *et al.* 1992), will be used in this discussion to organise findings from the other interview studies.

The power of perspective toward difficulties with reading and writing to damage or defend should not be underestimated. In a study comparing successful and less successful young people with learning disabilities, there were no demographic factors that could be isolated that accounted for the difference between groups. However, qualitative information demonstrated that the successful group were more self-aware and more accepting of their disability, more proactive and better able to adjust to life experiences, despite reporting similar difficulties due to their disability to the unsuccessful group (Spekman *et al.* 1992, cited in Hellendoorn & Ruijssenaars, 2000). Hellendoorn & Ruijssenaars (2000) had similar findings in that level of difficulty due to dyslexia was not significantly correlated to feeling disabled or

level of employment status. In MacDonald's (2009) study, four of five of the middle-class participants left school with qualifications adequate to attend university whereas the seven working class participants left school with 'virtually no academic qualifications' (p355). MacDonald makes the argument that dyslexia has no impact on the ability of a person to obtain qualifications; rather ability to acquire qualifications rests on social class. All these findings suggest that the severity of difficulty does not have to dictate well-being and/or educational/employment outcomes.

As a note of caution, it is worth mentioning that studies that compare 'successful' and 'unsuccessful' people can always be criticised on the basis that how success is defined is a matter of opinion, and who decides this criteria greatly affects results (Schoon, 2006). For example, for young people from socio-economically deprived backgrounds, leaving school at age sixteen and going straight into paid employment rather than continuing in education may be a more realistic and personally beneficial choice, despite the fact that this is considered 'less successful' within Western cultures by the educational elite who tend to carry out such comparative studies. The studies can be helpful, in the case described here, for understanding associations between continuing and/or not continuing in further/higher education, however the evaluative nature of the word 'success' should be contextualised.

### **The model of vocational success**

Gerber *et al.* (1992) carried out a large-scale mixed methods study in which 71 learning disabled adults were matched on a number of demographic details into two groups, 'high success' and 'moderate success'. The adults were then involved in an in-depth semi-structured interview and surveys measuring self-esteem, motivation and relationship style. The intention of the study was to isolate cause for 'high success' by identifying differences between groups. The authors identified a theme that transcended the entire cohort of participants, representing both groups on a continuum: the desire to control one's life. Though all participants expressed a desire to control their lives, the participants in the 'high success' group expressed stronger desire and demonstrated more achievement of this goal than the participants in the 'moderate success' category. Operating from the desire to control one's life, the authors described two mechanisms: *Internal decisions* and *External manifestations*.

*Internal decisions* were comprised by 1) *Desire* – the highly successful group communicated a strong desire to excel; 2) *Goal orientation* – the highly successful group consciously set goals, and success in one goal led to confidence which formed the foundation for the next goal and so on; 3) *Reframing* – involves reinterpreting ones' experience of being learning disabled in a

more positive way. This occurs in four stages: *Recognition* (coming to recognise one's areas of difficulties), *Acceptance* (accepting that the difficulties will always be a part of one's life to some extent; acceptance can include affirming that one is valuable despite difficulties), *Understanding* (involves becoming aware of areas of strengths, weaknesses, learning styles and compensation strategies) and *Action* (these are represented below as *External manifestations*). The stages can be moved through in unison or consecutively. Adults in the moderately successful group had not moved through the four stages to the same degree.

*External Manifestations* were comprised by 1) *Persistence* – the highly successful participants worked very hard 2) *Goodness of fit* – the highly successful participants knew their strengths and found employment that optimised these 3) *Learned creativity* – the highly successful participants developed strategies and coping mechanisms to overcome difficulties related to learning disabilities, and used areas of strength to advantage 4) *Social ecologies* – highly successful participants sought out people to support and mentor them; moderately successful participants may have had support available but were either reluctant to take it up, or relied completely on it.

The authors create a model of these findings (see Figure 2.1) placing control as central to contributing to the extent of success and acting with success, *Internal decisions* and *External manifestations* in a dynamic system of reciprocal relationships. The authors qualify their model by stating that greater levels of control create greater likelihood of success, but that it is never a guarantee because of outside factors that contribute, such as good or bad luck. *Internal decisions* and *External manifestations* work in a unique inter-relational way for each person; still the authors claim it is possible to map each unique person's experience of success using this model. They also claim that all elements of the model are alterable; they can be taught and learned, and this has positive implications for education.

Gerber *et al.*'s (1992) Model of vocational success (MVS) is useful because it conceptualises the relationship between self-perceptions and action referred to in many of the other studies represented here. Although it is formulated in employment terms it can be used to conceptualise other relationships between self-perspectives and action, for example in terms of education and social relationships. Perhaps most relevant to the literature, though, is the authors' idea of *Reframing*. Gerber *et al.* (1996) identifies reframing as a particularly important aspect of the MVS as it is the fulcrum point between internal processes and action. When people's perceptions of dyslexia change to become more positive, they become more active in

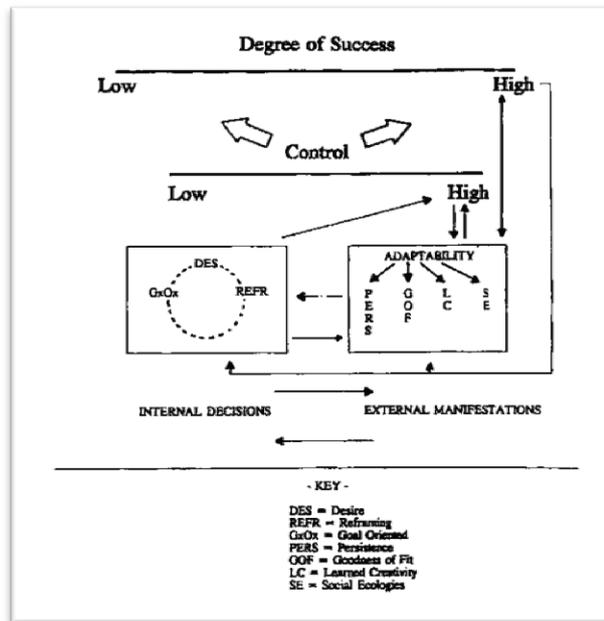


Fig 2.2. Gerber et al.'s (1992, p485) diagram of the Model of vocational success.

response. I will therefore use the MVS as a structure from which to discuss findings about the development of positive self-perceptions about being dyslexic.

### Early self-perceptions

As school is the context in which a person learns to read and write, a dyslexic person will first perceive what difficulties learning to read and write mean based on the attitudes within their primary school toward reading, writing and learning in general. The ideal circumstance, which was experienced by a minority of the dyslexic people interviewed in the studies represented here (e.g. Hellendoorn & Ruijsenaars, 2000) is for primary school to provide an experience of inclusion and acceptance, where despite any difficulties the dyslexic person is valued and their difficulties are supported appropriately. In this situation there is no need to reframe. However, as discussed above, what is described by many dyslexic people is that they first understand their difficulties to mean they are unintelligent and/or lazy, or they think 'there is something wrong with me', or perceive that they are different from their peers and do not belong. The most common experience, then, is for initial self-perceptions to be negative, which creates the necessity for reframing. But how does reframing occur?

### Change in self-understanding related to academic context

Somewhat paradoxically, some participants speak of gaining motivation to excel because of the negative comments made about them, for example by teachers. They become determined

to 'show' the teachers they were wrong (McNulty, 2003, Riddick *et al.*, 1997), and this prompts them to work hard. They may then experience success and become aware of strategies to overcome their difficulties. This process closely mimics the 'steps' described in the internal aspects of the MVS.

McNulty (2003), in his analysis of storylines and interviews with dyslexic adults, identifies a pattern of functional compensation he calls *Compensation*. This is where the dyslexic adult overcomes his or her difficulties with reading and/or writing to the extent that they can work toward goals that rely heavily on those skills. The adult, through academic success, is able to address (or reframe) the understanding of themselves as unintelligent/lazy, as well as doubts about belonging. There is cost involved in this pattern however. Because of the time required to devote to studies, the person is likely to miss out socially and endure continuing frustration.

### **Change in self-understanding related to identification of dyslexia**

The fact that the majority of those interviewed said they understood themselves to be different from their peers before dyslexia was identified, suggests that the first stage of reframing, *Recognition*, is often begun before identification. However, identification of dyslexia can also be seen to be part of this stage. It can prompt reframing, as it brings recognition of difficulties to the fore and provides opportunities for developing understanding of why a person might have such difficulties. A response of increased support from family and/or through intervention, for example tutoring, provides a context for developing understanding of strengths/weaknesses and coping strategies. However, some participants interviewed did not reframe in response to being identified as dyslexic (Dale & Taylor, 2001). This may be related to the way significant others explain dyslexia at the time, and whether or not appropriate intervention follows (Dale & Taylor, 2001, Ingesson, 2007, McNulty, 2003). Other participants reframed without identification of dyslexia, for example in response to success in employment (Dale & Taylor, 2001).

Following identification of dyslexia, educational psychologists, parents, teachers and the media will all be important contributors to a dyslexic person's understanding of what it means to be dyslexic (Burden 2005; McNulty 2003). Unfortunately, the most prominent understanding expressed by these sources is that of the medical model, which attributes the difficulties to the individual in the form of cognitive/neuropsychological deficits, and most dyslexic people are therefore on some level at least, likely to understand that they are intrinsically deficient (Pollak 2005). In this way the medical model can provide a real barrier to the *Acceptance* stage of reframing (Armstrong & Humphrey, 2009). The educational psychologist reports analyzed by

Pollak (2005) also expressed *Student* and *Hemisphere* discourses, however, and these both can support reframing through emphasising intelligence and the idea of strengths as well as weaknesses. The media can also provide information supportive to reframing, for example through publishing stories of successful dyslexic people who provide examples to follow of the journey to positive self-perceptions and successful lives (Pollak 2005).

### **Change in self-understanding due to experiences of 'niche'**

In a number of studies dyslexic participants described reframing due to excelling in areas outside reading/writing, for example in sport, music and/or art. Such activities support *Acceptance* and *Understanding* because they develop awareness of strengths and weaknesses and because they affirm value. McNulty (2003) called excelling outside of academia 'finding a niche', and identified it as a key means to support adaptation and improve self-perceptions, whereas not finding a niche encouraged continuation of difficulties. Armstrong & Humphrey (2008) remarked on a similar trend in their study, dubbing it 'investing in the alternative'. Their participants were all drawn from a further education institution specialising in music qualifications. Many of the participants spoke of their success in music as though it compensated for the difficulties they had experienced in more academic subjects.

It is also possible for success in a niche to have negative aspects, as in the pattern of compensation McNulty identified as *Gifted overcompensation* when a niche was found in an area of giftedness. For some, past failure and insecurities led them to overcompensate as adults. A similar situation was identified in Gerber *et al.*'s (1991) study, where the participants in the highest achieving employment were found to have lower levels of well-being than those in moderately achieving employment because they had to spend inordinate amounts of time working to maintain high levels of success. Gerber *et al.*'s (1992) study also found that being in the 'highly successful' category often 'meant working harder than anyone else they knew' (p482).

The 71 dyslexic teenagers and young adults in Ingesson's (2007) study improved in well-being once they began their upper secondary school years. Ingesson attributes this to a gradual reframing process as the person better understands their difficulties and what dyslexia means, but also to the fact that in upper secondary years most pupils began vocational training. In other words, they entered into study in which they found themselves successful because reading and writing were no longer of primary importance. This is supported by the result that the young people who continued on with academic study had less of a sense of well-being and achievement than those who entered employment, and 2/3 in employment felt that dyslexia

no longer affected them outside of reading and spelling. This suggests that involvement in activity outside of academia supports *Understanding* and *Acceptance* aspects of reframing by providing a context in which a person is made aware of their strengths, supporting their sense of themselves as valuable.

Similarly, some of the students in Dale & Taylor's (2001) study described a process whereby achievement in the workplace led them to doubt their previous understanding of themselves as 'thick' which they developed during their school years. These doubts then led them to act by seeking out an explanation, and they recognised a similarity between their own experiences and comments from friends/family, books or the media about dyslexia. In this case the experience of reframing led them to identify themselves as dyslexic, rather than identification of dyslexia leading them to reframe. The authors speculate that it was initiation of the process of reframing that led many to act by enrolling on the study course.

### **Change in self-understanding due to parenting a dyslexic child**

Two studies referenced here find that being the parent of a dyslexic child offers a dyslexic adult the opportunity to re-evaluate their own dyslexia. McNulty (2003) describes Bill and the process of his son being diagnosed. Bill struggled against his wife having their son assessed because he felt it suggested there was something wrong with him. Their exchanges demanded he confront the issue 'there's something wrong with me' for both himself and his son.

However, Bill then described that identification of dyslexia was different for his son, because his son's feelings were taken into account, and his son understood dyslexia to mean '... I know I'm not stupid' (p376). Eight of 27 adults in Hellendoorn & Ruijsenaars' study (2000) had children, and eleven of the nineteen children had been identified as dyslexic. The parents said they felt guilty to some extent, but they also 'championed' their children, and were active in parents' associations. The implication is that supporting one's child to develop positive self-perceptions and handle the difficulties involved with dyslexia, though potentially painful because it brings negative self-perceptions to the fore, also enables new associations and understandings, and therefore creates a chance to reframe.

### **Change in self-understanding due to talking to others**

McNulty (2003) found that a number of dyslexic adults described trusted friends and/or family whom they spoke to about their self-perceptions and dyslexia. By being in relationship with people who listen and accept them, McNulty suggests that past experiences of being misunderstood can be counterbalanced. This relates to the acceptance stage of reframing. Hellendoorn & Ruijsenaars (2000) found that most those who sought professional support in

the form of counseling, psychomotor or play therapy found it helpful in learning to understand and accept themselves, and express their emotions in a healthy way. However, some of the participants had negative experiences because the professionals 'didn't know the first thing about dyslexia' (p236). Five of sixteen dyslexic university students in the study by Riddick *et al.* (1996) had average to above average self-esteem. Of these, three were identified early and were supported in school and one had a very supportive father. The fifth had traumatic, damaging experiences at school, but sought out cognitive therapy where he addressed his negative emotions. It would appear that being listened to and being accepted, either formally or informally, can contribute to reframing.

## **Conclusions from research interviewing dyslexic people**

I would now like to return to the question posed at the beginning of this section, 'What do dyslexic people talk about when they talk about dyslexia, and does this differ from the focus of professionals?'

I have discussed how research in dyslexia is hyper-focused on cognitive patterns of information processing, neuropsychology and teaching intervention methods. Dyslexia is primarily understood by both professionals and lay people as a problem with reading and writing caused by deficiencies in the brain.

The focus of talk done by the dyslexic participants in these studies was not about their cognitive/neurological functioning, nor was it about the benefit particular teaching methods had in teaching them to read and/or write (though some touched on these issues). The focus of their talk was rather on the way people treated them in relation to their difficulties. To the educational practitioner, they are a spanner in the works; the mainstream educational system is not set up to support their needs. On the whole the experience the participants in this study shared was one of taking the blame for their difficulties learning to read and write whilst at school – they were unintelligent, lazy, didn't belong; there was something wrong with them.

Further, the success many of these dyslexic participants experience later in life is rarely attributed by them to the educational support they received at school, the purpose toward which the vast bulk of research on dyslexia aims. Rather it is more often characterised as a process of interaction between personal support, the development of positive self-perceptions, and experience of success in some realm, most often a realm outside of education. This is not to say that learning to read and/or write was irrelevant to them, it just did not seem to hold the fundamental importance usually attributed to it by professionals.

Rather, self-perceptions and the emotions linked to them were of central concern to dyslexic people. They wanted to understand how and why they were different from their peers. Self-perceptions have a strong part to play in motivation and the actions that dyslexic people take. They ultimately, therefore, have an important impact on educational and employment outcomes. It is somewhat ironic that the focus by academics, researchers and educational practitioners on within-person difficulties compound the negative self-perceptions that interfere with better educational and employment outcomes toward which these professionals strive. The experience these dyslexic people most often talk about is one of success through personal support and development whilst fighting against public perceptions and provision.

## **Methodology of studies**

The following section will take a closer look at the methodologies employed by the studies in this literature review in order to inform the design and analysis of my own study. The studies reviewed here all contributed to knowledge about the experience of being dyslexic, but used different methods to come by this knowledge. The method used had a significant part to play in what kind of knowledge was contributed. This analysis will continue in the next chapter on Methodology, drawing on methodology literature, however, the studies just reviewed give specific examples which can inform how to better carry out my study, so I will take advantage of the insights they offer.

Because the issue of concern in this literature review is human experience, a number of the studies involve qualitative methods. The past 30 years have seen an explosion in re-evaluating and re-conceptualising qualitative methods and an interpretative approach. This means that even relatively recent qualitative researchers have not had access to the developments in conceptualisation which are relevant to my thesis today. In terms of critically analyzing the research in this literature review, then, any application of current methodological theory to research carried out before such theory was developed is not meant to be critical in terms of negative judgment, but rather is analysis carried out to highlight problems inherent in prior methodologies in order to explicate reasons for adopting chosen methodology in my own research.

Both outcome studies and studies that look at the self-perceptions and well-being of people are inadequate to pursue the type of knowledge I am seeking. The type of information analyzed tends to be relatively narrow, for example level of educational qualification or survey

response. Furthermore, such studies are carried out from a professional perspective. Professionals decide what questions are relevant, and develop the format for the questions and the responses. In this way they give little opportunity for a detailed expression of experience from an individual perspective.

By contrast, semi-structured interviews do offer the opportunity for a broader more detailed viewpoint from a participant, and if designed and carried out sensitively, interviews can give the space for a participant to identify what is important. However, even within the interview studies reviewed here, there is variation in the scope of the information it was possible for participants to share, and this and the means of analysis had an impact on the character of the data collected. For example, Hughes & Dawson (1995) comment on the difference in character of data according to type of question within their own study. They gave out questionnaires that were tape recorded, with fifteen closed questions, three open questions and a request for open comment. The authors quote statistics to represent the responses to the closed questions, but write,

*... these bare statistics perhaps give some clues to the generally negative recollections of school by so many of this sample group ... extreme feelings, however, were revealed in the responses to the open-ended questions and free comment section and it is these that truly illuminated the consequences of failure at school (p183).*

Here closed questions masked the intensity of participants' response. A good example of complexity of response is shown by a participant in Pollak's (2005) study,

*... she found [identification] 'really shocking'. She recalled having three simultaneous emotional responses: relief that she had not been pronounced unintelligent, gladness that her difficulties had been recognized and dismay that she had low reading and spelling ages (p100-1).*

Such complexity and conflict resonates with my own experience of the field of dyslexia, and I believe that allowing space for contradiction and complexity is a must if participants' experience is to be more fully represented. Another aspect which varied between interview studies was the means of qualitative analysis. Some studies simply reported responses to a range of questions developed before the interview process (Riddick, 1996) or shared life stories of participants summarized by the researchers without systematic analysis being carried out (Riddick *et al.*, 1997). These studies contained a huge amount of valuable information, but it was difficult to conceptualise it, perhaps because of the amount of information involved. The reasons for inclusion or exclusion of data were also not made explicit. Studies that developed models to represent findings, for example Gerber *et al.* (1992)

and Armstrong & Humphrey (2008), made information easier to conceptualise, retain and apply. The models also represented a development of theory which could be applied and tested in future research.

Burden (2008), in his review of research on self-perceptions, argues that it is of little use to document that academic self-esteem is lower in dyslexic children than their peers. Such a correlation does not establish causality and does not give information about how such negative self-esteem develops. He therefore recommends investigating more specific aspects of self-perceptions of young dyslexic pupils, exploring aspects of locus of control, learned helplessness and self-efficacy in a framework of attribution theory. In other words, theoretical frameworks and models help organise complexity and allow the development of ways of thinking about dyslexia that support better research and application by practitioners of what is learned. Riddick (2000) also emphasises the importance of conceptualisations about dyslexia to enable practitioners to identify, understand and support the needs of children struggling to read and write.

Finally, because of the prevalence of negative, even traumatic school experiences in the study of dyslexia, the way emotion is treated within my research is a topic I need to address. In Edwards' (1994) study the experience of dyslexia is represented as one of emotional trauma. There is little attempt to look at wider issues, such as changing societal attitudes towards the use of violence and humiliation as a tactic to control children in schools. Undoubtedly such tactics were used against other non-dyslexic children by the same teachers. It is also arguable that such an emotive, negative focus does not in fact lead to more positive attitudes or situations for dyslexic people.

Goffman (1968) describes a paradox of disability – describing the need or stigma associated with a disability can perpetuate negative perceptions and discrimination by setting out differences between disabled and non-disabled people. However, if the disability is not acknowledged the person does not receive support. Morris (1991), who is a disabled author, describes the dislike many disabled people feel about others who express pity for them, or, conversely, say how wonderfully they are coping with their disability. This can be patronising and paternalistic because the underlying assumption is that disabled people are helpless in the face of their tragic disability. Morris says that disability is no more difficult to handle than many other difficult situations 'normal' people face, and that disabled people should be respected as able, active people, not glamorised nor stigmatised. A focus on negative experiences may trigger a response of pity in teachers and/or parents, and this may bring

about a self-perception of 'victim' in the dyslexic pupil. Eighty seven student teachers responding to a Likert-scale survey about attitudes to dyslexia (Gwernan-Jones & Burden, 2010) reacted with significantly more agreement after teaching practice than before to the statement 'The label 'dyslexia' can be an excuse for a child to stop trying'. This suggests some of the students encountered situations in their teaching practice where dyslexic children did in fact use dyslexia as a reason to give up.

## Conclusion

The purpose of this literature review has been to set my own study in context and to sharpen up the focus and design of it, as well as taking on methodological lessons. I would therefore like to conclude by applying the information taken from the studies reviewed here to my PhD thesis.

To quickly recap my intentions, I want to contribute to knowledge about the experience of being dyslexic. This desire originated in my own experience tutoring a mature adult student, Gary, in response to both his account of school experiences and his shift in attitude and action to be more positive and more active as he came to understand himself as dyslexic. I became interested in knowing more about the experiences involved with in difficulties learning to read and write, and the impact these and being identified dyslexic might have on self-perceptions and identity.

From this literature review it is apparent that semi-structured interviews designed to allow space for participants to take the lead in subject matter is important if I want to find out about the experience of being dyslexic from a dyslexic person's point of view. I would also like to use specific theoretical models or frameworks to analyze the data, in order to develop available conceptualisations of dyslexia and organise the results in a way that can be clearly conceptualised and communicated to others. It has also become clear to me that in my study I would like to strike a balance between respecting the emotional suffering that many dyslexic people have faced and still face, and holding fast to the expectation that they have the ability to learn to cope with it in positive ways.

While writing this literature review I was interested by Gerber *et al.*'s (1992) conceptual framework for developing positive self-perceptions and action, and the way this model dovetailed into the other research reviewed. Also, Pollak's (2005) work on discourses of dyslexia and the links he made between the way dyslexia is understood and the ability of the person to

cope with their difficulties echoed the changes I witnessed in Gary. By charting participants' accounts according to the discourse they use and how this links to the MVS I can contribute to knowledge about how dyslexic people make positive sense of their difficulties. Such knowledge is at an early stage in the field of dyslexia, and I think this kind of analysis, in addition to contributing to knowledge in the field, will be helpful to dyslexic people, practitioners, and parents of dyslexic children in helping them know better how to go through the process of reframing themselves, or to support others in doing so.

## CHAPTER 3: METHODOLOGY

*Wellington (2000, p7) defines methodology as 'the activity or business of choosing, reflecting upon, evaluating and justifying the methods you use' (p22), and this is what I will do in this chapter. I start with discussion of my research questions and the research framework I chose in order to answer those questions. I end with a more detailed discussion of the methods involved in life history carried out through analysis of discourse mapped onto the Model of vocational success (MVS) (Gerber et al., 1992).*

### Research design

In designing research one's primary purpose is to decide what process would be most appropriate to provide relevant and sufficient data about the questions being asked (Goodson & Sikes, 2001). This process therefore begins with the research questions. At the beginning of my doctoral studies, these were based on my experiences of hearing about my student Gary's life experiences, identifying dyslexia in Gary and observing his subsequent rethinking of himself as intelligent, and the resulting changes I observed in his attitudes and actions (described in Chapter 1, p16). I wanted to know what other dyslexic adults experienced, whether understanding themselves as dyslexic changed their self-perceptions; and, if so, how it happened and how it impacted upon what they did. With the completion of the literature review these questions were refined to incorporate the theoretical aspect of the MVS, to:

- 1) How does a dyslexic person's understanding of their difficulties with reading and writing, as represented by their use of discourse, relate to the way they understand themselves?

- 2) What are specific examples of aspects of the MVS in dyslexic adults' lives?
- 3) What cultural and environmental factors are involved with 1) and 2)?
- 4) What are the relationships between 1) and 2)?

To answer these questions it was obvious that I needed to talk to dyslexic adults, and I would need data that not only described their lives, and therefore their experience of being dyslexic, but also that provided fairly personal information such as the way they viewed themselves. The analysis involved in the research also needed to be able to take into account the context of the person, as from my experiences I was aware that events such as identification of dyslexia could have a big impact on the experiences of the person. I was also aware that an element of my purpose involved developing information that could improve or support better experiences for dyslexic people in future, as previous encounters with dyslexic people had demonstrated that economic and emotional suffering due to dyslexia was common, and my literature review confirmed this. Over the course of my PhD I have become aware of a number of shortcomings inherent in research that speaks on behalf of marginalized people which I discuss further in the section in this chapter on ethics (p99), however this remains part of the purpose toward which I am working.

Having identified questions and purposes it then remained for me to place them within a research framework that had the potential to deliver the information I wanted. Crotty (1998) writes, 'Justification of our choice and particular use of methodology and methods is something that reaches into the assumptions about reality that we bring to our work ... it also reaches into the understanding you and I have of what human knowledge is, what it entails, and what status can be ascribed to it' (p2). To put together a cohesive research project I therefore need to address my own stance on reality and knowledge. Because different academics use words related to these issues quite differently, I will adopt the research framework described by Crotty himself. Crotty describes four areas that provide a research framework from which beliefs can be made explicit: method, methodology, theoretical perspective, and epistemology. 'Method' represents the way the data is gathered/analyzed; 'Methodology' represents the larger plan, the strategy that links method to desired outcomes; 'Theoretical perspective' represents the philosophical foundation that provides logic to the research process; and 'Epistemology' represents the way knowledge is understood. The research framework I have chosen for this thesis involves a life history method including analysis of discourses of dyslexia and use of the Model of Vocational Success (Gerber *et al.*, 1992); the methodology of standpoint research and the theoretical perspective of critical theory within a social constructionist epistemology (see Fig. 3.1).

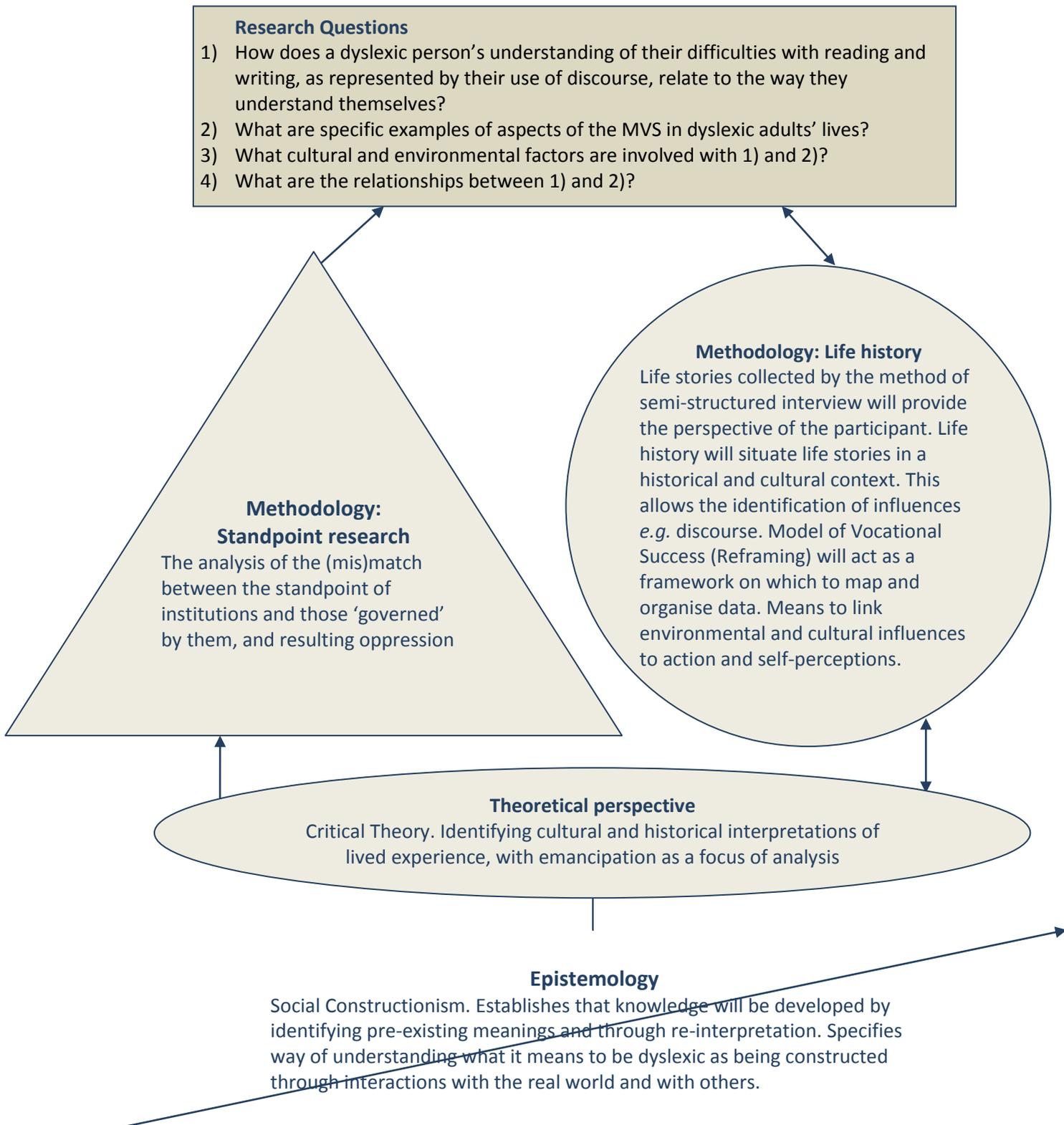


Fig. 3.1. Diagram of the research framework. The research questions will be answered using the method of semi-structured interview through a Life history methodology including analysis of discourses of dyslexia and use of the Model of Vocational Success (Gerber et al., 1992); the methodology of standpoint research; and the theoretical perspective of critical theory, founded upon a social constructionist epistemology.

Listing them this way could be understood to imply discrete categories as well as a hierarchy with Method at the top of the tree. However, in actually carrying out research these boundaries blur into each other and issues run between categories. This framework is imposed in order to make analysis of the categories more straightforward and/or more convenient (Crotty, 1998).

## **Epistemology**

'Epistemology' refers to beliefs about the nature of knowledge; what can be known, and how knowledge comes to be. The belief about knowledge from which this research has been carried out is Constructionism. Constructionism embodies the belief that 'all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context' (Crotty, 1998, p42). A constructionist belief about a tree is that were there no people on earth, the tree would still be there, however all knowledge related to 'tree-ness' would not. It would not be a 'tree', because people are required to ascribe such meaning. To further clarify constructionism, I will describe two other belief systems about knowledge, objectivism and subjectivism. Objectivists would believe that, were there no humans on earth, the tree would still be a tree, including its aspects of tree-ness. Objectivists believe that objects contain their own meaning, separate from human beings. Subjectivists would believe that, were there humans on earth or not, it is impossible to know if the tree is there. Subjectivists believe that people project ideas onto reality. Constructionism therefore is an intermediate position between objectivism and subjectivism, incorporating both the real world and a human process of meaning-making.

Social constructionism, a perspective from which this research is carried out, further develops the notion of knowledge creation, in specifying the social nature of its construction. 'We are all born into a world of meaning. We enter a social milieu in which a 'system of intelligibility' prevails' (Crotty, 1998, p54). As we grow up, we learn how to understand things through the perspective of our culture; not only what things are and how they are to be understood, but what to notice, what to ignore, what to value, what to denigrate. This perspective has a great impact on this research, as it is intricately involved in theories of the development of a sense of self (see sections later in this chapter on Identity/self, p94). Research carried out from a social constructionist perspective, because it understands all meaning to be a prior construction, is involved in re-interpretation and re-construction. In the case of this research, I

will be involved in establishing current ways people make sense of being dyslexic, as well as analyzing how culture may either contribute to or dismantle positive identities.

Social research can be contrasted to research of the natural world in terms of layers of interpretation. Natural scientists create one layer of interpretation, because the natural world does not interpret itself. However, the social scientist, in carrying out research, is adding another layer of interpretation onto one that already exists. Each participant in this study will have already interpreted their lived experience when they tell me about it during interview. Then, I will add another layer of interpretation when drawing the interviews together in my analysis. These two layers correspond to the 'life story' and the 'life history': I will discuss these terms in more detail in relation to the life history methodology (see p78).

I hold Realist beliefs – I believe there is a real world, and we construct our understandings and meanings through interaction with that real world. This belief stance has had implications for this research, for example in my ultimate decision to reject Positioning Theory (a form of discourse analysis) as a means to analyze my data, because it had the effect of stripping out the influence of all but social relationship.

## **Theoretical perspective**

As stated earlier, the theoretical perspective provides the philosophical framework of logic behind a methodology. As such, the theoretical perspective behind standpoint research and life history in this thesis is Critical Theory (Denzin, 1997). Similar to an interpretative approach in that it involves identifying cultural and historical interpretations of lived experience, in contrast to an interpretative approach, it sets emancipation as a focus of analysis. Horkheimer first distinguishes interpretative and critical approaches by stating that the former is a theory that describes the current situation whereas the latter seeks to change it (Horkheimer, 1937, cited in Crotty 1998). Although I would agree with Radnor (2002) who argues that interpretative research is critical by virtue of its emphasis on treating different voices with equal respect, I think critical theory is more appropriate to my own research because it openly acknowledges issues of oppression. The very fact that I am interviewing a marginalised group sets inequality centre stage, and my own experiences of oppression related to dyslexic people means it is a matter of relevance to me.

Changes in the relationship between ideas of culture and society have impacted upon the way social inequalities are recognized. According to Marcuse (1968, cited in Crotty 1998), from Plato until the rise of capitalism, culture was viewed as something above the practical day to

day realities of society. It was accepted that the vast majority of people had to devote their time and effort to basic necessities, and that only a very few had the luxury of focusing on aesthetics and truth. Then, culture was seen as an ideal and held in contrast to society.

With capitalism, according to Marcuse, this relationship between culture and society changed. With bourgeois society culture became an internal matter, where truth, beauty and meaning were thought to be within the grasp of every person. In this new relationship, it is possible to dismiss inequality in access to wealth, because every person is understood to have equal access to the riches of culture. Thus culture 'exonerated external conditions from responsibility for the "vocation of man", thus stabilizing their injustice' (Marcuse, 1968, p120, quoted in Crotty 1998, p158-159). Currently then, oppression is not only accepted, it can be invisible.

Researchers working from critical theory regard the belief that all have equal access to the riches of culture with suspicion. The accounts people give of their lives, rather than being understood straightforwardly as lived experience as an interpretative researcher might view them, are rather seen as expressions of 'the voice of an inherited tradition and a prevailing culture' (Crotty, 1998, p159). Denzin (1997) identifies this juxtaposition between discourse and lived experience as problematic. If what one says is actually socially-derived, already-there discourse, lived experience disappears. However, my own view is that 1) people's accounts of lived experience are given through discourse that is selected due to 'best fit'; and 2) people's accounts of lived experience are not only based on discourse. I believe that interactions with the world also contribute to understanding, though this may be at an unconscious or pre-verbal level (Heron, 1996). Pring (2000) describes the physical world as providing limitations to the construction of knowledge. Knowledge is not absolute, because we cannot remove ourselves so that we are outside of the local, situated-ness of concepts. However, knowledge is not relativistic, either; all ideas are not equal. As Pring notes:

*One is forced to acknowledge 'reality' as something not entirely 'created' or 'constructed' or 'negotiated', but constraining and limiting – something which is independent of us, which shapes the standards of what we can justifiably say, and which restricts the conclusions that can be correctly drawn from the evidence given (2000, p50).*

Thus one is able to choose discourse according to one's experience; however, discourse is always inadequate to represent it. 'We substitute concepts for what they represent but no concept can ever capture the richness of the reality' (Crotty, 1998, p132); 'objects do not go into their concepts without leaving a remainder' (Adorno, 1973, p5, quoted in Crotty 1998, p132). I believe discourse shapes the way we interpret experience; however the limitations

imposed on ideas through interaction with the world also create a dissonance between discourse and experience. Through a process of dialogue, with oneself or another, I believe it is possible to develop or create new discourse that is better able to represent previously silent aspects of lived experience. This issue is dealt with again in the section on standpoint theory and discourse (pp 73 & 89).

## **Research strategy**

As noted above, methodology is a researcher's plan of action, the strategy behind the choice of particular methods to answer the research questions. My chosen methodologies are standpoint theory and life history. Standpoint theory guides the critical, emancipatory aspects of this thesis, while life history organizes the means to use the method of interview, by contextualizing and re-presenting life stories with reference to the research questions.

## **Standpoint Theory**

Feminist standpoint theory was initiated by a sociology doctoral student in the 1970s, Dorothy Smith (Ezzy, 2002). She developed the theory in response to the hegemony of the objectivist, scientific stance that there can be a knower who can stand outside the known and describe or represent objective, unbiased reality. Instead, she argued that knowledge is always contextual and political, influenced by the experiences and orientation of the one in the position of 'knowing' (Smith, 1974). In Western society the knower is the white male, and Smith calls the system of concepts, symbols and institutions built up on the basis of white males' world – his context and politics – 'the governing body'. As a woman sociologist she described her disadvantage on two fronts; 1) the governing body was disjointed from her own experiences (that of the 'domestic world') and therefore so were the 'schemes' through which she was able to think about it and 2) her position was unequal to a man's; men's world is constituted in authority over women's world; 'the domestic world stands in a dependent relation to that other and its whole character is subordinate to it' (p7). The effect of this was 'to impose the concepts and terms in which the world of men is thought as the concepts and terms in which women must think their world. Hence in these terms women are alienated from their experience' (p7). Smith concludes that the reason men are able to claim that they are objective and unbiased in the creation of knowledge is because their position within society is set up so that normal links with the body and experience are severed through the work of women. Women take care of men's physical needs, enabling them to remain in a conceptual realm, and the 'fit' between the structures of the governing body and their own lives is so tight that the bias involved in their creation of knowledge is invisible to them. Smith's response to

this situation was to suggest that 'if sociology cannot avoid being situated, then sociology should take that as its beginning and build it into its methodological and theoretical strategies' (p11). In order to circumvent the structures of symbols and concepts already established by the governing body, she would attend to lived experience, whilst identifying the contextual and political bias involved in her analysis.

Feminist standpoint theory has since been adapted by many minority groups – for example Afrocentric, Native American, Asian, Third World, Queer, as a means to draw on individual experiences in order to develop a framework of symbols and concepts that 'speak to the logic and cultures of these communities' (Denzin, 1997, p54). Such analysis can produce new discourse from the perspective of the minority group: 'The notion of a standpoint outside discourse holds a place in discourse for she who has not yet spoken, not yet declared herself, not yet disinterred her buried life' (Smith, 1993, p183).

There are a number of parallels between Smith's (1974) 'governing body' and women, and the institutes of science and education and dyslexic people. These suggested to me the appropriateness of this methodology for the purposes of my research.

For example, the predominant discourse of dyslexia is a medical one, where it is perceived as a problem within the person, and described in cognitive psychological terms, such as problems of phonological coding and auditory short-term memory (Pollak, 2005). Not surprisingly, most dyslexic people also understand themselves in those terms (Pollak, 2005). They are 'alienated from their experience' (Smith, 1974, p7) in that the discourses available to them involve abstract conceptualization removed from their lived experience. In describing sociology and/or 'the governing body', Smith (1974) writes,

*Sociology is part of the practice by which we are all governed and that practice establishes its relevances. Thus the institutions which lock sociology into the structures occupied by men are the same institutions which lock women into the situation in which they find themselves oppressed (p8).*

The analysis of the (mis)match between the standpoint of institutions and those 'governed' by them, and resulting oppression, is also particularly relevant to the study of dyslexia. The institute of education has been founded on the ability of its subjects to read, write and spell, and it celebrates linear thought. Dyslexic people have difficulty with reading, writing and spelling, and rather than linear thought, holistic, spatial thought and creativity are claimed by many dyslexic people to be strengths (Davis & Braun, 1997, West, 1997). Dyslexic people are

oppressed by the concepts and terms of education that foreground their areas of weakness as those which are relevant.

There is also an echo between feminist standpoint research and the idea that dyslexia is the 'battle cry' of middle class parents against the institution of education that would cast out their offspring as academically unsuitable. Dyslexia is often referred to as the 'middle class disease', and has not been taken up in the same way by working class parents. This fits well with feminist standpoint theory that the institution of education can be seen as a mechanism by which the white male perpetuates the governing body. The white male of the governing body is educated; therefore the boy who does not learn to read and write is prevented from being integrated into the governing body. This is objectionable to middle class parents, whereas integration into the governing body is not so often part of the discourse of the working class. It also makes sense of the greater finding of dyslexia in boys.

Standpoint research demands analysis of lived experience. Though present discourses can be identified and new discourses can be developed, these originate in the realities of people's lives:

*I propose a point d'appui for sociological inquiry in the actualities of people's lives. I'm talking about a place to begin, not a topic, nor a subject-matter, nor an object. From this beginning, we can, I hold, discover something at least of how this leviathan we live in is put together in the concerting and coordinating of people's ongoing activities, including those of discourse ... I learned in the early years of the women's movement that there was indeed a site beyond and inclusive of the text-mediated, text-based discourses of professional sociology and academia. Or of the media, popular culture, or high culture. You might describe it as where we live. As particular individuals, embodied, in particular actual places with particular actual others, at the time it is right now (Smith, 1993, p183).*

That discourse is a point of interest in Standpoint research in terms of its interplay with real life is also an aspect of this theory which convinced me that it was appropriate to my research. It is consistent with my Realist belief stance of the importance of the real world alongside that of discourse.

Standpoint research is usually carried out by a member of the minority group in question, and in my case, I am not dyslexic. However, my identity is intertwined with those who are dyslexic, for example my brother, my aunt, my husband and my son. Inasmuch as the scientific project can be seen as a fulfillment of society's aspirations for a man, as described by Smith (1974), creating knowledge that is of benefit to one's loved ones might also be seen to be a fulfillment of a woman's aspirations in society (Belenky *et al.*, 1988). In this way I name the contextual

and political bias involved in my analysis, whilst also staking my claim to be able to carry out standpoint research in the name of others. However, my position as semi-outsider also makes it particularly important that I engage with my participants about my analysis. This issue will be discussed further in the section on rigour (p82).

## **Life history**

Though the life history methodology will be considered in more detail below, I will briefly summarise here how it suits the purposes of my research. Life history as a methodology guides the way I will deal with the interview method; the way participants talk about their lives in 'life stories'. The life story provides a window into individual perspective. Although there are limitations to the way a life story is re-presentative of lived experience (which will be discussed below) life stories are 'as close [to lived experience] as it is possible to get' (Goodson & Sikes, 2001, p56). This is imperative to the purposes of my thesis as I want to portray the lived experience of being dyslexic. The life history methodology emphasizes the importance of linking aspects of life stories to the part that context plays in these experiences. This spotlights the process of interaction between the person and society, important for example in looking at the process of how a person comes to understand what it means to be dyslexic, and also in understanding how it might be possible to modify the environment of dyslexic people in the future in order to improve their experiences. As Goodson & Sikes (2001, p88) put it, 'The life story individualises and personalises; the life history contextualizes and politicises'. I will examine participants' use of discourse in order to identify links between society and a person's understanding of dyslexia, analyzing how use of discourse links to issues of identity, and employ the Model of Vocational Success formulated by Gerber *et al.* (1992) to map the life experiences of my participants and organize the analysis of links between context, discourse and individual.

## **Method**

The method I adopt is that of semi-structured interview. In order to answer my research questions about the way dyslexic adults understand their difficulties with reading and writing, the way they relate these difficulties to themselves, and how they have learned to cope with these difficulties, it is necessary to talk with them in some depth. Other means of gaining personal information, for example surveys, would limit the scope of what the person would be able to say (Van Manen, 1997). It would have been appropriate to gain in-depth information from written sources such as diaries, however the participants' difficulties with reading and writing made this impossible. The interviews were semi-structured in order to both open up

the interview to allow participants to lead with the information they found important, and to allow specific probing by me in order to steer the participant toward the interests of my thesis. The process of interview is discussed in detail in Chapter 4 (p113).

During the course of this thesis, I have rued my willingness to submit to the requirements of others during my childhood. I stilled my voice so others' could be heard, and this made writing this thesis difficult, because it has required me to find my own voice, an exercise with which I had previously not had much practice. However, my training during childhood in listening and respecting others, in trying to understand their perspectives, I have found of good use during my thesis interviews. Reissman (2008) writes,

*We must also learn to listen attentively. Despite the significance of listening, Molly Andrews notes that the complex process is rarely included in social scientists' professional training. Yet when we learn to listen in an emotionally attentive and engaged way, we expose ourselves and enter the unknown with "new possibilities and frameworks of meaning." (p26).*

Listening attentively is something I came to the PhD already knowing how to do.

## **Life history research**

I will now discuss life history in more detail. Life history research involves two-level interpretation; first, the participant is involved in a process of interpretation as they craft what they say about their lived experience into a life story, then, the researcher interprets what they have said by setting the life stories in the context of culture and environment and represents it in a life history. I would like to start this discussion, though, by clarifying my position in relation to a few 'sticky issues' in social science research: objectivity and representation. Although the crisis of representation, according to Denzin and Lincoln (2005b), occurred in the 1980s while I was an undergraduate, I was not aware of it until I began my MSc in Educational Research in 2005. Between the 1980s and 2005, qualitative research in the social sciences has come a long way toward establishing itself widely; as Richardson (2005) writes about creative analytical processes in ethnography (CAP),

*Any dinosaurian beliefs that "creative" and "analytical" are contradictory and incompatible modes are standing in the path of a meteor; they are doomed for extinction. Witness the evolution, proliferation, and diversity of new ethnographic "species"—autoethnography, fiction, poetry, drama, readers' theater, writing stories, aphorisms, layered texts, conversations, epistles, polyvocal texts, comedy, satire,*

*allegory, visual texts, hypertexts museum displays, choreographed findings, and performance pieces, to name some of the categories that are discussed in the pages of this Handbook. These new “species” of qualitative writing adapt to the kind of political/social world we inhabit—a world of uncertainty. With many outlets for presentation and publication, CAP ethnographies herald a paradigm shift (p962).*

Thus, my discussion about objectivity vs. subjectivity, representation and rigour in qualitative research is in some ways ‘old hat’, and justifying a postmodern position unneeded. However, because I have come across postmodernism as a novice, I would like to explore and express the issue in my thesis at greater depth than strictly necessary because I have a need to think through and write about what has been a paradigmatic shift for me. Having established these issues it will be easier for me to describe the life story and its relationship to lived experience, and to discuss the process of contextualising life stories to create a life history.

## **Objectivity vs. subjectivity, representation and rigour in life history research**

The history of research development and the relatively recent explosion in the development of interpretative approaches means scientific approaches to rigour in interpretative research have a surprisingly wide influence, rather than approaches that are more appropriate to qualitative issues. I will be approaching rigour from the latter perspective, which will combine interpretivist and political concerns after giving some background to the historical controversy surrounding rigour in research.

There are a number of charges levied against qualitative research, usually made from a Modernist perspective. Modernist thinking has been a powerful force in past times, particularly during its zenith between 1950-1970, and is still powerful today; for example, it is seen in the prioritising by governments in recent years of ‘narrowly defined governmental regimes of truth. The new “gold standard” for producing knowledge that is worthwhile is based on quantitative, experimental design studies’ (Denzin & Lincoln, 2005a, pxi). There are also social scientists who are not persuaded of a postmodern stance (for example see Hammersley, 2008).

Guided by Modernist thought social scientists pattern their research after positivist attitudes in the natural sciences, such as the idea that objective fact has supremacy over subjective attitudes and beliefs. From this perspective, positivist approaches to research produce ‘“truth” that can transcend opinion and personal bias’ (Denzin & Lincoln, 2005b, p8). By this

perspective, qualitative research in the social sciences, with its focus on the subjectivity of being human, can be regarded as fiction rather than fact.

However, the positivist claim of objectivity has met much criticism itself during what Denzin and Lincoln (*ibid.*) call the 'crisis of representation' and the Post-modern period that followed. In the 1980s, awareness grew, particularly within the field of anthropology, that what had previously been understood as 'objective' analysis, where the researcher removed themselves from their writing, in fact was anything but objective. Instead the objective anthropologist was often revealed as a white, western male with perspectives embedded in imperialism, colonialism and patriarchy, claiming authority of perspective not through any ability to ascertain 'truth' objectively, but rather through the norms of his own culture which set him in a position of power (Clifford & Marcus, 1986, Smith, 1974). The early female ethnographer can also be seen to be fulfilling her western, culturally defined role of femininity in her choice of subject matter (Tedlock, 2003). It also became recognized that participants always give an interpretation of their lived experience, rather than their accounts being a direct representation of lived experience as previously claimed (Denzin, 1997). The startling realization that 'objective reality can never be captured' (Denzin & Lincoln, 2003, p8) has impacted wider realms of research, including the natural sciences (Atkinson, 1990, Sparkes, 2002, Vidich & Lyman, 1998), and the crisis of representation has brought ethical issues of the researcher-participant relationship to the fore (Lincoln, 1995).

In addition, the essentialism of positivism has come under attack. Essentialism refers to the practice of deciding on a few salient characteristics and treating these as though they are comprehensive. A scientific approach focuses on isolating cause and effect, operationalising theoretical relations and measuring and quantifying phenomena, and excludes all but generalisable findings. Qualitative researchers view a scientific approach as eliminating crucial elements of the subject matter under study, particularly in the social sciences, and either see it as one more 'way of telling tales about society or the social world' or reject a positivist approach outright because of the effect it has of producing only narrow data and silencing voices (Denzin & Lincoln, 2003, p15).

This concern has relevance to the field of cognitive psychology, in particular to its relationship with dyslexia. Bruner (1990), as a founder of the cognitive movement in psychology, describes how it was originally 'inspired by the conviction that the central concept of a human psychology is *meaning* and the processes and transactions in the construction of meaning' (p33). However, the conviction that founded the cognitive psychology movement was diverted by the metaphor of the mind as computer, and a shift to a focus on information processing,

presumably because such a framework fits itself much more neatly into the more valued modes of positivist approaches in psychology. He concludes,

*There is no question that cognitive science has made a contribution to our understanding of how information is moved about and processed. Nor can there be much doubt on reflection that it has left largely unexplained and even somewhat obscured the very large issues that inspired the cognitive revolution in the first place (p10).*

In the case of dyslexia, cognitive psychology greatly overshadows other areas of research in dyslexia, as mentioned in the literature review. Cognitive psychology has made great strides on a number of fronts, the most promising being its identification of phonological coding as part of the causal cognitive mechanism behind dyslexia (Vellutino *et al.*, 2004). However, this and other results from cognitive science are only one piece of a much bigger puzzle. The influence of cognitive psychology can be said to have supported an essentialist view of dyslexia, where all but issues of information processing are relatively ignored.

From Bruner's (1990) perspective, biology is not constitutive of mind; 'rather, it imposes constraints on action, constraints whose effects are modifiable' (p34). According to Bruner, culture, imposed upon the constraints of biology, is constitutive of mind, and 'cultures characteristically devise "prosthetic devices" that permit us to transcend "raw" biological limits' (p34). In the case of dyslexia, from this perspective, difficulties in phonological coding limit the ease and speed in which it is possible for a dyslexic person to be able to learn to read and write, but the way this is understood and dealt with is a matter of culture. What meanings do dyslexic people make about their difficulties, and how do meanings relate to self-identity? What part does our culture play in the meanings that dyslexic people make? What "prosthetic devices" has our culture already devised, or might be devised, that allow or might allow dyslexic people to transcend the limits imposed on them by biology? These, too, are important questions, and it may be argued that answering them has more potential to offer support to dyslexic people than understanding cognition.

An essentialist tendency to view research in cognitive psychology as the only piece of the puzzle of dyslexia, not only is insufficient in describing dyslexia, it comprises a disservice to dyslexic people. Bruner (1990) writes,

*Scientific psychology, after all, is part of that same cultural process, and its stance toward folk psychology has consequences for the culture in which it exists (p15)*

As was shown in the literature review, the 'patient' discourse of dyslexia (Pollak, 2005) is dominant, in which dyslexia is seen as a deficiency in a person's brain. This perspective causes deep-seated problems for dyslexic people in the development of positive identity (*ibid.*). Undoubtedly the prominence of research in cognitive psychology plays a role in the pervasiveness of this discourse. The impact of cognitive psychology on dyslexic people is an example of the way the practice of 'objectivity' required by a scientific approach can have the effect of concealing the social and political impact of such research (Goodson & Sikes, 2001). It is presented as 'objective' and removed from context and the meaning-making process. In this way the subjectivity of qualitative research can be viewed as a virtue because addressing political/ethical issues becomes a necessity that confronting subjectivity inevitably demands (Radnor, 2002).

Modernist perspectives may still be common, however qualitative, interpretivist approaches can no longer be dismissed as they were previously (Marcus, 1998), and in some cases, qualitative research is acknowledged as taking priority. For example, in a session at the International Congress of Qualitative Inquiry in 2006, Janice Morse stated in response to a question regarding the future of qualitative research,

*I want to talk about where we are now and where we are going. At the moment, I think we are in a good position, but we are not in such a fortunate position everywhere ... In his closing address of the QHR [qualitative health research] conference in Edmonton a few months ago, Carl Mitcham, who is a philosopher of science and technology, made a very interesting argument that the sciences in quantitative inquiry have almost outdone themselves—quantitative inquiry is becoming increasingly expensive for smaller and smaller gains in knowledge and discovery. And the time for qualitative inquiry is coming, for there is still much to discover qualitatively. I kept thinking of the \$28 million project funded [S.U.P.P.O.R.T.] by Robert Wood Johnson on end-of-life care, which had no statistically significant finds. And at the end, they called in qualitative folk to try and save this project' (Ellis et al. 2008, p278).*

My opinion is that criticisms of qualitative research as 'soft science' can be 'regarded as an attempt to legislate one version of truth over another' (Denzin & Lincoln, 2005b, p8), and I have chosen an interpretive approach because I understand it to be the best way of answering my research questions. Ethical issues are also of primary importance to my critical stance, and the approach of confronting subjectivity sets a better foundation for addressing such issues.

Perhaps to avoid the risk of being dismissed, many qualitative researchers address issues of rigour in their research from the perspective of a scientific approach, attempting to develop qualitative equivalents to scientific issues of rigour in a sort of apology to the hegemonic

scientific research community (Ezzy, 2002). However scientific issues of rigour do not easily translate to an interpretative/critical approach. For example,

- People's meanings and interpretations shift in response to changes in society, therefore scientific issues of reliability are not appropriate;
- Events do not have one meaning, but many. Although some interpretations are better than others, scientific approaches to validity are not appropriate;
- Being 'objective' simply means the researcher is not addressing subjective influences (Ezzy, 2002).

The question that remains then is how rigour is established if it is not based on scientific traditions? According to Ezzy (2002), there are two approaches to rigour that focus on issues relevant to qualitative research. The first is related to rigour in interpretation, and rather than attempting to establish correspondence between 'reality' and representation as in a scientific approach, it attempts to demonstrate sensitivity and thoroughness in representing the systems of meaning, interpretation and feeling in research participants. One description of aspects of this endeavour (from Gubrium & Holstein, 1997, summarised in Ezzy 2001 p54) is represented below:

- scepticism (looking beyond ideas of common sense and quantitative research about social life)
- Close scrutiny (immersing oneself in the data to enable the appreciation of the detail of participants' lives),
- thick description ('rich, clear and nuanced description of social life'),
- focus on process (awareness that social life is continually re-constructed),
- appreciation of subjectivity (social life is based on meaning, interpretation and feeling and these aspects must be a focus) and
- tolerance for complexity (simple explanations of social life and culture tend to be inadequate – research needs to be able to represent complexity).

The second approach to rigour currently used by qualitative researchers involves a commitment to addressing ethical, political issues involved when a researcher represents a group of participants. The ethical practice of hearing participants as well as respecting them is a natural extension of the rigour of interpretation described above (Ezzy, 2002). Political aspects of the research can be approached from the questions, 'How is knowledge created? By and for whom? And with what consequences for individuals, groups and society?' (Richardson, 1997, p102, quoted in Ezzy 2002). Though both political and ethical issues are contextually bounded and therefore good practice is difficult to prescribe, the following set of criteria (Lincoln, 1995) provide a model for rigour involving political and ethical issues:

- Positionality (the position from which the researcher speaks should be made clear)

- Community as arbiter of quality (responses to the research from participant, academic and/or political communities contribute to judgments about research value)
- Voice (research should give voice to those normally marginalized in society)
- Critical subjectivity (the researcher should practice reflexivity in their sensitivity to participants)
- Sacredness – ‘a profound concern for human dignity, justice, and interpersonal respect’ (Lincoln, 1995, p284)
- Sharing privileges (the researcher should not be the only one to benefit from carrying out the research. Research results and other benefits, for example, any royalties, should be shared between participants and researcher)

I will employ these latter two sets of criteria in my attempts to establish rigour within this research. I refer to issues of rigour in many places within this thesis, for example when I describe below how I collected and analyzed the data, and above when I stated my position in the discussion of standpoint research. My success in meeting these criteria will also be examined in Chapter 5: Conclusion.

One of the criteria that establish rigour, mentioned above, that I regard as particularly important is reflexivity. Reflexivity refers to a researcher’s awareness that rather than directly representing reality, ‘texts themselves are implicated in the work of reality-construction’ (Atkinson, 1990, p7). Therefore a researcher’s task involves not only being aware of issues of convention in the texts being studied, but also exposing one’s own conventions in the research text being produced. The choice of research subject, the perspective from which the problem is understood, the data that is collected and the meaning that is made from it are all implicated in this issue (Mauthner & Doucet, 2003). Reflexivity therefore is an important part of an interpretative/critical research project, as it is the means to represent the role of subjectivity in that project. Marcus (1998) describes it as the ‘crucial turn’, ‘a departure from the ideology of objectivity, distance, and the transparency of reality to concepts’ (p393). Perhaps because of this it is an issue of much debate. There are a number of criticisms of reflexivity, for example that of narcissism: it can result in research that contains more information about the researcher than about the subject matter under study (see Canagarajah, 2005). My endeavour to decide what information about myself as researcher is necessary and supportive to the research, and what is surplus, has been one I have found difficult.

In reading the literature, I find that I am not the only researcher with such experiences. Choosing how one is to be reflexive and putting this into practice can be considered a complex issue that is rarely addressed (Mauthner & Doucet, 2003). Finlay (2002) dubs engaging with reflexivity as ‘negotiating the swamp’ of ‘interminable deconstructions, self analysis and self disclosure’ (p209). Though I have practiced reflexivity in a number of ways during this

research, I have primarily chosen a dual approach. The first involves the traditional practice of the ethnographer who 'sets the stage' for her study by giving a personal narrative in the introduction (Pratt, 1986, p35); this is to establish the perspective from which I have carried out the research. However, in the body of the thesis my focus is on reflexivity 'as a politics of location' (Myers, 1988). This type of reflexivity 'is one that emphasizes the intertextual or diverse field of representation that any contemporary project of ethnography enters and crosses in order to establish its own subject and define its own voice' (Marcus, 1998, p398). The nature of my analysis as standpoint research makes the task of analyzing the data a practice in identifying and mediating between different perceptions of dyslexia, that of the dyslexic adult, the educational practitioner, the cognitive psychologist, the mother, the media. My goal is to extract and represent the voice of the dyslexic adult, unpicked from all the others. It is therefore particularly important in this research to keep at the fore a reflexive awareness of the discourses used by the participants to construct their life stories and my own tendencies to interpret what is said based on my position as mother, practitioner and academic, whilst attempting to locate the 'silences' that will help develop the discourse of the dyslexic adult (Smith, 1993).

## **The life story**

The starting point for this research was the desire to understand better what it is like to be dyslexic. To go about finding this out I am interviewing dyslexic adults. But how does what they say during interview relate to what their experiences of life have been? This question is related to the sticky issue of representation touched on in the last section. Were I concerned with determining 'reality' – searching the interview transcripts for a true representation of events in my participants' lives – I would be faced with enormous difficulty. Certainly, psychological research looking at retrospective memory has demonstrated clearly that what is remembered can vary dramatically from the way events actually transpire (Schacter, 2007). As I have already discussed, it is impossible to represent one's experience through anything but interpretation. However, the purpose of my study is not to evaluate whether or not what people say happened in the way they described it, but rather to identify and analyze dyslexic adults' meaning-making process. As Goodson and Sikes (2001) write, 'life history work is interested in the way people *do* narrate their lives, not in the way they *should*' (p16).

## Narrative

### *What is narrative?*

Attention to narrative has increased dramatically over recent years in what some have called 'the narrative turn', as this increase has developed alongside the postmodern turn. As it became more accepted that knowledge can only be partial, always constrained by cultural context and perspective, sociologists and anthropologists also began to discuss whether participants' accounts of their lives were a clear and straightforward mirror of lived experience or partial descriptions constrained by context, as well (for example Geertz, 1973; Clifford, 1986). Understanding of narrative with regards to literature/story extended to the telling of ones' life, a process heightened not only by increasing questions about realist epistemologies, but also by the growth of memoir, stories told by marginalized groups and therapy (Langellier, 2001, cited in Reissman, 2008). These extended understandings of narrative have burgeoned to what Reissman (2008) describes as the growth of use of the term 'narrative' to 'mean anything beyond a few bullet points' (p4).

As is true for dyslexia, there is no one definition of narrative. Reissman (2008), while describing the explosion of references to narrative as 'the tyranny of narrative' (p5), specifies that 'narrative is everywhere, but not everything is narrative' (p4), citing description, for example lyric poetry, as an example of text that is not narrative. She links different definitions of narrative to the needs of different contexts; *e.g.* greek tragedy (narrative is action sequenced through plot, with a breach to the expected), social linguistics (discrete topically and temporally organized response to a survey question), history and anthropology (an entire life story), sociology and psychology (long sections of description about life experiences, that may develop over repeated interviews). She defines narrative herself as,

*a speaker connects events into a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story. Events perceived by the speaker as important are selected, organised, connected, and evaluated as meaningful for a particular audience (p3).*

She characterises this definition as one commonly used by academics in social sciences to refer to texts that include the sequencing of events in a way that connects them for meaning, and qualifies the term 'story' as being a subcategory of narrative; story being a narrative that includes a 'rupture' or break in the expected playing out of events. She also admits, however, to have come to adopt over the years the use of the term narrative to be equivalent to 'story', as is common in popular culture. Polkinghorne (1995) discusses the inherent plot within narrative, thereby also paralleling it with the idea of 'story'.

Bruner (1986) describes narrative as a form of knowledge that is different from that produced by logical, linear models of causation in the natural sciences (the logico-scientific mode).

Rather, this form of knowledge regards meaning not as inherent to an object or action, but a construction of social relationship and discourse. Bruner therefore contrasts narrative to the natural sciences. However Richardson (1997) argues that both these, the narrative and the logico-scientific modes of knowledge, are represented narratively. Richardson characterizes narrative reasoning as, 'the type of reasoning that understands the whole by the integration of its parts' (p28). Polkinghorne (1995) can be seen to have a similar emphasis, as he explains, 'Narrative is the type of discourse composition that draws together diverse events, happenings, and actions of human lives into thematically unified goal-oriented processes' (p5).

Porter Abbott (2002), an academic in the field of literature, defines narrative quite broadly as 'the representation of an event or a series of events' (p12). He draws attention to the 'event' – some form of action – as delineating narrative from description, but does not require events to be linked causally in the quest for meaning as Reissman does. Porter Abbot's perspective on narrative involves the analysis of literature and stories rather than the creation by a specific person of narrative to make sense of life experiences during interview.

In this thesis I will be adopting Reissman's definition. I take her point that narrative is defined in relation to the context in which it is being used, and I will approach narrative in the way that suits my purpose by treating it as a stringing together of life events, chosen and sequenced in such a way as to create meaning, as the meaning-making aspects of narrative are the focus of my thesis. Because the structures of story, such as plot and a 'rift', are not a focus, I will not treat them as important to the definition (though my participants include these aspects of story in their interviews). I thus view my interview data as narrative; each participant chooses to detail and sequence specific events in their lives in order to make sense of their life experiences for me during interview. The participant narratives in this thesis will be represented at the level of the life story, which is made up of successive interviews.

In the discussion above about the definition of narrative, it was demonstrated that the narrative of a life is a re-presentation. Through narrative we make sense of the jumble of sometimes conflicting and endlessly complex sensory experiences with which we are bombarded every day of our lives. A narrative does not present life experience as it is; it makes sense of it. Porter Abbot (2002), in discussing pictorial art that does not make obvious sense, writes,

*...our narrative perception stands ready to be activated in order to give us a frame or context for even the most static and uneventful scenes. And without understanding the narrative, we often feel we don't understand what we see. We cannot find the meaning' (p11).*

So the narratives of each participant in this thesis are re-presentations of participants' lived experience (which parallels the life story). Bruner further explains how and why people make sense of their lives in the way they do through what he calls 'folk psychology';

*A set of more or less connected, more or less normative descriptions about how human beings "tick", what our own and other minds are like, what one can expect situated action to be like, what are possible modes of life, how one commits oneself to them, and so on. We learn our culture's folk psychology early, learn it as we learn to use the very language we acquire (Bruner, 1990, p35).*

Folk psychology then is a framework that our culture gives us to make sense of our lived experiences, a structure that we construct implicitly through language from our experiences interacting with other people from birth. Bruner (1986) draws on Vygotsky to establish language as a tool that makes it possible to extend and develop our ability to think, and that language is therefore constitutive as well as representational. As a child learns folk psychology from the people in his or her life, s/he constructs knowledge about the way things should be. However, folk psychology is not 'copied' from culture to individual. Derrida (1988), in his deconstruction of writing as subordinate to speech, demonstrates that there is always a cleft in linguistic meaning, which he calls absence. Absence takes many forms; the absence of full awareness of the speaker/writer as to their own intentions, the absence of full awareness by the listener/reader as to the speaker's intentions, and/or the absence of the speaker/writer's full awareness of the interpretation of the listener/reader. Derrida draws on the work of Austin (1962) who both identified that language is not only a system of reference but also a system of action; and the importance of context in determining what action is possible through speech. Derrida clarifies that to be used language must be already known – knowledge of folk psychology learned by a child gives an example of this developing – but because the context in which speech occurs can never be completely known as represented by Derrida's explication of absence, meaning is not finite but polysemic. In this way language is transformed even as it is perpetuated through repeated use, and therefore concepts and possible action are also transformed as they are perpetuated.

In other words, people hold different understandings from each other about the same thing, as well as holding common understanding, and no one ever has full awareness of the extent to which their understandings correspond to another's. Understanding will vary according to

differences in interactions with the world. In this way folk psychology forms the basis of a person's way of understanding and framing the world, however each person can also contribute to an ongoing transformation of folk psychology as they communicate their own personal 'take'.

Bruner describes narrative as a human tool used in conjunction with folk psychology to make sense of the extraordinary. We implicitly assume the ordinary or canonical structures within society, gained through the internalization of folk psychology, and use narrative to make sense of exceptions to the rule,

*The "negotiated meanings" discussed by social anthropologists or culture critics as essential to the conduct of a culture are made possible by narrative's apparatus for dealing simultaneously with canonicity and exceptionality. Thus, while a culture must contain a set of norms, it must also contain a set of interpretive procedures for rendering departures from those norms meaningful in terms of established patterns of belief. It is narrative and narrative interpretation upon which folk psychology depends for achieving this kind of meaning. Stories achieve their meanings by explicating deviations from the ordinary in a comprehensible form (ibid. 1990, p47).*

McNulty (2003), who analyzed interviews with dyslexic adults on the basis of narrative structure, found that in the case of dyslexia the narrative is established when school children are not able to read and write in the same way as their peers – this is the exception to the rule on which the narrative hinges. The development of the narrative is based on a figurative journey to answer the question 'what's wrong with me?' with resolution of the narrative occurring by means of a range of ways through which the adults come to understand their difficulties. By telling their life stories about dyslexia, then, the participants will be sharing the meanings they have made in relation to their difficulties with reading and writing, thereby justifying the way their lives have been an exception to folk psychology.

## **Discourse**

Wetherell (2001) gives a general definition of discourse by stating that 'the study of discourse is the study of language in use ... [and in a broader definition] the study of discourse is the study of human meaning-making' (p3). In an overview of different kinds of understandings of discourse, Phillips and Jørgensen (2002) discuss three approaches : Ernesto Laclau and Chantal Mouffe's discourse theory, Critical discourse analysis and Discursive Psychology. I will discuss the latter two as they are most relevant to the discourse analysis in this thesis. But first I will describe the aspects of social constructionism on which these ideas of discourse are all founded as explained by Phillips and Jørgensen (*ibid.*), who list four:

- 1) A rejection of the notion of objective truth, since all knowledge is a result of the way in which we construct our experiences through categories or discourse.
- 2) The anti-essentialist perspective that knowledge is historically and culturally dependent ; each person's approach to experience could have been different according to when and where they live, and can continue to change over the lifespan. Discourse is social action that has a role in constituting knowledge, identity and social relationships, and so is implicated in social structures.
- 3) A stance that the origin of knowledge is in social interaction; people construct and compete about what is true and what is not.
- 4) There are social consequences to different forms of knowledge; over time patterns of knowledge become imbedded within people's worldview so that some types of action are expected and others unacceptable.

These aspects represent similarities between the three approaches; I will now describe Critical Discourse Analysis and Discursive Psychology, discuss how they differ and what their significance is to the discourse analysis in my thesis.

Critical Discourse Analysis is dominated theoretically by work from Norman Fairclough, whom Phillips and Jørgensen (*ibid.*) characterize as providing 'the best developed theory and method for research in communication, culture and society' (p60). Fairclough has a linguistic focus; in fact he originally calls his form of analysis 'critical language study'. He positions Critical Discourse Analysis as drawing on aspects of linguistics but restructuring their relationships to each other. Rather than linguistics 'proper' (*ie.* phonology, morphology, syntax and semantics) being at the top of a hierarchy with other aspects (*e.g.* sociolinguistics, pragmatics, conversation analysis etc.) considered to be sub-disciplines, Fairclough shifts emphasis so that all these revolve around the social nature of language, which he holds to be linguistics' core. He is more interested in asking 'how?' and 'why?' than the more commonly answered question in linguistics, 'what?', and his language analysis is carried out by charting the historical struggles between groups to maintain or gain power through use of language. He also acknowledges an inter-related role for non-language-based social structures in the gain and maintenance of power. His purpose is to document change in use of language and the power relationships in and behind use and change in use of language, in order to support the emancipation of those who are oppressed (Fairclough, 2001).

Fairclough particularly looks at use of language in wider society, for example through analysis of political and institutional documents and texts (a text is the transcription of spoken language) (see for example Fairclough, 2000a; 2000b; 1995). His framework for language

analysis involves the examination of the production and interpretation of language, and the way this sits within the immediate social environment, the wider social institution and finally the level of society as a whole. In Pollak's identification of discourses (2002) he draws primarily on Fairclough (2001) in that he establishes discourses of dyslexia on the basis of a survey of historical developments of concepts and ideology in conjunction with institutional usage (Educational Psychologist reports and information about dyslexia from Higher Education institutions) and the way dyslexia was discussed by the participants in his study. Pollak also draws on the work of Ivanič (1998) who traces identity formation in writing by mature students in higher education to theorise the relationship between discourse and identity. In this work Ivanič also theorises discourse analysis through work by Fairclough, but acknowledges his focus on identity in terms of 'fluctuating cultural and institutional values', and so turns to Vygotsky and others to conceptualise processes of change in identity for individuals.

Pollak's approach to discourse analysis is important as I implement the discourses he has identified deductively in my data analysis. These discourses represent ideologies readily available for understanding dyslexia in our culture (with the exception of the Campaigner discourse (see below p223), the conceptualization of which appears to be more difficult to access). Pollak's approach of identifying societal-level perspectives of dyslexia was appropriate to his study, the purpose of which he describes to be primarily practitioner-based; 'My intention is to increase understanding of dyslexia, to produce insights which may help Universities to work with this kind of student, and ultimately to contribute to the debate about academic literacy ... and reductionist views of special educational needs' (Pollak, 2002, p7-8). My own purposes focus more specifically to a process of personal meaning-making on the part of participants because it is their perspective which has priority in this thesis. I am particularly interested by the possibility of the origination of discourses in response to experience of disability as discussed in above in the section on Standpoint Theory (p. 73). Like Pollak, I acknowledge the fundamental role available repertoires of discourse play in the construction of identity, and wish to draw on Fairclough's framework for the production and interpretation of language; however I would also like to explore the responses of dyslexic people to the marginalizing impact of many of these discourses and for this Discursive Psychology offers some useful insights.

Phillips and Jørgensen (2002) describe Discursive Psychology thus;

*The aim of discursive psychologistis is not so much to analyze the changes in society's 'large scale discourses', which concrete language use can bring about, as to investigate*

*how people use the available discourses flexibly in creating and negotiating representations of the world and identities in talk-in-interaction and to analyze the social consequences of this (p7).*

This approach is commensurate with my desire to explore the relationship between different discourses of dyslexia and the MVS, looking for patterns as to how each discourse links with the development of positive self-perceptions and action as represented by the MVS. This approach to discourse also supports my desire to look for the creation of discourse by dyslexic adults, to more accurately describe their embodied experiences. Discursive psychology emphasizes that choice of use of discourse is a form of 'social accomplishment' (Potter & Wetherell, 1987, p116), that certain discourses are chosen by a person to accomplish particular goals, for example blamings or justifications. With reference to the dyslexic narrative plot, this takes the form of blame for the origins of difficulties with reading and writing and justification for personal response to those difficulties. I want to know how dyslexic adults make sense of these issues. While the four discourses identified by Pollak (2005) can be seen as mainstream societal discourses which have developed independently from the experience of dyslexic people (with again, the exception of *Campaigner* which can be said to originate from people with disabilities), four of the five discourses I identify (see pp100-108) (*What's wrong with me?*, *Extra-able*, *Show them* and *Educational Responsibility*) arise specifically from the situation of the dyslexic person, *in response to* general societal attitudes toward difficulties with reading and writing. The other discourse I identify, *Stupid/lazy*, with its two subcategories, DRW=Stupid/lazy and Dyslexia=Stupid/lazy, is a societal-wide discourse. I will therefore be combining Critical Discourse Analysis with Discursive Psychology, in order to explore the personal responses of dyslexic adults to societal-level discourses, and how they combine and create discourse to lay blame for and/or justify responses to difficulties with reading and writing. In doing so I am following advice by Phillips and Jørgensen (2002), who write:

*... it is possible to create one's own package by combining elements from different discourse analytical perspectives and, if appropriate, non-discourse analytical perspectives. Such multiperspectival [author's italics] work is not only permissible but positively valued in most forms of discourse analysis. The view is that different perspectives provide different forms of knowledge about a phenomenon so that, together, they produce a broader understanding (p4).*

My use of discourse in analysis is a means of situating and contextualizing the life stories of my participants, and exploring how action links to different understandings. The discourses the participants use are not neutral reflections of the world, but create and change the social relationships and identities of those involved. Social conditions are embedded in these

utterances (Kress, 2001). For example a *Patient* discourse of dyslexia where a person describes a deficiency in their brain as the cause of their difficulties learning to read and write can be seen to originate in the work of medical doctors in the late 1800s who found that brain injury could result in the loss of the ability to read (see the Introduction p17 for a more detailed discussion).

