

## University of Southampton Research Repository

Copyright © and Moral Rights for this thesis and, where applicable, any accompanying data are retained by the author and/or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This thesis and the accompanying data cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder/s. The content of the thesis and accompanying research data (where applicable) must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holder/s.

When referring to this thesis and any accompanying data, full bibliographic details must be given, e.g.

Thesis: Rosa Gibby-Leversuch (2018) "Dyslexia or literacy difficulties: what difference does a label make? Exploring the perceptions and experiences of young people.", University of Southampton, name of the University Faculty or School or Department, PhD Thesis, pagination.

Data: Rosa Gibby-Leversuch (2018) Dyslexia or literacy difficulties: what difference does a label make? Exploring the perceptions and experiences of young people. URI [dataset]



# **UNIVERSITY OF SOUTHAMPTON**

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCES

School of Psychology

**Dyslexia or literacy difficulties: what difference does a label make? Exploring the perceptions and experiences of young people.**

by

**Rosa Gibby-Leversuch**

Thesis for the degree of Doctorate in Educational Psychology

June 2018

Total word count: 20,300

Chapter 1: 10,181

Chapter 2: 10,119



UNIVERSITY OF SOUTHAMPTON

## **ABSTRACT**

FACULTY OF SOCIAL, HUMAN AND MATHEMATICAL SCIENCE

School of Psychology

Thesis for the degree of Doctorate of Educational Psychology

### **DYSLEXIA OR LITERACY DIFFICULTIES: WHAT DIFFERENCE DOES A LABEL MAKE? EXPLORING THE PERCEPTIONS AND EXPERIENCES OF YOUNG PEOPLE.**

Rosa Gibby-Leversuch

This systematic review investigates the links between literacy difficulties, dyslexia and the self-perceptions of children and young people (CYP). It aims to further understanding by building on Burden's (2008) review and explores how the additional factors of attributional style and the dyslexia label may contribute to the self-perceptions of children and young people. 19 papers are included and quality assessed. Quantitative papers measured the self-reported self-perceptions of CYP with literacy difficulties and/or dyslexia (LitD/D) and compared these with the CYP without LitD/D. Qualitative papers explored the lived experiences of CYP with LitD/D, including their self-views and how these were affected by receiving a dyslexia diagnosis. Results suggest that CYP with LitD/D may be at greater risk of developing negative self-perceptions of themselves as learners, but not of their overall self-worth. Factors found to be relevant in supporting positive self-perceptions include adaptive attributional styles, good relationships with peers and parents, and positive attitudes towards dyslexia and neurodiversity. In some cases, CYP with LitD/D felt that others perceived them as unintelligent or idle; for these CYP, a diagnosis led to more positive self-perceptions, as it provided an alternative picture of themselves. There is a need for further research to explore the impact of attributional style and the potential for intervention, as well as CYP's experiences of diagnosis and the associated advantages or disadvantages.

There has been ongoing debate around the use of the term 'dyslexia' to describe the literacy difficulties of certain individuals, however, CYP's perceptions of the advantages

and disadvantages of the use of the term have not been directly sought. This study aims to explore the views of young people (YP), with and without experiences of dyslexia, with a particular focus on the impact of labels. A qualitative methodology is used to explore the views of a range of individuals currently in secondary education (aged 13-19). The views of 36 YP (12 with self-reported dyslexia, 12 with self-reported literacy difficulties and 12 with no reported literacy difficulties) were gathered using an online survey. In depth one-to-one interviews were also carried out with six YP who reported having dyslexia. Results show that YP saw the dyslexia label as an important factor in gaining appropriate support for difficulties, and highlight the potential for discrimination in terms of access to diagnosis and therefore access to support. The dyslexia label led to changes in perceptions and helped to remove the sense that a YP may be to blame for their difficulties, as dyslexia was seen as having a biological origin. This was beneficial for those individuals who had the label, but led to more negative judgements being made in relation to individuals with literacy difficulties but no dyslexia label. Furthermore, the label was associated with permanence, which is discussed in terms of attribution theory. Implications for Educational Psychologists and school staff are discussed in terms of ensuring that YP, and their teachers, have a good understanding of their literacy needs and are empowered by the way their needs are described, and are not subject to selective stigmatisation.

# Table of Contents

<b>Table of Contents .....</b>	<b>i</b>
<b>Table of Tables .....</b>	<b>v</b>
<b>Table of Figures .....</b>	<b>vii</b>
<b>Academic Thesis: Declaration Of Authorship.....</b>	<b>ix</b>
<b>Acknowledgements .....</b>	<b>xi</b>
<b>Definitions and Abbreviations .....</b>	<b>xiii</b>
<b>Chapter 1 Literature Review: What are the Links Between Dyslexia, Literacy Difficulties and the Self-Perceptions of Children and Young People? .....</b>	<b>1</b>
1.1 Introduction.....	1
1.1.1 Context.....	1
1.1.2 Linking dyslexia and self-perceptions .....	3
1.1.3 Defining self-perception .....	5
1.1.4 Current Review.....	6
1.2 Method.....	8
1.2.1 Search Strategy .....	8
1.2.2 Data Extraction .....	11
1.2.3 Quality Assessment .....	11
1.3 Results.....	14
1.3.1 Selected Papers .....	14
1.3.2 Quality Assessment .....	15
1.3.3 Dyslexia and Self-Perceptions .....	18
1.3.3.1 Global Self-Perceptions (GSP) .....	18
1.3.3.2 Domain-Specific Self-Perceptions.....	22
1.3.3.3 Educational Settings.....	27
1.3.3.4 Attributions .....	28
1.3.3.5 Labels.....	33
1.4 Discussion.....	36
1.4.1 Summary and Implications.....	36

## Table of Contents

1.4.2	Strengths and Weaknesses of this Review .....	39
1.4.3	Implications for Future Research .....	41
1.5	Conclusion.....	42
<b>Chapter 2 Dyslexia or literacy difficulties: what difference does a label make? Exploring the perceptions and experiences of young people..... 43</b>		
2.1	Introduction .....	43
2.1.1	Study Aims .....	46
2.2	Method .....	47
2.2.1	Design .....	47
2.2.2	Epistemology.....	47
2.2.3	Sample and Recruitment .....	48
2.2.4	Procedures .....	50
2.2.5	Data Analysis.....	54
2.3	Results .....	58
2.3.1	Online Survey .....	58
2.3.2	Interviews .....	69
2.4	Discussion .....	89
2.5	Implications and Conclusions .....	98
<b>Appendix A Literature Review: Search Terms and Strategy.....</b>		<b>101</b>
<b>Appendix B Literature Review: Examples of Excluded Papers .....</b>		<b>103</b>
<b>Appendix C Literature Review: Data Extraction Table .....</b>		<b>105</b>
<b>Appendix D Literature Review: Quality Assessment .....</b>		<b>115</b>
<b>Appendix E Ethics .....</b>		<b>121</b>
E.1	Setting Study information sheet and consent.....	121
E.2	Sample study information: survey .....	123
E.3	Sample study information and consent: Interviews .....	126
E.4	Interview debrief.....	131
E.5	Ethics approval.....	132
<b>Appendix F Online Survey .....</b>		<b>133</b>



<b>Appendix G Interview Schedule .....</b>	<b>137</b>
<b>Appendix H Example Use of Note Taking and ABC Technique in Interviews.....</b>	<b>139</b>
<b>Appendix I Records of Survey Data Analysis.....</b>	<b>141</b>
I.1 Example of initial notes and codes recorded manually .....	141
I.2 Using NVivo to analyse survey data.....	142
I.3 Reflexive note taking alongside reading of survey transcripts.....	143
I.4 Recording thoughts on theme development .....	144
I.5 Table of themes, with contributing codes and examples of quotes .....	145
<b>Appendix J Records of Interview Data Analysis .....</b>	<b>153</b>
J.1 Reflexive note taking.....	153
J.2 Using NVivo to analyse interview data.....	155
J.3 Interview codebook.....	156
J.4 Manual arrangement of codes into themes .....	161
J.5 Table of themes, with contributing codes and examples of quotes .....	163
<b>Appendix K Extract from a Survey Transcript.....</b>	<b>183</b>
<b>Appendix L Extract from an Interview Transcript .....</b>	<b>185</b>
<b>List of References.....</b>	<b>191</b>



## Table of Tables

Table 1. Self-perception terms defined .....	6
Table 2. Inclusion and exclusion criteria .....	11
Table 3. Quality assessment for qualitative papers.....	12
Table 4. Quality assessment for quantitative papers.....	13
Table 5. Characteristics of selected papers .....	14
Table 6. Research questions .....	46
Table 7. Survey participants .....	50
Table 8. Interview participants .....	50
Table 9. Use of survey support .....	52
Table 10. Phases of Thematic Analysis taken from Braun and Clarke (2006, p.87). .....	55
Table 11. Research questions and relevant themes, with source groups in brackets.....	59
Table 12. Themes not discussed .....	59
Table 13. Mean scores assigned to scaling questions and differences in mean scores .....	69
Table 14. Participants' descriptions of their dyslexia.....	70
Table 15. Research questions and relevant themes .....	71
Table 16. Themes not discussed .....	72
Table 17. Comparison of Solvang's (2007) advantages and disadvantages of dyslexia labelling with those from the current research.....	90



## Table of Figures

<i>Figure 1: Paper identification and screening process</i> .....	10
<i>Figure 2: Survey recruitment procedure.</i> .....	49
<i>Figure 3: Survey vignettes.</i> .....	51
<i>Figure 4: Survey data collection procedure</i> .....	52
<i>Figure 5: Thematic Map for online survey findings</i> .....	60
<i>Figure 6: Thematic Map for interview findings</i> .....	73
<i>Figure 7: Participants' views of the advantages and disadvantages of the dyslexia label.</i> .....	77



## Academic Thesis: Declaration Of Authorship

I, Rosa Gibby-Leversuch, declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Dyslexia or literacy difficulties: what difference does a label make? Exploring the perceptions and experiences of young people.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed: .....

Date: 24-07-18 .....





## **Acknowledgements**

Firstly, I would like to thank my supervisors, Sarah Wright and Klair Norman, for their enthusiasm and support of this project from day one to day 641. Their questioning, guidance, encouragement and feedback were integral to this research and I have learnt a huge amount from working with them.

It was a pleasure and a privilege to work with the young people who have contributed to this study, and particular thanks go to the six students who gave up additional time to be interviewed by me, and were so thoughtful and open in their responses. I am also grateful to the SENCOs and Educational Psychologists who helped me to recruit for this study, and who showed real interest and support for this piece of research.

Finally, I would like to thank my family, friends and fellow TEPs, for supporting me, debating with me and distracting me, and Jack, for providing unconditional love and encouragement and endless cups of tea.



## Definitions and Abbreviations

AtS	Attributional style
BPS	British Psychological Society
CASP	Critical Appraisal Skills Programme
CYP	Children and young people
EP	Educational Psychologist
GCSE	General Certificate of Secondary Education
GSP	Global self-perceptions
LitD/D	Literacy difficulties and/or dyslexia
LoC	Locus of control
QAT	Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies
SpLD	Specific learning disability
UK	United Kingdom
USA	United States of America



# **Chapter 1 Literature Review: What are the Links Between Dyslexia, Literacy Difficulties and the Self-Perceptions of Children and Young People?**

## **1.1 Introduction**

### **1.1.1 Context**

Morgan (1896) first described congenital word-blindness: a developmental difficulty in learning to read and write in an otherwise intelligent person. Soon after, Hinshelwood (1900) predicted that such difficulties may be common and highlighted the importance of recognising them amongst children. Word-blindness has since evolved into what is commonly termed dyslexia and Hinshelwood's prediction would appear to have been correct. In 2013, Snowling estimated that the prevalence of dyslexia ranged from 3-10% of the population and a broad field of research now exists, some of which has focused on the social and emotional aspects of dyslexia, specifically self-perceptions. Research in this field has revealed mixed findings: some papers indicate that dyslexia is linked with experiences of stigmatisation and lowered self-concept (e.g. Polychroni, Koukoura, & Anagnostou, 2006; Riddick, 2000) whereas others find that dyslexia is not associated with negative self-perceptions (e.g. Burden & Burdett, 2005) or that the labelling of dyslexia can increase self-esteem (e.g. Gibson & Kendall, 2010; Solvang, 2007).

#### **Defining Dyslexia**

Despite the reported prevalence of dyslexia, it is not consistently defined in professional, research or social domains (Solvang, 2007). A wide range of terms are used within Europe (e.g. 'specific learning disability' 'literacy difficulties') without clear

## Chapter 1

distinction or agreement on what they mean (Elliott & Grigorenko, 2014a). Educational Psychologists (EPs) in Britain often use the BPS definition (British Psychological Society, 2005):

“Dyslexia is evident when accurate and fluent word reading and/or spelling develops very incompletely or with great difficulty. This focuses on literacy learning at the ‘word level’ and implies that the problem is severe and persistent despite appropriate learning opportunities. It provides the basis for a staged process of assessment through teaching.” (p.11)

This definition does not enable professionals to distinguish dyslexia from other literacy difficulties. However, some argue there is no need to make this distinction, given there appears to be no difference in the support or intervention required, as the same challenges underlie both (Elliott & Grigorenko, 2014a; Elliott & Gibbs, 2008). Indeed, it has been argued that it is potentially discriminatory to distinguish between ‘poor readers’ and children with dyslexia if access to appropriate resource and intervention is dependent upon diagnosis, rather than need (Elliott & Gibbs, 2008). The belief that a distinction can be made is perpetuated by continued use of the discrepancy model, which defines dyslexia as reading at a level significantly below what would be expected based on predictions from intelligence scores (Siegel, 1992). Despite the discrepancy model being largely discredited (Elliott & Grigorenko, 2014a; Snowling, 2013; Tanaka et al., 2011) it continues to be used in research (e.g. Novita, 2016) and perpetuated by organisations such as The International Dyslexia Association (“Definition of Dyslexia”, n.d.).

For the purposes of this review, the terms dyslexia and literacy difficulties will both be used, but not to imply that they are necessarily distinguishable, only that, in one case, a diagnosis has been given and in another, it has not. In reviewing the research, the terminology used will reflect the paper being discussed. The title of this review

consciously names both dyslexia and literacy difficulties, reflecting the fact that the majority of research papers use the term dyslexia and rely on diagnosis as a criterion for participation, and the fact that this review comes from the perspective of a Trainee EP, a profession in which the term literacy difficulties is more commonly used and diagnosis is not a criterion for EP involvement. The term ‘literacy difficulties and/or dyslexia’ (LitD/D) will be used to speak generally about children and young people (CYP) who have difficulties with literacy, diagnosed or not.

The focus of this paper is on the experiences of CYP who struggle with literacy, regardless of diagnosis. However, that is not to say that the terminology is not of importance. The impact of using different labels will be discussed, as a number of qualitative studies explore the impact of diagnosis on self-perceptions.

### **1.1.2 Linking dyslexia and self-perceptions**

Whilst a wide range of factors influence school achievement, reading is a skill that permeates the whole curriculum and any difficulties are likely to impact on children’s learning (Snowling, Muter, & Carroll, 2007). Research has shown that LitD/D may impact negatively on a number of areas, including family life (Snowling et al., 2007), social, emotional and behavioural development (Terras, Thompson, & Minnis, 2009). Given these potential difficulties, it may not be surprising that dyslexia has repeatedly been associated with negative self-views (e.g., Arishi, Boyle, & Lauchlan, 2017).

Although a range of difficulties have been associated with experiences of LitD/D, a number of positive attributes have also been reported. Despite the significant imbalance in favour of deficit-focused research, some papers have highlighted that individuals with dyslexia demonstrate excellent oral communication, leadership skills, visual-spatial strengths and an ability to “think outside the box” (Kotecha, 2012, p.71; Von Károlyi, Winner, Gray, & Sherman, 2003).

## Chapter 1

Two reviews have looked specifically at LitD/D and self-perceptions. Chapman & Tunmer (2003) focused on reading difficulties and found that letter-name knowledge and phonological ability at the start of school predicted later reading performance, self-concept and self-efficacy. The authors suggested that attributional style (AtS) was an important factor in developing self-perceptions and that intervention in this area has potential to challenge negative self-beliefs.

In 2008, Burden asked “is dyslexia necessarily associated with negative feelings of self-worth?” (p. 188). Burden reviewed research looking at the relationship between dyslexia, self-concept and self-esteem. He found that while academic self-concept tended to be lower in CYP with dyslexia, compared to typically achieving peers, this did not necessarily impact on self-esteem as “It is only when the task or activity in question is perceived as particularly important or meaningful that success or failure in that activity will have a direct effect upon one’s self-esteem” (p. 192).

Burden’s paper is highly relevant to the current review, however, the large majority of papers included were written prior to 2000 and Burden found a number of flaws within the research, including causal attributions being drawn from correlational studies, and the need for domain-specific measures utilising theory-based approaches such as self-efficacy, learned helplessness and attribution theory (p.193). Burden called for further research looking at the impact of influential factors such as educational environment and AtS. Updating Burden’s work by examining more recent literature and exploring these additional factors, will be the purpose of this review.

Whereas Burden’s review included many papers from the USA, this review will focus on European studies only. As Burden noted, there are differences in diagnosis in other parts of the world and the term “learning disability” is used in America, which cannot be assumed to be equivalent to dyslexia, or specific to literacy difficulties.



### **1.1.3 Defining self-perception**

In this review, the term ‘self-perceptions’ is used to encompass the range of terms used in research to explore thoughts and feelings about the self. Multiple terms have been included in the search for relevant papers (Method, Chapter 1) so that a range of self-perceptions can be explored and the use of different definitions and measures can be evaluated.

Self-esteem, self-concept and self-efficacy have been explored by researchers looking at similar constructs, but are not always appropriately defined. As Marsh (1990) pointed out: "Self-concept, like many other psychological constructs, suffers in that ‘everybody knows what it is,’ so that researchers do not feel compelled to provide any theoretical definition of what they are measuring" (p. 79). In order to review and discuss the included papers, the different terminologies are operationalised in Table 1.

Table 1.

*Self-perception terms defined*

<b>Term</b>	<b>Type</b>	<b>Definition and Description</b>
Self-efficacy	Task-specific	<b>A person's "expectations and convictions of what they can accomplish in given situations"</b> (Bong & Skaalvik, 2003, p.5). Self-efficacy is judged against specific goals and is a measure of confidence in one's ability to achieve that goal. Self-efficacy is malleable and can be considered a precursor to the development of self-concept (Bong & Skaalvik, 2003).
Self-concept	Domain-specific	<b>Views of the self in relation to a specific domain based on experiences of that domain.</b> Self-concept is multidimensional and hierarchical (Marsh, 1990a); individuals can have a positive self-concept in one domain and a negative self-concept in another. Domains could be 'reading' or 'academic' self-concept. The development of self-concepts are influenced by social comparison; causal attributions; appraisal from significant others; previous experiences; and perceived importance of the domain (Bong & Skaalvik, 2003).
Self-esteem	Global	<b>"The lived status of one's competence at dealing with the challenges of living in a worthy way over time"</b> (Mruk, 2006, p. 28). Self-esteem is based on personal values, which provides an affective component, as well as perceptions of competence, which is evaluated in comparison to personal frames of reference such as the 'ideal self'. Self-esteem evolves over time and has an element of stability.
Self-worth	Global	<b>Another term for self-esteem.</b> Self-esteem and self-worth relate to perceptions of oneself as worthwhile.
Attributional style (AtS)	Task-specific	<b>AtS depends on the factors to which people attribute their successes and failures.</b> These attributions reflect locus of control (LoC); for example, attributing test performance to a teacher's skill reflects an external LoC as the teacher is not controllable by the individual. (Weiner, 1985).
Self-perceptions	General	<b>A term designed to encompass all of the above</b>

**1.1.4 Current Review**

This review investigates the links between literacy difficulties, dyslexia and the self-perceptions of CYP, thus highlighting their voices and experiences. It seeks to further understand the relationship between LitD/D and self-perceptions, by exploring additional factors that have been researched since Burden's review. The specific questions that it was

possible to ask of the literature evolved as papers were found and studied. The additional factors explored focus on the impact of individual differences in AtSs and how receiving a diagnosis of dyslexia may influence self-perceptions.

## **1.2 Method**

### **1.2.1 Search Strategy**

The papers included in this review were sourced via systematic searching and a manual search of relevant papers (Figure 1). The systematic searches were conducted within three electronic databases: PsychINFO, Web of Science (WoS) and ERIC. Synonyms of ‘dyslexia’ and self-perceptions terms were generated based on reading of known papers on these topics. See Appendix A for a full list of search terms and the search strategy. The databases were searched for papers with titles containing dyslexia and self-perception terms. Filters ensured that only papers published in the English language, between 2000-2017, in academic journals were retrieved. After filters were applied, 324 papers were returned from the databases. The titles and abstracts of those papers were screened for relevance to the review, leaving 29 papers remaining.

Additional papers were identified through a manual search of the reference lists of retrieved articles. This included searching two relevant review articles (Burden, 2008; Chapman & Tunmer, 2003). Any cited papers that met criteria for this review have been included; however, the two review papers were excluded as the majority of papers cited were written prior to the year 2000. The manual search returned 14 papers.

During the process of reading the selected papers, it was noted that a number looked at AtSs of CYP with LitD/D. After consideration of the links between self-perceptions and attributions, it was decided that an additional systematic search would be done to look specifically for papers exploring the links between LitD/D and AtS. This involved searching the original databases for papers with both a dyslexia term and an attribution term (Appendix A) in the title. As illustrated in Figure 1, these papers were screened and five new papers were sourced.

After screening titles from the initial search, the manual search and the attribution search, 48 papers remained. The pre-determined inclusion and exclusion criteria (Table 2) were applied to these 48, leaving 19 papers to be included in the review. Of these 19, 12 were sourced from the initial search, five from the manual search and two from the attribution search.

The initial systematic search was conducted on 08-09-2017 and the search for papers including attribution terms was conducted on 13-10-2017.

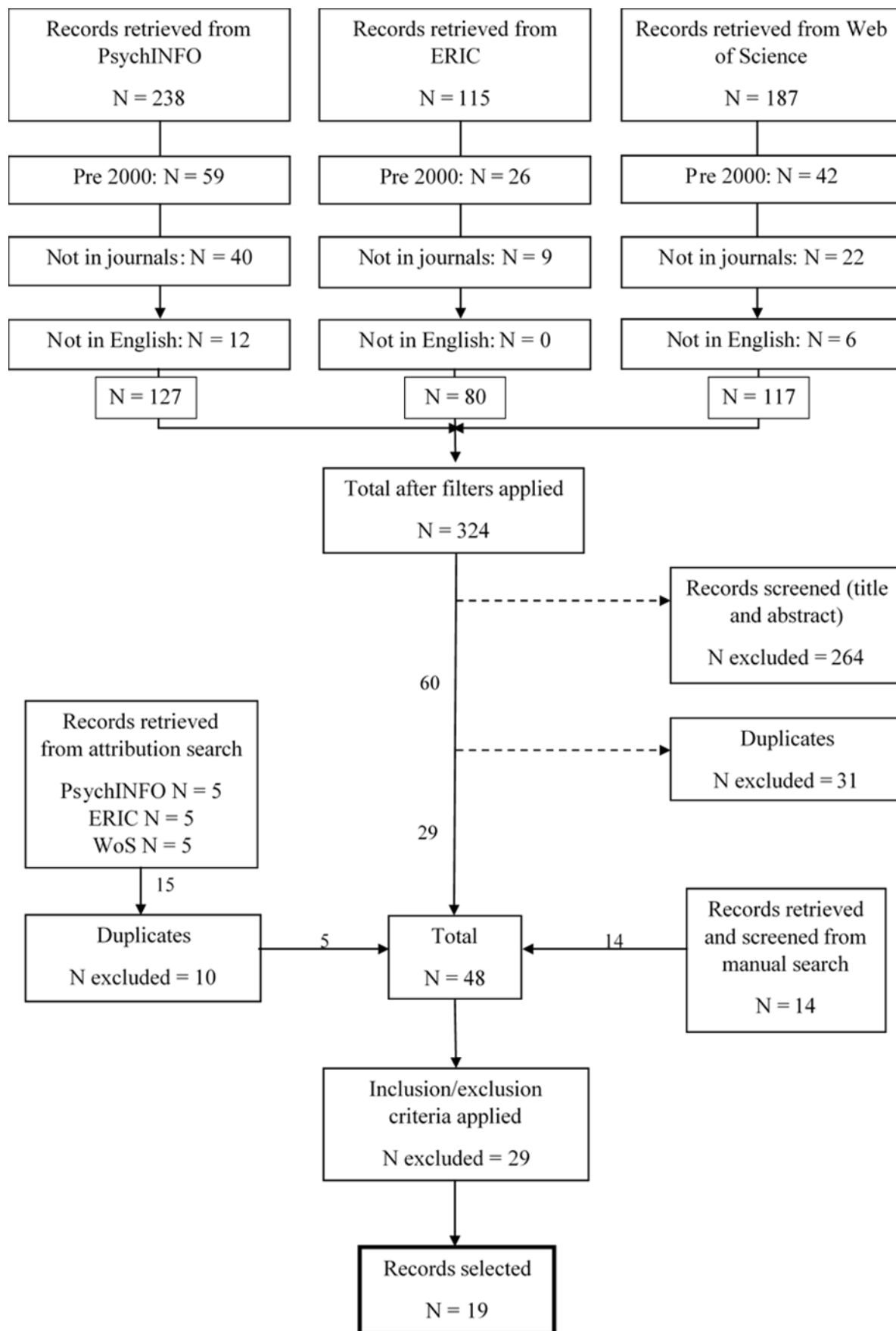


Figure 1: Paper identification and screening process

Table 2.

*Inclusion and exclusion criteria*

<b>Inclusion</b>	<b>Exclusion</b>
Papers focusing on participants with dyslexia or specific difficulties with literacy.	Papers focusing on participants with general learning difficulties or other conditions that may incorporate literacy difficulties (e.g. ADHD, ASC). Papers that do not make it clear whether they are focusing on individuals with a specific difficulty in literacy.
Papers focusing on the self-perceptions of individuals with dyslexia or literacy difficulties. Qualitative or quantitative methods. Papers may utilize report by others, but will include at least one self-report method with the individuals with dyslexia or literacy difficulties.	Papers that do not measure the self-perceptions of individuals with dyslexia or literacy difficulties. Papers that include a self-perception measure as an addition to, but not as the focus of, the paper.
Papers focusing on the self-perceptions of children and young people (ages 5-25).	Papers focusing primarily on adults with dyslexia: individuals >25 years of age. Papers focusing on children <5 years of age.
Papers involving participants based in Europe	Papers involving participants based in countries outside of Europe

For examples and reasoning behind the exclusion of a selection of papers, see Appendix B.

### 1.2.2 Data Extraction

The 19 selected papers were reviewed systematically and data were extracted relating to authors, year and country, sample characteristics, design and methods, measures and inclusion criteria, and main relevant findings. See Appendix C for data extraction table.

### 1.2.3 Quality Assessment

Quality assessment of the qualitative papers was completed using the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (Critical Appraisal

## Chapter 1

Skills Programme, 2017). The CASP Checklist was adapted to include two additional criteria relevant to the review question and produced a score out of 12 for each paper employing qualitative methods.

Quantitative studies were assessed using a checklist created by the author, based on two well-used checklists; the Downs and Black Checklist (Downs & Black, 1998) and the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (National Heart, Lung and Blood Institute, 2014). A new quantitative checklist was created to ensure that it included questions most appropriate to the cross-sectional methodologies of the included studies, as well as the addition of further items designed specifically to answer the review question. This checklist provided a score out of 16 for each paper.

Tables 2 and 3 demonstrate the outcome of the quality assessment. Eight papers were assessed for their qualitative methods; the scores ranged from 4-9 out of 12. Thirteen papers were assessed for their quantitative methods; the scores ranged from 6-14 out of 16.

See Appendix D for full details of checklists and outcomes of quality assessment.

Table 3.

### *Quality assessment for qualitative papers.*

<b>Quality Rating</b>	<b>Qualitative Paper</b>
Low (0-4)	Burton, 2004
Medium (5-8)	Armstrong & Humphrey, 2009; Casserly, 2013; Gibson & Kendall, 2010; Glazzard, 2010; Humphrey & Mullins, 2002b; Stampoltzis & Polychronopoulou, 2009
High (9-12)	Singer, 2005



Table 4.

*Quality assessment for quantitative papers.*

<b>Quality Rating</b>	<b>Quantitative Paper</b>
Very Low (0-4)	
Low (5-8)	Alexander-Passe, 2006; Burton, 2004; Humphrey & Mullins, 2002a, 2002b; Saday Duman et al., 2017
Medium (9-12)	Humphrey, 2002; Novita, 2016; Pasta et al., 2013; Polychroni et al., 2006; Terras et al., 2009
High (13-16)	Burden & Burdett, 2005; Frederickson & Jacobs, 2001; Lindeblad et al., 2016

## 1.3 Results

### 1.3.1 Selected Papers

See Appendix C for full details of selected papers.

Table 5.

*Characteristics of selected papers.*

Total no. of papers selected	19
Journals	11 different British or European journals
County of origin	10 conducted in England, 1 in Scotland, 1 in Ireland, 7 in other European countries (Italy, Greece, Sweden, The Netherlands, Turkey and Germany)
Methods	6 qualitative, 11 quantitative, 2 mixed methods
Design	17 making group comparisons or comparison against norm-referenced data, 2 intervention evaluations All studies prioritised CYP's self-report, 2 also utilised parent/teacher report
Self-perception measures	Quantitative papers used primarily self-report scales assessing self-esteem (4), self-concept (6), self-efficacy (2), and AtS (4)
Additional Measures	Self-report measures of depression (3), anxiety (3), coping (1), teacher-student relationship (1), reading attitude (1), approach to learning (1), understanding and perceived impact of dyslexia (1), strengths and difficulties (1), and literacy assessments (1)
Qualitative Measures	Qualitative papers primarily used individual semi-structured interviews, with some using structured interviews, focus groups or questionnaires
Identification of LitD/D	13 studies relied solely on teacher or self-identification (usually the CYP were attending special school, receiving additional support or had been diagnosed by a psychologist) 6 studies carried out their own literacy assessment in order to select participants
Age range	7-26 years old (majority falling within the middle of this range)
Ethnicity	1 study provided information on participants' ethnicity
Gender	Participants with LitD/D 60-100% male Comparison participants more equal distribution
Number of participants	Roughly 1,122 (exact number unclear)

### 1.3.2 Quality Assessment

#### Qualitative Papers

All eight papers were deemed to have used appropriate methodologies and five reported appropriate designs, the remaining papers did not provide enough information or did not sufficiently justify their choice. On the whole, the papers provided clear statements of their aims and embedded this within relevant literature.

The majority of papers used individual semi-structured interviews, which allowed researchers to uncover the priorities of participants and be flexible in the topics discussed, meaning that the researcher reduced the impact of their own beliefs and expectations of the research and gathered rich data. However, only two of the studies provided their interview schedules, which reduced transparency and replicability.

As a dataset, there were a number of weaknesses. No papers adequately considered the researcher-participant relationship nor reflected on the researcher's role in data collection and analysis. As many of the participants were children, considering the balance of power and influence of the researcher as an adult is important. Only two papers made reference to ethical issues (Gibson & Kendall, 2010; Glazzard, 2010), but little consideration was given to the potential impact of the research on participants.

Further weaknesses were apparent in the reporting of procedures and data analysis. Only Singer (2005) and Stampoltzis and Polychronopoulou (2009) clearly described the characteristics of their sample and recruitment. Five studies did not provide sufficient description of their data analysis. For example, Burton (2004) made no mention of the method of analysis and other papers cited their method but provided insufficient description of it (e.g. Stampoltzis & Polychronopoulou, 2009). However, Casserly (2013) and Singer (2005) gave detailed descriptions of the frameworks used and the process of

## Chapter 1

coding and drawing out themes. Singer (2005) also transposed coded data into a numerical system and determined interrater reliability.

Three papers (Burton, 2004; Casserly, 2013; Humphrey & Mullins, 2002b) gave adequate consideration to their use of self-perception terms. Burton provided a definition of self-esteem and considered the multi-dimensional nature of self-perceptions. Humphrey and Mullins discussed self-perceptions and the challenges arising from the use of different terms. Casserly also considered and defined a range of self-perception terms. Armstrong and Humphrey (2009) looked at individuals' conception of the self and identity, incorporating a range of self-perceptions, although no definitions were provided. Four papers (Gibson & Kendall, 2010; Glazzard, 2010; Singer, 2005; Stampoltzis & Polychronopoulou, 2009) discussed self-esteem without providing any definition. Glazzard, and Stampoltzis and Polychronopoulou used a number of self-perception terms interchangeably without explanation.

Six of the eight studies scored >6 out of 12 and all studies were deemed to make a valuable contribution to their area of research and to the review question.

### Quantitative Papers

The majority of quantitative studies clearly described their aims and hypotheses, used appropriate statistical analyses and clearly reported their findings, although only 3 papers appropriately reported P-values. Sample sizes ranged from 19 to 242, with some studies analysing data from large comparison groups and others only including CYP with LitD/D.

Seven studies included clear and thorough descriptions of their sample, however some failed to provide information on gender (Humphrey, 2002; Humphrey & Mullins, 2002a, 2002b) or number of participants (Burton, 2004). Ten out of 13 papers clearly

described inclusion and exclusion criteria for participation although fewer provided sufficient information on recruitment procedures.

A wide range of outcome measures were utilised and all papers clearly described these. Five papers gave insufficient evidence to demonstrate the accuracy, validity and reliability of their outcome measures. One of these (Saday Duman et al., 2017), used a measure of self-concept (The Piers-Harris Children's Self-Concept Scale) that has been criticised by previous researchers for using a composite measure of global self-concept (Bear, Minke, & Manning, 2002).

Three papers utilised outcome measures that could not be deemed valid and reliable. Burden and Burdett (2005) and Lindeblad, Svensson, and Gustafson (2016) composed their own measures and did not assess reliability and validity. Humphrey and Mullins (2002a) reasoned that attributions are unstable over time and context and, therefore, cannot be expected to be reliable.

The self-perception measures used were almost entirely self-report by CYP. Given that participants in every study had literacy difficulties, any self-report measures needed to be appropriately administered, either orally or with consideration of reading level. However, only three papers (Burden & Burdett, 2005; Frederickson & Jacobs, 2001; Lindeblad et al., 2016) acknowledged this and reported steps taken to address the issue.

A strength of the dataset is that 10 of the 13 studies provided definitions of their self-perception terms and used them consistently and accurately. In addition to providing definitions, several papers discussed the importance of terminology in detail. However, Terras, Thompson, and Minnis (2009) used a range of self-perception terms without providing any definitions, or distinguishing between them. Similarly, Polychroni, Koukoura, and Anagnostou (2006) discussed academic self-concept and academic self-

## Chapter 1

esteem, without definition or differentiation. Saday Duman et al. (2017) did not provide any definitions and used a self-concept scale to measure self-esteem.

The majority of studies were not conducted over time and therefore not subject to participant loss, although neither of the two intervention studies commented on lost participants. Burton's (2004) intervention study provided a clear and replicable description of the intervention that was carried out, however Saday Duman et al.'s (2017) intervention was insufficiently described.

In some studies, it would have been possible to blind the researcher to participants' group membership (i.e. LitD/D or control), however none of the nine studies that could have provided this additional rigour reported on doing so. Six papers acknowledged and considered the impact of key confounding variables.

On the whole, the quantitative studies provided valuable information to the review question and scored well in terms of quality, with all but 3 studies scoring  $\geq 8$  out of 16.

### **1.3.3 Dyslexia and Self-Perceptions**

#### **1.3.3.1 Global Self-Perceptions (GSP)**

Seven papers utilised quantitative measures of self-esteem or self-worth, including two papers from Burden's (2008) review. In order for useful comparison and conclusions to be made, only measures that fit with the definitions of this review are included.

Two cross-sectional studies in the UK assessed GSP in groups of children with and without dyslexia. Frederickson and Jacobs (2001) found no significant differences between scores in each group on their self-worth subscale. However, Humphrey and Mullins (2002b) did report significantly lower global self-concepts amongst CYP with dyslexia in mainstream schools, compared with a control group, although not amongst CYP with dyslexia attending specialist provision. Humphrey and Mullins (2002b) used the 'total self'

scale of the Self-Description Questionnaire (Marsh, 1990b), made up of responses to general-self statements as well as accrued scores for responses to statements in specific domains. It has been argued that a GSP measure should not be a composite score of domain-specific items as it is its own distinct aspect of self-perception (Mruk, 2006). An individual may have low self-perceptions in a specific domain but still view themselves highly in terms of overall self-worth, therefore, these findings are treated with caution.

Three studies assessed GSP by comparing participants with dyslexia to previously gathered data. Terras et al. (2009) compared 68 CYP who met the criteria for dyslexia diagnosis with norm-referenced data and found no discrepancy in self-esteem. These findings were corroborated by parent-report of CYP's self-esteem.

Alexander-Passe (2006) did find differences between his 19 students (aged 15-16) and norm-referenced data for self-esteem, depression and coping style. Overall, the participants reported below average self-esteem compared with data from a range of previous studies; however, this difference was accounted for entirely by the female participants. The difference in self-esteem and gender seemed to be linked with coping styles: the female participants used more emotion-based coping styles (internalising or externalising behaviours), whereas the male participants used task-based coping (being proactive and persistent), which has previously been associated with more effective coping. Similarly, in Singer's (2005) qualitative study, children with dyslexia utilised various coping methods designed to protect self-esteem. In some cases, these methods were highly adaptive and reflected task-based coping, which was found to have a positive impact on self-esteem. However, the majority of children reported withdrawal or externalising behaviours, which reflected emotion-based coping. Although the function of these behaviours was the same (to protect self-esteem), withdrawal or externalising of emotions was deemed less effective in achieving this goal.

Lindeblad et al. (2016) used the Beck Youth Inventories Self-Concept Questionnaire with 67 pupils with literacy skills at least one standard deviation below age-expectations. No differences in self-concept were found between the participants and norm-referenced data. Although this measure is termed 'self-concept', it is designed to measure general perceptions of competency and self-worth (Beck, Beck, & Jolly, 2001), and fits with the definition used here for GSP. Additionally, Lindeblad et al. found no differences in anxiety and depression scores between the participants and norm-referenced data.

In contrast to Alexander-Passe (2006), Lindeblad et al. found no gender differences. The gender differences reported by Alexander-Passe may well be accounted for by the differences in coping styles, but as there were only 12 males and 7 females in his study, no real conclusions can be drawn around gender.

In Stampoltzis and Polychronopoulou's (2009) qualitative research, 9 out of 16 university students reported low self-esteem related to their dyslexia. Negative self-perceptions were attributed, by some students, to the reactions of others and to their frustrations with the difficulties themselves. The remaining seven students did not feel dyslexia affected their self-esteem. Clearly, these are mixed findings in terms of the link between LitD/D and self-worth; individual differences in coping style (emotion-based vs. task-based) may be one factor influencing this link.

Two intervention studies aimed to increase the self-perceptions of CYP with dyslexia. Burton (2004) evaluated an intervention specifically aimed at improving self-perceptions, whereas Saday Duman et al. (2017) evaluated a literacy intervention. Burton's UK study was very small-scale and data from only seven participants were analysed quantitatively. Small increases in self-perceptions were demonstrated, indicating that this type of intervention is worth investigating in the future. Saday Duman et al.'s intervention,



in Turkey, included 50 CYP with specific learning disabilities (SpLD) in literacy, who received literacy intervention and were compared to 50 CYP on a waiting-list and 50 children without SpLD. Pre-intervention, the children with SpLD in both the intervention and wait-list groups reported lower scores on a Happiness and Satisfaction scale than the control group. This subscale was not described specifically as a GSP measure, but fits with the definition used here as it relates to self-liking and evaluation of self-worth. Although very little information is provided about the intervention, the authors found some improvements in GSP post intervention and concluded that self-perceptions may be improved through literacy interventions for children with SpLD.

Although no real conclusions can be drawn from just two intervention studies, further research of this nature could be extremely useful in determining causal links between LitD/D and self-perceptions.

#### Summary of GSP

Across the seven studies discussed, six different self-perception measures were used; both Frederickson and Jacobs (2001) and Terras et al. (2009) used the Self-Perception Profile for Children (Harter, 1985) and found no differences in GSP for CYP with LitD/D. The measures used in some studies appeared to have greater construct validity than others, with the Self-Perception Profile's self-worth scale fitting well with the definition used for this review.

When drawing conclusions, the results of quality assessment should be considered. The three studies that found no difference in GSP amongst CYP with LitD/D (Frederickson & Jacobs, 2001; Lindeblad et al., 2016; Terras et al., 2009) were high and medium scoring papers, whereas the three papers that did detect a difference (Alexander-Passe, 2006; Humphrey & Mullins, 2002b; Saday Duman et al., 2017) were all low scoring, suggesting, taken with the findings of Burden's 2008 review, that LitD/D are not

directly linked with lowered GSP in any consistent or predictable way. Changing attitudes and knowledge may be a protective factor in preventing difficulties in specific areas from impacting on overall sense of self-worth (Lindeblad et al., 2016), as well as more task-based coping styles (Alexander-Passe, 2006; Singer, 2005). Other influencing factors will be considered throughout this review.

### **1.3.3.2 Domain-Specific Self-Perceptions**

Ten papers used self-perception measures related to specific domains. One of the most commonly assessed domains was academic self-concept: beliefs about the self in terms of academic performance. These scales had various names (e.g. perceived scholastic competence, school-based self-esteem) but related to the same construct.

Amongst a sample of 60 CYP with dyslexia and 64 without, Novita (2016) found that children with dyslexia reported significantly lower school-based self-esteem, with a weak-medium effect size, whilst no differences were found in self-esteem at home. Similar findings were reported by Alexander-Passe (2006) and Saday Duman et al. (2017) and by Terras et al. (2009) who compared their participants with dyslexia to norm-referenced data and found significantly poorer perceptions of scholastic competence as rated by children and their parents.

Terras et al. also found that children with higher perceived scholastic competence had better psycho-social adjustment. The authors reported that dyslexia was perceived by children and parents as impacting on both academic and socio-emotional aspects of life, although findings from the Self-Perception Profile indicated that this was not impacting children's social and behavioural self-perceptions. When parents held positive attitudes towards dyslexia and had a good understanding of their child's difficulties, their children had higher self-esteem. The authors concluded that children's close relationships, social

support and knowledge about their difficulties contributed to psycho-social adjustment and positive self-image.

Five qualitative studies found that social and family support were integral to coping with dyslexia and maintaining self-esteem (Armstrong & Humphrey, 2009; Gibson & Kendall, 2010; Glazzard, 2010; Singer, 2005; Stampoltzis & Polychronopoulou, 2009). Singer developed four profiles of inner logic (connections made between actions/goals and emotions) based on children's responses to a fictional scenario in which a child with dyslexia is being teased. Children whose parents responded more negatively to their emotions about dyslexia were more likely to try and hide their feelings and develop internalising coping styles. These children described lying about their grades, concealing disappointment and withdrawing from peers. Children in this profile felt guilt and shame around their dyslexia, so emphasised their powerlessness as a method of protecting self-esteem. Other children demonstrated externalising behaviours that aimed to conceal their feelings of shame or guilt; these children were less likely to share feelings with parents. On the other hand, children who described their parents as academically and emotionally supportive showed greater desire for self-improvement and experienced fewer negative emotions. The authors concluded that children with dyslexia adopt a number of different strategies designed to protect self-esteem. However, certain strategies are more adaptive than others. Being able to safely discuss feelings with parents seems to be a protective factor in developing more positive self-perceptions and coping styles.

In Frederickson and Jacobs' (2001) study, participants with dyslexia again reported significantly more negative perceptions of scholastic competence than their peers without dyslexia. This study had a significant strength, not replicated by any of the other studies: the authors administered word reading tests and used this data to evaluate self-perceptions whilst controlling for actual reading performance. The authors found that the children with dyslexia were more likely to hold negative self-perceptions of their scholastic competence,

## Chapter 1

even when compared to peers reading with the same level of accuracy, but without dyslexia. The authors concluded that children with dyslexia believed they were not performing as well as others in terms of their school work, although this did not lead to lower self-worth.

The remaining studies divided self-perceptions into specific areas. Humphrey and Mullins (2002b) found that, whilst participants without dyslexia demonstrated average self-concept scores, participants with dyslexia in mainstream school had lower self-perceptions of their reading, maths and ‘general school’ ability, although, perhaps surprisingly, only differences in the ‘general school’ domain were significant.

Humphrey (2002) used an alternative method of measuring self-perceptions, known as the “semantic differential method” (p.31). This method provided a seven-point scale of 10 different constructs (e.g. popular-unpopular) and asked individuals to place on that scale where they are now and where they would like to be. This measure of self-esteem fits well with the definition used in this review as it reflects the difference between a person’s current self-concept and their ideal self. This method provides the evaluative element of self-esteem and allows individuals to express either their satisfaction or dissatisfaction with their current self.

Using this method, Humphrey (2002) found that, in comparison to children with no learning difficulties, a sample of children with dyslexia attending mainstream schools demonstrated significantly lower self-perceptions in the domains of reading, writing, spelling, intelligence, English ability, popularity and importance, but not maths or being hardworking. As will be discussed later, differences were found for participants with dyslexia who attended specialist provision in both of Humphrey’s studies.

A study conducted in Greece reported similar findings: Polychroni et al. (2006) made comparisons between children with dyslexia, a group of low-average achieving peers

without dyslexia and a group of high achieving peers without dyslexia. Children with dyslexia reported significantly more negative self-concept regarding penmanship/neatness, arithmetic and school satisfaction, when compared with both the high and lower achieving groups, and regarding reading/spelling and general ability compared to the high achieving group only. Unfortunately, the authors do not provide information that makes it possible to compare the achievement levels of the different groups; therefore, it is unclear whether the children with dyslexia had comparable achievement to either of the other groups, or how homogenous those groups were. The authors suggested that further research should examine the similarities and differences between learners with dyslexia and learners who have comparable achievement, which could provide information about the impact of the label itself on self-perceptions.

A Swedish study (Lindeblad et al., 2016), looked at literacy related self-efficacy through a questionnaire designed to assess participants' beliefs about how they would perform on a specific task (e.g. 'I can read an email from a friend') (p.456). Based on standardised literacy assessment, the participants were not performing at the level typically expected, but the GSP of these children had not been negatively impacted. The results of the self-efficacy assessment indicated that the majority of participants felt confident to manage their school work and perceived few, or very few, limitations in their literacy ability. Although this is in contrast with their actual performance, the authors linked the positive self-attitudes of these participants with broader changes in the country towards inclusive schooling and improved attitudes and understanding of dyslexia, perhaps leading students to make fewer peer comparisons and focus more on their own progress.

Many papers utilised other subscales in addition to those relating to academic self-perceptions. Commonly, self-perceptions relating to social/peer acceptance, physical appearance/performance and behaviour were assessed.

Six papers reported on social self-perceptions (Alexander-Passe, 2006; Frederickson & Jacobs, 2001; Humphrey, 2002; Humphrey & Mullins, 2002b; Saday Duman et al., 2017; Terras et al., 2009). Only half of these reported significant differences between social self-perceptions of individuals with/without dyslexia (Alexander-Passe, 2006; Humphrey, 2002; Saday Duman et al., 2017); however, these papers were of lower quality and differences were in opposing directions.

A similar pattern was found for perceptions of physical appearance and physical ability, which were assessed in four studies (Frederickson & Jacobs, 2001; Humphrey & Mullins, 2002b; Saday Duman et al., 2017; Terras et al., 2009). Three studies found no significant differences and one found lower self-perceptions in the participants with dyslexia attending mainstream, but not a specialist provision. Of the three papers that assessed self-perceptions of behavioural conduct (Frederickson & Jacobs, 2001; Saday Duman et al., 2017; Terras et al., 2009), only Saday Duman found that participants with dyslexia reported lower self-perceptions of behaviour than control participants, which was a lower quality paper.

### Summary of Domain-Specific Self-Perceptions

Generally, research suggests that individuals with dyslexia are less likely than their peers to develop positive self-perceptions in certain domains. These domains relate directly to the difficulties that are typically experienced by CYP with LitD/D: reading, writing and school achievement. Preliminary findings suggest that CYP with dyslexia may hold lower self-perceptions than CYP who are reading at the same level, but do not have a dyslexia diagnosis (Frederickson & Jacobs, 2001). However, the findings are not universally found and, although there appears to be a risk factor associated with LitD/D, an individual's environment, as well as their personal characteristics and social support, seem to play an important role and these will be looked at in more detail.

### 1.3.3.3 Educational Settings

One qualitative and one quantitative study specifically explored the impact of mainstream versus specialist educational settings on the self-perceptions of CYP with dyslexia. Humphrey's research (Humphrey, 2002; Humphrey & Mullins, 2002b) used two self-report methods and a teacher-report method; the semantic differential method and the questionnaire indicated that CYP in mainstream education held the most negative self-perceptions, whereas the CYP in specialist provision held self-perceptions only marginally lower than the control group. However, teacher reports, measuring behavioural manifestations of self-esteem, showed the highest level of maladaptive behaviours to occur in the specialist setting, which both contradicts, and calls in to question the validity of the findings. Humphrey's qualitative data (Humphrey & Mullins, 2002b) also revealed some themes that seemed to contradict the quantitative findings, with more CYP in the specialist setting than the mainstream setting reporting feeling "less intelligent than their peers" (p.5).

Casserly (2013) followed 20 participants over four years, during which time all participants moved from mainstream to a specialist dyslexia setting and then back to mainstream. Through interviews with children, their parents and teachers, Casserly found that children generally had low reading self-concept and self-esteem upon entry to their specialist setting, which was increased through the targeted support that they received in their specialist setting and remained good after their return to mainstream.

When asked what they thought had improved their children's self-perceptions, parents cited the benefits of increased praise and encouragement, teachers' belief in their child's ability, making academic progress, having positive relationships, and peers with similar difficulties that they could relate to. The teachers reported a long list of strategies and approaches that they felt supported children's self-perceptions: They felt it was

## Chapter 1

important to help CYP to understand their difficulties, which included teaching them about learning differences and dyslexia. They discussed the need for atmospheres of respect and valuing others, as well as promoting generally positive attitudes towards literacy and school. They used high levels of differentiation to ensure that work was at the right level and pace to instill a sense of achievement and acknowledge the children's strengths as well as difficulties. They also cited smaller classes, with more individual attention as well as the benefits of being able to make more favourable peer comparisons.

Casserly discussed social comparison theory as a possible reason for improvements in self-esteem within the specialist settings. However, although social comparisons were mentioned by participants, I would argue that this ignores the many strategies that were also put in place to support these children in their learning and wellbeing. Self-esteem remained high once they had left the provision and spent a year in mainstream class, even though they still reported finding things more difficult than other children. This suggests that the children had learned to value themselves differently and perhaps developed better coping skills or acceptance of individual differences. It may be the case that, due to the specialist provision, the children developed resilience that protected their self-esteem.

### Summary of Educational Settings

There is very little research to be drawn upon to make conclusions about the impacts of different educational settings. However, by comparing two different settings, Casserly's study provides some useful insight into the factors that were beneficial in terms of improving the self-perceptions of CYP with dyslexia.

#### **1.3.3.4 Attributions**

Four quantitative papers measured the AtSs of CYP with LitD/D and one examined goal orientations, which link with attributions. Two qualitative explorations also revealed participants' AtSs.



Humphrey looked specifically at the AtSs of CYP with and without dyslexia (Humphrey & Mullins, 2002a) by asking CYP to rank order possible reasons for success or failure in fictional test scenarios. In success scenarios, participants with dyslexia were more likely to attribute their achievement to teacher quality (an external factor) than the children without dyslexia. This was seen as potentially detrimental by the authors, as children would not receive positive self-referential information as a result of their success (p.201). However, the authors were comparing the second most commonly cited reason for success, when, in fact, the most commonly cited reason given by both groups was effort.

In failure scenarios, the control group felt that lack of effort, followed by the difficulty of the test, would be the most likely causes, suggesting a belief that they could succeed on a difficult test in the future if they applied more effort. However, the children with dyslexia cited difficulty of the subject, followed by difficulty of the test as the most likely reasons for failure. As both of these things are outside of the individual's control, this might imply that they could not control whether they succeeded on a difficult test in the future.

A study conducted in Italy used hypothetical scenarios to assess AtS (Pasta et al., 2013). Children with SpLD in literacy were compared to a group of controls without SpLD with matched levels of achievement and a group without SpLD with higher achievement. The AtSs of children with SpLD tended to reflect less of a 'strategic effort' (p.660) approach than their peers; they placed more emphasis on external, uncontrollable factors such as luck and task difficulty than their equally and higher achieving classmates. However, pupils with SpLD did emphasise the importance of effort in both success and failure, although to a lesser extent than the control groups. In addition, teachers perceived children with SpLD as more dependent than their peers, including those with matched achievement. The authors suggested that this reflects the children's external LoC and

## Chapter 1

indicates that the children with SpLD underestimated their potential as independent learners.