Different discourses have different impact on the social/power relationships and identities involved, including what people understand they are able to do in relevant contexts (Bruner, 1990). Following on with the example of the *Patient* discourse, this discourse provides a focused framework from which to carry out brain research, and a medical approach to disability results in a structure where lack of diagnosis precludes support – but it excludes consideration of many other factors that might be involved in learning to read and write. It creates a power imbalance by privileging the professional while placing the site of the problem within the individual. It also has an impact on the way the dyslexic person understands themselves and what they perceive they are able to do, for example the perception that the problem is a defect in their brain can lead to negative self-perceptions (Pollak, 2005) and a sense of learned helplessness in themselves and even from the practitioners who are responsible for teaching them (Kerr, 2001).

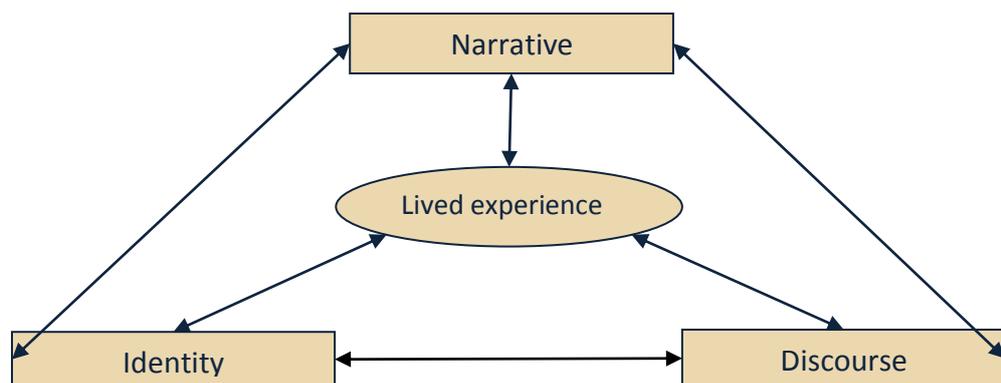
### **Identity/self**

Bruner (1990) notes that narrating our lives involves a project of constructing identity. Identity in this case is not essentialist; it is not ‘a substance or an essence that preexisted our effort to describe it’ (*ibid.* 1990, p99). Rather, ‘Self too must be treated as a construction that, so to speak, proceeds from the outside in as well as from the inside out, from culture to mind as well as from mind to culture’ (*ibid.* 1990, p108). Schafer (1981, cited in Bruner 1990) notes that we not only tell stories about ourselves to others; we also tell stories about ourselves to ourselves, and in this way, the self *is* a narration, where one person ‘tells’ the self to another.

When narrating their life, a person is involved in choosing aspects of their lives to create meaning. Discourses offer a range of possibilities for framing, categorizing and explaining a person’s experiences, and adoption of different discourses in the telling of a life story leads to the creation of different kinds of identity. In one sense the creation of an identity is limited by the discourses available, however resistance to prevailing discourse is also possible, through the development of new discourse (*e.g.* Dimitriadi, 2006). Competing discourses are held by those struggling to secure hegemony and knowledge (Phillips & Jørgenson, 2002). A good example of the creation of new discourse and its potential for impact on power relationships is

the development of the social model of disability and the resulting empowerment experienced by the people with disabilities who adopted this discourse (e.g. Morris, 1991).

I will now return to the question with which I started this section, 'What are participants communicating when they tell their life story?' Lived experience is represented in a life story through the limitations of language and frames of reference established by folk psychology. Lives are told as a story, and their narrative character means that explaining exceptions to the norms established through folk psychology will provide the hinge(s) upon which the story is told, and in telling the story the person will be constructing a self. The relationship between narrative, discourse and self is reciprocal (see Fig. 3.2), where each element contributes to both of the others, and is also constituted by them. Our lived experiences are formed from bodily senses of the interaction between the physical world and culture, and lived experience both contributes information to and is constituted by narrative, discourse and self.



*Fig 3.2. The reciprocal relationships between lived experience, narrative, discourse and identity.*

There is one final aspect of language and discourse that I would like to consider, that of the mechanisms through which new discourse and ideas come about. In writing about Bruner's ideas of folk psychology and discourse and the development of systems of meaning above, I found myself wanting to distinguish between meaning acquired through the interaction of other people's actions and language, and meaning acquired where one's own experiences are not in accord with what is said and done by others. This links to the section on standpoint theory above, and is important because this kind of experience of dyslexia is something I would particularly like to identify and give voice to. After reading about narrative and discourse, I started to listen for the use of identifiable discourse in the media and by my family and friends. I was surprised at how straightforwardly we repeat and employ sets of ideas. In thinking about my own use of discourse, I believe I go through a trial and error process of

comparing ideas to find ‘best fit’ ways of expressing experience in a way most appropriate to the particular context in which I find myself, rather like deciding what outfit is right for a night out (though in a much faster and usually subconscious process). In thinking about it this way, I am choosing to express myself through already-established ideas. However, ideas and discourse also change over time. How does this happen? Someone must be the first person to utter a new way of thinking about things. How does one articulate one’s experiences when they are not in accord with available discourse?

I have already touched on a few aspects of the way language and ideas change in my discussion of Derrida’s idea of absence and through the way culture is reflected in discourse, so discourse changes with cultural changes; people may also combine existing discourses in a new way. However from my own experiences of non-verbal understanding, I believe there is knowledge outside discourse that results from our interactions with the physical world. Smith (1993) describes such embodied experience as the beginning – a place from which to speak. Hunt writes about the process of verbalizing felt reality as ‘climbing out of the void’ (Hunt, 2001, p351), and though she found it ‘extremely uncomfortable’ (*ibid.* 2001, p364) she found she was able to express the way her spiritual ideas relating to *Gaia* impacted upon her professional practice,

*The sense of being in a void was always present. It was a dark place, fluid and formless, where half-glimpsed images and ill-defined thoughts ‘told’ me there were links between concepts and experiences of community and spirituality, and between these and the holistic principles of Gaia. Tantalisingly, though, they mostly appeared too far away to be grasped completely or my mind too slow to hold them together for long enough to see order in their shapes. Gradually, as I struggled to make meaning out of this cognitive chaos by drawing extensively on metaphors, lived experience and a wide range of literature from several disciplines, I began to feel a ‘solidifying’ of ideas. Just as randomly scattered pins can be brought together in one heap by the presence of a magnet, so the ideas began to cluster in a way that then gave me something more solid on which to build new models. As a result of their construction, I was eventually able to climb out of the void onto a new platform of understanding, but not without incident or pause! (*ibid.* 2001, p357).*

As a result of her reflexivity she was also able to theorize her process of verbalization by conceptualizing it using Heron’s (1996, cited in Hunt 2006, see Fig. 3.3) framework for ‘ways of knowing’, which includes nonverbal or private aspects of knowing (the Void—unmanifest; Experiential—sensing and Presentational—shaping) and public, verbal aspects of knowing (Propositional—speaking and Practical—doing). Between the private and public aspects of knowing is what Hunt calls a creative space. This is where she describes non-verbal, ‘void’, experiential and/or presentational knowledge being transformed into public, propositional and/or practical knowledge. Hunt describes traversing this space through a process of reflexive

writing (2001) and through the vehicle of metaphor (2006). This framework has been helpful in thinking about the process my participants might go through in verbalizing new discourses about dyslexia. The fact that they are dyslexic, and would not be part of my study if they did not have difficulties reading and writing, precludes the likelihood of them being willing to put voice to previously unexpressed lived experiences through reflexive writing. Also, the arduousness of verbalising the non-verbal is a task more difficult than I feel it is appropriate to ask them to engage. However, if the creative space can be seen to be a process, then the experience of talking about being dyslexic during the interviews is likely to support more developed conceptualizations about dyslexia and their relationship to it, and a number of participants told me this in fact had been their experience when I asked them what it had been like to be interviewed (see the beginning of Chapter 4, p116).

Heron's 'ways of knowing'	Personal interpretation	Process	Domain
↑ Practical ↓	Expressed in <i>action</i> in choices about approaches to professional practice	<i>Doing</i>	PUBLIC
↑ Propositional ↓	Expressed in <i>terms</i> of community/spirituality [words, concepts, 'head knowledge' privileged in academia]	<i>Speaking</i>	
	<i>Imaginal processes of mythopoesis operate fluidly and wordlessly below. Usually need to be 'reified' before acceptance above.</i>	Creative space	
↑ Presentational ↓	[images, feelings, 'heart knowledge'] Expressed in <i>imagery</i> of Gaia/contrasted with imagery signifying separateness – clockwork universe ( <i>Mythogenesis sensed below, becomes operational here?</i> )	<i>Shaping</i>	PRIVATE
↑ Experiential ↓	Knowledge arising as <i>sense</i> of interconnectedness [wyrð knowledge] <b>Spirituality</b> ( <i>'transpersonal' perspective</i> )	<i>Sensing</i>	

↑ Void ('locus of creation')      ↑ Enters world via the individual Spirituality ('transcendental' perspective)      ('unmanifest')

Fig. 3.3. Heron's (1996) 'ways of knowing', a framework for understanding the relationships between pre-verbal and verbal knowledge.

In terms of Hunt's latter means to bring about verbalisation, metaphor can be seen to be a particularly appropriate vehicle considering the numerous references participants made to use of visualisation as a compensatory strategy for their difficulties (see particularly the life histories of Chapter 4). Indeed during interview I asked them to describe dyslexia visually, and although analysis of these metaphors was beyond the scope of my thesis, I intend to analyze them for publication at a later date. This thesis is limited by the point at which participants are

in the process of verbalizing their lived experiences of dyslexia outside of available discourses. I will attempt to be open, however, to noticing 'silences'.

### **Impact of time-in-life and context of interview**

The life story is simultaneously a cultural and personal representation of lived experience, with elements of both consistency and contingency. While the project of the self is one of making relatively consistent and ordered meaning of one's life thus far in order to avoid *anoesis* (the experience of a lack of understanding) and *anomie* (experience of hopelessness or lack of purpose) (Goodson & Sikes, 2001), it also changes according to time and context. One's self has the potential for ongoing revision; new experiences or understanding can provide a chance for reflection and revision of meanings. As Bruner (1990) writes,

*[The self] stands both as a guardian of permanence and as a barometer responding to the local cultural weather. The culture, as well, provides us with guides and strategems for finding a niche between stability and change: it exhorts, forbids, lures, denies, rewards the commitments that the Self undertakes. And the Self, using its capacities for reflection and for envisaging alternatives, escapes or embraces or reevaluates and reformulates what the culture has on offer (p110).*

A good example of the potential for the reformulation of identity is the identification of dyslexia, which can initiate re-thinking past experiences and identity, as is shown in the interview transcripts (see below) and this is not a one-off process but ongoing, where understanding can continue to develop over time.

The interview is not only time-specific but also context-specific; and context has an important part to play in what the participant says during interview, with differences in what is said depending on where, with whom, and to what purpose it takes place. According to Goodson and Sikes (2001), not everyone should carry out life history research:

*Life history is an approach best suited to people who are able to listen attentively and beyond what is actually being said, and who can ask pertinent questions in a non-threatening manner. It demands the willingness to share one's own experiences, if this seems appropriate, and, of supreme importance, it requires the researcher to be the sort of person that people want to talk to (p20).*

The relationship between the researcher and participant is important, and impacts the content of the data collected. Issues of gender, ethnicity and in this case disability make a difference, and require a reflexive approach by the interviewer in remaining sensitive to any imbalances in power. The extent of trust established in the relationship will influence the quality of the data, therefore some texts recommend that researchers purposefully match themselves to the

culture of the interviewee and share personal experiences themselves in order to encourage personal revelations. However, such an approach can be seen as manipulative and raises questions of ethics (Goodson & Sikes, 2001). Other issues related to context can be controlled to diminish power imbalances or the likelihood of discomfort for participants, such as holding the interviews in a place in which the participant feels comfortable. Finally, the perceptions the participant has about the purpose of the interview will impact what is said. It is common for interview participants to feel concerned about giving appropriate information, the kind the researchers want to find out,

*They ask, 'Is this relevant?' or comment, 'I don't know if this is the sort of thing you're interested in'. In effect, what they are doing is seeking confirmation that they are telling the 'right' version of their story, the version that they believe the researcher wants to hear (and ... the researcher is then implicated in deciding which version to privilege) (Goodson & Sikes, 2001, p46).*

This was true with many of the participants in this study, and my responses were part of the co-creation of the interviews (for more discussion see below, p116).

## **The life history**

Creating a life history involves contextualizing and interpreting life stories according to socio-cultural influences. There are three aspects of creating a life history I intend to look at in detail; 1) issues of analysis of the life story to create a life history 2) ethical issues involved in representing others and 3) the process of contextualization.

### **Analysing the life story: narrative analysis and analysis of narratives**

Reissman (2008) defines narrative analysis to be 'the systematic study of narrative data' (p6).

Polkinghorne (1995) distinguishes differently, between:

- a) *Analysis of narratives, that is studies whose data consist of narratives or stories, but whose analysis produces paradigmatic typologies or categories; and*
- b) *Narrative analysis, that is, studies whose data consist of actions, events, and happenings, but whose analysis produces stories (e.g. biographies, histories, case studies) (p6).*

The distinction between a) and b) can be thought to be misleading in that all research reports re-present findings from data in narrative form, and so it could be argued that all reports of data findings are stories (Richardson, 1997; Sparkes, 2002). However I will use Polkinghorne's distinction as it provides a platform from which to explore different aspects of the narrative approaches to research I take in this thesis.

The division Polkinghorne (*ibid.*) makes follows on from Bruner's (1985) distinction between logico-scientific (Polkinghorne's 'a') and narrative modes of knowledge (Polkinghorne's 'b'). Polkinghorne explicates the process of establishing categories in the logico-scientific mode, or paradigmatic mode ('a'), where essential elements are identified for categories and analysis proceeds by identifying these elements in the data (or vice versa in the case of inductive analysis). The result is the simplification of large amounts of data, enabling conceptualization by category. In paradigmatic qualitative analysis, there is often a second level of analysis that establishes relationships between the categories identified.

I carry out such analysis of narrative in this thesis through the identification of aspects of the MVS and use of discourse by participants, a process of identifying categories in order to clarify the processes and patterns the participants go through in making sense of the experience of being dyslexic, and of learning to cope with the related difficulties. I then look at relationships of categories between participants.

Another example of analysis of narrative by category involves exploring their narrative structure. Human beings have been exploring what makes a narrative 'work' for centuries, for example Aristotle's exploration of Greek tragedy identified the representation of characters involved in actions strung together (the plot), with the presence of a rupture in what is expected. McNulty (2003) applies narrative analysis to the interviews he carries out with dyslexic adults, identifying Aristotelian aspects of narrative in the interviews and writing a collective story that represents common dyslexic experiences (his collective story is an example of re-presentation via research, discussed further below). Identifying similar aspects of narrative in participants' life stories will not be a focus in this thesis, however I do note that the exposition or starting point of the collective dyslexic story identified by McNulty, the self-realisation that 'something's wrong with me', and the focus of the collective plot, of surmounting difficulties reading and writing, was true for my participants with one exception (Adam), whose exposition involved the loss of his father rather than revolving around difficulties with reading and writing.

There are many other forms of analysis of narrative that examine characteristics of narrative, some of which are relevant to the analysis of interviews I will be undertaking. Porter Abbot (2002) describes three forms of narrative interpretation: intentional, symptomatic and adaptive. Although he discusses the analysis of fictional writing, plays and films, he also states that 'narrative interpretation is not different from analysis in most other fields in which meaning must be culled from data' (p90), and therefore I will discuss these approaches with reference to my thesis.

The third of these approaches, adaptive interpretation, is not one I will be undertaking but rather one that I will be avoiding. In this approach, during re-presentation of a narrative, the author overreads (adds interpretation that is not present in the narrative), changing the narrative to the extent that the re-presentation is more a creation by the author than an interpretation of the narrative. This approach is common in re-presenting novels in film or on stage; however in social science research it contradicts the very aims of human research by re-presenting the perspectives of its participants speciously.

The first and second of these approaches, intentional and symptomatic interpretation, I will be adopting in tandem. To discuss these approaches it is necessary to first describe what Porter Abbot calls 'wholeness in narrative'. This refers to the tendency people have to approach narratives as though their inherent parts fit together to form a cohesive message, or as Polkinghorne (1995) puts it, narratives are 'thematically unified' (p5). The assumption is that a person has created the narrative with the goal of communicating an integrated message. On the basis of the participant interviews, the interviews gave time and space to try to create this wholeness, though sometimes participants found it impossible to do so. For example, Bob associated identification of dyslexia with the positive turning point in his educational career, and debates whether that link carried further meant that, if had he been identified earlier, the severity of his negative experiences would have been at least partially alleviated. At other times he also argues against this idea in his attempt to be fair to both his parents and his teachers.

In intentional analysis, the assumption of wholeness in narrative is adopted, and analysis of the narrative proceeds with the identification of themes which represent the purposeful communication of the participant. This approach is one that I take in the analysis of the participant interviews. This has parallels to the idea discussed above (p73) about the possibility for the creation of discourse. So, using already-available cultural discourses in combination with participants' particular embodied and specific experiences of their lives, they can depict a representation of their unique experiences. Part of the purpose behind the particular experiences they choose and the way they communicate them, will involve an attempt to make sense of these experiences; create something thematically unified. As Porter Abbot (2002) writes, 'Narrative is one way of making order out of chaos' (p95).

In symptomatic interpretation, the analysis involves seeking the cultural influences behind what the narrator says. According to Porter Abbot, this approach is contradictory to the idea of wholeness in narrative, because the expression of the narrative depends on culture rather than the author, 'the question of the work's wholeness becomes moot' (p99). A symptomatic

analysis may be at complete variance to an intentional one. This approach parallels more with the idea of discourse at the societal level (discussed above p95), where participants' experiences are only re-presented through already-available discourses, and societal/cultural forces are the driving factors in life re-presentations rather than personal experience.

Although I take a symptomatic approach by identifying use by participants of societal-wide discourses, such as *Stupid/Lazy*, I do not exclude the intention of participants to create wholeness in their narratives. Wholeness can be seen to be part of their intention, whether they use societally-available discourses or not. I also do not see a contradiction in adopting both intentional and symptomatic approaches. A dual approach such as this supports the depiction of the complexity inherent in any attempt to re-present a life, and can be seen to be a postmodern approach to analysis in that it addresses multiple meanings.

I will also be carrying out what Polkinghorne refers to as 'narrative analysis' ('b') – see above p99); the creation of a story to re-present data findings. Polkinghorne writes:

*Narrative analysis is the procedure through which the researcher organizes the data elements into a coherent developmental account. The process of narrative analysis is actually a synthesizing of the data rather than a separation of it into its constituent parts ... The result of a narrative analysis is an explanation that is retrospective, having linked past events together to account for how a final outcome might have come about (1995, p15-16).*

The life history I create for each participant is narrative synthesis, re-presenting each participants' re-presentation of their lives, synthesizing aspects that I concluded were most relevant to the topic of my thesis, how making meaning of dyslexia related to participants' self-perceptions and coping skills. Although this entire thesis presents the findings of my research in narrative form: *e.g.* I have chosen what to include in the Introduction on the basis that it has causal links to what follows – my personal experiences of dyslexic family members are what led to an abiding interest in dyslexia and ultimately the questions of this thesis – the life history chapters each form their own, stand-alone narratives.

Polkinghorne (1995) writes that narrative analysis uses plot to organize. The two most basic narrative plots are the tragedy and the comedy. In the tragedy the protagonist (main character of the story) does not achieve the goal, and in the comedy the protagonist does. As mentioned above, McNulty (2003) found the plots of interviews with dyslexic adults to be their ability to overcome their difficulties. My life history narratives follow this plot, documenting via participant quotes how ways of understanding difficulties with reading and writing related to self-perceptions and learning to overcome the difficulties. The life history narratives in this

study are mostly comedies, in that the dyslexic adults have, at least to a large extent, overcome their difficulties with reading and writing and developed positive self-perceptions. However, this is not by any means straightforward, for example Pablo's frustration and marginalization following his success at university, and Amber's difficulties during her Master's degree following success in her Bachelor's. Adam is also less straightforward, because the plot of his interviews was not about overcoming dyslexic difficulties, rather it seemed to hinge on finding a Father. However, the life history narrative I wrote about Adam documented his process of overcoming his difficulties.

Although the plots of the life history narratives are about how dyslexic adults understand their difficulties, and how this relates to their self-perceptions and how they cope with the difficulties, I also include quite a lot of information about other topics, including family structures, illnesses, social and cultural environment, in addition of course, to educational experiences which are closely linked to the plotline. The plot for each narrative develops over the lifetime of the participant to their present situation, and the history of their life is written to link important events that brought them to their current position.

### **Ethical issues involved in re-presenting others**

The life story is primarily the creation of the participant, though as discussed above it is also a co-construction between participant and researcher. The life history, on the other hand, is primarily a creation of the researcher, thanks to the 'inevitable selections, shifts and silences' involved in data analysis (Goodson & Sikes, 2001, p17). It is common for researchers in any field to choose to work on research that interests them, 'Most people's preference among research topics is likely to be for ones which have meaning and interest for them, and this meaning and interest generally stems from something in their own lives' (Goodson & Sikes, 2001, p52). Writers too, have a purpose for writing, and texts involve a persuasive function (Baronne, 1995). Thus subjective feelings and experiences of researchers have a role to play in any research project; however in life history they are an explicit element in contrast to research in other fields, particularly that carried out in a Modernist tradition (Goodson & Sikes, 2001). In fact, subjective experience can be regarded as an asset in interpretative research,

*The subjectivity that originally I had taken as an affliction, something to bear because it could not be foregone, could, to the contrary, be taken as 'virtuous'. My subjectivity is the basis for the story that I am able to tell. It is a strength on which I build. It makes me who I am as a person and as a researcher, equipping me, from the selection of topics clear through to the emphases I make in my writing. Seen as virtuous, subjectivity is something to be capitalized on, rather than to exorcise (Glesne & Peshkin, 1992, 104, cited in Radnor 2002, p30).*

My own experiences as the mother/sister/niece *etc.* of dyslexic people, tutor of dyslexic children and adults, and academic in the field of dyslexia, and the emotions I feel in relation to these roles, mean that I have an extensive foundation of experience from which to understand personal, professional and academic perspectives about dyslexia, and am engaged in the subject of this research project. These, I think, are virtues in regards to the process of creating a life history about dyslexia. However, what I must be vigilant against is to tell not my own story, but that of my participants. In hooks (1990) essay *Choosing the Margin* she writes,

*It is not just important what we speak about, but how and why we speak. Often this speech about the "Other" is also a mask, an oppressive talk hiding gaps, absences, that space where our words would be if we were speaking, if there were silence, if we were there. This "we" is that "us" in the margins, that "we" who inhabit marginal space that is not a site of domination but a place of resistance. Enter that space. Often, speech about the 'other' annihilates, erases: No need to hear your voice. Only tell me about your pain. I want to know your story. And then I will tell it back to you in a new way. Tell it back to you in such a way that it has become mine, my-own. Re-writing you, I write myself anew. I am still author, authority. I am still the colonizer, the speaking subject, and you are now at the centre of my talk (p151).*

This issue relates to interpretative and ethical rigour, which has already been discussed above. I will be explicit in representing the participants in this study through the extensive use of transcript quotes, demonstrating close connection between conclusions and the data, and through participant checks of data analysis.

### **The process of contextualization**

Life history research demands the analysis of personal narrative in terms of its relationships to culture, and in this way the 'problems' faced by people are made sense of in a wider context; 'without contextual commentary on issues of time and space, life stories remain uncoupled from the conditions of their social construction' (Goodson & Sikes, 2001, p17). This is common in studies of dyslexia, where much of the research carried out approaches it as a within-person deficit and does not explore other aspects, and the predominance of findings from such research re-confirms the perception that it is solely a within-person deficit. The kind of analysis contained in this thesis can provide valuable knowledge not only about how difficulties related to reading and writing are experienced, but also how these difficulties are related to the cultural environment.

In this study, I will be using analysis of discourse to signal societal influences on participants' understandings of themselves. I have chosen discourse, rather than for example narrative structure or storylines/scripts, as the unit of analysis, because of the opportunity to build on the work of Pollak (2005). As was noted above, cultural conditions and attitudes are embedded

in discourse, and the links Pollak makes between societal conceptions and discourses demonstrate this relationship clearly. His use of the discourses of *Patient*, *Student*, *Campaigner* and *Hemispherist* are particularly relevant because of their links to theoretical debates within the fields of both disability studies and dyslexia. The medical model of disability is linked by Pollak to the *Patient* discourse and the social model of disability to the *Campaigner* discourse. The discrepancy model and its relationship to perceptions about intelligence (linked by Pollak to the *Student* discourse) continues to be an important aspect of current conceptualizations of dyslexia in education. Finally, the *Hemispherist* discourse is relevant to cultural trends in the field of dyslexia that discuss it as a difference rather than a difficulty (DfES, 2004, Singleton *et al.*, 1999). By analyzing the participants' life stories according to Pollak's theoretical perspective I am undertaking content analysis (Ezzy, 2002).

In addition to the discourses identified by Pollak, I identified five others; 1) *What's wrong with me?*, 2) *Stupid/lazy (while distinguishing its use before and after identification of dyslexia with DRW=Stupid/lazy used before identification and Dyslexia=Stupid/lazy used afterward)*, 3) *Educational responsibility*, 4) *Extra-able* and 5) *Show them*. By identifying new discourses of dyslexia I am involved in thematic analysis (Ezzy, 2002). None of these five discourses is referred to explicitly as a discourse in the literature. Nevertheless, the concepts themselves are all discussed, and it was the combination of prior knowledge from the literature review and my own experiences, followed by a majority of the research participants talking about them, that caused me to identify these discourses. One of the five discourses originate in wider cultural views about the relationship between an educated person and intelligence (*Stupid/lazy*), and the remaining four originate from the experience of being dyslexic; they are responses by the participants to the way they are positioned within culture, particularly the educational system. Below I describe each new discourse and references to them in the literature.

### *What's wrong with me?*

This is an important discourse for understanding identity formation and dyslexia because it indicates the time when and reason why a participant first describes a difference between themselves and their peers in relation to difficulties with reading and writing. Before this, the participant did not understand themselves as having a 'problem'; they did not have need to reframe their difficulties in order to improve self-perceptions. Studies with dyslexic children and adults often discuss the realization as children that they are different from their peers; parents identify this time because the child shows distress or negative behavior (*e.g.* Riddick, 2010). Participants' realization that they were different to their peers was described by

Ingesson (2007), Burden (2005), Pollak (2005), McNulty (2003), and Hellendoorn & Ruijsenaars (2000) (see Chapter 2, p41).

McNulty (2003), in his narrative analysis of dyslexic participants, specifically identifies *What's wrong with me?* as the first stage, the hinge of the story; the exception to folk psychology that gives reason to tell a story as Bruner (1990) would say.

*By early to middle school, each participant encountered unexplained difficulties and failures that called into question their sense of intelligence and motivation. Others often misunderstood their problems. These experiences resulted in the child feeling as if "something's wrong with me." This situation was the exposition in their stories (McNulty, 2003, p371).*

This discourse originates in participants' experience of having difficulties reading and writing at school, so is directly related to participation in education and normative comparison with peers.

### *Stupid/lazy*

The *Stupid/lazy* discourse represents the most easily accessible cultural explanations for a lack of ability to read and write. I have combined the two aspects because they are both used so commonly and both serve a similar function as explanations.

The first part, 'Stupid', has historical links to a time when only the religious and/or elite were educated and being educated *was* about being able to read and write, and perhaps because of the association of power and literacy, was considered a corollary to intelligence. The historical link between reading and writing and education/intelligence can be seen in derogatory comments that infer low intelligence from spelling mistakes, when correct spelling is more of a clerical matter than one of intelligence. The 'Stupid' part of the *Stupid/lazy* discourse is a logical contradiction to this understanding; someone who cannot read and write even though they have been educated must be thick. In thinking about this discourse reflexively, I have to acknowledge it is a subject I find difficult to think clearly about, and this probably reflects my own deeply but implicitly held values about intelligence and education. Its emotiveness speaks for the power that the issues of being able to read and write and being intelligent hold in our culture, and the severe stigma that is invoked with any lack.

The second part, 'lazy', can be seen to be an alternative explanation used for difficulties in learning to read and write. If a child does not engage in the learning process or avoids doing any work, this can be an explanation for lack of progress. When a person is clearly intelligent, for example if they are verbally precocious, laziness can still explain their inability to read and

write. Laziness may also be a slightly more politically correct way to explain difficulties learning to read and write despite being educated.

It is common in interview studies with dyslexic people for them to say that their difficulties with reading and writing were explained by teachers as them being thick and/or lazy (Dale & Taylor, 2001, Edwards, 1994, Hellendoorn & Ruijsenaars, 2000, McNulty, 2003, Pollak, 2005, Riddick, 2010, Riddick *et al.*, 1997); or if they were not told by others, to make that assumption about themselves (Dale & Taylor, 2001, Ingesson, 2007, McNulty, 2003). This discourse originates in our historical culture, from links between education, reading and writing, and intelligence, and the links are so culturally embedded that children are aware of them whether they are told explicitly about them or not.

Because I am particularly interested in the role the identification of dyslexia has for dyslexic adults in making sense of their difficulties, in the thesis I distinguish between the use of Stupid/lazy as an explanation for difficulties with reading before and after identification of dyslexia. DRW=Stupid/lazy (DRW an acronym for 'Difficulties Reading and Writing') will be used to refer to use of this discourse before the identification of dyslexia. Dyslexia=Stupid/lazy will be used to refer to use of this discourse after identification of dyslexia.

Dyslexia=Stupid/lazy is therefore a derogatory way to discuss dyslexia. Use of both discourses is common, though they can be considered to be politically incorrect so may not be present in official documents or said by people acting in an official capacity.

Dyslexia=Stupid/lazy was trendy in the 1980s when dyslexia was referred to as 'the middle class name for stupid'. Dyslexia is still often referred to in this way in the media, as shown by an article in *The Times* on 28<sup>th</sup> May 2007; *Dyslexia 'is used by parents as excuse for slow children'*. This discourse is highly emotive, which may be why the media so often uses it in headlines.

This way of understanding dyslexia is something of a paradox, as it is the opposite to other ways of thinking about dyslexia, particularly the *Student* discourse. Outrage was expressed by participants in response to this discourse; having reframed their lack of intelligence through the idea of dyslexia, they are then told that actually, Dyslexia=Stupid/lazy, too. Such an analysis makes sense of the hugely negative responses by dyslexic people and their families to shows like 'The Myth of Dyslexia', shown on the television show 'Dispatches' in 2005. This opposition in discourse can be seen to reflect a power struggle between non-dyslexic and dyslexic people as to legitimacy to their claim of disability. Armstrong & Humphrey's (2009) analysis of participants' understanding of the meaning of dyslexia also describes this discourse,

*Some participants had clearly developed constructs of 'dyslexia equals stupidity', and being stupid, according to their perceptions, is a label that the teachers and school had tried to attach to them: 'They wanted to make out that I was stupid at school but I'm not' (Anthon, I). Anthon's defensive reaction to the question 'do you see yourself as being dyslexic?' is revealing. He commented: 'I'm not dyslexic, I'm not stupid' [I], indicating that he equates dyslexia with stupidity and non-achievement. Anthon's logic is: 'teachers say I am stupid; dyslexia = stupid; therefore I am not dyslexic' (p99).*

This account suggests that Anton has not been exposed to, or at least has not accepted, other more positive understandings of dyslexia, such as Hemispherist.

It is extremely difficult (impossible) to know where the saying 'middle class name for stupid' originates. This discourse was used most commonly by participants in this study in reference to the way they thought the general public understood dyslexia.

### *Educational responsibility*

This discourse involves discussion of the part played by the educational system in a person's difficulties or successes with reading and writing. It can be seen as a resistance to the *Patient* discourse, where the problems are understood to be in the individual. *Educational responsibility* shifts responsibility away from the individual to the educational establishment by identifying aspects of schools that contributed to or ameliorated difficulties experienced by the participants. In this way it can be seen to link to the social model of disability in understanding society as constructing disability rather than it being a result of impairment. Dale & Taylor (2001) describe a participant in their study talking in a discourse of *Educational responsibility*,

*We could go further to argue that, whilst the issue of the oppression of disabled people was not explicitly addressed in the course, students were enabled to change their world view, to re-vision themselves as learners, or indeed to elect out of formal learning. For example, Suzanne felt very positive about her decision not to progress to an Open University degree, rather than interpreting it as evidence of her inability to study. In talking about this episode she drew attention to inadequacies of support offered and she rejected the implicit messages of the official withdrawal form, which categorised the reasons for withdrawing as individual problems (e.g. ill-health and finance). The shift in her perception resonates with a social model of disability drawing attention towards disabling barriers and away from individual deficits (p1006).*

*Educational responsibility* can be either negative or positive; it involves recognition of the aspects of learning to read and write that depend on teachers and the structure of the education system. A dyslexic person can talk about the beneficial and/or non-beneficial role played by school/FE/HE.

### *Extra-able*

This discourse involves discussing better-than-normal abilities that are attributed to being dyslexic. Many studies described in the literature review discuss dyslexic people's strategy of capitalizing on personal strengths, for example Gerber *et al.*'s (1992) *Learned Creativity* and the *Hemispherist* discourse (Pollak 2005), but the discourse of *Extra-able* is different because being dyslexic is understood to mean a person can do things *better* than most people. Other research in dyslexia refers to it: Logan (2009) found a 22% incidence of dyslexia in US entrepreneurs and a 19% incidence of dyslexia in UK entrepreneurs, a result that is high in contrast to estimates of less than 10% of dyslexia in the general population. She proposes that skills necessary for success in starting businesses, such as delegation and oral communication, are compensatory strategies dyslexics have to learn in school, and which give them an advantage in the business world. Ehardt (2009) cites other authors as identifying special abilities in dyslexic people in mechanics, holistic thinking, problem solving and 3D/visualization, and suggests there is a high prevalence of dyslexia in the population now because these abilities provided an advantage in the past in hunter-gatherer populations.

The *Extra-able* discourse is commonly seen in the media, where the lives of famous dyslexic people like Susan Hampshire (1990) are depicted. A few years ago the British Dyslexia Association website had a list of famous dyslexic people on its website (see Fig. 3.4). West (1997) described Leonardo da Vinci, Thomas Edison and Albert Einstein amongst other famous people as having specific learning difficulties, and suggested that it enabled them to be visionary thinkers who had unique contributions to make to society. So this is a commonly available discourse to dyslexic people which can be helpful for building positive self-perceptions and high personal expectations. As Alice says, 'that's what I was always told [by my parents], you know, 'all the people who are dyslexic are famous' ... I was always told 'you can do it' and not to worry' (Interview 3).

This discourse can be understood to describe special ability as a genetic 'gift' as Ehardt (2009) and West (1997) suggest, or it can be understood to be a result of the inability to fit into linear, text-based education which is formative for most people, supporting the development of other, unusual skills in dyslexic people, as suggested by Logan (2009). This latter seems to be in line with Adam's comment,

*I know some dyslexic people and I just think they're great ... you know, really clever ... and uh have found their own unique way, and I'm quite wowed by them ... they're all self-taught to be honest, you know, they've all found their own method, methodology of doing things (Interview 3).*

**Adie Allen.** Actress. **Anthony Andrews.** Actor. **David Bailey CBE.** Photographer. **Michael Barrymore.** TV personality. **Marlon Brando.** Actor **Richard Branson.** Entrepreneur. **Sarah Brightman.** Actress and singer. **Gary Chapman.** Film script writer. **Cher.** Pop star, actress. **Agatha Christie.** Author. **Winston Churchill.** Politician, author. **Margi Clarke.** TV presenter and actress. **Dr Simon Clemmet.** Scientist. **Chuck Close.** Artist. **Brian Conley.** Comedian and actor. **Tom Cruise.** Actor. **Leonardo da Vinci.** Artist, inventor. **Jonathan Dalby.** Novelist. **Ronald Davis.** American author. **Mike Drury.** Engineer. **Thomas Edison,** inventor. **Dorothy Eison.** Psychologist, writer, lecturer. **Albert Einstein.** Scientist, mathematician. **Sophy Fisher.** Journalist, former BBC correspondent. **Lorna Fitzsimmons.** MP. **Gustave Flaubert.** French novelist. **David Fogel.** Buying and Merchandising Director of Hamleys. **Esther Freud.** Novelist. **Noel Gallagher.** Oasis Rock Group, song-writer. **A.A. Gill.** Journalist. **Whoopi Goldberg.** Actress. **Duncan Goodhew.** Swimmer. **Antony Gormley.** Sculptor. **Hamish Grant.** Chief Executive of Axcel, a Technology company. **Nanci Griffith.** Folk Singer. **Susan Hampshire.** Actress. **Guy Hands.** Nomura Bank. **Woody Harrelson.** Actor. **Lord Philip Harris.** Carpet shop entrepreneur and millionaire. **Salma Hayek.** Actress. **Johnny Herbert.** Formula One Racing Driver. **Tommy Hilfiger.** Clothes Designer. **Anthony Hopkins.** Actor. **Jack Horner.** Palaeontologist. **Bob Hoskins.** Actor. **Bertil Hult.** Owner of a company, EF. **Louise Hunt.** Actress, "Gold Blend Girl". **Crispin Hunt.** Singer and guitarist with pop group 'Longpigs'. **John Irving** Author. **Eddie Izzard.** Comedian. **Demitri Jagger.** Actor, nephew of pop star Mick. **Felicity Kendall.** Actress. **Jodie Kidd.** Super-model. **Lynda La Plante.** TV Series writer. **Lloyd Le Blanc and Judith Holmes Drewery.** Sculptors. **Sandy Lyle.** Golfer. **Charles Rennie Mackintosh.** Artist and Designer. **Lord McAlpine.** **Simon Menzies.** Painter. **Andrew Menzies.** Hollywood Art Director. **Paul Merson.** Football Star. **Sarah Miles.** Actress, author and playwright. **Nicholas Negroponte.** Founder of the Media Lab at the Massachusetts Institute of Technology. **Phoebe Nicholls.** Actress. **Mike Norris.** Head of Computacenter. **Dominic O'Brien.** Word memory champion. **Olaf - King of Norway** (and his children). **Jamie Oliver.** TV chef. **Paul Orfalea.** Founder of Kinko's the 24-hour copy and printing chain. **General George S. Patton.** Famous US General in 2nd World War. **Robert Rauschenberg.** Artist. **Sir Steven Redgrave.** Winner of 5 Consecutive Olympic Gold medals for Rowing. **Oliver Reed.** Actor. **Beryl Reid.** Actress. **Zara Reid.** Business woman. **Guy Ritchie.** Film Director. **Auguste Rodin.** Sculptor. **Lord Richard Rogers.** Internationally famous architect. **Francois Schuiten.** Comic strip artist. **Scott.** From the Pop Group '5ive'. **Peter Scott.** Naturalist. **Eric Shipton.** Mountaineer and explorer. **Tomasz Starzewski.** Clothes designer. **Sir Jackie Stewart.** Racing driver. **Peter Stringfellow.** Entrepreneur, Night Club owner. **Matthew Sturgis.** Journalist. **Mackenzie Thorpe.** Artist. **Anthea Turner.** TV Presenter, National Lottery, etc. **Kevin Viner.** Chef. **Ben Way.** Head of a £60,000 computer business at the age of 17. **Zelda West-Meads.** Relationship Counsellor and author. **James Whale.** TV presenter. **David Whiffen.** Chef. **Marco Pierre White.** Chef and restaurateur. **Mark Wilkinson.** Furniture designer and maker. **Toyah Willcox.** Ex-pop star. **Robbie Williams.** Pop star. **Lord Willis.** Author. **Terence Woodgate.** Furniture designer. **William Butler Yeats.** Poet. **Murray Lachlan Young.** Millionaire poet. **Benjamin Zephaniah.** Poet.

Fig. 3.4. Famous people who are dyslexic, from the British Dyslexia Association website (<http://www.bdadyslexia.org.uk/extra354p.html>), accessed March 2005).

This discourse seems to parallel the work of identity politics, where stigmatized aspects of group identity are turned on their head to become badges of pride (Bickenbach *et al.*, 1999). Those who are unable to learn to read and write are symbolically dismissed by education as incapable; here dyslexic people celebrate their ability to do what others cannot.

However there are negative aspects to this discourse. The mainstream popularity of stories of people who cannot read/write who then become famous fulfills the non-disabled stereotype of disability of the 'Super-crip' who, against all odds, overcomes disability through individual striving (Morris, 1991). Not only does this stereotype ignore social contributions to disability, it affirms non-disabled as 'right' and disability as only acceptable when changed back to 'normal',

*The status quo likes us to be seen "fighting back", to resent and bewail the fact that we can no longer do things in their way. The more energy and time we spend on over-achieving and compensatory activity that imitates as closely as possible "normal" standards, the more people are reassured that "normal" equals right. If we succumb to their temptations they will reward us with their admiration and praise. At first sight this will seem preferable to their pity or being written off as an invalid. But all we will achieve is the status of a performing sea lion and not (re)admittance to their ranks (Pam Evans, quoted in Morris 1991, p101).*

For those dyslexic people who find it difficult to identify their strengths and/or their niche, this kind of discourse could also have the effect of othering them from dyslexia as it becomes associated with high status/cultural success.

### *Show them*

The discourse *Show them* involves imagined meetings between a dyslexic person and others who have humiliated them and/or sentenced them to failure, where the dyslexic person shows them

their achievements thereby proving the accusers wrong. McNulty (2003) describes this as one way dyslexic participants integrate negative emotions experienced during school years during adulthood,

*Thoughts or fantasies involving confronting experienced adversaries and paying homage to allies appear to affirm positive feelings and dispel negative feelings about the self that stem from misunderstandings and traumatic experiences in childhood (p375).*

This discourse originates in humiliating experiences during dyslexic people's school years, and can be thought of as a form of reframing, where the person comes to understand previously painful experiences in a new light. Before, as children, they could not be sure what they would be able to achieve and some may have believed the personal, negative attributions made about them because of their difficulties with reading and writing. However, as successful adults they are able to re-evaluate and discount such negative attributions by virtue of their experiences in life. Imagined interaction with the people who made negative attributions supports emotional resolution. *Show them* can also be a spur where negative prognosis from others motivates a person to persist and succeed in order to prove the others wrong. Like *Educational responsibility*, *Show them* shifts responsibility for difficulties away from the dyslexic person, and as such can be seen as being aligned with the social model of disability that situates the cause of disability in the attitudes and/or structures of society rather than within individual people.

### *Niche*

I did not anticipate the need for this category, however its importance quickly became clear as I began to analyze the data. A number of participants experienced aspects of the Model of Vocational Success, learning to understand themselves and cope with difficulties in a positive manner, that had nothing to do with an understanding of dyslexia. Distinguishing categories of dyslexic discourse versus non-dyslexic discourse related to the MVS gives a tool to examine the role identification plays in the process of making sense of, and learning to cope with, difficulties with reading/writing. It is often the case that a participant speaks about their difficulties, how they understood them and how they overcame them before they were identified as dyslexic outside a discourse of dyslexia. Because of parallels with similar descriptions in interviews with dyslexic adults carried out by McNulty (2003), Ingesson (2007), Gerber *et al.* (1991), Gerber *et al.* (1992) and Dale & Taylor (2001) (which was described as finding a 'niche' by McNulty), extracts like these I categorised as *Niche*.

At times participants discuss experiences before identification with '20-20 hindsight', applying later understandings gained from identification as dyslexic to these earlier times. When these fitted characteristics of discourses of dyslexia I represented them accordingly. At times, too, participants discuss aspects of dyslexia before or after identification that fit none of the discourses and this I categorised as *Dyslexia unspecified*, which is not a discourse of dyslexia, but is discussion of dyslexia that does not conceptualise it in any particular way.

### *The Model of Vocational Success (MVS)*

Life history analysis contextualizes the individual life story. In this study, discourse will be used to signal societal influences on participants' understandings of themselves; the Model of Vocational Success (MVS) will act as a framework from which to explore meaning-making about difficulties with reading/writing, the development of more positive self-perceptions and actions to cope with difficulties. In the MVS *Internal Decisions* link most directly to meaning-making about difficulties and the development of more positive self-perceptions and *External Manifestations/Action* link most directly to actions related to coping mechanisms; however the relationships can be reciprocal and interlinked, as will be discussed below.

The MVS is a model developed from an early interpretive study carried out under the pressure of a research community dominated by Modernist perspectives. So, although based on semi-structured interviews using inductive analysis of themes, the sample was chosen through an intricate process justified by the need to produce a representative sample, and the researchers describe the design of the study thus,

*a causal comparative, or ex post facto, type of research design was utilized to help isolate factors that are characteristic of the population of highly successful adults with learning disabilities ... The basic approach is to start with an effect (such as success) and seek possible causes (Gerber et al., 1992, p476);*

in other words the study was driven by the need to establish cause and effect. When I first came across the study by Gerbet *et al.* (1992), I was still in the midst of struggling through a transfer phase, where I was working to replace life-long established objectivist assumptions with new, constructionist beliefs, and working to make sense of interpretivist approaches in light of my much greater experience with positivist strategies. This process took a number of years (and no doubt I will continue with some vestiges for years to come). I am not alone in these struggles, for example, Richardson (1997) notes she continued to think dichotomously well into postmodernism.

So, the care taken over the sample and the familiar, positivist focus I initially found re-assuring. However, what really caught my attention was the way I recognized dyslexic people I have known or tutored, and my study participants, in the findings of the study. For example, my experiences with Gary re-thinking himself as 'intelligent' rather than 'stupid', then changing his behavior in response for example through buying and learning to use a computer (which was the foundation for carrying out this study) was represented well by the concept of 'reframing' and its links with *Action* developed in Gerber *et al.*'s (1992) study. That the MVS enabled analysis of links between internal processes and action was particularly interesting to me,

because it theorized how changes in attitudes and perceptions could result in the development of coping skills. Therefore, although my initial interest in the study related to its combination of positivist and interpretivist design, my decision to adopt the model in this thesis was based on the studies' high level of transferability to my own experiences with dyslexic people and its ability to address the questions of my thesis related to internal changes in understanding and external actions.

In using the MVS for analysis I would confirm its relevance to the life stories of my participants. However there were a few areas that I would like to elaborate, that did not fit the model as well. I would also like to discuss my process in deciding how to code aspects of the MVS. Although the authors (Gerber *et al.*, 1992) discuss complexity, 'some individuals moved through all stages almost in unison; others moved methodically from one to the next. Clearly, the four stages interact closely with one another' (p482), this does not adequately represent the relationship between the stages of reframing I found in my participants. I particularly found inaccurate the idea that prior stages of reframing were the impetus for later action; rather *Goodness of Fit* and *Persistence* (both aspects of stage 4 of reframing: action) acted as initiators of reframing stage 3: *Understanding*. The authors write,

*...in terms of the reframing process, stage four we call action. All the recognition, acceptance and understanding in the world is useless without the conscious decision to take specific action toward one's goals. The successful adults with learning disabilities all chose to do something about their circumstances that fostered their success (p481).*

But in fact many of my participants first experienced *Goodness of Fit* and this contributed to *Understanding* (which then directed them toward conscious decisions to seek out similar situations), or in the cases of Alice and Elizabeth, the fact that they were required to *Persist* led them to the *Understanding* that they could achieve, which then informed future decision-making.

The aspect of *Recognition* in the MVS caused me some confusion. Initially I linked *Recognition* directly to identification of dyslexia, as this is the manner in which I understood it to be described in a paper by Gerber *et al.* (1996) that focuses on the Reframing process. The authors write 'The first stage of reframing was *Recognition*, the ability to recognize the disability' (emphasis theirs) and they characterize *Recognition* with the following two examples statements from participants, 'You can't overcome it if you don't recognize it'; 'I know that I am LD, and that poses opportunities and challenges' (p100). However in re-reading the initial study (Gerber *et al.*, 1992) *Recognition* is described more widely:

*The first [step] is the need to recognize the handicap. For many, that meant simply realizing that they did things differently, and did not have to be like everyone else ... before one can begin to discover ways to successfully learn or succeed in other areas of life, a recognition of who and what one is is necessary (p481).*

This passage implies a wider understanding of *Recognition* to specify the process of realizing one is different and what the areas of difficulty might be, with or without identification of dyslexia. This is the criteria I have adopted to classify *Recognition*, and it has been helpful in clarifying my process of analysis including understanding the benefit or lack of benefit to identification of dyslexia.

It also took me some time to decide how to code *Acceptance*. I initially understood *Campaigner* and *Educational responsibility* discourses to support *Acceptance* on the basis that they transferred blame from the individual to society, thereby making the individual more acceptable. However on re-reading the study by Gerber *et al.* (1992) I believe this meaning is not the authors' intention. They refer to a person accepting that they have difficulties – this is almost in opposition to the way I was applying it because *Campaigner* and *Educational responsibility* discourses regard the educational system to be the party with difficulties. In the end I have made a link if there was reference to accepting that one is disabled and/or acknowledging personal value nonetheless.

I also initially found it difficult to decide when a person exhibited *Desire* and *Goal Oriented* behavior. These are a common aspect of most activities. In the end I only identified *Desire* and *Goal Oriented* behaviour when a person explicitly described a conscious decision to excel (in the case of *Desire*) or to complete a task successfully (in the case of *Goal Oriented*). These aspects of the MVS were not commonly described by the participants in this study, possibly because of cultural differences between the US where explicit shows of ambition are admired in contrast to the UK where modesty about personal goals are the cultural norm.

I have chosen to use the MVS because the four stages of reframing (unlike the aspects of *Desire* and *Goal Oriented*) are highly relevant to the life stories of the participants in this study, and therefore offer a useful model to structure the analysis of participant's meaning-making process about their disability, the development of positive self-perceptions, and their actions to cope with difficulties. Its high level of relevance to this study gives further validity to the initial research by Gerber *et al.* (1992), and has links to the issue of saturation:

*A single life story stands alone, and it would be hazardous to generalize on the ground of that one alone, as a second life story could immediately contradict those premature generalizations. But several life stories taken from the same set of sociostructural*

*relations support each other and make up, all together, a strong body of evidence*  
(Bertraux, 1981, p187, original emphasis, quoted in Goodson and Sikes 2001, p24).

Having discussed theoretical considerations in this chapter, in the next I will describe the process of carrying out the study followed by analysis and discussion of the life stories of each participant.

## CHAPTER 4: DATA ANALYSIS AND DISCUSSION

*In this chapter I begin by describing the process of interviewing and analyzing the data, and the chapter concludes with the life histories of each participant; Adam, Alice, Amber, Bob, Country Boy, Elizabeth Kirner and Pablo Jennings (see Table 4.1). The life histories combine a summary of each participant's life story with analysis of his/her use of discourse about dyslexia and how it relates to aspects of the MVS. They represent each participant's experience of making sense of their difficulties with reading and writing and the methods they develop to cope with them. Each life history includes a visual representation of this process in the form of a map.*

### The process of interviewing participants

#### The sample

Purposive, opportunistic, convenience and snowball sampling methods are common in life history because it is essential that participants are prepared and able in terms of both time and verbal ability to talk for extended periods. In addition, the research topic is likely to be focused on a specific social situation, thus requiring informants to have the appropriate knowledge and experience (Goodson & Sikes, 2001). Because in life history the subjective, emic and ideographic is valued, it is argued that 'large sample size is unnecessary and even inappropriate because objective, etic and nomothetic generalization is not the aim' (*ibid.*, p22); also this means the sample does not need to be random as it is not intended to be generalized. Sample sizes are also usually small because interviewing, transcribing and analysis are very time consuming (*ibid.* 2001).

<b>Name</b>	<b>YOB</b>	<b>Age at 1<sup>st</sup> interview</b>	<b>Gender</b>	<b>Father's occupation</b>	<b>Mother's occupation</b>	<b>Date of 1<sup>st</sup> interview</b>	<b>Interval in months</b>	<b>Date of 2<sup>nd</sup> interview</b>	<b>Interval in months</b>	<b>Date of 3<sup>rd</sup> interview</b>
<b>Adam</b>	1960	46	M	Farmer	Farmer	30.01.07	3	23.04.07	13	07.05.08
<b>Alice</b>	1978	28	F	Medical Consultant	Medical Doctor	21.01.07	4	03.06.07	12	29.05.08
<b>Amber</b>	1983	23	F	Surveyor	Homemaker	16.02.07	2	05.04.07	14	21.05.08
<b>Bob</b>	1979	27	M	Manager	Homemaker	01.11.06	2	11.01.07	12	13.01.08
<b>Country Boy</b>	1933	73	M	Gardener	Lady's maid	10.01.07	2	14.03.07	14	05.05.08
<b>Elizabeth Kirner</b>	1971	36	F	Crane driver	Homemaker	27.02.07	12	28.02.08		None
<b>Pablo Jennings</b>	1966	40	M	Chef	Factory worker	17.01.07	2	27.03.07	14	16.05.08

Table 4.1. Participant information.

The sample in this study was purposive, because to be included participants had to have struggled with reading and/or writing and to identify themselves as dyslexic. I also chose participants to represent both genders (latterly seeking out female participants to balance a larger number of males) over as large an age range as possible, although I wanted more young people because dyslexia to earlier generations was likely to have been unknown during their school years. The sample was opportunistic and a convenience sample in that I invited people whom I already knew (Alice is a distant relative by marriage) and/or found out were dyslexic (Bob, Country Boy and Adam, all with whom I was barely acquainted at the time of the first interview) to be part of the study. Two participants (Jenny and Elizabeth Kirner) responded to a poster I put up in two Disability Support Centres at two Universities in the Southwest of England. Finally, one participant was found through the snowball method (Pablo Jennings) when another person I asked to participate but who was unable to, recommended someone they knew. One of the participants (Alice) lived in the Midlands during the interviews; the remaining six lived in the South West of England. All seven were of British Nationality.

Goodson and Sikes (2001) do not recommend carrying out research with family members due to the potential for them to be cautious about what they say during interview. Nonetheless, I chose to interview my husband's relative (Alice) because I knew her very little however I was aware of a number of factors about her that I thought might provide valuable information. The fact that all five children in the family have been identified as dyslexic with both parents self-identifying, as well as the verbal strengths of the family which were known to me, made me want to know what she would have to say about dyslexia, and how she had made sense of herself as dyslexic. In addition, I thought Alice's privileged education and high status profession would provide a valuable perspective which might be otherwise difficult to secure. Having analyzed her life story I believe I was justified in this approach, particularly as she gave thick, rich description of her experiences.

This sample is undoubtedly biased. However, by admitting it is biased I am not apologizing, as all research is biased because it is historically and politically situated (Ezzy, 2002). Instead, as suggested by Goodson and Sikes (2001), I will attempt to identify the form of the bias. All the participants were white, and all but one (Adam) had completed or were working on undergraduate degrees and/or post-graduate degrees. I think this was an advantage for this particular study, because thick, rich data was important in communicating the experience and self-understanding related to being dyslexic, and my own identity as white with experience of higher education made it easy to develop rapport with participants. I do not claim that these interviews represent all dyslexic people. It is likely that experiences differ greatly for others,

and this is an important area for future research (for further discussion see the section on further research in the Conclusion, p238). Further bias results from my own standpoint, that of a person on the continuum of SpLDs with a number of dyslexic family members, a specialist dyslexia practitioner and academic. As I stated earlier in the chapter, though, I seek to give voice to dyslexic participants over the voice of others such as educational practitioners or academics, and although the analysis of the participants' life stories is predominantly my own, it is not my own story I am telling but theirs.

## **The Interviews**

For this study I interviewed a total of eight participants between one and four times, with each interview lasting between just over an hour to two and a half hours. I planned to interview each of them three times, 1) an initial interview, 2) a follow-up interview 3 months later, and 3) a final interview a year after that. The rationale behind this schedule was to ask the participants to tell me their life story in the first interview, to probe for missing information in the second interview, and to meet again for a third interview in order to be able to gauge changes in attitudes and understanding longitudinally and to ask what the experience of interview had been after the participants had plenty of time for reflection. After reading about rigour in qualitative research, and because I am not dyslexic myself, I decided to interview the participants a fourth time to ask for their responses to my life history analysis. Because they all found reading something of a chore, and many had confessed to not reading their transcripts, I read out my data analysis to them, first explaining the MVS and what I meant by discourse, and their maps.

The actual interview schedule played out reasonably closely to this plan (see Table 4.1) for seven of the participants, however for one it was adapted. The second interview for Elizabeth Kirner was postponed by both of us a number of times for various reasons; as a result I decided to combine the second and third interview and saw her only three times, the second interview following the first almost exactly one year later, with the third interview involving discussion of her life history. I believe we were able to successfully combine the planned aspects of interviews two and three in one interview.

The participants knew I was doing a PhD interview study about the experience of dyslexia; however I avoided explaining more than that before the first interview. At the first interview I explained that what they said to me was their life story and their property, and that I would analyze what they said for the purposes of my PhD and that this analysis was in effect my property. I asked each of them for a pseudonym and explained that I would refer to them

using that name whenever I discussed the project with supervisors, colleagues etc and/or wrote about the interviews, and that I would change place names and other identifying words in the transcript in order to maintain anonymity and confidentiality. I also clarified that I anticipated wanting to carry out multiple interviews, but that they had the right to decide not to be a part of the study at any time in the future, for any reason. A letter of consent including my supervisor's contact details was then signed by both of us, with a copy for each of us to keep.

I began interviewing by saying 'tell me about your life' rather than referring to dyslexia. In this way I attempted to hand power to the participants to structure their life story according to what they understood to be important rather than structuring the interview according to my own pre-conceptions. One of my interests in the first interview was 'what will they decide to talk about without any guidelines?' The participants knew I was interested in dyslexia, because difficulties with reading and/or writing and self-identification as dyslexic were the criteria for inclusion in the study. The extent to which dyslexia was mentioned in this first, open part of the interviews varied widely between participants. Some, for example Bob and Alice, talked almost exclusively about dyslexia and their experiences of education and how this had impacted employment. Adam barely mentioned education or dyslexia in his life story. Those who talked extensively about dyslexia tended to be the participants who had spent the longest time in education, and Adam, who talked least about it, was the only participant who did not have experience of further education, and had self-identified as dyslexic rather than being identified professionally. This suggests remaining in education has an impact on the discourses available to people; it may also be that prolonged presence in an educational context required the participants to address their difficulties more deeply because the difficulties were highlighted for longer periods.

All the participants except for Elizabeth Kirner asked at different times whether the information they were giving me was appropriate. As noted earlier, Goodson and Sikes describe this kind of question as 'Am I telling the right version?' (2001, p46). In response I tried to convey that their perception of what was valuable and relevant was what I wanted. For example, the following extract is from the first interview with Amber,

*Amber: Do you want a lot about the dyslexia side of my life as well?*

*Ruth: I'm interested in the dyslexia side but I'm interested in other things doesn't only have to be about dyslexia*

*Amber: yeah, ok*

*Ruth: anything that you think is important is important (Interview 1).*

I asked Bob and Alice to give a broader picture of their lives outside of dyslexia, as their initial life stories were highly focused on dyslexia. Despite trying to allow the participants to demonstrate what was important to them, by my responses I also guided the life stories and this is an example of the part I played in their co-creation.

I had anticipated that the extent to which dyslexia was discussed in the initial life story, before I began asking any questions, would give me a sense of the prominence dyslexia had played in participants' lives. However, I think this was an inaccurate assumption. Rather, I think the perceptions they had about the purposes of the research were key; Bob and Alice, the participants who talked most about dyslexia, both asked what kind of research I would be carrying out later in the interviews. They told their life stories in terms of the way dyslexia related to it, and rather than this reflecting the importance of dyslexia in their lives, I think it showed their desire to frame their life story according to the context of speaking to a researcher about dyslexia. When comparing them to Adam, who spoke least about dyslexia, attempting to determine who was affected most by it is impossible. Dyslexia affected Bob and Alice deeply because they spent longer in education and battled long and hard to overcome their difficulties, as well as struggling over longer periods to make sense of who they were in the hostile context of education. Dyslexia affected Adam greatly because he did not develop an understanding of his difficulties until much later in life nor did he overcome them to the same extent, and dyslexia limited his employment opportunities significantly as an adult because of lack of qualifications.

We began the second and third interviews by discussing the transcripts of the previous interviews. Surprisingly, many of the participants read the first transcript despite finding reading difficult. Fewer participants read the second and third interview transcripts. They gave very few corrections or clarifications, though a number commented on how surprised they were at the incoherence of what they said, and we discussed the difference between written and spoken language, and that it was normal in spoken language for there to be fragments, repeats and poor grammar.

The third interviews centred round the participants' perceptions of dyslexia, how it impacted themselves, and how others perceived dyslexia. By this time I had established relationships with the participants, and some really interesting thoughts came out. Perhaps because we knew each other better the participants were willing to discuss things they weren't sure of, and this is when, for example, Bob began discussing dyslexia in a discourse of Educational Responsibility. I had the sense that if we had continued our conversation he might have

developed this into something similar to a Campaigner approach, as he had expressed concern for other dyslexic people and the responsibility of society.

During the interviews some of the participants experienced strong emotions, including tears. Later in the final interviews when I asked about their perceptions of being interviewed, two of the participants, Country Boy and Amber, referred to finding the intensity of these experiences uncomfortable,

*I've been reading it again and it hasn't upset me the second time through, the first time was very upsetting, because you're examining your life and the drawbacks that there were as well as advantages, but a lot of drawbacks. Especially as a child. The other things that upset me was it brought home to me, well it brought up a picture actually, talking about being in hospital as a child and seeing all those men wounded and so on. And the thing that jumped out at me is I've seen two instances where men were absolutely terrified (Country Boy, Interview 4).*

*Amber: I was a bit thrown at first when I realised it was life history as well as dyslexia ... it was a bit of a shock to go, now she wants to know about me.*

*Ruth: because I have been a little bit concerned ... [about] what you said about remembering negative memories ... I was aware that it might have brought up things that weren't positive for you*

*Amber: it did. That's a tricky one, because there's no way you'd know in advance for a start, it's, I've dealt with some of those issues a lot over the past few years ... not the first time told in recent years, so in that sense that's easy for me, whereas the first time I told someone who didn't know me, that's a lot harder ... I've never felt I had to tell you something for the sake of it. So it has been, yeah, it was a difficult issue but it is part of who I am, and therefore I feel it's important (Interview 3).*

Both found talking over their past difficult, as they re-lived distressing experiences. This kind of event was less difficult over the course of the interviews as our relationships developed, but such times involve risk due to the vulnerability of the participant. They seemed to regard the telling of painful memories as potentially valuable despite the discomfort, as Amber says, 'it was a difficult issue but it is part of who I am, and therefore I feel it's important' (Interview 3). Elizabeth Kirner acknowledged emotional distress but also said the interview process affirmed her difficulties as relatively normal,

*I didn't realise how emotional it could be ... it sometimes normalises it for me ... Because ... people don't [normally] say ... 'What's it like to be inside your head?' and to be able to sort of discuss that with somebody and them to go, 'oh, right' and ask questions about it, kind of normalises it ... to talk about it like this is actually quite a positive thing because it puts it into a, 'oh, that's actually quite normal for dyslexia' ... 'that's fine', mmm, yeah, that's good (Interview 2).*

The participants' understandings of themselves were further affected by reading my analyses. Pablo said as I left (unfortunately I had already turned off the voice recorder!) that reading about the discourses had helped him formulate categories for thinking and talking about dyslexia that made him more aware of what might be helpful/unhelpful to him and others. In a quote I did manage to catch, Elizabeth Kirner said,

*... if it hadn't been for [the analysis] I wouldn't have been able to say to my mum when we were in Stratford , 'hang on a minute, this is my disability' because I read it before I was off to Stratford ... I had her in a wheelchair ... there was an Oxfam ... I took her in, in the wheelchair, there was space to get in the door ... I parked her and I was looking at the books. And ... she got really cross with me and made me take her out of the shop ... found somewhere to sit and have a cup of tea and she had a go at me about ... not being aware of the lack of space around her , that was making her feel uncomfortable, people not being able to get by ... all the time in the wheelchair since we'd been there, we were walking down the street and I would be pushing her and she [acted very stressed out about where we were on the pavement] ... I said '... I am looking, but I might be looking slower than you would be' and I did point out to her that ... I need to check that and check that because my concentrations not good and then ... she gets wound up with me, then that's when I tend to knock things because she's taken my attention away from what I am actually focusing on [steering the chair] ... and she actually apologised to me. I'd said, 'I have a disability that you have to take into consideration. You're not the only disabled one here'. I said it in quite a firm way, because I was upset. I think it took her aback, and it's the first time I've really spelled out to her how much difficulty I have in everyday life. And that was because I'd looked at [the analysis] ... and it got me thinking, and it was good to be able to express that to her (Interview 3).*

This gives a specific example of the way changes in understanding impact upon action and relationships. Despite the sometimes painful emotions experienced by participants in relation to telling me about their pasts, they described the influence of the interview process upon them as positive. This supports my assertion that this study was carried out ethically.

## **The process of analyzing the data**

The process of analyzing the data was circular rather than linear (see Fig. 4.1a), involving a process of spiral learning (Bateson 1994) where I re-visited similar ideas each time from a new perspective, because of new knowledge and experience. For example, in the beginning of my third year I carried out a literature review on identity and wider disabilities (Gwernan-Jones 2009). The topic included matters of disability rights and the social model of disability, and my developed knowledge in these areas contributed to being able to better conceptualise social contributions to dyslexia. In this section I will describe the practical processes involved in data analysis from transcription of the first interviews to checking my analysis with participants.

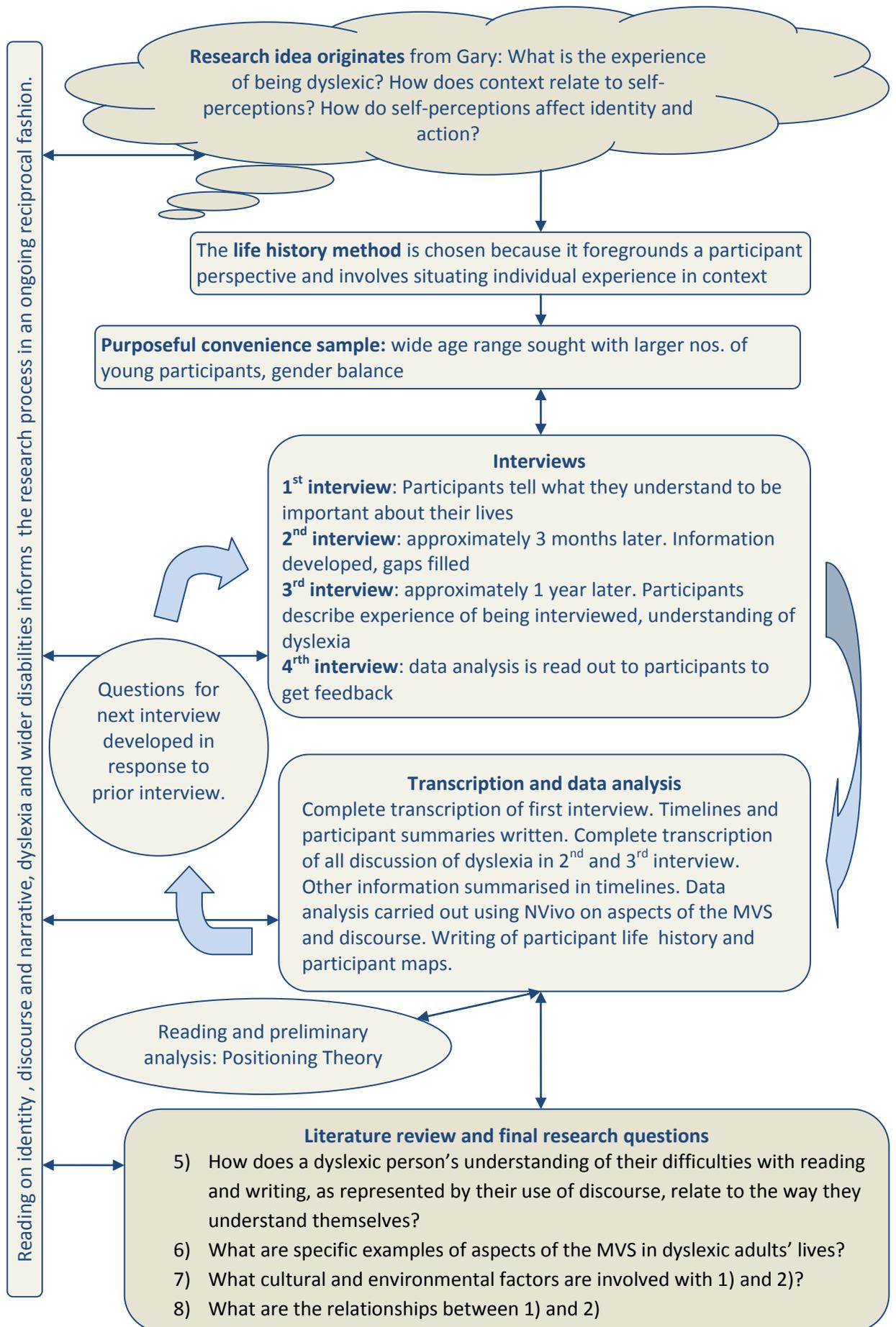


Fig. 4.1a. Circular nature of the process of data analysis.

Each first interview was recorded and transcribed verbatim, and from these transcripts I created a timeline and participant summary (see Appendix 1 for an example set of these documents). The timeline organized the data according to time in life on one axis (*e.g.* pre-school, education, employment) and other contexts such as family, school, hobbies, friends and experiences of dyslexia on the other. This enabled me to identify any gaps in information that I then asked about in Interview 2. The summary helped anchor my understanding of each participant. During transcription of Interviews 1 and 2 I also noted themes that were appearing, and these supported the development of questions to ask during the next interview that probed each participant's understanding of dyslexia and how it impacted them. During the interviews I had not yet decided to pursue analysis via discourse and the MVS so these did not contribute to the questions I asked. Rather, I explored the participants' understanding of themselves as dyslexic, and what their perceptions were as to way others viewed dyslexia.

My process of transcription evolved over the course of the data analysis phase. Initially I transcribed in detail, including every 'um' and 'mmm' and noting pauses. I also broke the line for each change in speaker. However as I began working with the transcripts I found this detail to be unnecessary and distracting, and I began transcribing only real words. I also noted short comments within the text of a monologue of the other, such as within this description by Amber, 'I often used to highlight a lot more than I needed to just because it made it a lot easier [you were in effect creating a yellow overlay] yes! In a sense! I laugh at it now looking back because it makes a lot more sense' (Interview 2); my own comment is shown in brackets. I found this better supported keeping the flow of the spoken interview in the written text. Due to time constraints, when transcribing interviews 2 and 3 I transcribed verbatim all parts of the interviews where issues relating to difficulties with reading and writing/dyslexia were discussed, however I summarized other information in the timelines. I used a different colour of text for each interview in the timelines to identify from where the words had come.

During year two I experimented with positioning theory (Harré & van Langenhove, 1999) as a means of analyzing the data but, as I mentioned earlier, this excluded some aspects of experience so I rejected it as a form of data analysis. It was not until I completed my literature review in my third year that I encountered the MVS. Because it incorporated categories of action in addition to conceptualizations of internal processes, and because it signposted changes toward more positive self-understanding, I decided to use it as a framework for mapping the meanings participants made about being dyslexic. I then chose to use the MVS in tangent with discourse, because discourse provided a link to signify the relationship between cultural understandings and personal understandings.

To organise the analytical process, I chose to use the qualitative software NVivo (v.8). I have an affinity with computers; I experience them as an extension of my brain and having developed good typing skills while in employment previous to my postgraduate work, can write quickly on them. In contrast, I do not enjoy writing things out by hand, and am apt to lose pieces of paper. I had some exposure to NVivo during my MSc in Educational Research, and at that point realised its capacity for storing and organising large numbers of documents, and for organising the coding process involved in the analysis of transcripts. Realising the software made it possible to highlight text, code it and then having worked through a transcript, pull up all instances of a code, was enough to convince me it was worth using, as I had anticipated compiling coded text categories on paper to be painstakingly tedious. Deciding to use NVivo was therefore straightforward. My choice was based on the desire to organise data analysis on a computer rather than on paper, though, rather than the desire to use the analytical tools present in the software. This is a common first (and ongoing) approach to the use of NVivo (Richards 2002).

Despite my desire for support in data organisation rather than analysis, NVivo will have impacted my process of data analysis. Since the inception of software to support qualitative data analysis (NVivo's forerunner, NUD\*IST 1, was developed in 1981), there has been ongoing debate about the impact of such software on the analysis process. Those who see its benefits describe it as giving greater ease in contrast to manual analysis (e.g. Bazeley 2006; Richards 2002); certainly this is what prompted my choice to use it based on my introduction to it during my MSc. However, I cannot comment on how it changed the interpretive process, not having experienced manual analysis.

However, Gilbert (2002) describes a study exploring the experiences of interpretive researchers who, having carried out manual analysis, switched to NUD\*IST3/4. She identified a three stage process; 1) the tactile-digital divide, 2) the coding trap and 3) the metacognitive shift. The tactile-digital divide was experienced as discomfort at not having pieces of paper to hold and move about as desired and working instead from a screen. The researchers described this as a feeling of distance from the text. Some researchers decided not to continue with the software for that reason, others used paper for some aspects of their analysis. Some became used to it. Having worked as an on-screen copy-editor in former employment, this was not an issue of discomfort for me.

The coding trap refers to an excess of closeness to the text. NUD\*IST (and NVivo) enable coding that both displays occurrences of codes together (as well as broken down into smaller categories, such as by participant name or gender), and allows the researcher to go back into

the original transcripts to view the context of each separate item of coded text. The researchers described this aspect of the software as making analysis more thorough than their manual experiences of analysis. However, the ease created a situation where they could feel 'bogged down' (p218) by the coding process. The way they dealt with this was to create strategies that required distancing themselves from the data, some of which I also used during analysis, for example writing memos and coding systematically for specific research-related themes (see below, p125).

The metacognitive shift refers to a stage where the researcher reflects on their use of the software as it impacts the analysis. This usually was in reference to pitfalls such as potential errors and the coding trap. It involves the awareness of what mistakes can be made, which allows one to be watchful for those errors. NVivo lists recently used codes in a drop-down box which can be used as a shortcut; the error I made most was to inadvertently choose the wrong code in the list. I learned to pay more attention to this part of the coding procedure, and to be alert for items that did not fit a code when looking at text organised by code. In the beginning of my use of NVivo, becoming familiar with how to do what I wanted to do was frustrating, but over time I began to use it with fluency, and I agree with the researchers in Gilbert's study who said they felt 'one with the machine' and that the software 'fit their thinking' (p222).

On reflecting on my use of NVivo, I believe it supported a more systematic and thorough analysis. Had I not used NVivo, my analysis would have inevitably been different; simply the order of the coded text extracts may have made some more or less obvious to me (Crowley et al. 2002). However I preferred working with NVivo to the first stage of my analysis, during the first two years of the PhD, when I carried out interviews and produced timelines, summaries and notes on emerging themes without the use of NVivo. I felt a sense of being overwhelmed and confused by the amount of data, and consequently found it difficult to think about. Much of this is to do with the fact that I had not decided on a theoretical approach to analysis yet. But also, it involved the way I was able to conceptualise the text. Even in the timelines, where text was organised by time of life and contexts (family, school, work, friends, hobbies etc), I found ideas difficult to draw together. The way NVivo allowed me to straightforwardly view together text from different codes, without losing the ability to see the context of those extracts, facilitated the way I was able to think about the data. In reading papers about NVivo, I came across the understanding a number of times that the researcher does the analysis not the computer (e.g. Denzin and Lincoln 2005a; Leech and Onwuegbuzie 2011). I would agree with this, but also I believe the software enabled me to do analysis that went beyond what I would have been able to do through manual analysis. The first step was to create Nodes in

NVivo. 'Nodes' represent the system by which codes are stored in NVivo, drawn from the name used to denote the branching or linking networks of plants in horticulture (Bazely 2007). Free nodes represent lone codes for which relationships with other nodes have not been established. Tree nodes represent nodes which are linked through a hierarchical relationship system. The process of coding text in NVivo, as mentioned before, involves highlighting text and indicating a node to which one would like it linked. The original transcript (or other document) remains unchanged, but that particular node will now display that text in connection with it. Text can be linked to as many nodes as desired. Text linked to a node, from multiple transcripts/documents, can be displayed together, with indication of their source.

The beginning of my process of analysis using NVivo has been deductive; I approached the transcripts with the pre-developed aspects of the MVS, previously identified discourses, information about experiences of dyslexic adults taken from the literature review, and themes I had noted during my initial stage of analysis. I created a tree Node for each of Pollak's (2005) four discourses (summarised in Table 2.2, p50), and one for each of the aspects of the MVS (for a summary see Table 4.2). These began as tree nodes, with the four discourses organised by the node 'discourse' and aspects of the MVS organised under 'Internal Decisions' and 'External Manifestations'. I also went back to the literature review and created a tree node for each of the themes I had identified in the section of the literature review, with sub-nodes based on sub-headings (see p34). I also created free nodes based on ideas I had noted in the first phase of data analysis, when I created timelines, for example 'disclosure'.

I then categorised in Nodes text within each participant's transcripts that expressed Pollak's (*ibid.*) discourses and aspects of the MVS, as well as text I thought might express other potential discourses. This was time-consuming, and required constant focus to consider the different possibilities for Nodes, but became easier over the course of participant transcripts as I became more aware of what was required.

The Nodes changed and developed over the course of coding the eight sets of participant transcripts. Through the process of coding I became aware of inconsistencies in my understanding of the categories, for example the difficulties in identifying the *Internal Decisions Desire and Goal Oriented* (see discussion pp 116). When uncertain about such an issue I noted this in a memo. Over the process of coding I was able to clarify the inconsistencies and make decisions on coding boundaries, assisted by the information documented in the memo's.

Aspect of the MVS		Description
Internal Decisions	Desire	Explicitly described conscious decision to excel
	Goal Oriented	Explicitly described conscious decision to complete a specific task successfully
	Reframing	
	Stage 1: Recognition	The process of realising what one's areas of difficulty are
	Stage 2: Acceptance	Acceptance that one has difficulties, often alongside valuing oneself regardless
	Stage 3: Understanding	<ol style="list-style-type: none"> <li>1) Development of understanding about oneself, for example strengths and weaknesses</li> <li>2) Development of understanding about the meaning of having difficulties, for example development of understanding about dyslexia</li> <li>3) Development of understanding about how to apply knowledge of strengths and weaknesses in life, for example choosing contexts in which strengths are maximised</li> </ol>
External Manifestations	Stage 4: Action	
	Goodness of Fit	Experience of success in a context where personal strengths are valued
	Learned Creativity	Developing strategies and coping mechanisms to overcome difficulties
	Persistence	Working hard in order to overcome difficulties
	Social Ecology	Seeking out or receiving personal and/or practical support from others to help with difficulties

Table. 4.2. Description of aspects of the MVS.

Having coded all the transcripts, I identified new discourses on the basis of participants' talk that mimicked concepts described in the literature review and that represented themes identified in the first phase. Any potential discourses that were expressed by a majority of participants were added to the analysis, and I went back to earlier transcripts to re-analyze them in light of the new discourses (for a summary see Table 4.3), and at this time I also revisited previously coded nodes (MVS and Pollak's four discourses) in light of decisions made about coding boundaries. I then created life histories using the participant's timeline and summary, discussing use of discourse and aspects of the MVS that were relevant to their ongoing narrative. I then chose quotes that I judged most clearly demonstrated the participant's life story through use of discourse for the participant's map. The writing of the life

<b>New discourse of dyslexia</b>	<b>Origins/research documentation</b>	<b>Characteristics</b>	<b>Potential positive impact</b>	<b>Potential negative impact</b>
<b>What's wrong with me?</b>	Originates in our text-based educational system and the experience of having difficulty learning to read and write. Ingesson (2007), Burden (2005), Pollack (2005), McNulty (2003), and Hellendoorn and Ruijsenaars (2000)	Internal question asked by person in response to noticing difference between themselves and their peers in ability to learn to read and write	Brings awareness of the presence of difficulties which is the starting place for seeking compensation	Most readily available answer without identification of dyslexia is the Thick/lazy discourse
<b>DRW=Stupid/lazy</b>	Historical associations between being educated and intelligence; confusion over seemingly intelligent children who tend to produce written work of poor quality. Edwards (1994); Riddick, Farmer et al. (1997); Hellendoorn and Ruijsenaars (2000); Dale and Taylor (2001); McNulty (2003); Pollack (2005); Riddick (2010)	Difficulties in reading and writing are understood to signify a lack of intelligence. Or, particularly for those who are verbally able, teachers attribute poor written work to lack of effort	Motivation to succeed through discourse Show them or to work hard to escape association with those in the bottom set as in the life history of Pablo Jennings	Negative self-perceptions, negative affect, lack of motivation, avoidance of schoolwork
<b>Dyslexia= Stupid/lazy</b>	Historical associations between being educated and intelligence. During the 1980s dyslexia described as 'the middle class name for stupid' became common. Armstrong & Humphrey 2007 describe those who resist identification of dyslexia to use this discourse	Difficulties in reading and writing are understood to signify a lack of intelligence. Because dyslexia represents those who have difficulty with reading and/or writing, dyslexia is understood to mean unintelligent	Motivation to succeed through discourse Show them or to learn coping mechanisms to avoid bullying as in the life history of Bob	Negative self-perceptions, negative affect, lack of motivation, avoidance of schoolwork, refusal of support
<b>Extra-able</b>	The media, where the lives of famous dyslexic people like Susan Hampshire (1990) are depicted; Logan (2009); Ehardt (2009); West (1997)	This discourse involves discussing better-than-normal abilities that are attributed to being dyslexic.	Involves identity politics where stigmatized aspects of group identity are turned on their head to become badges of pride; dyslexic people celebrate their ability to do what others cannot.	Can be a fulfillment of the non-disabled stereotype of disability as 'Super-crip', a person who, against all odds, overcomes disability through individual striving (Morris 1991)

Table 4.3. Summary of new discourses of dyslexia identified (continued on p.128)

New discourse of dyslexia	Origins/research documentation	Characteristics	Potential positive impact	Potential negative impact
<b>Show them</b>	This discourse originates in humiliating experiences relating to an educational context. McNulty (2003)	Imagined interaction with people who made negative attributions regarding potential. The person demonstrates their success as an adult for example by showing their degree. Or, one is motivated to succeed in order to prove those who discounted one's ability to be wrong.	Resolution of negative emotions; motivation to persist and succeed.	
<b>Educational responsibility</b>	Based on the Social model of disability, where disability is understood to result from barriers in society. Dale and Taylor (2001) describe the development of awareness of the role played by dyslexic adults' schools in creating/compounding their difficulties with reading and writing.	Often involves retrospective understanding about benefits to self-perceptions and learned compensatory measures following identification of dyslexia; the person begins to think how their lives would have been improved had they been identified earlier. Also can be positive, as in Alice's life history when she attributes her professional success to the teachers who required her to work hard; this taught her she was able to succeed with persistence.	Teachers belief in pupils and teaching the value of hard work is powerful in its potential to support dyslexic pupils. Appropriate support for learning to read and write including coping mechanisms can greatly ameliorate difficulties. Schools can be structured to allow demonstration of knowledge in activities other than reading and writing.	Teachers may lack belief in ability/have low expectations – this is powerful in its potential to limit dyslexic pupils' achievement. Without appropriate teaching dyslexic pupils may not learn to read or write; if pupils are not allowed to demonstrate knowledge in activities other than reading and writing they may be unable to gain qualifications.

Table 4.3. Summary of new discourses of dyslexia identified (continued).

histories was therefore a culmination of a number of different processes, all relating to different aspects of immersion in interview data. This occurred first through presence with participants during interview, then through the transcription process and through the compilation of timelines and summaries, then through coding in NVivo. The timelines, summaries and text linked to Nodes in NVivo then became secondary sources which supported me to prioritise what to include in the life histories.

I found it quite difficult to characterise the participants in their life histories. I felt a responsibility as a researcher to quote them as much as possible in order to represent their stories; also, their perceptions were often complex and their reasoning was developed in some cases over long passages which were impossible to represent succinctly. Inevitably I had to leave out interesting and illuminating information in order to meet the thesis word limitations;

to do so I prioritised aspects of the interviews related to discourses and the MVS, as this was the focus of my analysis. This forced limitation is common to any research endeavour and is well described by Marcus,

*once we know, or analytically fix by naming, that we are writing about violence, migration, the body, memory, or whatever, we have already circumscribed the space and dimensions of the object of study—we know what we are talking about prematurely. But you can be sure that the object of study always exceeds its analytic circumscription, and especially under conditions of postmodernity. That is, there remains the surplus of difference beyond, and perhaps because of, our circumscription (1998, p391).*

However, I hope to develop neglected aspects of the data in future publications, for example in relation to the social difficulties attributed to being dyslexic that were described by most of the participants, the participants' description of dyslexia as a metaphor and gender differences. I have also laid the groundwork for a book written for dyslexic adults by myself and the participants, where each participant writes their own life story chapter and I provide analysis based on the work done in the thesis. All eight participants expressed interest in being involved in this future project, and I see it as a way to further strengthen this research on ethical grounds, because it allows for direct authoring by participants, makes its focus of communication other dyslexic adults rather than academics/practitioners, and would provide further opportunity for the participants to positively reframe and develop their own discourses of dyslexia, their ongoing processes being documented in a way which will then be made accessible to others. Two of the participants are

particularly able in the area of IT and have ideas about non-textual versions for access on DVD and in podcast form.

I decided to make visual representations of the relationships between use of discourse and aspects of the MVS – the participant maps – in response to repeated comments by participants during interview that visualization was a powerful way for them to understand and communicate, and that text simply was not. As Pablo says, ‘There isn’t enough stuff in visual formats. Just in such a frustratingly obvious way sometimes, the way stuff is still being bandied about on paper when people are discussing dyslexia. There’s so much text’ (Interview 3). Though there is a good deal of text on the maps they visually represent relationships between each participants’ lifeline, use of discourse and development of understanding about themselves and coping strategies as represented by the MVS. Use of red for harmful, green for helpful and neutral colours to represent potentially helpful and/or harmful discourse also provides an alternative means of communicating information. I find the maps somewhat visually confusing – but I see this as useful because it draws attention to the complexity of the relationships and the variety of possible links.

A further limitation of the maps is that of spatial constraint. I have chosen quotes I felt best represented key aspects of participants’ experience, and inevitably this involves exclusion as well as inclusion. For example, due to space limitations, Bob’s positive experiences working in the theatre and the church as a teenager are only represented once each on the map, despite the fact that he discussed their relevance at length, and I was unable to find space to represent his experiences playing in a band. I chose to leave this out because it was an outgrowth of the church work which was represented. The maps are also limited because they do not represent repetition. For example, in the centre of Country Boy’s map the large quote spoken in the *Niche* discourse links to *Acceptance, Understanding, Goodness of fit* and *Social Ecologies* once each. However it represents a number of life experiences over his adulthood which linked to these aspects of the MVS. If each event were considered separately the number of links would be quite different. In these ways the maps do not represent participants in a quantitatively direct way. What I have attempted to create instead is a qualitatively accurate perspective; the maps represent the events that seemed most meaningful in each person’s process of making sense of their difficulties.

Having completed the life histories I then met the participants for a fourth interview to ask for feedback. The participants asked me to change very little. There were a few factual corrections – for example I was one year off on Alice’s date of birth, and I described a tutor who was supportive

to Amber as a woman when he was a man – but none of the participants disagreed with the way I depicted their process of understanding themselves and developing coping mechanisms in response to dyslexic-type difficulties. That the participants felt the life histories represented them well is the most important facet of my claim that my interpretation is of high quality. Some participants, particularly Adam, might have felt at a disadvantage because of the difference between our levels of academic qualifications, as well as being less familiar with academic writing, and this might have led him to be less willing to voice any reservations he might have had about his analysis. Our conversation following reading his life history was as follows,

Ruth: *did I get anything wrong in terms of facts but also in terms of*

Adam: *interpretation*

Ruth: *yeah.*

Adam: *uh, no. I thought it was spot on. Nothing sort of stood out for me that said that's completely wrong or that's not right*

Ruth: *ok, any nuances of 'is that really what I think?', or 'do I really feel like that?'*

Adam: *I just repeat the answer I gave a moment ago – spot on.*

Other participants had high levels of education, so they are more likely to be practiced in giving critical responses. I particularly thought Amber with her Master's degree in Research methods and Pablo with his high level of knowledge about social aspects of dyslexia would be a real test of my process of analysis. Both were positive in their responses to my question as to whether I had represented them accurately, as were the remaining participants. The process of analysis was very much one of priority, where I had to choose the statements I thought best characterized the life stories of the participants. On the whole I did this accurately though there were a few items I was asked to re-insert, for example Elizabeth Kirner asked me to include her love of animals in her analysis as it is particularly meaningful to her.

Reading the life histories to the participants initiated further discussion of the issues, sometimes prompting new information. For example, Elizabeth Kirner described a practice of compartmentalization that she had learned as a child to support coping with her difficult circumstances which she has carried into her adult life. None of the new information impacted the analysis in a way that required re-writing. However some of it added understanding, for example I learned that Amber had previous experience of campaigning for disability rights and I was able to clarify her process of retrospectively regretting that she was not identified before she went to university. Such refinements I added into the relevant participant's life history.

Having described the process of interview and data analysis, the remaining chapter consists of the life histories of each participant.

## Adam

Adam's life, especially his childhood, was very much action- rather than language-centred – his home culture valued work and skills, and he has brought that focus with him into adulthood. Therefore it is unlikely Adam has spent very much time talking with others about his difficulties, and possibly little time thinking about them as well. In this way what he says about his difficulties is possibly all the more valuable, because there is more potential for what he says to be a struggle to develop discourse from his experiences as much as drawing on available cultural discourse. Adam's life story hinges upon his need for a father rather than any difficulties with reading and writing. In terms of plot the loss of his father was the 'exposition', or circumstance that sets the beginning of the story, and his search for a father figure the underlying 'quest' throughout the story, with a literal journey in his late twenties seeking it. Resolution in Adam's story comes as he himself becomes a stepfather and father, but a responsible and loving one, committed to being supportive to his stepdaughter and son. This is the axis on which Adam has made sense of his life, and he seems to have spent little time consciously developing meaning about his life that focuses on dyslexia. In one sense it can be said that Adam's difficulties with reading and writing have been of little consequence to him; his lack of qualifications did not trouble him because he wanted to work for himself and he has developed his areas of strengths in a unique and valuable way as a community performer. However, had he been able to complete academic qualifications his life choices would have been greatly broadened.

Adam was born in 1960 and was 47 at the time of the first interview. Adam has two older sisters and when he was born his parents were managing a garden nursery. When he was 3½, his parents separated and he, his sisters and his mother moved onto a farm with Adam's stepfather. Adam's stepfather ran a dairy farm, and Adam describes growing up there,

*...there were benefits to being on the farm ... we bred new forest ponies. And my mother bred gun dogs ... I had guns and I had a ... sailing boat, and I fished... I could drive tractors by 7 ... drive a car by 9 (Interview 1).*

Adam's home life taught him very early, then, that he was capable of many things; driving cars and tractors, taking care of animals, riding, shooting, fishing. But he also describes obstacles,

*I think the break up started when I was about 3 and a half ... I didn't really know what was going on. Actually, I had a stutter. I think emotionally didn't deal with it very well ... I suppose ... my continuity was broken ... it was broken from my grandfather ... I wasn't with my father ... that sense of belonging ... I didn't really have a ... father figure around ... that I was connected with (Interview 1).*

Adam does not have particularly negative memories of school; he didn't talk about feeling humiliated there, of teachers who hindered or teachers who helped. School was something boring to be endured,

*I don't think I was that interested in school work ... I was really bored in school to be honest I was looking out a window most of the time ... you could say I was laid back really in the sense of it was something you had to do (Interview 2).*

He said he did well in sports, 'I was quite good sporting ... I was captain of the rugby team ... and the hockey team and athletics' (Interview 2), and said he felt happy as a schoolchild, though he suggests his happiness at school was limited to playing with his friends, 'I was quite, quite happy ... in the sense of ... friends, and doing things ... I think I was far happier out of the classroom than in the classroom' (Interview 2). These passages suggest Adam was adept socially; however he attributes a lack of social confidence – he says he now feels uncomfortable discussing books, films *etc.* in everyday conversation – to being dyslexic. He also attributes a sense of insecurity that he 'carries' to being dyslexic. Both of these perceptions suggest that his lack of academic engagement at school also impacted him socially and personally.

Adam's main memory relating to difficulties learning to read and write revolve around being physically punished by his stepfather, and this is the only place in his first interview where he describes his experience of having difficulty learning to read and write,

*the step-father, who was quite, well, a violent man, that, you know, you're in fear of physical abuse really. If you crossed him or you didn't do it exactly how he wanted it or if he thought it was stupid, or, which he did, I mean stupid is definitely what he thought of me. He, I was slow to read, you know, and he was giving me reading lessons, reading the Telegraph, at sort of 8, 8, 9. And you'd get a word wrong and you'd sort of get knuckled by*

*him and it was just awful, absolutely awful, I just remember always coming out of there and crying, you know, always ... And it was hell, absolute hell. And he was trying to help, I suppose, in his own ignorant way, really. But it really put me off (Interview 1).*

This passage is an example of the *DRW=Stupid/lazy* discourse (see Fig. 4.1b), and does not support Adam in any aspects of the MVS. Adam hints at a sense of confusion about his difficulties, in that he doesn't understand why he couldn't remember words he had just been told; this can be seen as the *What's wrong with me* discourse,

*[my difficulties] didn't make sense. I didn't, I couldn't remember a word ... it was ridiculous ... [my stepfather] might have said it for me, or, you know, broken it down or something, but then it came up again and I still wasn't recognising it. I certainly couldn't spell it (Interview 2).*

Adam describes his stepfather as explaining *What's wrong with me* with the *DRW=Stupid/lazy* discourse (above), but Adam does not admit to internalising that understanding; he never says during one of the interviews, 'I thought I was stupid', and 'lazy' is a description he never makes of himself. When I met Adam to go over my initial analysis of his interviews I asked him if he had ever thought he was stupid and he said he hadn't. I had suggested this was because of the practical abilities that were obvious to him because of his early responsibilities on the farm, and he agreed with this. But he also said,

*I was defiant, and that's why I got such a battering ... I knew ... he wasn't going to kill me ... I would survive somehow, or there was some part that ... he would not invade. And it's that thing about being dominated ... by a powerful grown up and hating it ... but being unable to escape from it ... yet having some sort of dignity and self belief and worth ... I was quite religious when I was young and you know it could well have been ... God you know, spiritual belief (Interview 4).*

This suggests that spiritual belief is potentially an aspect missing from the MVS as a source of positive self-perceptions and actions. Adam makes clear links between his upbringing on a farm and his work ethic as an adult,

*... everyone worked hard and I think the only way you could score points was by being the hardest worker ... I look at how my sisters are so driven ... and how I'm driven ... there are always jobs to be done [on a farm]. And we're all really hard working and it's all come from that (Interview 1).*

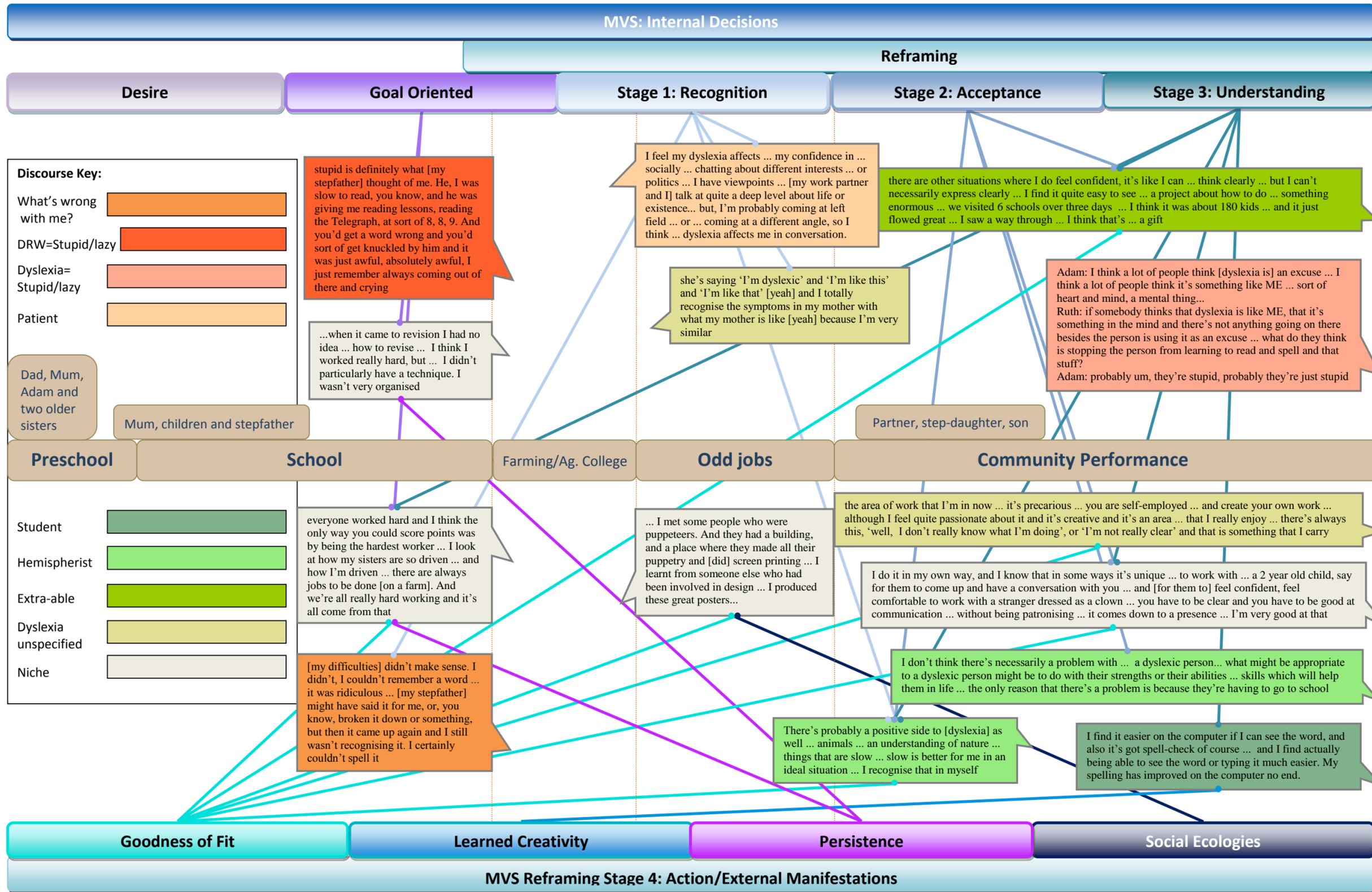


Figure 4.1b. Adam's process of making sense of his difficulties with reading and writing and the methods he develops to cope with them, analyzed by mapping his use of discourse onto the Model of Vocational Success (Gerber et. al 1992).

Figure 4.1 shows a representation of Adam's process of making sense of his difficulties with reading and writing and the methods he develops to cope with them, analyzed by mapping his use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

Stages of Adam's life are represented across the centre of the model, and the size of each stage is in ratio to the length of the stage in years (so 'Community Performance' is the largest stage because he has worked in this way for twenty years whereas 'Preschool' is the smallest because it lasted only 4.5 years).

Quotes from Adam's life story are placed according to the time in his life that he is referring to, so quotes about experiences that occurred during his school years are located above or below the stages 'School'. Quotes shown in the figure are highlighted grey in the text.

Aspects of the MVS are identified across the top and the bottom of the figure, with Internal decisions listed across the top, and the fourth stage of Reframing, Actions/External Manifestations, listed along the bottom. Colour coded links are made between different aspects of Internal decisions and Actions/External Manifestations and quotes from Adam's life story. Links from Internal decisions attach to the top centre of a quote, and links from Action/External Manifestations attach to the bottom of a quote. The numbers in the colour boxes indicate how many times an aspect of the MVS was linked to each discourse.

Finally, discourses of dyslexia are represented by the background colour behind each quote, and the key to what discourse is represented by each colour is located on the left side of the map. Discourses represented by reddish colours are less likely to support aspects of the MVS whereas discourses represented by greenish colours are more likely to be supportive. Discourses represented by neutral colours can be either supportive or detrimental. The numbers in the colour boxes in the key indicate how many times each discourse was linked to an aspect of the MVS.

This excerpt provides an example of *Niche*, where as a child Adam was *Goal Oriented* to 'score points' by 'being the hardest worker', and this gave him the opportunity to learn the value of *Persistence*. This also contributes to *Understanding* because he applies it later to other aspects of his life. Adam learned this in a context outside of academia, and this is not a discourse of dyslexia. By the time he was a teenager,

*...when it came to revision I had no idea ... how to revise ... I think I worked really hard [to prepare for exams], but ... I didn't particularly have a technique. I wasn't very organised. I think my eldest sister, she's done 2 degrees and, you know, very academic, very good ... at one point she showed me how to take notes, and how to break those down and then how to recall the whole thing. But that was ... almost too late, really (Interview 2).*

This is not a discourse of dyslexia, and does not lie straightforwardly in the *Niche* discourse because he does not succeed at exams. However, it has the beginnings of *Niche* because the experience does link to the MVS in some aspects, as he began to be *Goal Oriented* in trying to achieve O-levels; he began to apply *Persistence* to schoolwork, but he did not have access to the study skills he needed to succeed. In terms of the MVS, this demonstrates the inadequacy of being *Goal-Oriented* and applying *Persistence* for a dyslexic person to bring about academic success without *Understanding* of study skills or *Learned Creativity*.

Things between Adam and his stepfather came to a head when Adam was 17; Adam had worked two shifts at a garage over the weekend, staying with a friend overnight in between, and when he came home Sunday his stepfather confronted him because Adam had not worked on a field he had told him to plough and seed,

*... he had a go at me for ... disappearing for the weekend ... apparently I should have rolled this field ... and he accused me of being a liar ... he was so steamed up that he came to the garage where I was just parking my bike and he attacked me ... because he was wrong, you know, because I'd been working the weekend and he wasn't really in touch with what I did. So we had this scrap which ended up piling into the carport ... I managed to overpower him, I didn't hit him or anything but I put him over the bonnet of the car and, and then he was packing his bags ... my mother was crying ... And I just heard myself saying 'I'll go'. 'I want to go'. And I did (Interview 1).*

Adam soon found a job on a big estate and the estate manager set Adam up at an agricultural college whilst he worked there. He completed an agricultural qualification over the next three years. He went into a good farming job straight after he qualified, but only worked a year there; 'I'd sort of done the life cycle of this crop and it was wearing thin, and I saw the first bit after 6 weeks and I just thought, 'this is it?'' (Interview 1). Adam spent the next seven years

unconventionally; working in a variety of places and doing a variety of jobs, including running a market stall, a number of construction jobs, cooking for staff at festivals including Glastonbury and the Elephant Fair, and crewing yachts. He lived for much of these years in an old RAF ambulance he bought for £30, and later a caravan. He preceded almost all accounts of the work he was doing with 'I had a friend so-and-so and he needed some work done', or he took the initiative in suggesting jobs to people or creating them himself,

*I was moving a lot, just sort of going from one thing to another thing ... the chap who actually drove the lorry ... he had a house that he'd been doing up for 2 years ... I helped him finish his house ... this chap I know ... they needed somebody to crew this catamaran that was going to the Bahamas ... I knew that there was a juggling convention in Granada ... I knew that some people from England were going to be coming to that ... so I went ... myself and [my friend], we ... did a kind of a dance, a movement, performance based project with some lecturers there. And at the same time I met 3 guys, or a bunch of people who were students who were there, who had interest in juggling, or performing or street theatre and that sort of thing and so it was all a very creative time ... I met some people who were puppeteers. And they had a building, and a place where they made all their puppetry and [did] screen printing ... I learnt from someone else there who had been involved in design ... I produced these great posters...* (Interview 1).

This passage is an example of a description of finding *Niche*, and links to *Goodness of Fit* where Adam was capable of making a living based on practical skills and his relationships with others. His reliance on relationships and work is an example of *Social Ecologies* as Adam compensates by swapping skills he has for skills he does not have. In this passage he describes his gradual development of interest in circus skills; eventually he signed up to a government programme run during the Thatcher years, for small business start-up as an entertainer. He did extremely well during his first year, 'I had a great 12 months, first year in official business, and made more money than I'd ever had' (Interview 1). However, Adam then travelled for the next two years, following a spiritual guru in Europe and America, whilst he continued to perform as a clown,

*... when I think about it I guess I was looking for a father figure ... something sure or some sort of spiritual belief that gives you fortification ... moral, spiritual sense of oneself ...*

*[we were] living in groups of 6 and its actually quite a pressure cooker type situation where ... [one is] quite seriously looking for a transformation ... spiritual growth ... what I learnt was what I didn't know ... the actual discussion and that side of things I struggled with the understanding of ... and it came to a point where I just ... missed my family, both my sisters had their first children ... and I came back* (Interview 1).

When Adam returned to England at age 29 he renewed previous contacts and re-established his business. He began a relationship with his current partner, who already had an eight-year-old daughter. Adam's partner soon became pregnant with their son, and they bought a house in North Devon. Adam began a partnership with another circus skills performer and they put together an award-winning act which is now one of the most popular acts in the rural touring arts and performance network they belong to. Adam moved to the city when his step-daughter was 16, so she could more easily access social and work ties. He has continued with his clown character and with the circus skills partnership to the present. In addition to performance, his business partnership goes into schools, teaching children circus skills then leading them in carrying out performances of their own.

Adam did not self-identify himself as dyslexic until his adult years, in response to his mother's self-identification as dyslexic,

*... she's saying 'I'm dyslexic' and 'I'm like this' and 'I'm like that' ... I totally recognise the symptoms in my mother with what my mother is like ... because I'm very similar (Interview 2).*

This passage is about dyslexia but not clearly linked to any discourse of dyslexia so it is *Dyslexia unspecified*; Adam is identifying a similarity between his mother's description of difficulties and his own, and the passage therefore links to *Recognition*. However, it does not directly relate to other aspects of the MVS. The way Adam characterises dyslexia is different from most of the other participants. He links dyslexia to confusion, an insecurity that he carries, and a sense that he is 'slow' in terms of processing information, which he also links to feeling inadequate in social situations,

*I'm a fairly confused person! ... I could feel quite a kind of a fog ... like cotton wool ... not crisp and defined ... that's part of being dyslexic, is the sort of confusion, undefined ... I [can] have quite a sergeant-major type of crisp ... approach to life ... that's what I feel more comfortable with, being quite sure and self-assured and quite confident, and clear about things ... the area of work that I'm in now ... it's precarious ... you are self-employed ... and create your own work ... although I feel quite passionate about it and it's creative and it's an area ... that I really enjoy ... there's always this, 'well, I don't really know what I'm doing', or 'I'm not really clear' and that is something that I carry (Interview 2).*

This passage demonstrates some of Adam's complexity, even contradiction. He likes clarity, 'a sergeant-major type of crisp ... approach to life'. However, the career for which he has discovered *Goodness of Fit* is unique and not an established area that it is easy to be crisp and

clear about. In fact it revolves around his ability to be creative and innovative. As a self-employed performer he creates the characters and acts he performs and he can be described as shockingly unconventional in his performances at times. It may be that the confusion Adam feels is due to the fact that his perceptions differ from others, and this difference is what makes it possible for him to create something different, something particularly valuable. This way of thinking about it belongs to a discourse of dyslexia as *Extra-able*, and is similar to Elizabeth Kirner's experiences. Because Adam did not speak about his work in this way I have not connected the passage to the *Extra-able* discourse but to *Dyslexia unspecified*. Adam finds expressing his unique perceptions a difficult process, 'it's always quite a leap to try and get through this fog' (Interview 2). However,

*there are other situations where I do feel confident ... I can think clearly ... but I can't necessarily express clearly ... I find it quite easy to see ... a project about how to do ... something enormous ... we visited 6 schools over three days ... the people from Oxford council ... wanted it to be inclusive ... to be a collaborative thing ... we did it ... alphabetically ... I split the performance area into 3 ... organised three schools on one side and three schools on the other side. And then we lit it so that you could either have the whole stage lit, 3 areas, or you could actually just light each one individually ... I think it was about 180 kids ... and put them through in quite a short time and it just flowed great ... when it came to the day I was very calm because ... it was very clear ... I saw a way through ... I think that's ... a gift (Interview 2).*

Here Adam shows *Understanding* of his abilities and also *Acceptance* that they are valuable, both through his experience of *Goodness of Fit* with performing and teaching circus skills. He sees his ability to clearly orchestrate a complex situation as a gift, something that many other people would be unable to do, and because he tells this story in the context of discussing dyslexia, this corresponds to the discourse *Extra-able*.

When Adam describes himself in terms of being 'slow' at processing information, he does not equate it with being unable to process information well,

*... insecurity ... self-esteem, identity ... all ... are affected by dyslexia I would say ... There's probably a positive side to it as well ... It's interesting ... what I would feel uncomfortable with. And ... what I would feel comfortable with. Animals, animals, and I guess that's an understanding of nature ... wide open spaces and just looking for signs of animal life, and looking after sort of habitat, things that are slow ... I think my pace is slow ... I need time to think ... if I'm playing golf, for example, I have a very slow swing. Some people are just swing and back through, very quickly ... I slow down as much as I can ... considered ... I've just taken up fly fishing ... I like very slow, a rod that responds slowly. You can get these rods that are very quick to recover ... very powerful ... very fast action ... I want a rod that I can just slowly see what's going on ... because of the speed in which I ... think. ... if I play tennis ... if I'm going to do a shot ... I like to be*

*right at the back of the court ... and I don't hit the ball that hard, but quite precisely ... I've got quite good dinky shots ... it's clever, but ... having the time is what I like ... slow is better for me, in an ideal situation ... I don't think I can go much faster ... I don't run off on different gears ... I recognise that in myself* (Interview 2).

Adam has obviously spent time analysing in detail how he and others swing a golf club, cast a rod, hit a tennis ball, as well as the special ability he has to relate to animals and nature. He has taken care in describing his reasoning, been exact in supporting his statement that he works best at a slow pace. It is an intelligent description, and he does not give it quickly! Though starting by describing negative aspects of dyslexia with negative impact on self-perceptions and description of slow speed of processing, which corresponds to a *Patient* discourse, his description of himself demonstrates the strengths Adam has by having a slower pace of processing, and in this way it expresses a *Hemispherist* discourse. Adam has thought about himself in comparison with others and has come to understand that he needs more time to process information, but he does not discount himself for this difference, in fact he enjoys what he is like, he values it. In this way he demonstrates *Acceptance* and *Understanding*, and at the beginning of the passage describes *Goodness of Fit* in terms of his affinity with nature.

Adam attributes his lack of ease in social situations to dyslexia, and this may link to his speed of processing and difficulties with word-finding as 'chit-chat' involves the ability to think quickly, and be able to name quickly, as well as his perception that he has a 'different take' on things,

*I feel my dyslexia affects ... my confidence in ... socially sort of chatting about different interests ... or politics ... I have viewpoints ... [my work partner and I] talk at quite a deep level about life or existence or things ... but, I'm probably coming at left field quite a lot of the time or ... coming at a different angle, so I think ... dyslexia affects me in conversation* (Interview 2).

Unlike Adam's resistance to internalising the *DRW=Stupid/lazy* discourse, he does seem to have internalised his feeling of unease in social situations as a lack in himself, 'it's a social situation and I'm just crap at it' (Interview 3). This passage has similarities to a *Patient* discourse because Adam sees it as a problem with himself, and therefore it links to *Recognition*, but not to any other aspects of the MVS. As an adult Adam learns to cope with difficulties reading and writing through the computer,

*I find it easier on the computer if I can see the word, and also it's got spell-check of course ... and I find actually being able to see the word or typing it much easier. My spelling has improved on the computer no end* (Interview 2).

Here, unlike during revision for exams as a teenager, Adam experiences success in academic-related pursuits, but this time he comes to the task with *Learned Creativity* – he uses his computer as a coping mechanism, and so this passage relates to the *Student* discourse. His success using the computer adds to his *Understanding* of what he needs to do to succeed in such situations in future.

Adam's understanding of what difficulties he has in relation to dyslexia differs from other participants, however his description of dyslexia is similar to others,

*I don't think there's necessarily a problem with ... a dyslexic person, there's only a problem if, if you're trying to learn English or Maths ... what might be appropriate to a dyslexic person might be to do with their strengths or their abilities ... skills which will help them in life ... the only reason that there's a problem is because they're having to go to school* (Interview 3).

Adam's qualification that 'I don't think there's necessarily a problem with dyslexia, the problem lies in that they're having to go to school' is reminiscent of a *Campaigner* discourse as Adam focuses on the societal context as the problem rather than the person; however he does not speak in regard to human rights issues or advocacy so it is not the *Campaigner* discourse. His reference to a dyslexic person's strengths and abilities in contrast to difficulties at school resonates with the *Hemispherist* discourse. He understands the source of the difficulties according to a difference in the brain (demonstrated by his description of slow speed of processing), but sees the problem from a social model of disability standpoint, that the person is ok outside the context of school as long as they are aware of their 'strengths or their abilities ... and skills which will help them in life'. This approach is consistent with the way he presents himself, as out of sync at school but able to succeed in work in real life. He describes the perceptions of non-dyslexic people about dyslexia quite differently,

*I think a lot of people think [dyslexia is] an excuse ... I think a lot of people think it's something like ME, you know ... sort of heart and mind, a mental thing ...*

*Ruth: if somebody thinks that dyslexia is like ME, that it's something in the mind and there's not anything going on there besides the person is using it as an excuse ... what do they think is stopping the person from learning to read and spell and that stuff?*

*Adam: probably um, they're stupid, probably they're just stupid* (Interview 3).

This is an example of the *Dyslexia=Stupid/lazy* discourse, and it does not link to any aspects of the MVS. Despite Adam's perception that others understand dyslexia in that way, he seems to have come to a strong, positive sense of his abilities and himself. Although Adam's difficulties

with reading and writing prevented him from acquiring qualifications that would have supported him in obtaining employment, his desire has always been to work for himself anyway. He has created a job which he enjoys, which he is good at and which is successful. His job is in a sense a resolution of his helplessness during the years he was dominated by his step-father, because he has done it his own way,

*I know I've done it differently ... I do it in my own way, and I know that in some ways it's unique... to work with ... a 2 year old child, say for them to come up and have a conversation with you ... and feel confident, feel comfortable to work with a stranger dressed as a clown ... you have to be clear and you have to be good at communication ... without being patronising ... it comes down to a presence ... I'm very good at that (Interview 3).*

This cannot be said to link to a discourse of dyslexia, so represents the *Niche* discourse, and it links to *Goodness of Fit* as Adam describes his ability in his job, to *Acceptance* as he describes it as valuable, and *Understanding* as he demonstrates his knowledge of his abilities and how to use them successfully in employment.

## Alice

Alice was born in 1978 and was 28 at the time of the first interview. Her father is a consultant ENT specialist and her mother is a doctor who works part-time in a family planning clinic. Alice has four younger brothers and sisters, and all seven of the family identify themselves as dyslexic. Perhaps for this reason, Alice has a keen awareness of the diversity that can be represented by dyslexia, 'even my brothers' dyslexia is different ... to mine ... and I think that's what confuses a lot of people ... just because you're dyslexic doesn't mean you're like another dyslexic' (Interview 2). Alice is the only participant in this study whose parents were supportive of her in coping with her difficulties. Although she wondered 'What's wrong with me?' from an early age, and talks about teachers who she perceived regarded her from a *DRW=Stupid/lazy* perspective, she never internalised this discourse and her explicit description of why is a helpful example of the healthy development of self-perceptions. Alice learned to understand and compensate for her difficulties from an early age. Despite this she still suffers emotionally due to being dyslexic in an academic environment for 23 of her 28 years, however over the course of the three interviews she demonstrated how quickly she was able to move past negative emotions from the past once she left an educational context.

Alice moved three times during her early childhood; first attended a nursery school in London briefly before moving, and then she attended an independent Primary School until age eight when the family moved again. It was at her first Primary School that Alice became aware that she was different to her peers,

*the first time I can really remember having difficulties was when I went to [my first Primary School], which was possibly the worst school in the world ... by the time I got to the second class I started to realise everybody was reading and I wasn't ... what I used to do was go 'I don't feel very well, could I please have a sleep' and they'd go 'Ok, then' ... I was unbelievably ingenious at getting out of doing anything ... I can remember panicking ... every time I had to do written work but luckily never really had to do much, because the school didn't make you (Interview 1).*

Her realisation that ‘everybody was reading and I wasn’t’ corresponds to the discourse ‘What’s wrong with me’ and *Recognition* (see Fig. 4.2). She was aware that difficulty learning to read is often associated with low intelligence,

*I had teachers who thought ... I was no good for anything really ... I always knew that I wasn’t stupid ... I knew that I could do things ... that other people couldn’t do ... so I just thought, ‘well, no, they’re wrong’ (Interview 3).*

Here Alice is acknowledging that her teachers might have thought she was stupid, however, because she had been in situations where she was capable she rejected the discourse of *DRW=Stupid/lazy*. Part of Alice’s reference to ability in comparison to peers may be related to her awareness of her good verbal ability,

*I’m fine on interviews, and vivas and things like that and I’m absolutely fine at talking to adults, partly because my parents always had their friends round and we knew how to talk to them. And a lot of my parents’ friends I suppose are, you know, they know judges and they know doctors that most people would be, ‘Oh my God’, scared to talk to, you know, somebody who’s in a certain position of power, or very intelligent in that set, and we were used to it, and I’m quite happy to talk to someone like that (Interview 1).*

Alice speaks here in a Hemispherist discourse as she describes her strengths. Her verbal ability – interview, vivas, talking with adults ‘in a certain position of power, or very intelligent in that set’, even as a young child, provided an experience of *Goodness of Fit* that would logically support her conclusion that she was not ‘stupid’. During the fourth interview, when we talked over this analysis, Alice re-iterated that her friends supported the self-belief that she was intelligent (see also below).

*... I always ended up being friends with the encouraging kids who were doing really well at school, I was never really friends with the kids who weren’t doing well at school, even though I was the one who couldn’t write the things off the blackboard (Interview 4).*

Alice was the first in her family to be identified as dyslexic, when she was 8. Alice was identified as dyslexic near the time of the family’s move when she was eight years old, and the following three passages identify in detail the ways identification of dyslexia was helpful to Alice in enabling her to better conceptualise her difficulties with reading and writing,

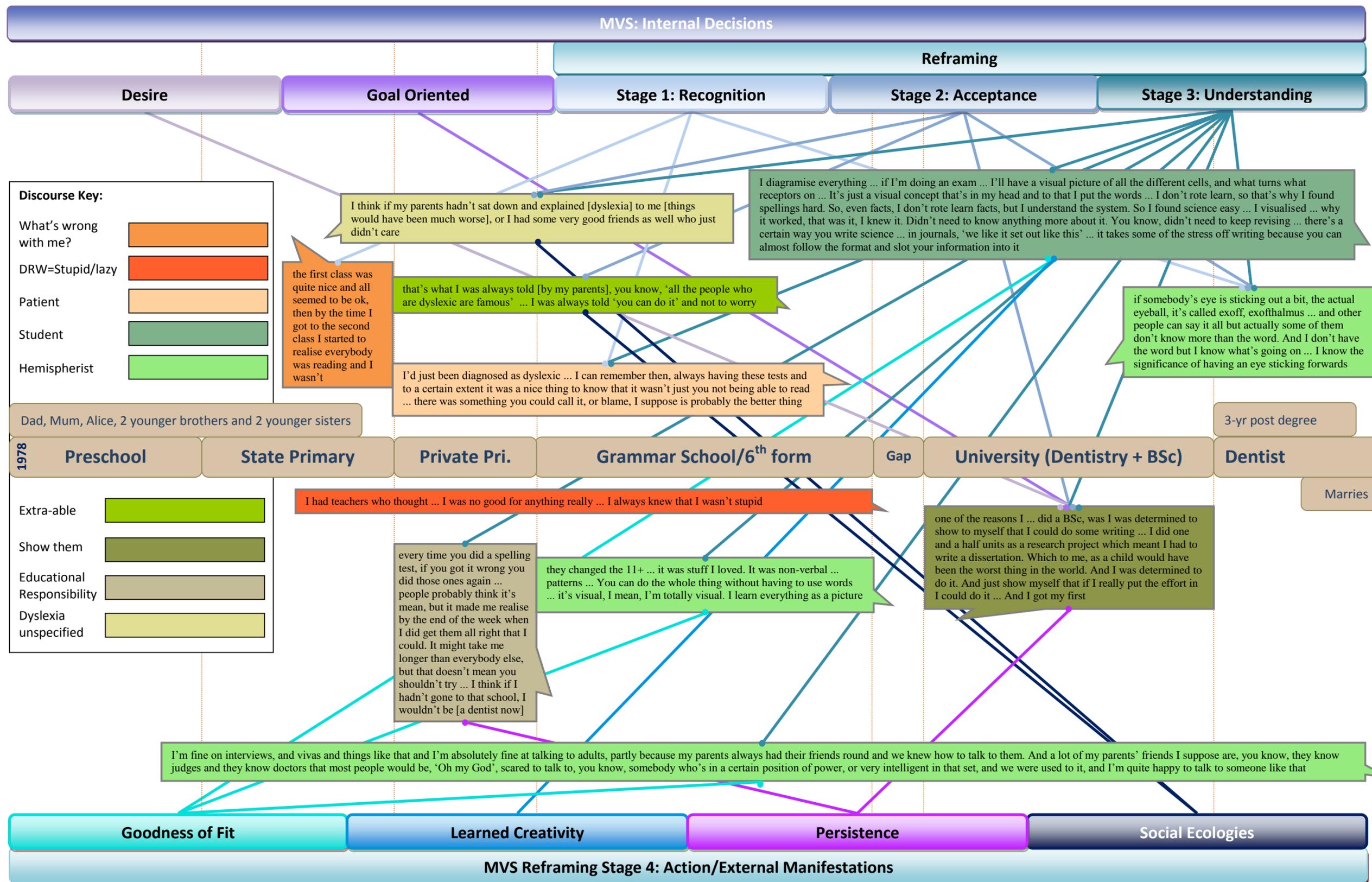


Figure 4.2 shows a representation of Alice’s process of making sense of her difficulties with reading and writing and the methods she develops to cope with them, analyzed by mapping her use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

Stages of Alice’s life are represented across the centre of the model, and the size of each stage is in ratio to the length of the stage in years (so ‘Grammar School/6<sup>th</sup> form’ is the largest stage because she is there for 7 years, whereas ‘Gap’ is the smallest as it lasted only 1 year).

Quotes from Alice’s life story are placed according to the time in her life that she is referring to, so quotes about experiences that occurred during her school years are located above or below the stages ‘Primary School’ and/or ‘Grammar School’. Quotes shown in the figure are highlighted grey in the text.

Aspects of the MVS are identified across the top and the bottom of the figure, with Internal decisions listed across the top, and the fourth stage of Reframing, Actions/External Manifestations, listed along the bottom. Colour coded links are made between different aspects of Internal decisions and Actions/External Manifestations and quotes from Alice’s life story. Links from Internal decisions attach to the top centre of a quote, and links from Action/External Manifestations attach to the bottom of a quote.

Finally, discourses of dyslexia are represented by the background colour behind each quote, and the key to what discourse is represented by each colour is located on the left side of the map. Discourses represented by reddish colours are less likely to support aspects of the MVS whereas discourses represented by greenish colours are more likely to be supportive. Discourses represented by neutral colours can be either supportive or detrimental.

Figure 4.2. Alice’s process of making sense of her difficulties with reading and writing and the methods she develops to cope with them, analyzed by mapping her use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

*I'd just been diagnosed as dyslexic. My parents had read something in the newspaper that was happening in Oxford University about dyslexia. And my Mum says 'that's you, Alice'. Took me along, and they said 'yes'. And I can remember then, always having these tests and to a certain extent it was a nice thing to know that it wasn't just you not being able to read ... there was something you could call it, or blame, I suppose is probably the better thing (Interview 1).*

In this excerpt it is not very clear what discourse of dyslexia is being used. Although the Student discourse is implied through use of reference to tests, her reference to explanation, 'it wasn't just you not being able to read', 'there was something you could call it, or blame' is similar to other participants' use of the Patient discourse. This passage supports *Recognition* of what her difficulties were through testing and the development of *Understanding* related to identification of dyslexia.

*I suppose you do notice that other people can do things quicker ... they used to write stuff on the board and then you used to have to copy it ... and then once you were done you could go out ... and I was there an hour longer than everybody else ... you do start to notice things as a kid ... everybody else is doing this it's quick and, everybody else is writing it beautiful. And it does bother you. And I think if my parents hadn't sat down and explained to me, or I had some very good friends as well who just didn't care (Interview 2).*

Alice begins this excerpt in a What's wrong with me discourse, and links satisfactory resolution of her question to *Social Ecologies* – support from her parents and friends. Her parents' explanations of dyslexia supported *Understanding* and good friends who 'just didn't care' about her difficulties helped Alice with *Acceptance* that her differences didn't matter – they liked her anyway. It is difficult to identify a discourse of dyslexia in the latter half of the excerpt, so this passage is represented on Alice's map as Dyslexia unspecified. However later Alice describes her parents explaining dyslexia through the Extra-able discourse, ... that's what I was always told [by my parents], you know, 'all the people who are dyslexic are famous' ... I was always told 'you can do it' and not to worry (Interview 3). In this excerpt Alice's parents support her through *Social Ecologies*. Through identification of dyslexia she is able to identify with people who achieve extraordinary things and this supports *Acceptance*. Alice began receiving specialist tuition soon after identification. She was withdrawn from class to attend the sessions at the local Dyslexia Institute, and Alice thinks this support was helpful. But she attributes greater relevance to the attitude of her teachers at her second Primary School. She frames this story through a comparison between the first and second Primary Schools she attended,

[I] went from doing no work for school ... to where I really had to work. And I certainly struggled ... I had to have a spelling test every week ... they were strict as anything and I hated it and I wanted to go home but they didn't believe me when I stuck my head on the radiator at this school (Interview 1);

... they were very good to me in that they were strict ... Because I could have quite easily just decided I wasn't going to work. And every time you did a spelling test, if you got it wrong, you did those ones again, and if you got it wrong, you did them again, and you were kept in at break time and you did it again. And in some ways, people probably think it's mean, but it made me realise by the end of the week when I did get them all right that I could. It might take me longer than everybody else, but that doesn't mean you shouldn't try. And, that was the best thing that that school did for me. And I think if I hadn't gone to that school, I wouldn't be [a dentist now] (Interview 1).

Here Alice is speaking through a discourse of Educational Responsibility in regards to the Primary School where she was not expected to do any work and by attributing her current success to the 'strictness' of the latter school in forcing her to persevere. She perceives this strictness as positive despite acknowledging the extremity of the stress it caused her 'Even with the crying and tears and the storming and the ripping up of the spellings' (Interview 1); however she also acknowledges that it is something of a balancing act in a later interview when she says, 'though I suppose it's difficult for teachers to know if they're trying to push somebody beyond what they can do' (Interview 3). Being forced into *Persistence* taught her that she could succeed, contributing to *Understanding* by demonstrating that in order to succeed she simply had to be willing to put in more time than her peers did.

During Alice's three interviews she describes a process of coming to *Understanding* through experience of *Goodness of Fit* and *Learned Creativity*,

... they changed the 11+, and they changed it to being verbal and non-verbal ... And I took the first exam, the mock exam and Mum got told by the Headmistress, 'I think she should, you should go look round the Grammar School, because I think she's going to get in'. And it was purely because it was stuff I loved. It was non-verbal, you know, patterns ... You can do the whole thing without having to use words ... it's visual, I mean, I'm totally visual. I learn everything as a picture (Interview 1).

Because Alice is acknowledging strengths and weakness here she is speaking about dyslexia in a Hemispherist discourse. She describes *Goodness of Fit* in her ability with non-verbal patterns – ability on the entrance exam intelligence tests that enabled her to be accepted into Grammar School – and her growing *Understanding* about her visual strengths supports *Learned Creativity* that enables her to succeed in an academic environment,

*I still remember my Physics teacher used to find it fascinating because I couldn't write Physics very well ... But she said ... she said she'd never seen people draw pictures or diagrams [like I did] ... I diagramise everything ... if I'm doing an exam ... I'll have a visual pattern, I'll have a visual picture of all the different cells, and what turns what receptors on, but I've no words anywhere. It's just a visual concept that's in my head and to that I put the words ...*

*I don't rote learn, so that's why I found spellings hard. So, even facts, I don't rote learn facts, but I understand the system. So I found science easy. Because once I understood why it worked, and I visualised, I could visually see, and it was to me, logical why it worked, that was it, I knew it. Didn't need to know anything more about it. You know, didn't need to keep revising, revising ... But I always had a very good ... overview of everything. And logically understood everything. But when you put words to it ... Can't keep it in my head ...*

*there's a certain way you write science ... once you get your brain into that, it makes writing easier. And there are certain words that everybody uses ... they even tell you in the papers, you know, in journals, 'we like it set out like this' ... it takes some of the stress off writing because you can almost follow the format and slot your information into it (Interview 1).*

Here Alice puts her *Understanding* of visual strengths into effect during revision and exams, an example of *Learned Creativity*. She also uses her *Understanding* to inform her choice to follow science as a career because it is possible to visualise and therefore remember complex systems. She therefore chooses a situation where her *Understanding* suggests she will experience *Goodness of Fit*. The formulaic structure of writing in science also supports her to be able to tackle what she otherwise finds extremely difficult, which can be seen as another example of *Learned Creativity*. That Alice uses her self-understanding in choosing her career is another aspect common to the 'Hemispherist' discourse.

Alice describes the development of *Understanding* as a long process, but one that is clear to her now,

*it took me a long time to understand what my dyslexia was. And I know what I can't do, ... it's literally a link that doesn't connect when it comes to the written word and the spoken word (Interview 3).*

*if somebody's eye is sticking out a bit, the actual eyeball, it's called exoff, exofthalmus, ... and other people can say it all but actually some of them don't know more than the word. And I don't have the word but I know what's going on ... I know the significance of having an eye sticking forwards (Interview 2).*

Alice shows that she has carefully thought through her difficulties. She knows what she can't do and she knows what she is particularly good at. These passages demonstrate *Recognition of*

her difficulties and *Acceptance* – not only has she accepted that there are areas she will never cope with easily, she also knows her strengths and that these mean what she has to offer is valuable nonetheless, ‘I don’t have the word but I know what’s going on’.

In working toward resolving negative emotions from the past Alice uses the Show them discourse,

*I think a lot of people ... who probably taught me in my younger years, if I went up to them now and they saw me now they’d probably just never believe it, really. I sometimes hope that they come into my dental practice ... ‘yes, I still can’t spell, but!’ Yeah, it’s odd, we had, we had to have, this lady came in and you had an interview with her, and she said ‘what do you want to do, and why do want to do this’ and it was just sort of careers advice side of things. And I remember meeting her after I got my A-levels and was going off to dental school and she goes ‘do you know, Alice, I tell people about you. Because I never thought a dyslexic could do something like dentistry. And now I tell them they can’ (Interview 1).*

At the first interview, Alice had not long completed a post-graduate qualification following her Dentistry degree; she had been in an educational context for 23 of her 28 years. She explains her reasons for choosing to do an Intercalated Bachelor’s degree, adding a year to her five year Dentistry degree,

*for my degree, one of the reasons I took a year out and did a BSc, was I was determined to show to myself that I could do some writing, so I did a degree in developmental biology ... you had certain units that you had to do, four units. And different things counted as a half unit or a unit and so I did one and a half units as a research project which meant I had to write a dissertation. Which to me as a child would have been the worst thing in the world. And I was determined to do it. And just show myself that if I really put the effort in I could do it. But it worked. And I got my first, it’s the only thing I got a first in (Interview 1).*

This excerpt is similar to the Show them discourse, except that rather than a fantasy where the dyslexic person imagines themselves showing a dismissive teacher from the past proof of their success, Alice is proving to herself that she can ‘beat’ her difficulties with reading and writing. In terms of the MVS, the passage above involves the *Desire* to excel, in order to show herself once and for all that she is capable. She is *Goal Oriented* in that she chooses the dissertation as her goal, and chooses *Persistence* as her approach to ensure success, ‘I was determined to do it. And just show myself that if I really put the effort in I could do it’. Succeed she does, with a first. Alice relies on *Understanding* about herself gained previously pertaining to persistence and study skills, and this knowledge means her goal is realistic. This process does seem to have

supported resolution, including *Acceptance* that she is capable, as well as resolving some of her negative emotions,

*But it's sad that even now, you know, you have to write papers to get on a bit further and things, and I just, I still do everything to avoid it. I still don't want to write a paper (Interview 1).*

*in dentistry, if you're good in your job and patients like you, you get more patients and it's a very simple thing (Interview 2).*

*I don't feel I have to prove myself anymore which I used to do ... I can say, if anybody ever says to me, 'oh God, you can't write' I can go, 'well actually, I got a first in my dissertation' (Interview 3).*

In the excerpt from Interview one Alice seems to question whether she should carry her academic pursuits further, but in the excerpts from Interviews two and three she seems happy in her choice of dentistry practice, no longer feeling the need to prove herself.

## Amber

A characteristic about Amber that stands out is the power *Social Ecologies* have for her to both support and sabotage. Perhaps because she comes from an extended Welsh family she talks about her experiences in the context of relationships with others, and her experiences of coming to terms with dyslexia have been deeply affected both positively and negatively according to her relationships. To say that Amber experiences life in the context of relationships is not to suggest that she is dependent on them, however, she has a strong sense of herself and is willing to strike out on her own when relational support is lacking, for example she has chosen to be financially independent during her latter university years. Amber has well developed critical and analytic skills, and her conceptualisations of dyslexia are sophisticated and complex despite the relatively recent timing of identification of dyslexia. She was identified as dyslexic at university a few days after her 21<sup>st</sup> birthday, and was 23 at the time of the first interview.

Amber was born and grew up in South Wales with her parents and her brother who is sixteen months younger than she is. Her father worked as a building surveyor while she was growing up and her mother was a homemaker, though she worked at times, for example in the local shop. When Amber was seven her family moved to another area of the same city, to a house her father built in his spare time,

*... we had to move into the house as we were building it. So we had like breeze block walls, we all lived in the kitchen and that was our living room, eating room, sleeping room ... we had our beds one side of the room then a settee and a tv, and i'll always remember going to bed and Mum would have the tv on really quiet, and trying to look round to see what was on it while pretending to be asleep. We thought it was well posh when we moved into two rooms, we never really had a kitchen for a long while we had a microwave and a little camping stove thing. We had a toilet but you had to have a bucket of water to chuck down it and we had an outside water tap for a good few months, we used to bring water in and boil it, we went to my grandparents once a week for a bath (Interview 2).*

Amber achieved academically at very high levels during Primary school, gaining Level 5s in English and Science and Level six in Maths in Year six. Her mother was keen on education and

taught her at home before she went to nursery school so she could read at age 3. Amber is asthmatic and during her years in primary school she was often in poor health with asthma-related illnesses such as pneumonia and bronchitis, so spent much time at home. Her mother used to pick up work from school for her and she would complete much more than she was assigned, three or four pages instead of the one page a day the school asked her to do. She says she always looked forward to the 'extension' homework in maths and enjoyed challenging herself,

*... we used to do a lot with work cards and so you'd do your work card, you'd take it out, do it, marked and back, and so in the end I used to take two. I'd get in trouble now and then for it 'you need to take more time' it's like 'why, it's right' and the guy who used to sit next to me in the end we used to start a competition going how many of these we could get done in a day, I think we reached fifteen one day instead of one ... it always used to come back on my maths report each year 'yeah, we've had trouble finding extension work for her this year', I used to think 'yeah that means I've done well' (Interview 2).*

This is an experience of *Niche*, where Amber is *Goal Oriented* (see Fig. 4. 3) in her explicit attempt to see how many math cards she could complete, and that she remembers enjoying successful remarks on her reports shows *Desire* to excel. These also link to *Persistence* where Amber learns that by working hard she is successful and is rewarded, and to *Goodness of Fit* because she is so able to achieve. However, her academic experiences were not solely positive,

*the new school used the same reading scheme that we had and I got moved back an entire level and I've only recently known why because Mum said apparently I could read the words but I didn't understand it ... always got on parent's evening 'got to work at your English', 'got to do your spelling' ' (Interview 1).*

Her difficulties within education increased as she progressed through the years. At secondary school this related mostly to the amount of time she spent on homework ,

*[at secondary school] I buried myself in my work, but I really enjoyed it at the same time. Whereas my brother would get very, he could do it in seconds and be done and he'd be fine and he'd get there. I'd take hours (Interview 1).*

Here Amber relies on *Persistence* to maintain good academic results. She was also motivated to work because she felt it was a means to escape from problems at home,

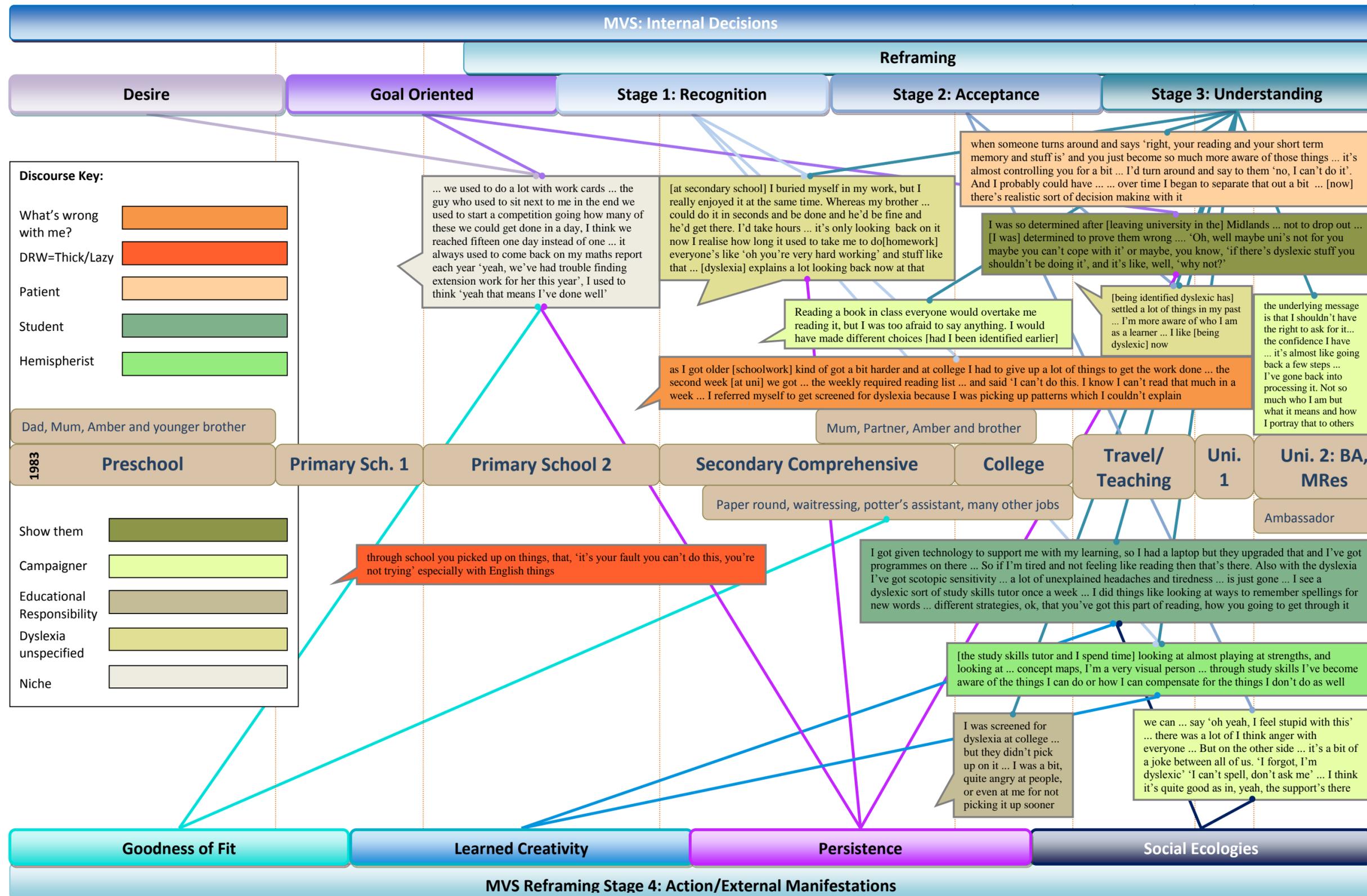


Figure 4.3 shows a representation of Amber’s process of making sense of her difficulties with reading and writing and the methods she develops to cope with them, analyzed by mapping her use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

Stages of Amber’s life are represented across the centre of the model, and the size of each stage is in ratio to the length of the stage in years (so ‘Secondary Comprehensive’ is the largest stage because she is there for 5 years, whereas ‘University 1’ is the smallest as she was there for only 1 year).

Quotes from Amber’s life story are placed according to the time in her life that she is referring to, so quotes about experiences that occurred during her secondary school years are located above or below the stage ‘Secondary Comprehensive’. Quotes shown in the figure are highlighted grey in the text.

Aspects of the MVS are identified across the top and the bottom of the figure, with Internal decisions listed across the top, and the fourth stage of Reframing, Actions/External Manifestations, listed along the bottom. Colour coded links are made between different aspects of Internal decisions and Actions/External Manifestations and quotes from Amber’s life story. Links from Internal decisions attach to the top centre of a quote, and links from Action/External Manifestations attach to the bottom of a quote.

Finally, discourses of dyslexia are represented by the background colour behind each quote, and the key to what discourse is represented by each colour is located on the left side of the map. Discourses represented by reddish colours are less likely to support aspects of the MVS whereas discourses represented by greenish colours are more likely to be supportive. Discourses represented by neutral colours can be either supportive or detrimental.

Figure 4.3. Amber’s process of making sense of her difficulties with reading and writing and the methods she develops to cope with them, analyzed by mapping her use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

*at the end of the first year [of secondary school] a lot was happening at home with my family ... there were a lot of problems. It was quite nice just to go to school for a lot of it ... there were a lot of issues with my parent's relationship. A lot of arguments. My father has mental health problems as well and can be quite violent ... Mum found ... that she had osteoporosis so over the long term she was gradually becoming disabled so I had a lot of caring responsibilities as well for me and my brother ... at home I'd always be trying to [do homework] ... sometimes it was an excuse to get away from sitting in a room where nobody is talking ... it's only looking back on it now I realise how long it used to take me to do [homework] everyone's like 'oh you're very hard working' and stuff like that ... [dyslexia] explains a lot looking back now at that* (Interview 1).

In the latter part of this quote Amber reframes her understanding of her experiences during secondary school after she has been identified as dyslexic. She has new *Understanding* about why it might have taken her so long, as well as *Recognition* of her difficulties. However, she does not speak in any particular discourse of dyslexia. After secondary school Amber chose to complete a baccalaureate qualification rather than A-levels. During these two years things continued to be stressful at home; her parents had divorced during her GCSEs and her mother took two part-time jobs while Amber continued caring responsibilities at home in addition to working for her qualification. From age thirteen Amber had held various part-time jobs from waitressing to working in a pottery, and these jobs represent an experience of *Goodness of Fit* because she enjoyed them so much and was successful in them. She had also been involved in various musical endeavours including choir and playing violin, clarinet and piano. However she found work at college to be very difficult, 'as I got older that kind of got a bit harder and at college I had to give up a lot of things to get the work done' (Interview 1). When she completed the qualification she decided she needed a break and went travelling for a year rather than straight on to university. She worked in Europe then taught in Tanzania and Thailand, and enjoyed it so much she now describes travelling as her passion. On her return to England she attended a university in the Midlands where she began a degree in Philosophy. Within two weeks she changed to Biology,

*... the second week we got all the handbooks and got the weekly required reading list. I went and got one of them and looked at the list and said 'I can't do this. I know I can't read that much in a week' and so kind of mass panicked and tried to change ... obviously I was two weeks behind at biology ... we used to do 20 hours a week, so that was 40 hours behind plus the current work. And I just felt kind of lost with it ... [in the first term] I referred myself to get screened for dyslexia because I was picking up patterns which I couldn't explain ... but their process was very long and over the term they still hadn't decided [whether I was dyslexic or not] by which point I was very stressed and fed up ... I felt completely stupid and I'd sit in a lecture room and everyone*

*would know what was happening and I wouldn't ... [I] decided to leave and start again (Interview 1).*

In the grey highlighted text above Amber is describing the *Recognition* stage of reframing, where she is coming to realise that she has difficulties. She can be seen to be using a *What's wrong with me?* discourse as she says 'I was picking up patterns which I couldn't explain' (Interview 1). Amber questions her intelligence despite academic success during Primary School years, and when the university don't resolve her question about whether she is dyslexic or not she decides to 'leave and start again'.

The following autumn Amber began a degree in Politics at a university in the Southwest of England. She referred herself again and this time she was assessed and identified as dyslexic by the end of November, although her Local Education Authority took a number of months to provide Disabled Student's Allowance to pay for technical aids and specialist tutoring. Eventually when she did receive this support she found it enormously helpful,

*I got given technology to support me with my learning, so I had a laptop but they upgraded that and I've got programmes on there ... I've got like a dictation programme which is a lot quicker [than typing] and I've got like a programme that will read things back to me so I can hear what I've written, and a scanner that I can scan a book in and the computer will read it to me. So if I'm tired and not feeling like reading then that's there. Also with the dyslexia I've got scotopic sensitivity ... so I can change the colour setting on [the computer] and I've got glasses ... and I find that's helped enormously ... because a lot of unexplained headaches and tiredness ... is just gone ... I see a dyslexic sort of study skills tutor once a week ... I did things like looking at ways to remember spellings for new words ... different strategies, ok, that you've got this part of reading, how you going to get through it ... [the tutor and I spend time] looking at almost playing at strengths, and looking at ... concept maps, I'm a very visual person ... through study skills I've become aware of the things I can do or how I can compensate for the things I don't do as well ... and since study skills my marks have gone up quite a lot with that and especially in comparison to going to university in the Midlands ... I've seen that 'oh, yeah, you can actually do this. This is ok' and with that you feel more confident to go and do the next bit (Interview 1).*

When Amber discusses academic compensation techniques she is using a *Student* discourse; these techniques involve *Learned Creativity* and contribute to *Understanding* and she develops understanding and coping mechanisms through support from a study skills tutor, a form of *Social Ecology*. When she refers to 'playing at strengths', including her visual abilities, and what she can and can't do she is talking in a *Hemispherist* discourse. Her development of clearer awareness of her difficulties is part of the *Recognition* stage, and development of her

strengths, for example use of visual skills, shows *Learned Creativity*. Development in both these areas demonstrates additional *Understanding*. In the latter part of this excerpt Amber is talking in a discourse of *Educational responsibility* where she attributes her improved academic success to the study skills she has gained from Learning Support, and contrasts her experiences in the Southwest to those in the Midlands, which did not help her rather they hindered her because they confused her and knocked her confidence. Her academic success supports an *Understanding* that she can succeed, and also *Acceptance* that although she has difficulties it is possible to cope with them. In this way identification of dyslexia made a big difference to Amber in terms of her ability to succeed academically because of the technical and learning support it enabled, and in terms of re-establishing positive academic self-perceptions. Amber also describes an aspect of motivation that she believes contributed to her success,

*I was so determined after [leaving university in the] Midlands ... 1) not to drop out, because that has financial implications for me in terms of my funding ... and 2) I got so fed up with everyone having their own judgement about what had happened without asking me ... [I was] determined to prove them wrong .... 'Oh, well maybe uni's not for you maybe you can't cope with it' or maybe, you know, 'if there's dyslexic stuff you shouldn't be doing it', and it's like, well, 'why not?'* (Interview 1).

Here Amber is speaking in a *Show them* discourse; in her determination to show those who doubted her ability to do an undergraduate degree she is *Goal Oriented* and her determination also links to *Persistence*.