Overall, correlations between AtS and test performance showed that the more pupils attributed results to effort (internal LoC), the better they performed and the more pupils attributed results to task difficulty (external LoC), the worse they performed. Emphasising the importance of effort is seen as an adaptive AtS as it is within the control of the individual and is not fixed. Although the children with SpLD generally had less adaptive AtSs, this study demonstrated that children with SpLD with more adaptive styles displayed higher achievement. This could be an important area for intervention.

In Gibson and Kendall's (2010) qualitative research, participants expressed a range of AtSs relating to their success in school. One participant conveyed feelings of determination to do well in the face of others' beliefs that they could not overcome their difficulties. Other participants demonstrated resignation at being assigned to lower sets that were perceived as being for less intelligent students. These participants seemed to have their sense of control stripped from them by an educational system that wanted to categorise and restrict them.

Burden and Burdett (2005) provided valuable insight into the nature of AtSs amongst CYP with dyslexia by looking at a context in which students with dyslexia were succeeding. They developed a questionnaire measuring LoC, learned helplessness (associated with maladaptive, passive AtSs) and depression to be used with 50 boys attending a high achieving, independent school for learners with dyslexia. The questionnaire revealed that the majority of respondents did not demonstrate learned helplessness or perceive themselves as being held back by their dyslexia. Pupils believed that effort is essential for success and would enable them to achieve their goals, suggesting strong internal LoC. Responses to certain items indicated that their internal LoC may be a

protective factor for self-esteem; participants generally agreed that they had the ability to be good at specific things *if they wanted to*. Therefore, even if they believe they are not as good as others, their belief in their own ability to succeed may mean that their low self-concept does not negatively impact on their overall self-esteem. Burden and Burdett concluded that whole-school promotion of personal responsibility and self-worth is essential for producing learners with a positive sense of self.

In Singer's (2005) study, 16% of all participants were characterised as having adaptive approaches to protecting their self-esteem, including desire for self-improvement, concentrating on academic work and reducing periods of negative emotions by focussing on positive thoughts. These children emphasised the importance of effort and belief in their ability to improve, and maintained high levels of self-esteem. Compared with the others in the study, these children showed signs of having developed adaptive AtSs.

Frederickson and Jacobs (2001) provided further evidence that AtS is linked with self-perceptions. They found that children with dyslexia were significantly more likely to make uncontrollable attributions than their peers and that uncontrollable attributions were associated with lower reading scores. Furthermore, children making uncontrollable attributions had significantly lower perceived scholastic competence than those who showed controllable attributions, even after controlling for actual reading accuracy. This was the case for both the children with and without dyslexia. The authors suggested a need for research evaluating the impact of attribution retraining programmes to further explore the causal relationships and practical implications of this research. They also suggested a link with learners' goal orientations and the effects of learning vs. performance goals on self-perceptions amongst learners with dyslexia.

Goal orientations were explored by Polychroni et al. (2006), although they referred to them as approach to learning, with a 'surface' approach to learning characterised by the

## Chapter 1

intention to reproduce learned material for the sake of performance, and a ‘deep’ approach to learning characterised by an internal desire to seek meaning (p.418). The surface approach is akin to performance orientation, in which the goal is to show success and the deep approach is akin to learning orientation, in which the goal is to satisfy an intrinsic desire to learn (Watkins, 2010). In this study, both the children with dyslexia and the children with matched achievement but no dyslexia, reported significantly higher levels of surface approaches than the higher achieving children. Amongst children with dyslexia, there were correlations between having a surface approach and having lower academic self-concept, suggesting that a deep approach to learning could be a protective factor against lowered self-perceptions, as well as being associated with more enjoyment, intrinsic motivation and greater achievement (Watkins, 2010), making this a potential area for intervention.

### Summary of Attributions

Four out of five of these quantitative studies indicated that children with dyslexia are more likely to make attributions for success and failure that are outside of their control, meaning they have AtSs that are associated with lower achievement, more negative self-perceptions and less effective approaches to learning. However, this is not always the case and research shows that with the right environment and support, children with dyslexia will make more adaptive attributions, linked to improvements in both performance and self-perceptions. At this stage, the causal links are unclear; it may be the case that performance influences self-perceptions, which influence AtS or, more likely, that these factors influence each other in a non-linear fashion. Research into the impact of attribution retraining programmes on the performance and self-perceptions of CYP with dyslexia will help to shed light on this.

### 1.3.3.5 Labels

Four qualitative papers explored the impact of receiving a diagnosis of dyslexia for their participants. All three thematic analysis studies (Gibson & Kendall, 2010; Glazzard, 2010; Stampoltzis & Polychronopoulou, 2009) reported themes relating to diagnosis and labelling. The studies included a total of 29 participants between the ages of 14 and 26 attending school or university. In each study, references were made to the negative consequences of not having a recognised diagnosis; Gibson and Kendall described feelings of school failure amongst their participants, as well as lack of appropriate support and, in some cases, very negative attitudes and low expectations from teachers. Glazzard reported that having a diagnosis of dyslexia and owning that label was essential for creating a positive self-image amongst participants. Glazzard noted feelings of increased self-esteem once the diagnosis had been made, partly because it enabled them to explain their difficulties to themselves and others. This is mirrored by a quote from Gibson and Kendall's research from a participant who said '*I didn't know what it was, I thought I was thick.*' (p.192) indicating that the diagnosis of dyslexia relieved these feelings.

Amongst Greek participants (Stampoltzis & Polychronopoulou, 2009), there were similar stories of not understanding difficulties prior to diagnosis and 9/16 participants reported having had low self-esteem. Prior to diagnosis, they felt that they were different, not trying hard enough and embarrassed by their difficulties. For most participants, diagnosis was associated with feelings of relief and increased understanding. However, some felt it was not helpful as it did not give useful information. The participants were able to positively reframe many aspects of dyslexia to incorporate it into their self-image. Most showed optimism in terms of overcoming their difficulties and saw dyslexia as part of their identity and what makes them individual. However, interestingly, 11 of the students preferred not to disclose their dyslexia at university as they did not think it would help and they did not want to be seen as different. The authors reported that, in Greece, the only

## Chapter 1

provision routinely (and legally) offered to students is oral examination for entry into higher education. Therefore, as no support is available, high numbers do not disclose their dyslexia. This is an interesting finding given that they found the label so helpful, and suggests that it was more helpful to them personally than as an explanation for others.

In all of the qualitative studies, references were made to alternative labels to dyslexia. Primarily, these included ‘thick’ ‘lazy’ or ‘stupid’. Many participants spoke about applying these labels to themselves, or having them applied by others who did not know about, or understand, their dyslexia. Glazzard alluded to the dyslexia label replacing these negative judgements and participants reported that their label boosted their perception of their own intelligence. Stampoltzis and Polychronopoulou noted that some participants felt that their diagnosis changed others’ perceptions of them as lazy. In Singer’s (2005) study, children who tended to internalise their emotions of guilt or shame found it helpful to emphasise their label as it gave a reason for their difficulties that took responsibility away from themselves. Negative comments coming from other people generally made participants feel bad about themselves, although, in one case, low expectations and negative attitudes from teachers added to a participant’s determination to succeed (Gibson & Kendall, 2010).

A study by Armstrong and Humphrey (2009) with 20 college students was designed specifically to look at reactions to diagnosis. Using grounded theory, the authors developed a model of psychological reactions to diagnosis conceptualised on a continuum from resistance to accommodation. Resistance is characterised by not accepting dyslexia as part of the self and holding negative connotations of dyslexia, whereas accommodation involves integrating dyslexia into the notion of self and recognising both positive and negative aspects. The amount of resistance or accommodation displayed by individuals clearly stemmed in part from their perception of dyslexia: those who felt dyslexia was equal to stupidity were less likely to accept it into their notion of self, as this would

damage self-perceptions. Two participants reported feeling angry about being diagnosed when they reached college and another resisted the label saying '*I don't see myself as being dyslexic*' (p.98). The authors suggested that individuals diagnosed later in life may require additional psychological support to accommodate their diagnosis, as participants who had been described as having dyslexia at a younger age seemed more willing to accommodate it.

Although reactions to diagnosis were generally positive, there were negative responses to the idea of being labelled; participants preferring the language of 'having dyslexia' as opposed to 'being dyslexic'. Individuals who accommodated dyslexia were more likely to be motivated and successful in their studies, take up support, and adjust to their difficulties. Failure to accommodate, however, was suggested as a risk factor for increased negative self-views, use of self-defeating strategies, lowered self-esteem and negative emotions.

### Summary of Labels

Mixed results suggest that reactions to receiving a dyslexia label are individual and can be conceptualised as lying on a continuum from resistance to accommodation. A number of factors seem to influence where one may lie on this continuum; individuals who were labelled for the first time in late adolescence perceived dyslexia as stigmatising, did not feel they needed help, did not perceive the label as informative or supportive, and were more likely to resist the label. On the other hand, those who felt they had already been labelled with negative terms such as 'lazy', the label of dyslexia was a welcome alternative, providing a boost to their self-esteem.

## **1.4 Discussion**

### **1.4.1 Summary and Implications**

Consistent with findings from an earlier review (Burden, 2008), evidence suggests that CYP with LitD/D are generally very aware of their specific difficulties, but if they experience supportive family, teacher and peer relationships, and are able to recognise their successes in other areas, negative self-perceptions relating to academic competence are unlikely to impact on their overall self-worth.

Nevertheless, evidence also suggests that CYP with dyslexia are at greater risk of developing maladaptive AtSs, based on an external LoC. This style is associated with lower achievement, more negative self-perceptions and less effective approaches to learning. CYP with dyslexia who emphasise the importance of their own effort in their achievement are more likely to succeed academically and to hold positive self-concepts. Preliminary evidence suggests that these adaptive AtSs develop in the context of supportive and accepting environments in which CYP can experience success, however, more evidence is needed.

It is important to note that at least half of research papers included in this review utilised a discrepancy-based definition, and most of the remaining papers did not specify whether a discrepancy-based definition had been used or not. This is likely to have impacted the findings of the review as children who meet the discrepancy-based definition of dyslexia have average or above-average IQ scores. Higher IQ scores are typically linked better academic performance (Laidra, Pullmann, & Allik, 2007), which may well lead to more positive academic self-concept. Therefore, individuals with LitD/D who do not meet the discrepancy-based definition may be at greater risk of low academic self-concept than the participants in the majority of studies reported here.



Frederickson and Jacobs (2001) found that children with literacy difficulties, but no dyslexia diagnosis, did not experience the same negative impact on self-perceptions. It may be that having attention drawn to one's literacy difficulties (through diagnosis) increases the likelihood of a negative effect on self-perceptions. However, qualitative research sheds a different light on experiences of receiving a diagnosis. Individual reactions to diagnosis vary and may lie on a continuum between resistance and accommodation of the label (Armstrong & Humphrey, 2009). Many CYP reported having been labelled, prior to their diagnosis, as 'lazy' or 'stupid' and felt that their label of dyslexia counteracted this experience. For others, the label was perceived as stigmatising and unhelpful. Given the mixed nature of these findings, EPs, dyslexia specialists, and school staff should continue to treat every student as an individual and exercise caution in terms of using the dyslexia label, considering, alongside the child, whether the label is justified and useful to the individual. Furthermore, it is important that an accessible and accurate explanation of any LitD/D is given, dispelling any pre-existing stigmatising or negative connotations that the child may have.

EPs are also well-placed to reinforce school staffs' understanding of the possible impacts of LitD/D on self-perceptions. CYP who do experience lower self-perceptions can respond in a variety of ways, which may include both internalising and externalising behaviours (Singer, 2005). EPs can support school staff in problem-solving around behaviour that may be linked to difficulties with literacy, whether diagnosed or not.

Although evidence of the role of AtS in the development of self-perceptions amongst CYP with LitD/D is currently limited, there is evidence that teaching CYP about attributions can be beneficial for their achievement and motivation (e.g. Blackwell, Trzesniewski, & Dweck, 2007). EPs could share the psychology of AtSs and learning approaches with schools, parents and CYP, supporting a sense of personal control in both

## Chapter 1

teachers and learners, and encouraging and modelling deep rather than surface learning approaches, so that CYP can continue to make progress, despite literacy difficulties.

Preliminary evidence from two intervention studies suggests that interventions targeting both self-perceptions and literacy skills can be beneficial for CYP with LitD/D. One such intervention, which EPs are trained in, and is readily available to schools, is Precision Teaching (Lindsley, 1995). Recent research suggests that Precision Teaching can have motivational benefits and increase self-esteem, as well as being highly effective for teaching literacy skills (Griffin & Murtagh, 2015).

Self-efficacy is more malleable and less stable over time than self-concept or self-esteem; furthermore, it can be seen as an active precursor to self-concept (Bong & Skaalvik, 2003). In which case, there may be benefit from targeting self-efficacy by way of intervention, for example, through asking students to make self-efficacy judgements before completing tasks. With repeated exposure and success, greater self-efficacy in specific domains may lead to enhanced self-concept in those domains. There would be benefit from future research evaluating this type of intervention amongst learners with LitD/D who are suffering from negative self-perceptions.

The importance of social and familial support in coping with LitD/D and maintaining self-esteem was highlighted in several studies. Being able to safely discuss feelings with parents helped children with LitD/D to maintain positive self-views, whereas negative interactions with peers could damage them (Glazzard, 2010; Singer, 2005). Furthermore, parents having a good understanding of dyslexia and associated needs may be a protective factor (Terras et al., 2009). Lindeblad et al. (2016) suggested that recent political reforms in Sweden, aiming to achieve greater equality within the education system, may be responsible for the positive psychological adjustment and self-perceptions found amongst their sample of CYP with LitD/D. They noted that being exposed to positive attitudes from significant others such as teachers or peers has the potential to

protect against the development of negative self-perceptions. EPs and school staff should continue to promote understanding of the difficulties that some CYP face in learning to read and write, thereby increasing acceptance of these difficulties and encouraging attitudes of inclusion and embracing individual differences.

Finally, a small number of studies aimed to explore the impact of different educational settings. More research is needed to draw conclusions about differences in the self-perceptions of those attending mainstream versus specialist settings, however, initial findings from one qualitative study has shed some light on the features of educational settings that may support CYP to hold positive self-perceptions. CYP with LitD/D and, arguably, all CYP, may benefit from settings that provide nurturing and acceptance, which support their students to understand dyslexia and provide high quality differentiated teaching. These approaches may contribute to more positive self-perceptions amongst pupils and the development of resilient learners. Findings from this review suggest that CYP with dyslexia thrive when they are accepted and their needs are understood, something that is not unique to any one setting, or to those with dyslexia.

#### **1.4.2 Strengths and Weaknesses of this Review**

One of the aims of this review was to operationalise self-perception terms, and, by imposing definitions on a dataset that used multiple definitions and terms I have attempted to organise the evidence base in some useful way. This is an overall strength of the review. Indeed, many quantitative papers showed explicit consideration of self-perception terms, which made this an easier task, yet, in some cases, where no guidance was given, it was necessary to make assumptions about what exactly was being measured. A further strength is that the contributions of individual studies have been considered in terms of the quality assessment, with more emphasis being placed on the findings of higher quality studies. Furthermore, this review has helpfully built upon and extended Burden's (2008) review.

## Chapter 1

The majority of reviewed papers emphasised the voice of CYP through self-report measures or interviews. Seeking and valuing the voice of CYP should be acknowledged as a strength (and is in line with guidance from the UK Children and Families Act, 2014). However, some may argue against over reliance on self-report measures due to their potential for bias. One such bias is the impact of transient mood states (Podsakoff, MacKenzie, Lee, & Podsakoff, 2003). The majority of data from these studies was collected at a single time point, so individual variations in mood may have influenced self-perceptions. Yet, arguably, only the individual can provide insight into their own self-perceptions; therefore, report from others is less valuable and we may need to accept that there will be some biases with self-report data.

The papers in this review were restricted to studies conducted in Europe due to differences in diagnosis in other parts of the world. However, even within Europe there are wide ranging cultural differences in the construct of LitD/D. For example, Lindeblad et al. (2016) described how awareness and understanding of dyslexia in Sweden may have led to more inclusive education, whereas Stampoltzis and Polychronopoulou (2009) report how lack of provision for CYP with dyslexia in Greece leads to minimal disclosure amongst students. Furthermore, literacy difficulties themselves are different in different languages due to variations in orthography, which influence the prevalence of LitD/D in different countries (Paulesu et al., 2001), potentially impacting children's self-perceptions. Given these differences, caution should be applied when making cross-cultural generalisations, acknowledging that 12/19 of the studies reviewed were conducted in the UK. Additionally, it should be noted that the majority of participants with LitD/D in these studies were male, which reflects the population being studied, but should be considered before generalising further.

A weakness of many papers was their failure to adequately consider the impact of localised and wider environmental, cultural and social influences on the emotional

development of CYP. A number of the papers took a distinctly within-child perspective when discussing self-perceptions. This review has aimed to evaluate the research within the context of current systems of education and dyslexia assessment, however, there are other factors that were rarely explored within the available research. For example, the value that the UK national curriculum places on traditional academic and literacy skills. This review has concluded that CYP need to be educated in environments that understand and celebrate diversity; that there are CYP who feel a lack of self-worth related to their difficulties is not entirely surprising given that ‘our modern society places great value and high expectations on scholastic performance’ (Novita, 2016, p.280).

### **1.4.3 Implications for Future Research**

School-based interventions for CYP with learning disabilities have been found to enhance self-concept (Elbaum & Vaughn, 2001). However, as this review focused specifically on LitD/D, only two intervention studies were available, both of which were low quality. Further intervention studies would be beneficial in highlighting factors influencing the development of positive or negative self-perceptions. The current research provides evidence that LitD/D is linked with lower perceptions of academic competence and maladaptive AtSs, but intervention studies would allow us to understand how these factors influence each other in a causal way.

More research is needed on AtSs and approaches to learning amongst CYP with LitD/D, not only regarding differences, but how these styles develop and change over time. This kind of evidence could be sought through adding a qualitative element to the research and studying changes over time, as well as looking at the impact of attribution retraining programmes, as suggested by Frederickson and Jacobs (2001) and the benefits of deep approaches to learning.

A number of publications have focused on exploring attitudes to dyslexia and labelling (e.g. Arishi, Boyle, & Lauchlan, 2017). Various authors have considered the practical use and validity of the dyslexia diagnosis (e.g. Elliott & Grigorenko, 2014a; Lauchlan & Boyle, 2007); however, fewer have looked at CYP's perceptions of their dyslexia label and fewer still have directly asked CYP about the benefits or harms of the label. Given the current labelling debate, research looking specifically at the advantages and disadvantage of the label from the perspectives of CYP would be beneficial.

### **1.5 Conclusion**

This review extends current literature by systematically reviewing research exploring the links between self-perceptions and CYP with LitD/D. These CYP appear to be at greater risk of developing negative perceptions of themselves as learners, although, this does not necessarily impact on their general sense of self-worth. Current research suggests that some key factors may be relevant in supporting CYP with LitD/D to develop, and maintain, positive self-perceptions; these include holding adaptive AtSs (having an internal LoC in relation to overcoming difficulties), good relationships with peers and parents, and positive attitudes towards dyslexia and neurodiversity. In some cases, CYP had negative educational experiences because of their difficulties and felt that they had been labelled as unintelligent or idle, for these CYP, the label of dyslexia led to more positive self-perceptions, as it provided an alternative picture of themselves. There is a need for further research to explore the impact of AtSs and the potential for intervention, as well as CYP's experiences of labelling and any associated advantages or disadvantages.

## **Chapter 2    Dyslexia or literacy difficulties: what difference does a label make? Exploring the perceptions and experiences of young people.**

### **2.1      Introduction**

#### **Literacy Difficulties and Dyslexia**

The National Literacy Trust have reported that literacy within communities facilitates social justice, economic independence and personal health and wellbeing (Dugdale & Clark, 2008). However, almost 15% of adults in England have literacy skills equivalent to, or below, those expected at the age of 11 (Harding et al., 2012). Although overall literacy levels are rising in the UK, young people (YP) leaving school (aged 16-18) have been ranked as having the lowest levels of literacy out of 18 (mainly European) countries (Wheater et al., 2013). The National Literacy Trust have suggested that the reasons why individuals struggle with literacy range from significant educational needs to “disaffection from learning and low aspirations” (Dugdale & Clark, 2008, p.9). Dyslexia is thought to be one such hurdle in developing literacy skills, and estimates of its prevalence range from 3-10% of the population (Snowling, 2013).

Educators, psychologists and researchers have debated dyslexia for many years and various terms and definitions are utilised, with little consensus (Elliott & Grigorenko, 2014a). More than 10 years ago, Solvang (2007) described this as a “situation of vagueness” which “opens the diagnostic practices to social demand” (p.80) and the situation has not improved. Two agendas, with opposing demands, have been identified: one that seeks to encourage the recognition and relevance of dyslexia and another that objects to the use of a medical model to pathologise childhood and identify the problem as being within-child (Solvang, 2007).

Another tension is that operationalised definitions are usually necessary in order to conduct research, whereas educators may be more concerned with understanding and supporting individuals' needs. In the past, the 'discrepancy model' was used to define dyslexia; dyslexia being present when there was a significant difference between an individual's cognitive 'ability' (determined by IQ testing) and their performance in literacy assessment (Siegel, 1992). This model, however, has been largely discredited (Elliott & Grigorenko, 2014a; Snowling, 2013) and excludes individuals who would achieve low scores on both an IQ measure and a literacy assessment. There is general agreement that the primary symptoms of dyslexia include difficulty in acquiring literacy skills, but, Elliott and Grigorenko note, the difficulty is not with distinguishing those who struggle with literacy from those who do not, but rather with the suggestion that there is a difference between individuals with dyslexia and individuals who just have poor literacy skills.

A report by the BPS (British Psychological Society, 2005) provided the following definition for the use of Educational Psychologists (EPs) in Britain:

“Dyslexia is evident when accurate and fluent word reading and/or spelling develops very incompletely or with great difficulty. This focuses on literacy learning at the ‘word level’ and implies that the problem is severe and persistent despite appropriate learning opportunities. It provides the basis for a staged process of assessment through teaching.” (p.11)

This definition does not emphasise a distinction between dyslexia and other forms of literacy difficulty, a distinction which some may argue is unnecessary, particularly as the same challenges appear to underlie both. Regardless of IQ-discrepancy, research has found no difference in the support or intervention required (British Psychological Society, 2005; Elliott & Gibbs, 2008). One might argue, therefore, that the terminology is inconsequential. However, the BPS acknowledged that the term dyslexia is very much



within the public domain and requires consideration from a social psychological standpoint (2005, p.16). Beliefs around intelligence and access to specific interventions, perpetuated by the discrepancy model, raise issues around equality of opportunity and potential discrimination (British Psychological Society, 2005; Gibbs & Elliott, 2015).

### **Labelling**

Although most would agree that literacy difficulties should be recognised and supported, the labelling of these difficulties is contentious. Changing attitudes towards dyslexia and labelling in general have seen an increase in the number of publications exploring both the advantages and disadvantages of labels. For example, Lauchlan and Boyle (2007) explored the use of labels in special education; raising questions about the practical use and validity of labels and exploring the notion of stigmatisation. Riddick (2000) argued that stigmatisation occurs due to differences, regardless of label, but it has also been suggested that labels have the potential to provide a sense of relief and freedom from ‘blame’ for the difficulties (Lauchlan & Boyle, 2007; Riddick, 2000). In some cases, this has been described as replacing one accusing, unhelpful label, e.g. ‘lazy’, with another that is perceived as more helpful and accepting i.e. ‘dyslexic’ (Glazzard, 2010).

Researchers looking specifically at the impact of the dyslexia label have identified a number of advantages and disadvantages. Gibbs & Elliott (2015) found that the label can lower the self-efficacy of teachers, and others have suggested that it is linked with children’s low self-concept (Polychroni et al., 2006). However, other researchers have argued that having the label, to explain the difficulties, can increase self-esteem (Gibson & Kendall, 2010; Solvang, 2007). Qualitative research with YP diagnosed with dyslexia suggests that there are large individual differences in response to the label, some resist it, whilst others accommodate it into their sense of self (Armstrong & Humphrey, 2009).

Whilst many researchers and practitioners have argued against the dyslexia label for pragmatic reasons, qualitative research suggests that individuals who have the dyslexia label value it. However, this qualitative research has not directly asked YP, currently in education, what it is about the dyslexia label that they value, and whether they experience any disadvantages, as well as advantages, once they have the label.

Solvang (2007) suggested that medical labelling of educational needs is “both empowering and problematic” (p.84) and discussed the ‘dark’ and ‘light’ aspects based on a review of four studies. However, there is a need for research that focuses on the perspectives of YP, to offer explanations for the perceived advantages and disadvantages of the dyslexia label, in terms of exploring the lived experiences of those directly affected by it. There is little consensus regarding the conceptualisation of dyslexia from a professional perspective, but even less is known about how YP conceive of it.

### 2.1.1 Study Aims

This study aims to explore the views of YP, with and without experiences of dyslexia, with a particular focus on the impact of labels, using a qualitative methodology.

The following research questions will be addressed in two ways:

Table 6.

#### *Research questions.*

Research Questions	Method
1. How do YP understand dyslexia?	Online Survey
2. How do YP perceive dyslexia in comparison to other literacy difficulties?	
3. Does choice of label affect perceptions of the permanence of difficulties?	
4. What are YP’s experiences of dyslexia diagnosis?	Individual Interviews
5. What do YP perceive as the advantages and disadvantages of the dyslexia label?	

## **2.2 Method**

### **2.2.1 Design**

A qualitative, exploratory methodology was used to gather rich information about the experiences and beliefs of participants. The participants were purposively sampled to represent YP with and without literacy difficulties. The aim of this research was not to generate generalisable data, but to develop a deeper understanding of how a group of individuals perceived dyslexia, thereby adding to the existing literature. Two data collection methods were used: (i) an online survey exploring the perspectives of YP with and without dyslexia, and (ii) one-to-one semi-structured interviews with YP who identified themselves as having dyslexia.

### **2.2.2 Epistemology**

This research was approached from a social-constructionist stance; the perspectives of participants were understood to represent their individual constructions of the world based on their experiences and interactions and the language they and others use to describe those experiences (Willig, 2013). Social constructionism provides a dynamic model of meaning, that is both shared and negotiable, based on social and interpersonal experience (Kelly, Woolfson, & Boyle, 2008, p.21). This study did not seek to find an objective truth, but to explore individual interpretations of the world, within a shared cultural and societal context. This approach retained an ontological relativism, acknowledging that individuals have their own realities, which may be unique or shared, consistent or conflicting (Guba & Lincoln, 1994). This study did not intend to make claims about reality, but about phenomena being experienced by a certain group at a certain time.