Despite her positive remarks about learning support, Amber said identification of dyslexia caused her emotional distress for 12-18 months afterward. She felt that though her academic needs were well met, she was very much left on her own in terms of emotional needs, 'There are study skills and services but no one actually told us what dyslexia meant' (Interview 1). Amber describes her initial response to identification as a combination of negative and positive emotions. One negative effect of identification included a hyper-focus on difficulties,

*when someone turns around and says 'right, your reading and your short term memory and stuff is' and you just become so much more aware of those things ... I mean, you don't disagree or it's not that you haven't noticed them before but ... you're so much more conscious every time you do something in relation to that, like my short term auditory memory is not that great and when I used to work I could not take a phone message and write the phone number down properly because I'd forget it ... which used to be quite funny at the time and everyone in the office would laugh because I'd put the completely wrong phone number and things ... but, it kind of explained that ... it's almost as if that's so much the focus of your life that it's almost controlling you for a*

*bit, and it did affect things I did like, I stopped reading for pleasure, I was determined I couldn't spell things, so if someone else were to ask me to write down I'd turn around and say to them 'no, I can't do it'. And I probably could have ... over time I began to separate that out a bit so although it's not separate, and it is part of who I am, it doesn't control who I am ... I'm not going to volunteer ever to read the encyclopaedia and proof read it for someone because I know that's a waste of time for everyone! ... So you know, there's realistic sort of decision making with it (Interview 1).*

Here Amber is talking in a *Patient* discourse of dyslexia, where the assessment process alerted her to problems attributed to deficits in her brain (e.g. problems with short term auditory memory). Although she had been aware before of these problems she previously shrugged them off or made them a joke, however with identification of dyslexia she began to say 'I can't do it'. The idea of deficits in her brain became dominant in how she understood herself. However this was a temporary situation and she eventually came to understand her difficulties in a way that contributes useful information to her decision-making process and therefore to *Recognition*. She also describes this aspect of identification helpful because it explained the difficulties she had previously noted. These latter outcomes are positive aspects of what was otherwise an unpleasant process. Two other negative emotions she describes in response to identification were anger and confusion,

*There was a lot of anger at the time as well. Because I was screened for dyslexia at college ... but they didn't pick up on it ... I was a bit, quite angry at people, or even at me for not picking it up sooner ... And then there's a lot of confusion because you're given a report but that's about it and you don't know, almost what it means. It kind of, affects your identity ... you're kind of a person with dyslexia ... At first. At the time. It's just normal now ... and it's fine. But at the time it was like, well, what does this mean? (Interview 1).*

Here Amber is talking in a discourse of *Educational responsibility* where she felt anger because dyslexia was not identified sooner. This contributes to *Understanding* that that the educational system could have supported her to better cope with her difficulties. She feels that had she understood her difficulties sooner she would have dealt with them better emotionally and been able to make better decisions,

*More on an emotional level than anything else I think it would have [been helpful to be identified earlier], because, yeah, even through school you picked up on things, that, 'it's your fault, you can't do this, you're not trying' especially with English things, especially the negative experience I had with Midlands and study, even at college I struggled quite a lot with it. We had to read so much. Reading a book in class everyone*

*would overtake me reading it, but I was too afraid to say anything. I would have made different choices [course-wise] I think (Interview 1).*

Amber continues in a discourse of *Educational responsibility* in this excerpt as she is explaining why she felt angry that she was not identified earlier. She describes teachers attributing her difficulties to laziness in school, and this is the *DRW=Stupid/lazy* discourse. She is inferring that the difficulties would have been understood differently had she been identified as dyslexic at the time, or at least she would have been able to make different sense of them. She also refers here and elsewhere to making different choices had she been identified earlier; she believes that had she understood herself to be dyslexic earlier her post-16 educational choices would have been better informed. This final sentence links to the *Campaigner* discourse because Amber is talking about her right to be educated. The above two excerpts can be seen to link to *Understanding* where identification of dyslexia brings a different way of looking at her difficulties which moves attention away from her taking full responsibility for them to her seeing that the educational system also plays a part in the difficulties she experiences. This validates her experiences and enables more positive self-perception and greater assertiveness.

Amber's description of experiencing negative emotions following identification which eventually resolve is in line with studies carried out by Riddick (1996) and Armstrong & Humphrey (2009) which document a similar process. Amber attributes her emotional resolution in great part to a group of four or five other female students who have been diagnosed as dyslexic on her course. As a group they supported each other by sharing feelings and experiences related to being dyslexic,

*it's kind of been good as we can talk and we can turn around and say 'oh yeah, I feel stupid with this' or 'that's rubbish' there was a lot of I think anger with everyone because it explained a lot for each of us in our own ways. And sort of getting to grips with that. But on the other side we kind of, we've kind of turned it into, it's a bit of a joke between all of us. 'I forgot, I'm dyslexic' 'I can't spell, don't ask me' lots of friendly, light-hearted banter, which if someone else had turned around and said to us we'd probably be quite annoyed, but 'we're special', there's a lot of that but I think it's quite good as in, yeah, the support's there (Interview 1).*

This excerpt is related to the *Campaigner* discourse because Amber is referring to a group of people supporting each other on the basis of being dyslexic, and it is thus a form of identity politics. This excerpt can be linked to *Understanding* where experiences and knowledge are shared to support each other and also *Acceptance*. By meeting together they are not alone and

not different, and as they joke about their difficulties they turn the concept of disability on its head – their difficulties are a reason to belong, to be on the inside, a reason for enjoyment.

By the time of the first interview Amber felt she had resolved both the negative emotions following identification and her dyslexia-related difficulties to the extent that she could say,

*[being identified dyslexic has] settled a lot of things in my past. A lot of things I used to get annoyed by I've now kind of almost put to bed which is nice, like my English school reports ... I first was angry but I've now gone 'eeh, it's not a problem, not an issue' ... I'm more aware of who I am as a learner, which I'm really pleased about ... I know how I work and how I learn ... So, that I quite, I like [being dyslexic] now. It's a weird process to go through. Yeah, me as a person, it's almost like it doesn't really mean much (Interview 1).*

Amber is speaking here about dyslexia but not in a particular discourse of dyslexia. Her comments link again to *Understanding* where dyslexia has explained the difficulties she has experienced. The process of coming to understand her strengths and weaknesses has taught her about the way she learns, and she is demonstrating *Acceptance*, where her dyslexic difficulties no longer impinge in any great way on her as a person.

However, her perceptions had changed a great deal in the fourteen months between the time of her second and third interview. In this time she worked toward a Master's degree (MRes) in Politics, and the support she received from the Department staff was less positive than it had been during her Bachelor's degree. First, her undergraduate tutor wrote her a reference for the course, stating that because of disability and health reasons she didn't think Amber was suited to it, and that without Learning Support she would not have been able to complete her Bachelor's degree. Amber was advised by Learning Support to take the reference to the data protection department at the university,

*... basically the person in charge of the legal stuff for data protection took one look at it and said 'she can't write this' ... according to university regulations she wasn't allowed to write such negative comments in a reference, she was discriminating against disability which is illegal, she was disclosing what was in a sense confidential information from tutorials ... if the university had acted on it I could apparently take them to court if they had not offered me the place and I did get asked if I wanted to formally complain and the woman was very keen to do that (Interview 3).*

Amber was offered a place, negative sections in the reference were removed and Amber did not make a formal complaint. However the fact that her tutor, whom she had thought was

very supportive, held negative impressions about her ability knocked her confidence. She then found on the course that the lecturers were reluctant to make the reasonable adjustments Learning Support suggested for her, which included providing reading materials prior to the lectures to give Amber additional reading time and/or printing out any reading material for the course on lilac rather than white paper to reduce visual stress. When the adjustments were not done it could cause Amber real difficulty,

*they'll turn up with sort of 13 pages to read for everyone ... I don't get through hardly any of it by the time everyone finishes then we've got like a 40 minute discussion about what it was, so I just sit there twiddling my thumbs and some days I think I just miss 3 hours and I could have been doing something else ... if they've done a Powerpoint ... on this lovely white background and you ask them [if they could change the background or print it out on lilac paper], they go 'you can download it after the lecture' 'yes but I can't access the lecture now' it's tricky because as an undergrad I did that sometimes, I'd get lots of headaches from looking at it, but [this course has evening lectures], in the evenings during the drive back from the lectures I can't risk having a severe headache ... it's not safe. It's frustrating (Interview 3).*

When Amber reminded lecturers about the adjustments in one case she was challenged in front of her peers about being dyslexic,

*I went up to a lecturer I hadn't had before and asked her if she'd produced a pack of information on lilac paper for me, and she was like 'oh no, why's that' well 'I'm dyslexic, you've had the learning plan' and then she questioned me about, she kind of went along the lines of 'well, what exactly is this, why do you need purple paper, what about reading books, why can you read books' and I was like, I have an overlay and then she started questioning what the difficulties were in quite a patronising way (Interview 3).*

Amber said she felt intimidated and frustrated by this exchange, and it was public enough that some of her classmates asked her about it afterward. Though there is much to say about these experiences in terms of power relationships and structural discrimination, the focus of this analysis is on the way Amber's self-perceptions, understanding of her difficulties and her actions were affected. These experiences challenged her prior understanding of what it meant to be dyslexic; they damaged her positive self-perceptions and made her more reluctant to disclose her dyslexia,

*... the underlying message is that I shouldn't have the right to ask for it, that's what I pick up from it, or it's not their responsibility ... I lost a lot of confidence ... I felt I was settled with the dyslexia ... but having seen the reference and then the experience [of the MRes] it's changed ... the confidence I have ... it's almost like going back a few*

*steps ... I've gone back into processing it. Not so much who I am but what it means and how I portray that to others* (Interview 3).

These excerpts can be seen as part of the *Campaigner* discourse, where Amber is discussing her educational rights. They also link to *Understanding* and *Acceptance*, where Amber feels less accepted (so this link is not marked on her map) and develops *Understanding* about how to better manage disclosure of dyslexia in order to protect herself. The experiences demonstrate the importance of *Social Ecologies* (and again this is not marked on her map because this is an example of a negative effect of *Social Ecologies*). Perhaps the best way to communicate the power held by her lecturers to impact her self-perceptions is to demonstrate the disparity in Amber's feelings when supported and not supported. During her undergraduate degree her lecturers were aware of the need to print material on coloured paper and complied happily, with one particularly sensitive lecturer,

*We had a very good lecturer last year. We have about three different coloured papers we need between us. There's one lilac and there's one peach and there's one green. So he said 'what can I do to help?' Well he actually turned round and instead of printing ours separately, she printed three different coloured papers and handed one out to everyone in the class ... especially new people in the new module, nobody actually knew who was dyslexic or not* (Interview 1).

This kind of context allowed Amber to thrive. In contrast, Amber characterised her experiences on the Master's degree as 'a nightmare' (Interview 3). Her experiences suggest a *Campaigner*/social model perspective on disability is helpful to self-perceptions and willingness to be assertive but can also set a person up for frustration, disappointment and possible humiliation when those in more powerful positions do not share that perspective. Despite the barriers Amber experienced on her Master's course, she completed it and is now working in Political research.

## Bob

As an adult Bob has come to a place where he feels he has overcome the difficulties that caused him a great deal of turmoil during his childhood, and over the three interviews he described many coping mechanisms he has developed to do so. Central to his success were experiences of *Goodness of Fit* as a teenager and identification of dyslexia at a similar time, which enabled him to make more positive sense of his difficulties and develop study skills to overcome the barriers they presented. Bob has developed unique visual and media skills which he uses in his job and he feels he has particularly good problem-solving ability; both he attributes to the need to compensate for areas of difficulty. Bob talks in a wide range of discourses of dyslexia; in fact he uses all but the *Campaigner* discourse. He comes very close to speaking in a *Campaigner* discourse through his talk of *Educational responsibility*; however he never completely loses the sense that dyslexia means a within-person problem, perhaps because he internalised the discourse *DRW=Stupid/lazy* as a child. Bob shows real determination and strength particularly during his late Secondary School years; it is during this time period when he faces so many difficulties that is actually a turning point for him.

Bob was born in 1979 and was 27 at the time of the first interview. He grew up in what he calls 'a normal family' (Interview 1) in a small village in Kent with his younger sister. His father worked as a transport manager in a pallet firm and his mother managed the house while running a mobile dog- trimming business.

Bob describes his feelings related to schoolwork as an inverted bell curve. He said things went along fine in Primary School until Year three or four, and then slowly got more difficult until the worst time, about Year eight or nine, when things slowly began to improve again. The downward trend began when he noticed that he was not reading and writing to the same standard as his peers,

*I started to struggle, noticed that I wasn't sticking to the same sort of standard of reading and writing probably when I was, aw crikey, I think it must have been the*

*equivalent to Year 3 or 4 ... the thing that made me realise ... was the fact that I was taking reading books from the class below* (Interview 2).

In this passage Bob speaks in a discourse of *What's wrong with me?* (see Fig. 4.4) as he notices he is different in learning to read from his peers, and the passage links to *Recognition* as he identifies that he has a difficulty; however it does not link to any other aspects of the MVS because he does not understand why he is having difficulty or what he might be able to do about it. In Year six Bob turns to his Headteacher for help,

*I remember ... talking to my Head ... saying my, my eyes get tired when I read ... she thought I needed an eye test, and arranged for an eye test to be done. And, my eyes were fine. And, so ... although I was never told that I was stupid, I think it was ... put down to that ... Bob's pretty slow, he's not particularly bright, you know, he just scrapes through ok. And my dad would get very angry with me because he could never understand why I couldn't ... do spellings ... I think my parents thought I was certainly quite lazy, and ... so, I went through primary school ... thinking well ... I'm not particularly clever* (Interview 1).

In this excerpt, Bob attempts to resolve his question, 'What's wrong with me?', going to the person with the greatest authority in the school for an answer. When the Headteacher arranges an eye test that determines that his eye sight is normal, Bob understands his teachers and parents to fall back on the discourse *DRW=Stupid/lazy* to explain his difficulties. In this way the initial part of this passage relates to the discourse *Educational responsibility* – Bob turns to the Head for help and the Head does not provide it. The latter part of the passage is an example of the discourse *DRW=Stupid/lazy*. Neither discourses link to an aspect of the MVS because they do not support *Internal decisions* or *Action* in Bob. Unlike some of the other participants who reject the *DRW=Stupid/lazy* discourse, Bob internalises the idea that he is thick – perhaps because this is the message he understands from both his teachers and his parents. The development of the perception can be seen to be quite logical; he becomes aware that he is not able to do what his peers are able to do. He has access to two ways to understand his difficulties; that he 'not particularly bright' or 'quite lazy'. Because he is actually doing his best, he decides he must be 'not particularly clever'.

Bob found his move from Primary to Secondary School very difficult, '[it] was quite a tough transition ... from a small village school to a... catholic school, of like 8 to 900' (Interview 1). In fact, he characterises his time there as 'miserable' (Interview 2). There are a number of reasons for

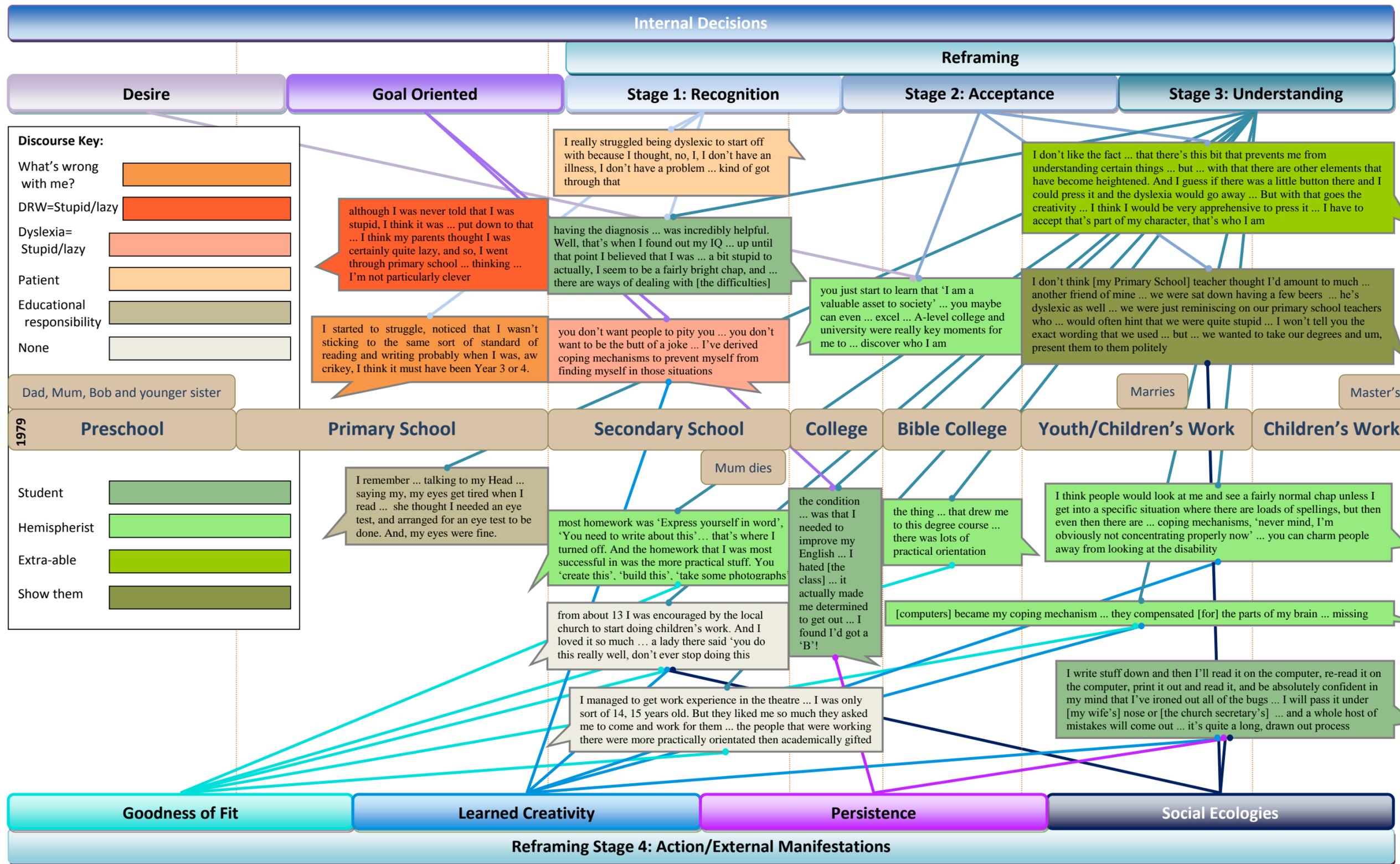


Figure 4.4 shows a representation of Bob's process of making sense of his difficulties with reading and writing and the methods he develops to cope with them, analyzed by mapping his use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

Stages of Bob's life are represented across the centre of the model, and the size of each stage is in ratio to the length of the stage in years (so 'Primary School' is the largest stage because he there for 7 years, whereas 'College' is the smallest because it lasted only 2 years).

Quotes from Bob's life story are placed according to the time in his life that he is referring to, so quotes about experiences that occurred during his school years are located above or below the stages 'Primary School' and/or 'Secondary School'. Quotes shown in the figure are highlighted grey in the text.

Aspects of the MVS are identified across the top and the bottom of the figure, with Internal decisions listed across the top, and the fourth stage of Reframing, Actions/External Manifestations, listed along the bottom. Colour coded links are made between different aspects of Internal decisions and Actions/External Manifestations and quotes from Bob's life story. Links from Internal decisions attach to the top centre of a quote, and links from Action/External Manifestations attach to the bottom of a quote.

Finally, discourses of dyslexia are represented by the background colour behind each quote, and the key to what discourse is represented by each colour is located on the left side of the map. Discourses represented by reddish colours are less likely to support aspects of the MVS whereas discourses represented by greenish colours are more likely to be supportive. Discourses represented by neutral colours can be either supportive or detrimental.

Figure 4.4. Bob's process of making sense of his difficulties with reading and writing and the methods he develops to cope with them, analyzed by mapping his use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

this; when he was fifteen his mother died of cancer, but also his teachers berated him for his homework and he was bullied regularly. Life was therefore difficult both at home and at school.

Bob describes himself as being in trouble with teachers a lot during the first years of Secondary School, not because of misbehaviour, but because he was constantly told his homework was inadequate. He did the homework to avoid being held in at breaks and to prevent detentions, but only to a poor quality. Things came to a head with his French homework,

*I remember getting my first after school detention in French ... I couldn't do the work, but it's not because I didn't try to do the work, it was just I couldn't do it ... I tried to explain this to the teacher and she wasn't having that, she was like "that's not good, you've not done it". And so she gave me three after school detentions in succession. (Interview 2).*

Bob confided to his English teacher about it, who also happened to be the Learning Support teacher. This teacher initiated assessment of Bob's difficulties near the end of Year eight and he was identified as dyslexic, and in Year nine Bob received a Statement<sup>2</sup> which allocated funding for additional support. From that point his French classes were replaced with English support sessions, he was allowed to drop English Literature at GCSE, and he was given extra time in exams. Additional support meant things improved for him academically, and he went from being 'a D and E straight boy' (Interview 2) to achieving Cs at GCSE except in English Language and Music.

Bob identifies the time following his Statement as the beginning of the upward trend in the bell curve that he uses to represent his experience of dyslexia in school. He says he initially disliked being labelled as dyslexic,

*I really struggled being dyslexic to start off with because I thought, no, I, I don't have an illness, I don't have a problem. And, and yeah, kind of got through that (Interview 1).*

Bob describes identification of dyslexia here through the *Patient* discourse, where he understood dyslexia medically, as an illness or a problem. He explicitly states that his initial negative understanding of being dyslexic changed; 'kind of got through that'. This suggests the *Patient* discourse, because of its negative within-person connotations, can provide a person

---

<sup>2</sup> A statement represents the provision made by an LEA for special educational needs.

with a reason to resist identification of dyslexia, and that other understandings make dyslexia more acceptable. Bob also describes more positive facets of identification,

*...having the diagnosis ... was incredibly helpful. Well, that's when I found out my IQ ... I suppose up until that point I believed that I was just a slow learner and a bit stupid, to actually, I seem to be a fairly bright chap, and ... there are ways of dealing with it (Interview 3).*

Bob describes dyslexia here through a *Student* discourse because he contrasts above average intelligence and his difficulties reading and writing, and mentions coping mechanisms related to schoolwork. The passage links to *Recognition* because he learns more about his difficulties and *Understanding* because he learns he is intelligent and that there are ways to cope with his difficulties.

Simultaneous to this development of more positive ways to understand his difficulties, though, Bob describes others' understanding of dyslexia in terms of the *Dyslexia=Stupid/lazy* discourse to cause increased bullying,

*... people started to realise that perhaps I wasn't as 'sharp' as doing the whole academic stuff ... I had to go off and ... do special lessons, [bullying] got a lot more difficult ... So that kind of really blew apart my self confidence into the sort of mid to last part of secondary school (Interview 2).*

Not only did the bullying intensify while he was trying to come to terms with being identified as dyslexic; undoubtedly this period was particularly hard for Bob because it was during this time that his mother became ill with cancer and died. In the third interview he describes how he was motivated to learn to avoid stigma,

*... you don't want people to pity you, but you want people to understand and ... you don't want to be the butt of a joke ... in the early years ... I was worried about those ... elements. And I guess that's how I've derived coping mechanisms to prevent myself from finding myself in those situations (Interview 3).*

This excerpt is unusual because it describes a situation where the discourse *Dyslexia=Stupid/lazy* supports aspects of the MVS. Bob is *Goal Oriented* to avoid the stigma he dislikes, and as a result develops *Learned Creativity* in the form of coping mechanisms to avoid bullying.

During Secondary School, Bob describes a growing awareness of his strengths as well as his weaknesses. Although this occurred mostly outside of an educational context, Bob did mention one way in which school supported his self-knowledge,

*...most homework was 'Express yourself in word', 'You need to write about this', 'You need to ... write a report on this' And I think that's where I, I turned off. And the homework that I was most successful in was the more practical stuff. You 'create this', 'build this', 'take some photographs of this' 'bring in this'. And that was always the work that I did the best on. (Interview 1).*

Bob is speaking in a *Hemispherist* discourse here as he describes his abilities with practical work and difficulties with writing. Homework assignments that did not require reading or writing, 'more practical stuff', allowed Bob to experience *Goodness of Fit*. His success in this kind of work developed his *Understanding* of what he was good at, and he later acted on this knowledge, for example in his choice of Bible College,

*the thing that I wanted, that drew me to this degree course ... there was lots of practical orientation ... it encouraged you to do placements in churches, in community organisations, and I had 3 overseas placements which was fantastic (Interview 2).*

This is again a *Hemispherist* discourse as he uses his *Understanding* of his strengths from experience of *Goodness of Fit* to choose a higher education course in which he is likely to succeed. Outside of an educational context, Bob also had a number of experiences that developed awareness of his strengths during Secondary School. Like the situation above, these appear to have provided information which Bob used later to make decisions about his life, and a context to develop skills which he has used ever since. The first niche involved church and its youth group,

*...from about 13 I was encouraged by the local church to start doing children's work. And I loved it so much. And then me and [my friend], we would go and do the worship. [My friend] was quite good at the guitar at the time, so he would do the music and I would do the singing and the dancing and the stupid things to get the kids involved and stuff. And ... a lady there said 'you do this really well, don't ever stop doing this, I mean it's a really important thing' ... we wrote numerous songs and we performed our own concerts ... my music tech course allowed me to record the band, because we needed to do practical projects (Interview 2).*

This excerpt does not represent any discourse of dyslexia, and is therefore the discourse *Niche*. At church Bob experiences *Goodness of Fit*. It is an environment that doesn't require reading and writing, but perhaps even more importantly it is a place where he says he was encouraged

to experiment. Bob received a 'D' in Music at GCSE despite the fact that he was leading worship at church at that time and playing in bands, because he was unable to learn to read music. At church he could succeed with music anyway,

*I didn't need to know how to sight read, I didn't need to have a good understanding of how music works to do that. I was just ... being encouraged to experiment (Interview 1).*

Through the context of church Bob also developed *Learned Creativity* – he learned to play and write music without having to learn to read it. This supported *Understanding* about what he is capable of and about applying these abilities. By the time Bob was at college he was generalising this knowledge to an academic context – he records the band for his practical assignments in music tech. The woman who encouraged him never to 'stop doing this' represents an experience of *Social Ecologies*; later, a youth leader said to him, 'you know, you might want to consider taking your faith to a higher level, have you thought about going to Bible college?' (Interview 2). That Bob remembers being told these things and that he followed both sets of advice by becoming a Children's Worker, leading children's groups and worship in church, suggests how key this support was.

Bob also experienced *Goodness of Fit* and developed additional *Understanding* about his skills in his work at the theatre;

*I managed to get work experience in the theatre, in the local theatre, and so I was only sort of 14, 15 years old. But they liked me so much they asked me to come and work for them ... And no disrespect ... but the people that were working there were more practically Oriented than academically gifted, and so they were a nice bunch of people, really I enjoyed working with them (Interview 2).*

This passage is also not related to a discourse of dyslexia, and represents an experience of *Niche*. Bob finds this niche because of his Secondary School work placement scheme, and therefore this is an indirect way in which Bob was supported in aspects of the MVS by his Secondary School.

Although his father and teachers expected him to continue to the sixth form at the Catholic school to do a GNVQ in leisure and tourism, Bob decided instead to attend a local college to re-take English GCSE and do A-levels in music technology and media studies. Another way that an academic context supports aspects of the MVS is when Bob re-takes his English GCSE at this college,

*the condition for me to do these A-levels was that I needed to improve my English grade, which was fair enough. So they re-enrolled me in a one year GCSE English class ... which actually I hated because it was full of people that basically were there because they didn't want to learn ... which was a real shame. Well, actually, probably not. Because it actually made me determined to get out of this English class as quickly as possible. And so I did it. And I worked as hard as I could and the ladies in the special education area helped tremendously. And then ... I found I'd got a 'B'!* (Interview 2).

This situation is similar to the one where Bob learns coping mechanisms to avoid being the brunt of jokes. His dislike of the class makes him determined to 'get out ... as quickly as possible'. His productive behaviour is therefore in response to a negative situation. He speaks here in a *Student* discourse because of his reference to help from Learning Support, and this passage links to *Goal Oriented* behaviour as he explicitly set his goal of getting out of the class, and *Persistence* as he works 'as hard as I could'. With his success in achieving a B in English he contributes to *Understanding* as he becomes aware that he can take this approach to succeed in academia in future.

Bob describes his time at college and Bible College both to support *Acceptance*. With identification of dyslexia in Secondary School Bob was involved in a process of accepting that his difficulties would always be a part of his life, but it is later, in college and Bible college, that he comes to accept that he has something valuable to offer,

*you just start to learn that 'I am a valuable asset to society' ... you maybe can even ... excel ... A-level college and university were really key moments for me to ... discover who I am* (Interview 1).

This excerpt is spoken in the *Hemispherist* discourse because it involves the awareness of strengths and ability. It links not only to *Acceptance* but also *Desire*, where Bob explicitly states a desire to excel. At the time of the third interview, Bob shows *Acceptance* to the extent that he says,

*I don't like the fact that, that there's this bit that prevents me from understanding certain things, or, but ... with that there are other elements that have become heightened. And I guess if there was a little button there and I could press it and the dyslexia would go away, I think I would be apprehensive to press it ... press the button and I could read novels ... and process information ... write beautiful news articles and whatever, that would be lovely. But with that goes the creativity ... I think I would be very apprehensive to press it ... So I have to accept that's part of my character, that's who I am* (Interview 3).

Here Bob takes *Acceptance* one step further. He not only accepts that he will always have difficulties with reading and writing, he feels that his difficulties have heightened his abilities and he would rather keep those abilities and the difficulties than lose both. His description of heightened ability links this excerpt to the discourse *Extra-able*. Elsewhere he says,

*... I'm quite good at ... problem solving, and I think ... that comes back to trying to cope with ... quite a lot more problems than ... on average ... as a result I seem to find myself able to problem solve a lot easier [than others] ... I can usually come up with a way round something (Interview 1).*

In other words, the difficulties he has experienced with reading and writing have meant he has learned to problem-solve in a way that he would not otherwise have done, and that he may as a result be even better at problem-solving than most people. Bob uses the discourse *Extra-able* from a non-genetic perspective; he does not see himself as genetically more able, but to have developed higher skills in response to his difficulties. Bob attributes his particularly creative presentation style at work to unorthodox means of development. In music he learned primarily through experimentation rather than formal lessons. His own need for a combination of multi-sensory input and use of computers to cope with his difficulties has supported him to develop his own unique style based on audio-visual multimedia which also happens to be particularly effective with the children he works with.

Bob now uses electronics daily to compensate for his difficulties with reading and writing and organisation. His connection with computers started in Primary School, and developed particularly in Bible College when he built a computer from 'bits' that he could afford (he bought his own because he did not find out about Disabled Student's Allowance until it was too late to pursue support at university),

*...instantly, as soon as our first computer came in the classroom, I kind of, I still kind of, without sounding, what's the word, boasting, well ... I do seem to be able to operate computers very well. And understand the logic behind computers (Interview 1),*  
[computers] *became my coping mechanism ... they compensated the parts of my brain because that was what was missing (Interview 2).*

Though the latter excerpt could be understood as a *Patient* discourse because Bob refers to something missing from his brain, I have chosen a *Hemispherist* discourse to represent it because he is discussing the way he uses areas of strengths (computing) to compensate for his areas of weakness. Bob draws on *Understanding* of previous success with computers (an

experience of *Goodness of Fit*) and use of computers represent *Learned Creativity* as he compensates for his difficulties.

*...it's interesting the variety of coping mechanisms you do build up. You know, like spelling ... I do panic about putting publications out. Because I write stuff down and then I'll read it on the computer, re-read it on the computer, print it out and read it, and be absolutely confident in my mind that I've ironed out all of the bugs ... I will pass it under [my wife's] nose or [the church secretary's] ... and a whole host of mistakes will come out ... I was always taught you, you know, you must check ... [more] than a normal person ... then give them to people to proof for you and that's important, and then go back and made the amendments and then get them to proof it again, you know what I mean, so it's quite a long, drawn out process (Interview 3).*

In Bob's job he leads children's groups and church services using PowerPoint; he also writes regular newsletters and letters to parents. Spelling, therefore, is an ongoing issue in his work. He employs a combination of strategies to deal with it, including using word processing and a diligent process of checking it himself, then passing it to others to proof-read. He therefore draws on a combination of *Learned Creativity*, *Persistence* and *Social Ecologies* to deal with this difficulty.

Bob speaks in a *Show them* discourse below,

*I don't think [my Primary School] teacher thought I'd amount to much ... another friend of mine ... we were sat down having a few beers ... he's dyslexic as well ... we were just reminiscing on our primary school teachers who ... would often hint that we were quite stupid ... I won't tell you the exact wording that we used ... but ... we wanted to take our degrees and um, present them to them politely (Interview 3).*

He and his friend share the fantasy of showing their degrees to teachers who did not think they would amount to much. This passage links to *Acceptance*; both men already have amounted to something and their fantasy affirms this. The passage also links to *Social Ecologies*; as they laugh together they work toward replacing painful memories of failure, helplessness and rejection with enjoyment, power and belonging.

By the time of our interviews, Bob demonstrates confidence and capability in dealing with his difficulties, to the extent that he believes dyslexia is invisible to others and even to himself;

*I think people would look at me and see a fairly normal chap unless I get into a specific situation where there are loads of spellings, but then even then there are ... coping mechanisms, 'never mind, I'm obviously not concentrating properly now' ... you can charm people away from looking at the disability (Interview 3).*

It is difficult to identify a specific discourse of dyslexia in this passage but it links to the *Hemispherist* discourse because Bob is describing dyslexia as a difference rather than a difficulty, 'people would look at me and see a fairly normal chap', and the coping mechanism he describes to deal with spelling mistakes doesn't relate to study skills but 'charm', so it is not the *Student* discourse. Bob is suggesting that across the different demands in his life he has now learned to compensate for his difficulties, even in a context nightmarish for a dyslexic person – 'where there are loads of spelling', he is confident that he would be able to cope. The excerpt links to *Learned Creativity* and *Understanding*; he is describing the fact that over the years he has developed knowledge about how to compensate for his difficulties, and this means dyslexia is no longer much of a problem.

However at other times he describes ongoing issues related to dyslexia. He discusses dyslexia through a discourse of *Educational responsibility* a number of times; in relation to his Primary Head, loss of self-esteem that sometimes still plagues him due to internalising the *DRW=Stupid/lazy* discourse, the fact that his College did not give him information about the Disabled Students' Allowance even though he disclosed dyslexia. The discourse *Educational responsibility* raises a contradiction in himself. He is proud of what he has accomplished through initiative, innovation and hard work, and this success is a foundation on which he has built positive self-perceptions. He is aware though that the difficulties he faced might have been much less had he had access to the support and information he only began to receive in his mid-teens. He is also aware that others are not as fortunate as he is in terms of levels of initiative and ability,

*I often worry about people that perhaps, aren't as ... forward as I am ... lots of people within the country ... have this learning difficulty and ... are either afraid to ask for help ... or just simply haven't got a clue ... what's available for them ... like on the NHS ... you can get glasses ... But, when it comes to dyslexia ... you're on your own now, you've got to deal with this yourself. And, part of me thinks, well ... should that be the case? (Interview 1).*

Bob's ponderings are bringing him close to a *Campaigner* discourse, in terms of his awareness of dyslexic people as a group and in terms of his reference to the responsibilities of society as well as the individual. This is also true in the following passage,

*if people found out that I'm dyslexic ... even now, I'm worried that people would discredit me as a person ... they would label me ... stupid ... unable to do things, I suppose like a person in a wheelchair would say 'well, I can do everything an able-*

*bodied person can' but an able-bodied person would look at a person in a wheelchair and say 'well, no you can't' and actually we know it's down to the determination of that person anyway, and who are we to say that he can't achieve stuff ... you don't want people to look at you and say 'well, he won't be able to manage that' when you know in yourself 'I can manage that' (Interview 3).*

Here Bob refers to the contradictory issues he is trying to tease out – the responsibility of the individual and the responsibility of society; he is talking about the actions of society but also says 'we all know it's down to the determination of that person'. He believes in his ability and right to excel, and is aware of the power others have, through his experiences in Secondary School, to try to take that away from him. Bob has not been educated about the social model of disability nor has he been involved in rights advocacy unlike the two other participants who speak in a *Campaigner* discourse, Amber and Pablo. Presumably the dominance of the *Patient* discourse in society makes the *Campaigner* discourse quite a leap to make unaided.

## Country Boy

Country Boy has highly developed understandings of dyslexia, perhaps because of his work researching it recently for a qualification in Specific Learning Difficulties (SpLDs). However, he did not talk at great length about his perceptions, particularly in reference to himself. Such views as he did give he gave succinctly. He talked at more length about attitudes toward dyslexia in reference to the dyslexic students he has tutored.

Country Boy was born in 1933 and was 73 at the time of the first interview. He grew up in a small village on the southern outskirts of London, second of four boys. His father was a gardener, his mother a Lady's maid and his paternal grandfather Head Gamekeeper for the local estate. Country Boy describes an awareness that he was different from his peers from the earliest days he was in school,

*... if they wanted to find me they always had to come and look for me in the woods because that's where I preferred to be, because I knew I was different. I wasn't like the other children, I couldn't read, my schoolwork was hopeless, and yet I knew within me that I wasn't stupid, although everyone tried to tell me, including all the school teachers, except [my neighbour], and so I used to take myself off into the woods. I loved being in the woods and in nature and watching the birds and things like that ... that was, I mean, early recognition that I couldn't do schoolwork, was when I was probably about 5. I just, I just couldn't get it (Interview 1).*

In this excerpt Country Boy describes the realisation that he was different from others, demonstrating a discourse of *What's wrong with me?* and *Recognition* of difficulties with reading (see Fig. 4.5.). Here Country Boy also speaks of his rejection of the discourse of *DRW=Stupid/lazy* in reference to himself. When we went over the life history in the fourth interview he explained that even as a child he could figure out how things worked better than those around him, so he knew he was intelligent. This passage conveys loneliness, a sense of being an outsider, and seeking

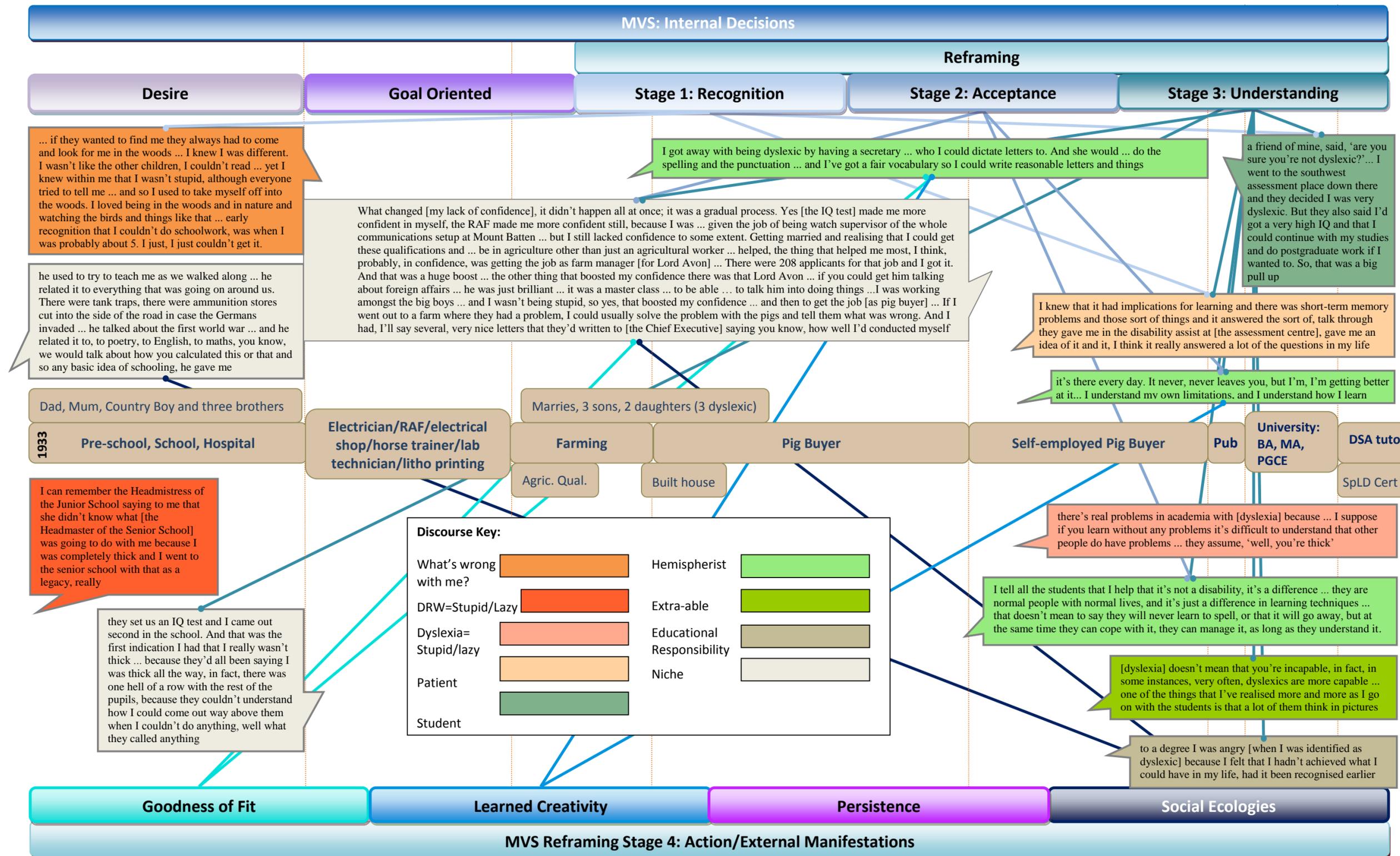


Figure 4.5 shows a representation of Country Boy's process of making sense of his difficulties with reading and writing and the methods he develops to cope with them, analyzed by mapping his use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

Stages of Country Boy's life are represented across the centre of the model, and the size of each stage is in ratio to the length of the stage in years (so 'Pig Buyer' is the largest stage because he worked in that profession for 17 years, whereas 'Pub' is the smallest because it lasted only 2 years).

Quotes from Country Boy's life story are placed according to the time in his life that he is referring to, so quotes about experiences that occurred during his school years are located above or below the stage 'Preschool, School, Hospital'. Quotes shown in the figure are highlighted grey in the text.

Aspects of the MVS are identified across the top and the bottom of the figure, with Internal decisions listed across the top, and the fourth stage of Reframing, Actions/External Manifestations, listed along the bottom. Colour coded links are made between different aspects of Internal decisions and Actions/External Manifestations and quotes from Alice's life story. Links from Internal decisions attach to the top centre of a quote, and links from Action/External Manifestations attach to the bottom of a quote.

Figure 4.5. Country Boy's process of making sense of his difficulties with reading and writing and the methods he develops to cope with them, analyzed by mapping his use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

comfort in nature. This is a theme that runs through Country Boy's life story. In the first interview, before I had asked a question beyond 'tell me about your life', Country Boy spoke little of friendships. When I asked him about them at the end of the interview, he said,

*I haven't made many, really close friends in my life ... But those I do have, I generally try to stick to if I can, but there are ones that tend to fall off, fall off I must say (Interview 1).*

Country Boy describes a number of friends he has had over the course of his life, some of whom are still friends, and he speaks with enjoyment of his family. It is not that he hasn't had close long-term relationships, however there is a sense that Country Boy feels that he has not had as many close relationships as perhaps he would have liked. That he views nature as a friend is also repeated over the interviews, for example in the fact that he chose the pseudonym 'Country Boy' to identify himself, his later references to the desire to be outside and not stuck in a factory – preferring the outdoor work of horse training and farming, and his choice of degree subject, Heritage and Landscape. That Country Boy links a sense of being different and removing himself from others to his difficulties at school suggest that these difficulties contributed to his sense of loneliness, but that also they supported his close relationship with nature.

Although Country Boy did not do well at school, his Primary School years were overshadowed not only by this but also by the fact that he contracted tuberculosis in his neck at age seven, and spent two years in hospital during the war years,

*The hospital filled up with local people that were bombed out of their premises, and the Dunkirk wounded ... every passageway was filled with troops that were wounded at one time, and so I had, I've always had a lot of variety in my life you could say, I mean, at the age of 7 I was seeing men die, and you know, horrendous wounds (Interview 1).*

It could be argued that his difficulties at school were a result of missing these two years of Primary School, as well as the trauma involved with being seriously ill in a war hospital, and Country Boy himself makes this attribution when his friend suggests he might be dyslexic many years later (see below). However, the earlier excerpt about his difficulties in school from the age of five argues that his difficulties were due to more than the trauma of illness and missing time in school. Country Boy shared a number of memories about his school years, both good and bad,

*I can remember the Headmistress of the Junior School saying to me that she didn't know what [the Headmaster of the Senior School] was going to do with me because I*

*was completely thick and I went to the senior school with that as a legacy, really* (Interview 1).

This description is a vivid portrayal of the *DRW=Stupid/lazy* discourse because Country Boy ascribes these words by the Headmistress as having power over his senior school years by tagging it as a 'legacy'. Country Boy had a close friendship with his neighbour who was Headteacher of his junior school before retiring, and this relationship can be seen to represent a *Social Ecology* that supported positive self-perceptions. Country Boy attributes what he learned during school to his relationship with this man,

*... he used to try to teach me as we walked along ... and he was very successful ... I mean he related it to everything that was going on around us. There were tank traps, there were ammunition stores cut into the side of the road in case the Germans invaded, there was, you know, whatever had happened that night, or that day, and so we talked a lot, he talked about the first world war, where he'd been terribly wounded, and he related it to, to poetry, to English, to maths, you know, we would talk about how you calculated this or that and so any basic idea of schooling, he gave me, really, in that period* (Interview 1).

This passage suggests that a relevant context, meaning and relationship provided a *Niche* in which Country Boy was able to learn, and that the more abstract nature of learning in school may have failed to provide such support. Country Boy says he taught himself to read during senior school when one of his teachers began reading 'Treasure Island' aloud to the class,

*the English teacher ... read us Treasure Island ... and that triggered my fascination, my interest so much that I was determined to read it and I did. So I learnt to read at the senior school* (Interview 1).

Again, Country Boy learned in response to a subject meaningful to him, but he does so outside the context of school. When he was 15, his final year in school, all students were given an IQ test,

*...they set us an IQ test and I came out second in the school. And that was the first indication I had that I really wasn't thick ... because they'd all been saying I was thick all the way, in fact, there was one hell of a row with the rest of the pupils, because they couldn't understand how I could come out way above them when I couldn't do anything, well what they called anything* (Interview 1).

Here Country Boy's earlier conviction that he wasn't stupid was confirmed externally; in fact by this measure he was more intelligent than all but one of his peers. This passage is not a discourse of dyslexia because Country Boy was not identified as dyslexic then, and this demonstrates that it is possible for reframing to take place without identification of a disability

through experience of *Niche*. The internal impact discursively is very similar, in that a discrepancy between his school attainment and intelligence was made clear and this confirmed his sense that he was intelligent, offering him a strengthened way to offset the negative evaluations of his intelligence made by teachers and peers. Externally there was no impact; the educational system had no provision or conceptualisation for a person who was intelligent but had low attainment in reading, writing and maths. Country Boy knew as early as senior school that he wanted to go to university,

*I wanted to go to university when I was, what, 14, 15, it's one of the things that, you know, they said to me at school 'what do you want to do' I said 'to go to university' and they laughed because, you know, there was no chance. I was not going to be able to do that (Interview 2).*

Country Boy's experience of school bears some similarity to that described by dyslexic adults in the literature review. He describes feeling humiliated as he is unable to do what his peers do, and tells stories of teachers who help and teachers who hinder, and the strong impact both have. His parents did not support him to understand his difficulties, but he grew up decades before dyslexia was commonly recognised so explanation and intervention through identification of dyslexia was not an option.

After he left school he worked as an apprentice electrician until being called up at seventeen to military service, which he spent with the RAF. There his high IQ scores meant he was considered twice for officer training, but because of his low general knowledge and maths skills was rejected. On coming out of the RAF Country Boy tried a number of jobs, such as working in an electrical/radio shop and different factories, but he said he never liked being stuck inside. When discussing early jobs he was most animated when describing a few years when he worked at a riding school,

*I'd always liked being outdoors and with horses so I worked with a variety of horses – hunters and show-jumpers at a riding school they had there, and [my employer] taught me to ride and to jump and to go into gymkhanas, hunter trials and things like that. So, for a couple of years I had a whale of a time (Interview 1).*

As he began courting his wife-to-be, Rachel, though, he looked for better paid work, and soon after they were married he took a job as a pig farmer because it offered a tied cottage. Whilst doing this job he completed City & Guild agricultural qualifications, and then moved to a job managing a farm in Oxford shire. From there he secured a job against a number of applicants to work for Anthony Eden (later Lord Avon), running his farm in Wiltshire, and during this time Country Boy made the acquaintance of a number of statesmen and celebrities. Eventually

differences of opinion led Country Boy to leave Lord Avon's farm, and he began to work as a pig seller in a large company, where he quickly moved up the ranks to senior management levels. During this period of Country Boy's life story it becomes particularly clear how hard he works – while managing Lord Avon's farm he had bought a condemned house which he tore down and completely rebuilt. He began by working on it in the evenings, and then completed it between the end of his job with Lord Avon and beginning to work as a pig seller.

In the second interview I asked Country Boy to tell me more about the way the IQ testing when he was fifteen changed the way he thought about himself, and this led him to discuss a number of roles that impacted his self-perceptions positively,

*I've always been a retiring sort of person ... I was always shy ... I wasn't confident because, because I wasn't very good at academic work ... it stopped me reaching the potential I could have had ... [the IQ test changed my reticence] to some degree, yes a bit, not a great deal. What changed it, it didn't happen all at once; it was a gradual process. Yes [the IQ test] made me more confident in myself, the RAF made me more confident still, because I was ... given the job of being watch supervisor of the whole communications setup at Mount Batten ... but I still lacked confidence to some extent. Getting married and realising that I could get these qualifications and do, to be in agriculture other than just an agricultural worker ... helped, the thing that helped me most, I think, probably, in confidence, was getting the job as farm manager [for Lord Avon] ... There were 208 applicants for that job and I got it. And that was a huge boost ... the other thing that boosted my confidence there was that Lord Avon ... he could be quite vain, in a way. And could be arrogant, but if you could get him talking about foreign affairs ... he was just brilliant ... it was a master class ... to be able ... to talk him into doing things ... I was working amongst the big boys ... and I wasn't being stupid, so yes, that boosted my confidence ... and then to get the job [as pig buyer] ... and solve the farmer's problems ... If I went out to a farm where they had a problem, I could usually solve the problem with the pigs and tell them what was wrong. And I had, I'll say several, very nice letters that they'd written to [the Chief Executive] saying you know, how well I'd conducted myself and how knowledgeable I was and so on ... That was a really good boost (Interview 2).*

This passage demonstrates a number of elements from the MVS that supported him to reframe the understanding he developed as a result of his failure in school that he was incapable, to understanding himself as very capable. Primarily the experience of *Goodness of Fit*, where Country Boy experienced situations in which he was able to succeed – in the RAF, in marriage, as farm manager rather than farm worker, being able to talk Lord Avon into doing things, being able to solve pig farmer's problems – changed this perception. This led to better *Understanding* of what he was capable of and *Acceptance* that he was someone with something valuable to offer. Although Lord Avon did not act as a personal mentor, he did provide Country Boy a *Social Ecology* where Country Boy developed his ability to communicate with and work amongst 'the big boys' – and it was a boost to know that he was able to work as

an equal with men of such high status. This excerpt is not a discourse of dyslexia, because Country Boy had not been identified as dyslexic when these events occurred, and so is an experience of *Niche*. This provides an example of the way in which reframing can occur without *Recognition*.

Though much of the employment Country Boy was engaged in was removed from a context of reading and writing, when working for Lord Avon Country Boy was forced to revisit his difficulties,

*I used to have to write to Lord Avon when he used to spend the winter in the Caribbean because he wasn't very well, and I used to have to write a letter to him every so often about the progress on the farm, and it absolutely terrified me (Interview 1).*

In later years he resolved this issue with the help of a secretary,

*I got away with being dyslexic by having a secretary ... who I could dictate letters to. And she would ... do the spelling and the punctuation ... and I've got a fair vocabulary so I could write reasonable letters and things (Interview 1).*

Country Boy continued to compensate for his difficulties with writing with a secretary later during his years of self-employment, and this is an example of *Goodness of Fit* contributing to *Learned Creativity* and the *Hemispherist* discourse, where Country Boy shows awareness of using his strong verbal ability to compensate for his weakness with the written word. This is an interesting passage because Country Boy refers retrospectively to himself as dyslexic – at the time he had not been identified.

After seventeen years as a pig seller the company was bought out and Country Boy made redundant. He made contact with his previous clients and ran his own business selling pigs for thirteen years, when in the late 1980s his bank began to charge high interest rates on his overdraft (up to 34%). Because of the poor economy he was unable to sell his business, house or equipment in order to clear the overdraft and interest was added to it until the bank took the property in lieu of debts in the early 90s.

At age 59, then, Country Boy found himself unemployed. He was told when he went to sign on that he would not be able to find a job. Soon after, at the Devon County Show, he was hired by an internet-based business selling pigs, where he worked for a year until that business, too, went under. For the next year Country Boy worked in a pub for an old friend of his. It was there that he became aware he might attend university,

*there was a girl that came into the bar one day and I asked her what she did ... 'I'm a student at [a local university]' she said, I said 'oh, that's interesting' she said 'well, you could go there', I said 'no, I couldn't, I'm too old, they wouldn't want me' and she said 'no, you go to an open day, you'll see, they'll take you on as a mature student'. I went to an open day in February and one of the lecturers was talking to the students and I said 'well, could I do a course here?' 'yes' he said. 'Well, I haven't got any qualifications, only agricultural qualifications' and he said 'you've been to the University of Life, that'll do' (Interview 1).*

Country Boy spent the next five years at university, completing a BA, MSc and PGCE. He was identified as being dyslexic in the second year of his BA,

*... the first essay I did and it came back with a note on it saying 'there's not a single verb in here' ... he was trying to make a point. And a friend of mine said, 'are you sure you're not dyslexic?' .... I said 'I don't think I'm dyslexic, it's just, you know, I haven't had much schooling, and he said, 'why don't you go and find out' so I went to the southwest assessment place down there and they decided I was very dyslexic. But they also said I'd got a very high IQ and that I could continue with my studies and do postgraduate work if I wanted to. So, that was a big pull up' (Interview 1).*

Here Country Boy describes dyslexia through a *Student* discourse, as he discusses high IQ in the context of difficulties with academic work. The encouragement that it was appropriate for him to be in higher education, indeed that it would be appropriate for him to carry on with postgraduate work, was an affirmation of his original desire to go to university when he was a teenager. This excerpt represents the *Recognition* stage of reframing, and supported *Understanding*. In his working life Country Boy had established for himself that he was an able, worthy person through what he was able to accomplish. However, identification of dyslexia still supported him to develop a better understanding and acceptance of himself,

*I wasn't aware that I was dyslexic; nobody said ... I was just called 'thick' at school so nobody had diagnosed me as dyslexic. When I was first diagnosed, it was a relief ... but I still really didn't understand it. I didn't understand it to be truthful, until I came on that [SpLD] course ... I knew that it had implications for learning and there was short-term memory problems and those sort of things and it answered the sort of, talk through they gave me in the disability assist at [the assessment centre], gave me an idea of it and it, I think it really answered a lot of the questions in my life ... to a degree I was angry because I felt that I hadn't achieved what I could have in my life, had it been recognised earlier ... on the other hand, it helped me to understand myself a lot' (Interview 3).*

In the excerpt from above, Country Boy describes his relief when he was identified as being dyslexic. This suggests there is more to the helpful nature of identification of dyslexia than being told one is intelligent, since Country Boy had known he had a high IQ since he was a teenager. At the time, he also confesses he did not really understand what it meant, though he seems to have been given an understanding through a *Patient* discourse when assessed

because of his description of within-person deficiency in short-term memory that contributes to *Recognition*. That he felt relief anyway communicates the power such identification has to explain – ‘it really answered a lot of the questions in my life’; ‘it helped me to understand myself a lot’; this represents the development of *Understanding*. Country Boy thinks that had dyslexia been identified earlier it would have enabled him to achieve more; he begins the passage by saying that at school he was called ‘thick’ rather than what he now knows would have been more helpful to him, being called dyslexic. This is a discourse of *Educational responsibility*, and it contributes to *Understanding* by allocating blame for his difficulties not only internally but also to the part played by the educational system.

*... it's there every day. It never, never leaves you, but I'm, I'm getting better at it ... more so now, doing this job, and doing the course, than ever before ... I understand my own limitations, and I understand how I learn* (Interview 2).

Country Boy's understanding of what dyslexia is and how he is affected by it develops as he works on the SpLD course and tutors dyslexic students. This developed *Understanding* contributes to *Acceptance* as he understands his own limitations and how to compensate for them, and *Learned Creativity* as he applies ‘how I learn’. It is difficult to say what discourse this is. It can be thought to be a *Student* discourse because it relates particularly to an academic context, as Country Boy refers to his work as a tutor and a student on the SpLD course. However, the way he describes dyslexia as ‘there every day. It never, never leaves you’ contradicts the academically compartmentalised *Student* discourse. For this reason I have identified it as a *Hemispherist* discourse, as he can be seen to be describing his understanding of his strengths and weaknesses. Ironically, Country Boy eventually dropped out of the SpLD course because it was insufficient in its support of dyslexic students.

Country Boy passes understanding gained from his own process of making sense of his difficulties on to his students,

*I tell all the students that I help that it's not a disability, it's a difference ... I try to get them to understand that, because they are normal people with normal lives, and it's just a difference in learning techniques, that's all. Um, and you know, that doesn't mean to say they will never learn to spell, or that it will go away, but at the same time they can cope with it, they can manage it, as long as they understand it* (Interview 3).

Country Boy's explanation to other students is given in a *Hemispherist* discourse and demonstrates the extent to which understanding himself as dyslexic has supported his feelings about being able to cope with his difficulties. Such *Understanding* supports *Acceptance* – ‘they can cope with it, they can manage it, as long as they understand it’.

... [dyslexia] *doesn't mean that you're incapable, in fact, in some instances, very often, dyslexics are more capable ... one of the things that I've realised more and more as I go on with the students is that a lot of them think in pictures* (Interview 3).

Here Country Boy discusses dyslexia from a discourse of *Extra-able*. His work with other dyslexic people has clarified this for him, particularly the ability for many of them to use visualisation to overcome their difficulties.

In Interview 3 I asked Country Boy how others perceived dyslexia, and he answered,

... *there's real problems in academia with this because a lot of, I suppose if you learn without any problems it's difficult to understand that other people do have problems ... they, they assume, 'well, you're thick' that's the, that's the impression* (Interview 3).

This is a discourse of *Dyslexia=Stupid/lazy*, where dyslexia is understood to be a lack of intelligence. However, this discourse does not necessarily impact Country Boy negatively – he is simply sharing his thoughts about the way other people perceive dyslexia, and it does not seem to undermine his own, more affirming, perceptions.

In summary, Country Boy spent most of his life not thinking of himself as dyslexic. In common with many other dyslexic adults described in the literature review, Country Boy's school career did not provide a foundation for his later successes in life; rather his school experiences left him with the sense that he was incapable, a perception he spent his working life overcoming. He worked very hard, completing agricultural qualifications and building a house outside of working hours. He found his employers thought he was very able, as was demonstrated by the level of responsibility he was given in his jobs. As a result of these successes he went through a process of reframing himself to be capable. By the time he was in his 60s, despite the fact that he already had positive self-perceptions about his ability, identification of dyslexia helped him resolve more completely the personal challenges thrown up by the difficulties he had experienced at school.

## Elizabeth Kirner

Elizabeth Kirner has a range of difficulties from within the Specific Learning Difficulties spectrum, with not only difficulties in reading, writing and maths, but also clumsiness, fine motor control and pragmatics/the social use of language. Her family circumstances as a child were difficult, and they are not easy as an adult. It is not surprising that she has experienced depression at times during her life. Despite these difficulties, Elizabeth has a confident presence, and during interview she was assertive about expressing her thoughts and experiences. She is a person who engages in creative resistance to powerful non-disabled discourses of disability (Dimitriadi, 2006); she has developed her own discourses in relation to her difficulties, and she is not afraid to voice her unique take on life either to me or others.

Elizabeth Kirner was born in 1970 and was 36 at the time of the first interview. She lived the bulk of her childhood with her mother, grandmother and great-grandmother, and describes her upbringing as taking place 'in a predominantly female household' (Interview 1). She had a number of difficulties to contend with as a child. Her Grandmother kept foster children which added to the emotional stress of the household. Her father, a crane driver, was schizophrenic, abusive to Elizabeth and her mother and left them when Elizabeth was 6. Her mother had cancer when Elizabeth was in Primary School and she lived in a foster home while her mother recovered. Finally, she was bullied at school over many years,

*Some of it was name calling, some of it was violent ... I used to get my head kicked in, so, yeah. That was primary school. Secondary school I used to spend, because they used to say 'I'm going to beat you up at lunchtime' or whatever, so I used to go sit in the library, and then they used to stop our year group, you could only go in one day a week, which is difficult, that made life a lot harder ... [Ruth: so it was quite a regular thing] yeah, oh yeah. [Ruth: over years?] over years (Interview 2).*

The bullying encouraged her to stay away from school whenever possible in response to a number of illnesses,

*I had a lot of illnesses when I was a child, I had ... measles and mumps and croup, and I just went through the whole lot because the house was very damp. And I was just a pretty sickly kid. When I got to secondary, by about the 3rd year I was having so many problems at school I was always off ill ... [we had] the attendance officer around. Umm and I, part of it, looking back now probably was a bit psycho-somatic. Probably if I'd enjoyed school more I would have gone in ... even if I was feeling a bit under the weather ... Umm, but again I got bullied (Interview 1).*

Elizabeth kept a number of animals as a child, from hamsters and dogs to water snails, and she describes her relationship with animals as soothing and comforting. Resonance with animals and nature was also mentioned by Country Boy and Adam. Elizabeth had a significant experience of *Goodness of Fit* during Primary School which provided the foundation for future success,

*[My mum] took me to a local speech and drama teacher, you know, we'd gone through a whole load of [extra-curricular activities] ... and I think probably I'd been there about 6 months and I wanted to leave, like I always did ... but she said I had to tell the teacher myself and I was too terrified to tell the teacher because she was quite scary ... so that's how I ended up doing drama ... The good side was because I did drama I had to learn poems and pieces of drama by heart so I learnt to learn things by rote and ... I got interested in books that way ... in terms of reading at home and like reading for pleasure I read a lot of plays (Interview 1).*

This experience of *Goodness of Fit* is unique in that Elizabeth only experienced it because *Persistence* was forced upon her by her mother (see Fig. 4.6). Not only did she find she could succeed at drama, her enjoyment supported her to read and learn by rote. Her ability to carry out rote memorisation helped her in a number of aspects of schoolwork, for example to learn her multiplication tables, one of the only aspects of maths in which she excelled at school. From drama she also learned to put words to tunes to help memorise them, something she does to this day, which is an example of *Learned Creativity*. These experiences contributed to *Understanding* about her strengths. She had additional experience of the benefits of *Persistence* at home from an early age, though she rarely had time to put it to good effect at school,

*we did a lot of like creative writing at home ... so that was fine, so my written work at home was fine because I would spend all evening doing my homework ... when I came to do class work I would get low grades because ... couldn't get the work finished ... I just wrote too slowly and made too many mistakes (Interview 1).*

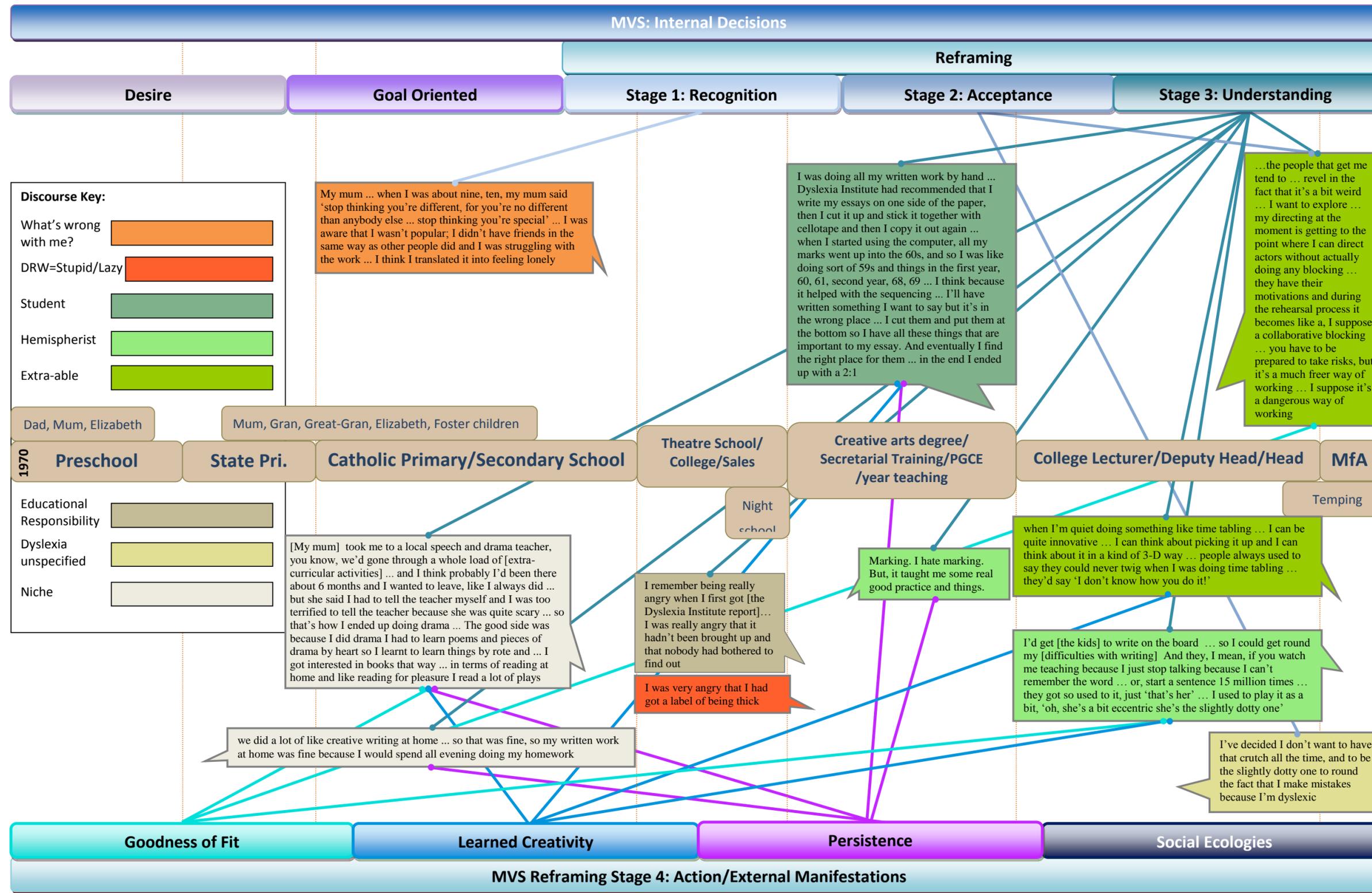


Figure 4.6 shows a representation of Elizabeth Kirner's process of making sense of her difficulties with reading and writing and the methods she develops to cope with them, analyzed by mapping her use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

Stages of Elizabeth's life are represented across the centre of the model, and the size of each stage is in ratio to the length of the stage in years (so 'Catholic Primary/Secondary School' is the largest stage because it lasted 8.5 years, whereas her first year spent on her Master's is the smallest).

Quotes from Elizabeth's life story are placed according to the time in her life that she is referring to, so quotes about experiences that occurred during school are below 'State Pri.' and 'Catholic Primary/Secondary School'. Quotes shown in the figure are highlighted grey in the text.

Aspects of the MVS are identified across the top and the bottom of the figure, with Internal decisions listed across the top, and the fourth stage of Reframing, Actions/External Manifestations, listed along the bottom. Colour coded links are made between different aspects of Internal decisions and Actions/External Manifestations and quotes from Amber's life story. Links from Internal decisions attach to the top centre of a quote, and links from Action/External Manifestations attach to the bottom of a quote.

Finally, discourses of dyslexia are represented by the background colour behind each quote, and the key to what discourse is represented by each colour is located on the left side of the map. Discourses represented by reddish colours are less likely to support aspects of the MVS whereas discourses represented by greenish colours are more likely to be supportive. Discourses represented by neutral colours can be either supportive or detrimental.

Figure 4.6. Elizabeth Kirner's process of making sense of her difficulties with reading and writing and the methods she develops to cope with them, analyzed by mapping her use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

No discourses of dyslexia are identified in the two excerpts above because Elizabeth had not been identified as dyslexic yet, so these are experiences of *Niche*. Because she was willing to put in large amounts of time at home on school work, she passed O-levels that included an element of coursework, such as English Language, Geography and History. She passed English Literature because of her ability to remember quotes.

However, she did not pass maths (Grade 2 CSE), and didn't pass Chemistry because of the maths involved. After Elizabeth did her exams she left school and completed a Foundation course in Theatre, then went back to college to do A-levels. This was a difficult time for her, as she lived at home with her Mum, with whom she was not getting on well, worked in a pub and had an abusive boyfriend while studying for A-levels. The courses themselves demanded that Elizabeth operate in her areas of weakness, for example the History lectures consisted of an hour of note-taking, and the theatre studies class was verbal and written rather than based on performance. Her results reflected these difficulties,

*I came out of that after 2 years, with, I got a 'C' in film studies, and again that had a coursework component ... and I got an 'A' for my coursework, but I got a 'C' overall, by the time I did my exams, cause I couldn't write enough in the exams it was like you were supposed to write about 2 or 3 pages ... well I'd get ¼ of a page written ... and my hand would be cramping ... and I got an 'E' in theatre studies, and I failed History (Interview 1).*

Following A-level exams Elizabeth began employment in sales administration, and took A-level night classes in Sociology and History. During this time Elizabeth was identified as dyslexic because a friend who experienced similar difficulties was told by her film studies tutor that she might be dyslexic. Elizabeth decided to go for assessment as well,

*I remember being really angry when I first got [the Dyslexia Institute report]. Umm, yeah, I was really angry that it hadn't been brought up and that nobody had bothered to find out ... I was very angry that I had got a label of being thick, and by that time I was quite onto sort of, 'oh, it doesn't matter I'm thick' (Interview 1).*

In the excerpt above Elizabeth describes the explanation that has been given for her academic differences in the *DRW=Stupid/lazy* discourse, 'I was very angry that I had got a label of being thick' (Interview 1). That she says this in response to identification of dyslexia and an educational psychologists' report demonstrating that she is intelligent shows use of the *Student* discourse, and her response of anger that 'nobody had bothered to find out' shows use of the discourse *Educational responsibility*. Therefore she is combining three discourses of

dyslexia here (though as *DRW=Stupid/lazy* and *Educational responsibility* are most obvious I have shown these on her map). The excerpt demonstrates aspects of the *Recognition* and *Understanding* phases of the MVS, as her assessment contributes to knowledge about her difficulties and she learns she is intelligent, but this links to the *Student* aspect of her use of discourse so are not shown on her map. However, *Understanding* links to *Educational responsibility* as she re-allocates blame not only to herself but also to her teachers.

The excerpts above and below provide an example of Elizabeth's ability to re-think prominent discourses in a way that works for her,

*I couldn't have injections or, when we had our BCG in the 4<sup>th</sup> year, the doctor put me on um, I don't know, some sort of relaxant sort of thing. So I could have the injection. Well, I had a maths test. So I after my injection I was still quite woozy ... but I went back and did the maths test and I failed dismally. It was kind of at that point that I realised it didn't really matter. So I stopped. I found [maths] hard. I didn't understand it ... so, I just, I just literally gave up on it really ... it was quite a revelation to realise I didn't have to do my best all the time, you know. The world didn't come to an end (Interview 1).*

Her statements 'it doesn't matter I'm thick' (two excerpts above, Interview 1) and 'it was quite a revelation to realise I didn't have to do my best all the time, you know. The world didn't come to an end' (above, Interview 1) demonstrates her ability to dismiss societal pressures for academic success as irrelevant; whether or not she was thick or able to pass her maths exam, she was able to affirm a sense of self-worth. Fisher and Goodley (2007) discuss similar resistance to dominant western discourse that foregrounds linear, future-orientated, individual achievement. In their study, mothers voiced counter-narratives that took a 'present and becoming' stance in reference to their disabled babies (p66).

Identification as dyslexic required her to drop her understanding of herself as thick, and she resented having gone through what was obviously a difficult process to come to terms with her difficulties in one way only to find that she is intelligent, after all. Her identification as dyslexic enables her to succeed academically, and subsequent years of her life are very much involved with academia, as will be demonstrated below; therefore identification of dyslexia seems preferable to her prior resolution of difficulties, that she is thick, and that academic achievement does not matter.

Unlike the other participants, in her initial interviews Elizabeth did not speak clearly in the discourse *What's wrong with me?*, though she did use it obliquely. She was obviously aware of

being different from her peers, as shown by her detailed description of why she was bullied. She also describes feeling humiliated by teachers in front of her peers, for both her difficulties with reading and with maths,

*I had a teacher who taught us the times table by making us all stand on chairs in the morning ... and she'd fire times questions at us ... and if you got them wrong you stood on your chair for the rest of the morning. And I was [six foot tall] when I was 10, 11 ... so, you know. That just absolutely mortified me. So I used to go to school doing my times tables, all the way round, all the way back ... what I used to hate, because ... I'm not very good with sight reading. And the ... English teacher had a go at me because I hated having to read out in class. And she always used to pick me? And then I would read it but I wouldn't read it very well and I remember her telling me that I should be better at it because ... I was a drama person so she would say 'call yourself a drama person, you know, how ridiculous' you know, I think she thought I was being awkward but I just couldn't read out loud (Interview 1).*

But she did not explicitly state that she struggled to understand why she was different to her peers. In my final interview with Elizabeth, when we went over her life history, I asked her if as a child she asked herself *What's wrong with me?* She said she had been aware of differences from her peers but her mother did not allow her to express it,

*My mum ... when I was about nine, ten, my mum said 'stop thinking you're different, for you're no different than anybody else ... stop thinking you're special' ... I was aware that I wasn't popular; I didn't have friends in the same way as other people did and I was struggling with the work ... I think I translated it into feeling lonely (Interview 3).*

Here Elizabeth explains that she did think in the *What's wrong with me?* discourse, but was rebuked for it by her mother, and this links to the *Recognition* stage of the MVS. Not being allowed to ask the question presumably made it difficult to find answers, though as she states elsewhere she decided she was 'thick' especially in relation to maths and science by her Secondary School years. That Elizabeth emphasises social difficulties before difficulties with reading and writing suggest Asperger-type difficulties are most relevant to her, ahead of dyslexic- and dyspraxic-type difficulties. Elizabeth describes a strong sense of not belonging, both as a child – 'I found socialising really difficult and I never really settled at playschool (Interview 1); 'I didn't make friends a lot at school, I got bullied a lot' (Interview 1); and then as an adult '[my partner and I] call it Johnny no-mates' (Interview 2). At work she develops her identity as 'different' into a persona of eccentric (see below). Elizabeth also expresses a lack of awareness at times; she sees things differently but isn't always aware that the way she sees

things is different to the way others do. In describing her relationship with her partner she says,

*... he just picks up on everything, like, if I can't say a word, or I'll start a sentence 4 5 6 times before I get the right word that I want, or just leave off half way through ... he kind of takes the mickey out of me ... so I'm picking up on those things now. [Ruth: so you think you're understanding the things that cause you problems better?] yes, slowly, and also part of it is recognising that they are the disability, because, for a long time you just think that you've been wrong, or even, like for me, a lot of the time I do things that I think are quite normal, and my partner will go, 'that's very odd, you know' and 'nobody else I know does that', and it's like, and then I start thinking, maybe, maybe that's not just an odd habit (Interview 1).*

In this excerpt Elizabeth describes the sense that she has been 'wrong' (this is her most explicit use of the *What's wrong with me?* discourse before Interview three), surprise that what she does is different than others and then a reframing process where she re-attributes her behaviour from being 'odd' to being dyslexic. Here and at other times she finds it difficult to decide what is 'wrong', 'odd' and/or what is dyslexia (and/or other SpLDs). This can be seen as a difficulty with the *Recognition* stage of reframing, where she is not clear about what she has difficulties with. In another way it can be understood as a strong, positive sense of self, where she accepts herself but others have trouble in understanding her – she does not have a problem, they do. This may also be related to the complexity of her difficulties; the relationship between what is difference, what is impairment and what is discrimination is indeed complex. In common with advocates for Asperger's Syndrome (Farrugia, 2009), at times she describes her social and cognitive stance not as wrong but as simply different; she prefers low levels of emotional intimacy because she finds higher levels overwhelming,

*[my partner and I are] quite independent, we do our own, well, particularly me, I do my own thing but it doesn't unduly bug me [Ruth: yeah, I was going to say, do you feel lonely?] Sometimes, but not often ... sometimes I get a bit down ... we call it Johnny no-mates ... but I tend to fill the void with lots of things going on and if anything I'm craving alone time cause I need a huge amount, my partner said to me just after we moved in together, years ago, 'I know you like a lot of alone time and I like a lot of alone time but you like more alone time than me' ... I sense that people want more from me, that I don't give it ... I can be emotional but I'm not good at ... emotional intimacy ... cause I just feel they're overloading me, it's too much (Interview 2).*

In terms of the ability to reframe according to the MVS – recognise, accept, understand and act; the complexity of Elizabeth's difficulties and her opposing sense of being wrong/odd vs. being normal, the contradiction between stigma and/or admiration from peers (see below)

and confusion about what is and what isn't related to Specific Learning Difficulties at times makes it difficult for Elizabeth to establish a straightforward understanding of herself.

However, she can also be seen as involving herself in a process of identity management, where she takes the approach that provides the most advantage in the context (Skelton & Valentine, 2003).

Because of her identification as dyslexic Elizabeth was given additional time in her exams, and because of her slow processing and writing speed this had a great impact on what she was able to achieve. With exam concessions she came out with a 'B' in Sociology at A-level and she passed History at AS level. With these results she was accepted at university to do a Creative Arts degree. Identification also had a great impact on her results at university. Initially her LEA refused to accept the Dyslexia Institute identification of dyslexia but the learning resources department at the university intervened, and she was eventually awarded a computer and software through the Disabled Students' Allowance.

*I got a computer and I was so terrified because I never, you know, even turned it on for the first 3 weeks. But once I got going on it ... I was doing all my written work by hand ... Dyslexia Institute had recommended that I write my essays on one side of the paper, then I cut it up and stick it together with cellotape and then I copy it out again ... so I did all my essays like that. ... I'd probably be cutting it out 3 or 4 times before I copied it across again correctly ... when I was started using the computer, all my marks went up into the 60s, and so I was like doing sort of 59s and things in the first year, 60, 61, second year, 68, 69 ... I think because it helped with the sequencing ... I'll have written something I want to say but it's in the wrong place ... I cut them and put them at the bottom so I have all these things that are important to my essay. And eventually I find the right place for them ... it made quite a big difference ... in the end I ended up with a 2:1 (Interview 1).*

Elizabeth is speaking in a *Student* discourse here because of the excerpt's compartmentalised context of study skills at university. This excerpt demonstrates *Persistence* in that Elizabeth was initially reluctant to use a computer, but through perseverance it becomes a tool for coping with her difficulties. The *Understanding* she has gained from the Dyslexia Institute about methods that help her write she applies to use on the computer, developing *Learned Creativity*. Elizabeth attributes her improved essay marks to the development of this study skill, which results in the attainment of a 2:1 rather than the 2:2 she would have received had she continued to receive marks in the 50s.

After her degree Elizabeth completed a PGCE followed by a year teaching when she gained Qualified Teacher Status. She describes this as a particularly difficult time,

*I got my first teaching post ... so I spent the year teaching up there ... one of the hardest years of my life! Really, really, hard time. Marking. I never had a pile below about half the height of my sofa, ever. Marking. I hate marking. But, it taught me some real good practice and things.*

Her slow speed of reading, processing and writing made marking extremely time consuming. She requires *Persistence* to complete marking, but through this persistence she develops *Understanding* that improve her skills as a teacher. Her experiences of having to work incredibly hard to keep up in employment echo the experiences of adult dyslexic participants in Hellendoorn and Ruijsenaars' study (2000); 'all [employed participants] were convinced that whatever they did, they had to work much harder than others to achieve the same results' (p234). She is speaking in a *Hemispherist* discourse here as she describes her weaknesses and the strengths developed from overcoming them.

After her first year teaching Elizabeth moved to the southwest of England, where she began a job as Lecturer at a further education college, and soon moved on to a position as Deputy Head of Team. Elizabeth enjoyed these posts very much, and discovered she had skills that particularly suited school management,

*I did well as a Deputy Head of Team because I don't get flustered. I tend to work things through very slowly and logically ... when I was a kid ... I'd sort of go from A to Z and not make the connections in between, I'd just come up with an idea or an answer ... and [my mother would] go 'I don't understand ... How did you get to that?' and she'd make me trace it back through ... until I was screaming, and shouting at her, and crying and that until she'd actually got me to trace it all back ... when I'm quiet doing something like time tabling ... I can be quite innovative ... I can think about picking it up and I can think about it in a kind of 3-D way ... kind of what I do with that thing I was talking about with my mum ... people always used to say they could never twig when I was doing time tabling ... they'd say 'I don't know how you do it!' (Interview 1).*

Here Elizabeth discusses her timetabling abilities in a discourse of *Extra-able*. She attributes her ability to being forced by her mother as a child to work back logically, step-by-step, how she arrived at an idea, so she sees her ability as developed in response to difficulties rather than innate. This is an example of *Learned Creativity*, and her awareness of her ability shows *Understanding*.

After eight years Elizabeth was promoted to Head of Team at another FE college in the Southwest. However paperwork continued to cause problems, and Elizabeth links the non-stop

effort involved in her job to problems with depression that eventually led to voluntary redundancy,

*...I suffered with depression for years and years ..., I had quite a lot of depression when I was a teenager but it never really got picked up. And, I probably had it first picked up when I was at university. And then ... when I was [Deputy Head of Team] ... I started to get really bad with panic attacks ... so they put me onto anti-depressants. And, I've been on those for 5, 6 years ... what I'm finding is that more and more paper work year in and year out ... I was working away I used to get up at 5 ... back to my digs and probably carry on [working] until 11, 11.30, 12 o'clock, and still not get all the work done ... it just takes me so long (Interview 1).*

After leaving the FE college, Elizabeth did temping for the county council until beginning a Master's in Fine Arts. While at the FE college Elizabeth had developed, and purposely fostered, a reputation of eccentricity, however during the first interview she said she viewed this as a 'crutch' and felt she now wanted her eccentricity to be understood as an aspect of being dyslexic,

*I worked at [the FE college in the Southwest] as a Lecturer then a Deputy Head of team ... when you're teaching you develop a bit of a persona ... I'd get [the kids] to write on the board ... so I could get round my [difficulties with writing] And they, I mean, if you watch me teaching because I just stop talking because I can't remember the word ... or, start a sentence 15 million times ... they got so used to it, just 'that's her' ... I used to play it as a bit, 'oh, she's a bit eccentric she's the slightly dotty one, that's fine' you know, and it was fine ... I hadn't realised was how much I'd been accepted for having those little idiosyncrasies ... so when I then became a Head of Team and I moved job down, down here, umm, I became much more aware of how my dyslexia was affecting me. And again, when I came here as a student ... I've kind of thrown off, I've decided I don't want to have that crutch all the time, and to be the slightly dotty one to round the fact that I make mistakes because I'm dyslexic (Interview 1).*

Developing a persona of eccentricity can be linked to a *Hemispherist* discourse, where a person develops coping mechanisms through an awareness of their strengths and weaknesses. She can be seen to be demonstrating *Understanding* of her weaknesses and *Learned Creativity* in dealing with them; *Goodness of Fit* is also evident as she finds herself in a context where such a persona is considered acceptable. Later, though, in her first year of the MfA, she regards this approach as a 'crutch', understanding it as an attempt to hide her difficulties. She begins to want to disclose herself as having a disability as an explanation for her behaviour. This can be seen to link to the *Acceptance* stage of reframing, though it is difficult to relate this statement to any discourse of dyslexia. However in the second interview she has shifted her ideas again

because in the second year of her Masters she had begun to experience her eccentricity as a creative strength that gave her an advantage in her theatre work,

*I still find that I look at things in a different way ... I've found collaborative work really difficult ... if people get me it's fine. But if people don't get me it's really hard ... the people that get me tend to ... revel in the fact that it's a bit weird, and it's strange ... We had a project to do at Christmas ... I was the only other person who had an idea for the project, and I wanted to do it in the pub and explore something completely different. And he wanted to do a podcast ... I was like, 'no, I don't want to work on that with you ... you want to do it in ... this very linear way and I want to explore' ... my directing at the moment, is getting to the point where I can direct actors without actually doing any blocking ... they have starting points and ending points ... I haven't got it completely down. But they have enough courage in the character ... they have their motivations and during the rehearsal process it becomes like a, I suppose a collaborative blocking if you like ... you have to be prepared to take risks, but it's a much freer way of working ... I suppose it's a dangerous way of working ... So, anyway the group came back because they'd been trying to put the two projects together ... I felt like there was a huge amount of pressure being put on me to conform ... I just said 'no I don't want to do that project, I'm going to do my own project, I'll get some second years to help me.' And there was this kind of, 'oh, fuck'. But the people involved in it, the second years, kind of are like, they enjoy working with me but I think they enjoy working with me because, you know they're always saying 'you're a bit odd' and they're always like, 'can I push it that far, can I push it that far' I'm like 'yeah, push it that far' and it seems like some other people don't get it, they just see it as a mad idea (Interview 2).*

Here Elizabeth demonstrates a developing confidence that although she may be different from others, her difference is not a disability but gives her a creative edge (evidently her course leaders see it that way as she has since been awarded her MfA with distinction). She speaks above in a discourse of *Extra-able*, where her different way of thinking means she thinks in a creative, ground-breaking and free way. In order to express herself she has to challenge others, and her lack of dependence on relationships – which she refers to elsewhere as an aspect of her Specific Learning Difficulties – can be seen to support her to be able to resist 'a huge amount of pressure being put on me to conform' (Interview 2). This approach seems to be a further step toward *Acceptance* as she shrugs off her difference as not a disability but a strength; develops *Understanding* of herself and puts this into action through *Learned Creativity* in a context that provides the latitude as well as valuing such expression in an example of *Goodness of Fit*.

Elizabeth's first interview was during the first year of her MfA; the second interview near the end of her second year. It was the prospect of completing her MfA and returning to the endless work involved with teaching that brought Elizabeth to tears during the second

interview,

*I'm actually quite frightened of going out and getting a job again. You know, it's stupid, I can hold down a job ... I'm working at the moment, I do a lot of freelance work. But I'm quite nervous of having a permanent job again because of how stressful I find keeping up with all the paperwork (Interview 2).*

After completing her MfA, Elizabeth decided to continue academic studies and is now working on a PhD in Fine Arts.

## Pablo Jennings

Pablo speaks primarily from a *Campaigner* discourse, forefronting social aspects of dyslexia. By his knowledge and ability to express it visually, he demonstrates that he is extremely able in adult dyslexia advocacy, but in this work he has challenged very powerful groups and long-established structures and as a result his ability has been a thorn in the side of those who might provide him with steady income. Instead he has struggled along for many years whilst others used his ideas without giving him the respect and employment that might have gone with them had the subject matter of the ideas been different. In his role as campaigner challenging the status quo of those in power he has faced extensive resistance and therefore much of the positive action he has taken has been damaging to him, particularly because the power relationships in which he has found himself often echo those in which he failed at school.

Pablo was 40 at the time of the first interview. He spent his childhood in Wiltshire, where his father was a professional chef who was also an avid musician. His mother worked in a factory, first as a seamstress and then assembling electrical components. Pablo, his sister and his brother were each born eighteen months apart and all three were born before his parents reached their twentieth birthdays.

Pablo describes difficulties with reading and writing in school from the very beginning,

*When I got to school, then obviously the way that people teach in schools impacted virtually straight away because I had little idea of what was going on, really ... I couldn't express my ideas or organise them at all ... there's incidences from early childhood at school that weren't very pleasurable ... my Head at my Primary School ... had me in for special one to one classes and ... said 'do you know what a simpleton is?' Well obviously I didn't, by the time I got home to my parents it was explained to me (Interview 1).*

Here Pablo is speaking in a *DRW=Stupid/lazy* discourse, and this discourse does not link to any aspects of the MVS (see Fig. 4.8). Pablo describes a sharpening awareness of his difficulties in comparison to his peers on his transfer to Secondary School,

*by the time I got to senior school I realised that I was way off pace, that I couldn't read, well, you find that one out when somebody says, when one of the teachers says 'right, you read' and we were doing 'of mice and men' and your vocabulary in terms of reading is 'they', 'that', 'before', if you're lucky ... and even 'the' after awhile is not gonna come, because it's swimming and you're panicking (Interview 2).*

This passage contains the discourse *What's wrong with me?* as Pablo identifies his inability to read in contrast to his peers, describing himself as 'way off pace'. It connects to the *Recognition* stage of the MVS as he is describing self-awareness that he has difficulties. But, because he does not describe a way of making sense of his difficulties or actions to cope with them, it does not link to any other aspects of the MVS. These early years of Senior School were quite difficult for him; he says 'My sister will tell you when I went from Primary to Senior School I think I changed colours. I just was green and yellow with just worry' (Interview 2). He says,

*I had the stuffing knocked out of me I suppose, you go to somewhere like that and you just realise 'Christ, I can't function here' ... you're with the thick-o's ... I got myself into B sets, it took me a couple of years to get there. I pretty much thought well this is fine ... it was about how people perceived you I suppose. I didn't like the idea, well, nobody likes being called thick do they? So if you can get out of the thick-o sets, which I worked as hard as I could to do. Taking into account that I couldn't go home and do extra homework because there was no computer ... to go home and write with, because I couldn't write, well, I couldn't read (Interview 2).*

The fact that Pablo was referred to as a 'thick-o' for his literacy difficulties without mention of dyslexia links this passage to the *DRW=Stupid/lazy* discourse. This circumstance is an example of one of only two times in this study that the *DRW=Stupid/lazy* and/or *Dyslexia=Stupid/lazy* (see Bob for the other) discourses support the development of MVS *Internal Decisions* and *Action*. The fact that Pablo does not want to belong to the 'Thick-o' group inspires *Goal Oriented* behaviour and *Persistence*. From the middle set Pablo manages to achieve all his CSE qualifications at age sixteen. However, despite this relative success he describes his experiences at school as leaving him 'a broken man',

*I came out of school partly a broken man ... I always felt like, not that I was stupid, but that I had something to prove, a little bit of a chip on my shoulder, maybe (Interview 1).*

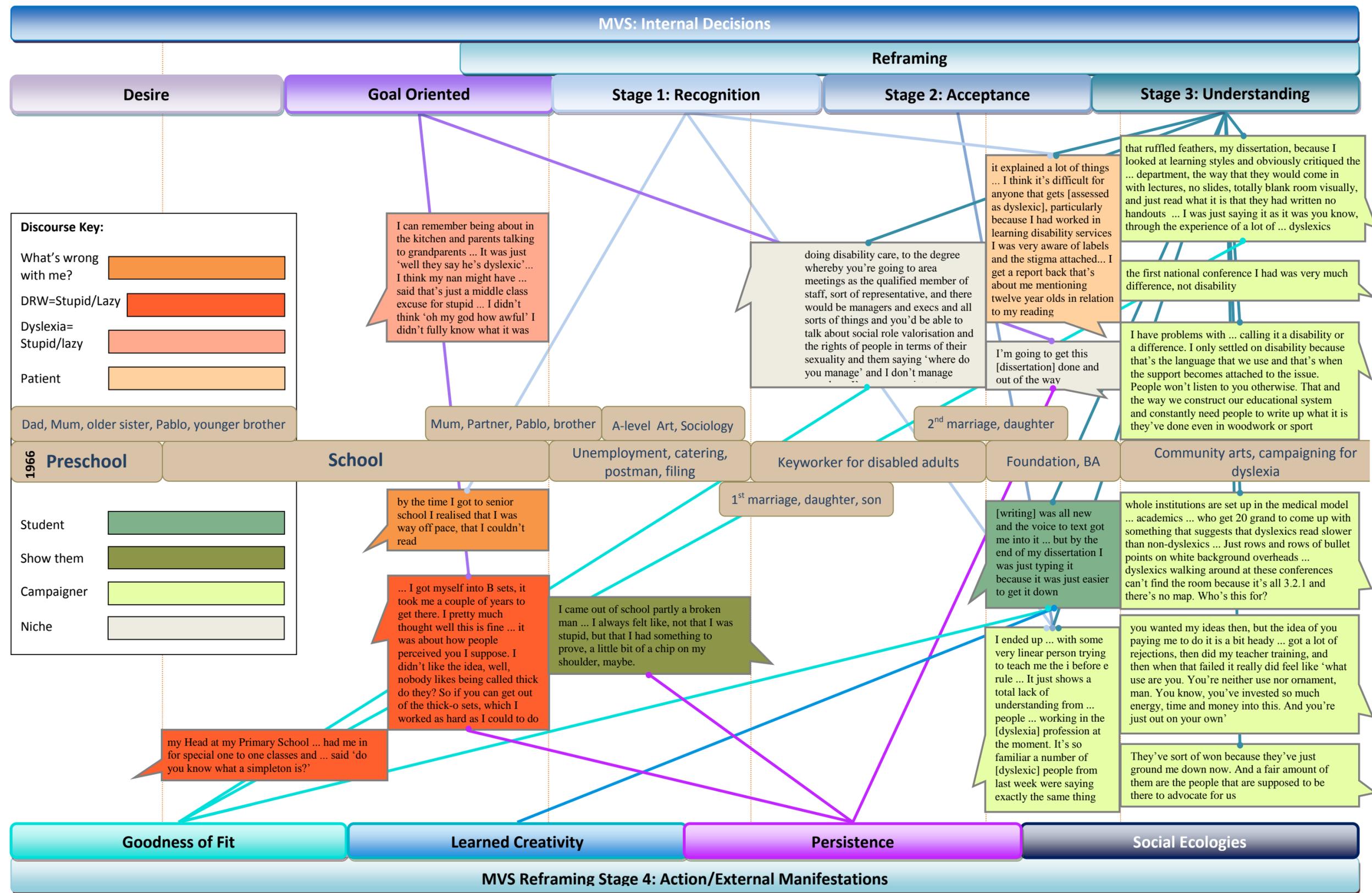


Figure 4.8 shows a representation of Pablo's process of making sense of his difficulties with reading and writing and the methods he develops to cope with them, analyzed by mapping his use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

Stages of Pablo's life are represented across the centre of the model, and the size of each stage is in ratio to the length of the stage in years (so 'School' is the largest stage because he was in school for 12 years, whereas 'Foundation, BA' is the smallest because it lasted only 4 years).

Quotes from Pablo's life story are placed according to the time in his life that he is referring to, so quotes about experiences that occurred during his school years are located above or below the stage 'School'. Quotes shown in the figure are highlighted grey in the text.

Aspects of the MVS are identified across the top and the bottom of the figure, with Internal decisions listed across the top, and the fourth stage of Reframing, Actions/External Manifestations, listed along the bottom. Colour coded links are made between different aspects of Internal decisions and Actions/External Manifestations and quotes from Pablo's life story. Links from Internal decisions attach to the top centre of a quote, and links from Action/External Manifestations attach to the bottom of a quote.

Finally, discourses of dyslexia are represented by the background colour behind each quote, and the key to what discourse is represented by each colour is located on the left side of the map. Discourses represented by reddish colours are less likely to support aspects of the MVS whereas discourses represented by greenish colours are more likely to be supportive. Discourses represented by neutral colours can be either supportive or detrimental.

Figure 4.8. Pablo's process of making sense of his difficulties with reading and writing and the methods he develops to cope with them, analyzed by mapping his use of discourse onto the Model of Vocational Success (MVS) (Gerber et. al 1992).

This quote has links to the *Show them* discourse, where Pablo feels he has something to prove. This feeling may have contributed over the years to the tenacity with which he approaches advocacy for adult dyslexics (see below) and therefore links to *Persistence*.

Pablo remembers first hearing the word 'dyslexic' in reference to himself when he was fifteen. Although his grandmother responds to the term 'dyslexia' with the *Dyslexia=Stupid/lazy* discourse, Pablo does not understand what dyslexia means so it does not contribute to *Internal Decisions* or develop his ability to carry out *Action*;

*I can remember being about in the kitchen and parents talking to grandparents ... It was just 'well they say he's dyslexic' there was nothing changed at school, no extra time or anything like that, it was acknowledged that I was but I don't think anywhere near as much was known about it now as was then ... I think my nan might have turned around and said that's just a middle class excuse for stupid. There was that idea at the time that it would only be quite well off people who would have dyslexic sons that the rest of us were just stupid. I don't know, I didn't think 'oh my god how awful' I didn't fully know what it was (Interview 2).*

Pablo describes the next few years as 'just wilderness, wasted years' (Interview 2). His parents divorced when he was sixteen and he lived with his mother and her new partner, whom Pablo disliked, until he was nineteen. He was involved in some government Youth Training Schemes that did not bring him employment and worked in catering, doing filing for a Building Society and as a postman. At the same time he did an A-level in Art and then an O-level in Sociology, both of which he passed. When twenty-two he began a job as a careworker with disabled adults, a position in which he worked for seven years. Pablo found he was in his element in this job and his experiences there are the foundation for many of his perspectives and the life choices he has made since,

*... there were concepts ... that I found myself quite happily having rows [about] with somebody who had had their nursing training for three or four years. And saying ... that individual who was 22 you can dress her up and take her out as much as you like but at the end of the day she wants a relationship and everyone is skirting around that, so, things about values and actually involvement ... I was trying to advocate for people and change things positively. But again you're always finding that sort of thing difficult because you're cutting against 'well that's the way it's always been' ...*

*I worked with a chap who was born deaf and blind so we developed a communication system ourselves ... he was my tutor, he was incredibly bright and intelligent and articulate and had just been dumped in institutions all of his life ... that whole thing about communication and advocating and [understanding of the] social model I suppose it all came out of those years of seeing what it was like for somebody who had, I mean things like tea and coffee. He could sign 'I want a drink' [but wasn't given a choice between the two], the guy was 50 and never had a choice in his life. Drank tea boiling because in an institution if you're blind you drink your tea quickly, somebody will have it away (Interview 2).*

Here Pablo shows his willingness to address issues others avoid, for example the 22-year old woman with Learning Disabilities' desire to have a relationship. Because of his O-level qualification in Sociology and his passion and ability to argue the issues Pablo was made staff representative,

*doing disability care, to the degree whereby you're going to area meetings as the qualified member of staff, sort of representative, and there would be managers and execs and all sorts of things and you'd be able to talk about social role valorisation and the rights of people in terms of their sexuality and them saying 'where do you manage' and I don't manage anywhere I'm a care assistant somewhere so it gets you thinking about university* (Interview 1).

Pablo's experience here is not related to a discourse of dyslexia, so it is an experience of *Niche* and *Goodness of Fit* that makes him aware that he is particularly capable in discussing social rights, a contribution to *Understanding* that leads to his decision to go to university. When he was twenty nine Pablo attended a Foundation course where they screened everyone for dyslexia, and there he was formally assessed by an educational psychologist,

*[being assessed] was interesting because you get your profile and you see where you peak and where you trough ... and so straight away I understood what I was good at and what I wasn't. I mean, it explained a lot of things ... I think it's difficult for anyone that gets that, particularly because I had worked in learning disability services I was very aware of labels and the stigma attached... I get a report back that's about me mentioning twelve year olds in relation to my reading ... and then top 1 percentile in reasoning skills* (Interview 1).

In this passage Pablo speaks in a number of discourses of dyslexia. He refers to the *Hemispherist* discourse as he describes peaks and troughs and hints at more of a *Patient* perspective when he refers to stigma because that tends to link to within-person difficulties. Finally, he uses the *Student* discourse here as he compares low attainment in reading to high intelligence scores. This passage demonstrates the complexity of ideas that can be involved in the discussion of dyslexia. On his map I have represented this quote with the *Patient* discourse because his focus seems to be on describing the experience of feeling disadvantaged by a professional report identifying an adult to have a child's level of function. Like other participants, despite its negative aspects he agrees 'it explained a lot of things'.

Pablo received Disabled Student's Allowance first during the Foundation year and then again during the three years of his bachelor's degree, including a computer, software and time with a Learning Support tutor. However, he found the Learning Support tutor to hold different priorities to his own,

*I didn't want to end up in that small little room in which I ended up ... with some very linear person trying to teach me the i before e rule ... after 2 hours I said 'look, I can't do this' she stormed back and said 'he's refusing to do it, he's refusing help' ... it's a nonsensical rule anyway, why when I'm struggling with structure are you worrying about finer detail. It just shows a total lack of understanding from the vast majority of people who would be working in the profession at the moment. It's so familiar a number of people from last week were saying exactly the same thing [at the conference I attended] (Interview 2).*

This description is characteristic of Pablo's approach; he is very aware of his rights, and here he speaks in a *Campaigner* discourse as he is quick to clarify that the support being offered him did not meet his needs, as well as showing an awareness of political issues by his reference to attitudes in the profession of dyslexia in general and the way that relates to dyslexic adults as a group. This selection links to *Recognition* where Pablo understands his areas of difficulty and *Understanding* in terms of his personal priorities for learning, as well as *Acceptance* because by asserting his needs he demonstrates that he values his own perspective.

Instead of being tutored Pablo 'broke through the literacy barrier' (Interview 1) using his computer, '[writing] was all new and the voice to text got me into it ... but by the end of my dissertation I was just typing it because it was just easier to get it down' (Interview 2). In this passage Pablo is speaking in a *Student* discourse as he describes computer skills that have supported him to work better academically. It links to *Goodness of Fit* because Pablo was able to teach himself to write on a computer, *Learned Creativity* as he develops coping skills to get round his difficulties and *Understanding* as he develops knowledge about what he needs to do to be able to write. The subject of developing writing skills also relates to *Goal Oriented* behaviour as he explicitly describes his decision to complete his dissertation, 'I'm going to get this done and out of the way' (Interview 3) and *Persistence*, a high degree of which was almost certainly required as he taught himself to read and write adequately to do academic work in Higher Education having failed to learn during his school years.

Pablo's dissertation was entitled 'A Dyslexic Artist in a Word-based Education System'. He initially wanted to look at billboard liberation but was steered into dyslexia,

*It was a red flag to a bull going to [University] because [the degree] was Art in a Social Context and again the whole dyslexia thing was something that picked me rather than me pick it ... it was like 'you're [dyslexic] ... go and do that then' ... they could see that I was working in a way that was challenging the status quo and that was what they were about, a bunch of old lefties ... who were quite happy to set me off on a collision course (Interview 2).*

Pablo refers to the dissertation as a collision course because on receiving it back again it was marked as a First, however was downgraded to a 2:1,

*that ruffled feathers, my dissertation, because I looked at learning styles and obviously critiqued the ... department, the way that they would come in with lectures, no slides, totally blank room visually, and just read what it is that they had written no handouts ... I was just saying it as it was you know, through the experience of a lot of dyslexics, particularly in that faculty ... it said I'd got a first, there was lots of other paperwork where the ... department had basically sent it around to absolutely everybody ... to say well look, downgrade ... What reasons could there possibly be for it not being a first ... [I was told] 'this was not referenced enough' (Interview 1).*

Here Pablo speaks in a *Campaigner* discourse as he describes his dissertation, the subject of which is how dyslexic university students are disadvantaged by the way lectures are structured, where he carries out critical analysis with a view to changing that system. He not only describes himself writing about his own experiences, but sees himself representing 'the experience of a lot of dyslexics,' and this orientation toward group identity is another characteristic of the *Campaigner* discourse. This passage links to *Goodness of Fit* because his work was of a very high standard and to *Understanding* as he demonstrates a deep knowledge of dyslexic difficulties in an academic context. He was disappointed and frustrated to be awarded a First only to have it downgraded; any student would have been. However for Pablo getting a First is particularly significant because it represents the pinnacle of academic achievement and provides recipients with an edge in the employment market; these characteristics are exceptionally meaningful in the context of Pablo's history of failure at school and years of unfulfilling employment or unemployment. Having his First downgraded is also particularly significant because it echoes the sense of slight he has experienced so many times in education in relation to dyslexic-type difficulties. Pablo interprets the downgrade as a political manoeuvre by the department which is criticised in his dissertation. The means by which the downgrade is justified is a lack of referencing – a technicality rooted in rule-orientated academic criteria that devalues the innovation and insight he shows. The event can therefore be seen as a symbolic repetition of prioritization of method over meaning in which Pablo is disadvantaged and the educational system is advantaged, a relationship he also experienced during his years at school when he was unable to learn to read and write in the way he was taught. Interestingly, this event also involves power struggles within the university, as some lecturers encouraged him to critically analyze his context and/or prioritised his ability in this area, and others worked to uphold historically established structures.

In the ten years since Pablo has completed his BA he has been involved in several community arts projects including work with art and youth offending, a number of projects related to art in education, and work with art in relation to marginalised groups. He has worked specifically on his own art at times, spending a year painting and drawing exclusively, and he has exhibited his work on numerous occasions at venues across the UK including the House of Lords , Oxford

University, and in America. He has also devoted a great deal of energy and time to campaigning for dyslexia. He describes himself as coming out of university as a 'dyslexic firebrand' (Interview 1). He has given more than one hundred workshops, seminars and lectures, including papers at academic dyslexia conferences, and has published chapters and articles in dyslexic charity publications and other well-known periodicals such as *The Times Educational Supplement* and *The Big Issue*.

In the following passages I will be discussing Pablo's use of discourse and experiences while he campaigned for dyslexia. Analysis of these passages is complicated by the fact that they are by definition *Campaigner* discourses. However, I am also analyzing these passages for other kinds of discourse. I represent any of the passages chosen to be on his map as *Campaigner* on the map, whilst discussing the presence of any other discourses in these passages in the text. Over the ten years since Pablo left university his orientation toward dyslexia has changed,

*the first national conference I had was very much difference, not disability* (Interview 1).

*about celebrating dyslexic talent ... 'neurodiversity' well that's ok ... but in the real world you try telling somebody who's in prison on a five year stretch that their dyslexia is a gift, and you can track their leaving school and their offending behaviour and link it totally to their experiences in an educational environment ... Try telling them that it's a gift* (Interview 2).

*That's where I have problems with this issue of calling it a disability or a difference. I only settled on disability because that's the language that we use and that's when the support becomes attached to the issue. People won't listen to you otherwise. That and the way we construct our educational system and constantly need people to write up what it is they've done even in woodwork or sport* (Interview 3).

Above he is discussing his way of describing dyslexia when he campaigns. He suggests that straight out of university his approach centred round a *Hemispherist* viewpoint, where he described dyslexia as a difference. However, he developed this view for a number of reasons related to the need to take context and relationship with other, particularly non-dyslexic, people into account when understanding the impact of dyslexia on dyslexic people. In this way he has changed his approach so that he describes dyslexia primarily from a *Hemispherist* discourse, where it is a difference that includes both strengths and weaknesses; but he now combines this with a *Campaigner* discourse to set the idea in context. Doing so makes it possible to address the idea that society makes dyslexia a disability through structures inherent in education and employment, and also through the attitudes of others. His response to my request for his definition of dyslexia further describes this approach,

*For ages I didn't like to think of myself as disabled but that's what it is. And disabled by society. I've got neurological strengths and weaknesses but my weaknesses are*

*brought to the fore because of the way that we choose to teach and test ... chalk and talk plainly doesn't work. So then your self-esteem, your motivation and your whole personality is in part shaped by the environment you find yourself in, and your opportunities are diminished by your lack of ability to function in that very text-based way (Interview 2).*

Pablo speaks primarily in this combination of *Hemispherist* and *Campaigner*, however he also talks about the predominance of the *Patient* discourse in others, particularly amongst academics specialising in dyslexia and those selling interventions and cures,

*when I say cranky academics I'd say that's non-dyslexics that haven't got the slightest idea about the social implications of what it is they're talking about. And they are taking a medical condition ... and looking for cures ... you know, flying off [to conferences] and getting funding for it, and arguing amongst themselves constantly ... but ... where's the practical application of that (Interview 1).*

*It's very difficult to not be personal about it when whole institutions are set up in the medical model ... all the academics as well ... individuals who get 20 grand to come up with something that suggests that dyslexics read slower than non-dyslexics ... [Conferences where information about dyslexia is communicated with] Just rows and rows of bullet points on white background overheads ... And lots of dyslexics walking around at these conferences can't find the room because it's all 3.2.1 and there's no map. Who's this for? (Interview 2).*

*the likes of [cognitive psychologists] and [people selling interventions and cures] do see it as dysfunctional, they see that the dyslexic brain is dysfunctioning in some way ... and they shape that individual through these perceptions but there's no discussion that the system should adapt to meet people's need (Interview 3).*

The excerpts above are examples of the way a disabled persons' perceptions can differ from the perceptions of professionals working to support disabled people. Pablo wants there to be change in society so that there are real alternatives to text-based learning and communication, but from his experiences during dyslexia conferences and seminars he feels that many professionals and those with products to sell are more interested in their careers and/or the money they can make – they don't even bother to make the conferences about dyslexia dyslexia-friendly. As Pablo says, 'Who's this for?' The academic careers that connect most readily to power and status are in the fields of cognitive psychology and neuroscience, and whether this perspective perpetuates a *Patient* discourse which proves problematic for dyslexic people is rarely if ever addressed. Likewise, those selling a product, particularly with claims of 'cure', both maintain a *Patient* discourse and potentially exploit the vulnerability of dyslexic children and their parents.

That Pablo's focus on social context is low in status in comparison to the established realms of cognitive psychology, neuropsychology and intervention in the field of dyslexia is supported by the placement of his lecture slots at conferences,

*Lecturing [at an international dyslexia conference] and being [scheduled at 9pm] on a Sunday night, with [two other academics working on dyslexia in a social context], on at the same time and there's wine being served in the main hall with some sort of website launch you're thinking 'nobody's going to come' well, not half the people will come that need to come (Interview 3).*

He describes the way difficulties changing text-based structures is perpetuated for dyslexic people because they are excluded from most decision-making positions, including the barriers he faced in getting qualifications to go on a PGCE Art course,

*[dyslexic people] have very little power because there's very few of us involved within certain institutions ... most teachers would have had to achieve academically at school to enable them to be a teacher. At the moment I can't be a teacher, it took me ages to get qualifications together ... having to re-sit English when I'm a published writer ... when I want to be an art teacher ... constantly barriers are put up and you're expected to work twice as hard to achieve because it's not set up for my sort of brain, it's set up for a linear brain (Interview 2).*

About three years ago Pablo completed English and Maths GCSEs in order to qualify to do an Art PGCE. He left after half a term because of similar barriers,

*This time last year I was doing my teacher training and that went totally belly up because the university that were backing it really didn't want to know about my disability ... what I wanted to do is ... to be able to use a whiteboard ... and there was table slamming and finger pointing from these two women that had me, again, probably just in pieces that evening ... I'd taken a certain amount of flack on a personal level, really, 'don't use this as an excuse' and ... 'you've got to be able to get up and teach regardless of the technology you think you need and we're not paying for it' so I quit ...*

*I said to them 'it's going to benefit the people that I'm teaching, because that's the way I teach, I'm very visual ... That, and if you're talking about art and design ... there's no point handing a book round ... the two women that were involved in the training, one from the school and one from the university, were just very much different brained than I was ... After that first meeting I'd come along and I'd mind mapped the first standard, and it was like I'd been sick on the page, they were like, woah, and I said, 'look, I listed my competencies overleaf' [blowing out] well, I suppose that's ok. You can edit that, I've never seen it before' just being so antagonistic ... 'do it our way or just go away' so I went away (Interview 1).*

In this PGCE course Pablo was subjected to humiliation in a similar way to his school experiences. Despite good ability and knowledge of art, he did not communicate this knowledge in a way that was acceptable to the educational leaders on the course. Considering he is a verbally able adult with deep knowledge about art, dyslexia and disability rights but was unable to fight for reasonable adjustments, as well as his description of his emotional response ('these two women that had me, again, probably just in pieces that evening') suggests that emotions associated with similar experiences from the past combined with this situation to

make it 'untenable' (Interview 1). Pablo intimates at the difficulties the connection between past and present can bring when he says,

*I aligned myself with trying to make a career out of something that I believe in so passionately and that has so many closed doors to it ... it's difficult to deal with disappointments because the two are tied together (Interview 3).*

His personal involvement in the issue can be seen to be both a strength and a weakness, a strength in that the extent to which he cares makes him persistent and because he knows about dyslexia deeply through first-hand experience, but it is a weakness because the blows he receives in response to his campaign are on one level deeply personal; his experiences as a child mean he is vulnerable and the ways he continues to be marginalised scour wounds from the past.

Pablo has contributed large amounts of energy and time to different organisations, including dyslexia charities, with little or no pay, and at times without citation next to his artwork. Pablo attributes the fact that he can be 'in your face' to his difficulties finding employment and describes how this has impacted him,

*you wanted my ideas then, but the idea of you paying me to do it is a bit heady ... [the video I made] is a bit in your face. But it was purposely in your face. I thought through what it was that I was trying to say, I was trying to rock the apple cart. It's not like I can't work with anybody. So, got a lot of rejections, then did my teacher training, and then when that failed it really did feel like 'what use are you. You're neither use nor ornament, man. You know, you've invested so much energy, time and money into this. And you're just out on your own' (Interview 1).*

Pablo is an angry man, and although he has reason to be angry, this aggressive undercurrent gives others an excuse to dismiss his perceptive but insurrectionary voice. This passage is in a *Campaigner* discourse, but it does not link to any aspects of the MVS; he is not accepting of himself in this passage, nor does he seem to have learned positive lessons from it so it cannot be seen to develop *Understanding*. When I met Pablo for the second interview he had just returned from coordinating an exhausting week-long dyslexia event and was, he said, unusually pessimistic,

*They've sort of won because they've just ground me down now. And a fair amount of them are the people that are supposed to be there to advocate for us (Interview 2).*

This passage is in the *Campaigner* discourse; I have linked it to *Understanding* as Pablo is showing awareness of how difficult it is to bring about real change. This knowledge can

support him to be better prepared if challenged in future. During the third interview he seemed to be mustering forces for further campaigning work,

*It's a big wall and I've been walking round it for a bit. I might come back awhile later with a great big crane (Interview 3).*

At the time we met to go over this analysis, he was in the process of filing a grievance against the government relating to accessible information.

## CHAPTER 5: CONCLUSION

*In this last chapter I will draw the study together. First I will establish the extent to which the participants in this study parallel those described in the literature review in terms of their experiences of dyslexia. I will then revisit the research questions in light of participants' life histories and consider how findings from this study relate to the literature review regarding discourse and aspects of the MVS. Next I will evaluate the rigour of the study based on criteria set out in the Methodology chapter, I will specify the unique contributions made by this study to the field of dyslexia, and finally will suggest topics for future research.*

### **Comparison of participants' experiences with those in the literature review**

The experiences of dyslexia told in the participant's life stories in this study are mostly commensurate with those of other dyslexic people depicted in interview studies described in the literature review. Each participant's life story is unique as is demonstrated visually by the participant maps; differences in context, life events and orientation make them so. However there is also a familiarity in their stories. There are many similarities I think best described through the idea of syndrome. Each participant was different but they all shared a number of aspects of experience related to their difficulties with reading and writing – in different combinations – which made their experience as dyslexic recognisable. Elizabeth Kirner was less

similar than others; I have attributed these differences to co-occurring SpLDs that are more dominant than dyslexia. Adam, too, is less similar, and this I attribute to his relatively short time in education and the fact that he has never been formally identified. Both types of life experiences would benefit from future life-history research.

To describe some of the pattern of familiarity between participants and those described in the literature review, Bob's life story mimics Ingesson's (2007) study of 75 dyslexic teenagers incredibly closely as he uses the analogy of an inverted bell curve to represent his well-being in relation to dyslexia during his school years. Bob, Alice, Country Boy, Elizabeth Kirner and Pablo had familiar stories to tell of feeling humiliated as their difficulties with reading and writing were made apparent in front of their peers, including stories where teachers purposefully brought such difficulties to public attention. Bob, Alice and Country Boy also told stories of teachers who helped them. Alice says 'it's amazing just a couple of teachers who say 'actually, you can do this. Because you know, I'm not worried about you' (Interview 1). Though it wasn't clear from the literature review exactly what the incidence of bullying was for dyslexic pupils, it was suggested that the incidence was higher than the 10% estimated for mainstream pupils. Two of seven (29%) of the participants (Bob and Elizabeth Kirner) in this study were bullied, supporting that suggestion. All the participants spoke of awareness that they were different from peers in school and all described attributions of low intelligence and/or laziness that were made about them by others on the basis of their difficulties. Identification of dyslexia was also experienced as helpful overall by all but one of the participants, though Bob and Amber in particular experienced dislike of being identified as dyslexic initially which resolved during a process of meaning-making over a period of time. These latter issues link directly with the analysis of discourse and the MVS carried out in the life histories, so will be discussed in more detail below.

The most substantial difference between participants in this study and the experiences of dyslexic people in the literature review regards support from parents. Many studies emphasise the pivotal role played by parents in providing emotional support and/or paying for specialist educational support for most participants (Burden, 2005, Hellendoorn & Ruijsenaars, 2000, Ingesson, 2007, Riddick, 1996). Of the seven participants in this study only one, Alice, received this kind of support from her parents (though both Amber and Elizabeth Kirner's mothers did tutor them extensively at home in English). This difference in findings is likely due to differences in methods of choosing participants; the other studies (except for Hellendoorn and Ruijsenaars 2000) located participants through private dyslexia schools and/or clinics, where the presence of supportive parents is likely. The majority of participants in this study come

from working class backgrounds (see Table 4.1) and this may also have contributed. Finally, this study looks at adults rather than children, so knowledge about dyslexia was likely less available for the parents of participants in this study.

## **Response to research questions**

I will now return to the research questions stated in Chapter 3:

- 5) How does a dyslexic person's understanding of their difficulties with reading and writing, as represented by their use of discourse, relate to the way they understand themselves?
- 6) What are specific examples of aspects of the MVS in dyslexic adults' lives?
- 7) What cultural and environmental factors are involved with 1) and 2)?
- 8) What are the relationships between 1) and 2)?

In the following sections I will address all four questions together by discussing each discourse in turn, including the way participants' use of discourse relates to the MVS and cultural and environmental factors. Question two has been answered in depth in the life histories; however I will refer to specific examples of MVS in participants' lives below at times as well. Question three was partly answered by discussion of the cultural origins of each discourse in Chapter three; however I will refer to further cultural and environmental links here. I will also refer to the way this study fits into the wider context regarding similar issues in interview studies with dyslexic participants.

### **What's wrong with me?**

All seven participants used this discourse during interview (see Table 5.1). Elizabeth Kirner describes awareness of social difficulties before describing difficulties with reading and writing. For her, dyslexia is mild in relation to other SpLDs. This discourse signals initial self-awareness that a person has difficulties reading and writing. Country Boy described awareness that he had difficulties from age five; Alice age six; Bob, Adam and Elizabeth Kirner about age eight; Pablo age eleven and Amber age sixteen. The participants do not describe their awareness as due to being told they had difficulties but through self-comparison with peers. Some of the teachers and parents of the participants may have avoided addressing difficulties in an attempt to protect them; for example Elizabeth Kirner's mother told Elizabeth "stop thinking you're different, for you're no different than anybody else ... stop thinking you're special"

Discourse	Adam	Alice	Amber	Bob	Country Boy	Elizabeth Kirner	Pablo Jennings	Total no. of participants
What's wrong with me?	✓	✓	✓	✓	✓	✓	✓	7/7
DRW=Stupid/lazy	✓	✓	✓	✓	✓	✓	✓	7/7
Dyslexia=Stupid/lazy	✓			✓	✓		✓	4/7
Patient	✓	✓	✓	✓	✓		✓	6/7
Student	✓	✓	✓	✓	✓	✓	✓	7/7
Hemispherist	✓	✓	✓	✓	✓	✓	✓	7/7
Show them		✓	✓	✓			✓	4/7
Extra-able	✓	✓		✓	✓	✓		5/7
Educational Responsibility		✓	✓	✓	✓	✓		5/7
Campaigner			✓				✓	2/7
Dyslexia unspecified	✓	✓	✓			✓		4/7
Niche	✓		✓	✓	✓	✓	✓	6/7
Total no. of discourses	9/12	9/12	10/12	10/12	9/12	8/12	9/12	

Table 5.1. Use of discourse by each participant.

(Interview 3). Even if well intentioned this strategy simply further undermines a child by denying the validity of their experiences without giving them any positive means to cope.

This discourse links directly to the *Recognition* stage of the MVS because it signals the beginning of self-awareness that the participants have difficulties. If one thinks about the MVS in terms of ability to cope, it presents this time in a child's life as one where self-perception of difficulty begins, but before they have access to understanding or coping mechanisms. It links directly to an educational context; none of the participants talked about being aware of difficulties before they were at school. If we go back to the discussion of narrative and identity in Chapter 3, this discourse is the beginning of the story, it is the exception to normality that signals the need for meaning-making to occur. The other discourses (with the exception of *Show them*) can be seen to be a range of potential ways to answer this question.

Use of this discourse by participants has implications for the issue of labelling. The participants need an answer to their question in order to make meaning of their difficulties and to develop an understanding of who they are, how they fit in with others and to understand how they might cope with their difficulties. The answers they develop, as will be seen below, have a close relationship to the extent to which they value themselves and the extent to which they

are able to cope with their difficulties. As is true for a number of studies described in the literature review (e.g. Burden, 2005, Ingesson, 2007, McNulty, 2003), this study indicates the importance and potential benefit of helping children who have difficulties with reading and writing to understand their difficulties from an early age.

Though the benefits of early intervention can be seen as a mantra common to findings in almost all kinds of dyslexia research, the emphasis here is orientated differently. Rather than a focus on implementing multi-sensory language programmes and/or study skills, findings from this study focus on the importance and benefit of supporting self-understanding. A number of the participants (e.g. Bob, Alice, Amber, Pablo) refer to a lack of support in understanding what it meant to be dyslexic, for example,

*I went to my dyslexia lessons, you were never really told it's almost like the logical side of things, they never told you about dyslexia you just got taught that you needed to do these special things for spelling to learn that 'ch' was /ch/ but you never really had somebody sit down with you go, 'everybody's dyslexia is different, you need to find ways to get round your problems, and if you work hard you can do as well as somebody who isn't dyslexic and it doesn't mean that you're stupid but it does mean that you have to work hard, that you can't just say, 'I can't do this' ... other people have to work hard at different things ... a lot of the time people never talk to you actually about your dyslexia they just show you strategies ... you get told you know, 'you're dyslexic' and you can't really understand it (Alice, Interview 3).*

Most of the participants (with the exception of Pablo) valued the learning support they received, whether it was in the form of private lessons as in the case of Alice, support within school as is the case for Bob, or learning support gained through Disabled Student's Allowance as is the case for Country Boy, Elizabeth Kirner and Amber. The participants' experiences validate the worth of such intervention; what needs more recognition is the importance of the way dyslexic people are supported to conceptualise their difficulties.

### **DRW=Stupid/lazy**

All seven participants use this discourse during their interviews (see Table 5.1). Even Amber, who was successful academically in Primary School, recounts attributions of laziness from teachers in relation to her writing. In six participants use of this discourse does not link to an aspect of the MVS; it does not support the development of positive (and/or accurate) self-perceptions or positive action. For Pablo, being called 'thick-o' by peers motivates him to work hard to move out of the bottom set and so supports being *Goal Oriented* and *Persistence*.

Of the nine participants who talked in the *DRW=Stupid/lazy* discourse, seven rejected it as an overall answer to *What's wrong with me?* on the basis that they were able in areas outside of reading and writing and/or an awareness of how hard they had worked before failing. Two participants, Bob and Elizabeth Kirner, internalised the understanding that they were thick and/or lazy during their childhoods and had to re-think this later in their teenage years. The potential damage of the *DRW=Stupid/lazy* discourse is described well by Pablo Jennings,

*The sense of self is sort of damaged, once it's damaged it remains damaged, the self-esteem. I think all sorts of people, with all sorts of backgrounds will be ridiculed at school for all sorts of reasons. I think the dyslexia side of things, it's your intellect, it's how clever you are, that part of you is brought into doubt. That's you with the adults but also you with your peers, that has an effect that causes self-doubt for most and rebellion for others. It's not good because I think then a lot of people even when they're successful have to cover that, either by getting your armour on and being over confident or slinking off into despair. That doesn't set a person up right, makes them feel like they're not good at learning and you need to learn all the way through life. That's not a good way to start (Interview 3).*

The participants who reject the *DRW=Stupid/lazy* discourse in reference to themselves from childhood still describe long-lasting harmful responses to it, for example Alice says,

*I've done A-levels and I've done well at them so it shouldn't bother me anymore. And then you get to university and it still bothered me ... to the point that it can make me cry ... If it was a written exam, I might even have the same stuff written on. But I swear, it sounds like a child writing it. And the minute it looks like that, people ... don't think your view is intelligent. The minute they look at it ... you dread people looking at your notes and realising you've spelled everything totally incorrectly (Interview 1).*

That Alice might carry such self-doubt with her well into a successful career as a dentist is commensurate with McNulty's finding that the dyslexic adults he researched experienced 'an added sense of emotional insecurity' (McNulty, 2003, p363). All seven of the participants displayed this.

In terms of cultural and environmental factors related to the *DRW=Stupid/lazy* discourse, it is interesting in the two excerpts above that the distress Pablo and Alice describe are not due to difficulties with reading and writing, but rather other people's attitudes toward these difficulties. This emphasis relates directly to the idea of the social model of disability, where disability is a result of barriers in society rather than impairment.

## **Dyslexia=Stupid/lazy**

Four of the seven participants talked in this discourse (see Table 5.1). Two of them, Bob and Pablo, referred to attitudes toward dyslexia expressed by others soon after they were identified. In Bob's case, it was his peers' understanding of dyslexia to mean stupid that motivated him to learn coping mechanisms to avoid their bullying, so his use of the *Dyslexia=Stupid/lazy* discourse linked to *Goal Oriented* and *Learned Creativity*. This example is the only one from this study where the *Dyslexia=Stupid/lazy* discourse supported positive development. The other two participants using this discourse, Adam and Country Boy, talked about it in response to my question asking what they thought others' perception of dyslexia was, and their responses referred to current social understanding. Country Boy referred to those in academia, Adam to the population in general. Pablo, Adam and Country Boy talked about this discourse without rancour; their attitude was one of discussing the belief systems of other people without it seeming to affect them. They seemed to regard this attitude toward dyslexia as ignorant – reflecting on the stupidity of those who held it rather than reflecting on them.

This discourse is the basis for rejection of identification of dyslexia for those participants in the study carried out by Armstrong and Humphrey (2009) who equated dyslexia to mean stupid. However, none of the seven participants interviewed in this study understood dyslexia in that manner. Four of the participants, Alice, Amber, Bob and Pablo, expressed discomfort in relation to identification; however their unease links to the *Patient* discourse rather than the *Dyslexia=Stupid/lazy* discourse.

## **Patient**

Six of seven participants speak in this discourse (all except Elizabeth Kirner, see Table 5.1), and it is primarily linked to expression of discomfort – either the participants speak of resistance to understanding themselves in that way or they seem to accept the idea that they experience difficulties because their brains are dysfunctional but feel badly about themselves as a result. Bob, Alice and Amber speak about the *Patient* discourse as though it were a brief, uncomfortable stage of a process of coming to understand dyslexia which developed into other understandings relatively quickly. Pablo was critical of the way in which he was identified, 'I get a report back that's about me, mentioning twelve year olds in relation to my reading' (Interview 1). He did not enjoy the process but rather than internalising the perspective that he is dysfunctional he holds the educational psychologist to account; afterward Pablo told him he thought the report was inappropriate in its use of reading age and

psychological jargon. All the participants using this discourse, except for Adam who was never formally identified, speak in the *Patient* discourse when they discuss identification. Country Boy and Alice talk about negative aspects of the *Patient* discourse in conjunction with positive aspects, referring to the benefits of additional understanding about their difficulties and a shift away from full individual responsibility for their difficulties, 'I think it really answered a lot of the questions in my life' (Country Boy, Interview 3); 'there was something you could call it, or blame' (Alice, Interview 1).

This latter sense of relief at having something external to 'blame' is in contradiction to the discomfort expressed elsewhere at being told by professionals that one's brain is dysfunctional and one's difficulties are due to internal deficiencies. Farrugia (2009) discusses the benefits to within-person attribution of difficulties in his study about Autistic Spectrum Disorders (ASD) and parental negotiation of stigma. He describes parents as reframing behaviour categorised as 'naughty' before identification of ASD as having biogenetic origins after identification. In this way they are no longer culpable for their child's 'naughty' behaviour. The expressions of relief from Country Boy and Alice above can be understood in this light; their difficulties are not due to laziness as has been attributed to them in the past, but to brain dysfunction over which they have no control. The contradictory messages of unease in the face of identification of brain dysfunction can be understood according to context. The former understanding is helpful to their sense of identity because it absolves them of blame for socially unacceptable behaviour, the latter is harmful to their sense of identity in understanding who they are. That contradictory understandings are held simultaneously demonstrates the complexity of disabled identity management (see Skelton & Valentine, 2003 for discussion of the complexity of identity in deafness), and descriptions of moving on from the latter understanding in order to support more positive identity (*e.g.* in the cases of Bob and Amber) is a further example of the process of 'creative, agentic' use of discourse described by Farrugia (2009, p1016).

Adam seems to have internalised aspects of the *Patient* discourse. He sees his social difficulties as an internal problem due to his dyslexia, but this is his only difficulty he understands primarily negatively. He makes sense of his slow processing speed in a positive manner and compensates for difficulties with reading and writing using a computer (see *Hemispherist* and *Student* below).

Use of the *Patient* discourse linked most to *Recognition* (five times); its primary contribution was to provide participants with a conceptualisation for their difficulties with reading and writing that was preferable to the *DRW=Stupid/lazy* discourse. It also linked to *Understanding* (four times) because it supported further understanding about the nature of the difficulties,

for example in its conceptualisation of the role that short term memory and speed of processing play. The *Patient* discourse therefore does have the potential for positive impact, however the fact that it does not link to other aspects of the MVS underscores the limited role it can play in supporting more positive self-perceptions and action. The low self-esteem and anxiety reported by Pollak (2005) for the participants he characterised as understanding themselves in the *Patient* discourse, demonstrate that it can be a damaging and self-limiting way to understand one's difficulties with reading and writing.

## Student

The participants talked primarily about two features of the *Student* discourse; the understanding that one can be intelligent and still have difficulty with reading and writing, and a focus on development of compensatory measures to enable one to succeed in an academic context. Because of its role in supporting self-perceptions and positive action it contributed to both *Internal decisions* and *Action* in the MVS. All seven participants spoke in a *Student* discourse (see Table 5.1), with three (Bob, Country Boy and Pablo) referring to high IQ scores from dyslexia assessments. This impacted *Internal decisions* by developing *Recognition* of difficulties with greater *Understanding* of them in light of confirmation of intelligence. Six participants (Adam, Alice, Amber, Bob, Elizabeth and Pablo) talked in a *Student* discourse when describing the development of study skills that compensated for difficulties. This related to a combination of *Understanding* and *Action* – most often *Learned Creativity* (e.g. Alice's application of visualisation skills in science revision) or *Goodness of Fit* (e.g. Pablo's discovery that he is able to teach himself to write using a computer). Amber and Bob discussed the role of *Social Ecologies* as they depend on Learning Support and proofreaders; Elizabeth and Bob apply *Persistence* because of the time-consuming nature of their compensatory measures.

The *Student* discourse is one of the more empowering discourses of dyslexia because it provides a way to make positive meaning of difficulties through affirmation of intelligence combined with hope for overcoming the difficulties via study skills which have proved successful for many dyslexic people. This is demonstrated visually in Fig. 5.1, which shows that the *Student* discourse links to more aspects of the MVS than any other discourse except *Hemispherist*. Pollak (2005) characterised 12/33 (36%) of his participant's understanding of dyslexia in the *Student* discourse making it the most commonly used. However, I would characterise none of the participants in this study through it. They understood aspects of dyslexia in the *Student* discourse but none oriented themselves from that perspective. This may be related to the fact that only three of the participants in this study were involved in full

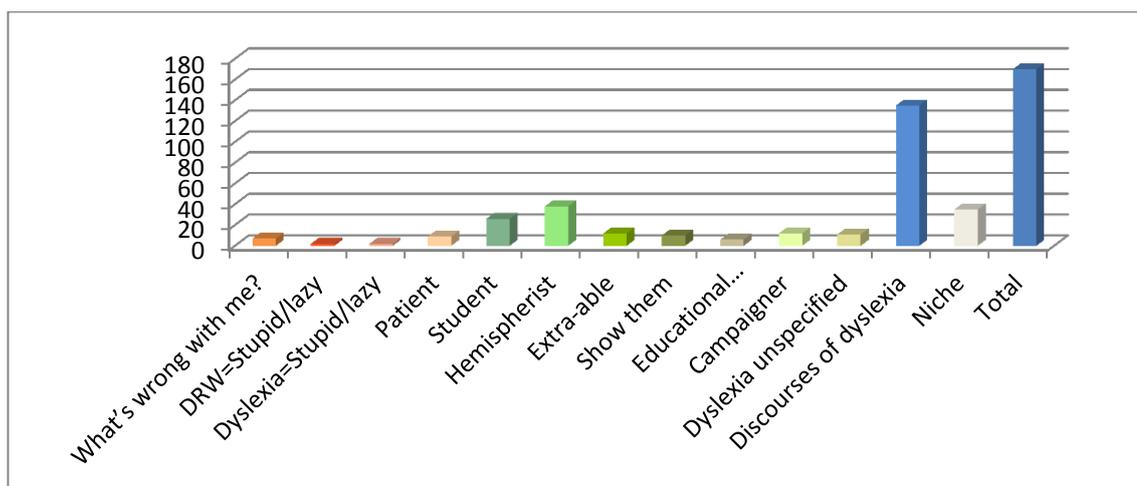


Fig. 5.1 Number of times each discourse linked to an aspect of the MVS.

time education when interviewed, as opposed to Pollak's group who were all attending higher education.

The *Student* discourse, like the *Patient* discourse, was initiated with identification for all of the participants except for Adam, who was never formally identified and developed computer skills to compensate for his difficulties with reading and writing independently. Five of the participants (Bob, Alice, Country Boy, Elizabeth Kirner and Amber) remarked upon the improvement in their marks that resulted from Learning Support that followed identification. For example, Amber, after identification and with Learning Support, completed her undergraduate degree with a 2:1 having had to leave the first university she attended because she was failing. Alice received private specialist lessons from the Dyslexia Institute which she described as helpful, and Country Boy, Elizabeth Kirner and Amber received the Disabled Student's Allowance (DSA), giving them computer hardware and software and specialist learning support which they described very positively. Bob received Learning Support within his Secondary School funded by a statement, and unlike many participants in the literature review who regarded such support as inappropriate, he found it extremely helpful. Pablo was eligible for specialist tuition through the DSA and went for a few sessions before deciding what was offered was inappropriate. However, he still relied on the hardware and software provided by the DSA to compensate for difficulties.

That Learning Support was so helpful in bringing about academic success following failure for those participants with dyslexic-type difficulties raises questions of equality; all four

participants who received DSA funding for Learning Support put themselves forward for assessment for dyslexia and would not have received the support had they not been identified. This raises a question of under-identification – what about failing pupils/students who are not identified but would benefit similarly? Bob asks this question in his interview,

*... that's the thing I learned about ... being dyslexic, I kind of learned to deal with it ... by myself. I kind of learned my own coping mechanisms and things like that. And particularly within my A-levels, and university time, then I think ... lecturers ... said 'well, he's dyslexic, we know that he's got a learning difficulty so therefore we'll just kind of let him get on with it' ... And all the way along really it was ... me, asking for the help ... I often worry about people that ... aren't as perhaps, forward as I am, and think, well, are there, like, lots of people within the country, within the world ... that have this learning difficulty and they are either afraid to ask for help, or they don't feel that they can ask for help, or just simply haven't got a clue what, what's available for them ... part of me thinks, well should that, should that be the case? (Interview 1)*

Lack of initiative on the part of educators to identify dyslexia may be a result of difficulty in identifying which pupils/students would benefit from this kind of support; even in this small study Pablo's experience demonstrates that not all do. Financial limitations, lack of awareness and differences in perspectives and attitudes are also likely involved. Regardless of why, only two participants (Bob and Pablo) were put forward for assessment by their own teacher/lecturer. Exploring the attitudes of teachers and lecturers and the context in which they work so as to better understand this situation would be a beneficial topic for future research.

## **Hemispherist**

The *Hemispherist* discourse, of all the discourses, links the most number of times to aspects of the MVS (see Fig. 5.1), and therefore is most successful in allowing participants to make positive meaning of their difficulties and act in constructive ways. All seven participants use this discourse (see Table 5.1). The most common way in which the *Hemispherist* discourse supports participants is in a combination of *Internal decisions* and *Action*; it most often links to *Understanding* followed by *Goodness of Fit*, *Acceptance* and *Learned Creativity* (see Table 5.2).

Its emphasis on strengths and weaknesses means it supports *Internal decisions* because it encompasses a means to make sense of difficulties in the light of knowledge of one's own value. This impacts *Understanding* and *Acceptance*. Knowledge of one's strengths then enables positive action through purposely choosing contexts in which they are maximised (*Goodness of Fit*) whilst applying coping mechanisms for areas of weakness (*Learned Creativity*). Though both *Student* and *Hemispherist* discourses offer support to *Internal decisions* and *Action*, the

Table 5.2. Number of times each discourse links to an aspect of the MVS.

Discourse	Aspect of the MVS									Total
	Desire	Goal Oriented	Recognition	Acceptance	Understanding	Goodness of Fit	Learned Creativity	Persistence	Social Ecologies	
What's wrong with me?			7							7
DRW=Stupid/lazy		1						1		2
Dyslexia=Stupid/lazy		1					1			2
Patient			5	0	4					9
Student		2	2		8	2	6	4	2	26
Hemispherist	1		3	6	13	8	6	1		38
Extra-able				4	4	2	1		1	12
Show them	1	2		2	1			3	1	10
Educational Responsibility					5			1		6
Campaigner			1	2	7	1			1	12
Dyslexia unspecified			2	3	3	1		1	1	11
Discourses of dyslexia total	2	6	20	17	45	14	14	10	6	135
Niche	1	3	0	2	9	9	2	5	4	35
Total	3	10	22	19	54	23	16	17	10	170

*Hemispherist* discourse is superior in its scope for doing so because of its adaptability. Whereas the *Student* discourse is helpful specifically in educational contexts, the *Hemispherist* discourse is valid both within and outside of an educational setting.

## Extra-able

The *Extra-able* discourse can be seen to be an extension of the *Hemispherist* discourse. It is similar in its orientation toward dyslexia as a combination of strengths and weaknesses; however one or more of the strengths are considered to be superior to other people's ability to carry out the same thing. Five participants spoke in the *Extra-able* discourse (see Table 5.1)

and it is again similar to the *Hemispherist* discourse in that it linked to *Understanding*, *Acceptance*, *Goodness of Fit* and *Learned Creativity*. Participants spoke in the *Extra-able* discourse in two ways; 1) either in reference to general knowledge e.g. 'dyslexic people are always famous' (Alice, Interview 3) or 2) in response to experiencing unusual ability in an area oneself e.g. Elizabeth Kirner's discovery that her ideas were unusual enough for her to become known as weird, but also good enough that others 'revelled' in them (Interview 2).

## Show them

Four of seven participants (see Table 5.1) talk in the *Show them* discourse. Bob and Alice use it retrospectively by fantasising about showing their bachelor's degrees to schoolteachers who doubted their ability to succeed academically. This visualisation is similar to that described by McNulty (2003) as a means of resolving past negative emotion, and supports *Acceptance* as the participants acknowledge their value despite difficulties. Bob's experience also links to *Social Ecologies* because he swaps daydreams with another dyslexic friend who has shared both the experience of teachers doubting him and the completion of a degree. Alice, Pablo and Amber use the *Show them* discourse about the future; they decide to show those who express a lack of belief in their academic ability that they are wrong. In this case, the discourse links to combinations of the *Desire*, *Goal Oriented* and *Persistence* triad, where it acts as a spur to initiate and perpetuate action. This discourse is not a primary means to understand dyslexia positively as the *Student* and *Hemispherist* discourse are, but rather is a reaction against experiencing others' attribution of one's difficulties to the *DRW=Stupid/lazy* and *Dyslexia=Stupid/lazy* discourses.

## Educational Responsibility

The discourse *Educational responsibility* was used by five out of seven participants. In all five cases use of this discourse links to *Understanding*, because it involved participants thinking about their difficulties as an interaction between themselves and the school context, rather than taking on responsibility for their difficulties alone. In Alice's case it also linked to *Persistence* because her teacher's high expectations required her to persist in spelling and she came to understand that she could succeed. *Understanding* and *Persistence* are the only aspects of the MVS that link to this discourse, however. Because this discourse focuses on the responsibility of the educational system rather than that of the dyslexic person, it leaves little latitude for the dyslexic person to take action. The dyslexic person is reliant on the action of the educational system, over which they have little control. In this way it is similar to the *Campaigner* discourse (see below).

The origins of this discourse often seem to involve meaning-making about bad educational experiences followed by good ones, which supported a logical conclusion that if the good educational experiences had been there from the very beginning, much of the difficulties would have been prevented. The good vs bad experiences commonly related to support received post- vs pre-identification of dyslexia.

*I certainly think the earlier ways of dealing with my dyslexia at school could have been better, both from the understanding of the people I was with and, or how can I as an individual cope with it ... you do sometimes wonder if you had had better support, particularly earlier support, if a lot of the things you did struggle with would have been ... would have been made better ... if you could study Bob from being born now, and see the differences in character in 29 years time [but with support from the beginning], that would be fascinating, because I do believe I probably would, I think certainly there would be more confidence, I think there would be certainly more self-worth (Bob, Interview 3).*

*Educational responsibility* is potentially positive as well as negative; it recognises the power that the educational system has to ameliorate and/or circumvent dyslexic-type difficulties as well as compound them. However, Alice is the only participant who spoke both negatively and positively in this discourse when she describes her first Primary School as 'the worst school in the world' (Interview 1) because her teachers expected nothing of her, then attributes her eventual success as a dentist to the teachers at her second Primary School who required her to work hard, 'I think if I hadn't gone to that school, I wouldn't be [a dentist now]' (Ibid). The other participants only speak negatively in the *Educational responsibility* discourse.

## Campaigner

Only two participants speak in a *Campaigner* discourse; Pablo and Amber (see Table 5.1). *Understanding* difficulties with reading and writing as a result of the structure of education and employment as much as a problem in a person offers a powerfully positive way to conceptualise these difficulties, so it is strange that none of the other participants discussed it this way. Both Pablo and Amber worked advocating for (non-dyslexia related) disability rights on behalf of others before they were identified as dyslexic themselves. That none of the other participants speak in this discourse suggests that without education about the social model of disability it is so far removed from dominant forms of conceptualisation, *e.g.* the *Patient* discourse, that it does not suggest itself to most people, and that they may not understand it even when confronted by it. Recently I had the privilege of sitting in on the academic committee for the Rose Report on dyslexia (2009) and at one point I questioned whether couching the report from a social model of disability perspective might support dyslexic people better. There was a negative outcry in response to this from the other academics; I remember one saying ‘oh but [dyslexic] people suffer terribly from their difficulties’ before the topic was dropped. The comment implies that it was inconceivable that ‘the problem lies not in the person but in society’, the conceptualisation of dyslexia as a within-person deficiency was so strong. This may explain why more participants did not discuss dyslexia in relation to barriers in society – not having been exposed to this approach to thinking about difficulties they were unable to make the leap to doing so. Morris (1991) writes,

*If the experiences of disabled people are missing from the general culture this means that non-disabled people have few points of reference with which to make sense of our reality. Furthermore, the tools which they do have to interpret our experiences are those fashioned by non-disabled people. This can have significant consequences for our lives, particularly because we so rarely have the power to insist on the validity of our experience. It can mean that we are denied the basic human rights that non-disabled people take for granted; it can also mean that our experience is denied and this can have devastating consequences (p88-89).*

Thus lack of awareness of the experience of being dyslexic and the societal structures that focus on and misunderstand dyslexic-type difficulties impacts both dyslexic and non-dyslexic people. The common story dyslexic people tell of being judged stupid or lazy because of their difficulties when they are neither is an example of their experiences being denied, and the ‘added sense of emotional insecurity’ described by McNulty (2003, p363) a devastating consequence.

Although the *Campaigner* discourse conceptualises dyslexia in ways that allow positive development of self-perceptions, it does not directly lead to development of action to cope

with difficulties the way the *Student* and *Hemispherist* discourses do. Use of the discourse by Pablo and Alice linked to twelve aspects of the MVS, ten of which were *Internal decisions* and two of which were *Action*. The most common link (7/12) was to *Understanding* (see Table 5.2), where the *Campaigner* discourse contributed to making sense of dyslexia in positive ways. When Amber discusses her group of dyslexic friends and the support they give to each other this links to *Acceptance* and *Social Ecologies*. Pablo's dissertation on the way dyslexic people are disadvantaged in a 'word-based' educational system links to *Goodness of Fit* as his 2:1 demonstrates his ability to conceptualise and communicate such information. Finally, the *Campaigner* discourse links to *Recognition* and *Acceptance* when Pablo refuses to attend Learning Support sessions that are not appropriate to his needs.

The *Campaigner* discourse is similar to *Educational responsibility* in its lack of link to *Action*. Rather than individual action it relies on changes in the systems from which barriers originate, and resistance to these changes from those in power in the system can be very strong indeed. While the *Campaigner* discourse involves advocating for oneself, whether or not that advocacy results in action positive to the dyslexic person by those in power is out of the dyslexic person's control unless they are willing to make formal complaints/take legal action. That results of self-advocacy are not always positive is evidenced by experiences of both Pablo and Amber. Pablo's PGCE Art tutors do not accept Pablo's alternative way of establishing his knowledge for the course. Amber's request for lecture information in an alternative style – without which she cannot access the content and/or leaves the lectures with debilitating headaches – is resisted by lecturers, one of whom disputes that she needs such measures in front of her peers. Herrington, in her Foreword to papers from a conference exploring science, art, creativity and dyslexia, writes,

*Who has the power to say that dyslexia exists or what dyslexia is/involves? Whose narratives are most highly valued? Who decides on methods of identification? Who determines how HE curriculum process, content and assessment will respond to dyslexia? Who decides on the nature of individual 'support'? Who exercises the power to exclude these kinds of discussions from HE? Many of the answers to these questions have been created largely by non dyslexic people (2007, p3).*

Amber and Pablo's experiences related above seriously undermine the confidence and self-belief that had taken many years for them to develop after previous failure in academia. Amber says, 'it's almost like going back a few steps ... I've gone back into processing [dyslexia]. Not so much who I am but what it means and how I portray that to others' (Interview 3). From the experiences of Pablo and Amber it would appear that advocating for oneself as an adult in an educational context has serious risks to emotional well-being because when those in power

resist it compounds emotionally negative experiences from the past. In Pollak's (2005) study he accredits a *Campaigner* with the most positive attitude toward dyslexia, however this study qualifies that view by showing that although the *Campaigner* discourse gives a means to understand dyslexia in the most positive way, because it puts emotional security at risk it can also have serious negative consequences.

## Dyslexia unspecified

This category is not a discourse, rather it is a way to signify excerpts from interviews that referred to dyslexia and were relevant to the participants' process of making sense of their difficulties, but that did not conceptualise dyslexia in any particular way. Excerpts from this category often simply refer to dyslexia such as, 'she's saying 'I'm dyslexic' and 'I'm like this' and 'I'm like that' ... and I totally recognise the symptoms in my mother with what my mother is like ... because I'm very similar' (Adam, Interview 1). These excerpts linked mainly to *Internal decisions Recognition* (2x), *Acceptance* (3x) and *Understanding* (3x), which involved the participants making sense of themselves as dyslexic. They also linked three times to *Action* (see Table 5.2). The ability of the term dyslexia to support development of positive self-perception and action is similar to that seen in the *Patient* discourse, where the term alone provides benefit in the form of explanation for something that previously went unexplained.

## Niche

The *Niche* discourse is represented by quotes from participant life stories that described meaning-making about difficulties, development of positive self-perceptions and/or the development of ways of coping with difficulties outside the context of dyslexia. All participants except Alice spoke in this discourse (see Table 5.1). This may reflect the fact that she was identified at a younger age than the other participants (age 8) so has framed understanding of her difficulties and coping mechanisms from the perspective of being dyslexic from the beginning. The use of the *Niche* discourse involved depiction of experiences in which the participants did well before they were identified as dyslexic. Only three out of the thirteen *Niche* quotes shown on the participant maps included discussion of an educational context; the rest occurred at work (5) or through childhood activities at home, with friends or in clubs (5). This demonstrates that the context of education contributed less to making sense of difficulties, development of positive self-perceptions and ability to cope with difficulties than other contexts for these participants, but only before they were identified as dyslexic (see below). In terms of the MVS the *Niche* discourse corresponds most frequently to three aspects

of *Action*; *Goodness of Fit* (9 links), *Persistence* (5 links) and *Social Ecologies* (4 links), whilst interacting with two *Internal decisions*, *Understanding* (9 links) and *Goal Oriented* (3 links). The *Niche* discourse also links to the remaining aspects of the MVS with the exception of *Recognition*, but fewer times (see Table 5.2).

Figure 5.2 compares the way discourses of dyslexia combined support aspects of the MVS versus the *Niche* discourse. In all cases aspects of the MVS link more often to discourses of dyslexia than to *Niche*, however certain aspects of the MVS are linked a similar number of times to both – *Desire* (discourses of dyslexia: 2; *Niche*: 1), *Goal Oriented* (discourses of dyslexia: 6; *Niche*: 3), *Goodness of Fit* (discourses of dyslexia: 14; *Niche*: 9), *Persistence* (discourses of dyslexia: 10; *Niche*: 5) and *Social Ecologies* (discourses of dyslexia: 6; *Niche*: 4) (see Table 5.2). The remaining aspects of the MVS link much more frequently to discourses of dyslexia – *Acceptance* (discourses of dyslexia: 17; *Niche*: 2), *Understanding* (discourses of dyslexia: 45; *Niche*: 9) and *Learned Creativity* (discourses of dyslexia: 14; *Niche*: 2) (see Table 5.2).

This suggests that without identification of dyslexia people are able to develop positive self-perceptions and coping mechanisms, particularly through the aspects of the MVS that link most commonly to the *Niche* discourse. That this involves three of the four aspects of *Action* suggests that the mechanism by which this occurs is that an activity (*Goodness of Fit*, *Persistence* or *Social Ecologies*) presents a positive experience through which the person contributes to better *Understanding* of their strengths and/or about the potential role that *Persistence* offers in securing success. *Desire* and *Goal Oriented* pair with *Persistence* as the

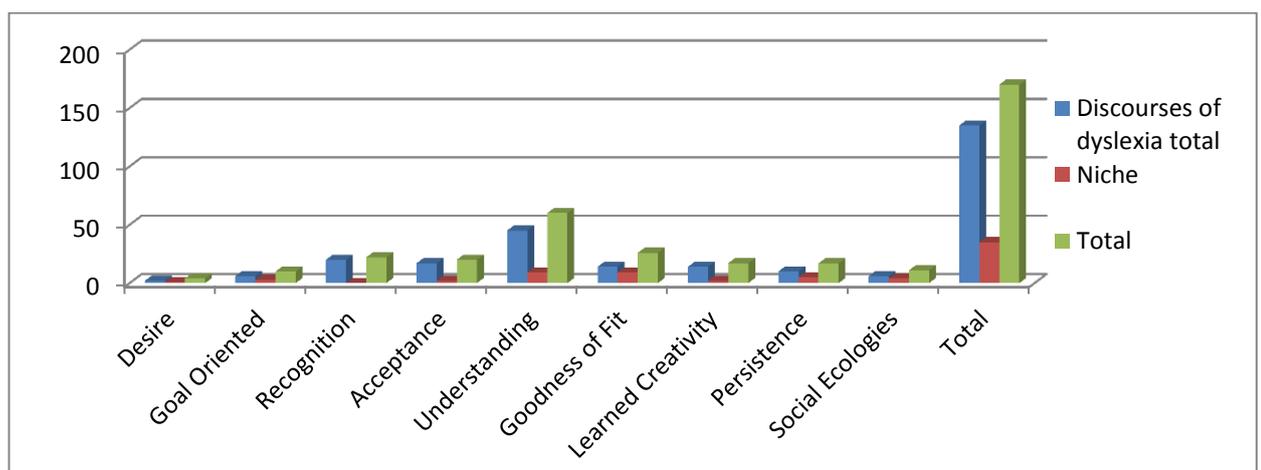


Fig. 5.2 Comparison of the number of times dyslexia discourses vs. non-dyslexia discourse (*Niche*) links to aspects of the MVS.

other two *Internal decisions* that often link to *Niche*. This corresponds to the process described by McNulty (2003) as finding a niche, 'Having a niche [in late teenage years or young adulthood] on which to build an academic program or a career improved adaptation and self-esteem and could dramatically change a person's life' (p373). The potential value of finding a niche is also emphasised in the study by Hellendoorn and Ruijsenaars (2000).