Here, the concepts of LitD/D are viewed as situated within current cultural contexts and discourses, such as the dyslexia debate (Elliott & Grigorenko, 2014a) and a society in

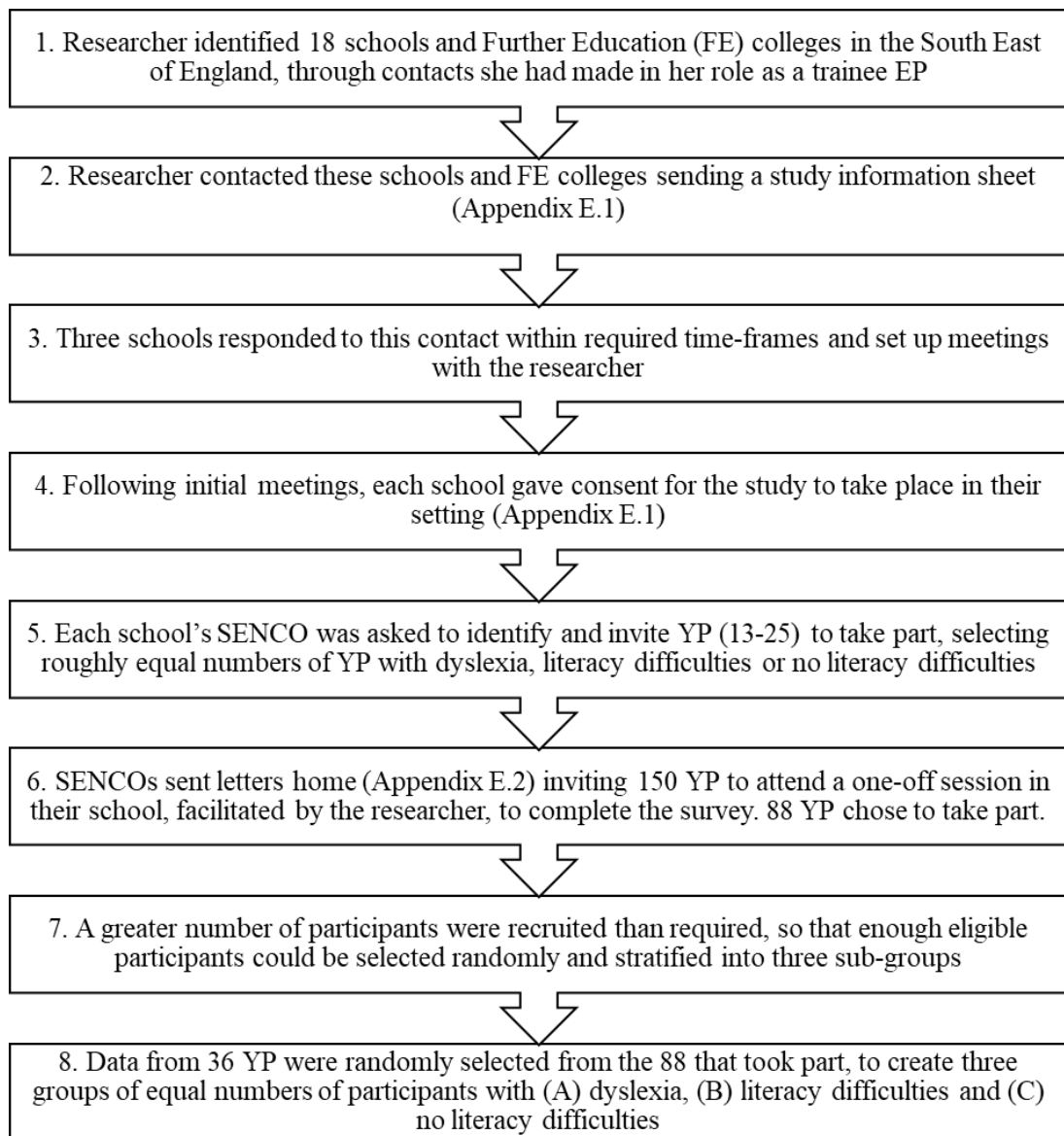
which literacy is a core and frequently measured aspect of YP's schooling, highly valued in employment and central to many aspects of daily life (Danermark, 2001).

The qualitative methodology and design of the current research, influenced by a social-constructionist approach, incorporated open-ended questions and semi-structured interviews utilising methods from Personal Construct Psychology (PCP). PCP adopts the philosophical perspective of constructive alternativism and assumes that all perceptions are individual and that meaning is constructed through experience (Kelly, 2003).

Although the participants were drawn from the same socio-cultural context, their differing personal experiences related to LitD/D were considered as impacting any findings. The researcher, alongside the participants, also constructed the results within the context of her own experiences and perspectives, for example, having a brother with a dyslexia label.

### **2.2.3 Sample and Recruitment**

Participants were recruited from three schools within a single Local Authority. Two schools had Sixth Form Colleges and two had Support Centres for YP with SEN. The schools varied in size and all schools reported providing additional support for students identified as having LitD/D. See Figure 2 for recruitment procedure.



*Figure 2: Survey recruitment procedure.*

### **Survey Participants**

The 150 YP invited to take part, and their parents, were sent an information letter (Appendix E.2). Parents of YP under 16 were asked to return an opt-out form if they did not want their child involved in the research. No opt-out forms were returned. Data collection took place during normal school hours and was arranged by the SENCO to ensure minimal impact on teaching and learning. YP who chose not to attend the survey attended normal lessons. Across the schools, participation rates ranged from 51% to 100% uptake. A total of 88 YP completed the online survey. Of these 88, 36 were randomly selected for data analysis. See Table 7 for participant details.

Table 7.

*Survey participants.*

<b>Self-Identification</b>	<b><i>N</i></b>	<b>Gender</b>	<b>Age</b>
Young person with dyslexia	12	Female 5 Male 7	13-19 ( $M=14.58$ )
Young person who struggles with literacy	12	Female 8 Male 4	13-16 ( $M=13.83$ )
Young person with no literacy difficulties	12	Female 7 Male 5	13-17 ( $M=15.33$ )

**Interview Participants**

Interview participants were recruited via the online survey and were eligible if they had both completed the survey and self-identified as having dyslexia. Of the 26 eligible, 20 opted to provide details to be contacted by the researcher about interviews. The researcher emailed these 20 YP with study information (Appendix E.3) and eight responded to indicate their interest. Of these eight, six followed through with making appointments, giving consent (Appendix E.3) and completing interviews. See Table 8 for participant details.

Table 8.

*Interview participants.*

<b>Pseudonym</b>	<b>Gender</b>	<b>Age at interview</b>	<b>School year at interview</b>	<b>School year at diagnosis</b>
Violet	Female	15	11	Year 4
Oz	Male	17	13	Year 5
Lucy	Female	13	9	Year 3
Theo	Male	16	12	Year 4
Charles	Male	19	13	Year 11
Moon	Female	16	12	Year 6

**2.2.4 Procedures****Survey**

The survey was created through the University of Southampton's iSurvey (Appendix F) and data were stored electronically in this system before being transferred for analysis. The survey consisted of two sections with predominantly open-ended, structured questions. The first section explored each participant's own experience and

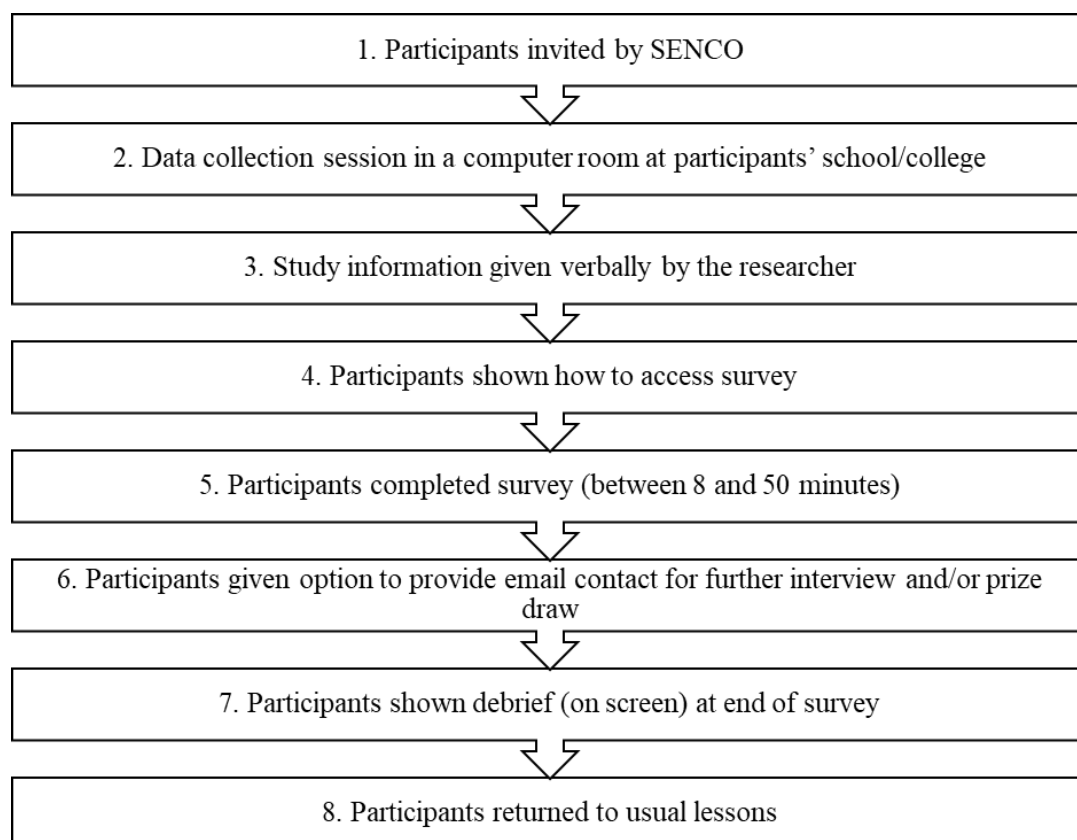
understanding of dyslexia. The second section required participants to answer questions related to two vignettes: one about a YP with dyslexia and the other about a YP with literacy difficulties (Figure 4). Both vignettes were presented at the same time and participants were asked to compare the two scenarios and answer questions about the YP's difficulties, support, likely outcomes and circumstances under which they could overcome their difficulties.

Charlie	Colin
Charlie is 13 years old. Over the years, he has made slow progress with reading and spelling. He reads slowly and he finds it hard to read new words. Charlie finds lots of things hard. He has been told, by someone at school, that he has dyslexia.	Colin is 13 years old, he finds school hard. He has been struggling with literacy for a number of years. He makes slow progress with reading and spelling at school. He finds learning new words very hard. People at Colin's school say he has literacy difficulties.

*Figure 3: Survey vignettes.*

The survey was developed by the researcher, with support from supervisors, specifically for this research. The use of vignettes was inspired by the research of Gibbs and Elliott (2015), who looked at the differential effects of labelling a child as having “dyslexia” or “reading difficulties” on teachers’ efficacy beliefs. Similarly, Ohan, Visser, Strain, and Allen (2011) have successfully used vignettes to explore perceptions of children with and without ADHD labels. The vignettes were designed to have a Year 6 reading level (Appendix F).

The procedure for survey data collection is outlined in Figure 3. All participants were made aware that at any point before step 7, they could choose not to attend the data collection session, or, once begun, to withdraw their consent and opt-out of the research without any consequence to them, and return to their usual lesson. It was also made clear that once their survey had been submitted, their data could not be withdrawn.



*Figure 4: Survey data collection procedure.*

Alongside the researcher, there was always at least one member of school staff present at data collection. All participants were offered support to help them access the survey: headphones to listen to audio recordings of the questions; voice recorder to verbally give answers to the questions (in another room); an adult (researcher or member of school staff) to read through questions and/or to type YP's answers. Table 9 indicates take up of this support out of all 88 participants who completed the survey.

Table 9.

*Use of survey support.*

<b>Support offered</b>	<b>Number of participants utilising support</b>
Headphones	10
Voice recorder	0
Reader	6
Scribe	6



## **Interviews**

An interview schedule was used flexibly to guide discussion and offer prompts when needed (Appendix G), allowing the researcher to follow the priorities of individual participants, thus reducing the impact of the researcher's own expectations on the data generated. Interviews were electronically recorded, then transcribed by a transcription service. Interviews lasted between 38 and 69 minutes.

### **Personal Construct Psychology (PCP)**

The interview schedule incorporated techniques from PCP (Kelly, 2003), and began by asking questions to elicit participants' constructs and experiences of dyslexia. This process was supported by the researcher creating shared notes and scales to illustrate the participants' responses (Appendix H).

The interview then introduced an adapted version of the ABC Model (Tschudi & Winter, 2012), a scaling technique designed to explore the positive and negative implications of an event or circumstance (Appendix H). In this study, the first scale (A) was used to demonstrate two poles, in this case, the presence and the absence of a dyslexia label. The second scale (B) was used to explore the advantages of having a dyslexia label and of losing that label. The third scale (C) was used to explore the disadvantages of the label and of losing the label. The ideas generated under each of these headings provided an insight into participants' constructs around the dyslexia label.

The idea that individual perspectives are unique is integral to PCP (Kelly, 2003), which makes it an appropriate tool for participant-led data collection (Burr, King, & Butt, 2014). Researchers have suggested that PCP techniques are less dependent than conventional interviews upon participants being verbally fluent and articulate (Burr et al., 2014), therefore were deemed particularly appropriate for YP with dyslexia (which has a high rate of comorbidity with language difficulties; McArthur, Hogben, Edwards, Heath, & Mengler, 2018).

### **Ethical Considerations**

This research was approved by the University of Southampton School of Psychology Ethics Committee and Research Governance (Appendix E.5). The survey and interviews asked participants to share potentially sensitive, or emotion-provoking information. Steps were taken to minimise any negative impact of this, for example, ensuring the participants, and their parents, were fully informed about the research and participants' rights to control their level of contribution. During data collection, I endeavored to reduce any experience of an imbalance of power in the researcher-participant relationship and make the experience as comfortable as possible, for example, through the use of transparent note taking in interviews using the participants own words. I made use of my experience as a trainee EP in working with YP, building rapport and eliciting information. All YP involved were informed about sources of support and encouraged to seek support for any concerns.

#### **2.2.5 Data Analysis**

##### **Data Preparation**

Survey data were exported from iSurvey into an electronic spreadsheet, where data were organised by participant and survey question. At this point, the researcher removed any identifying information that the participant had offered and participants were identified by number. Identifying information (email addresses) were held in a separate spreadsheet and used to contact participants relating to interviews or the prize draw.

Interview data were transcribed by a transcription service, and identifying information was removed. Pseudonyms chosen by participants were used to replace participant names in the transcript. Both survey and interview data were imported into NVivo 11 qualitative data analysis software (2017), which was used to assist coding.

### Thematic Analysis (TA)

Interview and survey data were analysed using the process of TA outlined by Braun and Clarke (2006) (Table 10). When used with a social-constructionist framework, TA can be used to theorise around sociocultural contexts, and structural conditions that facilitate individual perspectives (Braun & Clarke, 2006, p.85). In this research, TA was employed to look for themes (patterns) across each dataset, in order to capture important aspects and give meaning to the data in relation to the research questions. The steps are outlined below, however analysis was dynamic and recursive within these steps.

Table 10.

*Phases of Thematic Analysis taken from Braun and Clarke (2006, p.87).*

<b>Phase</b>	<b>Description of processes</b>
Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire dataset, collating data relevant to each code.
Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire dataset (Level 2), generating a thematic ‘map’ of the analysis.
Defining and naming	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

An inductive approach to analysis was used to allow themes to be developed without being directly informed by theory, meaning that themes were strongly data-driven and the influence of the researcher’s theoretical interest in the topic was reduced (Braun & Clarke, 2006). However, it is noted that the analysis cannot be entirely inductive due to the

## Chapter 2

researcher's prior reading in this area, including conducting a literature review on the topic, which may have influenced and sensitised her to certain aspects of the data.

Codes were derived from the data during analysis, using a range of methods. Descriptive coding was used to summarise the topic of an extract, latent codes focused on the researcher's interpretation of the participant's meaning beyond what had been explicitly said, and in vivo codes were used to capture the participants' own use of language and highlight the importance of participant voice in this research (Saldaña, 2013).

At multiple stages throughout the analysis, the researcher discussed themes, subthemes and data excerpts with the supervising researchers, both of whom are experienced in the use of qualitative methods. Supervision, along with the use of reflexive note-taking (Appendices I.3, J.1), was used to assist transparency and account for researcher influence and bias.

### **Survey Analysis**

Analysis of the survey began with repeated reading and note taking in order to become familiar with the data. Initially each participant's survey was read as a whole and responses were then looked at question by question. In order to make comparisons between the different groups, data was divided up into sets A (YP with dyslexia), B (YP with literacy difficulties) and C (YP with no literacy difficulties). Stages 1-3 of analysis took place for one dataset at a time, before bringing codes and potential themes together across all datasets for stages 4-6. See Appendix I for records of process.

### **Scaling Questions**

Some analysis of quantitative content was conducted. The survey contained two scaling questions, whereby the participant was asked to rate, on a scale of 1-10 how likely it was that the pupil in the vignette would overcome their difficulties. This was included to offer some triangulation in order to answer research questions and provide further evidence

for or against the themes derived through TA. This was carried out by calculating mean scores and ranges given by the participants in each group.

### **Interview Analysis**

Initially, each transcript was read individually by the researcher, alongside the audio recording. Notes were taken relating to general feelings and reactions to the text, interesting quotes and recurring ideas. This helped the researcher to become more familiar with the data and with the individual story of each participant. Each transcript was then imported into NVivo and re-read multiple times, where stages 1 and 2 of the analysis took place. Stage 3-6 were carried out through a combination of note taking by hand and on the computer, manually arranging codes into potential themes, using NVivo, discussing with supervisors and writing up findings. See Appendix J for records of process.

## **2.3 Results**

### **2.3.1 Online Survey**

#### **Participant Characteristics**

Participants were asked to self-identify into one of three categories: group A self-identified as having dyslexia, group B self-identified as having literacy difficulties, and group C self-identified as having no literacy difficulties.

See Method, Table 7, for participant demographics.

#### **Themes**

The thematic map (Figure 4) depicts the themes drawn from each dataset. The themes discussed are those deemed most resonant by the researcher, in terms of salience within the dataset, relevance to research questions and to professionals working with YP with LitD/D. This section addresses one research question at a time, presenting each theme in turn (Table 11). Table 12 presents the themes that are not discussed. Terms such as ‘some’ or ‘many’ participants are used to indicate internal generalisability (Maxwell, 2010) and illustrate the prevalence of particular views within the sample, but not to suggest that these views would be representative of a wider group.

Table 11.

*Research questions and relevant themes, with source groups in brackets.*

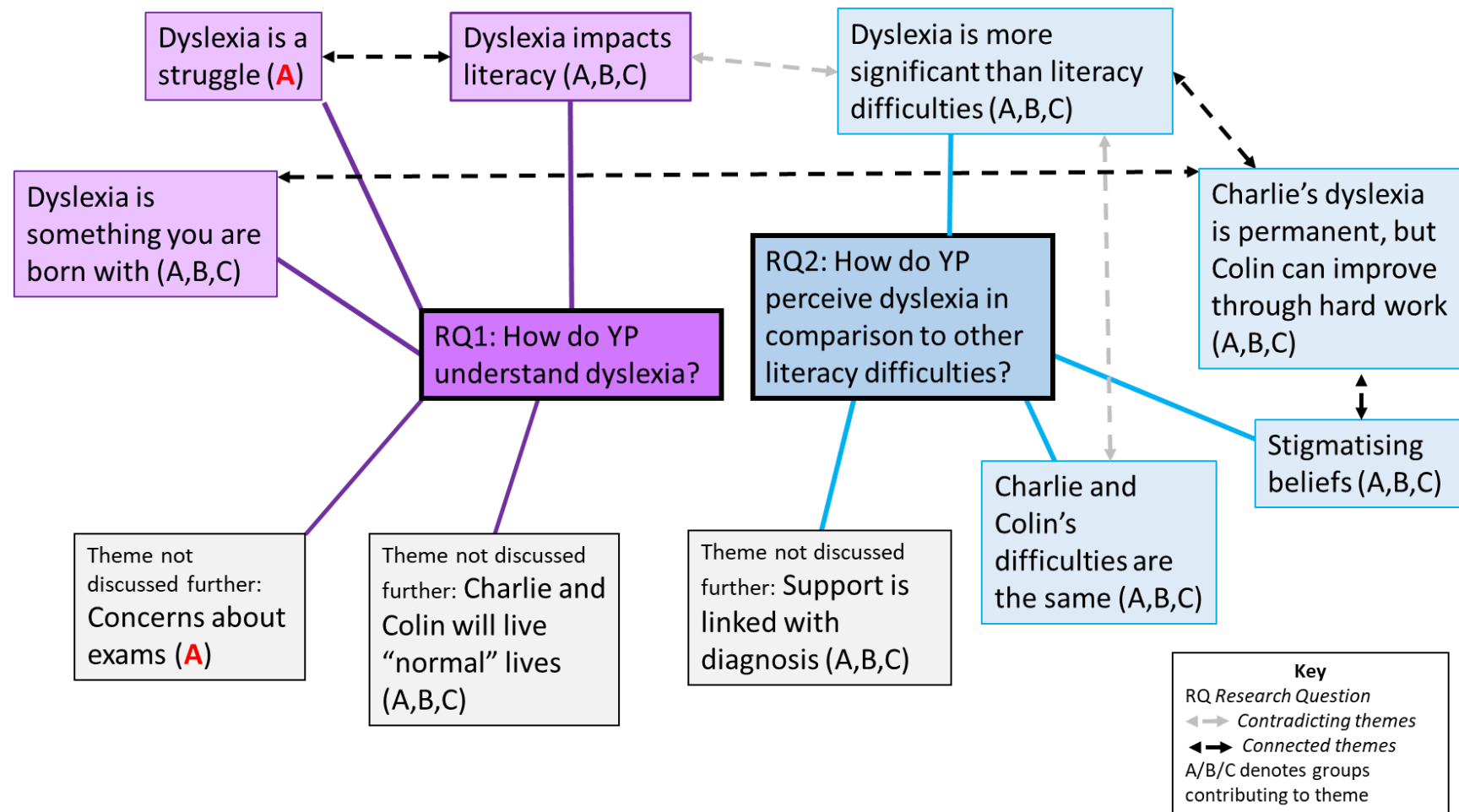
Research Question	Themes
1. How do YP understand dyslexia?	Dyslexia impacts literacy (A, B, C) Dyslexia is something you are born with (A, B, C) Dyslexia is a struggle (A)
2. How do YP perceive dyslexia in comparison to other literacy difficulties?	Dyslexia is more significant than literacy difficulties (A, B, C) Charlie and Colin's difficulties are the same (A, B, C) Charlie's dyslexia is permanent, but Colin can improve through hard work (A, B, C) Stigmatising beliefs (A, B, C)
3. Does choice of label affect perceptions of the permanence of difficulties?	Scaling questions (quantitative data, A, B, C)

Table 12.

*Themes not discussed.*

Theme	Description
Charlie and Colin will live "normal" lives (A, B, C)	Amongst all three groups, participants generally felt that students with dyslexia and/or literacy difficulties would live "normal" lives and have happy relationships. Several participants mentioned the impact of difficulties and/or low school grades on employment, but some participants pointed out that this would depend on the type of work and that "modern technology" can go some way to lessen the impact.
Concerns about exams (A)	Participants with dyslexia (group A) wrote about the impact of dyslexia on exam performance and the exam access arrangements that they require. Many reported that they needed extra time in exams, scribes, word processors, electronic readers or readers in order to perform well. They also suggested that they are likely to do less well in English than more practical, less literacy dependent, subjects.
Support is linked with diagnosis (A, B, C)	Some participants in each group felt that Charlie would receive more support than Colin because Charlie had a recognised, understood condition and Colin did not. There were differences of opinion on whether this was a fair distribution of support and some indicated that Colin should get the same help, but likely would not. The majority of participants felt that both Charlie and Colin would get some kind of literacy support, but it was also mentioned that Charlie may receive specialised support, resources or "therapies".

Figure 5: Thematic Map for online survey findings.





Quotes have not been edited and original spelling has been retained. Quotes are denoted with a letter to indicate that the participant self-identified as a YP with dyslexia (A), literacy difficulties (B) or no literacy difficulties (C).

### **1. How do YP Understand Dyslexia?**

Three main themes depict the way that YP with and without LitD/D understand dyslexia. The first theme (dyslexia impacts literacy) focusses on symptoms and difficulties, and the second (dyslexia is something you are born with) on aetiology. The third theme (dyslexia is a struggle) relates to experience of having dyslexia; this was described by group A only, as participants were asked to describe their experiences of *dyslexia*, rather than of literacy learning.

#### **Dyslexia impacts literacy**

This theme captured all participants' feelings that difficulties with reading, writing and spelling were the defining characteristics of dyslexia, although some acknowledged that there would be individual differences in the extent to which these would be affected.

*"I think dyslexia is when someone struggles to do things that others would find easy or natural, such as reading or writing."* (B)

Several participants' understanding of dyslexia included differences in information processing, as well as literacy. Some suggested that words like "*jumbled up*" captured features of dyslexia. As well as visual disturbances, participants described difficulties with remembering things and processing information accurately.

*"A condition that makes the brain misread or swap letters and words around in the brain."* (A).

All groups mentioned speed of processing within their understanding of dyslexia, particularly group A, where half of participants referred to needing more time to do things.

*“I write really slow” (A)*

### **Dyslexia is something you are born with**

The majority of participants in all groups implied, or explicitly stated, that dyslexia occurs as a result of differences in the brain, which may be hereditary and stem from genetic factors. Although a few participants also acknowledged the potential impact of environmental circumstances, such as upbringing, there was a general feeling that, regardless of upbringing, you are either born with dyslexia or you are not.

*“because everyones brains are different” (A)*

*“Charlie's difficulties are the result of his genetics, and so whilst his upbringing and his parent(s) style of support may have been good, he still has to fight his biology.” (C)*

### **Dyslexia is a struggle (A)**

This theme came from group A's descriptions of dyslexia and the difficulties that they face. Many YP used the term “*struggle*” to describe their experience of dyslexia and just one participant mentioned potential positives: whilst stating that dyslexia is “*really irritating*”, this participant felt that it helped her to think differently.