This study corroborates these findings, however it also demonstrates that dramatic impact can occur outside the time period identified by McNulty (2003) of late teenage/early adulthood. For example, Elizabeth Kirner's experience of the Drama club begins during Primary school, and supports coping mechanisms she can use in school to combat her difficulties from the beginning, later informing her course choice in higher education. Finding a niche was important for all the participants, and Pablo, who found his in his mid-twenties, suffered before finding a niche, calling the years following school and before he began working as a keyworker for disabled adults 'wilderness, wasted years' (Interview 2).

The two examples given above are of participants finding a niche before being identified as dyslexic; finding a niche after identification of dyslexia was similarly important, though conceptualised within the framework of dyslexia rather than outside it. When Alice finds she is good at non-verbal reasoning tests because they rely on pattern recognition, she attributes her ability to strong visualisation skills and links this to dyslexia. Similarly, when describing her confidence during interview, viva academic assessment and talking to 'high-powered' friends of her parents, she talks of good verbal ability that she sees as part of her individual pattern of strengths and weaknesses that are part of being dyslexic. Alice later uses knowledge of her pattern of strengths and weakness to find a niche in Science, because the amount of prose she is required to write is limited and her visualisation skills lend themselves well to learning biological systems.

A central finding of this study is that without identification of dyslexia, development of aspects of the MVS occur centred around the process and benefits of discovering a niche as described above, however following identification of dyslexia there is an upsurge in links to the other aspects of the MVS, the *Internal decisions Recognition, Acceptance and Understanding*, and the *Action Learned Creativity*. This involves a dual process of making sense of difficulties with reading and writing/developing more positive self-perceptions and coping mechanisms to compensate for difficulties. Figure 5.3 compares participants' maps according to discourse, links to aspects of the MVS and time of identification. Before identification of dyslexia the only way to conceptualise difficulties with reading and writing is through the *DRW=Stupid/lazy*

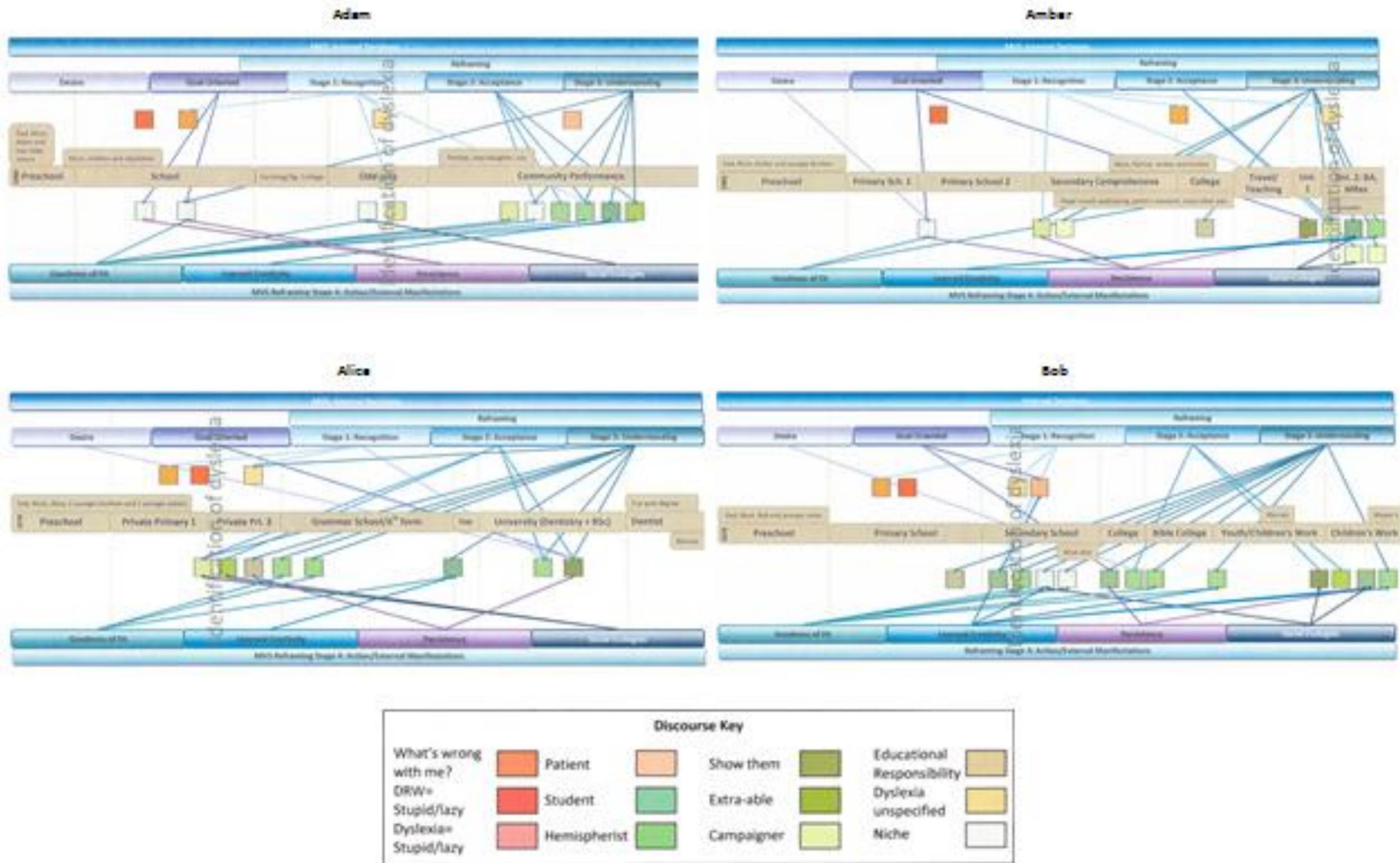


Fig. 5.3a. Comparison of participants' maps showing patterns of links to the MVS. Before identification of dyslexia links result most often from experiences of *Niche* linking to *Goodness of Fit*, *Social Ecologies* and/or the *Persistence/Goal Oriented/Desire* triad, and these frequently contribute to *Understanding*. Identification of dyslexia often initiates *Recognition*, *Acceptance*, *Understanding* and/or *Learned Creativity*, and experiences of niche following identification tend to be interpreted through discourses of dyslexia.

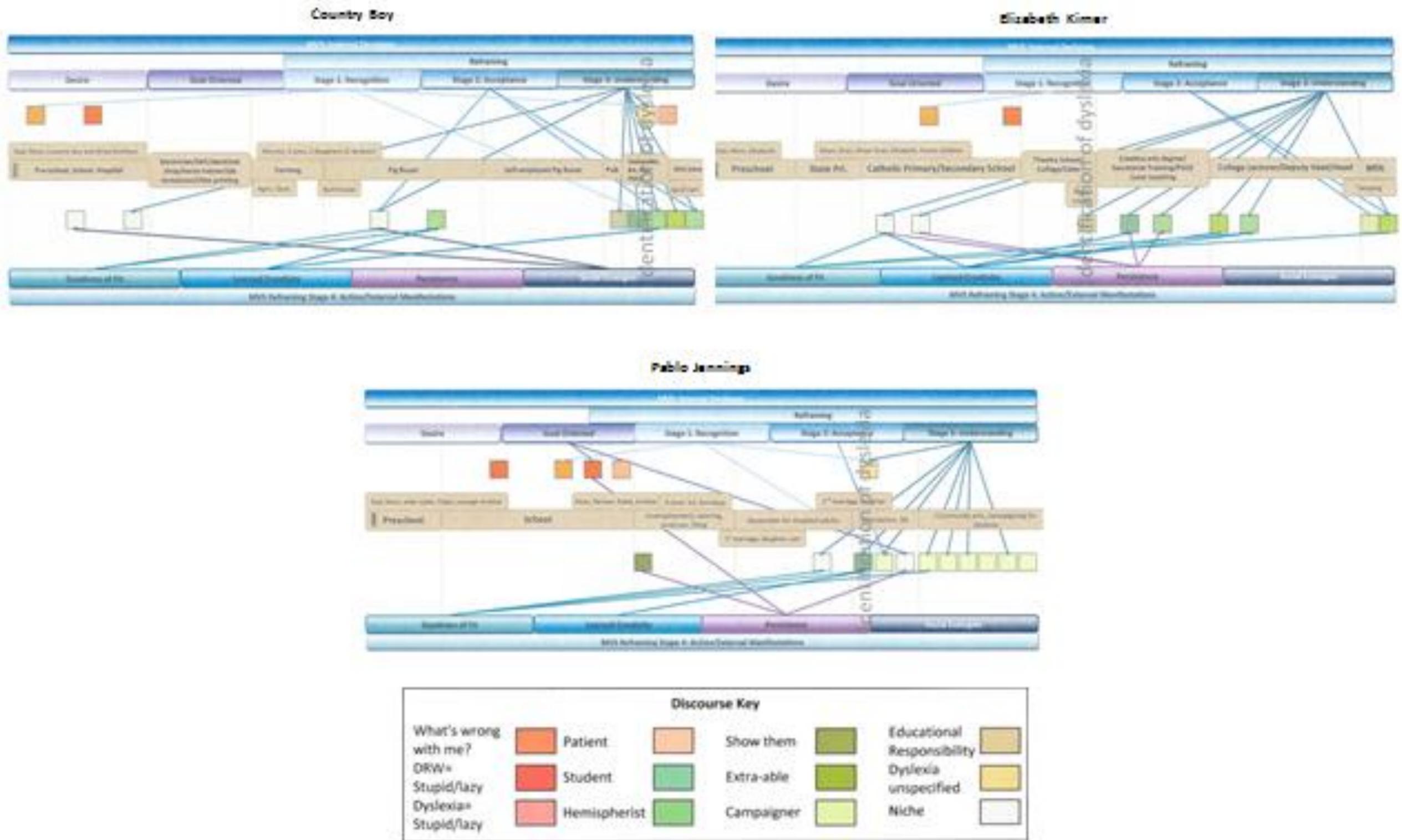


Fig. 5.3b. Comparison of participants' maps showing patterns of links to the MVS. Before identification of dyslexia links result most often from experiences of niche (represented by the *Niche* discourse) linking to *Godness of Fit*, *Social Ecologies* and/or the *Persistence/Goal Oriented/Desire* triad, and these frequently contribute to *Understanding*. Identification of dyslexia often initiates *Recognition*, *Acceptance*, *Understanding* and/or *Learned Creativity*, and experiences of niche following identification tend to be interpreted through discourses of dyslexia.

discourse.<sup>3</sup> The *DRW=Stupid/lazy* discourse prevents development of positive self-perceptions and inhibits motivation and belief that the difficulties can be compensated for. Low expectations not only impact participants but also teachers (Riddick, 2000), and in the case of Bob and Adam, parents/step-parents.

Amber's life story provides a good example of the benefit conceptualisations available through discourses of dyslexia have to offer. From Primary School Amber appreciated the value of *Persistence*. During her Secondary School years she applied this to the extent that schoolwork began to push out time for socialising and hobbies. One of the time consuming things she did which was to highlight most of the text she was reading during revision. With identification of dyslexia she was told she was exceptionally prone to visual stress, a disorder that is relieved by reducing the amount of contrast between background paper and foreground text. In effect, highlighting the text she was reading was a form of *Learned Creativity* because it was a way to compensate for her difficulties with visual stress. However, before identification she did not understand why she was highlighting everything. She now uses either an overlay or wears glasses to bring about the effect she previously produced by highlighting, and the number of disabling headaches she experiences has reduced dramatically. Her process of assessment contributed to *Understanding*. She now can make sense of her experiences in a way that enables more effective and efficient compensation and allows her to anticipate and plan for situations that are likely to prove difficult. The benefits are more than the practical solution to a difficulty, too; the *Understanding* she now has provides affirmation of her experiences rather than denial, and so supports more positive self-perceptions.

Country Boy's life story also provides a good example of what conceptualisations of dyslexia offer. Though others told Country Boy he was stupid as a child he did not believe it; in his final year at school at 15, when he was given an IQ test, he came out with the second highest score in the school confirming his self-belief that he was intelligent. However, it did not explain how he could be intelligent but have difficulty learning to read and write. Indeed, his peers did not believe it could be so, 'there was one hell of a row with the rest of the pupils, because they couldn't understand how I could come out way above them when I couldn't do anything, well they called anything' (Interview 1). Once he left school he found he was successful in the work he attempted, although the kind of work he could take on was limited because of his difficulties and lack of qualifications. His map demonstrates that over his lifetime he had a number of experiences of *Goodness of Fit* and *Social Ecologies* that linked to *Understanding*,

---

<sup>3</sup> In Fig. 5.3. use of discourses of dyslexia prior to identification are due to participants' retrospective meaning-making, where they reframe prior events in light of understanding about dyslexia developed after identification.

and on these terms he describes himself as a successful man. However with identification came a way to conceptualise why he had difficulties with reading and writing that had previously been missing, and additional links to *Recognition, Acceptance, Understanding* and *Learned Creativity* appear. He echoes a number of the other participants when he says 'I think [identification of dyslexia] really answered a lot of the questions in my life' (Interview 3).

Attempts to develop other conceptualisations to make sense of difficulties with reading and writing have been made. I was privileged enough to discuss the issue of dyslexia, SpLDs and labelling with Baroness Warnock, specifically in relation to her experiences chairing the Committee of Enquiry into the Education of Handicapped Children and Young People commissioned by the Department of Education in 1974, which was published as the Warnock Report: Special Educational Needs (1978),

- (1) *... going back, the word [dyslexia] had been in use but nobody was prepared to define it ... mainly the view was that it was simply an invention ... to obscure the stupidity of certain children mainly white middle class children ... it was so controversial that ... we were told [by the Department of Education] ... that we were not to discuss dyslexia ... so it doesn't appear in any form at all in the report that was published in 1978*
- (2) *... our mission in life was to try to get people to accept the concept that it didn't matter what you called the disability that the child had, what you had to do was find out what would help him overcome it. And so we were very much against using names at all ... in fact some of us became fanatical about not labelling. And just try to assess the needs of the child without preconceptions*
- (3) *... it was already obvious to us actually by the time we published the report that you couldn't pursue that policy you simply had to have ways of describing, ways of identifying the children you were talking about*
- (4) *... it was the Dept of Education as it then was that invented the term 'Specific Learning Difficulties' ... I think SpLDs was actually quite a good way to describe it but it did amuse me that they couldn't use the word dyslexia although they always had to translate it SpLD (dyslexia) so they did use the word but not officially ... So that is the history (Mary Warnock 26 November 2006).*

In these excerpts Baroness Warnock describes dyslexia in two ways; in the first excerpt she describes the *Dyslexia=Stupid/lazy* discourse as being prevalent during the mid 1970s; then in excerpt four she describes an attempt by The Department of Education to develop a term that describes the learning needs of the child; 'Specific Learning Difficulties'. This term communicates the idea that the child has difficulties in a specific area rather than general difficulties due to low intelligence. This latter description could be considered to be either in a *Patient* or *Student* discourse; the focus is on within-child difficulties but there is attention drawn to intelligence. As Baroness Warnock says, 'I think SpLDs was actually quite a good way to describe it'; the term affirms intelligence and suggests multiplicity in its use of 'difficulties',

an apt way to describe the broad spectrum of difficulties dyslexia is used to represent. However, despite the fact that the term 'SpLDs' has been around since the early 1980s it has not been embraced in the same way as the term 'dyslexia' by those experiencing the disability. Perhaps this is due to the connection between celebrity and use of the term; the *Extra-able* discourse can imbue a certain glamour and reason for pride which is in opposition to the more prevalent *Dyslexia=Stupid/lazy* and *Patient* discourses.

In excerpts two and three above Baroness Warnock addresses another issue pertinent to this study; despite her desire to avoid using labels at all but rather assess the needs of the child without preconceptions, she acknowledges the need 'to have ways of describing, ways of identifying the children you were talking about' (excerpt 3). Riddick (2000) also describes the need teachers have to be able to conceptualise difficulties, particularly those that are hidden and not obvious as a physical disability is (Riddick, 2001).

This study has made the need to conceptualise difficulties with reading and writing obvious, not only for the participants, but also for teachers and parents. The common educational response to labelling – that it stigmatises the child, that it results in a response dictated by stereotypical understanding of the label rather than actual needs of the child – is laudable in its desire to protect and support. However the reality in the case of dyslexia is more complex. Such a view does not take into account the need for the child to understand him or herself, nor does it acknowledge value systems that stigmatise informally with or without a label (Riddick, 2000). The participants in this study were aware they were different from their peers before they were identified as dyslexic, some many years before, and needed a way to understand the difficulties that were so plain to them. The attributions made for their difficulties by others were frequently the *DRW=Stupid/lazy* discourse, so before they were identified as dyslexic being low in intelligence or being lazy were the only ways they had to make sense of the difficulties they recognised in themselves. In contrast, with identification of dyslexia came the possibility of understanding their difficulties in a range of discourses which supported the meaning-making process including basis for more positive self-perceptions and coping skills.

However, all discourses of dyslexia are not equal in terms of the scope the concept has to support a person experiencing difficulties with reading and writing. Unfortunately the two most common ways non-dyslexic people understand dyslexia is through the *Dyslexia=Stupid/lazy* discourse that became well-known as Mary Warnock described, in the 1960s and 70s, or the *Patient* discourse. Both these can have serious negative impact for dyslexic people, though both can also have some positive impact (see Table 2.2). The participants in Armstrong and Humphrey's (2009) study who understood dyslexia through the

*Dyslexia=Stupid/lazy* discourse resisted being identified. Kerr (2001) argues against the usefulness of the concept of dyslexia because the adult education teachers who are the participants in his study describe it in a *Patient* discourse where it is understood as a deficiency in one's brain, leading to learned helplessness on the part of dyslexic student's teachers with the assumption that it has the same effect on dyslexic students. When dyslexia is discussed in the *Dyslexia=Stupid/lazy* and *Patient* discourses it tends to be perceived in negative ways and linked to negative outcomes for dyslexic people. Other discourses of dyslexia, such as *Campaigner*, *Show them*, *Extra-able* and *Educational responsibility*, have been shown by this study to offer flexibility to dyslexic people in understanding themselves and in developing ways to cope with difficulties, with the *Student* and *Hemispherist* discourses seeming to offer the most.

Figure 5.4 compares use of discourse between participants in relationship to timing of identification. In conjunction with the life histories, patterns emerge as to the development of discourses of dyslexia. *What's wrong with me?* and/or the *DRW=Stupid/lazy* discourse appear first, within the context of education. After a period of time which varies from less than a year for Alice and fifty plus years for Country Boy, they are identified as dyslexic. With identification come the *Patient* discourse, where their difficulties are described in terms of cognitive defect and the *Student* discourse when their intelligence is affirmed. For everyone except Adam the *Student* discourse also appears soon after identification in terms of development of coping mechanisms to combat difficulties with reading and writing. These are successful, improving academic achievement substantially for Bob, Country Boy, Elizabeth Kirner and Amber, and Pablo, though he refuses help from specialist tutors, learns to read and write using the computer he receives on the basis of the Disabled Student's Allowance.

Over a period of time following initial understanding of dyslexia according to *Patient* and/or *Student*, the other discourses appear according to experiences and context. The *Hemispherist* discourse develops as the participants understand themselves according to the idea of strengths and weaknesses. It is as though the process of identification which makes them aware of their weaknesses as well as their intelligence, followed by the development of successful coping skills, supports the conscious analysis of strengths and weaknesses and how this knowledge can be applied to the practical business of life. This discourse links forty times to aspects of the MVS, almost twice as many times as the next most helpful discourse, *Student* at 25 links. Together these discourses provided the participants with a way to understand themselves positively and realistically, and supported the development of coping skills. The

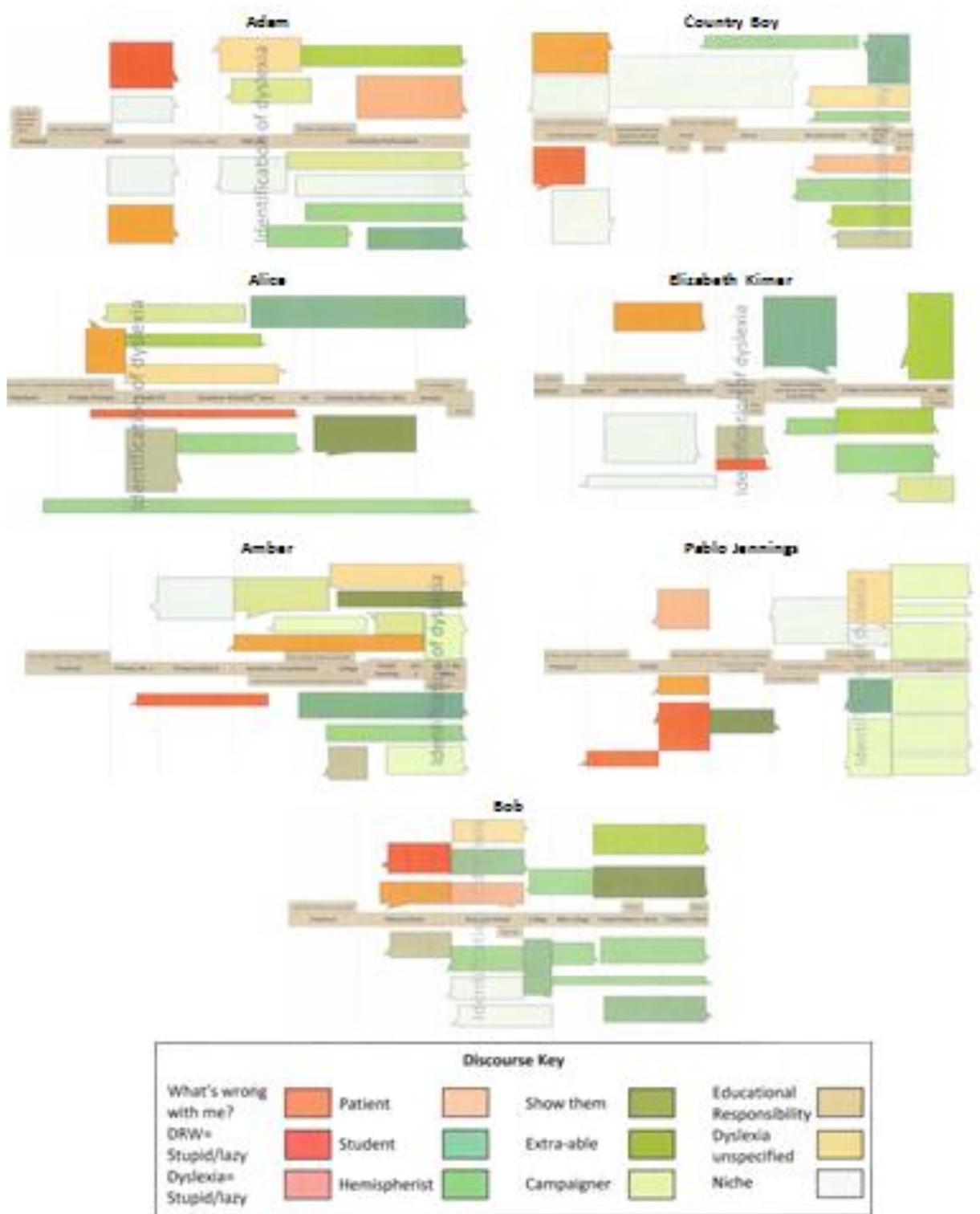


Fig. 5.4 Comparison of participants' maps showing the development of discourse. *What's wrong with me* and *DRW=Stupid/Lazy* appear in the context of school. The *Patient* and *Student* discourse originate with identification, with the *Hemispherist* discourse following on with development of knowledge about strengths and weaknesses. The remaining 'greenish' discourses occur according to context and experience. *Educational responsibility* follows realisation that difficulties can be compensated for. The *Dyslexia=Stupid/lazy* discourse reflects participants' perceptions of the way the general public views dyslexia.

*Extra-able* discourse seems to arise out of awareness of strengths and comparison with others that show ability better than most, sometimes with the conclusion that difficulties with reading and writing have supported the development of unusual abilities. In fact recognition of unusual ability was most often related to visualisation. *Show them* is sometimes a meaning-making exercise engaged in once the worst of difficulties are over; sometimes a spur to motivate work at future goals. *Educational responsibility* seems to occur retrospectively, and can be spoken with bitterness as the participant realises the suffering they went through could have been prevented. It can be thought to be a precursor to the *Campaigner* discourse, at least in Bob's life history as he considers the responsibilities of society toward dyslexic people. However the *Campaigner* discourse was only used by two participants, Amber and Pablo, who had previous experience of disability rights advocacy. This suggests that the *Campaigner* discourse may be different enough to dominant discourse that it requires awareness training to be understood.

## Rigour

As set out in Chapter 3: Methodology, I have chosen to make this study rigorous by following criteria set out for rigour in interpretation (Gubrium & Holstein, 1997) and by addressing ethical and political issues established by Lincoln (1995). My criteria therefore involve:

- scepticism (looking beyond ideas of common sense and quantitative research about social life)
- Close scrutiny (immersing oneself in the data to enable the appreciation of the detail of participants' lives),
- thick description ('rich, clear and nuanced description of social life'),
- focus on process (awareness that social life is continually re-constructed),
- appreciation of subjectivity (social life is based on meaning, interpretation and feeling and these aspects must be a focus) and
- tolerance for complexity (simple explanations of social life and culture tend to be inadequate – research needs to be able to represent complexity).
- Positionality (the position from which the researcher speaks should be made clear)
- Community as arbiter of quality (responses to the research from participant, academic and/or political communities contribute to judgments about research value)
- Voice (research should give voice to those normally marginalized in society)

- Critical subjectivity (the researcher should practice reflexivity in their sensitivity to participants)
- Sacredness – ‘a profound concern for human dignity, justice, and interpersonal respect’ (Lincoln, 1995, p284)
- Sharing privileges (the researcher should not be the only one to benefit from carrying out the research. Research results and other benefits, for example, any royalties, should be shared between participants and researcher).

I have summarised examples of meeting these criteria in Table 5.3. I worked hard to comply with these standards and believe I have done so in most cases. There are, however, a number of limitations to this study. I have based much of my analysis of patterns evident in the life histories on a counting exercise that is a result of interpretation on my part. The life histories involved prioritising the most important events in the participant’s lives in relation to their difficulties. It was impossible to include everything, in fact, even most items that I coded as a discourse or an aspect of the MVS. The number of times a particular discourse links to aspects of the MVS is therefore a matter of interpretation. However, that I have interpreted the life stories in a way that represents participants’ lives accurately is supported best by their positive responses to my analyses. I think the relevance of the study is also supported by the fact that it has developed out of the work of many others. Though centred on the life stories of seven participants, the fact that I have theorised my analysis on the work of Gerber *et al.* (1992) who interviewed 71 adults with Learning Disabilities and Pollak who interviewed 33 HE students, and developed the discourses through recognition of concepts described in a number of studies in the literature review, contributes to the extent to which it might be relevant to dyslexic adults outside of the study. I do not make claims for generalisability, however; my analysis and conclusions relate to the seven participants only. The group are skewed, with all seven participants being white, six of seven having completed undergraduate or higher degrees and, although I did not collect data on levels of ability, many of the participants appear to be unusually intelligent. The fact that I only interviewed people who self-identified as dyslexic also skewed the group; attitudes toward the concept of dyslexia were not surprisingly mostly positive.

<b>Criteria</b>	<b>Comments about/examples from the study</b>
Scepticism	The process of having the idea for this thesis and then carrying it out has been intimately linked with a re-appraisal and critique of dominant ways of thinking about dyslexia in our culture, particularly in terms of the way we normally research it
Close scrutiny	Hours and hours were spent immersed in the participants' life stories. These hours started with the interviews themselves followed by time with transcription, putting together timelines and summaries, coding in NVivo and then writing the life histories. I then read the life history to each participant, discussing it all as we went. Some of the final interviews were more than two and a half hours long. I then went through a second draft stage where I shortened and tightened the analyses, incorporating information from the final interview.
Thick description	The participants' life stories included description of personal, meaningful issues and their perceptions, feelings and beliefs.
Focus on process	The life histories developed in this PhD are intimately concerned with process; how a person becomes aware they have difficulty with reading and writing, how their understanding of the difficulties change over time and how their actions change. The participants' comments about the interview process further demonstrate this; the life history analysis changed the way they understood themselves.
Appreciation of subjectivity	Meaning, interpretation and feeling in relation to difficulties with reading and writing are the focus of this PhD
Tolerance for complexity	The analysis of the participants' life stories is complex – as depicted visually by their maps – I chose use of discourse analysed in conjunction with the MVS because it allowed a perspective that simultaneously conceptualised the relationships between an internal meaning-making process, personal context, action and societal views
Positionality	The position from which I have carried out this analysis was made clear in the Introduction and the chapter on Methodology
Community as arbiter of quality	I discussed each participants' life history with them in detail and each accepted my interpretation as representing them accurately. My work will be further scrutinised during the viva by experts in the field of dyslexia and life history
Voice	This research gives voice to dyslexic people who are marginalised by the way the educational system focuses on and judges them based on their areas of weakness while dismissing or ignoring strengths as unimportant
Critical subjectivity	During the interviews the participants were the centre of focus of my energies, and I did my best to understand the dynamics of our relationship as well as the stories they told about themselves. I think I was supported in my understanding of each participant by my familiarity with the experience of dyslexia as witnessed in my brother and son
Sacredness	The fact that the participants were happy to be involved with four repeat interviews over a time period of more than three years demonstrates that I managed to establish positive relationships of respect and trust. That all seven expressed interest in writing a chapter for a book for dyslexic adults also reiterates the quality of our relationships and their experience of being interviewed, particularly considering the fact that writing is not their favourite activity!
Sharing privileges	I will not receive money for completing this PhD so I have no royalties to share; however I will gain the status allocated to a person with a post-graduate degree. This I cannot share, either; but I can carry out my plan to write a collaborative book between the participants and myself in which we will share authorship and any royalties

*Table 5.3. Examples of criteria for rigour found in the thesis.*

## Unique contribution

This PhD makes a number of unique contributions to knowledge about dyslexia. The literature review, particularly with regards to the review of interview studies and the way I organised it according to themes, is original. The identification of five additional discourses of dyslexia contributes to knowledge about the way difficulties with reading and writing can be understood and talked about, and exploration of how these discourses link to the MVS contributes knowledge to the advantages and disadvantages of these discourses to dyslexic people. By exploring the relationship between Pollak's (2005) discourses and the MVS I have built on his research, adding knowledge about processes of meaning-making and the development of self-perceptions and coping mechanisms through analysis according to the MVS. The thesis also builds on work by Gerber *et al.* (1992) by exploring the way different discourses support aspects of the MVS. Finally, the thesis provides a detailed description of the experiences of dyslexic adults who do not have parental support, which was a previous gap in the research.

## Future research

This Thesis indicates that it would be beneficial to research a number of additional contexts in relationship to the experience of dyslexia and other SpLDs. In terms of an educational context, it would balance and inform perspectives of dyslexic participants to interview mainstream teachers in order to understand their perspectives toward dyslexic pupils and students, in relation to their use of discourses of dyslexia, whether they have contradictory responsibilities in terms of supporting dyslexic pupils/students and maintaining positive relationships in the teaching community of practice and whether pressures for higher attainment impact their attitudes and practice toward dyslexic pupils/students. In light of children's need to make sense of difficulties with reading and writing and the current tendency to attribute them to lack of intelligence, research exploring alternative ways to understand intelligence and how they affect self-perceptions in dyslexic pupils/students is warranted. For example, the impacts of teaching ideas of incremental intelligence (Dweck 2000) to those who struggle to read and write, their peers and their teachers could be explored.

This study has documented the complications of co-occurring SpLDs through its life history of Elizabeth Kirner. Further interview research exploring the way people with co-occurring SpLDs make sense of their difficulties, develop positive self-perceptions and learn to cope with their difficulties would be valuable. The life history of Adam is different from the others and this

may be due to the relatively short time he spent in an educational context compared to other participants. Research on those who self-identify as dyslexic having left school without qualifications is a little-known area, and further life history research following the lives of dyslexic adults who do not go to university and/or are not formally identified would be valuable. Finally, it would be worthwhile to carry out life history research with adults who struggle to read and write but do not self-identify themselves as dyslexic. Understanding the way they have made sense of their difficulties and developed coping mechanisms would be beneficial.

## **Conclusion**

I would like to bring this thesis to a close by briefly returning to the Introduction and the story I told about myself and my dyslexic family. My perceptions have changed a vast amount in the four years I have spent working on this thesis. I began the course with a Patient and Student view of dyslexia, and have left as a Hemispherist and Campaigner. If more academics and practitioners could do the same the situation for dyslexic people would improve, because they would be able to understand their difficulties constructively from an early age. However this seems unlikely. The success of cognitive psychology in establishing a reliable link between difficulties with reading and writing and phonological coding has brought into even sharper focus the idea of dyslexia as a brain deficit. Research in reading intervention and the benefits of structured language programmes persevere in teaching people to read. Both approaches doubtless provide benefit, especially in early years of education. But they aim to 'fix' the dyslexic person. My realisation in this thesis, one that I have always known but did not know how to put into words, is that there is nothing to fix; a dyslexic person is not broken. Instead I see now that it is the structure and attitudes of our society that need fixing. Writing this thesis has given me the words to express what was previously non-verbal knowledge – through the social model of disability – and I hope that the words I have written here may also help others to verbalise their own experiences.

## REFERENCES

- Abbot, R. C. & Frank, B. E. (1975) A follow-up of learning-disabled children in a private special school. *Academic Therapy*, 10, 291-8.
- Adorno, T. W. (1973) *Negative dialects*, (London, Routledge and Kegan Paul).
- Adult Literacy and Basic Skills Unit (ALBSU) (1987) *Literacy, numeracy and adults: Evidence from the national child development study*. Report for ALBSU (London).
- Ajzen, I. (1985) From intentions to actions: A theory of planned behaviour, in: J. Kuhl & J. Beckmann (Eds) *Action-control: From cognition to behaviour*. (Heidelberg, Springer), 11-39.
- Armstrong, D. & Humphrey, N. (2009) Reactions to a diagnosis of dyslexia among students entering further education: Development of the 'resistance-accommodation' model. *British Journal of Special Education*, 36(2), 95-102.
- Atkinson, P. (1990) *The ethnographic imagination: Textual constructions of reality*, (London, Routledge).
- Augur, J. (1981) *This book doesn't make (sens, scens) sense*, (London, Whurr).
- Austin, J. L. (1962) *How to do things with words*, (Cambridge, MA, Harvard University Press).
- Balow, B. & Bloomquist, M. (1965) Young adults ten to fifteen years after severe reading disability. *Elementary School Journal*, 66, 44-48.
- Barnes, C. (1991) *Disabled people in Britain and discrimination*, (London, Hurst & Co).
- Barnes, C. (1996) Disability and the myth of the independent researcher. *Disability & Society*, 11(1), 107 - 112.
- Baronne, T. (1995) Persuasive writings, vigilant readings, and reconstructed characters: The paradox of trust in educational storytelling, in: J. A. Hatch & R. Wisniewski (Eds) *Life history and narrative*. (London, Falmer Press), 63-74.
- Bateson, M. C. (1994) *Peripheral Visions: learning along the way*, (New York, HarperCollins).
- Bazeley, P. (2006). The Contribution of computer software to integrating qualitative and quantitative data and analyses. *Research in the Schools*, 13(1) 64-74.
- Belenky, M. F., Clinchy, B. M., Goldberg, N. R. & Tarule, J. M. (1988) *Women's ways of knowing: The development of self, voice and mind*, (Stockbridge, BasicBooks).
- Bertraux, D. (1981) *Biography and society: The life history approach in the social sciences*, (London, Sage).
- Bickenbach, J. E., Chatterji, S., Badley, E. M. & Üstün, T. B. (1999) Models of disablement, universalism and the international classification of impairments, disabilities and handicaps. *Social Science & Medicine*, 48(9), 1173-1187.
- Boetsh, E. A., Green, P. A. & Pennington, B. F. (1996) Psychological correlates of dyslexia across the lifespan. *Development and Psychopathology*, 8, 539-562.
- Bruck, M. (1985) The adult functioning of children with specific learning disabilities: A follow up study, in: L. Siegel (Ed.) *Advances in applied developmental psychology*. (Norwood, NJ, Ablex), 91-129.
- Bruner, J. (1986) *Actual minds, possible worlds*, (Cambridge, MA, Harvard University Press).
- Bruner, J. (1990) *Acts of meaning*, (Cambridge, MA, Harvard University Press).

- Buchanan, M. & Wolf, J. (1986) A Comprehensive Study of Learning Disabled Adults. *Journal of Learning Disabilities*, 19, 34-38.
- Burden, R. (2005) *Dyslexia & self-concept: Seeking a dyslexic identity*, (London, Whurr).
- Burden, R. (2008) Is dyslexia necessarily associated with negative feelings of selfworth? A review and implications for future research. *Dyslexia*, 14(3), 188-196.
- Bynner, J. & Ekinsmyth, C. (1994) *Young adults literacy and numeracy problems: Some evidence from the british cohort study*. Report for ALBSU (London).
- Canagarajah, S. (2005) Rhetoricizing reflexivity. *Journal of Language, Identity & Education*, 4(4), 309-315.
- Carter, B. (1964) A descriptive analysis of the adult adjustment of persons once identified as disabled readers. Indiana University.
- Chapman, J. W. (1988) Learning disabled children's self-concepts. *Review of Educational Research*, 58(3), 347-371.
- Clifford, J. & Marcus, G. E. (Eds.) (1986) *Writing culture: The poetics and politics of ethnography*, (Berkeley, CA, University of California Press).
- Clifford, J. (1986) Partial truths, in J. Clifford and G. E. Marcus (eds.), *Writing culture: The poetics and politics of ethnography*, 1-26. (Berkeley, CA: University of California Press).
- Corbett, J. & Norwich, B. (1997) Special needs and client rights: The changing social and political context of special educational research. *British Educational Research Journal*, 23(3), 379-389.
- Critchley, M. (1970) *The dyslexic child*, (London, Heinemann).
- Crotty, M. (1998) *The foundations of social research: Meaning and perspective in the research process*, (London, Sage Publications).
- Crowley, C., Harré, R. and Tagg, C (2002) Editorial: Qualitative research and computing: methodological issues and practices in using QSR NVivo and NUD\*IST, *International Journal on Social Research Methodology*, 5(3), 193-197.
- Dale, M. & Taylor, B. (2001) How adult learners make sense of their dyslexia. *Disability & Society*, 16(7), 997-1008.
- Davenport, L. (1991) Adaptation to dyslexia: Acceptance of the diagnosis in relation to coping efforts and educational plans. Dissertation Abstracts International.
- Davis, R. D. (1997) *The gift of dyslexia: Why some of the brightest people can't read and how they can learn*, (London, Souvenir Press).
- Denzin, N. K. & Lincoln, Y. S. (2005a) Preface, in: N. K. Denzin & Y. S. (Eds) *The Sage handbook of qualitative research* (3<sup>rd</sup> ed., pp ix-xix). (Thousand Oaks, CA: Sage).
- Denzin, N. K. & Lincoln, Y. S. (2005b) Introduction: The discipline and practice of qualitative research, in: N. K. Denzin & Y. S. (Eds) *The Sage handbook of qualitative research* (3<sup>rd</sup> ed., pp 1-32). (Thousand Oaks, CA: Sage).
- Denzin, N. K. & Lincoln, Y. S. (2003) Introduction: The discipline and practice of qualitative research, in: N. K. Denzin & Y. S. Lincoln (Eds) *Strategies of qualitative inquiry*. (vol. 2) Second edition (Thousand Oaks, Sage), 1-45.
- Denzin, N. K. (1997) *Interpretive ethnography: Ethnographic practices for the 21st century*, (London, Sage Publications).
- Department of Education and Science (1978) The Warnock report: Special educational needs. A report by the committee of enquiry into the education of handicapped children and young people. London, HMSO.
- Derrida, J. (1988) Signature event context, in: G. Graff (Ed.) *Limited, inc.* (Chicago, Northwestern University Press).
- DfES (2004) A framework for understanding dyslexia. Nottingham, QIA Publications.
- Dimitriadi, Y. (2006) Resistance from within: Children with dyslexia gazing at their disability, in: J. Satterthwaite, W. Martin & L. Roberts (Eds) *Discourse, resistance and identity formation*. (Stoke on Trent, Trentham Books).

- Dronkers, N. F., Plaisant, O., Iba-Zizen, M. T. & Cabanis, E. A. (2007) Paul Broca's historic cases: High resolution MRI imaging of the brains of Leborgne and Lelong. *Brain*, 130(5), 1432-1441.
- Durrant, J. E., Cunningham, C. E. & Voelker, S. (1990) Academic, social and general concepts of behavioural subgroups of learning disabled children. *Journal of Educational Psychology*, 82(4), 657-663.
- Dweck (1999). *Self-theories: their role in motivation, personality and development*. Philadelphia, PA: Psychology Press.
- Edgington, R. E. (1975) SLD children: A ten-year follow-up. *Academic Therapy*, 11, 53-64.
- Edwards, J. (1994) *The scars of dyslexia*, (London, Cassell).
- Ehardt, K. (2009) Dyslexia, not disorder. *Dyslexia*, 15(4), 363-366.
- Ekinsmyth, C. & Bynner, J. (1994) *The basic skills of young adults*. Report for ALBSU (London).
- Elliott, J. G. & Gibbs, S. (2008) Does dyslexia exist? *Journal of Philosophy of Education*, 42(3), 475-491.
- Ellis, E., Bochner, A., Denzin, N., Lincoln, Y., Morse, J., Pelias, R. and Richardson, L. (2008) Talking and Thinking About Qualitative Research. *Qualitative Inquiry*, 14(2), 254-284.
- Ezzy, D. (2002) *Qualitative analysis: Practice and innovation*, (London, Routledge).
- Fairclough, N (1995) *Media discourse*. (London: Edward Arnold).
- Fairclough, N (2000a) *New Labour, new language*. (London: Routledge).
- Fairclough, N (2000b) Discourse, social theory and social research: the discourse of welfare reform. *Journal of Sociolinguistics*, 4(2), 163-195.
- Fairclough, N (2001) *Language and Power* (Second edition). (Harrow: Longman Publishers).
- Fairhurst, P. & Pumfrey, P. D. (1992) Secondary school organisation and the self concepts of pupils with relative reading difficulties. *Research in Education*, 47, 325-331.
- Farrugia, D. (2009) Exploring stigma: Medical knowledge and the stigmatisation of parents of children diagnosed with autism spectrum disorder. *Sociology of Health & Illness*, 31(7), 1011-1027.
- Finkelstein, V. (1980) *Attitudes and disabled people*, (New York, World Rehabilitation Fund).
- Finlay, L. (2002) Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), 209-230.
- Fisher, P. & Goodley, D. (2007) The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. *Sociology of Health & Illness*, 29(1), 66-81.
- Frauenheim, J. (1978) Academic Achievement Characteristics of Adult Males Who Were Diagnosed as Dyslexic in Childhood. *Journal of Learning Disabilities*, 11, 21-28.
- Frederickson, N. & Jacobs, S. (2001) Controllability attributions for academic performance and the perceived scholastic competence, global worth and achievement of children with dyslexia. *School Psychology International*, 22(4), 401-16.
- Geertz, C. (1973) *The interpretation of cultures*. (New York: Basic Books).
- Gerber, P. J. & Reiff, H. B. (1991) *Speaking for themselves: Ethnographic interviews with adults with learning disabilities*, (Ann Arbor, MI, University of Michigan Press).
- Gerber, P. J., Ginsberg, R. & Reiff, H. B. (1992) Identifying alterable patterns in employment success for highly successful adults with learning disabilities. *Journal of Learning Disabilities*, 25(8), 475-487.
- Gerber, P. J., Reiff, H. B. & Ginsberg, R. (1996) Reframing the learning disabilities experience. *Journal of Learning Disabilities*, 29(1), 98.
- Gilbert, L. S. (2002) Going the distance: 'closeness' in qualitative data analysis software, *International Journal of Social Research Methodology*, 5(3), 215-228.
- Gjessing, H. J. & Karlsen, B. (1989) *A longitudinal study of dyslexia*, (New York, Springer).
- Glesne, C. & Peshkin, A. (1992) *Becoming qualitative researchers: An introduction*, (White Plains, NY, Longman).
- Goodman, K. S. (1989) Whole language is whole. *Educational Leadership*, 46(6), 69-70.
- Goodson, I. & Sikes, P. (2001) *Life history research in educational settings: Learning from lives*, (Buckingham, Open University Press).

- Gottfredson, L. H., Finucci, J. H. & Childs, B. (1983) *The adult occupational success of dyslexic boys: A large-scale, long-term follow-up*, (Baltimore, MD, Johns Hopkins University, Baltimore).
- Gottfredson, L. H., Finucci, J. H. & Childs, B. (1984) Explaining the adult careers of dyslexic boys: Variations in critical skills for high-level jobs. *Journal of Vocational Behaviour*, 24, 355-73.
- Griffiths, C. B., Norwich, B. & Burden, B. (2004) Parental agency, identity and knowledge: Mothers of children with dyslexia. *Oxford Review of Education*, 30(3), 417-433.
- Grolnick, W. S. & Ryan, R. M. (1990) Self-perceptions, motivation, and adjustment in children with learning disabilities: A multiple group comparison study. *Journal of Learning Disabilities*, 22(2), 120-124.
- Gubrium, J. & Holstein, J. (1997) *The new language of qualitative method*, (New York, Oxford University Press).
- Gwernan-Jones, R. C. & Burden, R. L. (2010) Are they just lazy? Student teachers' attitudes about dyslexia. *Dyslexia*, 16, 66-86.
- Gwernan-Jones, R. C. (2009) *Identity & disability: A review of the current state and developing trends*. Available online at: <<http://www.beyondcurrenthorizons.org.uk/identity-and-disability-a-review-of-the-current-state-and-developing-trends/>>).
- Hallahan, D. & Mercer, C. D. (2001) *Learning disabilities: Historical perspectives*. Report for Office of Special Education Programs (Learning Disabilities Summit).
- Hammersley, M. (2008) *Questioning Qualitative Inquiry*. (London: Sage).
- Hampshire, S. (1990) *Susan's story*, (London, Corgi).
- Hardy, M. (1968) Clinical follow up study of disabled readers. Toronto, University of Toronto.
- Harré, R. & Van Langenhove, L. (Eds.) (1999) *Positioning theory*, (Oxford, Blackwell Publishers).
- Harter, S. & Pike, R. (1984) The pictorial scale of perceived competence and social acceptance for young children. *Child Development*, 55(6), 1969-1982.
- Harter, S. (1996) Historical roots of contemporary issues involving self-concept, in: B. Bracken (Ed.) *Handbook of self-concept: Developmental, social and clinical considerations*. (New York, John Wiley), 1-37.
- Hattie, J. & Marsh, H. W. (1996) Future directions in self-concept research, in: B. Bracken (Ed.) *Handbook of self-concept: Developmental, social and clinical considerations*. (New York, John Wiley), 421-462.
- Hellendoorn, J. & Ruijsenaars, W. (2000) Personal experiences and adjustment of dutch adults with dyslexia. *Remedial and Special Education*, 21(4), 227-239.
- Heron, J. (1996) *Co-operative inquiry: Research into the human condition*, (London, Sage).
- Herrington, M. (2007) Foreword, in: M. Kiziewicz & I. Biggs (Eds) *Cascade: Creativity across science, art, dyslexia and education*.
- Heymsfeld, C. R. (1989) Filling the hole in whole language. *Educational Leadership*, 46(6), 65-70.
- Hinton, C. G. & Knights, R. M. (1971) Children with learning problems: Academic history, academic prediction and adjustment three years after assessment. *Exceptional Children*, 37, 513-19.
- hooks, b. (1990) *Yearning: Race, gender, and cultural politics*, (Boston, MA, South End Press).
- Horkheimer, M. (1937) Traditional and critical theory. *Zeitschrift fur Sozialforschung*.
- Hughes, W. & Dawson, R. (1995) Memories of school: Adult dyslexics recall their school days. *Support for Learning*, 10(4), 181-184.
- Humphrey, N. (2002) Teacher and pupil ratings of self-esteem in developmental dyslexia. *British Journal of Special Education*, 29(1), 29-36.
- Hunt, C. (2001) Climbing out of the void: Moving from chaos to concepts in the presentation of a thesis. *Teaching in Higher Education*, 6(3), 351-367.
- Hunt, C. (2006) Travels with a turtle: Metaphors and the making of a professional identity. *Reflective Practice*, 7(3), 315-332.

- Huntington, D. D. & Bender, W. D. (1993) Adolescents with learning disabilities at risk? Emotional well-being, depression and suicide. *Journal of Learning Disabilities*, 26, 159-166.
- Ingesson, S. G. (2007) Growing up with dyslexia. *School Psychology International*, 28(5), 574-591.
- Interagency Committee on Learning Disabilities (1987) Learning disabilities: A report to the US congress. Bethesda, MD, National Institutes of Health.
- Ivanič, R (1998) *Writing and Identity: The discursive construction of identity in academic writing*. Studies in written language and literacy volume 5. (Amsterdam: John Benjamins Publishing).
- Kalyanpur, M. & Harry, B. (2004) Impact of the social construction of ID on culturally diverse families: A response to Reid and Valle. *Journal of Learning Disabilities*, 37(6), 530-533.
- Kellam, S. G., Brown, C. H., Rubin, B. R. & Ensminger, M. E. (1983) Paths leading to teenage psychiatric symptoms and substance use: Developmental epidemiological studies in woodlawn, in: S. B. Guze, F. J. Earls & J. E. Barratt (Eds) *Childhood psychopathology and development*. (New York, Raven Press), 17-51.
- Kerr, H. (2001) Dyslexia and adult literacy: Does dyslexia empower?, in: J. Crowther, M. Hamilton & L. Tett (Eds) *Powerful literacies*. (Leicester, National Institute of Adult Continuing Education).
- Kerr, H. (2001) Learned helplessness and dyslexia: A carts and horses issue? *Reading: literacy and language*, 35(2), 82-85.
- Kress, G. (2001) From saussure to critical sociolinguistics, in: M. Wetherell, S. Taylor & S. J. Yates (Eds) *Discourse theory and practice: A reader*. (London, Sage).
- Lanczik, M. & Keil, G. (1991) Carl wernicke's localization theory and its significance for the development of scientific psychiatry. *History of Psychiatry*, 2, 171-180.
- Lawrence, D. (1971) The effects of counselling on retarded readers. *Educational Research*, 27(3), 32-9.
- Lawrence, D. (1985) Improving self-esteem and reading. *Educational Research*, 27(3), 32-9.
- Leech, N. L. and Onwuegbuzie, A. J. (2011) Beyond Constant Comparison Qualitative Data Analysis: Using NVivo, *School Psychology Quarterly*, 26(1), 70-84.
- Lewandowski, L. & Arcangelo, K. (1994) The social adjustment and self-concept of adults with learning disabilities. *Journal of Learning Disabilities*, 27, 598-605.
- Lincoln, Y. S. (1995) Emerging criteria for quality in qualitative and interpretive research. *Qualitative Inquiry*, 1(3), 275-289.
- Logan, J. (2009) Dyslexic entrepreneurs: The incidence; their coping strategies and their business skills. *Dyslexia*, 15(4), 328-346.
- Macdonald, S. J. (2009) Windows of reflection: Conceptualising dyslexia using the social model of disability. *Dyslexia*, 15(4), 347-362.
- Marcus, G. E. (1998) What comes (just) after "Post"? The case of ethnography, in: N. K. Denzin & Y. S. Lincoln (Eds) *The landscape of qualitative research: Theories and issues*. (vol. 1). (Thousand Oaks, Sage), 383-406.
- Marcuse, H. (1968) *Negations: Essays in critical theory*, (London, Allen Lane/Penguin).
- Maughan, B. (1995) Annotation: Long-term outcomes of developmental reading problems. *Journal of Child Psychology and Psychiatry*, 36(3), 357-371.
- Maughan, B., Gray, G. & Rutter, M. (1985) Reading retardation and antisocial behaviour: A follow-up into employment. *Journal of Child Psychology and Psychiatry*, 26, 741-758.
- Maughan, B., Hagell, A., Rutter, M. & Yule, W. (1994) Poor readers in secondary school. *Reading and Writing: An Interdisciplinary Journal*, 6, 125-150.
- Mauthner, N. S. & Doucet, A. (2003) Reflexive accounts and accounts of reflexivity in qualitative data analysis. *Sociology*, 37(3), 413.
- Mccall, R. B., Evahn, C. & Krantzler, L. (1992) *High school underachievers: What do they achieve as adults?*, (Newbury Park, Sage Publications).
- Mcgee, R., Feehan, M., Williams, S. & Anderson, J. (1992) Dsm-iii disorders from age 11 to 15 years. *Journal of the American Academy of Child and Adolescent Psychiatry*, 31, 50-59.

- McNulty, M. A. (2003) Dyslexia and the life course. *Journal of Learning Disabilities*, 36(4), 363-381.
- Montgomery, M. S. (1994) Self-concept and children with learning disabilities: Observer-child concordance across six context-dependent domains. *Journal of Learning Disabilities*, 27(4), 254-262.
- Morris, J. (1991) *Pride against prejudice*, (London, Women's Press).
- Myers, F. R. (1988) Locating ethnographic practice: Romance, reality, and politics in the outback. *American Ethnologist*, 15(4), 609-624.
- Norwich, B., Griffiths, C. B. & Burden, B. (2005) Dyslexia-friendly schools and parent partnership: Inclusion and home-school relationships. *European Journal of Special Needs Education*, 20(2), 147-165.
- Oka, E. R. & Paris, S. G. (1987) Patterns of motivation and reading skills in underachieving children, in: S. J. Ceci (Ed.) *Handbook of cognitive, social, and neuropsychological aspects of learning disabilities*. (vol. II) (Hillsdale, NJ, Lawrence Earlbaum Associates), 115-145.
- Oliver, M. (1990) *The politics of disablement*, (Basingstoke, Macmillan).
- Oliver, M. (1996) *Understanding disability: From theory to practice*, (London, MacMillan press).
- Palombo, J. (2001) *Learning disorders and disorders of the self in children and adolescents*, (New York, W.W. Norton & Company).
- Phillips, L. & Jørgenson, M. W. (2002) *Discourse analysis as theory and method*, (London, Sage).
- Polkinghorne, D.E. (2005) Narrative configuraton in qualitative analysis, in J. A. Hatch and R. Wisniewski (Eds.), *Life History and Narrative*, 5-23. (London: RoutledgeFalmer).
- Pollak, D (2002) *Dyslexia, the self and higher education : learning life histories of students identified as dyslexic*. (Unpublished thesis (PhD) De Montfort University).
- Pollak, D. (2005) *Dyslexia, the self and higher education: Learning life histories of students identified as dyslexic*, (Stoke on Trent, Trentham Books).
- Porter Abbott, H. (2002) *The Cambridge Introduction to Narrative*. (Cambridge: Cambridge University Press).
- Potter, J. & Wetherell, M. (1987) *Discourse and Social Psychology: Beyond attitudes and behavior*. (London: Sage).
- Pratt, M. L. (1986) Fieldwork in common places, in: J. Clifford & G. E. Marcus (Eds) *The poetics and politics of ethnography*. (Berkeley, CA, University of California Press).
- Preston, R. C. & Yarrington, D. J. (1967) Status of fifty retarded readers eight years after reading clinic diagnosis. *Journal of Reading*, 11, 122-9.
- Pring, R. (2000) *Philosophy of educational research*, (Second edition) (London, Continuum).
- Pringle-Morgan, W. (1896) A case of congenital word blindness. *British Medical Journal*, 2, 1378.
- Prout, H. T., Marcal, S. D. & Marcal, D. C. (1992) A meta-analysis of self reported personality characteristics of children and adolescents with learning disabilities. *Journal of Psychoeducational Assessment*, 10, 59-64.
- Pumfrey, P. D. & Reason, R. (1991) *Specific learning difficulties (dyslexia): Challenges and responses*, (Windsor, NFER-Nelson).
- Rackham, K. (1972) A follow-up of pupils at one word-blind centre. *ICAA Word-Blind Bulletin*, 4, 71-9.
- Radnor, H. (2002) *Researching your professional practice: Doing interpretive research*, (Buckingham, Open University Press).
- Rawson, M. B. (1968) *Developmental language disability: Adult accomplishments of dyslexic boys*, (Baltimore, MD, Johns Hopkins University Press).
- Riessman, C. K. (2008) *Narrative Methods for the Human Sciences*. London: Sage.
- Rice, M. & With Brooks, G. (2004) *Developmental dyslexia in adults: A research review*. Report for NRDC (National Research and Development Centre for adult literacy and numeracy) (London).
- Richards, L. (2002) Qualitative computing—a methods revolution?, *International Journal of Social Research Methodology*, 5(3), 263-276.

- Richardson, L. (1997) *Fields of play: Constructing an academic life*, (New Brunswick, NJ, Rutgers University Press).
- Richardson, L. & Adams St. Pierre, E. (2005) Writing: A Method of Inquiry, in: N. K. Denzin & Y. S. (Eds) *The Sage handbook of qualitative research* (3<sup>rd</sup> ed., pp 959-978) (Thousand Oaks, CA: Sage)
- Riddick, B. (1996) *Living with dyslexia: The social and emotional consequences of specific learning difficulties*, (London, Routledge).
- Riddick, B. (2000) An examination of the relationship between labelling and stigmatism with special reference to dyslexia. *Disability & Society*, 15(4), 653-667.
- Riddick, B. (2001) Dyslexia and inclusion: Time for a social model of disability perspective? *International Studies in Sociology of Education*, 11(3), 223-236.
- Riddick, B. (2010) *Living with dyslexia: The social and emotional consequences of specific learning difficulties/disabilities*, (2nd edition) (London, Routledge).
- Riddick, B., Farmer, M. & Sterling, C. (1997) *Students and dyslexia: Growing up with a specific learning difficulty*, (London, Whurr).
- Riddick, B., Sterling, C., Farmer, M. & Morgan, S. (1999) Self-esteem and anxiety in the educational histories of adult dyslexic students. *DYSLEXIA*, 5, 227-248.
- Rogan, L. & Hartman, L. (1976) *A Follow-up Study of Learning Disabled Children as Adults*. Final Report. Washington DC: Bureau of Education for the Handicapped, US Dept HEW
- Rose, J. (2009) *Identifying and teaching children and young people with dyslexia and literacy difficulties*. Report for Department for Children, Schools and Families (London).
- Rosenthal, J. (1973) Self-esteem in dyslexic children. *Academic Therapy*, 9(1), 27-39.
- Rutter, M., Tizard, J., Yule, W., Graham, P. & Whitmore, K. (1976) *Educational, health and behaviour*, (London, Longman and Green).
- Saracoglu, G., Minden, H. & Wilchesky, M. (1989) The adjustment of students with learning disabilities to university and its relationship to self-esteem and self-efficacy. *Journal of Learning Disabilities*, 22, 590-592.
- Saunders, W. A. & Barker, M. G. (1972) Dyslexia as a cause of psychiatric disorders in adults. *British Medical Journal*, 4, 759-61.
- Schacter, D. L. (2007) *How the mind forgets and remembers: The seven sins of memory*, (London, Souvenir Press Ltd).
- Schacter, Daniel L. (1999). "The Seven Sins of Memory: Insights From Psychology and Cognitive Neuroscience". *American Psychologist* 54(3): 182–203
- Schafer, R. (1981) Narration in the psychoanalytic dialogue, in: W. J. T. Mitchell (Ed.) *On narrative*. (Chicago, University of Chicago Press).
- Schoon, I. (2006) *Risk and resilience: Adaptations in changing times*, (Cambridge, Cambridge University Press).
- Sikes, P. (2010) The ethics of writing life histories and narratives, in: A.-M. Bathmaker & P. Harnett (Eds) *Exploring learning, identity & power through life history & narrative research*. (London, Routledge), 11-24.
- Silver, A. & Hagin, R. K. (1964) Specific reading disability; follow-up studies. *American Journal of Orthopsychiatry*, 34, 94-102.
- Silver, A. & Hagin, R. K. (1985) Outcomes of Learning Disabilities in Adolescence, in: M. Sugar, A. Esman, J. Looney, A. Schwartzberg & A. Sorosky (Eds) *Adolescent Psychiatry: Developmental and Clinical Studies*, vol 12. (Chicago: University of Chicago Press)
- Singer, E. (2005) The strategies adopted by dutch children with dyslexia to maintain their self-esteem when teased at school. *Journal of Learning Disabilities*, 38, 411-423.
- Singleton, C. H. (2008) *Intervention for dyslexia: A review of published evidence on the impact of specialist dyslexia teaching*. Report for University of Hull (Hull).
- Singleton, C. H., Cottrell, S. N. G., Gilroy, D., Goodwin, V., Hetherington, J., Jameson, M., Laycock, D., Mcloughlin, D., Peer, L., Pumfrey, P. D., Reid, G., Stacey, G., J., W. & D., Z. (1999) *Dyslexia in higher education: Policy, provisions and practice*. Report for University of Hull (Hull).

- Skelton, T. & Valentine, G. (2003) 'it feels like being deaf is normal': An exploration into the complexities of defining d/deafness and young d/deaf people's identities. *The Canadian Geographer*, 47(4), 451-466.
- Smith, D. (1974) Women's perspective as a radical critique of sociology. *Sociological Inquiry*, 44(1), 7-13.
- Smith, D. E. (1993) High noon in textland: A critique of clough. *The Sociological Quarterly*, 34(1), 183-192.
- Smith, F. (1978, 1985) *Reading*, (Second edition) (Cambridge, Cambridge University Press).
- Sparkes, A. (2002) *Telling tales in sport and physical activity: A qualitative journey*, (Leeds, Human Kinetics).
- Spreeen, O. (1987) *Learning disabled children growing up: A follow-up into adulthood*, (Lisse, Netherlands, Swets & Zeitlinger).
- Stanovich, K. (1986) Matthew effects in reading: Some consequences of individual differences in the acquisition of literacy. *Reading Research Quarterly*, 21(4), 360-407.
- Tedlock, B. (2003) Ethnography and ethnographic representation, in: N. K. Denzin & Y. S. Lincoln (Eds) *Strategies of qualitative inquiry*. (vol. 2, Thousand Oaks, Sage), 165-213.
- Thomson, M. & Hartley, G. M. (1980) Self-esteem in dyslexic children. *Academic Therapy*, 16(1), 19-36.
- Thomson, M. (1990) *Developmental dyslexia: Studies in disorders of communication*, (Third edition) (London, Whurr).
- UPIAS (1976) *Fundamental principles of disability*. Report for UPIAS (London).
- Van Manen, M (1997) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. Ontario: The Althouse Press
- Vellutino, F. R., Fletcher, J. M., Snowling, M. J. & Scanlon, D. M. (2004) Specific reading disability (dyslexia): What have we learned in the past four decades? *Journal of Child Psychology and Psychiatry*, 45(1), 2-40.
- Vidich, A. J. & Lyman, S. M. (1998) Qualitative methods: Their history in sociology and anthropology, in: N. K. Denzin & Y. S. Lincoln (Eds) *The landscape of qualitative research: Theories and issues*. (vol. 1) (Thousand Oaks, Sage), 41-110.
- Wellington, J. (2000) *Educational research: Contemporary issues and practical approaches*, (London, Continuum).
- West, T. (2009) *In the mind's eye: Creative visual thinkers, gifted dyslexics and the rise of visual technologies*, (Second edition) (Amherst, Prometheus Books).
- West, T. G. (1997) *In the mind's eye: Visual thinkers, gifted people with dyslexia and other learning difficulties, computer images, and the ironies of creativity*, (New York, Prometheus Books).
- Wetherell, M. (2001) Introduction, in: M. Wetherell, S. Taylor & S. J. Yates (Eds) *Discourse theory and practice: A reader*. (London, Sage).
- Yule, W. (1973) Differential prognosis of reading backwardness and specific reading retardation. *British Journal of Educational Psychology*, 43, 244-248.
- Zelege, S. (2004) Self-concepts of students with learning disabilities and their normally achieving peers: A review. *European Journal of Special Needs Education*, 19(2), 145-170.

## APPENDIX 1: AMBER'S TRANSCRIPTS, TIMELINE AND SUMMARY

First interview with Amber 17 February 1 hour 29 minutes 55 seconds

Ruth: I'm talking to lots of dyslexic adults and getting their life stories

Amber: ok

Ruth: and what I'm doing is using a pseudonym so that when I talk about them I'm not using their name. So is there a name that you'd like to use?

Amber: Amber?

R: Amber. Ok. Sounds good. So what we'll do today is you'll talk to me about your life story

Amber: ok

R: and then I'll type it up in a transcript and then I'll give that back to you. And that's considered your property, it's like your story. And what you're doing when you give permission is you're giving me permission to me to use that story in my research

Amber: yes

R: so I have permission to do that

Amber: yes, you do

R: ok. And anytime that we're interviewing if you feel that you'd rather stop please say

Amber: ok

R: and that's absolutely fine. Ok? For any reason

Amber: ok

R: and what's your date of birth?

Amber: 26/11/83

R: great. Ok, tell me about your life.

Amber: Gosh, how can I start. Born in ... South Wales. Sort of grew up there, all my childhood, really, since then have moved about a bit, done some travelling, then moved to the Midlands to go to University then moved to the Southwest of England to go to university where I am now. [pause] Do you want a lot about the dyslexia side of my life as well?

R: I'm interested in the dyslexia side but I'm interested in normal things doesn't only have to be about dyslexia

Amber: yeah, ok

R: anything that you think is important is important

Amber: yeah. Sort of went through school, really quite enjoyed it. I moved school when I was about 7. Moved to a very different area and sort of settled there. Family built a house but we lived in it as we built it so it was all a bit higglety-pigglety

R: yeah

Amber: all the way through. And then went to comp. I was, in terms of, home life wasn't great growing up. That got worse when I got to comp. I know I buried myself in my work, but I really enjoyed it at the same time. Whereas my brother would get very, he could do it in seconds and be done and he'd be fine and he'd get there. I'd take hours

R: mmm

Amber: to do it. Which suited me at the time, but something that nobody noticed. And then went through school, went to college. College was quite fun, went and did a baccalaureate  
R: mmhmm

Amber: which was good fun, very hard work, very stressful.

R: mmm

Amber: Went through that and really started struggling quite a bit with the work load. Never knew I was dyslexic

R: yeah

Amber: So yeah, kind of did that and wanted a break. So went travelling which is my passion.

R: Where did you go?

Amber: I went Interailing round Europe with a friend for quite a while. And stopping everywhere we could and then I went over to Tanzania for a bit and taught in a school over there for a little while. That didn't work out as well, there was a lot of problems with, the Iraq war was just starting

Ruth: oh no

Amber: hostilities that we had to leave for safety reasons. So I came back, earned a bit more money then went to Thailand to teach for a little while, which was absolutely amazing from, very hard to adjust back from

Ruth: yeah

Amber: you know it's good, I'm still in contact with a lot of the people there that I taught and worked with and yeah.

R: So did you teach English?

Amber: in Tanzania I taught maths and science, it was an English medium school. Though in Thailand I, well, attempted to teach English, realised I don't know anything about grammar at all. So I worked all the way to sort of pre-university age with monks who were 27, 28, in the temples and I can't spell. I've always had an issue with that so learned a lot very good tactic as in 'let's look it up together and let's learn how to use the dictionary'

Ruth: yeah

Amber: and things like that, it was good fun, for me, it really confirmed that I can't teach English long term, that was quite, I've never been hugely confident with it but it's kind of nice to do, in a way, it's weird, it's something I'd like to do but struggle to do. Yeah, so then came back from Thailand and I moved to Midlands Uni

R: yeah

Amber: I started a course there, started philosophy

R: yeah

Amber: and I did it for two weeks then changed to biology. But really struggled there in terms of the work and couldn't understand why I couldn't do it. And a lot of it, we had multiple choice through everything in the first year and I could narrow down two but I couldn't tell the difference between two when I read it I just misread it

R: right

Amber: with negative marking that was absolutely atrocious

R: so negative marking is

Amber: if you've got one right you've got one and if you get the wrong answer you get minus half

R: oh

Amber: so you could know half the stuff but if you put the other half wrong you'd still fail

R: oh

Amber: mmm. Yeah, that was nice

R: I've not heard of that

Amber: no, and then so I went, I referred myself to get screened for dyslexia because I was picking up patterns which I couldn't explain

R: yeah

Amber: but their process was very long and over the term they still hadn't decided by which point I was very stressed and fed up

R: yeah

Amber: and decided to leave and start again

R: yeah

Amber: so I came out. By chance I landed a job in careers guidance which was really good. It was, I was mainly just temping the admin side, but got a lot of information out of them

R: yeah

Amber: really a nice group of people, almost got on my feet, as in I can do something

R: mmm

Amber: as well.

R: ok, yeah

Amber: because Midlands had knocked me for six, basically. So yeah, no, that was quite good. They'd all done a politics degree and I was interested in politics from my travels so I thought, well, it looks good, looked into it and kind of rang up uni's to find someone that would accept me without having to wait another year

R: yeah

Amber: to apply. That's how I ended up in Southwestern [University]

R: ok

Amber: which is good. Which is great. And yeah, so, and in terms of the dyslexic side I got referred quite quickly through the system

R: once you were in Southwestern?

Amber: once I was in Southwestern.

R: ok

J: yeah, Learning Support here are great. They're just amazing people and very good at what they do in terms of getting people referred or the support they provide, which, I think without that I wouldn't have made it through a lot of the course work, yeah so, it was a bit weird, it was 2 days before my 21<sup>st</sup> birthday that someone told me I was dyslexic.

R: yeah

Amber: which for me seems a bit late, compared to some people

R: mmm

Amber: and yeah, that was quite hard to deal with at the time I think. There are a few of us on our course, there's about 5 of us and four of us, it wasn't until we were at uni that we found out we were dyslexic. In a way that's been quite nice we've almost formed our own little groups in terms of that

R: yeah

Amber: where we support each other, or we joke about it, or we take the mick, or we use it as an excuse, with kind of, got feedback, if someone tells you and then you're left, and there are study skills and services but no one actually told us what dyslexia meant

R: right

Amber: or and I know we'd all through the process spoke to somebody beforehand, we were kind of just left

R: right

Amber: and so the summer afterwards I read some stuff on it which really helped me, and passed it on to the others, but other than that, you

R: ok, can you tell me when you first were told you were dyslexic how you felt?

Amber: it was quite a mixture. There was a bit of relief, because it's quite weird almost referring yourself to it as you're worried that it's not and you'll look silly because you've made someone go out of their way or it explained a lot to me. And especially in the next few months afterwards when I kind of understood the areas, a lot of things slotted into place from the past? Like in school why, my physics teacher used to, really couldn't comprehend how I could, I could match the letters of the equation and I could do the word version of the equation but I can't match that

R: oh, right

Amber: or I could do it one way but to do it backwards was a huge issue for me. And little things people picked up over the years, so yeah, in some ways it was kind of a bit of a relief with it. There was a lot of anger at the time as well. Because I was screened for dyslexia at college, our college had a policy of screening everyone

R: right

Amber: but they didn't pick up on it. Or a lot of the things in the past, like people would have a go at me because I wouldn't learn my spellings and I'd just spent three hours trying to learn them and

R: yeah

Amber: it was my fault. And I was a bit, quite angry at people, or even at me for not picking it up sooner, as well, so there's a bit of that. And then there's a lot of confusion because you're given a report but that's about it and you don't know, almost what it means. It kind of, affects your identity slightly, really, in a way, you're kind of a person with dyslexia

R: mmm

Amber: or, it yeah, it's a bit strange. At first. At the time. It's just normal now.

R: mmhmm

Amber: and it's fine. But at time it was like, well, what does this mean? Which was quite confusing at the time.

R: You said that it affected your identity. Can you explain what you mean?

Amber: yeah, [horrible noise of hovering, moved recorder closer] it kind of affects me in terms of, I knew my spelling has always been pretty bad, but it turned out it's quite, [I don't think I have a normal distribution for it was] kind of middleish, which is ok, but in terms of things like, my reading was a lot worse than I thought it was,

Ruth: yeah

Amber: like comprehension. I knew that it was slower but I hadn't realised, all of a sudden I'm like well, no, I can't read. So I stopped reading, not a huge reader in the past, but you know, I'd read a book, it'd take me awhile, but do it, too. But now, I can't do this now, I can't read

Ruth: right, yeah

Amber: and I think there was a good 18 months before I picked up a book for my own, wanting to

R: ok

Amber: so yeah, it changed me [in terms of my identity] in that way. And it also changed me with my family. They've all reacted to it quite differently. It did cause some problems, actually. My dad doesn't believe it, doesn't think it's right, it's all a joke, he laughs at it, but, and then it's not been talked of since I told him

R: right

Amber: whereas my Mum sees it that I should have special treatment for everything and anything and is it been almost sorted and fixed

R: mmm

Amber: which put a lot of pressure on me initially at the time. So yeah, it kind of changes you for awhile. A lot of confidence issues with that.

R: helping or hurting?

Amber: Hurting. Yeah, and there's a lot of, when someone turns around and says 'right, your reading and your short term memory and stuff is' and you just become so much more aware of those things

R: mmhmm

Amber: I mean, you don't disagree or it's not that you haven't noticed them before but you become so aware that, you're so much conscious every time you do something in relation to that, like my short term auditory memory is not that great and when I used to work I could not take a phone message and write the phone number down properly because I'd forget it

Ruth: yeah

Amber: which used to be quite funny at the time and everyone in the office would laugh because I'd put the completely wrong phone number and things

Ruth: yeah

J; but, it kind of explained that but then I'd turn around and go 'oh no, I can't write this down ever'

Ruth: yeah

Amber: and there's a lot of almost regaining your identity and saying 'well, this is me, and that's the dyslexic bit but that's not, they're part and parcel but one doesn't have to control the other, almost. Yeah. [pause]

Ruth: ok, there's loads of bits to fill in. Can you tell me more about when you were a child, and about your family?

Amber: When I was little, gosh, when I was really little I remember being at home, Mum used to teach us a lot at home. And I mean, I started nursery the day after I was 3. That's what we do in Wales, everyone's at school at 3

Ruth: yeah

Amber: and yeah, I used to read, I used to do stuff and enjoy it. And so we went through until about, I was seven when we moved. But up until then, we went to school and Mum would do stuff with us after school. Dad worked a lot so he was never around much. I've got one younger brother. He's about 16 months younger than me so quite close age-wise

Ruth: mmm

Amber: and yeah, I was quite ill as a child a lot, so I'd often be off school for weeks at a time

Ruth: what were you ill with?

Amber: things like pneumonia, bronchitis

R: wow

Amber: anything you could get I'd get it. I was quite a sickly child. Then I remember being sick so Mum went and got me work from school. The school got quite annoyed because in the 6 weeks I was off with bronchitis I completed a year's work [Ruth laughing] just [?] not do a page a day I'd do a couple more of them, four of them or something. So yeah, they got a bit annoyed when I returned because they didn't know what to do with me. I was a year ahead of it and I was in a class at the time where I think it was the youngest of the year above us and we were the oldest of our year so we were a mixed class so it wasn't too bad

Ruth: yeah

Amber: but they weren't sure what to do with me the following year when I'd reached the top of the infants.

Ruth: yeah

Amber: but we moved then, so that kind of solved that problem.

Ruth: so you actually learned to read quite early?

Amber: yes. Quite early. I was reading before I was in nursery. I think mainly because Mum taught us. She was always big on learning lots of things though when I moved school at seven it was all before the National Curriculum came in but the new school used the same reading scheme that we had and I got moved back an entire level and I've only recently known why because Mum said apparently I could read the words but I didn't understand it. So yeah, that's not something I was aware of at the time I knew I'd gone back and I got very annoyed that I was reading the same books again

Ruth: yeah, huh

Amber: but yeah, no I knew, always from a young age maths was my strong point. I always used to be really good with numbers and feel that that, I always remember in primary school having the extension booklet

Ruth: yeah

Amber: for the, you've finished your book, do this and I always had it like a challenge, see how quickly you could finish the work to get onto the extension stuff

Ruth: yeah

Amber: that was a bit more interesting. But yeah.

Ruth: So you were quite successful at primary school?

Amber: Yeah. No, it was, always got on parent's evening 'got to work at your English', 'got to do your spelling' and I'd turn around and say 'I'm going to be a maths teacher it doesn't matter' [Ruth laughs] so yeah, no, everything was quite good. I did the SATs and did really well in them.

Ruth: Do you remember what you got?

Amber: Yeah, I got 5 in English and Science and 6 in maths.

Ruth: What, at year 6?

Amber: yeah.

Ruth: oh, ok

Amber: yeah, that shocked the school too

Ruth: that's very good [both laughing]

Amber: yeah, it was good. For some reason maths just clicked. Yeah, so

Ruth: ok. And then you went up to comprehensive

Amber: yeah, I don't know, comp was quite different for me. I was always quite a shy, quiet person, and so I'd gone from a very small school to this huge comp and had a few difficulties, I found. Though it was generally ok, kept with all my primary friends, almost, we all went up together

Ruth: yeah

Amber: yeah, and it was quite big with the music in the school, like choirs, violin lessons and clarinet lessons and all sorts. Used to spend most of my lunchtimes doing something

Ruth: yeah. So you were very involved in music?

Amber: yes, not necessarily very good at music, but I was always involved in it. It was quite fun and yeah, it's something I enjoyed quite a lot

Ruth: yeah

Amber: so yeah, I was quite involved with that. [pause] At the time I remember, at the end of the first year they, a lot was happening at home with my family.

Ruth: yeah

Amber: There were a lot of problems. It was quite nice just to go to school for a lot of it

Ruth: yeah

Amber: And yeah, so, but as we went up through comp the problems got more and I had a lot more responsibility but we'd

Ruth: Can you tell me some of what happened?

Amber: There were a lot of issues with my parent's relationship. A lot of arguments. My father has mental health problems as well and can be quite violent. And so there was a lot going on. And Mum found it, during that time that she had osteoporosis so over the long term she was gradually becoming disabled so I had a lot of caring responsibilities as well for me and my brother and yeah, juggling.

Ruth; yeah, ok.

Amber: Which is good and bad at times, it varied. But yeah, that went on through comp

Ruth: Ok. And sorry, so, what was it that your mother has?

Amber: Osteoporosis. Sort of brittle bones.

Ruth: ok

Amber: and osteoarthritis so she's in a lot of pain. But also she spent a lot of time coming to terms with it, almost?

Ruth: yeah

Amber: She spent a long time, almost like I did when I found I was dyslexic, trying to read as much about it, or find out as much information, she got very absorbed in that for quite a while.

R: Did you support her emotionally as well as physically?

Amber: Yeah, a bit. Or tried to. It's very difficult at that age with it. It's more in terms of she'd be out a lot, or when my parents eventually separated, she'd work two jobs so I'd get everything sorted for my brother and try to help her with stuff around the house or stuff like

that, really. Although my brother's not that much younger, emotionally we became very mother/son relationship, I'll look after him I'm the big sister role.

Ruth: mmm

Amber: so yeah, that's... [pause]

Ruth: What was school like at that time?

Amber: School, I kind of still enjoyed it. I found it quite hard because I'd often switch off in lessons and things like that but at home I'd always be trying to do homework or something, sometimes it was an excuse to get away from sitting in a room where nobody is talking and stuff like that, so I think in terms of school I'd have very big peaks and troughs sometimes with it. But yeah, it was generally my escape almost. And it's not, it's only looking back on it now I realise how long used to take me to do

Ruth: mmhmm

Amber: Everyone's like 'oh you're very hard working' and stuff like that

Ruth: yeah

Amber: which, I was and have always been conscientious, sort of... yeah, it explains a lot looking back now at that. And I don't know if I would have changed that knowing that, but yeah

R: yeah, ok, What about your friends? Tell me more about your friends?

Amber: Sort of, well, comp was friends from primary and then other groups of friends started joining in, yeah it was quite good. We often would meet at weekends and go to the cinema or go to town and things like that. [pause] It was, yeah it was quite, kind of just normal stuff for teenagers

Ruth: mmm

Amber: that I could do, which was quite good. [pause] I always used to find music an issue because I can't remember names of songs or people and things like that and I'd often feel quite left out with that

Ruth: yeah

Amber: but in terms of friendships I tended to have more very very close group rather than lots of different people, but yeah, we all had our ups and downs, we were all very good at supporting each other through different things, like they helped me a lot when, some went through similar experiences a few years later, and the other way around

Ruth: mmm

Amber: Lost contact with a lot of my comp friends when I went to college. It was, a kind of school thing, if you left you left, then that was it, you were outside. And a couple of other people in there that left found the same thing. Though I think in college it was quite good for friends. We were a group of 20 of us doing a course. We all really clicked and we were all on the same sort of level with work and boyfriends and it was, yeah, amazing, it was really good, it felt more like, kind of like you'd chosen that group rather than that we were put together, but, we chose to stick together which was quite good. [pause]

Ruth: You said that you went travelling with one friend was that a friend from

Amber: yeah, that was a friend from college. Yeah, it's quite funny actually. We got to college and we were doing exactly the same subjects. We had the same birthday, the same height [Ruth chuckles] we had the same mutual friends without knowing it [J chuckles] and we owned the same wardrobe though we did consciously try and change that [Ruth laughs] because that got quite annoying, but that was great, we were so close, I mean we went round travelling for a month. And you can go anywhere with your rail ticket. And we planned our route in 10 minutes because we agreed, and we wanted the same. I couldn't have thought of a better person to do something like that with, and yeah, I haven't been travelling with anyone quite in the same way since, though. Quite a hard one to match up with. But yeah, no, she's great.

R: mmm. [pause] Ok, and tell me more about your travelling. You obviously really enjoyed it.

Amber: yes, I did. I loved learning about culture. I've always been big on sort of, other cultures and what people do and different places and seeing things. And so yeah, we kind of almost did sightseeing slash local experiences so we'd go to like a big city, go and see all the famous

sights, but then go and get lost in the suburbs or something or go to a little town. We liked that quite a lot. I don't know. There's something about, I love moving about. I was moving about constantly. We lived on trains or in youth hostels [pause] I just liked the different experiences, especially in Europe where you can go from one country to the next and it can change so drastically, and you've only spent an hour on the train getting there. But I love trying the different food and... 'attempting' the local language. [both laughing] it doesn't always work out too well. And the friend I was with it kind of worked out really well. She could read maps really well. I can't. But I've got a sense of direction I can't explain. Whereas say, I can get you, I've done it, we went to Amsterdam and I went back three years later and without a map found exactly the same places again all over the city. I can just do that, I don't know how. Whereas, you give me a map and I'll get lost, and she was the opposite. So between the two of us, it worked. It worked really well. Not to say we didn't lost or get on the wrong bus numerous times.

R: It's all part of the adventure!

Amber: It's part of the adventure. And it's part of, if you're somewhere, I remember arriving at Frankfurt at quarter to six in the morning and got off the train and got out, and we looked, and we'd just been to Prague which is all pretty, and the buildings are lovely, and we'd met some really nice locals there who were showing us around for half the day, and we got to Frankfurt and it's very industrialised, dirty, cold, and we sort of looked at each other and said 'we don't like this' so we turned around and got back on a train out of there. And I just loved the fact that you could do that. You wake up in the morning and the only things you have to think about are 1) what you're doing, if you're doing anything 2) yeah, you've got to make sure at some point you get something to eat today and where you're going to sleep. And that's your only worries

R: yeah

Amber: really. You know, there no bills, there's no friends, because we won't take the mobile we refused. We emailed home every few days or phoned maybe once a week. But yeah, there's no, have to remember everything else and if you don't like it you move on. It's kind of, almost like a separate reality bubble. It's not real life. It's not the day to day stuff, but, yeah, kind of great.

Ruth: mmm

Amber: But once you start you can't stop [Ruth laughs] and then you have to keep going somewhere else, and somewhere new. Even though I buy travel books and I flick through them and I've got hundreds of trips I want to do in my head, and yeah, so even when I can't go like when I'm at uni – I'm not allowed to go travelling – doesn't mean I don't go on the internet and look at what I could be doing and stuff like that

Ruth: mmm. So you imagine... do you imagine?

Amber: oh, yes, all the time. Or use it as an incentive. 'Ok, now', the end of last year I think I was kind of fed up at the end of the year and we had lots of work on and I went to myself 'right, ok, you've got this, you've got a week to do this, you can finish this. You don't want to, you don't even want to look at the book. Right. If you get a 2:2, you can go here. If you get a 2:1 you do this. If you get a first you can really go away and do something' and use it as an incentive to get the work done.

Ruth: So did you go off somewhere at the end of the year?

Amber: I did and I didn't. I got a first in it and I wasn't expecting it and I couldn't afford what I'd offered myself

Ruth: aaaaw [both laughing]

Amber: which was a bit silly. But I had my second choice, an [arlot] of mine moved to Bulgaria last year who I'm very close to and missed quite a lot.

Ruth: yeah

Amber: so I went and stayed with her for a little while. So kind of compromised.

Ruth: yeah

Amber: but yeah, so [pause]

Ruth: So you must be doing quite well in your work to get a first  
Amber: yeah, I'm doing well. I think a lot of that has come down from study skills, the support I've had with them, and partly as well I was so determined after Midlands  
Ruth: yeah  
Amber: 1) not to drop out, because that has financial implications for me in terms of my funding  
Ruth: yeah  
Amber: and 2) I got so fed up with everyone having their own judgement about what had happened without asking me  
Ruth: mmhmm  
Amber: and, determined to prove them wrong  
Ruth: ok  
Amber: like, 'Oh, well maybe uni's not for you maybe you can't cope with it' or maybe, you know, 'if there's dyslexic stuff you shouldn't be doing it', and it's like, well, 'why not?' you know, so yeah, I find it, and almost in a way found my niche as well. Politics isn't something you can study before this level, so it's a bit of, almost a bit of a gamble, really  
Ruth: yeah  
Amber: as to whether it's right for you or not  
Ruth: yeah  
Amber: but I seem to have landed right there, really. I mean it's sort of, I found something I enjoy enough  
Ruth: so you're saying politics is your niche?  
Amber: yeah  
R: yeah  
Amber: yeah. I mean, a lot of things, I learned a lot from being at university in the Midlands. And I think without a lot of that I wouldn't have made a lot of the choices I've made while in the Southwest because I wasn't happy in the Midlands I'm not a huge city person  
R: yeah  
Amber: I like being near enough to the beach because I'm from the coast and I miss it when I'm not there  
Ruth: yeah  
Amber: and Midlands's a few hours on the train for me  
Ruth: yeah  
Amber: and the university, I mean it was so big, it used to take me half hour to walk to lecture? I was the opposite side of the campus to my lecture  
Ruth: right  
Amber: but just to walk across the campus took half an hour  
Ruth: wow  
Amber: and that was kind of, and you're very much a number whereas when I came down to Southwestern and especially at Southwestern  
Ruth: yeah  
Amber: it was all very small. Everyone says hi to everyone.  
Ruth: yeah  
Amber: And, there's a lot of other factors behind making the decision of what to study and where that I realised from Midlands. Because I think Midlands as well, there was a lot of 'I should go there' and 'I should study this because that will look good' or that's what people had said, or stuff like that, where I think Southwestern was a lot more, 'I want to do this' or 'I want to try it'  
Ruth: ok  
Amber: and I mean, I think that helped with the workload and I think it helped as well because I knew what to expect from Midlands? Ok I didn't meet what I was meant to be doing. But when I got to Southwestern I found, especially compared to others that I was a lot more aware

of what was required in terms of level in terms of reading in terms of independent study, that, I skipped the hurdle of having to know that so I could put a bit more effort into the work

Ruth: mmm yeah, that makes good sense, really

Amber: yeah, and a lot of stuff at college with the baccalaureate, as well, thoroughly different from A-levels I found, as in there's a lot of independent study there's a lot of group collaboration when you're learning topics, and there's a lot of, yeah, I mean, we did like a mini dissertation, we did a research project independently, and, you make up your own essay titles like you do at university whereas I found people who did A-levels on the course find that really hard to do and they here and they get quite frustrated and I'm like, 'well, no, because you can pick the bit you know you know, and write an essay on it' [Ruth chuckles] you don't have to turn it into a negative, you can really play it to your advantage. I think the experiences I had at college with that and obviously being supported a bit more as you did, like they do check your essay titles, ok [Ruth chuckles] before you write it and stuff like that, but you're kind of, I think you have an extra stepping stone

Ruth: yeah

Amber: So a lot of the stuff my friends at uni have had to learn is, I feel slightly at an advantage, that I've learned that already.

R: mmhmm

Amber: and in terms of independent living from travelling, and having almost 2 gap years if you include the Midlands year, I'm a bit older as well so a lot of that I skipped, I think that's helped me with the work really. [pause] And study skills is amazing

Ruth: Tell me what you've learned in study skills

Amber: Basically I see, it took awhile for my LEA to get the funding sorted

Ruth: yeah

Amber: which was a bit annoying, really. But I got given technology to support me with my learning, so I had a laptop but they upgraded that and I've got programmes on there, like, for some reason when I do work I can only ever hand write it I can't sit at a computer and type it straight?

Ruth: yeah

Amber: I just type a block. But that takes quite a while to type it all up so I've got like a dictation programme which is a lot quicker and, I've got like a programme that will read things back to me so I can hear what I've written, and a scanner that I can scan a book in and the computer will read it to me. So if I'm tired and not feeling like reading than that's there. Also with the dyslexia I've got scotopic sensitivity?

Ruth: mmhmm

Amber: Meares-Irlen Syndrome so I can change the colour setting on that and I've got glasses with

Ruth: right

Amber: that, and I find that's helped enormously

Ruth: right

Amber: because a lot of unexplained headaches and tiredness

Ruth: uh-huh

Amber: is just gone

Ruth: that's great

Amber: that's really quite drastic for me so I've got all the technology side of it but then I go and I see a dyslexic sort of study skills tutor once a week and I can basically do whatever I want with the session. So initially I did things like looking at ways to remember spellings for new words, I did things like Feuerstein and breaking it up [ruth laughing] and the multi-sensory approach

Ruth: I can't spell that

Amber: and different ways like that, and different strategies, ok, that you've got this part of reading, how you going to get through it

Ruth: yeah

Amber: what's the best way to do that. And looking at almost playing at strengths, and looking at concept, I do lots of things with concept maps, I'm a very visual person so actually taking that and using that for my work and learning how to do that. And also things, I mean, now I've done some of those initial things, you couldn't do that for 3 years so I do things like I take work that I've got with me, I either go through and plan an essay structure, or someone will go through and read it with me, like proof-read it, and learn bits of grammar as we go along [Ruth laughs] well, the same bits of grammar sometimes, I still can't do my apostrophes, no matter what. And things like that or even sometimes I find it quite useful, I'll go and I say 'Look, I'm doing this topic' and he's going 'well, tell me about it' and either by talking I realise I'm not getting where I want to be with it, or I don't know enough on this particular area because I can't say at that particular section of the essay

Ruth: yeah

Amber: or, and so then I can go away and go 'ok, I've got to do this' or sometimes just talking it through helps me to get my ideas sorted so it kind of works week by week as in what I want and sometimes we plan ahead with that and sometimes I turn up and say 'no, changed my mind, we're doing something else' but I find it really quite useful. And as well, I think it's helped my confidence a lot. Because I turned round and said 'well, no, you can't do this' and I became more aware of the things I couldn't do.

Ruth: yeah

Amber: through study skills I've become aware of the things I can or how I can compensate for the things I don't do as well.

Ruth: yeah

Amber: and since study skills my marks have gone up quite a lot with that and especially in comparison to Midlands so I've sort of seen the benefits and seen that 'oh, yeah, you can actually do this. This is ok' and with that you feel more confident to go and do the next bit, really

Ruth: ok

Amber: so, I mean, I think they're great, the study skills people. And I know, at Southwestern they've won awards for the work that they do. But yeah

R: ok. Now your diagnosis of dyslexia

Amber: yes

R: came at Southwestern

Amber: yes

R: can you compare, being at Southwestern with your diagnosis of dyslexia

Amber: mmm

R: and the study skills and stuff, and also the knock in confidence and the identity issues that you talked about

Amber: yeah

R: with being at Midlands, not knowing you were dyslexic

Amber: oh

R: and can you compare the two?

Amber: yeah, completely different. At Midlands I felt very lost with it. As in I felt overwhelmed by the course and the work and everything. And very confused. I mean, they were looking at dyslexia with me but I felt very frustrated that I could only see someone every other week because they didn't have enough staff and nobody could tell me either way. I felt completely stupid and I'd sit in a lecture room and everyone would know what was happening and I wouldn't. I felt very lost with that but also very pressurised that I should, I should be able to do this, or, there was a lot of expectation from family as well, I was trying to almost pretend, whereas I think, [pause] being at Southwestern with it, I don't know, maybe being at Nottingham as well, looking at it and looking at the dyslexia side of things, it was quite a negative and felt other people were quite negative about it. I remember going to see my tutor just before I decided to leave and he was like 'Oh, well, yeah, whatever', wasn't concerned

Ruth: what, when you said you were going to leave?

Amber: that I was going to leave the course and he was just like, 'well, you're not very happy here' and that was it, and I said about the dyslexia and he was 'well, you know, maybe something will come of that but if not' and he was quite dismissive of the possibility this might be why I'm struggling. And yeah, I remember in Midlands, I mean, I started with philosophy for two weeks and basically got, the first week for some reason we didn't really have any lectures, and then the second week we got all the handbooks and got the weekly required reading list. I went and got one of them and looked at the list and said 'I can't do this. I know I can't read that much in a week' and so kind of mass panicked and tried to change and sort, and obviously I was two weeks behind at biology which, compared to like 6 hours philosophy a week and we used to do 20 hours a week, so that was 40 hours behind plus the current work. And I just felt kind of lost with it

Ruth: mmm, not surprising

Amber: yeah. So yeah and everything was quite, it was all quite negative with it, and very uncertain but nowhere to reach out with it, whereas I found at Southwestern, yeah, that whole thing had a conclusion to it, it was hard to deal with it, though I found a lot more support with it, or a lot more, 'well, this is ok, don't worry about it', but not in a dismissive way. When you see the people at the study skills and you have the dyslexia screening and then you see the psychologist and then you have sort of technical needs assessments where you sit with someone and you work out, so there's quite a lot of different things that they do. But they're all kind of very 'ok, yeah, there's these things but this is quite normal, and this is ok' and that's kind of a different experience, I mean, it takes awhile to get on board, but it's a lot more, it's acceptable, almost. Whereas at Midlands it's very, 'well, why are you going into this office' 'well, to see the disability officer' 'oh, yes, but, no, why are you doing that? No, we won't go with you' and a lot of people's reactions are quite different. I think that's a lot to do with the universities as well? Midlands is very, gosh, every third person you see would turn around and say 'well, I did get an offer from Oxford but I turned it down' or, 'I should have been there' and I remember being ill one day and trying to get notes to copy up, and I wasn't living with people on my course. And it took me a week to get someone who was willing to lend me the notes to copy up from a lecture that I was ill, whereas here, everyone's like 'oh yeah, have a photocopy' or 'I'll email you my notes' or 'here's this' it's, I think the university in the Midlands is very competitive academically and everyone's out for themselves, whereas the university in the Southwest is a bit more laid back with that. Which I think makes the other things easier, so, in a lecture if you've missed something and you haven't got [?] then someone else will pass it over to you and it's not an issue and that kind of relaxes you a bit because in terms of if you know you're struggling with work or something, it's backup almost

R: yeah

Amber: yeah, [pause]

R: that's great, that's really interesting. Ok, what does your Dad do?

Amber: That's an interesting question. He is by profession a building surveyor

R: ok. You said before he was working a lot, that's why

Amber: yeah, he was a building surveyor, and he's in the same line, he's in the process of changing his job area at the moment

R: right

Amber: actually, currently, but yeah, building surveyor

R: and have you ever done work, I mean I know you worked as a teacher in various countries

Amber: I've worked since I was thirteen!

R: oh, right

Amber: yeah, it started with a paper round at 13, because we didn't get pocket money, and as I got older that's varied quite a lot. A lot of, when I was older if I wanted anything I had to work for it. Which I really appreciate, now.

R: right

Amber: And there was a lot of, as well, money was quite tight, so you didn't ask for things. But I've done things like waitressing, paper round, shop work. I worked in a pottery for 5 years

R: gosh

Amber: part-time. I was a potter's assistant. Kind of started with work experience when I was 15 for a week, and then went back in half term and then went back at Christmas and then went to weekends, and holidays, so I've done that quite a lot, really enjoyed that. I always loved art, I've always had a, almost like a divide in myself, whether I should be arty or a sciency side, since I've always liked science as well, science and maths and sort of stuff. So, yeah, so that. But then since then I did my gap year, so I was doing things like finance department, working for local newspapers, to office work, at the moment I work with the university, as ambassador so I do a lot of public relations, in the school, and stuff like that, and yeah [both talk at once]

Amber: a long cv! A lot of things with Swansea is part-time jobs and holiday jobs are very short term and very temporary. It's very unlikely that you'd go back the following summer to something. Whereas I know some people from different areas, they go back to the same job all the time

Ruth: yeah

Amber: it's open. Swansea is very short term so you can move from one thing to the next, so you do quite a lot of things but you're not doing as much. So I think at one point when I was 16 one summer I ended up with four jobs at once. I was the only 16 year old who had a diary where you had to work when I was working at which job. But they were all like one day here and one day there

Ruth: ok, and have your difficulties, like your dyslexic difficulties, I mean, I suppose you haven't known about them for that long, but do you think they've had any effect on your jobs? Have you had to work harder, or

Amber: yes, in terms of waitressing and taking orders it was always knowing that I wasn't very good at that. That was more laughed about that I did the wrong thing or put the order in the wrong place and stuff like that. I didn't notice as much, or I did the menu board and I'd misspell it and have to re-do the menu board, but not so much. I mean, office work I think has been the bigger challenge, especially sort of administrating 10 or so people and their diaries and people tell me something and they'd ring me and say 'have you done it' and I'd totally forgot they told me. So I'd have post-it notes everywhere and phone messages but was kind of ok with it. I found it affected me more work-wise after I knew. Because I mean, the work I did with careers was through a temping agency though it was long term temping. And so after the first year at Southwestern I went back home for the summer and originally had planned to ring up the temping agency and you know, say 'what have you got that I can do at the moment' but wouldn't because I didn't want to say about the dyslexia but didn't want to not say and then it come out and have trouble. I presumed people would react, especially when your jobs typing and you're writing, or keeping diaries, and I didn't have the confidence to do that again which is silly looking back on this. I did it for 9 months [Ruth chuckling] and ok we had problems, and we had funny phone messages and all sorts but I did it and no one was bothered or concerned enough, being a temp your job contract can finish in a day. If someone turns round, so, no one was that bothered with it. But yeah, it affected me in what I thought I could do with it, and also I considered teaching as a part of my degree. It's something I always thought, well, I might like to do, I've never been 100% with it. I became dead certain that I wouldn't because you couldn't be a dyslexic teacher, that was silly. And then I turned around and thought, 'no, it's not', I mean, I'm not planning to go into teaching now for other reasons, but, yes, it stopped me for awhile, with jobs, and doing that. Though I think a lot since, with study skills I've picked up other bits and bobs of tools I can use when doing that when working, I'm currently doing an internship with the [charity], with their education work and I've gone in there and I've said to them, 'look, I've got green glasses, purple paper, other than that you don't need to do anything' but I said 'you will find me with lots of post-its and if we have a meeting I will be writing lots of notes because I'll forget otherwise – bear with me' and they're quite good with that and they're like 'well, if there's anything you want us to do, that's fine' so now I can sort of go 'well, this is the issue, this is how I deal with it, if there's a problem I'll let you know'. But,

and it still causes problems I still forget things and I get rung, 'where are you' and it's like 'I'm at home!' it's like 'you're in a training session this morning' I'm like 'ohhh...' [both laugh] 'I forgot that one' and just little things, but, yeah... a lot of I think is, yeah, to step over it almost, or turning it into a positive, which I think comes a lot from the friendship group I have at uni in terms of the dyslexic thing

Ruth: yeah, tell me more about that

Amber: Basically, when I got here there was one other girl who was dyslexic, though didn't know her that well. Though I tried to ask her stuff all the time because especially being based at this campus and all of the disability resource centre at the other one

Ruth: yeah

Amber: it's quite difficult to just pop in and things like that, but she wasn't very forthcoming. I think she saw it as quite negative, her dyslexia, at the time. She'd only known for about a year herself. But then friends I've made anyway, gradually, they got referred to people, and, actually, someone I live with I referred to the people, because I was like, 'yeah, but the same as what I do! You should go and see these people!' and by the end of the year, I think there were about 4 of us, I think there might be 5 now and we'd all gone through various stages and it was kind of nice to almost compare like, we all had our reports and we all compared it with each other

Ruth: mmm

Amber: and we all went through an angry stage. I think I found it quite hard because I was the first one

Ruth: yeah

Amber: and the others were like a couple of months after me when they had [Fs] or with testing so I felt I've passed on to them rather than the other way, now it's a bit different but, yeah, it's kind of been good as we can talk and we can turn around and say 'oh yeah, I feel stupid with this' or 'that's rubbish' there was a lot of I think anger with everyone because it explained a lot for each of us in our own ways. And sort of getting to grips with that. But on the other side we kind of, we've kind of turned it into, it's a bit of a joke between all of us. 'I forgot, I'm dyslexic' 'I can't spell, don't ask me' lots of friendly, light-hearted banter, which if someone else had turned around and said to us we'd probably be quite annoyed, but 'we're special', there's a lot of that but I think it's quite good as in, yeah, the support's there. We help each other out a bit or make fun of it, or, we've all passed information on to each other, like I've had some good books for adults being dyslexic

Ruth: mmm

Amber: cause there's not a lot on that, and that we found quite hard. I don't need to know what it's like being a 6 year old dyslexic! [Ruth laughing] I tell you, I've been there, I've done it, it's not, there's a lot of patronising books, almost, if you're an adult reading them.

Ruth: yeah

Amber: One either they're really huge print, and it's like 'I'm not blind', ok, it's helpful to have nice print but I'm not blind. The other bit is, at school this, at school that, it's like, 'but I'm not anymore'. Between us all we've all managed to dig some stuff out that's helpful but there's not a lot there so I feel having them we've kind of learned about it between ourselves.

Ruth: mmm

Amber: the gap that's there, almost, with that, and then, all of us actually did last year a disability legislation module, which was really quite interesting and weird at the same time because we're learning about specific learning difficulties. One of my friends is dyslexic and dyspraxic so she's learning a bit about that

Ruth: yeah

Amber: so we're learning about these things, but there's what we've experienced as well

Ruth: yeah

Amber: and it yeah, kind of, I think that kind of helped, and it helped a lot of people around us on the course because it's very hard to explain to people sometimes like, we all get extra time in exams

Ruth: yeah

Amber: I get a break in mine as well, it's very hard to turn around to someone and they're like 'oh, but you've got extra time you'll get a better mark' it's like 'yeah, but my writing is slower than yours, my reading, and I need it to check through' and it's very hard not to internalise that sometimes or you feel bad because [they've expressed] they haven't finished and you've managed to finish. But I think having that module has helped in terms of other people and how they react to it. We had a very good lecturer last year. We have about three different coloured papers we need between us. There's one lilac and there's one peach and there's one green. So she said 'what can I do to help?' Well she actually turned round and instead of printing ours separately, she printed three different coloured papers and handed everyone out in the class, so even

Ruth: mmm

Amber: in the class especially new people in the new module, nobody actually knew who was dyslexic or not

Ruth: yeah, yeah

Amber: and we were like, 'wow! That was so simple' and we don't mind, because we've got to that place where I'm quite happy to say 'can I have the purple one, please' and explain why, but it's like, we didn't even have to bother doing that

Ruth: yeah

Amber: and that was quite nice. But simple. And you do find, lecturers react quite differently, especially when you take your Dictaphone into a course lecture, you have to say 'don't worry, I'm not going to quote you, I'm not going to sell this on' [Ruth laughs] and you know, they've got copyright of it all but they kept quite conscious of it at first. But you know, no, that's was quite a simple thing which we were a bit, 'hmmm – yeah'

Ruth: you mean when the teacher did

Amber: yeah, did all of them and every week, and they made sure you got the colour you needed obviously, but it's like 'what coloured stuff would you prefer' and it gets passed around

Ruth: yeah

Amber: everyone else gets quite happy and excited because they've got quite a colourful folder for that module [Ruth laughs] rather than the white. And little things like, you know, I think they used to be so small that everyone knows everyone almost

Ruth: yeah

Amber: as well but in the shop they all did yellow writing pad by mistake, but I went in and that's really helpful for me to have. And, it's like 'oh, why are you buying this' and explaining 'yeah, because there's a few of us' and it's like, 'when you're going to buy them again just let me know what writing pads you want and what size' and he gets them in for us

Ruth: mmhmm

Amber: and stuff like that so, it's, yeah, people are a lot more, and especially compared to [Midlands?] people are a lot more receptive and willing to accommodate and it makes a huge difference to it really.

Ruth: mmm. Can you tell me, if I were to ask you what is dyslexia, what would you say? Pretend I don't know anything about it

Amber: I'd say there isn't one explanation to that. Dyslexia I think there's, there's a difference between potential and attainment in some areas that can be reading and writing but also memory. But it can be very different for different people. It's very hard to put a finite definition on it, and I think that's half the problem sometimes with other people with it. For me it's almost a difficulty accessing things, like reading or writing and things like that. It's almost like a spectrum as well, I find. I struggle a bit more with reading a book, my writing is generally not too bad. Whereas a friend of mine, her writing is where she struggles and reading she does ok on. It's kind of, I think it's a big blur as well, sometimes it's hard to know what is the dyslexia, and what's just your own way. Which is, yeah. I think it's a big thing the difference is the main thing. What you could potentially achieve and what you are actually

achieving. Despite everything sort of being there, if you were in school, and you had a good teacher and you had all the support you needed and you still weren't necessarily meeting where you could be as opposed to if you never went to school and you didn't have anyone to help you learn or anything like that. You're not reaching your potential but it's not quite the same. It's a tricky one

Ruth: yeah [laughs]

Amber: and I think that's where all the media hype has come from, that hasn't necessarily helped a lot with that, but yeah

Ruth: ok. At one point earlier you said when you were talking about identity

Amber: yeah

and when you found out you were dyslexic

Amber: yeah

Ruth: you said something about, it's almost like there's the dyslexic part of me

Amber: yeah

Ruth: but that doesn't have to be in control?

Amber: yeah, something along that line. I think when I found out, I mean, it was quite late in my life to find something like that out, and it becomes quite a focus at first, 1) what is this, what does this mean, 2) what does this mean in relation to my past, what does this mean for the future as well, that you become quite, almost entrenched in it. And I think for awhile that became quite a big focus. Not only internally, but externally, I had to tell people. I had to go and get paperwork sorted for the uni, went and told the family, [?] to friends, and some of that's kind of almost a battle as well because some friends were like 'when you've made it to uni you can't be dyslexic' so it's like, 'well, I've not asked you to diagnose me, I've just come here to tell you, it doesn't really matter' and it's almost as if that's so much the focus of your life that it's almost controlling you for a bit, and it did affect things I did like, I stopped reading for pleasure, I was determined I couldn't spell things, so if someone else were to write down I'd turn around and say to them 'no, I can't do it'. And I probably could have

Ruth: mmm

Amber: some of it.

Ruth: mmm

Amber: and I think over time I began to separate that out a bit so although it's not separate, and it is part of who I am, it doesn't control who I am, I think more? It doesn't affect my choices as much. There's a part of it, sometimes, you know, I'm not going to volunteer ever to read the encyclopaedia and proof read it for someone [Ruth laughs] because I know that's a waste of time for everyone! For me, it would take me too long, and I know when I read through things I read often what I want to see, or what I think is there. So you know, there's realistic sort of decision making with it. But it's not controlling the decision, it's not the be all and end all for it really.

Ruth: What would you say is in charge?

Amber: Hopefully me. Lots of factors at the moment, deciding what to do when I finish my course. So, there's a lot of things like financial factors, family commitments [or my own?] commitments, my own personal 'would like' choices and also other factors like opportunities that exist, that I want something doesn't mean the opportunity is there at the current time for it, so, I'd love to say me but at the moment I feel there's quite a lot of other factors playing a bit part in that

Ruth: mmhmm

Amber: but yeah, we'll wait and see what [?]

Ruth: is this your third year?

Amber: yeah, this is my third year now

Ruth: it's all happening this year

Amber: oh, yeah, very much so

Ruth: not very long to go

Amber: yeah, it's going very quickly

Ruth: so do you know at all what you want to do

Amber: I have ideas. I'd like to go onto further study. Though I'm trying to work out the financial commitments of that because I'm financially independent from my family. I have to say that I'm on my own currently, anyway. So I've got to try and juggle that. Which, yeah. That would be nice, but we'll see what happens with that. I've also been offered some work with the [charity] that I do, just part time, it's an area I'd like to possibly go into in the future, so, it's there but there's a lot of getting your foot in the door

Ruth: mmhmm

Amber: maybe, yes, there's, a lot of work I do with the [charity] is sort of peer education, HIV/Aids awareness, humanitarian education, which combines my culture and travel side of me, but it's more getting it into schools or groups in this country so combined the age group I like working with, yeah, so, it's a new area for them and it's quite a new area for me

Ruth: mmm

Amber: so, it's one of those wait and see things, that, you know, that seems to be the direction. Who knows?

Ruth: I have three questions

Amber: ok

Ruth: 1) is if you could have chosen not to be diagnosed as dyslexic or to be diagnosed, which would you have rather? Would you have rather that it never happened or are you glad that it did?

Amber: I'm glad it did, really. I think, because I was in the position where the problems were affecting my life enough to like, leave Midlands, things like that. It's given an explanation for things. So, yeah, I think in the long run I'm glad of it. I wish it had been earlier.

Ruth: right

Amber: There's a lot of, and I think you do with life anyway, there a lot of 'oh, if I'd known this I'd do that' a lot of the choices I made, especially after my GCSEs and things, I think I would have changed.

Ruth: mmm

Amber: So, yeah, I think mainly because there were negatives that were causing me to get [? For it], it's helped with those. I think if I continued like I had at school, I don't think I'd mind either way

Ruth: what, when you got to university if it was like it was at school, is that what mean?

Amber: yeah, if it was like it was and there was no, no one had turned around and said this, then I think it would be ok not to be,

Ruth: ok, yeah, I see what you mean

Amber: yeah. But, yeah

Ruth: ok, and that's part of my second question, was just, if you do prefer that you have been diagnosed as dyslexic would you have rather been diagnosed earlier? Or do you think that would have made a difference?

Amber: oh, yes, definitely. More on an emotional level than anything else I think it would have, because, yeah, even through school you picked up on things, that, 'it's your fault, you can't do this, you're not trying' especially with English things, especially the negative experience I had with Midlands and study, even at college I struggled quite a lot with it. We had to read so much. Reading the book in class would overtake me reading it, but I was too afraid to say anything. I would have made different choices I think. Yeah.

Ruth: you said about emotionally it would have been better. How do you mean.

Amber: I think there's the time when I started questioning it myself or going to get help I was so stressed with work and other things and it knocked my confidence, that was [before that] quite drastically that I had to deal with all that as well as trying to learn what is dyslexia what is this sort of me

Ruth: mmhmm

Amber: so I think, in terms of that, if it's at a younger age and you can grow up knowing that, when you, that's not to say you won't face stresses or difficulties with it, but you can go in a bit more prepared

Ruth: ok

Amber: like I have with the [charity] now, I've gone in going 'ok, I'm going to have trouble organising this or sorting this' but I've gone in going 'ok these might be issues, just bear with me, it's ok' it does a lot of, yeah

Ruth: ok, and the third question is when you found out you were dyslexic as an adult, if you could have had a resource to turn to, that wasn't there, what would have helped you, do you think?

Amber: I think someone to sit down and explain it all. I mean, I've read books since which I've found helpful, and the internet, but I don't think that's the right thing to give someone who you've just told is dyslexic because I wouldn't have gone home and read it at the time

Ruth: mmm

Amber: that's something that comes afterwards. I mean, they told me about the strengths and weaknesses I have but I think it would be nice for someone to come and sit with you and either explain what this means, I mean, one thing that used to cross my mind was what does this mean for jobs, do I tell them, do I not

Ruth: mmm

Amber: can I not do certain jobs, can I... there's a lot of uncertainty, or for someone to turn around and tell you what it means and what it means for you almost. Yeah. And that's quite difficult because it is very individual and the more people I meet who are dyslexic, everyone one is, well, there's differences with everyone else's. But I think almost an opportunity to explore what that is, and we've had debates about this with the group at uni because we've often said, 'what could they do differently' 'what's best'

Ruth: mmhmm

Amber: because we do get asked, and even on some peer support level, mentoring level, which we've kind of provided for each other

Ruth: mmhmm

Amber: and we've been lucky with that, but with others I mean, if at university other students who are dyslexic, coming, having a chat, having coffee, sort of, yeah, kind of, we have a lot of support for the academic side of it, and that's why I think it's more effecting emoti, or it's affecting me more emotionally because the support's been there for the academic stuff

Ruth: mmm

Amber: if that wasn't there then it would affect that as well I think.

Ruth: yeah

Amber: quite drastically.

Ruth: ok, you had your academic support with the diagnosis but you would have liked more emotional support as well.

Amber: yes, I think, mmm

R: and you said about talking, you wanted to talk about what it meant to you personally.

Amber: yeah

R: Can you explain to me what it has meant to you personally?

Amber: It's, it's settled a lot of things in my past. A lot of things I used to get annoyed by I've now kind of almost put to bed which is nice, like my English school reports, or comments like, I first was angry but I've now gone 'eh, it's not a problem, not an issue' what it means to me personally, I don't know so much now. I'm more aware of who I am as a learner, which I'm really pleased about

Ruth: mmm

Amber: I know how I work and how I learn,

R: mmm

Amber: and, it's very hard when you go for your technical assessment for your equipment and someone says to you, 'so how do you like to learn?', it's like 'I don't know. I've never thought about it'

R: mmm, yeah

Amber: and friends now still don't know how they learn but I know how I learn, different things, and I've done a lot with that. So, that I quite, I like now. It's a weird process to go through. Yeah, me as a person, it's almost like it doesn't really mean, much, almost.

Admittedly I won't wear my green glasses in public that often, at school [Ruth laughing] cause they're not that attractive. And I'm hoping they bring out contacts one day

Ruth: oh yeah, what a good idea

Amber: in that. I have a very good optician who I've spoken a lot to about it. Yeah. I'm pulling for contacts. So it's going to be good. So yeah, there are some instances, and I can see people who don't know me looking, going 'why has she got coloured paper over there. That's a bit odd. She's trying to be different' or at least that's what I think people might be thinking. But in terms of day to day everything's become sort of normalish to me. I have days, I have days where I go 'I'm having a dyslexic day, I'm talking backwards again', everything par park and not car park, and I interchange that with my blonde days [both laugh] so but, yeah, it doesn't, it means I do things differently, sometimes, to other people, like in how I work or how I'll go about things. I think I'm quite lucky now, especially in terms of things like technology and stuff like that, there's a lot that can short track things. I have free time. And I never had free time before I had this. Every time I'd write an essay or plan it or do the reading for it would take so long, and even at uni with the study skills before I had some of the technology I could work 12 hours a day and not get to where I want to be at the end of it. And still a lot to do the following day. Whereas now I can do what I need to do. I'm doing the same tasks that I needed to do but the technology speeds it up or I can move some of it onto my Dictaphone on the train or, I've got more time for me.

R: So, you have, so you're saying, is that true through your school years, or is that mostly uni?

Amber: that's mostly uni because the things are there to help

R: no, I mean, you're saying you've never had free time, so

Amber: I've had free time to do, I always fill my free time, so if I have, like at school, any free time I filled with music

R: yeah

Amber: though as I got older that kind of got a bit harder and at college I had to give up a lot of things to get the work, like, done

R: yeah

Amber: and I found [R: unintelligible] when I got to uni I found to keep up with the work and to get where I wanted to be with it I lost track of the things I enjoyed quite a bit, like I wasn't in a choir,

Ruth: mmm

Amber: I'd have free time and I'd see friends but I never thought I had much choice as to how that was whereas now I can go and say, 'well, no, I don't go to the library on weekends, weekends are my time off' because I know I'll get that done

Ruth: yeah

Amber: and even when I've got a deadline it's more kind of when the workload's a lot, it takes so long, it's like 'well, I've got a deadline I've got to finish it, it's going to take me this much time' now I can actually say 'ok, I've got a deadline in a week, I can have a day off', because I know when I come it's going to take me this long to do, it's going to take me this long to read this many pages, to type it up

Ruth: mmm

Amber: or something like that. I've found, it's not that it's a clear cut, before I didn't, now I don't, I just have more, more flexibility and it's ok.

R: yeah, interesting

Amber: like, even things like books from the library, on a temporary loan, I've got a photocopier now so I can copy a lot more than I used to. Or, I can scan it into the computer and take it back, so I don't have to worry about getting that particular reading done in 5 hours, I've got the book.

Ruth: yeah

Amber: there's a lot of the time that's unrealistic for me

Ruth: yeah

Amber: but I know it's there so there's a lot less stress of having to do things, I can do things when it suits me and fit it around everything else

Ruth: would you say that you've used the technology that you've had a lot?

Amber: yes! [both laugh] if someone took it away I'd cry! I do. It takes awhile to get used to, and you've got to very consciously remember about it

Ruth: mmhmm

Amber: at first as well. But now, yes, I use it quite a bit

Ruth: Did someone train you to use it?

Amber: yeah, you get training sessions with it

R: ok

Amber: and I've had a few. I'm having a couple more now actually before my dissertation because I want to check I've remembered all the little bits and bobs and managing it all

R: mmhmm

Amber: but yeah someone comes along and they train you in that. It's designed so that you're at the same level as everyone else and it's not giving you an advantage over it

Ruth: no

Amber: which I think is totally fine

Ruth: yeah, it's important

Amber: yeah, and personally wouldn't want that

Ruth: no

Amber: anyway, but yeah, someone comes and they show you how to use it at your home so you've got it all set up. There's this, one thing I said to them when they were [setting out?] the different programmes, I was like, 'I'm not going to read the manual' [Ruth laughing] and he was like, 'well no, we're not expecting you are, that's why we're here!' so no, someone comes and they show you and you can get them back a couple of time, you get an allowance for that

Ruth: oh, ok

Amber: so yeah, you're not just left with it, because, and I think quite rightly, they, what they say is, 'it's all very well giving you the technology but if it's more of a problem to use it, you're better off without it'

Ruth: mmhmm

Amber: but no I've found it very helpful. It kind of replaces some of the stuff I've done anyway in the past. At Midlands they found it very hard working with me to try and establish if I was dyslexic or not because a lot of the strategies they teach people I'd had in place. I had my post-it notes. I had everything's highlighted all the way through, which, got rid of the black and white background

Ruth: mmm

Amber: but I didn't realise it

Ruth: oh

Amber: and things like that. So little things you know like, 'we don't know whether that's just you or that's you supporting your dyslexia through that'

Ruth: mmhmm

Amber: and little things like the computer now, I get it to read back my essay to me

Ruth: mmm

Amber: then I hear it, so I'm not reading what I think is there

Ruth: mmhmm

Amber: which is something I used to have to buy cd's for my brother and I'd get him to read it because

Ruth: mmm

Amber: he's a whiz at things like that. So there's little things that, it kind of compensates, the technology, for other things. I mean, it's a lot cheaper to get the laptop to read than my brother [Ruth laughs] buy cds that got quite expensive, and when he was doing his own degree, he's actually finished now already, his degree, you know, obviously, he wasn't as willing to read my stuff at the same time as, you know, his.

Ruth: yeah

Amber: so, no, the technology helps a lot.

Ruth: mmm. So are you the only dyslexic person in your family?

Amber: Yes and no. In my immediate family I'm the only person I'm the only person who is diagnosed with dyslexia. I think my mother has dyslexia, and I think she does now. I only found out recently one of my cousins is dyslexic. But he only, [interruption unexplained] he was part of a study, I'm thinking 1971, where they followed children born on a particular day, throughout their life up to 30.

Ruth: right, yeah

Amber: so through that he was diagnosed as dyslexic. As a family, extended family, we're very large, there's my mum's one of 7, and so I've got 20 cousins on her side so there's a lot of us  
Ruth: yeah

Amber: and as a family as a whole it's not very academically minded. Most left about GCSEs, me and my brother were the first to go off to university, we're [the only ones who would consider it?] there's a couple of younger ones might. So knowing what I know now about dyslexia, knowing about the family patterns, some of them, I think there are other dyslexics in the family

Ruth: yeah

Amber: just not diagnosed in it.

Ruth: yeah. Ok. Well, I think we should stop.

Amber: yeah

Ruth: I think that's been really helpful, it's been so interesting, really interesting, and you've said different things than other people have said

Amber: ok

Ruth: which is really good.

Amber: that's interesting.

Ruth: and I'm quite interested in your group of dyslexic friends. Have you told them about what I'm doing? [recorder turned off]

Ruth: ok, so what I thought today, because last time we talked so much about dyslexia [yeah] and um, it was really good, I thought you really have such a clear idea [yeah] which is good for me! [Amber laughs] um, but what I was hoping we could do today, this is a, what's called a timeline [oh] where, I've taken the transcript [yeah] and then I've just kind of put the information in the different boxes [yeah, oh right] well, there's a fair amount of summary [yeah] but it's a way of kind of, um, making sense [yeah] or at least [screening it] putting all the yeah, putting all the same available information together [putting it together] but, so what I want to talk about today is places where there's only a little bit of [ok] information? [yeah, sure] so it's kind of filling in the picture [yeah, filling in the gaps]. Yeah. And obviously there's a lot about education [yeah] because that's important but [mmm] so here, family, primary school, [yeah] don't have very much information there [mmm] um, education, childhood, preschool, probably don't remember that much anyway, but

Amber: um, I know a bit from doing my course because we had to look back and do it all, so yeah. Ok, cool

Ruth: and I thought it might just to have it in front of you then, so you can see the spaces

Amber: yeah I'm a very visual person so that's great

Ruth: oh, yeah, that's one thing I want to talk about today is just for you to tell me more about your visual kind of, visual strategies. Ok, tell me about like how you are a visual person

Amber: um, I've always liked pictures and looking at them. And a lot of the work I do, when I revise or when I learn something, I do in sort of a concept map sort of style [yeah] and I memorise that? It's not photographic memory, but it's kind of, like I can zoom into bits and out, so if I colour code it with different colours, so a concept map, I know the right hands red initially, and if I need to look at the red bit I can almost zoom in and remember what it looks like. And that involves doing lots of pictures and diagrams and in biology that was always really helpful. But also as well I've found, especially at degree level when you're doing things like in 3D, like a website [yeah] or, I remember doing maths in college and you were doing lines space, so the different sort of combinations, kind of, and equations are going through it. I can just sort of see it? And see around them, somehow, I don't know how or why, but I'm very good at working with 3D kind of things and combinations. It's just, put it in a linear form and I run away, I don't like it

Ruth: so when you revise, tell me more about when you revise and you use concept maps. Tell me more about the process you go through

Amber: I kind of, well it starts off just, for me, I can't, I find it very difficult writing an essay or revising work. I've got all the different bits on bits of paper in a folder. I have to have it, I get lots of A3 kind of bits of paper and it means writing it all out on the piece of paper [yeah] I need to see it all sort of, there in front of me. But when I kind of do that it kind of goes from one big one and it works its way down to kind of like summaries of it. So it could take maybe 2 or 3. Um, and then it's often sort of, somehow worked into a colour code of its own accord, but um, then you've got very general like a special educational needs exam [yeah] we had like um, 4 or 5 different areas to look at that had come up, so they all had one, but then I did like a summary of them onto 1 sheet? So you've got your hearing impairments and things linked, and your specific learning difficulties, and they were all different colours and then from that I can link it to their coloured piece of paper sheet [ok] and see it. I don't, I find it very hard to

explain to other students what I'm doing and why! [uh-huh] um, cause they don't get it at all. And a lot of my friends who are dyslexic are very linear people. [yeah] whereas I often go to study skills and go 'I've got a concept map how do I make that into a structure?' [yeah] and he's very linear so he can't read my concept maps so that's always a bit of an interesting session

Ruth: yeah, that's difficult

Amber: but, yeah, I don't know kind of how it works or why, but I can just so sort of see it in my mind and I can just focus on one bit or come away from it

Ruth: so when you go, when you actually do your exams [mmhmm] do you actually visualise your concept map when you're kind of trying to remember

Amber: yeah or I stop to scribble it down, I'll do a very brief sort of version of it. Um, cause I find that kind of tricky for the memory of it, but just writing it I can see where the gaps are, so I'll start with that for a few minutes and then if there's a bit I'm really stuck on and I can't quite remember I'll go back to that and try to write the bits I know already and then it will just come back somehow. [ok] yeah

Ruth: and can you tell me more about colour and the way you use it? I mean, I know you've told me a bit, but just

Amber: yeah, it's a lot to do, um, when I was at [?] being screened for dyslexia they got very confused whether it was dyslexia or because I was doing the strategies that they liked with it. A lot of it is sort of colour coded, especially if I'm writing on white, which I don't like to read, and it's not necessarily a set colour code I'll start colouring in something in one colour and then anything related to that will stay in that colour. And the next one I pick up [so you] sometimes certain things are particular colours, for instance Feurstein is always blue and I don't know why but he's always blue. And so anything linked to him is in this colour.

Ruth: ok, so you sort of organise text by colour into subjects

Amber: yeah, into subjects, or say if I've got a group of, or I'm reading like, lots of reports or something. Different things will become different colours? So, background information might be yellow and something that's really useful to me is in pink

Ruth: and you can remember the association between the colour and the subject?

Amber: most of the time, yeah, pretty much, or you can pick it up

Ruth: when you start at the beginning and you've used and you started something and you decided that was yellow [yes] if you go to the end when you see the same subject again, can you remember that you've done it in yellow to start with or do you have to look back

Amber: um, sometimes I just automatically do it without realising, sometimes, where there's huge amounts of reading I've had to go back and do, ok, this is this colour and that is that colour. But I do find, because I always used to do a lot with highlighters anyway [mmm] and wasn't conscious what I was doing with it I'd go back and look and see and I'd automatically kind of done it [ok] which yeah, is a bit freaky at times, but [yeah] and a lot of it was to do, I think, especially at school or at college, you know, looking back now was a lot to do with the black and white text, and it kinds of blocks that [yeah] so I often used to highlight a lot more than I needed to just because it made it a lot easier [you were in effect creating a yellow

overlay] yes! In a sense! I laugh at it now looking back because it and it makes a lot more sense because I think, when I first started doing it a lot of words I didn't need to highlight were highlighted [yeah] and now it's a lot more, just what needs to be highlighted [because you've already got your glasses on!] yeah, I've got the glasses on or I've printed it on colour paper, so [yeah]

Ruth: ok, and when you're doing a concept map talk to me more about how you use colour. And I know you've already said it, but

Amber: it usually comes afterwards. I'll leave it to, if I've got to do a few concept maps I often get different colour bits of paper anyway, and it's usually I've written the concept map out and often if it's like a, lot of quotes or something, references or something, then I'll go with a highlighter and highlight the relevant bits, keywords or something. Then if I'm doing something on a multi-subject it can kind of be one strand is one colour. So if you've got the concept map and in the middle you've got four main branches and it branches off, the four main ones will have different colours and then it can follow the colour pattern. It's almost as though, when you put it on the wall and step back, you'll say, oh, the top's blue, and it's segregating off, like little chunks. It does get to be a problem when you've got the overlapping ones and you've got multi-coloured bits [yeah] but um, yeah

Ruth: do you draw links between, [yes] say you've got a central one and you've got four things [mmm] and there are links between some of them [yeah, I draw links] how do you do that

Amber: um, yeah, no, I do that quite a lot. We learned a lot about concept maps in our first year we had to do them [?] so yeah, I don't like doing it in 2D, I very much like seeing it in 3D in my head [so you picture it in 3D in your head?] yeah, it's kind of, especially if you've got one point say, on the left hand side of the paper and the other point you write you've got to do the dotted line all the way around, whereas I can just see the, I'd love to do a 3D concept map, with strings, um, joining [yeah, it seems like there's a place in the market to invent something like that] [both laugh] yes, to develop, how you'd contain it I don't know, but yeah, I like to join the links especially on topics that are so similar it seems silly to have them on separate branches [mmm] but I like doing that back and forth. It can get a bit messy at times. But umm, I've actually got software on the computer that does concept maps [which one is it?] um I've got Inspiration [yeah] I've had mind manager before but I'm not a huge fan of it

Ruth: there's one called SparkSpace [oh] and it actually does a 3D thing, [ooo] really, almost [yeah] it pulls out, do you know Google Earth [yes] you know, when you're looking from the top, you can also go down [yeah] almost to the ground [yeah] and see the shapes from there, it's a little bit like that [yeah] but it's like, when you're looking at Inspiration from the top aren't you [yes] whereas in SparkSpace you can kind of go down [mmm] and then you can move it around so that you can have your like, place of perception in different places [oh, right, yeah] which is kind of interesting

Amber: I like my concept map because you can view it from a different angle and that's why I find things that you didn't know were connected, or [mmm] work, or, I like inspiration, especially if you've got a large concept map, just to put the things, you can move it round on the computer so it looks nice and I still have to copy it. I'm still very much a writing person.

Ruth: and do you develop it after you print it out

Amber: or sometimes I don't even print it out I copy the basic structure then [oh, right] yeah, I'm always persuaded to stick it on the computer and keep it but I always end up handwriting it [yes] it's a habit I've never got out of.

Ruth: and when you think [yeah] do you see pictures then?

Amber: um, yes and no, sometimes. A lot of the time I often find myself stuck with, you know what you want to describe and everything about it, but you can't think of the word and you've got the picture in your head. That's what I'm more, conscious of it. But yeah, I think a lot in pictures, and I always remember going to work or college and having an hour busride and I'm always big at daydreaming [yeah] and imagining different things and stuff like that. [yeah] I sometimes find it quite frustrating though when you can't articulate what the picture is for other people [mmm] and that's where I get quite frustrated like, I know the answer to this but I can't tell you. Um, yeah [that would be frustrating] yeah it is frustrating. Mmm

Ruth: do you, can you see words in your mind or is it only pictures?

Amber: um, it tends to be only pictures. People have tried to see words with me, when you, there's like techniques for learning to spell, and you're like visualising the word and that, and I just [doesn't work] no.

Ruth: do you think in colour then

Amber: yes [yeah?] yes

Ruth: ok, all right, well that's really interesting. Thank you for that. Ok, so start filling in the holes [ok] just have a look [ok] and choose something that you're, you'd like to talk about, or you can add something that you'd like to

... filled in timeline in blue...

... we used to do a lot with work cards and so you'd do your work card, you'd take it out, do it, marked and back, and so in the end I used to take two. I'd get in trouble now and then for it 'you need to take more time' it's like 'why, it's right' and the guy who used to sit next to me in the end we used to start a competition going how many of these we could get done in a day, I think we reached fifteen one day instead of four ... it was the second Primary School I went to and I'll always remember it always used to come back on my maths report each year 'yeah, we've had trouble finding extension work for her this year', I used to think 'yeah that means I've done well this year'

...

We had to move into the house as we were building it. So we had like breeze block walls, we all lived in the kitchen and that was our living room, eating room, sleeping room, the beds were like next to each other to fit in, I'll always remember we had our beds one side of the room then a settee and a tv, and I'll always remember going to bed and Mum would have the tv on really quiet, and trying to look round to see what was on it while pretending to be asleep, and we thought it was well posh when we moved into two rooms, we never really had a kitchen for a long while we had a microwave and a little camping stove thing. We had a toilet but you had to have a bucket of water to chuck down it and we had an outside water tap for a good few months, we used to bring water in and boil it, we went to my grandparents once a week for a bath

...

I used to play about in the mud too much looking back, I used to get very involved, I'd make pots, where they'd dug for foundations was natural clay underneath so I used to make little pots and when they dug up we found lots of Victorian bottles and ink pots so we've got loads of those but there were also lots of bits of broken crockery so I used to collect them and try to piece them together ... looking back it was really nice.

...

Ruth: Are there any questions that you would have thought I would have asked but I haven't?  
Jenny: Oooo. [pause] mmm. [pause] It's a tricky one. This is one I ask my research people [Ruth laughs] and it throws them as much as it's throwing me now. [pause] I don't know. Maybe more the future and dyslexia and stuff like that.

Ruth: ok  
Jenny: yeah.

Ruth: so tell me about the future  
Jenny: I don't know. I think it's like a main issue at the moment. Myself and friends and dyslexia.

Ruth: yeah  
Jenny: because we've got a good understanding from our course about it and our experiences, and a lot of us have had some, quite a few negative experiences hearing about what other people think. We're kind of like, do you put it on your application form for something or not? Or do you tell them if you get the job, or not, or, almost trying to work out where to, where to go in terms of your strengths with it. We found a very good book that was actually aimed at adults who are dyslexic, which, they're rare, sort of things we've found, sort of looking at going 'ok, no, you can actually sell this as a positive thing'

Ruth: yeah  
Jenny: but wondering whether to put down on an application form, and say it and stuff like that, so we're in a very, should we, shouldn't we kind of stage

Ruth: yeah  
Jenny: at the moment, because it's becoming more aware that people are still not necessarily knowing what that means on a day to day, office and stuff like that, so

Ruth: is it 5 friends that are dyslexic  
Jenny: yeah [both talking, indistinguishable]

Ruth: so, are you all sort of in 2 minds  
Jenny: we've all had very mixed because, one refused point blank to put it to this university on her application form, she didn't want it down.

Ruth: yeah  
Jenny: I was like, Susie, if you go and you've got a written test, [she did at this university?] and all of us were like, if you've got a written test at the other one, you can't turn around afterwards and tell them you are dyslexic. Cause that's really her weakness, is just going and doing the written test straight away. And so we had a bit of an argument about that. But yeah, lot of people, we've almost got like 2 application forms and 2 CVs

Ruth: yeah  
Jenny: with it.

Ruth: ok, so you've got one CV that says you're dyslexic  
Jenny: yeah

Ruth: and one that doesn't  
Jenny: yeah, one that doesn't

Ruth: right, ok  
Jenny: or one that sort of says, well, this is kind of my strengths, just try to link it to that and another one that just really doesn't mention like, that, or, instead of ticking the box, 'Do you have any special requirements' or stuff like that, actually just leaving it blank and saying, 'well, if I get offered this then I'll go and say, because

Ruth: ok  
Jenny: legally, they can't [withdraw their job offer if you haven't told them about a your dyslexia from the outset and you disclose the information later on] and they should [make reasonable adjustments for you], but, a lot easier than rather than sending a blank application off, and they've got a pile of 50, 100 for everything going

Ruth: mmm  
Jenny: I don't know, none of us have really wanted to take that chance step [being up front about our dyslexia from the outset when applying for jobs], unless you've got someone with a disability tick on their logo thing, where

Ruth: yeah  
Jenny: you almost find it works opposite, where they need to fill their numbers, so you turn back and think, 'well, I'm getting this letter just because I've ticked that box'

Ruth: yeah, quite difficult as well  
Jenny: that can be quite difficult, it is a bit really. I mean, I've applied to university a few different times, I tick a lot of admissions people's boxes, because I'm registered disabled with it

Ruth: yeah  
Jenny: my family haven't been to higher ed before me and my brother, and we're from the right area, I went to a state school, and I know, especially when I was applying for Physics, I was getting offers at universities that I couldn't get the grades for. And they knew I wouldn't get the grades for, but they still wanted me to go to have their form

Ruth: cause of the disability  
Jenny: I think, well, because of the disability and the other boxes with it really. Because they've got to meet their stats and you kind of sit back and go 'hang on a minute, you're saying this is your offer, you've given me'

Ruth: what, you mean because you're a woman  
Jenny: I think with Physics as well, there was a huge thing, because you do put on your form whether people have been to higher education or not in your family.

Ruth: oh, I see  
Jenny: And they do know where you've gone to school and college

Ruth: yeah

Jenny: I think as well because I didn't do A-levels, I tick another box in as I'm not the standard

Ruth: yes

Jenny: requirement. So there are quite a few

Ruth: yes, I see

Jenny: things that admissions

Ruth: cause you're state school

Jenny: yeah

Ruth: as well

Jenny: state school

Ruth: state school, woman

Jenny: state school, woman, dyslexic, tick, and not doing A-levels, it was kind of

Ruth: yeah

Jenny: you did get some offers going, 'guys this isn't', some would send it back saying 'ok, we want all these grades' and it was like 'but you've seen my predicted grades, why are you offering me this?'

Ruth: mmhmm

Jenny: 'because I'm not going to get that'

Ruth: yeah

Jenny: and one I think in South England actually wrote me to say 'well, we don't know what grades you get, just ring us if there's a problem with it. We really want you to come' I'm like, 'you've never met me. You don't know much about me. Ok'

Ruth: yeah. Do you dislike that?

Jenny: I dislike that a lot. And I think that's what we don't want either when we're looking now to do things, going

Ruth: you don't want a free ride

Jenny: no

Ruth: you want it to be based on what you merit?

Jenny: yeah, what you've done and what you can do.

Ruth: mmm

Jenny: so yeah, we're at the moment trying to find a balance with that. Cause a lot of us have only known in the past few years that we're dyslexic

Ruth: yeah

Jenny: it's, we've never had to face something like that before with it, and sort of work out what we do or don't

Ruth: yes, tricky.

Jenny: yeah

Ruth: Did the book that you read give you any kind of ideas about it

Jenny: I think it's helped us with the, actually, turning it into a positive

Ruth: yeah

Jenny: thing with it, and saying these are the strengths but it's also very good at strategies, like when I was working at [?] I had a terrible job taking phone messages

Ruth: yeah

Jenny: people tell me things, ring me an hour later to see if I've done it and I've forgotten

Ruth: mmm

Jenny: I think they were pretty good with that. But little things like saying 'Oh, I work in this way. I do have trouble remembering things so if it's ok with you when I talk to you, I'm going to have a notepad and I'll just jot them down'. And things like that, and I've done some of that with the Red Cross, and they laugh at the yellow pad that comes out whenever I go to talk to someone. Or things like post-it notes or emails or stuff like that. I mean, they've been, very good with that, and I think that has been a real confidence boost, because I've been open with them about it

Ruth: mmm

Jenny: said, they're 'just ringing me to remind me we've got our meeting in an hour' and I'm going, 'today, oh, ok, alright, I'll be there, give us 10 minutes or so, I'll jump in the car' [Ruth laughing] So, yeah, the book was quite good at things, I think that has helped me a lot with them, sort of saying, and they were all, 'what do you need us to do?' and I was thinking, 'I don't know what I need you to do'

Ruth: yeah

Jenny: and the book was quite good at actually, I think because it was specifically for adults, who either thought they were dyslexic, or just being found out they were dyslexic, or

Ruth: mmhmm

Jenny: just generally but actually looks at real life, applying for jobs, starting new jobs, something that's relevant

Ruth: yeah

Jenny: I found a lot of the books are so kids-based, it's like 'yes, but I don't need to learn how to read again'

Ruth: yeah

Jenny: it's great if you're a kid [Ruth indistinguishable] yeah, they don't read them, it's called parents, it's always talking about the children

Ruth: yeah

Jenny: and it's like, well, what about me. My mum's not reading these books, I am

Ruth: yeah

Jenny: so that bit was really quite good in terms of, it was relevant, and yeah, it was printed in a way that was nice to read

Ruth: mmhmm

Jenny: for dyslexics, but it wasn't 'let's put it in 18 font and say we feel like you're 2 because you've read 3 words on this page' or something

Ruth: yeah. It wasn't insulting

Jenny: no it wasn't, which was kind of nice. And it did come with a cd-rom version of it

Ruth: yeah, that's a good idea

Jenny: that you can put on the computer. And a lot of their like little strategies, cause it's got like strategies for reading, bits and bobs, but they're a lot of, like, printable things that you can print out, so say, there's like a semi-circle alphabet, so say if you're looking in the dictionary and you tried to find something, you've got like a semi-circle alphabet that you can pull out and you can find it

Ruth: yeah

Jenny: And it's also quite interesting because the book itself picked out a number of things I hadn't realised were linked to dyslexia, because they were, the rest always talks about what children do

Ruth: yeah

Jenny: but little things like, I cannot say the alphabet out loud, I have to sing it

Ruth: oh

Jenny: and I've tried, a few of us have tried since going 'no, we can't do it' and little bits like that you hadn't realised are linked to it.

Ruth: yeah. Any other interesting things?

Jenny: I think somewhere in it is that dyslexic children sometimes adults, aren't necessarily tidy, because they need to see everything. And it's not that I'm untidy with things, but I've often got like, little piles of things out. Put things away and I forget about it completely

Ruth: mmm

Jenny: If I get letters they have to say on the desk in a pile for me to remember that they're there

Ruth: yeah, you leave them out to remind you

Jenny: it's what I've always called an organised mess. And it used to drive my family around the bend, but yeah

Ruth: how are you at finding things that are lost?

Jenny: um, not very good. If it's say, something in my room, I very good at forgetting where I've put it. I often find something a month later. I generally have to go through everything, where I think it is, where it's not, then I look in the other rooms in case it's there and I go back and I can't find it. I kind of, almost have a routine of like, ok, we start with the desk, and we do all the drawers of the desk, and then we do this, and then we do that [mmhmm] [?] but sometimes I can go, like mobile phones, I'm like, fine, I can't remember where I put it [mmm] and I go, sometimes I'll ring it and then other times, and I go, and it's where I thought I put it down, but I've looked and I haven't seen it. So yeah, I'm quite good at losing things like that. Though I tend to find over the years I've come up with ways of sort of getting over it, like everything goes into a file, every tape that goes into something, so it tends to be a lot better, because I do like things organised [mmhmm] where I can find them

Ruth: ok, um, before when I talked to you, you were talking about how it would be really good for [mmm] dyslexic adults who are diagnosed [yeah] as adults to have some kind of, kind of group support [yeah] and I mean which you've actually sort of put together for yourself [yes, mmm] um, but I just wondered if you'd thought about talking to the DRC about that and just saying 'have you thought about this and is this something we can kind of develop at university, or

Amber: I have and I haven't. With the ambassador job [yeah] um, I'm the link if anyone wants to ask about that sort of stuff to pass on to me, um, if they've got prospective students that um, we've mentioned it to the DRC and I think this year they've got like focus groups that are not involved in looking at where they can move forward [?] the stumbling block that you hit with that is always confidentiality [yeah] and they can't say who's who to the next person [no] and even quite funny cause me and my housemate last year, um, we see the same person and he knows what we're all both doing in each other's lives [yeah] and we're like, oh, no you can talk about it, it's fine [?] but even in like study skills it has to be confidential [yeah] like, this year one of the first years was really struggling who was dyslexic and through a round about sort of way in a hypothetical um, approach, I said, well, you know, put them in contact with me that's fine but we had to go very round about [yeah it would have to be something where the person had information ... ?] yeah, I met this girl quite a few times and she's actually left now, which is quite sad she wasn't happy at Southwestern, really. I meet with her to discuss, but I think it's hard, there's still a bit of a block. I know we formed our own group. A lot varied at the start some people didn't want to be told because they didn't like it [yes] and they didn't want, or they didn't want this, so it's getting the timing with it as well [yeah and different people are different] yeah and I think, I mean, I know I was quite angry as well when I first had it, at people in the past, but you'd had so many screenings or tests and so many forms to fill out afterwards. I think something straight away I'd have turned around and said go away I don't want to see anyone else [mmm] with it. It's something I'll keep talking to the DRC about [mmm] um, because I think it would be useful, definitely to have something

Ruth: yeah, well and especially just really someone to explain what dyslexia is, you weren't really told what it is

Amber: no

Ruth: but as you said, [mmm] part of that is it's not an easy to explain [yeah] you can't really say it straight forwardly that's why people ?

Amber: yeah and I think people come straight to university as well **they spend the first year with study skills looking at how they learn and bits and bobs like that and looking at, you know, ways they can deal and then they start to get a sense of what the dyslexia is.** It's hard because if you had one definition you'd be [mmm] fine, um, but yeah, we've picked up stuff along the way that would have just been useful just to have all at once [mmm] I want to say book but knowing dyslexics probably not!

Ruth: what about diagrams maybe

Amber: well, yeah, but my friend who, my housemate this year who's dyslexic giving her a diagram doesn't work at all [yeah] and she's very wants to be linear but we've [yeah] actually got a lovely sheet of paper that's visual and linear thinkers [yeah there you go] and the things they do and the things they've got to watch out for and we're complete opposites with it. But we're like, oh, that you

Ruth: but in a resource you have a page [yeah] of linear next to a diagram

Amber: or something maybe that links to websites and things I think is a really good source, the internet [mmm] because most students live with the internet basically [yeah that's right] and we did a lot of research, mainly for our course rather than anything else [yeah] and finding bits and bobs out with that and that, I think the most accessible way to get to people because then you can look at it at any time and can't lose it

Ruth: I wonder about a module? [yeah] or, about dyslexia for dyslexics or something [ooo, that would be interesting] and they would actually [yeah]

Amber: well, we found the special educational needs module though it wasn't for us, really useful [yeah] cause one of my friends who was diagnosed at the end of her first year here, she was diagnosed dyslexic and dyspraxic but she will never say dyspraxic to anyone [mmm] and didn't know much about it and didn't really learn about that until we did that module [yeah] but yeah there's, a mini course or something, couple of times a year might be quite useful [yeah, could be good couldn't it] definitely [that just looked at all the SpLDs cause so many people have a bit of a couple don't they] or even just more accessible resources, leaflets or books or something, but more adult focused cause there's nothing worse than going into the bookshop and seeing it's all kids and then it puts you 'oh yeah, I can't do this' [yeah] I think we did all go through a 'oh, they've told me I can't do it, I can't do it' and that's what we've, we all really liked the books that said, 'well, actually you can do this and you can do this better

Ruth: actually, do you remember at the interview, it was like, when you're sitting in an interview you often pick up different things than, or at least I [yeah] seem, I don't necessarily pick up everything that was said [yes] when I'm sitting here, but doing the transcript and then doing this [yes] and then I also did a summary of what you said and it's just so clear to me that you know, you went through this process [mmm] um, especially, well, very difficult for quite a long time [yeah] difficult college, difficult uni [mmm] and then difficult being diagnosed [yeah] and lots of things happening [mmm] but, that you'd gone through this process and you're really not like that now [no] you know, you're really not in that place, you really seem to understand yourself

Amber: yeah, I think it's only been about the past year with it, really. That I've kind of moved forward, and I've found I can do things and challenge myself a lot with it [yeah] **I do think it's like a whole new identity, sort of, strand almost that you've got to go through. I've looked a lot at bereavement on my course this year and I was going, 'yeah, that's the same' because you've lost one sense of your identity and are finding another and it's almost like going through the whole grieving process sometimes**

Ruth: that did strike me [yeah] definitely struck me, with anger and denial

Amber: yeah, looking at the bereavement stuff I'm going 'oh my gosh' it's quite a bit of a revelation

Ruth: it's good to hear you say that because I was wondering about that

Amber: yeah, it really does, **I think that comes something with being diagnosed so late I think because I've spoken since to people who were diagnosed from the age of 6, 5, 8, and then they've grown up with that and they've not necessarily had the same process cause they were so young [yeah] that, ok, they face challenges with one with schoolwork or what other people have found with it, but they haven't necessarily had the same sort of, almost, anger and denial that I think a lot of my uni friends have had** in the same position. Um [yeah] I think, yeah. And we do often talk a lot about 'if you could go back, would you be diagnosed again' and I think we've all said yes now but we wouldn't have said it until very recently. Um. And a lot of it is, well, 'if you were back at college and you had known would you have done things differently?' it's like, 'yes. Definitely' [yeah] and I think there's a lot of, yeah, when you look back you can get quite angry with that and all of the sudden go, you know, I'm applying to do a Masters next year and they don't even ask anything below your degree level, it's like, well, 'what's the point of college?' so it doesn't, some of it's like, 'don't you want to know I did

go to college?' [and I worked really hard!] yeah! 'and I worked hard why don't you want to know about that!' no one's really interested in all that, that it's, we've kind of let it go, it doesn't matter as much. [yeah. It is a process] yeah, it does strike me it's like a grieving process [yeah] and my mum when I was 14 was diagnosed with osteoporosis [yeah] and has had trouble with it for years and looking back at her as well, she went through a very similar process with it

Ruth: yes, I do remember you said she did loads of research on it [she did loads of research] herself, which you did with dyslexia too

Amber: mmm. And um, then she got heavily involved in a local society with it [mmhmm] fundraising. And sort of immersed herself completely in it [yeah] and then she, she's getting a bit better I think, she wouldn't do things like, she wouldn't go ice skating in case she fell [mmhmm] I'm like, 'you've never fallen ice skating before' [yeah] and um, sort of stopped herself doing lots of things and then had to go, 'you can, that's fine, but you're not going to have much of a life if you keep doing this' [mmhmm] and she went through a quite of a big process with it [mmm] yeah. I think.

Ruth: ok. Um, there was something else I wanted to say what was it! Oh dear, actually should have had my notebook out. I can't think. So are you going to be here next year do you think?