*“i will have the ideas of what to wright but i cant do it sometimes but i think dyslexia also helps me in crective subjects and i cna think diffrent ley from other people.” (A)*

Participants described their “*struggle*” in relation to literacy and information processing difficulties. Some participants’ descriptions implied an emotional response to their difficulties, such as frustration or, in one case, losing self-confidence.

*“i have it and its be a rill struggle all of my life” (A)*

*“it is really irritating because it makes things harder for me than for other people”*

(A)

## **2. How do YP Perceive Dyslexia in Comparison to Other Literacy Difficulties?**

The vignettes depicted two male students, Charlie and Colin, with equal difficulties in terms of literacy learning and progress. The primary difference between the two descriptions was that “Charlie and his teachers are aware that he has dyslexia” and “Colin and his teachers are aware that he has literacy difficulties”. Based on these descriptions, across all groups, just over half of participants construed Charlie and Colin as having distinctly different needs, with Charlie’s needs being perceived as more significant. Four main themes evolved: dyslexia is more significant than literacy difficulties; Charlie and Colin’s difficulties are the same; Charlie’s dyslexia is permanent, but Colin can improve through hard work; and stigmatising beliefs.

### **Dyslexia is more significant than literacy difficulties**

Almost half of the participants implied in some way that Charlie’s difficulties were more significant and more pervasive than Colin’s and many clarified this by diminishing Colin’s difficulties, for example:

*“Charlie has got dyslexia whereas Colin just finds it hard to read and write.” (B)*

*“There is a difference between finding stuff hard and having dyslexia because dyslexia is like having something always at the back of your mind and stopping you from doing things and you not always aware of it” (A)*

*“Charlie would get more help because he has a more serious problem” (C)*

Despite the apparent assuredness of these opinions, the participants provided little explanation for their views. Some suggested that Colin was making more progress than Charlie or that Colin’s difficulties are “normal”, however, the vignettes describe identical profiles.

When it came to exam performance, the majority suggested that both Charlie and Colin would attain lower than average grades because of their difficulties. However, several suggested that Colin would do better because he does not have dyslexia.

*“I think that Colin will get a higher level in his GCSE because he doesn't suffer from dyslexia. Colin could possibly get a B-, but because Charlie suffers from dyslexia he might get a C- or even a D.” (B)*

Interestingly, a minority of participants viewed Colin’s difficulties as more pervasive or more significant than Charlie’s. These participants suggested that Colin must have “another type of learning difficulty” (A). This links with the third theme around stigmatising beliefs.

### **Charlie and Colin’s difficulties are the same**

In contrast, some of the participants described little difference between Charlie and Colin’s needs. Several participants explicitly stated that this was because Colin also has dyslexia, but is undiagnosed, so he and his teachers are not aware of it.

*“one knows he has dyslexia and the other one doesn't” (A)*

Other participants simply stated that there was very little difference between the two students, other than the label itself.

*“I think that they have the same difficulties, but Charlie has a diagnosis and Colin doesn't. I think this is the only difference.” (C)*

### **Charlie’s dyslexia is permanent, but Colin can improve through hard work**

Linked with the idea that dyslexia stems from biological factors, participants in all groups expressed views that dyslexia is something fixed, which cannot be treated or overcome, regardless of intervention. Some participants suggested that this was a key difference between Charlie and Colin:

*“Colin has difficulties with reading and writing, so he will need to be taught more about how to do it where as Charlie will get serious help because there is no cure to this, he will have it his entire life.” (C)*

*“Charlie has a condition which as far as we know cannot be treated” (A)*

This perception of dyslexia as something permanent and incurable suggests little sense of agency over being able to overcome one’s dyslexia, but participants across groups did feel that, whilst dyslexia will always be present, the symptoms associated with it may improve over time.

*“He will always be dyslexic but could make it weak dyslexia” (A)*

However, participants with dyslexia were more likely to focus on external sources of support, such as teachers, technologies or the need to search for “*cures and medication*” (A).

A thread ran through all groups around the need for hard work, commitment and effort in order to overcome difficulties. However, in all groups, this was far more

frequently applied to Colin, than Charlie. Participants talked about the importance of practising to improve literacy skills and continued effort and dedication in order to succeed in school and in employment.

*“All [Colin] has to do is practice and this will allow him to read and right well, this could take anytime from a couple of weeks to a year or two, I don't think he will still struggle after a couple of years help.” (C)*

*“if [Colin] studies hard and continues to practise allowing him to progress and evenly be smarter.” (A)*

### **Stigmatising beliefs**

Some participants conveyed that both Charlie and Colin could be subject to stigmatising beliefs, for example, in the world of work or in terms of people making assumptions about their intelligence.

All groups had varied views on intelligence in relation to dyslexia and literacy difficulties. For example, in group C, four participants repeatedly highlighted the fact that dyslexia is not associated with lowered intelligence and that *“many dyslexic people have turned out to be very clever.” (C)*

*“This learning difficulty does not affect intelligence only ones skill writing and reading” (C)*

In the vignettes, Colin is described as having comparable difficulties to Charlie, but without a diagnosis of dyslexia, which some participants interpreted as indicating that his difficulties were not specific to literacy.

*“Charlie has problems with reading and Colin has difficulties with learning” (B)*

Some participants commented on Colin's intelligence, suggesting that, as he does not have a dyslexia diagnosis, he may just be unintelligent:

*"I think that Charlie's difficulties is because of a genetic disorder whilst Colin's may be because of his intellect."* (B)

Some participants' comments implied that, whereas Charlie's condition stemmed from biological factors outside of his control, Colin may be responsible for his literacy difficulties, through lack of effort or intelligence, making him less likely to receive support:

*"I think Charlie would get a bit more help then Colin because Colin only seems to have literacy difficulties not dyslexia which some teachers may help more with because it genuinely isn't his fault where as difficulties could be just because he struggles or distractions may occur"* (B)

A few participants indicated that Colin's parents may be to blame for his difficulties *"as a result of a different upbringing where his carers weren't as involved"* (C).

There were conflicting views around the presence or absence of a stigma related to dyslexia. Group C were the most open in talking about stigma; some participants suggested that employers may, misguidedly, be reluctant to hire a person with dyslexia, or that individuals may want to hide their dyslexia:

*"Depending on how the dyslexia affects their grades could affect their job. Also if the employer knew about the condition the employer may be reluctant to hire somebody with the condition under the assumption it would restrict them from doing their job or a misunderstanding of the condition."* (C)

## Chapter 2

*“I don't know anyone in my friend group who has openly admitted they have dyslexia... many people hide dyslexia so someone may seem like they don't have it when they really do.” (C)*

However, not all participants made a distinction between the stigma that Charlie would face, with his diagnosis, and the difficulties that Colin would face, without one. One participant implied that stigmatising beliefs, or prejudices, are attached to having difficulties with literacy, but not necessarily with the diagnosis:

*“employer aren't interested in people who have trouble with reading and writing.”*  
(A)

There were also participants who felt there is no stigma attached to dyslexia:

*“I think that Dyslexia and learning difficulties shouldn't have any effect with relationships, success, or happiness, as long as these fields have nothing to do with literacy. Job wise, it would be naive to say that their conditions would mean that they would have less access in the job market.” (B)*

A small number of participants in each group mentioned potential “*self-esteem issues*” (B) for both Charlie and Colin, and that, through comparing themselves to others, “*they may not believe that they are good enough*” (B). One participant spoke about her own self-confidence:

*“i started to read Barrington Stoke books (books for kids with dyslexia). reading these books gave me confidence to start to read proper books again.” (A)*

This theme highlights the range of perspectives in how participants viewed individuals with LitD/D, but it was clear that stigmatising beliefs were not only applied to Charlie with his dyslexia label, but equally applied to Colin. Although participants' views were often conflicting, many made assumptions about Charlie and Colin's likelihood of



being successful and being perceived as intelligent and competent, based solely on the difference in label. This key finding is explored in the discussion.

### 3. Does choice of label affect perceptions of the permanence of difficulties?

To specifically address the issue of prognosis for Charlie and Colin, two scaling questions were included in the survey. Table 13 shows the scores assigned by participants to the questions “How likely is it that Charlie/Colin will beat his difficulties and no longer be dyslexic/find literacy so hard?” on a scale from 0-10 (with 0 being not at all likely and 10 being very likely).

Table 13.

*Mean scores assigned to scaling questions and difference in mean score.*

<b>Group</b>	<b>Mean Score for Charlie (<i>Range</i>)</b>	<b>Mean Score for Colin (<i>Range</i>)</b>	<b>Difference in Means</b>
A	2.50 (0-6)	6.25 (2-10)	3.75
B	4.20 (0-7)	5.75 (1-9)	1.55
C	4.10 (0-8)	6.30 (2-9)	2.20

In accordance with the qualitative data, participants in group A had less belief in Charlie overcoming his dyslexia than participants in groups B and C.

#### 2.3.2 Interviews

Of the eligible survey participants who expressed an interest in being interviewed, six responded to contact and took part in an interview.

#### **Participant Characteristics**

Table 14 outlines how each interview participant described their own experience of dyslexia and the specific characteristics or symptoms they identified in themselves.

Table 14.

*Participants' descriptions of their dyslexia.*

<b>Participant</b>	<b>Age</b>	<b>Characteristics of Dyslexia</b>
Violet	15	Violet experiences difficulties in English lessons at school: reading, writing and spelling are tricky and can take her longer than other people. Violet also described sometimes having difficulty in understanding or comprehending written text.
Oz	17	Sequencing, remembering lists and order of information (e.g. order of letters when spelling) are challenges for Oz. He has difficulties with organisation of activities and thoughts. He finds that things take longer than they do for other students. Oz perceived his dyslexia as “mild” and saw some benefits, such as learning to “think differently”.
Lucy	13	Lucy said that her dyslexia primarily affects her writing and performance in English. It takes her longer to learn new skills and to get her thoughts on paper. She feels that her brain works a bit differently to others’ and she sees things and thinks about things differently, which can be beneficial at times.
Theo	16	Theo finds that his dyslexia impacts on reading and writing and how he sees words; they might look wrong or get muddled up. Reading out loud or doing things at speed, under pressure is challenging. He also struggles with spelling and grammar.
Charles	19	Charles described difficulties with processing, comprehending and remembering written information. He finds spelling and remembering key words challenging. Charles feels that he needs more time for reading and writing and learning new information.
Moon	16	Moon talked about the impact of her dyslexia on her memory, particularly short term and working memory. Moon described being an avid reader and enjoying writing by hand. It took her longer to learn to read than other children and she still has quite a bit of difficulty with spelling. Moon also finds that she needs more time to process information.

All participants identified themselves as ‘dyslexic’ or having dyslexia and used this term to describe themselves in interviews. All participants talked about family members with dyslexia or similar difficulties, and many mentioned parents’ experiences of dyslexia. All interview participants were succeeding academically; either on track to do well in GCSE exams or completing A levels.

### **Themes**

This section addresses one research question at a time, presenting each theme in turn (Table 15). The thematic map (Figure 5) depicts all the themes, however, only those

deemed most resonant by the researcher (in terms of salience within the dataset, relevance to professionals and to the research questions) are discussed. Table 16 presents the themes that are not discussed.

Table 15.

*Research questions and relevant themes.*

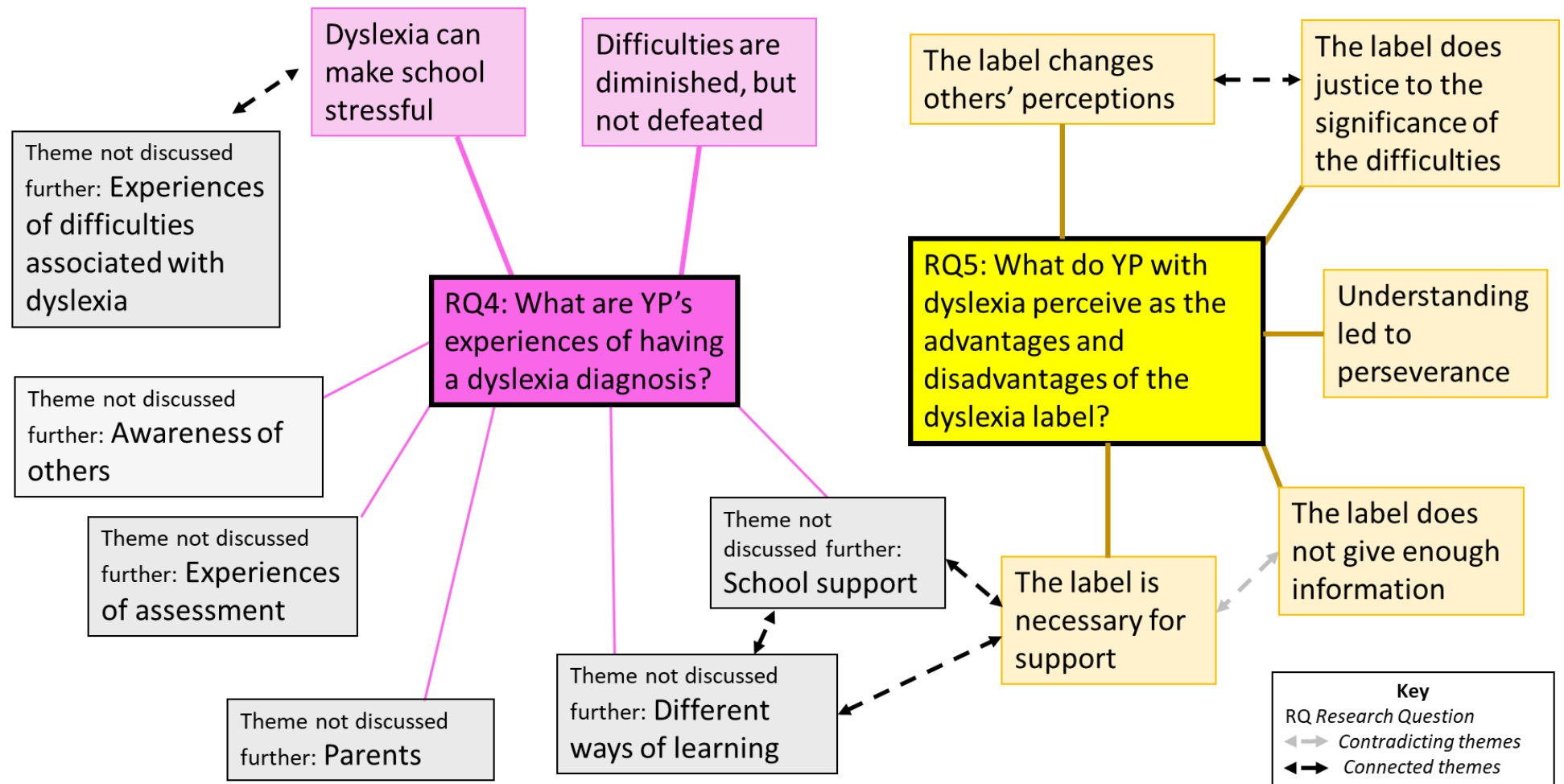
<b>Research Question</b>	<b>Themes</b>
4. What are YP's experiences of having a dyslexia diagnosis?	Dyslexia can make school stressful; Difficulties are diminished, but not defeated;
5. What do YP with dyslexia perceive as the advantages and disadvantages of the dyslexia label?	The label changes others' perceptions; The label does justice to the significance of the difficulties; The label does not give enough information; The label is necessary for support; Understanding led to perseverance

Table 16.

*Themes not discussed.*

<b>Theme</b>	<b>Brief Description</b>
Experiences of difficulties associated with dyslexia	This theme is not discussed, but an outline is presented under 'participant characteristics'
Experiences of assessment	Participants generally received their diagnoses in primary school and had limited memories of their assessment, but several said that they did not feel well-informed about the assessment at the time. Participants generally described indifference at the time of diagnosis due to lack of understanding.
Awareness of others	All of the participants said that they could talk to their friends about their dyslexia and did not generally feel it was something to hide. They felt that peers at school would be aware of the difficulties that they have and the additional support that they receive, but only one participant did not like how her support singled her out. Another participant had initially perceived a stigma around dyslexia and wanted to hide it, but as he got older felt differently and perceived the stigma as lessened. One participant talked about the importance of being open about dyslexia so as not to perpetuate negative views.
School support	Participants discussed the support that they received from school. Participants had differing views on what worked and what did not, but were generally very appreciative of support. Many participants found the use of assistive technologies very helpful. Participants talked a lot about exam access arrangements and these were perceived as a very important aspect of support. For some participants, this was the only support that they received.
Different ways of learning	Many participants felt that individuals with dyslexia have different ways of learning and therefore require non-traditional methods of teaching. Participants also spoke about the coping strategies that they themselves have developed and the different ways that they find of working with their individual strengths and difficulties.
Parents	All participants had a family member who had experienced difficulties associated with dyslexia and several participants described their parents own experiences. Participants also described how their parents have been instrumental in supporting them and ensuring that the school provide adequate support.

Figure 6: Thematic Map for interview findings.



#### **4. What are YP's experiences of having a dyslexia diagnosis?**

Two themes (dyslexia can make school stressful; and difficulties are diminished, but not defeated) were developed from participants' descriptions of their experiences of having a dyslexia diagnosis.

##### **Dyslexia can make school stressful**

Participants described the impact of their difficulties on their education as a whole. They found that their difficulties made a range of lessons more challenging for them, most commonly English. Some participants felt that their difficulties meant they put more pressure on themselves, or experienced more stress, in trying to achieve academically.

*Researcher: What do you think it would be like if you didn't have [the computer]?*

*Violet: Very distressful, especially in English. I get it for all the subjects except for Maths, so...*

All participants had some experience of failure throughout their school careers, but felt that they had benefited from the support and/or exam access arrangements that they received, without which, participants felt sure they would not be successful in education. This was often based on their previous experiences of not having support.

Neither the label itself, nor the difficulties associated with dyslexia, were perceived to have an impact on participants' opportunities or future successes, outside of education.

*Charles: Learning difficulty. It mainly affects education. It doesn't... I'd say it doesn't really affect like in life jobs because everything is done on a computer nowadays, so the only thing it really impacts is education.*

Where it was discussed, participants did not feel that it impacted on their social life or job prospects. They understood that they might be a bit different to other people, but also that they could still be successful.

*Lucy: Because I don't think it affects you really, to get sort of like the dyslexia label. In like... it's not going to, I don't think it would stop me from doing anything. Like for some people it may not help them, but I don't feel like it would stop me doing anything but it's almost like... I'm just like different. It doesn't mean I can't follow this career or I can't do that. It's just I'm different.*

### **Difficulties are diminished, but not defeated**

The participants viewed themselves as improving all the time; they all described ways that they have begun (to greater or lesser extents) to overcome their difficulties, through developing coping strategies, additional support from school and practise over time.

*Violet: I think I have overcome a lot of it. It's just if we're reading in class I am always a page or two behind.*

*Charles: I quite like a video because I will watch a video through, then I will watch the video through and I will make notes. And it will just help kind of if I can hear it, and then see it and hear it and see it, then it will help me be like 'Okay, I can get that right', by like one letter of something, which helps a lot in exams.*

However, there was a general feeling that, despite their progress, they would always have dyslexia; that their difficulties, in one form or another, would always exist. Some participants talked about how the 'symptoms' of their dyslexia (e.g. literacy difficulties) would improve, but ultimately, the underlying issues (speed/processing/memory etc.) would always be present. Three of the participants said

explicitly that, however much progress they make, they will always have dyslexia; even if they perform as well as their peers, things will still be more difficult for them.

*Theo: I don't know but I would probably find a way to get over sort of some of the symptoms. ... ...Like words would always still seem jumbled up but grammar and spelling would get easier. ... ... I think I would still have it but it just wouldn't affect me in the same way."*

Participants talked about accepting and being comfortable with their individual strengths and needs and referred to dyslexia as something to “*work around*”, to factor into their work and lives, as it would always be with them.

*Lucy: And then there's sort of like finally a reason that I can actually... when people are saying 'Why are you taking so long on that?' I will just be like 'Well, it's just the way I am'.*

*Oz: I had already started to work round the problems so I thought rather than stop I would use the help to help me work round the problems, in the way I had already kind of had to start doing it. And that's what used to help at primary school really, to kind of help me get round the first couple of problems that I had encountered.*

## **5. What do YP perceive as the advantages and disadvantages of the dyslexia label?**

Figure 6 represents the ABC model used with interview participants and provides a summary of their collective responses in terms of the advantages and disadvantages of the dyslexia label. Five themes were developed based on these responses: the label changes others' perceptions; the label does justice to the significance of the difficulties; the label does not give enough information; the label is necessary for support; and understanding led to perseverance.



<b>Dyslexia label</b>	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"> <li>• Relief from own or others' perceptions of them as unintelligent or lazy</li> <li>• An understanding of why they have struggled</li> <li>• Better understanding leads to increased motivation and perseverance</li> <li>• Additional support in school and exam access arrangements</li> <li>• The label signifies the significance of the difficulties and helps others to recognise this</li> </ul>	<ul style="list-style-type: none"> <li>• Seen as part of a homogenous group</li> <li>• Others may equate dyslexia with stupidity</li> <li>• Not everyone has access to diagnosis or support</li> <li>• Dyslexia is something permanent and cannot be overcome</li> <li>• Label may be linked with lowered expectations</li> </ul>
<b>No dyslexia label</b>	
<b>Advantages</b>	<b>Disadvantages</b>
<ul style="list-style-type: none"> <li>• A more descriptive term could provide a more nuanced understanding of strengths and difficulties on an individual basis</li> <li>• Support would be determined based on need</li> </ul>	<ul style="list-style-type: none"> <li>• Others may perceive individuals as unintelligent</li> <li>• Support may not be provided, leading to disadvantage in terms of academic outcomes</li> <li>• Lack of explanation for difficulties, leading to lowered self-perceptions, motivation and achievement</li> </ul>

Figure 7: Participants' views of the advantages and disadvantages of the dyslexia label.

### **The label changes others' perceptions**

Participants described how a dyslexia label can alter others' perceptions of them, in both advantageous and disadvantageous ways. Two conflicting views, existing across, as well as within, participants' dialogues, showed that, on one hand, participants felt that 'dyslexic' could be a preferable replacement for negative judgements made by others pre-diagnosis (e.g. lazy, unintelligent). Alternatively, some participants felt that the term dyslexia sets up the expectation that a person is unintelligent. The former view was more prominent, but ultimately both views highlight that the problem is with the negative judgements made by others, rather than the use, or not, of the label.

Oz, Theo and Charles expressed both views. Theo's had changed over time, as his understanding of dyslexia changed; at a young age, he felt that dyslexia had a stigma attached that would mean people would think he was "*stupid*", but as he got older, he no longer thought of dyslexia negatively and felt that, now, he would be perceived as stupid without the label.

Many participants thought that, if they did not have their diagnosis, others would see them as unintelligent or "*lazy*" and that their label proved that this was not the case, that there was a "*reason*" for their difficulties, which changed the perceptions of others.

*Violet: If I didn't have the diagnosis, people would just assume that I was a bit dumb.*

For many participants, these beliefs were based on the lack of support and understanding they received prior to diagnosis.

*Lucy: No. Definitely only afterwards. I never had any help before. Basically our primary school would be like 'Well, there's no reason so they just need to try harder'.*

The label therefore protected their self-image and self-esteem. Theo and Oz talked about “*self-fulfilling prophecy*” and the idea that, if you are labelled as unintelligent, you are more likely to think that about yourself.

*Researcher: How do you think you would feel if someone came along and said ‘Oh, we’re not going to use that term anymore’ and you stopped being able to use the term ‘dyslexia’?*

*Theo: Then people would probably just perceive me as not being as smart.*

*Researcher: Yes. So how would you feel then?*

*Theo: I would probably struggle a lot in class with paying enough attention, because if I’m labelled with something I’m more likely to just go with it than fight it.*

On the other hand, Moon felt that people’s perceptions and expectations of a person with a dyslexia label could be detrimental; that some people would see a person with dyslexia as unintelligent and have low expectations.

*Moon: No. I think people see you as dumb.*

*Researcher: Okay, so people might equate having dyslexia with being dumb?*

*Moon: Yeah, and unintelligent. And actually we could be more intelligent than you are. ... We just have a different... we’re just different.*

Oz, Charles and Theo also all felt that some people would perceive dyslexia as equating to lack of intelligence, however, they thought that this would happen without the label as well, suggesting that the assumptions of others are based on the difficulties that the participants face, rather than the label itself.

*Oz: It's not something I usually take out on the first meeting. Because I've found it's easier to explain to someone you are dyslexic once they know you are clever, than to explain to someone you are clever once they know you are dyslexic.*

Oz attended two different primary schools prior to his diagnosis and felt that, at his first school, he was labelled as lazy, but at his second he was seen as hard working and intelligent, even though he did not always “get it”. This provides support for the idea that the label itself is less important than the assumptions or judgements that people make.

*Oz: ...but I have vague memories of really not liking my old school. It was quite a small school and I can't remember much but I have a memory of being labelled as lazy and...*

*Oz: Well, prior [to diagnosis] it was kind of just... I think I was one of those students who is kind of, I was seen as hardworking but didn't necessarily get it, but reasonably clever. Um, and we wanted to learn but we couldn't quite grasp it.*

Lucy also spoke about how she had great teachers, and teachers who were not at all understanding, who perceived her negatively, suggesting that the label does not enable an accurate prediction of teacher response.

### **The label does justice to the significance of the difficulties**

Four of the participants felt that an important aspect of the dyslexia label is that it does justice to the difficulties that they face; they wanted others to recognise their struggle and the “*validity*” of their difficulties, in comparison to those who might find school difficult for other reasons. The majority of participants, either explicitly, or through describing their experiences, suggested that that dyslexia is more than just literacy difficulties. They felt that their difficulties were more significant and extended beyond literacy, i.e. influencing memory, processing, speed, understanding and comprehension.

Three participants (Oz, Theo and Moon) explicitly said that they felt the term ‘dyslexia’ carried more “*weight*” or had more “*credence*” than alternative terms that could be used, for example, those that just describe their specific challenges.

*Oz: But within kind of a... the diagnostic, the fact it's been diagnosed as a label, gives it some credence if you will. So maybe if you had, you know, the dyslexia but then you had an equivalent term, would probably be the best way of going round it. Because just dropping the label in its whole would, I think, remove the validity of whatever label took its place if it wasn't as... because the word 'dyslexia' doesn't sound English. ... ..It has a, shall we say, it has a rather un-English, almost medical feel to it. ... ..And that, even before you go away and look it up, adds some almost weight to the term.*

Theo and Lucy suggested that dyslexia and other literacy difficulties may be very similar, except that the dyslexia label is ultimately reserved for those who are really impacted by it, whose difficulties are more significant.