Amber: yes, [you are?] yes [Do you know?] no. [no, you just definitely] yes, I've got the form to fill out this afternoon. I'm applying to do it and well, if I don't, I sorted a house for next year to live and so either way I'm staying [ok] but yeah, no, decided to go for it [excellent] well, we'll see

Ruth: that's excellent. Especially, selfishly, for me [yes] because I want to see you again in about a year.

Amber Interview 3 21<sup>st</sup> May 2008, 1hour 40 mins

Ruth: so this is a concept of map

Amber: of the different points that you emailed me

Ruth: oh, wow, gosh, ok, what I want you to do is to explain it to me. Thank you so much for doing this. This is wonderful. Ok, so, if you can start from the middle and work your way outwards

Amber: just the interview, just what we're doing and then the main things coming off it are the points that you emailed me so you've got perceptions of what dyslexia is, changes in perceptions, how other people view it, how dyslexia has affected you as a person and the experience of being interviewed. The perceptions of what dyslexia is, is looking at learning in a different way. Almost like a spectrum of difficulties. There being a difference between ability and achievement, frustrating, that's how it feels sometimes. And I looked at how it changed over the years and I think it's masses of outside changes like changes in perceptions of other people and different practices that I've noticed over the years and how that affects me. So say like, the support you can get or how other people recognise it or know what it is and that affects me [yeah] quite a lot. [can you say, because if you say it can affect you differently I assume you mean positive or negative]? Yeah both ways I think there's more knowledge that it exists now [ok] than from what I remember growing up. I think that makes it just easier [you're less likely to have someone say 'load of rubbish] um oh no, you still get that but they actually know what it is rather than not knowing at all, or they think they know what it is [ok] and also that's changed in relation to my family because I've since found out that other cousins are dyslexic and more recently found out, a few months ago actually that's changed the perception of it within the family [so now there are 3 of you?] 3 known, so that's changing how people talk about it [what's happening] it's a bit more open, now it's like mentioned and talked about, they'll get me to talk to her about it before it was just 'ok, yeah, get on with it' it's now just more discussed [so what kind of things might somebody say] more in terms I've been asked what support she can have what types of things she needs to do, what does this mean [yeah] I mean the older one I don't know much about, I'll talk to my aunt, his mum, about it. And she asks me a lot of questions about it, for what they did for my degree as well [how old is she?] my aunt is in her 60s my cousin's in his 40s, he was part of the 1970 cohort study and so he had regular tests done and all sorts of things throughout his school life so he found out back in the 70s which is [wow that's way early] yeah so it was known but nothing was done about it [ok] a lot of my aunt asking questions about what it is and explaining it. [and you were diagnosed in 2000 and] 4 [ok and now your other cousin has been diagnosed and how old is she?] she's just doing her GCSEs right now, she found out at the end of last summer, so over the last year she's been getting to grips with it, [so she's asking about support ] she's had some support, she's had almost remedial classes to help her in a couple of subjects, which has boosted her confidence a lot [good] I think in the short term has helped with her GCSEs, her grades have changed quite a bit, specially maths based stuff [ok] it's more sort of, what can I do as a job now, and what can't i do [you know we talked about the whole sort of grieving process has she gone through that] I don't know, it's quite difficult because i'm at a distance it's yeah, quite tricky to sort of see the day to day [so you've not talked about the kind of emotional side of things] not so much at the moment. [yeah ok it's been more practical and knowledge wise] a lot of what we do is over email so we tend to write solutions

...

Ruth: that was a way major sidetrack. Can we talk about the way attitudes around you affect how you feel or your experiences

Amber: I think that affects me in terms of how open I am about it or not. When there's quite a lot of negative attitudes I tend to be 'do I even have the energy to try and fight it' [yeah it's been a huge difference between your first university experience and your second, tho i know lots has happened in the last year] yes, how that's changed

Ruth: that's really interesting because on the whole your bachelor's was quite positive

Amber: yes very. This one's not at all. Which is strange because it's the same department, same university

Ruth: we lay the mindmap aside for the moment, tell me about the last year

Amber: oh gosh, lot's happened, it started off the problems with my postgrad with my reference for it and the tutor who had been very supportive throughout the year and I'd been ill a couple of times during the year and she'd been supportive saying 'no, take a week off, take some time off, get well then come back and do your work' [yeah] took a very long time to write my reference so I asked personnel to see it and it started off really lovely and sweet and yes, she can do this this is fine and then she wrote about how she didn't think i was suited to the course because of my learning difficulty and other health related matters and because I'd had support in my undergrad course from Learning Resources without the support I wouldn't cope at all, which was quite a sort of stab in the back [but i don't really understand because it's not as though you wouldn't still have support] well no exactly [so with support you can do it] yeah but even just generally because of the difficulties I shouldn't do this. So I took it to Learning Resources and said look what she's on about how can she write this in a reference, he sent me to the data protection people at the university and so I saw basically the person in charge of the legal stuff for data protection and she took one look at it and said 'she can't write this'.

Ruth: because she was disclosing your dyslexia?

Amber: no, there's a few problems, one according to university regulations she wasn't allowed to write such negative comments in a reference, she was discriminating against disability which is illegal, she was disclosing what was in a sense confidential information from tutorials, so she didn't specify dyslexia or what the health problems were she stated them [so that was disclosure of confidential information and she was discriminating against you because] because of the dyslexia [when she had just said you were up to it but she didn't think you could do it because of the dyslexia] yeah basically if the university had acted on it I could apparently take them to court if they had not offered me the place and I did get asked if I wanted to formally complain and the woman was very keen to do that. But in the end i said 'give me a few days' I didn't want to create a rod for my back she's quite high up in the department now so I went away for a few days and in the meantime she got that section removed from my record because the other problem was that any member of staff at the university could see that reference. They removed that paragraph and the administrator said she'd have a word and I just left it at that. [so she knew that you'd brought the letter to data protection] I presume so I've never spoken to her about it. She has acted as though nothing happened and has been extremely friendly and I don't trust her. But that was the start of the problems with the course. It knocked me back quite a lot. I didn't have much support from anyone about doing this course, even family. It was hard to do.

The course itself has been a nightmare from the dyslexia side. The administrators in the dept have been great and have gone out of their way to do everything in advance and were very helpful but the actual staff, everything from forgetting things on coloured paper to questioning outright, in front of other students, if I was actually dyslexic and not making it up. I went up to a lecturer I hadn't had before and asked her if she'd produced a pack of information on lilac paper for me, and she was like 'oh no, why's that' well I'm dyslexic, you've had the learning plan and then she questioned me about, she kind of went along the lines of 'well, what exactly is this, why do you need purple paper, what about reading books, why can you read books' and I was like, I have an overlay and then she started questioning what the difficulties were in quite a patronising way. It was enough to make other students who did know about it come up to me afterwards to ask me what it was about and why she was doing it to you? [how did you feel after it?] intimidated, frustrated, I don't need to talk to them about why, I just need them to do it, I've had constant problems in accessing lectures, I find things like powerpoint quite hard to read and there's no notes or as well, it's difficulties like I've asked for reading to be given in advance of the lectures and they'll turn up with sort of 13 page to read for everyone in 20 minutes [mmm] which is bad enough, but if they're trying to help they'll go and spend 20 mins

trying to find coloured paper and the lectures are in the evening so I'm 10 minutes behind everyone else when I start the reading, the reading is slower anyway so I don't get through hardly any of it by the time everyone finishes then we've got like a 40 minute discussion about what it was, so I just sit there twiddling my thumbs and some days I think I just miss 3 hours and I could have been doing something else. It doesn't help, all my lectures this year have been in the evenings so in terms of lighting that's caused more problems compared to the daytime lectures and I'm more tired at that point of the day. I get long phases of insomnia which affects everything really. It's quite hard because you have a chat with the head of the course who is a specialist in the area, that field who says 'yes I'll make sure it's all sorted I'll have a word with everyone' and then he'll turn up and not have done anything and then wants my evaluation [that's your chance] oh yeah I filled it out, it gets a bit ironic when, I'm easily identified in the pile, I'm on the lilac. It's not really confidential but the comments I make aren't either [you stick out don't you. Every lecturer will know who said it. can you use your glasses instead of coloured paper? ] I kind of find the glasses, they help, they don't solve, I fall under the impression that some of the comments I make are so specific with the issues with the dyslexia that they'll know anyway and I don't really care anymore. I've also had difficulties where in terms of my dissertation, that caused a lot of problems within the department because I got pushed down the road of looking at Welsh Parliament despite saying 'you can't find a supervisor for me in this dept who has any knowledge in this area' and they said, 'oh, we'll find someone' so I went away and found something to research about it and I got given the same tutor who'd wrote me the reference as my supervisor so thankfully Learning Support jumped in and said 'no way' so it's been changed but it's been so uphill I often feel I'm quite a pain in the department's eyes because I don't just sit there and take it. It's a constant battle. [so you were told to do this thing on the Welsh Parliament, given a supervisor who was the person who wrote you the inappropriate reference, what happened then?] I emailed and asked why and they just said she has good expertise she should be able to supervise any dissertation. And then I just arranged a tutorial to talk about it, in that time Learning Support said, 'no, we want to come along to this because we don't trust your department', basically and so then went in said 'look, these are the reasons I don't want her to supervise me' in as vague details as possible because I didn't know what he knew and didn't know, there was a very defensive conversation with my tutor, he said he wouldn't mention it to the supervisor but would find someone else, in the meantime she came and sat next to me in a lecture asking if I knew she was my supervisor and if that was ok [so do you think she was aware that wasn't very appropriate?] I don't know I find it very odd she's called on me for favours this year to attend meetings that she can't find anyone. I honestly think she thinks she's done nothing wrong in the way she acts but I don't know [you don't think she might be trying to make things up to you, she's apologising] no, just knowing her from tutorials last year. No, she's never wrong. Well that's the impression she gives. [ok, so you had this conversation with your tutor and you were assigned a new supervisor for your dissertation and did you stay with the same topic?] no it's changed completely their interests are very different, mine have changed, the more I read, but also in the meantime I've started a new job part time and although the hours for that can be flexible for me to go to Wales to collect data is just not practical I can't, just the toing and froing I've just changed the focus of it so I don't have to do that. [and has it gone ok so far?] I haven't really started, yeah, we'll see [but you've got all of the modules out of the way now] yeah [that's good news isn't it] yes.

Ruth: how would you compare how you felt on the BA?

Amber: it's completely different which was really frustrating because by the time I got to the end of the BA it wasn't an issue it wasn't talked about, there were things you checked were in place and this one has felt like a constant battle just to get what's technically a requirement, or maybe requirement's not the right word. I find it frustrating that if I was blind for example and went into the lecture someone had forgotten a Braille copy, if I had a physical disability, then there would be complete uproar and I do generally feel that if it was physical there'd be panic if things hadn't been done. But I feel like I'm constantly fighting to ask and then you feel guilty

for doing that, it's almost like you're trying to push the disability to your advantage, or you get that feeling back off them.

Ruth: so they're positioning you as, what?

Amber: um, a bit of an annoyance. It's almost as if I'm asking for extra on top of what other students have but I'm not sure. It's tricky. [I expect it can be quite subtle, the different messages you're getting] oh yeah, some not so subtle and others are subtle, it's more when you ask in a lecture and you just get a sort of nonverbal response that you can see [ask what in a lecture] ask if they've got, say they're handing out lots of reading to be done I'll ask if you've got mine done in lilac, and then you get the reaction face, only for a second what they're saying might be the right thing to say. And that's not all of them, some of them even if they have forgotten would, they see you and say sorry I've forgot I'll get it on the break, but they tend to be the ones I've had as an undergrad. [so in some of the lectures there's been a resistance to the right that you have to ask for it] yeah, it's kind of like the underlying message is that I shouldn't have the right to ask for it, that's what I pick up from it, or it's not their responsibility, like if they've done a powerpoint and they spend 2 hours of a 3 hour session doing the powerpoint on this lovely white background and you ask them, they go 'you can download it after the lecture' yes but I can't access the lecture now' it's tricky because as an undergrad i did that sometimes, I'd get lots of headaches from looking at it, but in the evenings during the drive back from the lectures i can't risk having a severe headache and then drive home it's not safe. It's frustrating.

Ruth: how do you feel in yourself this year versus last year?

Amber: I lost a lot of confidence, completely, I felt I was settled with the dyslexia and it was fine and it was good but having seen the reference and then the experience [of the MRes] it's changed quite a bit at the moment. It's changed the confidence I have in terms of applying for jobs, turned that around slightly. It's almost like going back a few steps.

Ruth: cause I know, looking through the notes that I've written, I do get the sense that you were successful that you'd been through a lot of difficult things but that you'd learned through hard work and re-thinking, you'd processed the whole thing of dyslexia and you'd come out the other side, positive and happy to be who you were

Amber: yeah I've gone back into processing it. Not so much who I am but what it means and how I portray that to others. I think at the end of my undergrad year it was quite openly acknowledged and I brushed off any comments that were negative about it because it didn't matter but now it's a bit tricky because of the negative experiences over the past year that I'm just overly cautious again with what I say and what I do. I had a big dilemma when i applied for this job a few months ago. They knew i was dyslexic because I had volunteered for them. But there was a dilemma whether I should put this down on the application form and when i did get the job i had an occupational health visit as a standard sort of assessment basically that all staff have so I filled in the questionnaire, but a lot of it I felt was a bit too personal to fill in, asking about all different sorts of things and then it came to the disability and I put the dyslexia down. I ticked lots of other health boxes like 'do you take any medications' but I ticked the right ones but I hadn't expanded any 'expand' bits so the external occupational health person rang me and he was a doctor and they do a fitness to work quick question fires, and he quizzed me for 15 minutes about the dyslexia and if I could cope, if I could do this job because of the dyslexia, what does this mean, why do I need coloured paper, are you going to be able to type things up on a computer, really kind of, I was under the pressure I shouldn't be doing what I have been doing for the past 18 months, but then did not ask me one other thing about health related stuff which I thought was quite ironic really seeing as he was the GP. There were things I thought I would be asked about but he didn't ask me about those. I know I'm fit enough to work, but he really didn't think I could do the job, and this was over the phone so this made it harder to do that because you don't know when they're going to ring you so you're caught off guard. It wasn't inconvenient it just wasn't not what i was expecting. It makes me very cautious about other applications I been doing. I've been given the job but he could have said i couldn't work based on being dyslexic even though he's a medical doctor

Ruth: so at the moment you're feeling vulnerable?

Amber: yes and sometimes knowledgeable people who should know, I have chats with professors and they've been just bad as the rest of them, and that's quite hard.

Ruth: so thinking of the last year, let's talk about the perception of how others see dyslexia. Could you give me some negative attitudes?

Amber: I left my ambassador job at the uni for several reasons but the final straw was due to dyslexia issues where i was put in very embarrassing situations with clients and it was brushed off and joked about, I'd be sent somewhere with a list of very small typed questions on white paper and be expected to just get up and say them having never seen them before, I had a chat saying 'can you just get this to me before', 'oh, no we couldn't do that, don't be silly' I got quite frustrated. They were aware of my difficulties. And also they'd get annoyed with me if I misspelled something in an email and you'd get negative feedback about it. Email to them and clients, I would sometimes mix up dates, they frequently changed the dates, it's quite easy to do, but they'd get quite ratty with me. [did they bring dyslexia into or were they just negative] it's tricky they weren't as negative with other people about it, they'd come back with it and I'd say 'sorry you know I'm dyslexic you do know I occasionally mix this up' and they'd come back and say that's completely irrelevant. It was more a general underlying thing alongside a number of other things. It came to a head when I'd said how bad the situation was after reading things and they laughed about it and said it didn't matter and shrugged it off which to me is quite unprofessional. And then, not all work has been bad, my current work has been very positive, people who I've worked closely with or people who knew, like managers, are very supportive and are basically saying 'tell us what you need and we'll do it' which has been great like a data-base reader on the screen and stuff like that they've helped with the screen reading programme, but even in terms of day to day stuff like ordering coloured paper, it costs more than white paper, but it comes out of my budget and so they've arranged me to have more. They've been quite good. It's been quite strange because if I have an overlay out on top of something, we have a lot of staff from around the country who come into the office. They'll see the overlay and say 'oh, are you dyslexic' I was like 'yes, but this isn't dyslexia this is something else' which they don't listen to! They don't accept it, it's dyslexia and that's that. They've got one perception. You do sometimes get in the most friendly way some patronising comments like 'oh, you've done quite well with that' to stand up to read something, 'oh, well done' I'm like, it's two sentences, I can read it's not even complex English' so it's well intentioned but you get the impression there's a lot of misconception' 'oh, you did your degree. You've done very well to get this far' and it's like, well, ok, but it's well intentioned so you can't really be too negative. That's a different thing that's trying to be supportive.

Ruth: can you think about the thing that's been most positive in terms of accepting yourself and feel ok about being dyslexic, from another person

Amber: there was one with my current boss, I mentioned it at a meeting and she just said 'fine, if you need anything let me know, otherwise just get on with it' I said 'if you want to ask me anything about it, ask' and she was like, 'no, if you want to tell me anything tell me, but if not, ok' but that's all you need. A bit this year from, I've been outside of the box in my work quite a bit, partly because I don't care in this department, I've had enough, I just want to pass and get on with something completely different so I've almost challenged the kind of work they're setting and how I relate it back to them. So drawing pictures and taking different routes, I wrote a poem and put it in, and I got the feedback that it was ok, they liked it. I don't think they all would have liked it but I've done other things since and had a few ideas since which is away from the bog standard academic nonsense, well not nonsense. The idea of doing a presentation outside in a 3D thing didn't go down as well so I didn't do that one. That had a few 'what on earth are you doing' kind of looks so yeah they're not quite there with it. But I'm getting the feedback that it's ok.

...

Ruth: I think it's quite difficult for you to go through and say different points [about the mind map] and explain it, but I still think that would be good so maybe if I look at it and ask you

questions? I need to take a bit of time, Differences between basic understanding and books and experience – (changing perceptions over the years) I think you didn't look at any books for awhile after diagnosis because you decided you couldn't read, is that right?

Amber: yea! [both laugh] I found it got expensive, finding you could read. I had to slow down a bit I can't afford to read them. [so this is about reading bits and then having to think about how that related to what had happened to you] yeah, if you're dyslexic you must do this, this and this. It's like, well, you can't apply that to every situation and it's just oversimplifying it sometimes. And I do joke with my friends about having dyslexic and not so dyslexic days and that's a change from the book because you're always this and you're always that, no, when it's a really good day, in one aspect that can be great but that can be absolutely atrocious like my writing can be fine and no problems, my visual perception and spatial awareness of things is absolutely atrocious, and I'm bumping into everything. And then other days they can be fine other days they can be terrible, and there's a day when I should just sit still and do nothing. But there's, I think it relates a lot to books and how they're so child focused. There's very few that say, are adult, or the ones that are say the adult is very negative and has no self-esteem, there are those elements to it but if you're saying that's the only way you can be I think that's terrible. You might have low self-esteem but it's never going to change so deal with it. I just find it

Ruth: I'm thinking about your experience over the last year vs the year before that, and actually your self-esteem has everything to do with your situation

Amber: if I didn't have any self-esteem i wouldn't have fought them, I'd have left or I wouldn't have even started

Ruth: but I'm thinking about a book that talks about adult dyslexia saying an adult dyslexic has low self-esteem and not kind of including with that the context of what happens, in a sense it's no good saying it's about the adult when it's not about the adult, it's about the situation and whether they're supported and how they're supported

Amber: there's a couple, literally there's two books I found, that are for adult dyslexics and they're a lot better, they look at certain situations and the way you might be feeling depending on when you found out you're dyslexic and stuff like that, but they also look at the positives. They're almost, ones looking at work and ones looking at selling it to employers and making it positive for them and just almost like a checklist for what to ask for and what to say and all the things you can pick out. But it's not prescriptive as in 'these are the definite things' it's more like 'these are the examples and maybe out of this if you pick ones that are relevant to you or expand on it it's not so black and white

Ruth: can you say what books those were?

Amber: I can let you know what they are. I can picture them.

Ruth: 'It's not what a person is but part of a person' [Acceptance] so that's your, is that a change

Amber: yeah, I think that's a change in me, it's not necessarily a change for others. It's almost like, oh, you're dyslexic, but that's only a little bit of me. And you often get pigeon-holed into this, this is you, this is all of you. [Ruth: and you would say it's not] No, no, I hope not. Yeah, it's one of a number of things. I'm asthmatic but I don't necessarily go around going 'Hello, this is me, I'm asthmatic' that's it. And lots of people, it's part of you but it's not you.

Ruth: questioning why a label is needed not in a 'it doesn't exist' way

Amber: yeah, I think it can be quite negative at times. It's tricky, I toy with that one. It's like just a different way of being, it's not an issue it's just the situation we're in where the system requires you to work in these particular ways which is different to the ways you work. Then other parts of me say 'no, no, this is an issue that isn't just about learning differences, it's difficulties with that' and so I toy between, but I'm over cautious with labels generally, that they box people in.

Ruth: it sounded to me there like you were saying that this idea of dyslexia as a difference not a disability that there are times you think yes it's a difference, and there are times you think actually it's a disability is that right? Can you tell me about the times you think it's a disability?

Amber: I think for example I went to a course for work and the sort of activities we were doing as part of the set up, it reminded me of before I had the dyslexia stuff in place and I couldn't engage as much with it, it was a room full of people who didn't know each other from different organisations and that kind of 'ah, help!' sort of feeling, trying to get on with it and make a good impression but clearly not engaging in some of these activities as well, like having to read through a couple of pages to discuss with everyone in a couple of minutes, I couldn't do that. I'm trying to skim read it but I'm pfaing about with it and not getting anywhere, as well I've noticed the short term auditory processing issues and not being able to keep up with the conversation long to follow it long enough that's going quite quickly about topics you don't know and that kind of felt like I was cut off with the rest of the group.

Ruth: so when you were in that situation it reminded you of what it was like in college, and so you were thinking unless you have support it prevents you from, it's a real barrier to learning.

Amber: sometimes when I get meetings with people I do say to them 'I'll jot everything down because otherwise I'll forget it' and people are fine, but I do forget a lot, and I'll get asked a couple of hours later and I feel, I don't even remember the conversation. Some of that's probably just general, what everyone experiences but to some extent it's related to that and my difficulties with remembering names, I can tell what they were wearing, what they look like, especially people you've first met but I can't remember their names and then you've got to relay to someone else, at work it's like a hundred people coming in and out of the office each week and then there's people you haven't met on the phone and emails and I can't tell you who's who. So there's that and everyone else picks it up really quickly, you need to find out something, you don't know what you're meant to do, and you can't remember the name of the person you're meant to ask, so you can't phone them because you don't know who you're meant to phone and you can't ring up anyone because it's so specific what you want to know. In those times, I get them in the end, but, there's a couple of people who are getting used to me just asking them, but having experienced it for a couple of years,

Ruth: story selling. What's that?

Amber: there was a lot of in the media, I think I was at Nottingham, doesn't think dyslexia exists, and the impact of that in the newspapers but if in sometimes came up in relation to that after that, people would say oh, no, it doesn't exist. There was a lot of, I looked at it further and I've looked at what he said since then but the media haven't really portrayed that at all, they left it as the stormy grabbing thing and didn't put the counter argument he had given them, my cousin found it hard because it wasn't long after she found she was dyslexic, but I think the newspaper, 'this doesn't exist' what's going on. I can't tell, people think I'm lying.

Ruth: so the media can cause more problems. PGE course, the experience of being a pain. Interview. What about that.

Amber: I've been sent to interview new ambassadors and given questions even being told in an interview situation I'm not allowed to take notes during a 20 minute interview with them but then I've got to feedback on them afterwards, and I was saying 'I can't do this, I can't remember what they said' and that's caused a lot of problems and a lot of battling with them. I was a senior ambassador for quite awhile, so I was in charge of other ambassadors. There's a lot of problems with the whole scheme at the university, a lot of people were pretty frustrated with it. Because even when you are in a position where you're given a lot of responsibility, you're still just a student to them.

Ruth: it does seem extremely prescriptive

Amber: yes, definitely, even down to showing people around the university we've almost got a script that we've got to stay you've got to stop at certain points, and that goes for most of the work I've got to do it's almost like a marketing rounded product that they have to maintain, there's no real life in that

Ruth: shock, current shock

Amber: oh, yeah that's the shock, some people despite having worked with them for ages are shocked to find it out, that I'm dyslexic, they're shocked I think mainly because I don't work with them day to day anyway but also because I've already been doing things and they

wouldn't notice [so they're surprised that you can do your job well] or surprised, because they know I'm still studying, they're surprised I'm doing a Master's they think I'm almost borderline sort of, I'm really tampering in things I shouldn't be tampering with, or I'm taking a huge big risk to be doing a post-grad qualification. I managed my undergrad and that's fine. It's kind of, can you do this can you not. [not particularly affirming] No, it is tricky there's a lot of my role is breaking down stereotypes of young people to a middle class white female organisation volunteer-wise. So what a lot of what I do is breaking down barriers I'm not surprised to see not so much shock in negative comments, they're generally positive but not knowing much about it. And they're willing to listen or ask. It's not done against you, which I find work and this course has been, it's almost been against you where they're like 'oh, ok, right, what's this mean?' and that I don't see as a problem, I see it as a compliment when they say 'I would never have thought you were dyslexic' it's usually because they know much about it. But I take it as a compliment when they haven't seen me struggling with certain things.

Ruth: new emerging issues, internally, situations, external causes,

Amber: like the course the other week, new emerging issues, when I'm learning or working in written, academic work or job work I've already had in place things that will sort out, [so the name thing you've not worked out any strategy] and just a different environment it's almost in some ways I start from scratch about how I'm going to deal with that

Ruth: friends outside uni – uninterested. I like that. It's not an issue then

Amber: yes and no, a lot of friends outside uni are quite long term friends they know about it, some are like, 'no, you're not dyslexic', joking about it or, 'no excuses, get on with it' but they really don't care, they don't want to know anything about it. A couple have been like 'I might be dyslexic' and I say go and see about it

Ruth: generally quite set in their ideas

A: even people who think they know something about dyslexia, they don't like what they think challenged. They've got their assumption and that's that.

Ruth: negative – having to stand your ground with others

A: that's been the School mainly [you feel they have not supported you in terms of your self-esteem, what about your identity, has it changed who you think you are?] I find identity a weird concept in itself, yeah, I think it has, it changed it how I view it in some ways, in how I view myself, do I be determined but awkward or do I get back to sitting quietly. That's what I did at college, even though I didn't know I sat and didn't say the issues I was having with it, and it's also changed the way I think others view me, it's hard to say, it's still in a weird process for me, but it's me deciding how I want others to see me and how I portray that and that's a bit up in the air at the moment

Ruth: have you on the whole been quiet or on the whole stood up for yourself

A: in different situations different things. On the course I've stood up and I've been awkward. Partly because I've spent a lot of money to do this course [did you not get your] I got some funding to help toward the fees but in terms of living costs and general expenses it's all purely me [it's not your family] I financially have cut myself off from my family to their dismay, it's purely just me so it is costing quite a lot so I think I deserve some quality of standard.

Ruth: highlighting difficulties

A: me, I think I'm more aware of them and I accept them more, but it has highlighted things I didn't know about me, and there is some bliss in ignorance sometimes I'll get very frustrated with things like I'm trying to spell a word and no matter what I type into the computer or what I write down and I can't find it and I want to say this particular word. Or even breaking down words over the phone, you've got someone's name and you can't think of how on earth to say it, you've never seen it before, and knowing there's a reason for it is almost comforting but it's also frustrating because you're more aware of it. Whereas when you used to make up how words are pronounced I was unaware of how I was doing it, everyone else was a bit confused but I was none the wiser.

Ruth: future implications, jobs and kids. Are you thinking do I really want to have kids when they might be dyslexic?

A: there's that and also if I did have kids am I going to over-think they're dyslexic, when are they really showing any signs of it, they're just growing up, do I push, and if I did how do I, do I put them in a system where they're completely stereotyped still or do I leave it and let them find their own way

Ruth: ok, so you weren't questioning whether you would have children in the first place

A: no, that's not a question, but there is the inherited side of it which is becoming even more evident in my family. It's a possibility, it's like they're going to be asthmatic and they're going to have allergies and they're going to have certain things, they maybe won't but there is a likelihood they will from a genetic sort of viewpoint, but it's just what you do with that

Ruth: how dyslexia affected you as a person, hard to say other things affected me at the same time

Amber: it's hard to say what is related to dyslexia and what's not the past few years, so much else has gone on that it's hard to distinguish which one has affected you or what which is a cause and effect, I found that question really hard when I was looking at it. And the fact that it changes and my identity has changed quite a lot in the past few years. Part of it I think was just a natural progression that everyone goes through and others I think are related to specific events that change with that

Ruth: so are you saying you can't pick out what's dyslexia

A: I automatically go and I pick it out in terms of learning because that was the situation when I found out about it all and that's the situation that I've had the support with about it all and now I'm sort of working a lot more in paid work I'm relating back to working previously and recognising a lot more now in that, but seeing the outside world and dyslexia related things and that's changing, how I view it. Even down to little things like driving, it's not completely dyslexia but with the Meares-Irlen syndrome I have binocular vision where things are a lot further away I can see two of them, my depth perception is completely wrong so I should wear my glasses to drive but I don't I forget to but I can park some days and I think I'm half a metre from the curb and I'm crashing into it or I can think I'm parked quite close and I'm two or three steps away and then I've got to go in the car and re-park it. So that's changed a lot my life's less focused on learning, I'm seeing it in other areas of things, not necessarily bad or good it just changes how you view it

Ruth: how do you make the distinction between something that's dyslexia and something that's not dyslexia?

A: oh, I don't know. The most obvious is I think I tend to pick things that are related to the learning that appears in other aspects

Ruth: so when you can link it back to what you were going through with learning then you think it's the dyslexia

A: yeah, like following road signs and driving to Three Crosses instead of Three cliffs and I followed about 6 different road signs that all said 'Three Crosses' but I wanted Three cliffs, now I put down to the dyslexia, or just little things like strategies, I had, bought a satnav because I found driving extremely stressful and especially going to places I didn't know, or even places I did know, I'd get myself into such a state sometimes I'd just have to get out of the car whereas now I trust the satnav a bit too much and sometimes when you haven't seen lifeforms for 5 miles because you're going somewhere in the Cotswolds you start to worry, thinking 'this is a little box. I have no idea where I am' but the sort of hassle that's taken out of driving, it not only says 'turn left' or 'right', it also shows you because I often mix that up, but you can visually see where you going and you can see ahead where you're going. And in terms of timing it has something on it that tells me how long till I arrive roughly, rather than me trying to figure that out while I'm driving, and I relate a lot of those things as dyslexia rather than just me.

Ruth: Experience of being interviewed. Please: shorter than first transcript

A: I think the first one was 18 pages, I read three lines and said 'ah, I'm sure she's written what we said', this one I looked down and saw it was a few pages, towards the end I started to trail off but I did actually read all of it.

Ruth: did you find the timeline helpful?

A: in some ways I found it quite weird to read, it pinpoints things, it had that element because it had things that were said and it was things that were said rather than purely factual but it's a bit weird looking over things, especially family life that, it was quite difficult at times I'd say.

Ruth: I suppose those things are important because it's about understanding you as a whole person not as a dyslexic person, it's about how your whole life has been and those other things are really important, some of them a lot more than dyslexia anyway

A: I think I've written that down at one point [is that what you were thinking because I know that] there was also something about

Ruth: I think you've been very insightful in picking up things like the people who I've talked to who were diagnosed when they were young their experience of learning about being dyslexic was very different from your friends who were diagnosed as adults. Sometimes questioning what you said

A: thinking did I say this? I think part of it as well, I find reading transcripts really bizarre and you really just want to edit and correct. I also I think some of the things, obviously it was quite a long time ago, and things have changed, 'uni's great' and I want to write down 'no it's not' stuff like that was the change. It was that at the time but it's changing. I found the experience of being interviewed and seeing the transcripts, I relate back to my course when things come up and I can, the theoretical things we're taught, I can relate back to an experience

Ruth: can you tell me, in terms of being interviewed, can you tell me about ethical issues? How has it felt? Has it harmed you in any way?

A: that's a tricky one. Ethically I haven't seen any issues when I first started, and it wasn't till I started this current course and it was really looked at in depth I started looking at things. And there's an article about research in your own backyard and some of the experiences that we read a lot of questions I hadn't even thought about. Not in terms of the interview process, that's fine, just my connection with the people I'm talking about, and having read a lot of research papers where they have changed everything, no you've described this, I've never been there but I know where you're talking about. I think Jersey was given a really random, obscure name, but even the dimensions and the sort of the size of the island and where it was located it couldn't be anywhere else.

It's also in relation to the position I'm in, if it was a few years down the line where I wasn't anything to do with politics I'd be quite happy to say, 'no use my real name' but there's that desire to protect myself.

The other side of the interviewing has been kind of, although I developed some ideas of it I'd never thought about it in huge depth, so that's been quite eye-opening to me what I think, which is quite ironic since it's what I think. I find it a bit bizarre because our relationship has changed in the past year outside of the interviews, that's been fine, it has been fine, it's weird as in meeting for an interview but not weird in a bad way, but you're also kind of 'I want to make sure Ruth has got really good research but not giving you the answers you're looking for'

Ruth: uh, no, sorry you're going to have to spell that one out

A: you know when you get participants trying to please researchers, there's an element of that, there is and isn't, and I think that would have been irrelevant whether I knew you outside of this or not. There's an element of that but there's also an awareness of not giving answers that I think I should be giving, making sure that everything is there

Ruth: so you're being as true to you regardless of what that means for me

A: yeah

Ruth: good, that's what I'd want you to do

A: making sure, heck, not making sure the research is good for you, but the research itself is good.

Ruth: can we go back to, in terms of, as a participant, coming to interview, especially the first time when we didn't know each other at all, can you describe what your expectations were and what your perceptions were of what happened

A: I think a bit nervous, I didn't know what you looked like, I think there was a sense of finally, because I'd kept emailing you saying I couldn't make it because I wasn't well, in some ways it was almost exciting to know that someone was doing something in this area, I was sort of intrigued, what exactly is she doing. I think I was a bit thrown at first when I realised it was life history as well as dyslexia, which I appreciate the need for that and that's fine,

Ruth: did you feel that that was an intrusion?

A: no, I was just a bit shocked by it, I was just used to looking at dyslexia or anything similar if you speak to someone about it it's very factual or slightly, I don't know but it's specifically about that it never goes outside that. But it was nice, but it was a bit of a shock to go, now she wants to know about me.

Ruth: because I have been a little bit concerned that you were, cause I know, what you said about remembering negative memories, that maybe that's not a positive experience and I was aware that it might have brought up things that weren't positive for you

A: it did. That's a tricky one, because there's no way you'd know in advance for a start, it's, I've dealt with some of those issues a lot over the past few years outside of this, and so they're not always, not the first time told in recent years, so in that sense that's easy for me, whereas the first time I told someone who didn't know me, that's a lot harder.

Ruth: would it be fair to say you had other places to go if you had any issues, if what we had talked about had stirred up something, you had somewhere else you could go to talk about it

A: yeah. I've never felt I had to tell you something for the sake of it. So it has been, yeah, it was a difficult issue but it is part of who I am, and therefore I feel it's important.

Ruth: is there anything else you would have thought I might have said?

A: I really don't like this question. I don't think there is. The only thing I think of is the timeline and the bits since.

Ruth: did I ask you about a picture before, 'if you were to describe dyslexia as a picture how would you describe it?'

A: colourful, lots of swirls, there's a lot of movement in it. Kind of a darker edge at the bottom. A wavy one. That's all the not so nice stuff about it. There's some spaces down there. Lots of swirls and colours. That's what I see.

Ruth: you wouldn't paint it, would you?

A: yeah. I paint a lot now.

Timeline: Amber

Age at first interview: 23

1<sup>st</sup> Interview date: 17 February 2007

2<sup>nd</sup> Interview date: 05 April 2007

3<sup>rd</sup> Interview date: 21 May 2008

	Childhood	Primary School	Comprehensive School
Family	<p>Parents, brother 16 months younger</p> <p>Father a surveyor, 'Dad worked a lot so he was never around much'</p> <p>'Mum used to teach us a lot at home.'</p> <p>Mum's side of the family very close-knit, all live in South Wales, babysit for each other, see each other regularly. Amber one of 20 grandchildren. All spent millennium together – 50+ came</p>	<p>Family life 'not great'</p> <p>When father wasn't at work was working on building their house, 'we didn't see a lot of him other than house-related, [yeah] basically. I think as well he's very perfectionist so he'd spend all day doing one particular thing, yeah, so a lot didn't get done. Um, so yeah, I only really saw him a lot when were um, either helping with the house or doing something with the house or outside of that it just tended to be the three of us'</p> <p>Asthmatic – stopped her from doing things eg helping her dad because of the dust involved with building</p>	<p>Family life got worse. Parents arguing a lot, father with mental health issues, mother ill with osteoporosis. 'It was quite nice just to go to school for a lot of it'</p> <p>Parents eventually separated, mother did 2 jobs, Amber took on a lot of the household responsibilities, including caring for her brother</p> <p>Got computer at home at 15/16. She and brother fought over it, used to type up work</p>
Education	<p>Started nursery day after she was 3 (could read when she went to nursery)</p> <p>Went for a year. Remembers doing painted butterflies, where you put paint on half a sheet then fold it over</p>	<p>In mixed group with youngest of year above and oldest of year below together. Remembers reading schemes, maths puzzles with blocks. Cut out in groups and they were being assessed. Had to cut out straight lines – was only one that couldn't follow line to cut.</p> <p>Enjoyed</p>	<p>'I was always quite a shy, quiet person' found transition from small primary to large comprehensive somewhat difficult, but went up with primary friends</p> <p>Enjoyed it</p> <p>'Buried myself in my [home]work' in response to difficulties at home, 'sometimes it was an</p>

		<p>Ill with pneumonia, bronchitis, (related to asthma) off from school for weeks at a time, Mum taught her at home. Once in 6 weeks off, completed the year's workbook in that time, way ahead when she returned to school (this is before move)</p> <p>When moved to new house age 7, moved schools (end of Year 1). New school used same reading scheme as old but Amber was moved down (was level 7-pink at old school, moved down to Level 6 – orange) because though she could read the words she was not understanding them. Amber found this very annoying – did not understand why she had to read the same books again. She had been used to feeling ahead and then found it hard to be average.</p> <p>Still ill quite a lot after moved – first to catch cold etc. No glue ear.</p> <p>Excellent at maths – SATs level 6 in Year 6. Excellent Literacy and Science, too – level 5s</p> <p>Told at parent's evenings that she needed to work on English/spelling</p>	<p>excuse to get away from sitting in a room where nobody is talking' 'my escape almost'</p> <p>Took her hours to do her homework. Everyone's like 'oh you're very hard working'</p> <p>During time when home life was most difficult Amber found herself switching off in lessons, 'big peaks and troughs sometimes with it'</p>
Place	Born Cardiff	<p>Moved age 7. Lived in new house as it was built by father outside of full time job ('higglety-pigglety'). First 8/9 months lived with neighbour while house was started, moved in long before finished – started by all living</p>	

		<p>in one room, with microwave and camping stove. Outside tap to start. Then moved to 2 rooms etc.</p> <p>Moved in same city, totally different area, from low socio-economic area to privileged area. Even at age 7 noticed cultural difference. More organised activities she wondered 'why can't I just go out to play?'</p>	
Friends		<p>Had group of friends, parents were also friends so spent lots of time together</p> <p>Found it hard to get know people after they had moved. Mother was part of babysitting club so she and other children went back and forth for that. Cliques were hard to get into. Settled in after about a year.</p>	<p>Kept primary friends at comprehensive, 'other groups of friends started joining in'. Met at weekends, went to the cinema or town</p> <p>Tended to have fewer friends that were very close. Supported each other through difficulties, as several of their parents split up</p> <p>Sometimes embarrassed because she couldn't remember names of songs or people, felt 'quite left out'</p>
Hobbies		<p>Paddling pools, role play, mothers and daughters, nurses.</p> <p>In playgroup {at first primary school}, stuck in the mud, dungeons and dragons, catch people and putting them in there. Playground was on hill so couldn't really play ball.</p> <p>Played on house building site, in clay, found Victorian bottles and pots, broken crockery. Hid in the long grass</p> <p>'I've realised lately I picked up a lot of skills</p>	<p>Lots of music – choir, violin, clarinet, piano. Enjoyed v. much.</p> <p>In terms of reading music, treble clef fine, base clef harder, finds reading rhythm difficult eg symbols to beats, found memorising music difficult</p> <p>'I always loved art, I've always had a, almost like a divide in myself, whether I should be arty or a sciency side, since I've always liked science as well, science and maths and sort of stuff.'</p>

		from whatever he was doing because I do all the DIY at my house now, quite happily'	During 2 weeks work experience did one week in pottery and one week with a civil engineering PhD student  Reason she did baccalaureate because it meant she could mix science and art
Jobs			'we didn't get pocket money ... A lot of, when I was older if I wanted anything I had to work for it. Which I really appreciate, now.'  Paper round at 13  Worked in football grounds selling half time draw  Tesco's  Waitressing  Tutoring maths and science (refused to tutor English) – aged 15, taught piano  Potter's assistant. Started through work experience and then went back at half term, Christmas, then weekends/holidays

	College	Travelling	Midlands University
Family	Still lots of problems at home. Mum supported decision to go to college but dad thought I'd be	Family members were not happy about the different travelling. Mother was very anxious about it all and there were lots of arguments	Family (including brother and extended family) did not support decision to leave Midlands university and were openly very

	better off doing alevels. My brother started the baccalaureate a year after me	about it	angry about it
Education	<p>Baccalaureate. 'Good fun, very hard work, very stressful ... struggled a lot with the work load'</p> <p>Became very ill with anxiety and depression in the second year. Was given extensions to complete the coursework. In the end postponed three subjects to sit in the November exam session. Self taught physics, maths and history over the summer and autumn (had a tutor for maths) whilst also working.</p>		<p>Started degree in Philosophy. Read one article from the weekly required list and said 'I know I can't read this much in a week'. Changed to Biology, but began the course 2 weeks behind everyone else, felt lost and overwhelmed, 'completely stupid' in lectures because everyone else seemed to understand what they were doing and she did not.</p> <p>Difficulty with multiple choice tests. Could narrow down to 2 but couldn't tell the difference – just misread them. Used negative marking so often did poorly</p> <p>'I referred myself to get screened for dyslexia because I was picking up patterns which I couldn't explain' Midlands had still not said if she was or wasn't dyslexic a term after the screening. {were also unsure iif difficulties were due to dyslexia or anxiety} Said because she had so many strategies in place to cope with difficulties 'we don't know whether that's just you or that's you supporting your dyslexia through that'. For example, she used to highlight everything, in effect getting rid of a white background. Felt frustrated that they only gave her 1x1 tutor support {this wasn't study support but the actual screening process} every other week because there wasn't enough staff for more.</p>

			<p>Sense of quite a negative attitude there about dyslexia. Also a very competitive atmosphere, where her peers weren't willing to share lecture notes when she had been ill, also they were unsupportive about her visiting learning support. Amber felt this was related to the competitive, middle class ethos at Midlands.</p> <p>'I wasn't happy in Midlands I'm not a huge city person' Took her 30 minutes to walk across campus. Also sense that she did philosophy/biology for others rather than herself.</p> <p>Amber decided to leave. She perceived her tutor's attitude as 'Oh, well, yeah, whatever', and that he was dismissive of the possibility that dyslexia was part of the reason she was finding things difficult.</p>
Place	<p>Living at home with mother, brother and mother's partner (at weekends). Did try to move out but didn't because of financial issues</p>	<p>'Interailing round Europe with a friend'</p> <p>Tanzania</p> <p>Thailand</p>	
Friends	<p>Lost track of comp friends. Really 'clicked' with the group on her course.</p> <p>Friend she went Interailing with from college – both did same subjects, had same birthday, same height, same friends, same clothes. Travelled very</p>	<p>Went interailing with friend from college</p> <p>Still in contact with friends made in Thailand</p>	<p>Made friends with people I met during the first week near where I lived and flatmates. Also some friend on my course – a few other who had changed to biology in the first few weeks. Still in touch with some of them.</p>

	well together because agreed		
Hobbies	<p>Continued to learn piano and violin. Took up yoga, and various first aid courses. Going out clubbing with friends</p> <p>Most hobbies stopped after I got ill</p>	<p>‘My passion’</p> <p>Loved learning about culture – saw big sights but also mingled with locals</p> <p>Loved moving about, the freedom of choosing spontaneously what would happen that day, also having only a few responsibilities – deciding where to go that day, what to eat and where to sleep. Didn’t bring mobiles, ‘refused’ – phoned or emailed home every week. ‘It’s kind of, almost like a separate reality bubble’ [another escape from life’s difficulties?]</p> <p>Found different languages hard</p> <p>Couldn’t read maps (but friend could) but could retrace steps years later</p>	<p>Joined a girls choir which preformed regularly.</p> <p>Spending time with friends, often going to the cinema</p>
Jobs	<p>Was doing four jobs summer before started. Tutoring maths and science, football ground, pottery, Chemist</p> <p>Waitressing (laughed at for doing wrong thing, putting orders in wrong place, misspelling words on menu board – but ‘not much’)</p> <p>shop assistant</p>	<p>Tanzania – worked in a school. Iraq war started, had to leave for safety reasons. Taught maths and science</p> <p>Thailand – taught English, realised didn’t know grammar, couldn’t spell. Confirmed she didn’t want to be an English teacher, but found some satisfaction in it despite difficulties</p> <p>At home worked in a finance dept, local newspapers’ finance section and customer care, office work (forgot things she had agreed to do/meetings. Coped by having post-its</p>	<p>After leaving Midlands worked in careers guidance. ‘Almost got on my feet, as in I can do something as well, because Midlands had knocked me for six’</p> <p>Other employees had done political science degrees, so rang up universities that would accept her without having to wait another year – was accepted to Southwestern</p>

		everywhere.)	
Dyslexia	<p>Was screened for dyslexia as routine for new students. They were piloting a new computer package for this that year. As a course we got told there were a few low scores, but they put this down to doing the test on the computer.</p> <p>Stuggled with volume of reading for some courses but didn't want to admit this with tutors.</p>	As English teacher used tactics to get round her problems, 'let's look it up together and let's learn how to use the dictionary'	
Computers			Didn't have own computer unless I went to one on campus

	Southwestern University		
Family	<p>Amber and mother suspect mother is probably dyslexic. One cousin is diagnosed as dyslexic. Large extended family on mum's side, as a whole not very academically minded, of 20 cousins, Amber and her brother are the only ones to go to university, most left after GCSEs, 'knowing what I know now about dyslexia, knowing about the family patterns, some of them, I think there are other dyslexics in the family, just not diagnosed in it' {since last interview a cousin doing her GCSEs has found out she's slightly dyslexic and has been receiving some support from her school}</p>		
Education	<p>Enjoys Southwestern very much, small campus, everyone knows everyone else, near the beach. Amber feels her mistakes at Midlands' prepared her to succeed at Southwestern – in the subject she chose to study for herself rather than what she perceived others expected or felt was best, this helped with being dedicated to the work. Also, compared to others on the course she was more aware of what was expected because of her experience at Midlands'.</p> <p>Experience of DRC  'Referred quite quickly through the system' for dyslexia screening, was told she was dyslexic 24/11/04 – approx 6 weeks after starting at the uni. Her LEA took a long time to come through with funding for laptop and tutoring, though. Uses a dictation programme, software that reads back what she has typed in as she often reads what she thinks is there rather than what is there. Has a scanner that scans in books, which it</p>		

	<p>can then read to her. Also has green glasses and uses purple overlays {purple paper and green or peach overlays} to address Meares-Irlen Syndrome. Sees a study skills tutor (with specialist qualification in teaching dyslexic students) where she specifies what they do. Has worked on spelling, different strategies for reading comprehension, metacognition like playing to her strengths, using concept maps. She also asks for help planning essays and with proof-reading, particularly relating to grammar and punctuation. She also talks through her ideas to the tutor, which helps her identify areas in which she needs to do further reading, or places where 'I'm not getting where I want to be with it'. Has built her confidence by helping her understand what she has difficulty in doing and how to compensate for them, as well as what she does well. She says her marks have gone up, especially in comparison to Midlands. {I have also had support from a mental health mentor at the DRC for various issues. Aswell as other thing, it has helped a lot with organisation, time management and liaising with my department}</p> <p>In contrast to her experience at Midlands, the attitude toward dyslexia was not negative and/or dismissive, but was 'well, this is ok, don't worry about it', but not in a dismissive way – the screening was done quickly followed by ed. Psyche assessment quickly followed by technical needs assessment. 'I mean, it takes awhile to get on board, but it's a lot more, it's acceptable, almost'. Her peers' attitudes have also been very different from Midlands; many are happy to lend notes and/or be supportive in relation to her dyslexia.</p> <p>Sense of success at Southwestern:  'I'm doing well. I think a lot of that has come down from study skills, the support I've had with them, and partly as well I was so determined after Midlands' both because of financial implications and feeling judged 'determined to prove them wrong' like, 'Oh, well maybe uni's not for you maybe you can't cope with it' or maybe, you know, 'if there's dyslexic stuff you shouldn't be doing it', and it's like, well, 'why not?'</p> <p>Dyslexia has caused some problems in relation of some module choices I made. I ended up having to have special arrangements for one of them. There were also a few extensions to be able to complete work.</p> <p>Feels she has found her niche with politics, considering doing post-graduate work</p> <p>Amber has free time again for the first time since college – before recently she had to give up time spent on music and sometimes friendships because of the immense number of hours she had to spend on coursework. The degree to which she understands the way in which she learns means she can estimate the time she needs to spend on any given task, also meaning she can plan in time to enjoy herself.</p>
Place	
Friends	<p>Has 4 other friends who were diagnosed as dyslexic at Southwestern who support each other, joke about it, take the mickm make excuses</p> <p>Amber attributes this group to helping her see herself positively, and to relating to others positively about being dyslexic</p>

	<p>Amber encouraged one friend to be assessed because she realised she was having the same difficulties Amber had done</p> <p>Compared their assessments with each other to help each other understand what they meant</p> <p>'it's kind of been good as we can talk and we can turn around and say 'oh yeah, I feel stupid with this' or 'that's rubbish' there was a lot of I think anger with everyone because it explained a lot for each of us in our own ways. And sort of getting to grips with that. But on the other side we kind of, we've kind of turned it into, it's a bit of a joke between all of us. 'I forgot, I'm dyslexic' 'I can't spell, don't ask me' lots of friendly, light-hearted banter, which if someone else had turned around and said to us we'd probably be quite annoyed, but 'we're special', there's a lot of that but I think it's quite good as in, yeah, the support's there. We help each other out a bit or make fun of it, or, we've all passed information on to each other, like I've had some good books for adults being dyslexic cause there's not a lot on that, and that we found quite hard. I don't need to know what it's like being a 6 year old dyslexic! [Ruth laughing] I tell you, I've been there, I've done it, it's not, there's a lot of patronising books, almost, if you're an adult reading them.'</p>
Hobbies	<p>Buys travel books, plans trips, 'awards' herself travel for good marks</p> <p><a href="#">Continues expressing herself through art though only with things that take little time such as card making</a></p>
Jobs	<p>Works as an ambassador to the university, doing public relations in schools</p> <p><a href="#">Waitressing</a></p> <p>After dyslexia diagnosis found could not ring up the temping agency she had worked with previously because she didn't want to say anything about dyslexia, but also didn't want to not say in case it all came out and caused trouble. [Related to the 'I can't' identity she developed after the diagnosis?] 'I didn't have the confidence to do that again which is silly looking back on this. I did it for 9 months [Ruth chuckling] and ok we had problems, and we had funny phone messages and all sorts but I did it and no one was bothered or concerned'</p> <p>Since diagnosis has worked with [charity], told them 'look, I've got green glasses, purple paper, other than that you don't need to do anything' but I said 'you will find me with lots of post-its and if we have a meeting I will be writing lots of notes because I'll forget otherwise – bear with me' and they're quite good with that and they're like 'well, if there's anything you want us to do, that's fine'</p> <p>Also soon after the diagnosis felt trying to be a teacher was silly – but now thinks 'why not?' – though she has decided not to do formal teaching – has found she is bored of it after awhile, it's too repetitive, doesn't like the prescriptive curriculum. 'in teaching I see a lot of</p>

	<p>paperwork and a lot of stressed people'. From her work with careers, ambassador and with [charity] she feels informal education of 15 to 21 year olds was something she has enjoyed – is looking at that for the future.</p>
Dyslexia	<p>Because she referred herself for screening was worried she would look silly if she wasn't, and had 'made someone go out of their way'</p> <p>Immediately after diagnosis, Amber felt:</p> <p>Relief: 'things slotted into place from the past' like: physics teacher couldn't comprehend why she couldn't match symbols to words in equations and could do them one way but not another</p> <p>Anger: screened for dyslexia in college, not picked up; people having a go at her for not knowing her spellings when she had studied them 3 hours the night before – 'it was my fault';</p> <p>Confusion: 'you're given a report but that's about it and you don't know, almost what it means. It kind of, affects your identity slightly, really, in a way, you're kind of a person with dyslexia' 'There are study skills and services but no one actually told us what dyslexia meant'</p> <p>Identity:</p> <p>'yeah, it's a bit strange. At first. At the time. It's just normal now.'</p> <p>'My reading was a lot worse than I thought it was, like comprehension. I knew that it was slower but I hadn't realised, all of a sudden I'm like well, no, I can't read. So I stopped reading, not a huge reader in the past, but you know, I'd read a book, it'd take me awhile, but do it, too. But now, I can't do this now, I can't read'. Didn't read for pleasure for 18 months.</p> <p>'it kind of changes you for awhile. A lot of confidence issues with that.'</p> <p>The diagnosis drew attention to her areas of difficulties, making her over- aware of them. 'I think when I found out, I mean, it was quite late in my life to find something like that out, and it becomes quite a focus at first, 1) what is this, what does this mean, 2) what does this mean in relation to my past, what does this mean for the future as well, that you become quite, almost entrenched in it'</p> <p>Before diagnosis forgetting phone numbers was a joke, after she refused to take them – 'I can't write this down ever'</p> <p>Regaining identity:</p> <p>'well, this is me, and that's the dyslexic bit but that's not, they're part and parcel but one doesn't have to control the other'</p> <p>'I think over time I began to separate that out a bit so although it's not separate, and it is part of who I am, it doesn't control who I am, I think more? It doesn't affect my choices as much. There's a part of it, sometimes, you know, I'm not going to volunteer ever to read the encyclopaedia and proof read it for someone [Ruth laughs] because I know that's a waste of time for everyone! For me, it would take me too long, and I know when I read through things I read often what I want to see, or what I think is there. So you know, there's realistic sort of decision making with it. But it's not controlling the decision'</p>

Attributes her development of a positive dyslexic self-identity to her group of dyslexic friends: 'a lot of I think is, yeah, to step over it almost, or turning it into a positive, which I think comes a lot from the friendship group I have at uni in terms of the dyslexic thing'

'Yeah, me as a person, it's almost like it [dyslexia] doesn't really mean, much, almost.

Reactions of others:

Initially she over-focused on dyslexia, 'Not only internally, but externally, I had to tell people. I had to go and get paperwork sorted for the uni, went and told the family, [?] to friends, and some of that's kind of almost a battle as well because some friends were like 'when you've made it to uni you can't be dyslexic' so it's like, 'well, I've not asked you to diagnose me, I've just come here to tell you, it doesn't really matter' '

Dad didn't believe she was dyslexic, laughed about it when she told him, hasn't mentioned it again

Mum thinks she should have 'special treatment' for everything and expects it to be 'sorted and fixed, which put a lot of pressure on me initially at the time'

'I think without [DRC] I wouldn't have made it through a lot of the course work'

Read some books about dyslexia summer after diagnosed that helped

She and her dyslexic friends did the special needs module for their degree, in which dyslexia was covered; this helped them better understand what it meant to be dyslexic, also helped their peers understand them.

'it helped a lot of people around us on the course because it's very hard to explain to people sometimes like, we all get extra time in exams. I get a break in mine as well, it's very hard to turn around to someone and they're like 'oh, but you've got extra time you'll get a better mark' it's like 'yeah, but my writing is slower than yours, my reading, and I need it to check through' and it's very hard not to internalise that sometimes or you feel bad because [they've expressed] they haven't finished and you've managed to finish'

One lecturer printed out all handouts in the three colours of paper the dyslexic group respond best to, and so all students had coloured handouts, and the dyslexic students were not singled out as being different. Amber appreciated this greatly.

Some lecturers dislike being recorded on Dictaphone

	<p>Once the storekeeper ordered yellow pads of paper by mistake, when he found Amber and her friends were helped by it, he now buys them in for them</p> <p>Is glad of the diagnosis despite the emotional difficulties it brought about because the difficulties in education had become big enough to cause even greater problems – said if things had continued like they were at school – her being able to do the work and other activities – she wouldn't have cared if she was diagnosed or not.</p> <p>Wishes the diagnosis had come earlier because she feels she would have dealt with the emotional issues before education became very difficult. Also, things she blamed herself for, and others blamed her for, she would have understood as being related to dyslexia rather than value judgements like 'you can't do this, you're not trying' 'I would have made different choices I think.' [had she been diagnosed earlier]</p> <p>In terms of resources that would have helped when she was diagnosed, she doesn't wish there were more books for adult dyslexics, 'I've read books since which I've found helpful, and the internet, but I don't think that's the right thing to give someone who you've just told is dyslexic because I wouldn't have gone home and read it at the time, that's something that comes afterwards.'</p> <p>She would have liked someone to discuss with her what it means to be dyslexic, including information about disclosure in employment. Possibly peer support or mentoring; having a chat, having coffee. She feels the emotional side was difficult and the academic side was more positive because support has been there for the academic side from the beginning. She thought academically it would have continued to be difficult had the support not been there.</p> <p>Amber is much more aware of who she is as learner through the study skills support, 'which I'm really pleased about', 'I know how I work and how I learn'</p>
--	--

#### Notes

Amber seems to have coped extremely well with being dyslexic, so much that it is not a problem for her, in fact she has turned it into a strength because it has enabled her to understand how she learns, and control her success in education extremely well. This seems to be linked quite closely to having support via study skills and also through her friendship group, though the emotional aspects caused her difficulty for awhile.

I've been thinking about her story as opposed to Pablo's; his tutor support was not helpful to him, though his tutor was 'in control' of the sessions rather than him, unlike Amber's case. The technical support meant Pablo was able to 'become literate'. He still is not at peace emotionally, possibly because he is so aware of the political aspects of the disability? Amber is willing to work incredibly hard – Pablo expects a level playing field?

Issue of Midlands' university 'we don't know whether that's just you or that's you supporting your dyslexia through that' – perhaps a result of the BPS definition, where if you have learned to compensate you are not dyslexic – perhaps confusion about what was behind her difficulties, with a reluctance to diagnose in case of criticism? However, the difference acknowledging and supporting Amber has made would suggest this is the wrong approach. **I was told by then that they were reluctant to refer people to the ed psyche unless they pretty but certain you were dyslexic due to how much it cost}**

Contrast between everyone laughing about her not being able to write down a phone number accurately (discourse dizzy but loveable?) vs. after dyslexia diagnosis, when the discourse changed to 'something wrong with my brain – I can't'

During school years everyone saying how hard working she was when she spent hours doing work that her peers were doing in minutes – is there a gender issue here relating to dyslexia diagnosis – boys diagnosed because they cause problems, girls ignored because they are well behaved and willing to work hard enough to 'keep up'

Theme of group support coming up more than once – friend group during parents' divorce then again at uni with diagnosis of dyslexia

'separate reality bubble' – travelling – escape **definitely! – don't know if I've mentioned quite frequent short trips while at uni to visit friends across Europe**

Theme of 'prove them wrong'?

Theme of visual ability (is this an actual difference between her and others or is this taking on the discourse of visual ability related to dyslexia?)

War of identities – arty/sciency

No mention of any names besides placenames! **its been mentioned by others too. Part of this I think is a defence mechanism from having problems at home - either not being able to tell people things, and also people not being able to use things against you if they don't know exactly. It's now partly habit and also an assumption that if they person I'm talking to doesn't know the person Im talking about a name is quite irrelevant – a description/label of who they are is more useful. It does frustrate and confuse quite a few people though. My family are also very bad at remembering any names I tell them so Ive given up telling them any really**

## Jenny's summary

Jenny was born and grew up in South Wales with her parents and younger brother. She was not diagnosed as dyslexic until a few days after her 21<sup>st</sup> birthday, and is now 23.

Jenny has shown throughout her life a consistent willingness to work hard. Her interview communicated tangible enjoyment and satisfaction from meeting difficult challenges.

Her mother 'taught' her at home before she went to nursery school, so she could read by age 3. During her early years in primary school she was often ill, and she completed 3 or 4 pages instead of the 1 page a day the school asked her to do in the workbooks her mother picked up for her to do at home. She says she always looked forward to the 'extension' homework in maths, seeing how quickly she could work through the regular work, with the extension problems regarded as a treat. She achieved at a high level, with Year 6 SATs results of Level 5s in English and Science, and a Level 6 in Maths. Despite this, her memories of parent evenings are peppered with instructions by teachers to work harder in English, particularly with spelling.

During secondary school she spent hours each night on her homework, and received praise from her parents about how hard working she was. Her parents' relationship was breaking down by then, and she admits she turned to homework as an escape, 'sometimes it was an excuse to get away from sitting in a room where nobody is talking'. However, she also found herself switching off in lessons when things were particularly difficult at home, and she characterised her comprehensive career as 'big peaks and troughs'. Her parents eventually separated, and her mother took on 2 jobs, which meant Jenny became responsible for a number of household tasks, including caring for her brother.

Jenny enjoyed music very much at comprehensive; she was in the choir, and played the violin and clarinet. However, when she moved on to college to do a Baccalaureate degree, she was not able to carry on her activities in music as her schoolwork took up so much of her time. Jenny still described college as 'good fun', as well as 'very hard work, very stressful, struggled a lot with the work load'.

Jenny then took a gap year, and went travelling. She described travel as 'my passion'. She and a friend from college first went Interailing around Europe. She says she loved moving about, and the freedom of choosing spontaneously what would happen that day. She also enjoyed having only a few responsibilities – deciding where to go, what to eat and where to sleep. 'It's kind of, almost like a separate reality bubble'.

She then went to Tanzania, where she worked in a school teaching Maths and Science, but had to leave for safety reasons because the Iraq War began. She also went to Thailand, where she taught English. Here she said she realised she should never be an English teacher, as she found she knew nothing of grammar and had a lot of difficulty with spelling. She dealt with this by using tactics like 'let's look it up together and let's learn to use the dictionary'. Despite her difficulties in this job Jenny expressed satisfaction in it.

Jenny then began on her university career, with a few hiccups. She started with a degree in philosophy at Midlands University. Within 2 weeks she changed to Biology, because having read one article from the weekly required reading list she realised 'I can't read this much in a week'. However, she had missed out on 40 hours of lectures and labwork for Biology, and felt lost and overwhelmed. She also found the multiple choice tests extremely difficult because she often misread the items, making it impossible for her to choose between answers, and often did quite poorly.

She referred herself for dyslexia screening 'because I was picking up patterns I couldn't explain'. A term after the screening was carried out she still hadn't been told if she was dyslexic or not. They told her that because she already had a number of strategies in place, 'we don't know whether that's just you or that's you supporting your dyslexia through that'. For example, she used to highlight everything, in effect getting rid of a white background.

Jenny says she had a sense of quite a negative attitude there about dyslexia, for example her friends were suspicious rather than supportive of her visits to learning support, and wouldn't accompany her. Her tutor was also dismissive of the possibility that dyslexia might be part of the difficulties she was experiencing. She also described Midlands as having a very competitive atmosphere, where her peers weren't willing to share lecture notes when she had been ill. Jenny felt this was related to the middle class ethos there.

Jenny left Midlands after two terms. She said the experience 'knocked me for six'. She found work at a careers guidance firm, where she says she re-established some of her lost confidence, as she did quite well there. A number of her fellow employees had political science degrees, and having enjoyed politics in relation to her travel, she decided this would be a good subject to pursue. She rang up universities and was accepted to Southwestern University.

Jenny asked to be screened for dyslexia quite soon after starting at Southwestern, and her experience was very different from the one she had at Midlands. She was screened, then referred to an educational psychologist who diagnosed her as dyslexic by late November. Though her diagnosis came through quite quickly, her LEA took quite awhile to award her a disabled student's allowance.

In contrast to her experience at Midlands, she says most attitudes she has encountered about dyslexia at Southwestern have been 'well, this is ok, don't worry about it' but not in a dismissive way. On the contrary, she has received technical support in the form of software that reads text aloud from the screen and from scanned in books, has dictation and mindmapping software, green glasses to support Meares-Irlen syndrome and weekly study skills support that has supported spelling, reading comprehension and essay structuring, proof-reading and referencing. She also receives additional time in exams.

Jenny describes herself now as 'I know how I work and how I learn', and she is doing very well at Southwestern. She attributes her improved marks (including some firsts) to the dyslexia support, the fact that she came to Southwestern already understanding what was expected at university from her experience at Midlands, and because she arrived at Southwestern 'determined [to succeed] after Midlands' both because of financial implications and because she felt judged; she was 'determined to prove them wrong'.

Despite her positive remarks about dyslexia support at Southwestern, Jenny said the diagnosis caused her emotional distress for 12-18 months after the diagnosis. She felt that though her academic needs were well met, she was very much left on her own in terms of emotional needs, 'There are study skills and services but no one actually told us what dyslexia meant'.

After her diagnosis, Jenny said there were internal issues she had to sort out that seemed to relate to emotional stages. She said to begin with she felt **relief**, where things from her past that she had not understood now made sense, for example the complaints her physics teachers had had about her difficulty with equations vs words; **anger**, for example, that her parents had not recognised her difficulties and sought help for her – she was praised for being a diligent worker in secondary school rather than her parents wondering why she was spending hours on work that took her brother minutes; and **confusion**, where she didn't really understand what being dyslexic meant. Also, the diagnosis made her over-aware of her areas

of difficulties, and she experienced an 'I can't' attitude, for example she didn't read for pleasure for about 18 months after the diagnosis, though she had read for pleasure before.

Jenny also described external issues that caused her difficulty after her diagnosis, related to disclosing her dyslexia to other people. Jenny described this as 'almost a battle': her father didn't believe her diagnosis, and laughed about it; her mother treated it as something that needed to be 'sorted and fixed', which Jenny experienced as pressure; some friends were doubtful, for example by saying 'when you've made it to uni you can't be dyslexic'. Jenny also found the issue of whether or not to tell employers she was dyslexic difficult. At first she did not want to tell them, but was concerned 'in case it all came out and caused trouble'.

These issues, over about 12-18 months, have resolved for the most part: 'I think over time I began to separate [dyslexia] out a bit so although it's not separate, and it is part of who I am, it doesn't control who I am, I think more? It doesn't affect my choices as much. There's a part of it, sometimes, you know, I'm not going to volunteer ever to read the encyclopaedia and proof read it for someone because I know that's a waste of time for everyone! For me, it would take me too long, and I know when I read through things I read often what I want to see, or what I think is there. So you know, there's realistic sort of decision making with it. But it's not controlling the decision' and now, for Jenny, 'it's almost like [dyslexia] doesn't really mean, much, almost'.

Jenny attributes this emotional resolution in great part to a group of 4 or 5 other female students who have been diagnosed as dyslexic on her course. As a group they have supported each other by sharing feelings and experiences related to being dyslexic, 'it's kind of been good as we can talk and we can turn around and say 'oh yeah, I feel stupid with this' or 'that's rubbish' there was a lot of I think anger with everyone because it explained a lot for each of us in our own ways. And sort of getting to grips with that. But on the other side we kind of, we've kind of turned it into, it's a bit of a joke between all of us. 'I forgot, I'm dyslexic' 'I can't spell, don't ask me' lots of friendly, light-hearted banter, which if someone else had turned around and said to us we'd probably be quite annoyed, but 'we're special', there's a lot of that but I think it's quite good as in, yeah, the support's there.'

To me, Jenny's experience of dyslexia is a story of struggle with a happy ending, where Jenny has been able to conquer the academic and emotional difficulties dyslexia has faced her with through her own strengths and the support system she has found at Southwestern University. Perhaps as a result of her relatively recent successful navigation through the academic and emotional difficulties of diagnosis, her story deals more specifically, clearly and positively with the process of identity transformation in response to being diagnosed as dyslexic than other interviews I have carried out.

It is interesting that during the interview, my perception of Jenny was of someone fairly shy, who needed the structure of my questions to guide her in a way other participants had not. This led me to assume her answers would be less sophisticated than they are, revealing my own prejudices linking shyness with personal immaturity.

## Questions to be asked in interview 2 (10am Thursday 5 April)

Because Jenny dealt with dyslexia at length in the first interview, I thought I would ask her questions involved in life outside of dyslexia, to do with friends, childhood, work, hobbies and family. She has given information in all these areas, but I will try to develop them.

As Jenny is such a capable participant, I would like to trial showing her the timeline, and asking her to tell me more about the 'white spaces', and see whether it is helpful or not.

## APPENDIX 2: LETTER OF CONSENT



SCHOOL OF EDUCATION AND LIFELONG LEARNING

CONSENT FORM

I have been fully informed about the aims and purposes of the project.

I understand that:

there is no compulsion for me to participate in this research project and, if I do choose to participate, I may at any stage withdraw my participation

I have the right to refuse permission for the publication of any information about me

any information which I give will be used solely for the purposes of this research project, which may include publications

If applicable, the information which I give may be shared between any of the other researcher(s) participating in this project in an anonymised form

all information I give will be treated as confidential

the researcher(s) will make every effort to preserve my anonymity

.....  
(Signature of participant )

.....  
(Date)

.....  
(Printed name of participant)

One copy of this form will be kept by the participant; a second copy will be kept by the researcher(s)

Contact phone number of researcher(s):.....

If you have any concerns about the project that you would like to discuss, please contact:

.....  
OR

.....

Data Protection Act: The University of Exeter is a data collector and is registered with the Office of the Data Protection Commissioner as required to do under the Data Protection Act 1998. The information you provide will be used for research purposes and will be processed in accordance with the University's registration and current data protection legislation. Data will be confidential to the researcher(s) and will not be disclosed to any unauthorised third parties without further agreement by the participant. Reports based on the data will be in anonmised form.

## APPENDIX 3: ETHICAL CONSENT



School of Education and Lifelong Learning

## Certificate of ethical research approval

### STUDENT RESEARCH/FIELDWORK/CASEWORK AND DISSERTATION/THESIS

You will need to complete this certificate when you undertake a piece of higher-level research (e.g. Masters, PhD, EdD level).

To activate this certificate you need to first sign it yourself, then have it signed by your supervisor and by the Chair of the School's Ethics Committee.

For further information on ethical educational research access the guidelines on the BERA web site: <http://www.bera.ac.uk/publications/guides.php> and view the School's statement in your handbooks.

---

**READ THIS FORM CAREFULLY AND THEN COMPLETE IT ON YOUR COMPUTER** (the form will expand to contain the text you enter).  
**DO NOT COMPLETE BY HAND**

---

Your name: Ruth Gwernan-Jones      550027031

Degree/Programme of Study: 1+3 PhD

Project Supervisor(s): Robert Burden and Cheryl Hunt

Your email address: rg228@ex.ac.uk

Tel: 01404 850996

---

**Title of your project:** The experience of dyslexia in adults' lives: a life history study

**Brief description of your research project:**

Research suggests that issues of emotion and environment are closely linked with literacy, where both interact in either positive or negative ways to impede or support it. The ways in which dyslexic adults have experienced the attitudes and structures present within society relating to literacy is an area deserving exploration and better understanding.

To explore and deepen understanding of this area it will be necessary to become aware of such adults' experiences from the 'inside' – from their own point of view – and then place this perspective in the wider context of structures and/or changes relating to literature in our society. I therefore propose to carry out semi-structured interviews with up to 20 adults, analysing their life stories according to emerging themes and important life events, and relating these to a broader historical context, such as existing or changes in educational and/or societal policies.

**Give details of the participants in this research (giving ages of any children and/or young people involved):** The participants will be male or female dyslexic adults (aged 18 or over).

**Give details regarding the ethical issues of informed consent, anonymity and confidentiality (with special reference to any children or those with special needs)** a blank consent form can be downloaded from the SELL student access on-line documents:

Informed consent: The basis of the research will be explained to participants, including my interest in the experience of being dyslexic, an approximate time needed for interview and the participants' right to 'opt out' at any time, which includes their right to ask that any data they have already given be removed from the study. Transcripts of all interviews will be given to participants. They will be asked to sign the SELL consent form.

Anonymity/Confidentiality: The participants will be asked to create a pseudonym with which to represent themselves in the study, and I will use these pseudonyms when discussing and/or writing about the data. Names of people and places will be changed within the transcripts by me. Every attempt will be made to protect anonymity within the thesis and any journal articles or conference papers written about the data. The data will be kept securely in a locked file cabinet, and will be destroyed once the PhD is complete.

Special needs: It is possible the participants will be vulnerable in relation to being dyslexic, and I will be careful to be sensitive to this during interview. The interviews may still bring about an emotional response in the participant, though, and I will need to maintain a clear relationship as interviewer, as my training and role is not as a counsellor. In such a case I will respect the person and offer what help I can (for example a drink, a break, the option to end the interview, information about counselling).

**Give details of the methods to be used for data collection and analysis and how you would ensure they do not cause any harm, detriment or unreasonable stress:**

Data collection will be through semi-structured interview.

Though adaptable, 3 interviews over a 15 month period for each participant are planned. The interviews are expected to be approximately 1 hour each, but they may be shorter or longer in response to the participant (shorter if the participant does not seem to want to talk more, longer if the participant wants to continue).

I will also try to avoid harm, detriment or unreasonable stress to the participants by not pursuing any topics which seem to initiate distress. I will reinforce the understanding that they may withdraw from the study at any time by bringing it up at the beginning of each interview.

If any participant feels concern about issues of anonymity/confidentiality, I will offer to show them any texts to be published prior to submitting them. Ultimately, the participant has the right to request that I not use their material in the thesis.

**Give details of any other ethical issues which may arise from this project (e.g. secure storage of videos/recorded interviews/photos/completed questionnaires or special arrangements made for participants with special needs etc.):** Data will be kept in a locked file cabinet and destroyed after completion of the PhD.

**Give details of any exceptional factors, which may raise ethical issues (e.g. potential political or ideological conflicts which may pose danger or harm to participants):** N/A

**This form should now be printed out**, signed by you below and sent to your supervisor to sign. Your supervisor will forward this document to the School's **Research Support Office** for the Chair of the School's Ethics Committee to countersign. A unique approval reference will be added and this certificate will be returned to you to be included at the back of your dissertation/thesis.

I hereby certify that I will abide by the details given above and that I undertake in my dissertation / thesis (delete whichever is inappropriate) to respect the dignity and privacy of those participating in this research.

I confirm that if my research should change radically, I will complete a further form.

Signed: RC Aupus date: 18/05/08

*N.B. You should not start the fieldwork part of the project until you have the signature of your supervisor*

This project has been approved for the period: Sept 06 until: Sept 09

By (above mentioned supervisor's signature): R. L. Guden date: 14.05.08  
1415108

*N.B. To Supervisor: Please ensure that ethical issues are addressed annually in your report and if any changes in the research occurs a further form is completed.*

SELL unique approval reference: 0/07/08/31

Signed: Salah Trauti date: 7/06/08  
Chair of the School's Ethics Committee

This form is available from  
<http://www.education.ex.ac.uk/students/index.php> then click on On-line documents.