*Researcher: So, you would put yourself firmly at the end of someone who has dyslexia because that's kind of how you see yourself really.*

*Lucy: Yes.*

*Researcher: And it's more of a one or the other for you, rather than a continuum of...*

*Lucy: I suppose like sort of people who would have literacy sort of differences would be sort of there-ish.*

*Researcher: Okay, so they would be closer to the 'normal' end.*

*Lucy: Yes. They would be closer to that, I would say. In this half, or maybe it the third sort of quarter.*

### **The label does not give enough information**

Four participants (Theo, Moon, Charles and Oz) felt that using a single diagnostic term to describe their experiences was not always effective; in part because a lot of people do not fully understand dyslexia, and in part because the term is not sufficiently accurate or informative. Theo said that, he has dyslexia, and does not really know what it means, so it is likely that others do not understand it either:

*Theo: Well, if you don't give it a term as such, if you say 'they struggle with this' but if you have dyslexia a lot of people don't really know what it is a hundred percent. Because I don't really know what it is a hundred percent and I have it, so...*

*Researcher: Yeah, okay. So this [descriptive term] maybe is a bit easier to understand for people?*

*Theo: Yeah.*

Other participants similarly felt that they themselves had received limited explanations of dyslexia at the time of their diagnosis. Theo linked this to his perception of stigma and his initial belief that it equated to being stupid. Lucy was similarly left wanting a better explanation.

*Lucy: I don't really think so because they never talked to me about it, they were just talking to my mum while I was sitting on the floor going, 'Oh, okay'. ... Yeah, I don't really know what dyslexia like properly is because I was never really told about it.*

*Researcher: So do you still feel like that now?*

*Lucy: Yeah. I sort of... I like know a tiny bit I think, like roughly. But like I was never really told what it was.*

Moon pointed out that “*we tend to be a society that likes to label things*” as it makes us feel as though we understand them, but in reality, we cannot claim to understand everything. Moon felt that people often have misconceptions about dyslexia, and that it is an “*umbrella term*”, that does not describe individuals’ varied experiences of it. For example, three participants said how much they enjoyed reading, which might not typically be expected amongst a group of students with dyslexia.

*Moon: No, they are definitely not. They are individual people who have a personality.*

*Researcher: So obviously they are all individuals, but do you think the things that they find difficult due to their dyslexia are also all different? Or are they more...?*

*Moon: I think, yeah. For everyone it’s different. Everyone has got a different experience of dyslexia.*

Participants noted that a descriptive term is more accurate as a way of letting someone know about individual strengths and needs, however, a descriptive term would need to be personalised and individual, there is no one-size fits all.

Charles noted that there are lots of different types of dyslexia, so, although you might think you know how to help one person with dyslexia, that doesn’t mean it will work for another, and that, ultimately, being able to support the student is the most important thing.

*Charles: Having dyslexia used as a general term is good because it helps teachers and other people understand, 'okay, it's a learning difficulty'. But it would be, I'd say that with individual needs it's kind of neater than dyslexia itself. It would help teachers understand if it was broken down into different kind of sub-sections, I guess. ... ..If it was broken down into like different sub-sections then teachers would know, 'Okay, this is what I can do to help this student. This is what I can do to help this student. And this is what I can do to help this student'. So if there are different ways in which they find it easier to learn, then maybe the teacher can, like during lessons, can go and help those students just with... like put it into terms where they will be able to learn a little bit better.*

### **The label is necessary for support**

All of the participants believed that their diagnosis had been a necessary step in getting the support they needed. For all participants, this included exam access arrangements, and for some, included other forms of school support such as additional one-to-one or small-group teaching, and use of technology. Five participants had experienced not receiving any support prior to diagnosis. Charles and Theo both felt that their teachers were well aware of their difficulties, but Charles did not receive support until his diagnosis in year 11 and Theo did not get the help he needed until year 9, when he and his mother told the school about the diagnosis he received in primary school.

*Researcher: And in Year 7, although you weren't told the outcome of the test, are you aware if anything happened as a result of that? So you were flagged up as a maybe. Did you then get any extra support?*

*Charles: No, I didn't get any extra support or help. Because I wasn't told or my teachers weren't told. So it was just carrying on with how they normally did every lesson.*



Oz, on the other hand, felt that, although his teachers had tried to help him, they only fully knew what kind of help he needed after he had been diagnosed. However, it is unclear whether it was the label, or other information from the assessment that made this difference.

*Oz: Um, and we wanted to learn but we couldn't quite grasp it. But then they worked out why I didn't quite grasp it and they were able to deal with the problems.*

Moon and Charles, however, acknowledged that knowing a person has dyslexia does not necessarily equate to knowing what kind of support they need.

All of the participants in this sample had a family member with dyslexia, or similar difficulties, and four of them talked about their parents' own experiences of school. Parents had told their children that, having not been diagnosed, they were perceived by teachers in a negative way, and participants linked this with their parents' pursuit of diagnosis for their child:

*Moon: I always knew I had dyslexia. My dad is a head teacher and he had experience working with people, and my mum was dyslexic but it hadn't been diagnosed until she was much older so she didn't get any help at all at school, and she was kind of... labelled a failure. And then, in Year 6, they wanted me to have extra time for my SATs so they got me tested...*

Violet talked about a friend who was unable to access a dyslexia assessment, who she felt struggled even more than herself, but was not receiving the same level of support due to not having the opportunity to be assessed:

*Violet: Because she wants the test to make sure... to get the extra help because she doesn't get very much help at the moment. ... Yes, she's not diagnosed dyslexic. ... She's a lot worse than I am, yes. She just hasn't been tested.*

## Chapter 2

Charles and Lucy also reflected on differing levels of access to assessment, and how this may influence students' outcomes. Charles felt that those who do have dyslexia, but perhaps do not have access to the test, should still get support, and Lucy felt that anyone who is really struggling should receive the support they need.

*Lucy: But... and then it's sort of like people would get sort of the help easier. Because I suppose if you don't have dyslexia but you find a lot of things hard, people may just not be as inclined to give you help, which I think... it's not so much different. I think there should be the same help available if you have dyslexia or if you find it hard, if you find stuff hard. Because, in essence, you are still both finding stuff hard.*

On the other hand, Moon felt that it was unfair for people without diagnoses to be given extra time in classroom tests, as this is an unfair comparison.

*Moon: I understand that it's hard for them to give me extra time because it's within a lesson setting, but I could come back at lunch, I could... yeah. I don't think it... but if everybody gets extra time, I don't think that's fair but I've told the teachers and they said 'But you're still getting your extra time'. So...*

Although participants' experiences have led them to feel that their support is inextricably linked with having a label, ultimately, it seems that the participants' primary concern was around the support that they were receiving, rather than the label they were given.

*Violet: Yeah, I wouldn't really be fussed. As long as I still got the help I needed, I wouldn't care what it was called.*

*Lucy: Yeah. Because even though you haven't got this thing [dyslexia], you still find it hard. So in essence it's a very similar thing. And so you should still get the help for it if you...*

### **Understanding led to perseverance**

Four of the participants talked about how their label led to feelings of increased understanding about themselves and their school performance. Lucy and Theo talked about having a “*reason*” for the differences that they noticed between themselves and their peers, and Theo, Charles and Moon talked about how their dyslexia label had prevented them from labelling themselves as incapable. Moon predicted that, without her label and support, “*I'd have felt like I was a failure*”.

Charles reflected on how this lack of understanding could have a negative impact on an individuals' view of themselves and their ability to improve:

*Charles: So probably another disadvantage of that would be that an individual might not think they are good enough, if there wasn't the term dyslexia where you obviously help the individual know what's kind of... like what they need to do or why they struggle with certain tasks. So it would help them understand, even if the teacher didn't really, they would be like 'Oh, okay. I would be better off learning in this way. So if I can do it this way then I will be able to learn the material better'.*

All of the participants talked about how their own hard work and perseverance had been an important factor in their school success. Participants recognised that they need to challenge themselves more than other students, and some spoke specifically about how their label enabled them to persevere and “*just get on with it*”. Charles spoke about how his label changed his perspective of himself as a student and helped him to keep going:

*Charles: I felt quite dumb because I thought 'Oh, I'm clearly not as good as everybody else. I clearly can't read as well as everybody else. I'm clearly not as fast. I clearly can't spell very well compared to everybody else'. So I thought 'I am just really dumb. I can't do it'. Whereas, then when I found out that I did have dyslexia I was like 'I'm not dumb. I just need stuff to facilitate my learning and can help me in exams'. And that's how everything kind of changed my point of view. Because I wasn't... I thought I was just dumb or wasn't particularly gifted in education or... but then when I found out that I was dyslexic I was like 'Oh well, I can actually do this. I might not be dumb. It's just that I might not have received the help that I needed over the years'. And then you see, when I got the help in the exams, it helped me to get better grades.*

Oz, Theo, Charles and Moon talked about how they wanted to prove to themselves and others that they were capable and coping. Their response to their label was to make sure that they would succeed. Moon and Oz in particular reflected on their personalities and their strong desire to exceed others' expectations or prove their assumptions wrong. For example, Oz insisted on taking History, and Moon decided to learn Korean, when others suggested these might be too challenging.

*Oz: Yeah, then my reaction to being told I can't do something is to try and go out and do it. ... ..And I'm kind of fortunate that is my kind of stock reaction, to be vehemently told I can't do it. Um, that did bite me in the foot with having to pick History, even though I really enjoyed it, that was enough writing for me.*

## 2.4 Discussion

This research explored the perceptions of YP with, and without, LitD/D, alongside the experiences of YP who identified with the dyslexia label. The results were presented, in detail, in the context of each research question but will now be discussed in terms of the overarching themes.

Solvang (2007) identified both positive and negative aspects of dyslexia labelling based on his review of four Scandinavian studies analysing views of professionals and individuals with dyslexia, plus evidence from court cases. These aspects are considered in light of the current research in Table 17. The participants in this study contribute some additional and contrasting perspectives in relation to Solvang. It is clear that, for these participants, there were a number of advantages, as well as disadvantages, linked with the dyslexia label, but these were not clear-cut; whilst there were many consistencies in YP's experiences and perceptions, it is important to acknowledge inconsistencies, both within and across groups and individual participants. A number of themes contradict each other (see thematic maps, Figures 3 and 4), such as the idea that dyslexia is characterised by difficulties with literacy, but is also more than just literacy difficulties, and other participants' belief that dyslexia and literacy difficulties are the same.

Table 17.

*Comparison of Solvang's (2007) advantages and disadvantages of dyslexia labelling with those from the current research.*

<b>Positive aspects</b>	<b>Solvang's description</b>	<b>The current research</b>
De-stigmatisation	There can be an increase in self-esteem, stemming from ruling out alternative, negative explanations such as lazy or unintelligent.	This was the case for interview participants in this study, but participants felt that those negative judgements could still be applied to them and were still applied to those without access to diagnostic assessment.
Resource allocation	Parents perceived the diagnosis as leading to the distribution of educational resources.	This was also the experience of interview participants in this study, however, they did perceive some inequality in this. It may be counter to inclusive practice if the diagnosis is dependent on familial resource in the first place.
Social control conducted with a humanitarian face	Dyslexia can be seen as "a condition to be treated and not a social maladjustment to be punished" (p.86)	In this study, all participants saw dyslexia as untreatable but the label was consistently linked with receiving support.
<b>Negative aspects</b>		
The masking of the social	The focus is on the individual as the problem bearer, attention is taken away from family and school contexts.	Across all participants in this study, there was also a focus on dyslexia as a biological difference, within-child, with little consideration of environmental factors.
The potential for self-fulfillment	The label may lead to lowering expectations of the individual and self-fulfilling prophecies.	Interview participants recognised this as a possibility, but in some cases this also gave them the motivation to persevere.
Eradication of difference	The idea that dyslexia is something to be eradicated from society, rather than celebration of diversity and individual strengths and needs.	Interview participants in this study had positively accommodated their dyslexia label, accepted their difference and recognised their strengths.

A clear message came through from the interviews and from the survey participants with dyslexia that, however their difficulties are labelled, their struggle is real and has a significant impact on their school experiences. These participants described their difficulties as frustrating at times and, in some cases, impacting on self-confidence with

literacy, which fits with previous research findings (Burden & Burdett, 2007; Terras et al., 2009). Participants' perceptions of dyslexia as more significant than just literacy difficulties, and stemming from underlying cognitive factors, has similarly been found in others' accounts (e.g. Macdonald, 2010).

Despite perceived differences between those with and without dyslexia, interview participants did not see individuals with dyslexia as forming a homogeneous group. Participants had conflicting views of the label as having a helpful "weight" and "medical feel" that conveyed the significance of their difficulties, but, on the other hand, as an "umbrella term" that simplifies, at the cost of providing individualised information. Gibbs and Elliott (2015) argue that adopting essentialist beliefs may reduce uncertainty, but ultimately over-simplifies and misleads (p.325). Brante (2013) has similarly highlighted the heterogeneity behind the label and concluded that the label itself tells us nothing about intervention, and only assessment of individuals' strengths and needs can do this. She notes that "the weak spot in one student could be another student's resource" (p.84) making routine interventions based on diagnosis meaningless.

It was clear from the survey participants' responses to the vignettes that a range of judgements and assumptions were made based solely on a difference in label. Whilst some participants perceived a stigma associated with dyslexia, it was apparent that Colin was equally subject to stigmatising beliefs, without a diagnostic label. The more descriptive term used for Colin led participants to a range of conclusions, some of which could be detrimental (e.g. he struggles because he is unintelligent or idle) and others that may be beneficial (e.g. he can overcome his difficulties as there is no biological basis). This was the case for all groups, including those who identified themselves as having literacy difficulties (group B). Some of these participants thought that Colin would struggle less than Charlie, whereas others felt that his difficulties should be recognised as equally significant. There were several comments from participants in this group that cast negative

judgements on Colin's intelligence and implied that his difficulties, unlike Charlie's, were his own fault.

Interview participants also recognised, more explicitly, that their dyslexia label changed others' perceptions. They found that others were more understanding towards them post-diagnosis, and, for some, their dyslexia label replaced other negative labels (e.g. lazy/unintelligent), which some survey participants had applied to Colin. Whilst this change in perception made the experience of labelling positive for these participants, and participants in a range of other studies (e.g. Gibson & Kendall, 2010; Glazzard, 2010; Riddick, 2000), it is problematic for those who struggle with literacy and do not have a dyslexia diagnosis. Replacing one label with another, albeit more desirable label, may benefit those with access to this assessment, but improving understanding and inclusivity has the potential to change attitudes and benefit students like Colin as well. As Riddick (2000), and participants in this study highlighted, others can make negative judgements about individuals whether they have a specific label or not. For interview participants, it was apparent that the problem lay with the negative judgements, not the labels.

It is interesting how differently the two pupils in the vignettes were construed by participants having been primed towards the idea of labelling. Based solely on two short descriptions with one key difference, participants made a range of predictions and assumptions about the pupils' outcomes. Research demonstrates how stereotypes, expectations and assumptions can influence individuals to act in accordance with those assumptions by way of a "self-fulfilling prophecy" as mentioned by Oz (e.g. Jodrell, 2010; Jussim & Harber, 2005). This study demonstrates that the use of different labels can indeed lead people to certain conclusions.

Elliott and Gibbs (2008) argue that attempts to distinguish between dyslexia and other literacy difficulties is potentially discriminatory. As there is no meaningful way of distinguishing between them, or of choosing particular interventions, they argue that any



difference in resource allocation, following confirmation of a dyslexia label, is counter to inclusive practice. Furthermore, this current study suggests that differences in attitude, beliefs and expectations, based on labelling, are equally discriminatory and, as Elliott and Gibbs noted, perhaps most detrimental to those who do not seek or obtain the label.

Despite arguments that there is no difference in interventions to support individuals with dyslexia compared to other literacy difficulties (e.g. Elliott & Grigorenko, 2014a), interestingly, the participants in this study felt that the dyslexia label was key to specialist and increased support. However, some interview participants felt that this would not necessarily be justified, and that if any individual is struggling, they should receive support. Some survey participants indicated that Colin might be to blame for his difficulties (as there is no biological basis), somehow making him less worthy of additional support. Again, this highlights the potential for discrimination based on access to assessment and subsequent labels.

Further support for a diagnosis and label came from the interview participants who did not recall receiving sufficient support prior to receiving their label and experienced this as an essential step in obtaining support. Such experiences have also been reported in a number of others studies (e.g. Gibson & Kendall, 2010; Macdonald, 2010). In some cases, participants felt that their school was fully aware of their difficulties, yet support was only given when a dyslexia label was obtained/shared. However, the priority for participants was clearly the support that they received, not the label that was used.

In this sample, all but one of the interview participants had obtained a dyslexia label as a direct result of parental involvement. Results of the systematic review highlighted that parental understanding and support are an important protective factor for CYP's self-perceptions, regardless of label. The interview participants experienced this support, and their parents' pursuit of a label was one aspect of this. However, researchers have cautioned against the risk of support being provided only for those with "exceptional

parental support” (Brante, 2013, p.84), highlighting the potential for unequal access to support and therefore further potential discrimination based on labels.

Researchers have argued that changes in perceptions and support post-labelling are evidence of the need for early identification and diagnosis (e.g. Gibson & Kendall, 2010). However, an alternative argument can also be presented; that the problem lies with the negative judgements and lack of support that is experienced prior to labelling; that our education system is not yet inclusive enough. Participants wanted recognition of their difficulties, which came with their label, but arguably this could also have been achieved by teachers communicating their understanding and offering support, as some participants had experienced.

Almost all participants expressed beliefs that dyslexia has a biological basis, with very few recognising the impact of environmental factors. This belief is, in some ways, a misconception as dyslexia is understood to stem from a range of interacting factors (British Psychological Society, 2005). Whilst there is an element of heredity (Grigorenko, 2001), studies that have shown differences in the neurobiology of individuals with dyslexia are unable to assert whether such differences are a cause or effect of the literacy difficulties (Temple, 2002). The participants’ beliefs about the biological origin of dyslexia were linked with their view of dyslexia as being permanent, in contrast to other literacy difficulties (perceived as stemming from environmental or personality factors), which were seen as within one’s control and surmountable. Chapter one of this thesis discussed the self-efficacy and attributional styles of CYP with LitD/D, which are relevant to these themes. Participants did not feel that Charlie could overcome his dyslexia, even if the symptoms improved over time, whereas Colin was seen as more likely to beat his difficulties through “hard work”. This view was particularly prevalent amongst the survey participants with dyslexia (group A). This lack of internal sense of agency may have

implications for longer-term outcomes for this group, as self-efficacy is known to be an important predictor of learning and motivation (Zimmerman, 2000).

Although the interview participants also strongly felt that their dyslexia was permanent, they also had a clear sense of agency. The participants reflected on how they had begun to overcome some of their difficulties through developing coping strategies, utilising support from school, and hard work. The interview participants talked about their label as helping them to see that they could improve; although they might not be able to “cure” their dyslexia, it showed them that they are not failures, that there is a reason for their difficulty, which increased their self-belief and determination to succeed. Similarly to Gibson and Kendall's (2010) findings, some participants also wanted to challenge expectations and show of what they were capable. In apparent contrast to the survey participants with dyslexia, the interview participants associated their label with increased self-efficacy.

Research has suggested that individuals with dyslexia have a greater tendency towards making external attributions for their success, placing less emphasis on their own effort and more on factors outside of their control (Humphrey & Mullins, 2002a; Pasta et al., 2013), which may have been the case for the survey participants with dyslexia. However, this is not universal, and some individuals experience increased self-efficacy and determination linked with their label (e.g. participants in this study and in Gibson and Kendall, 2010).

Pupils with dyslexia who have a greater sense of agency may have better school performance (Burden & Burdett, 2005; Pasta et al., 2013). In this study, the participants who came for interview were achieving well, which may have been linked with their internal attributional styles as well as, perhaps, their willingness to come forward for interview. However, as academic data was not formally collected, it is not possible to

comment on any difference between the participants who only completed the survey and those who also came for interview.

### **Strengths and limitations**

A strength of this study is that it gathered rich qualitative data from individual interviews as well as data from a larger group of participants with a more diverse range of experiences. This research attended to the voices of YP currently in education, which adds to a literature base that is more often focused on the experiences of older groups. The interviews were designed to be person-centred and effectively utilised a technique from PCP to elicit views, prompt reflection and consider both the advantages and disadvantages of their dyslexia label. This approach fitted well with the use of TA, which enabled the researcher to work alongside participants to capture and summarise a wealth of data, looking at similarities and differences, confirmations and contradictions across datasets.

There was equal representation from both males and females, with and without dyslexia, which is a strength amongst a field of dyslexia research that often emphasises the male perspective, due to larger numbers of males with this label. However, there was limited cultural and ethnic diversity across participants, with only the views of White British students represented. This reflects the school population in which the study took place, but not the wider UK population.

Due to time limitations, a random selection of the survey data was sampled for analysis. It is hoped that the larger set of data may be analysed at a later stage in order to further refine results. Although the sample for this study was of a good size for qualitative research, it should be recognised that there is limited room for generalisation beyond the experiences of these students in a small number of schools. In particular, the interview data was ascertained from only six participants, who happened to have had quite similar educational experiences, and were achieving well in school.

A coding manual was not produced for the survey analysis; the analysis took place using NVivo (Appendix I) and, due to the volume of data, a coding manual would have been impractical. This may reduce replicability of this research. The analysis of survey or interview data did not include a secondary researcher to check for robustness and reduce bias. However, the researcher does not claim that this work is unbiased; the interpretation of data and creation of codes and themes was based on the researchers' own experiences and beliefs, which are discussed below.

### **Reflexivity**

My own experiences are acknowledged as having influenced the research as a whole. Throughout the process of designing the research, collecting, analysing and discussing data, I was aware of my own beliefs, values and experiences, which could influence or bias the results. I have experiences of dyslexia in my family and have seen myself how the dyslexia label can influence attitudes and behaviour. In addition, I was aware of how my role as a trainee EP influenced my interactions with the study participants, in particular, my behaviour as an interviewer; EPs are trained to search for opportunities for positive change, for example, by challenging the way a person thinks and positively reframing beliefs that may be interpreted as detrimental to the CYP. It was challenging to take on a more passive role, attempting to uncover people's thoughts, beliefs and experiences without influencing them. However, the interviews were designed to ask participants to consider both the advantages and disadvantages of the dyslexia label and used a specific PCP technique to facilitate this.

Reflecting on the design of the study and data collection methods, it would have been useful to conduct a pilot study in which participants were asked to compare the two vignettes with the last sentence (indicating the difference in label) was removed. This would have allowed exploration of whether some of the differences emerging between the two vignettes were still present.

### **Future research**

This study builds on the current literature base by exploring, via online survey, the views of individuals with literacy difficulties but no dyslexia label. However, this method of data collection limited the possibility of gaining rich and detailed accounts of their experiences. The first questions in the survey asked about experiences of dyslexia, rather than of literacy learning, meaning that the opportunity to explore the experiences of those with literacy difficulties, but no label were limited. Future research should focus on the voices of these YP, to explore their own experiences of literacy learning, access to support, others' perceptions and self-perceptions.

It would also be beneficial to carry out further research into the impact of how different attributional styles interact with participants' response to labelling, views of themselves and future educational attainment.

## **2.5 Implications and Conclusions**

The YP in this study perceived the label as having a powerful, and in many ways positive, influence over their school experiences. Participants were also aware of, and had experienced, potential disadvantage, but their priority concern was around the support that they received and the expectations and judgements of others, rather than the term used to describe their difficulties. The dyslexia label was perceived as being inextricably linked with receiving appropriate support. This is both problematic and potentially discriminatory for those who struggle with literacy but do not receive the label. There is a role for school staff and EPs in addressing this issue and ensuring that all children receive the support that they require to succeed, regardless of label.

The dyslexia label was also strongly perceived as being biological in origin, which was linked with the removal of any sense that familial or motivational factors were related to difficulties with literacy. This was experienced as beneficial for those participants with

the label, but was also associated with the belief that an individual without this “medical” label should be considered responsible for their difficulties and potentially judged negatively as a result. EPs and researchers should seek to clarify any misconceptions or misplaced assumptions stemming from the use of labels and work to reduce or avoid stigma for all children who struggle with literacy. Those working with CYP should strive for environments in which difficulties are accepted, without judgement or blame, and understanding and support are developed through seeking the views of the CYP. Teaching around attributions and beliefs of ability and intelligence may support CYP to develop adaptive attributional styles, which would be beneficial in terms of self-efficacy and achievement.

In order to determine what is best for each individual, it may be that professionals should adopt an “assessment for intervention rather than assessment for diagnosis” approach (Elliott & Grigorenko, 2014b, p.580) in order to clarify the type and level of support that is needed, and to consider development of academic skills as well as social and emotional needs. Working with CYP to develop a clear understanding of their difficulties may be beneficial in empowering them to explain this to others and take steps to managing and overcoming difficulties. EPs could be central in providing this through casework, consultation and training. Understanding more about how CYP make sense of their literacy struggles and identifying what helps them to persist and make progress is, therefore, a worthwhile endeavour, whether we support the existence of the dyslexia label, or not.





## Appendix A Literature Review: Search Terms and Strategy

### Dyslexia Terms:

dyslexi\*

“reading disabilit\*”

“reading difficult\*”

“reading impairment\*”

“literacy difficult\*”

“SpLD”

“specific learning”

“specific literacy”

### Self-perception Terms:

"self-esteem"

"self-perception"

"self-worth"

"self-efficacy"

worth\*

perception\*

esteem

efficacy

“self-concept”

### Attribution Terms:

attribution\*

“locus of control”

**Search Strategy:** Synonyms relating to dyslexia were separated with the command ‘OR’ to create a group of like-terms. The same was done for the self-perception terms to create a collection of dyslexia terms and a collection of self-perception terms. The command ‘AND’ was then used to search for titles that contained both a dyslexia term and a self-perception term. In order to extend the search to retrieve terms that may have different endings, asterisks were used at the end of words or phrases (e.g. dyslexi\* to include dyslexia and dyslexic). Quotation marks were used to search for complete phrases (e.g. “reading impairment\*”).



## Appendix B Literature Review: Examples of Excluded Papers

Total number of papers excluded due to each criterion:

(1) = 7

(2) = 11

(3) = 8

(4) = 3

Excluded paper	Reasoning
Burden & Burdett, 2007	It was decided that this paper measures perceptions of dyslexia, rather than the self-perceptions of individuals with dyslexia
Chapman, Tunmer, & Prochnow, 2000	The children in this study have not been identified as having literacy difficulties in any way. Children were grouped based on having 'negative' 'typical' or 'positive' academic self-concepts and the groups literacy skills were compared.
Gans, Kenny, & Ghany, 2003	It is unclear here whether 'learning difficulties' constitutes dyslexia or literacy difficulties, or whether it encompasses general learning difficulties.
Hornery, Seaton, Tracey, Craven, & Yeung, 2014	The purpose of this paper is to describe "the need for, and the structure and contents of, a reading program for children disadvantaged by reading difficulties" (p 131). With only 3 quotes from children given, there is not enough data to determine whether children's self-perceptions were appropriately measured; none of the quotes demonstrate an exploration of self-perceptions. Although pre-post measures were taken, they are not reported here.
Long, MacBlain, & MacBlain, 2007	Insufficient information is provided regarding the young person's self-perceptions. Both quantitative and qualitative measures are used, but neither are appropriately reported: no scores or statistics are provided for the pre and post self-concept rating and claims based on qualitative feedback are not backed-up by quotes from the young person.
Scanlon, McEnteggart, Barnes-Holmes, & Barnes-Holmes, 2014	Does measure attitudes towards the self in individuals with dyslexia, however this was not the focus of the study. The stated primary aim of the research is to explore the utility of a research procedure (IRAP) with a group who may experience challenges navigating the procedure, i.e. children who would struggle with the literacy aspect
Tunmer & Chapman, 2002	Does not focus on participants with dyslexia or literacy difficulties. This paper compares the self-perceptions of children based on their use of different word reading strategies.



## Appendix C Literature Review: Data Extraction Table

Author(s), date and country	Sample characteristics	Methods	Literacy measures / diagnosis	Self-perception measures	Other measures	Main Findings
(Alexander-Passe, 2006)  <b>England</b>	<b>N:</b> 19 36.84% female 63.16% male  <b>Age:</b> Mean academic year 11  <b>Ethnicity:</b> n/a	Self-report questionnaires - quantitative comparisons made between gender, depression, self-esteem and coping strategies for young people with dyslexia	Not stated how individuals were identified as having dyslexia. No information about specific areas of need or severity of symptoms.	CFSEI the culture-free self-esteem inventory (Form A) (Battle, 1992) CISS the coping inventory for stressful situations (adolescent version) (Endler & Parker, 1999)	BDI-II Beck depression inventory (Beck et al., 1996)	Lower general and academic self-esteem scores amongst females; typical scores amongst males. Types of coping strategies used impacted on scores. Males tended to use task-oriented coping strategies, whereas females used more emotional and avoidant strategies.
(Armstrong & Humphrey, 2009)  <b>England</b>	<b>N:</b> 20 25% female 75% male  <b>Age:</b> 16-19 years  <b>Ethnicity:</b> n/a	Qualitative data: individual semi-structured interviews and focus groups. Grounded theory using Lacey and Luff's (2001) analytical strategy.	Within previous year all CYP had been identified/confirmed as having dyslexia by the college SpLD diagnosis team.	All participants took part in individual semi-structured interviews, half the participants also took part in the focus group.		A theory is developed that conceptualises reactions to diagnosis on a continuum of resistance to accommodation. Resistance: not accepting the notion of dyslexia as part of the self. These participants held negative connotations of dyslexia. Accommodation: integrating dyslexia into the notion of the self.

## Appendix C

						Recognising positive as well as negative aspects of dyslexia.
(Burden & Burdett, 2005)  <b>England</b>	<b>N:</b> 50 100% male  <b>Age:</b> 11-16 years  <b>Ethnicity:</b> n/a	Interviews with quantitative data from self-report scales.	None. Pupil sourced from a school where admission criteria = longstanding learning difficulties despite average or above average intelligence	Specially constructed questionnaire: sense of self-efficacy and locus of control; learned helplessness	Specially constructed questionnaire: feelings of depression.	Majority of respondents did not demonstrate learned helplessness, or see themselves as being held back by their dyslexia. Pupils believed that effort is essential for success and would enable them to achieve.
(Burton, 2004)  <b>England</b>  Intervention	<b>N:</b> n/a 7 pupils in quantitative analysis  Gender n/a  <b>Age:</b> n/a (Years 7-9)  <b>Ethnicity:</b> n/a	Intervention study. Qualitative and quantitative (pre and post) data collected in order to evaluate self-esteem intervention.	None. Pupils were sourced from a resourced provision for dyslexia attached to a mainstream school.	The Five-Scale Test of Self-Esteem for Children (Pope, 1988)	Interviews	Pupils valued opportunities to talk/share difficulties with each other and became more confident in coping with dyslexia and school life. Quantitative findings for 7 participants: Mean increases in all 5 components, greatest in social.
(Casserly, 2013)  <b>Ireland</b>	<b>N:</b> 20 20% female, 80% male  <b>Age:</b> n/a (3 <sup>rd</sup> -4 <sup>th</sup> Class, approx. 8-9 years)  <b>Plus</b> 14 parents, 20 mainstream teachers, 20 support teachers	Qualitative data gathered using semi-structured interviews in a longitudinal multiple case study design over 4 years.	None. Pupils were selected from those entering a specialist provision for children with dyslexia.	Semi-structured interviews, structured interviews and self-report questionnaires.		Specialist placements had a range of socio-emotional benefits for young people with dyslexia, including increasing positive emotions, confidence and self-esteem. Self-esteem was perceived as a priority need for children upon entry to the specialist setting. Upon returning to mainstream, most children demonstrated continued improvements in self-esteem.

	and 10 specialist teachers  <b>Ethnicity:</b> n/a					
(Frederickson & Jacobs, 2001)  <b>England</b>	<b>N:</b> 40  20 children with dyslexia 15% female 85% male  20 children with no learning difficulties 55% female 45% male  <b>Age:</b> 8-11 years  <b>Ethnicity:</b> 95% White, 2.5% African Caribbean, 2.5% Asian	Quantitative data.  Comparisons made between reading performance, perceived competence and AtS of the CYP with dyslexia and TD groups.	Diagnosis not based on discrepancy model.  Dyslexia group - severe and persistent reading difficulties, which qualified them for individual teaching from the LA Support Service. Met definition set by BPS.  BAS II word reading test (Elliott, 1979)	Self-Perception Profile for Children (Harter, 1985). Items were read to participants and they marked their answers on the questionnaire.	Harter attribution elicitation procedure (Harter, 1985) - asks participants <i>why</i> they are like that (in relation to their answers to 6 academic competence Qs.)	CYP with dyslexia had lower perceived scholastic competence than typically achieving peers, but no difference in self-worth or any other subscales. CYP with dyslexia were more likely to make uncontrollable attributions, whereas typically achieving CYP were more likely to make controllable attributions. CYP with uncontrollable attributions had lower perceived scholastic competence even after controlling for reading scores. CYP with dyslexia had significantly lower perceived scholastic competence even when actual reading accuracy was controlled for.
(Gibson & Kendall, 2010)	<b>N:</b> 4 Gender n/a	Qualitative study - individual semi-structured	None. Participants had "recognised, diagnosed and disclosed	Two individual semi-structured interviews		There were consequences related to not have received diagnoses until college or university, feelings

## Appendix C

<b>England</b>	<b>Age:</b> n/a – first year of university <b>Ethnicity:</b> n/a	interviews. Interview schedule provided.	disability" - diagnoses of dyslexia  Two individual semi-structured interviews			of school failure and not having the appropriate support.
(Glazzard, 2010) <b>England</b>	<b>N:</b> 9 <b>Gender</b> n/a <b>Age:</b> 14-15 years <b>Ethnicity:</b> n/a	Qualitative study considering impact of teachers, peers and family on pupils' self-esteem. Semi-structured interviews (provided)	None. Participants were pupils in mainstream school who had an "official diagnosis of dyslexia"	Qualitative data from interviews		Peers, teachers and family contribute to the self-esteem of individuals with dyslexia. Having a positive diagnosis of dyslexia and owning the label is essential for creating a positive self-image. Feelings of learned helplessness prior to diagnosis were expressed.
(Humphrey, 2002) <b>England</b>  Forms part of a thesis*	<b>N:</b> 80 mainstream=23, provision=28, control=29  <b>Gender</b> n/a <b>Age:</b> 8-15 years <b>Ethnicity:</b> n/a	Quantitative data from self-report rating scales making comparisons between a groups of pupils with dyslexia in mainstream, in SpLD provisions and a control group.	None reported. Participants were either 'control', classed as having dyslexia and in mainstream or educated in a SpLD provision.	Lawrence's (1996) self-esteem checklist (adapted) of self-esteem related behaviours (teacher ratings of pupils)  Semantic differential method (Richmond, 1984) for pupil self-esteem - scale of 10 constructs with "I am" and "I would like to be"		Self-report: The mainstream group with dyslexia showed significantly lower levels of self-esteem across almost all domains in comparison to the control and, often, also in comparison to CYP in the SpLD provision.  Teacher-report: SpLD group had significantly higher levels of maladaptive behaviours than the control and, often, the mainstream dyslexia groups.
(Humphrey & Mullins, 2002a) <b>England</b>	<b>N:</b> 118 Dyslexia=61 Control=57  <b>Gender</b> n/a	Quantitative study measuring participants' AtS and personal constructs in	Inclusion criteria based on BDA definition of dyslexia and having a statement of SEN for dyslexia (or a note in	Measures of attributions: 8-item questionnaire asks participants to rank reasons for success or	Measures of personal constructs: laddering technique	In success scenarios, CYP with dyslexia were more likely to attribute their success to an external factor (teacher quality) and in failure scenarios, they were



Forms part of a thesis*	<b>Age:</b> 8-15 years <b>Ethnicity:</b> n/a	children with dyslexia and without in mainstream or SpLD provision.	lieu or awaiting assessment) and experiencing little or no other identified difficulty	failure in a fictional school test scenario (Bar-Tal & Darom, 1979).	(Hinkle, 1965) based on Kelly's repertory grid.	more likely to attribute their failure to internal factors (lack of interest, lack of effort, but not lack of ability). Author suggests this is protection of self-esteem.
(Humphrey & Mullins, 2002b)  <b>England</b>  Forms part of a thesis*	Qual. N:63 mainstream=28 provision=35  <b>Age:</b> 8-15 years  Quant. N:58 mainstream=19 provision=19 control=20  <b>Age:</b> 8-12 years  Gender n/a "majority male"  <b>Ethnicity:</b> n/a	Qualitative interview data collected from participants who had dyslexia in a mainstream setting and in a SpLD provision.  Quantitative data collected from participants with dyslexia in mainstream and in a provision and from a control group (TD).	Criteria for inclusion in either dyslexia group: Statement of SEN for dyslexia (or awaiting or a note in lieu) and little or no other identified difficulty.	Qualitative data: Semi-structured interview adapted from Riddick (1996)  Quantitative data: Self-description questionnaire (Marsh, 1990) - academic, non-academic and general self-concept.	Criteria for inclusion in control group: at least average intelligence (assessed by teacher judgement and any available test data) and not in any stage of the 5-stage intervention model for SEN	Differences in the self-concepts of CYP with and without dyslexia are mediated by educational provision. Quantitative data revealed significantly lower self-concept for those with dyslexia in a mainstream setting, but little difference between the control group and those in a provision. CYP in the provision were aware of differences with mainstream and recall negative experiences of being in mainstream.
(Lindeblad et al., 2016)  <b>Sweden</b>	<b>N:</b> 67 23% female 72% male	Quantitative data from self-report questionnaires for CYP with literacy	Children identified by teachers. Assessed for participation using word reading	Beck Youth Inventory (Beck et al., 2001) self-report	Beck Youth Inventory (Beck et al., 2001) self-report measures	In comparison to norm data, CYP did not depict negative self-image or show greater symptoms of depression or anxiety.

## Appendix C

	<b>Age:</b> 10-16 years <b>Ethnicity:</b> n/a	difficulties compared to norm-data representative of Swedish population.	(Laskedjor; Jacobson, 2001) and non-word reading (Oord; Svensson & Jacobson, 2001) tests, scoring at least 1 SD below age-equivalent	measures of self-concept.  Self-efficacy questionnaire, composed by authors	of depression and anxiety	Self-efficacy was generally high and CYP appeared to perceive 'few or very few limitations in their literacy ability' in contrast to the results of the literacy tests.
(Novita, 2016) <b>Germany (not clearly stated)</b>	<b>N:</b> 124 (60 with dyslexia, 64 without) 50% female 50% male  <b>Age:</b> 8-11 years  <b>Ethnicity:</b> n/a	Quantitative data analysis. Self-report measures used to make comparison between CYP with and without dyslexia.	Children with dyslexia diagnosed by psychologists using DSM-V or ICD-10  Culture Fair Intelligence Test-20 Revision, Weiss 2006)  Salzbug Reading and Writing Test (Landerl, Wimmer, and Moser 1997)	Self-Esteem Test for children and Adolescents, Schauder, 1991	Spence Children's Anxiety Scale, Spence, 1998	General levels of anxiety and self-esteem were not different for CYP with dyslexia, but were "impaired" in specific domains. CYP with dyslexia reported significantly higher generalised anxiety and lower school-based self-esteem (with weak-medium effect size). Control variables - all measures of reading and writing were good predictors of group membership (dyslexia/no dyslexia).
(Pasta et al., 2013) <b>Italy</b>	<b>N:</b> 108 42% female 58% male  3 groups: 38 with SpLD; 38 with no disability and matched achievement; 32 with no disability	Quantitative data ANOVAs and T-Tests  Comparison between self-reports of pupils in different groups.	SpLD diagnosis or with certification underway. 34/36 had literacy difficulties, 1 had numeracy difficulties and 3 had mixed. Achievement rated by class teacher based on Italian and maths	Attribution test for children from 4 to 11 (De Beni, Moè and Ravazzolo, 1998)	Student-Teacher Relationship Scale (Pianta, 2001)	CYP with SpLD emphasised the importance of effort in both success and failure scenarios, although to a lower degree than their peers in the control groups, especially the higher achieving group. The SpLD group placed more emphasis on "luck" and less on "ability". Overall, there was a correlation between achievement test performance and attributions -

	and “opposite” achievement  <b>Age:</b> years 2-3 (mean age = 8y3m)  <b>Ethnicity:</b> n/a		performance on a scale (low, med, high). Nationally Validated Standardized Achievement tests in Italian and Mathematics			more emphasis on effort was linked with better performance and more emphasis on the ease of the task was linked to poorer performance.
(Polychroni et al., 2006)  <b>Greece</b>	<b>N:</b> 242  32 with dyslexia 31% female 69% male  210 without diagnosis 43% female 57% male  <b>Age:</b> 10-12 years  <b>Ethnicity:</b> n/a	Quantitative comparison of children with and without dyslexia.  Self-report questionnaires.	Children with dyslexia had statements of dyslexia. Diagnosis based on assessment of intelligence, cognitive skills and literacy.	Students' perception of ability scale (SPAS; Boersma & Chapman, 1992).	Reading attitude scale (Teale, 1980)  Approached to learning inventory (Burnett & Proctor, 2002)	CYP in the dyslexia group reported lower self-concept regarding reading ability, penmanship, arithmetic, school satisfaction, general ability and total academic self-concept score, compared to the high and average/low achieving comparison groups. Both dyslexia and low/average groups reported higher levels of surface approach to learning than the high achievement group. Correlations found between surface approaches and lower academic self-concept.
(Saday Duman et al., 2017)	<b>N:</b> 150	Intervention study with waitlist control group.	Diagnosis of SpLD with IQ greater than	Piers-Harris Children’s Self-Concept Scale (PH)	Wechsler Intelligence Scale for Children	CYP with SpLD had significantly lower scores for total self-concept and in happiness, anxiety,

## Appendix C

<p><b>Turkey</b></p> <p>Intervention Study</p>	<p>50 with SpLD receiving intervention (22% female 78% male)</p> <p>50 with SpLD on waiting list (22% female 78% male)</p> <p>50 TD children 26% female 74% male</p> <p><b>Age:</b> 9-11 years</p> <p><b>Ethnicity:</b> n/a</p>	<p>Quantitative data from a range of self-report, parent-report and teacher-report data.</p>	<p>85. Diagnostic check – administered the Specific Learning Disorder (SLD) Test Battery (expanded from Korkmazlar, 1993) and WISC-R</p>		<p>Schedule for Affective Disorders and Schizophrenia (to exclude comorbid disorders)</p> <p>Child Behavior Checklist for Ages 6-18 (CBCL 6-18)</p> <p>Teacher's Report Form for Ages 6-18 (TRF 6-18; Achenbach et al.)</p>	<p>behaviour and intellectual and school status subscales. For the intervention group, there were significant improvements post intervention for total self-concept, happiness and anxiety and behaviour scores. The interaction with group, indicated that total score was significant. Parent and teacher report - CYP with SpLD scored significantly lower on competence subscales and higher on behaviour problem subscales. Compared with the wait-list control, the intervention group improved significantly more in measures of literacy skill.</p>
<p>(Singer, 2005)</p> <p><b>The Netherlands</b></p>	<p><b>N:</b> 60 40% female 60% male</p> <p><b>Age:</b> 9-12 years</p> <p><b>Ethnicity:</b> n/a</p>	<p>Qualitative data collected through individual, structured interviews. Analyses based on theoretical framework of cognitive– affective processes.</p>	<p>Average or above average IQ according to school reports, with formal diagnosis of dyslexia according to DSM-IV (discrepancy model).</p>	<p>Qualitative interview instrument, designed for the research. Began with a fictitious scenario in which a made up child is the only child in a class with dyslexia and is being teased.</p>	<p>Parent and Teacher report on Child Behavior Checklist - To confirm that participants had "no other major disabilities"</p>	<p>CYP explained their actions in responses to bullying. Adaptive and non-adaptive strategies, targeted at protecting self-esteem. Four profiles of inner logic are formed: 43% described internalising behaviours 16% described devoting themselves to self-improvement 18% described choosing to fight back 10% used the strategy of explaining dyslexia</p>

(Stampoltzis & Polychronopoulou, 2009)  <b>Greece</b>	<b>N:</b> 16 31% female 69% male  <b>Age:</b> 19-26 years (mean 22 years)  <b>Ethnicity:</b> n/a	Qualitative interview study.  Thematic analysis.	Childhood diagnosis by a multi-disciplinary team, including test of intellectual ability and achievement in literacy. Adult Dyslexia Checklist used to confirm that difficulties remained.	Individual in-depth interviews (40-50 minutes) exploring students' experience of dyslexia: past experiences, present difficulties at university and future goals/expectations.		Participants talked about their self-perceptions prior to diagnosis: feeling different, believing that they're not trying hard enough, not understanding the difficulties. 9/16 students reported lower self-esteem; feeling embarrassed and frustrated at school had impacted their self-concept.
(Terras et al., 2009)  <b>Scotland</b>	<b>N:</b> 68 35% female 65% male  <b>Age:</b> 8-16 years  <b>Ethnicity:</b> n/a	Quantitative data from self-report and parent-report. Analysis of correlations between questionnaires and comparison to norm data from the general population.	Sample taken from children assessed by the Dyslexia Institute Scotland and diagnosed with dyslexia on the basis of the discrepancy model. Dyslexia severity calculated using Turner's Dyslexia Index (1997).	Self- Perception Profile for Children (Harter, 1985) Child and parental versions plus the Teacher's Rating Scale of Child's Actual Behaviour (Harter, 1985), which was completed by parents.	Strengths and Difficulties Questionnaire (SDQ; Goodman, Meltzer & Bailey, 1998) parent version and child version  Understanding and Perceived Impact of Dyslexia Scale (parent and child)	Findings suggest link between dyslexia and internalising difficulties. No self-esteem deficit found. Perceived scholastic competence mean score for both parent and child ratings was significantly lower than norm data. Children and parents perceived dyslexia as impacting a range of socio-emotional and academic aspects of life. Relationships between higher self-esteem and more positive attitudes towards reading difficulties.



## Appendix D Literature Review: Quality Assessment

Qualitative Study	Armstrong & Humphrey, 2009	Burton, 2004	Casserly, 2013	Gibson & Kendall, 2010	Glazzard, 2010	Humphrey & Mullins, 2002b	Singer, 2005	Stampoltzis & Polychronopoulou, 2009
1. Clear statement of aims	YES	NO	YES	YES	YES	YES	YES	YES
2. Appropriate qualitative methodology	YES	YES	YES	YES	YES	YES	YES	YES
3. Appropriate design	YES	UTD	YES	YES	NO	NO	YES	YES
4. Recruitment and sample explained	NO	NO	NO	NO	NO	NO	YES	YES
5. Inclusion/ exclusion criteria	YES	NO	YES	YES	NO	YES	YES	YES
6. Self-perception terms considered	NO	YES	YES	NO	NO	YES	NO	NO
7. Appropriate data collection	YES	UTD	YES	YES	YES	YES	YES	YES
8. Participant-Researcher relationship considered	NO	NO	NO	NO	NO	NO	NO	NO
9. Ethical consideration	NO	NO	NO	YES	YES	NO	NO	NO
10. Rigorous data analysis	NO	NO	YES	NO	NO	YES	YES	NO
11. Clear findings	YES	YES	NO	YES	YES	NO	YES	YES
12. Valuable	YES	YES	YES	YES	YES	YES	YES	YES
<b>Total score out of 12</b>	<b>7</b>	<b>4</b>	<b>8</b>	<b>8</b>	<b>6</b>	<b>7</b>	<b>9</b>	<b>8</b>

YES = 1, NO = 0, N/A = Not applicable = 1, UTD = Unable to determine = 0

**Adapted Qualitative Research Checklist (Critical Appraisal Skills Programme, 2017)**

1. Was there a clear statement of the aims of the research? Is the relevance, importance and goal of the research clear?
2. Is a qualitative methodology appropriate? Does the methodology fit with the aim of the research?
3. Was the research design appropriate to address the aims of the research? Has the research design been justified?
4. Was the recruitment strategy and sample appropriate to the aims of the research? The characteristics of the sample should be described. It should be clear how participants were recruited.
5. \* Were inclusion and exclusion criteria for participants clearly specified and consistently applied? It should be clear why these participants were recruited, based on the aims of the study, and how participants were identified as having/not having literacy difficulties.
6. \* Have the authors considered their use of self-perceptions terms? Is it clear which types of self-perceptions are being looked at and what these mean?
7. Was the data collected in a way that addressed the research issue? Consider the setting, methods and data and how these are explained.
8. Has the relationship between the researcher and the participants been adequately considered? Has the research examined their own role in the research development, data collection and interpretation?
9. Have ethical issues been taken into consideration? Consider impact on participants, ethical approval and consent.
10. Was the data analysis sufficiently rigorous? There must be a description of the analytic process, including how themes were derived, presentation of quotes, quantity and quality of data.
11. Is there a clear statement of findings? Are findings explicitly stated, with adequate evidence of considering the credibility of findings, relation to the research question and evidence for and against conclusions.
12. How valuable is the research? The research is valuable if it contributes to existing knowledge and understanding, is related to current literature, identifies new areas for research and/or considers how the research findings can be applied.

\* Additionally added criteria





# Appendix D

<b>Quantitative Study</b>	Alexander-Passe, 2006	Burden & Burdett, 2005	Burton, 2004	Frederickson & Jacobs, 2001	Humphrey, 2002	Humphrey & Mullins, 2002a	Humphrey & Mullins, 2002b
1. Aims/ hypothesis clearly described	NO	YES	NO	YES	YES	YES	YES
2. Outcome measures clearly described	YES	YES	YES	YES	YES	YES	YES
3. Valid and reliable outcome measures	YES	NO	UTD	YES	YES	NO	YES
4. Self-perception measures appropriately administered	UTD	YES	UTD	YES	UTD	UTD	UTD
5. Sample clearly described	NO	YES	NO	YES	NO	NO	NO
6. Assessment of literacy levels	NO	NO	NO	YES	NO	NO	NO
7. Definition of self-perception terms that were measured	YES	YES	YES	YES	YES	YES	YES
8. Ps inclusion/ exclusion criteria	NO	YES	NO	YES	NO	YES	YES
9. Population and recruitment procedures	YES	YES	YES	NO	NO	NO	NO
10. Lost Ps described	N/A	N/A	UTD	N/A	N/A	N/A	N/A
11. Interventions clearly described	N/A	N/A	YES	N/A	N/A	N/A	N/A
12. Key confounders considered	NO	NO	NO	YES	NO	NO	NO
13. Findings clearly described	NO	YES	NO	YES	YES	NO	YES
14. P values reported	NO	N/A	NO	YES	YES	YES	NO
15. Blind to literacy levels	N/A	N/A	N/A	NO	NO	NO	NO
16. Appropriate statistical analysis	NO	YES	N/A	YES	YES	YES	NO
<b>TOTAL score out of 16</b>	<b>7</b>	<b>13</b>	<b>6</b>	<b>14</b>	<b>9</b>	<b>8</b>	<b>8</b>

<b>Quantitative Study (cont...)</b>	Lindeblad, Svensson, & Gustafson, 2016	Novita, 2016	Pasta, Mendola, Longobardi, Prino, & Gastaldi, 2013	Polychroni, Koukoura, & Anagnostou, 2006	Saday Duman, Öner, & Aysev, 2017	Terras, Thompson, & Minnis, 2009
1. Aims/ hypothesis clearly described	YES	YES	YES	YES	YES	YES
2. Outcome measures clearly described	YES	YES	YES	YES	YES	YES
3. Valid and reliable outcome measures	NO	UTD	UTD	YES	UTD	UTD
4. Self-perception measures appropriately administered	YES	NO	UTD	UTD	UTD	UTD
5. Sample clearly described	YES	NO	YES	YES	YES	YES
6. Assessment of literacy levels	YES	YES	YES	NO	YES	NO
7. Definitions of self-perception terms that were measured	YES	YES	YES	NO	NO	NO
8. Ps inclusion/ exclusion criteria	YES	YES	YES	YES	YES	YES
9. Population and recruitment procedures	YES	NO	NO	NO	NO	YES
10. Lost Ps described	N/A	N/A	N/A	N/A	UTD	YES
<b>11.</b> Interventions clearly described	N/A	N/A	N/A	N/A	NO	N/A
12. Key confounders considered	YES	YES	YES	YES	NO	YES
13. Findings clearly described	YES	YES	YES	YES	YES	YES
14. P values reported	NO	NO	NO	NO	NO	NO
15. Blind to literacy levels	N/A	UTD	UTD	UTD	UTD	UTD
16. Appropriate statistical analysis	YES	YES	YES	YES	YES	YES
<b>TOTAL score out of 16</b>	<b>14</b>	<b>10</b>	<b>11</b>	<b>10</b>	<b>7</b>	<b>10</b>

YES = 1, NO = 0, N/A = Not applicable = 1, UTD = Unable to determine = 0

### **Quantitative Checklist**

1. Are the aims of the study, and the hypothesis if applicable, clearly described?
2. Are the outcome measures clearly described?
3. Are ALL outcome measures used demonstrated to be accurate, reliable and valid?
4. Are self-perception measures appropriately administered given participants' difficulties with literacy? E.g. The reading level of the questionnaire was considered or the questionnaire was administered orally.
5. Are the characteristics of the sample clearly described? Must include number, age, gender and country.
6. Was there an assessment of literacy levels that was used to inform analyses? E.g. are any connections made between severity of symptoms and self-perceptions? Results of literacy assessment must be reported.
7. Were definitions provided for the self-perception terms that were measured? Were these used consistently and accurately? Did the measure reflect their definition of the term?
8. Were inclusion and exclusion criteria for participants clearly specified and consistently applied? Must include how participants were identified as having/not having literacy difficulties.
9. Are the source population and recruitment procedures described? The study must identify the source population for the research and explain how participants were recruited/selected from this population.
10. Was there appropriate description and consideration of any participants lost over time?
11. If this was an intervention study, was the intervention clearly described? The intervention should be able to be replicated.
12. Have the authors acknowledged and considered the key confounding variables and how these may impact the results of the research?
13. Were the findings relevant to the literature review clearly described?
14. Were actual probability values reported? I.e.  $p=0.022$  rather than  $p<0.05$ , except where  $p<0.001$
15. Were there attempts to blind investigators administering outcome measures to the literacy levels of the participants?
16. Were the statistical analyses used appropriate?

## Appendix E Ethics

### E.1 Setting Study information sheet and consent

#### EDUCATIONAL SETTING LETTER AND CONSENT (Version 4, 26-01-2018)

**Study Title:** From the perspective of young people, what factors precipitate, perpetuate or prevent the use of the dyslexia label?

**Researcher:** Rosa Gibby-Leversuch

**ERGO Study ID Number:** 25187

Dear [NAME],

I am a trainee educational psychologist from the university of Southampton, conducting a thesis research study as part of my postgraduate training, exploring the impact of the dyslexia label. I am contacting you because I would like to ask the young people in your setting to participate in my research.

There are two phases to the research:

- (i) An online survey, to be completed by young people (aged 13-25), with or without experiences of dyslexia.
- (ii) Face to face interviews with eight young people who have dyslexia (recruited from those who complete the online survey).

This letter includes information about the study that will help you make an informed decision about whether you give consent for it to take place in your setting, with your students.

#### **What is the purpose of the study?**

I am trying to find out more about what people think of dyslexia and the impact of having a diagnosis of dyslexia. This will mean asking a wide variety of people with a range of experiences about their views, there will not be any assessment of reading or writing.

#### **What does the online survey involve?**

The first part of the research would involve you sending out a letter to the parents/carers of all your students who are between the ages of 13 and 25. This letter would inform parents about the research and let them know how they can access the online survey if they want to see it. It will also give parent/carers the option to prevent their child from taking part in the research if they choose (if their child is under the age of 16). Once parents have been informed, I would like to come into your setting to facilitate classes of young people to complete the online survey (which will be done individually with computers and, where necessary, headphones).

The survey contains 12 questions and would take around 30-40 minutes to complete. Most students will be able to access this questionnaire independently and there will be an option to listen to, rather than read, the questions. However, some pupils may require support

## Appendix E

from a member of staff to write their answers (e.g. a scribe) or can choose to use a voice recorder to submit answers.

At the end of the survey, young people who do have dyslexia, will be asked if they are interested in being contacted about taking part in the second stage of the research.

All data that is collected will be kept completely confidential complying with data protection acts and university policies.

Young people who complete the survey will be able to be entered into a prize draw to win one of these Amazon.co.uk vouchers: 2 x £75, 2 x £ 45, 2 x £ 25.

### **What do the interviews involve?**

Any student who expressed an interest in being involved in the interview stage of the research will be contacted by the researcher at a later date. They (and their parents, if under 16) will be given further information about the process. If the student is under the age of 16, they will require parental consent to take part.

The second stage of the research is about the experiences of young people with dyslexia and what they believe are the advantages and disadvantages of the dyslexia label. To find out about this, I want to interview 8 young people with dyslexia (aged 13-25) using a technique from Personal Construct Psychology, which enables exploration of the pros and cons of a concept. The interview will be about an hour long and I would like it to take place in a private room in your setting, so that the young person can feel safe and secure. The interview will be audio recorded so that it can be transcribed later, when all information that could identify that young person will be removed or changed. All data that is collected will be kept completely confidential complying with data protection acts and university policies.

There are very few risks involved in taking part in this study and it is unlikely that there will be any stress associated with the research. The meeting will be an interactive process and will be adapted to best suit the individual, who can choose to skip any questions that they do not want to answer and will be able to stop the interview at any time.

All young people who attend an interview will be thanked with a £20 Amazon.co.uk voucher.

This research is organised through the School of Psychology in the University of Southampton.

If you have any further questions about the research project, please contact me at [rg11g15@soton.ac.uk](mailto:rg11g15@soton.ac.uk)

If you agree for this research to take place in your setting, with one (or more) of your students, please return the consent form attached.

Yours sincerely,

Rosa Gibby-Leversuch

*Trainee Educational Psychologist*

If you have any concerns or complaints related to the current study, please contact the Chair of the Ethics Committee: School of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone Number: (023) 80593856. Email: [fshs-rso@soton.ac.uk](mailto:fshs-rso@soton.ac.uk)

### Consent Form

Please initial the boxes and sign below to indicate your consent for this research to be carried out in your setting with one (or more) of your students.

I have read and understood the information about the purpose of this study and its procedures

☐

I give consent my students to participate in this research, provided that they, (and their parent(s) if under the age of 16), give consent

☐

I agree for the online surveys and any research interview(s) to take place in my setting, at a mutually agreeable time

☐

I understand that participation is voluntary and that the students can withdraw their consent at any time, without any consequence to them

☐

Name: .....

Role: .....

Signed: .....

Date: .....

## E.2 Sample study information: survey

### PARENTAL LETTER, OPT-OUT AND INFORMATION FOR QUESTIONNAIRE (Version 5, 26-01-2018)

**Study Title:** From the perspective of young people, what factors precipitate, perpetuate or prevent the use of the dyslexia label?

**Researcher:** Rosa Gibby-Leversuch

**ERGO Study ID Number:** 25187

Dear [Parent],

I am a trainee educational psychologist from the University of Southampton, conducting a thesis research study as part of my postgraduate training, which looks at people's views of dyslexia. I have arranged with [Name], the [SENCo/Head Teacher] at your child's school to conduct an online survey with students in your child's class. This will involve them spending a lesson being introduced to the research and being asked to complete 12 questions in an online survey, which asks them about their personal views on dyslexia,

## Appendix E

what it is and what it means for people. This will **not** involve any assessment of your child's reading and writing. Please read the fact sheet attached, for further information about the research and what your child will experience if they take part.

If your child has dyslexia, the survey will also ask if they are interested in being contacted about taking part in a face to face interview about their experiences. But, your child will **not** take part in this interview without you providing further parental consent.

If your child is under the age of 16, and you do **not** wish them to complete the online survey and be involved in the research, please return the attached opt-out form to your child's school by [date].

If you are interested in seeing the online survey, you can find it at [[hyperlink to survey](#)] and you will need the password [**password**] to access the survey.

Everyone who takes part in the survey will have the opportunity to be entered in to a prize draw to win one of these Amazon.co.uk vouchers:

**2 x £75**

**2 x £ 45**

**2 x £ 25**

Yours sincerely,

Rosa Gibby-Leversuch  
*Trainee Educational Psychologist*  
email: [rg11g15@soton.ac.uk](mailto:rg11g15@soton.ac.uk)

-----  
-----  
I **do not** want my child to take part in the online survey for dyslexia research.

Child's Name: \_\_\_\_\_ Parent/Carer Name: \_\_\_\_\_

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

## FACT SHEET

### Why are we doing this research?

We are trying to find out more about people's views of dyslexia and we want to listen to your child's thoughts about this. The survey is about people's views of dyslexia and what they understand dyslexia to be. It is not about how good they are at reading and writing.

### Why has my child been invited to take part?

All of the young people (aged 13-25) in your child's school are being invited to complete this survey. We would like to hear about the views of a whole range of people. You have received this letter and fact sheet because your child's school expressed an interest in the research and agreed for it to be carried out in their school.

### Does my child have to take part?

No, it is up to you and your child. Before you make this decision, you can ask the researcher to answer any questions that you might have. If you would be happy for your child to take part, you don't need to do anything. If you prefer that child is not involved in



the research, you should return the opt-out form at the bottom of the letter to the school, by the given date. Before anyone completes the survey, your child will be asked to read some information about it and to give consent/assent to taking part. If your child changes their mind half way through, they can close the survey webpage. Please note that once the survey is submitted, the data cannot be withdrawn because it will be anonymised.

### **What will happen if my child takes part?**

If your child agrees take part, they will complete a survey that has 12 questions. All the questions have an audio file attached, so there is an option to listen to the questions rather than read them. If your child needs help with the writing to complete, someone at school will help them, or they can choose to record their answers onto an audio recorder. There are no right or wrong answers, we just want to find out about people's views. Your child can skip any questions he/she doesn't want to answer.

### **Will anybody find out what is said?**

Nobody else will find out how each person answers the questions because once the survey is submitted, the data will be anonymised. If your child voice-records their answers, they may be identifiable, but their data will be stored and treated confidentially. All voice-recorded questionnaires will be transcribed (by a transcriber who will understand that this data is confidential) and the transcription will not include any information that could identify your child. Once transcribed, the audio recording will be securely destroyed.

However, if you or your child would like to be entered into the prize draw to win an Amazon.co.uk voucher, an email address will need to be provided at the end of the questionnaire. There are six vouchers available: 2 x £75, 2 x £45 and 2 x £25.

If your child has a diagnosis of dyslexia, they will also be asked if they are interested in being contacted about taking part in a face to face interview about their experiences. This will also require providing their name and email address at the end of the survey. But, if your child is under 16, they will **not** take part in this interview without you providing further parental consent. If an email address and/or name is provided, these will be stored securely and separately from their answers to the survey.

### **What are the benefits of taking part?**

There may be no direct benefit to your child by taking part in this research but there might be benefit to other people. The research will help people that work with schools to understand how people think and feel about dyslexia.

### **What happens when the study is finished?**

When the study is finished, I will look at all the information that we have heard from people and put it together into a report. I will share this information with other people so they can find out more about dyslexia, but I will never share your, or your child's name or any other information that could identify you or them.

### **What if there's a problem or something goes wrong?**

There are very few risks involved in taking part in this study and it is unlikely that there will be any stress associated with the research. If you are worried about anything you can contact the research, and you, or your child can decide you want to stop at any time without any consequences to you or your child.

### **Who is organising and funding the research?**

## Appendix E

The research is organised through the School of Psychology in the University of Southampton and it is funded by the University of Southampton.

### **Who has reviewed this study?**

The study has been reviewed by the ethics committee at the University of Southampton. They make sure that the research is fair. They have agreed that they are happy that this research is ethical and safe to do.

### **What happens if I want to find out more?**

You can ask me any questions you have now or you can contact me at [rg11g15@soton.ac.uk](mailto:rg11g15@soton.ac.uk)

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email [fshs-rso@soton.ac.uk](mailto:fshs-rso@soton.ac.uk)

## **E.3 Sample study information and consent: Interviews**

### **PARENT LETTER FOR INTERVIEW (Version 4, 26-01-2018)**

**Study Title:** From the perspective of young people, what factors precipitate, perpetuate or prevent the use of the dyslexia label?

**Researcher:** Rosa Gibby-Leversuch

**ERGO Study ID Number:** 25187

Dear [Name],

I am a trainee educational psychologist from the University of Southampton, conducting a thesis research study as part of my postgraduate training, which looks at young people's views of dyslexia. I am hoping to meet with young people, like your [son/daughter], to explore what they believe it means to be dyslexic and what they see as the advantages and disadvantages of having a diagnosis of dyslexia. The study is not about your child's ability to read or write.

This is a two-part study and, as you will be aware, your child has already participated in the first part of the research, which was an online survey about dyslexia that your child completed at school. At the end of the survey, your child was asked if they would be interested in taking part in the face to face interview.

I am writing to you because your child indicated that he/she has a diagnosis of dyslexia and would be interested in taking part. Please read the information sheet for the research attached to find out more information about what the research is about; why your child has been chosen and what would happen if your child took part.

Yours sincerely,

Rosa Gibby-Leversuch.

After reading the information sheet, if you have any questions please contact me:

[rg11g15@soton.ac.uk](mailto:rg11g15@soton.ac.uk)

If you have any concerns or complaints related to the current study, please contact the Chair of the Ethics Committee.

Address: School of Psychology, University of Southampton, Southampton, SO17 1BJ

Phone Number: (023) 8059 3856

Email: [fshs-rso@soton.ac.uk](mailto:fshs-rso@soton.ac.uk)

### **PARENT INFORMATION SHEET FOR INTERVIEW (Version 4, 26-01-2018)**

**Study Title:** From the perspective of young people, what factors precipitate, perpetuate or prevent the use of the dyslexia label?

**Researcher:** Rosa Gibby-Leversuch

**ERGO Study ID Number:** 25187

I am asking if you would like your child to take part in a research project to find out more about his/her experience of dyslexia. Before you decide if you want your child to join in, it is important to understand why the research is being done and what it will involve. So please consider this information sheet carefully. **If you decide you would like your child to participate in this study, you will need to sign the attached consent form and return it to the researcher in the stamped, addressed envelope.**

#### **What is the research about?**

I am a trainee Educational Psychologist from the University of Southampton. As part of my Doctoral Thesis research I am trying to find out more about young people's experiences of dyslexia and I want to listen to your child's thoughts about this. The study is about people's experiences of being told that they have dyslexia and what the *label* means. It is not about how good they are at reading and writing; your child will not need to do any reading or writing (except to fill out the assent form) and there will not be any tests.

#### **Why has my child been invited to take part?**

You will have previously received a letter from your child's school informing you about an online dyslexia survey that all of the pupils over the age of 13 were being asked to complete. Your child chose to complete that online survey and indicated that he/she has dyslexia and would also be interested in taking part in a face to face interview.

### **Does my child have to take part?**

No, it is up to you. Before you make this decision, you can ask the researcher to answer any questions that you might have. The final decision about taking part is up to you and your child. If you think you might want your child to take part, you can fill out the form at the end of this information sheet. If you give consent for your child to be in the study, it will be up to your child to decide, on the day of the interview, whether or not they wish to take part. You will be able to keep this information sheet and if you agree for your child to take part, they can stop at any time, without giving a reason and you can also withdraw your consent at any time, without your rights being affected.

### **What will happen if my child takes part?**

If you consent to your child's participation in the study, your child will be invited to a meeting with me, the researcher. We will arrange a mutually convenient location for the meeting, probably at your child's school. In the meeting, I will ask your child some questions about his/her experiences of dyslexia and what he/she thinks dyslexia is. Then we will do an activity where we explore the advantages and disadvantages of having a diagnosis of dyslexia. Your child will be assured that he/she can skip any questions he/she doesn't want to answer. The meeting will be audio-recorded so that it can be transcribed. The audio recording will be transferred onto a password-protected computer before being transcribed. As soon as it is transcribed, the audio recording will be deleted. A pseudonym will be used in the transcription and any other information that could identify your child will be changed. The data from the meeting will not be used for any purposes other than this research.

The only situation in which anyone else would find out what your child said in the meeting, would be if he/she told me something that indicated your child was at serious risk of harming themselves or others, in which case I would have to share that information without permission, in order to keep your child safe. If I did this, I would discuss it with your child first.

Once data is collected, it will be kept completely confidential complying with data protection acts and university policies. All data collected will be kept on a password protected computer and will only be accessible by the research team. Identifying information will be stored separately from the experimental data. If results are publicised they will not contain any information that may lead to your child's identification. Transcripts will be anonymised and the recordings from the meeting will be deleted so there will be no information which can link the data with your child.

### **What are the benefits of taking part?**

There may be no direct benefit to your child from taking part in this research but there might be benefit to other young people. The research will help people that work with schools to understand how young people think and feel about dyslexia.

If your child attends an interview, he/she will receive a £20 Amazon.co.uk voucher as a thank you for their time and participation in the research.

### **What happens when the study is finished?**

When the study is finished, I will look at all the information that I have heard from young people and put it together into a report. I will share this information with other people so they can find out more about dyslexia, but I will never share your child's name or any other information that will let people know who you are.

### **Are there any risks involved?**

There are very few risks involved in taking part in this study and it is unlikely that there will be a problem. The meeting will be an interactive process and will be adapted to best suit your child. The meeting will have a relaxed atmosphere and be held somewhere your child feels comfortable. Your child may feel uncomfortable about the presence of the audio recorder. If this is the case the researcher will allow them to see how the audio recorder works and also give them the opportunity to start and stop the recording. This will make them feel more in control.

If your child is worried about anything, he/she can decide to stop or not take part. If you have any other questions or concerns, please contact me.

If this study raises any issues for you or your child, you can contact these resources:

Dyslexia Action: <http://www.dyslexiaaction.org.uk/get-help> or 0300 303 8840

Child Line: <https://www.childline.org.uk/> or 0800 1111

If you want further support, you can contact the chair of the ethics committee: Psychology, University of Southampton, SO17 1BJ, UK. Phone: +44 (0)23 8059 3856, email [fshs-rso@soton.ac.uk](mailto:fshs-rso@soton.ac.uk)

### **What happens if I change my mind?**

You are free to change your mind and decide to withdraw your child from the research without any consequences and this will not affect your legal rights. Your child can also decide to withdraw without any consequences to them. Your child's data can be withdrawn at any point before the end of January 2018. In January 2018, interview data will be transcribed and anonymised and will no longer be able to be withdrawn.

### **Who is organising and funding the research?**

The research is organised through the School of Psychology in the University of Southampton and it is funded by the University of Southampton.

### **Who has reviewed this study?**

The study has been reviewed by the ethics committee at the University of Southampton.

Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email [fshs-rso@soton.ac.uk](mailto:fshs-rso@soton.ac.uk)

### **What happens if I want to find out more?**

If you have any further questions, please contact me at [rg11g15@soton.ac.uk](mailto:rg11g15@soton.ac.uk)

**Please see the consent form on the additional sheet. If you decide to consent to your child participating in the research, please discuss the study with your child, then sign the consent form and return it via email or in the stamped, addressed envelope.**

Yours Sincerely,

Rosa Gibby-Leversuch,

*Trainee Educational Psychologist*

*University of Southampton*

**PARENT CONSENT FORM FOR INTERVIEW (Version 4, 26-01-2018)**

**Study Title:** From the perspective of young people, what factors precipitate, perpetuate or prevent the use of the dyslexia label?

**Researcher:** Rosa Gibby-Leversuch

**ERGO Study ID Number:** 25187

If you are happy for your child to take part in this study, please initial the statements that you agree with and sign your name below.

I have read and understood the information sheet (dated 26-01-2018, version no. 4) and have had the opportunity to ask questions about the study

☐

I understand that my child will be involved in a study that aims to explore students' experiences of school and support that they receive at school

☐

I understand that my child will be invited to meet with the researcher for up to an hour to discuss their views and experiences of dyslexia

☐

I understand that the conversations that my child has with the researcher during this meeting will be electronically recorded and that recordings will be destroyed as soon as they are transcribed.

☐

I agree to my child taking part in the above research project and agree for their data to be used for the purpose of this study

☐

I have spoken to my child about the study and they agree with my decision to give permission for them to participate

☐

I understand my child's participation is voluntary and they may withdraw at any time without their legal rights being affected

☐

Name of child (print name) .....

Name of parent/carer (print name) .....

Signature of parent/carer .....

Date.....

## E.4 Interview debrief

### DEBRIEFING STATEMENT (Version 2, 27-04-2017)

*(Verbal and written – a copy will be given to the participant, the researcher will also read it with the participant)*

**Study Title:** From the perspective of parents and young people, what factors precipitate, perpetuate or prevent the use of the dyslexia label?

**Researcher:** Rosa Gibby-Leversuch

**ERGO Study ID Number:** 25187

Thank you again for taking part in my study. The aim of this research was to hear your views about dyslexia and your diagnosis. The information you gave me will help people to understand how young people experience dyslexia and what it means to have a dyslexia label. As I said at the beginning, the results of the study will not include your real name or anything else to identify you. If you want, you can choose a fake name to be used in the report. You will be given a copy of this summary to take home. I don't know what the results of the study will be yet, but you will be offered a summary of the findings from the whole study, when it is finished.

**If you have any further questions, please contact me by email:**

[rgl1q15@soton.ac.uk](mailto:rgl1q15@soton.ac.uk)

It was great to meet you.

*Rosa Gibby-Leversuch*

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email [fshs-rso@soton.ac.uk](mailto:fshs-rso@soton.ac.uk)

If you feel concerned or worried about the things we have talked about, you can also find help here:

Dyslexia Action: <http://www.dyslexiaaction.org.uk/get-help> or 0300 303 8840

Child Line: <https://www.childline.org.uk/> or 0800 1111

E.5 Ethics approval

You are logged in as Rosa Gibby-Leversuch (Log out)

Accessibility Tools

ERGO II

Ethics and Research Governance Online

UNIVERSITY OF  
Southampton

Home

Submissions

31699 - From the perspective of parents and young people, what factors precipitate, perpetuate or prevent the use of the dyslexia label? (Amendment 3)

Submission Overview

Submission Questionnaire

Attachments

History

Details

Status

Approved

Category

Category

A

The end date for this study is currently 06 March 2018

Request extension

If you are making any other changes to your study please create an amendment using the button below.



## Appendix F Online Survey

The vignettes, along with the whole survey, were designed to be easy to read, given that many participants would have reading difficulties. The two vignettes had equivalent numbers of words (47/46), sentences (5) and average number of characters per word (4). The Flesch reading ease analysis (conducted at [https://www.online-utility.org/english/readability\\_test\\_and\\_improve.jsp](https://www.online-utility.org/english/readability_test_and_improve.jsp)), which gives a score between 1 and 100 with higher scores reflecting more easy-to-read material, suggested that both vignettes were relatively easy to read (scores 89.29 and 73.09) and should be readable by an individual aged 10-11 years old.

### **SURVEY:**

Your age: 13-99

Choose a category that fits you:

Young Person:

- (a) Young person with dyslexia
- (b) Young person who struggles with literacy
- (c) Young person with no literacy difficulties

Are you: male/female/other

1. What is your experience of dyslexia?
2. What do you think dyslexia is? There are no right or wrong answers, just describe your thoughts.
3. Why do you think some people have dyslexia and others do not?

Appendix F

Please read about these two young people:

Charlie	Colin
Charlie is 13 years old. Over the years, he has made slow progress with reading and spelling. He reads slowly and he finds it hard to read new words. Charlie finds lots of things hard. He has been told, by someone at school, that he has dyslexia.	Colin is 13 years old, he finds school hard. He has been struggling with literacy for a number of years. He makes slow progress with reading and spelling at school. He finds learning new words very hard. People at Colin's school say he has literacy difficulties.

4. Compare Charlie and Colin. What kind of help do you think each person would get?
5. What do you think are the differences between Charlie's difficulties and Colin's difficulties?
6. What kinds of grades do you think Charlie and Colin will get?
7. What do you think Charlie and Colin's lives will be like? E.g. relationships, jobs, happiness, success.
8. How likely is it that Charlie will beat his difficulties and no longer be dyslexic?
- 0 = Not likely10 = Very likely
- 0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
9. How likely is it that Colin will beat his difficulties and no longer find literacy so hard?
- 0 = Not likely10 = Very likely
- 0-----1-----2-----3-----4-----5-----6-----7-----8-----9-----10
10. What would it take for Charlie to beat his dyslexia?
11. What would it take for Colin to beat his literacy difficulties?

Thank you for answering the questions.

If you want to enter the prize draw to win an Amazon.co.uk voucher, please give your email address: \_\_\_\_\_

If you have dyslexia, and you want to meet with the researcher to talk more about your views, please give your name and email address: \_\_\_\_\_

**Followed by debrief:**

Thank you very much for taking part in this survey, you have contributed to a thesis research project and I am very grateful.

Your data will be stored anonymously and used as part of a research project looking at individuals' experiences and understanding of dyslexia and the impact of having a dyslexia diagnosis.

If you have any questions about this research, please contact me at: [rg11g15@soton.ac.uk](mailto:rg11g15@soton.ac.uk)

We have tried to make sure that this survey does not cause any distress. However, it is possible that you have some concerns, and support is available. If participating in this study raises any issues for you, you can contact these resources:

Dyslexia Action: <http://www.dyslexiaaction.org.uk/get-help> or 0300 303 8840

Child Line: <https://www.childline.org.uk/> or 0800 1111

You may also wish to discuss any negative feelings with a trusted adult at school or at home, this could be the school SENCO, a Tutor, Teacher or Parent.

If you have provided an email address for the prize draw, it will be stored separately from your data once data collection is complete (estimated June 2017). Then you will be entered into a random draw with the opportunity to win one of six Amazon.co.uk vouchers: 2 x £75, 2 x £45 and 2 x £25. If you are a winner, your voucher will be emailed to you.

If you have provided an email address because you are interested in taking part in a face to face interview, it will be stored separately from your data once data collection is complete (estimated June 2017). You will then be contacted by the researcher and given further information about the face to face interviews, so that you can decide whether you would like to take part.

Thank you,

Rosa Gibby-Leversuch, *Trainee Educational Psychologist*

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3856, email [fshs-rso@soton.ac.uk](mailto:fshs-rso@soton.ac.uk)



## Appendix G Interview Schedule

*This is a guide for the interviewer; each participant's experiences and interests will shape the conversation in a unique way.*

"I would like to begin by discussing what dyslexia is, and what it means to be dyslexic, from your perspective. Let's start with your understanding of what dyslexia is; how would you describe dyslexia to a person who had never heard of it before?"

"Has anyone ever tested you for dyslexia?" or "Who told you that you have dyslexia and how did they find out?"

"What have you, or anyone else, done as a result of the diagnosis/identification?"

"Okay, let's talk about what it means to be dyslexic. I know that an assessor has given you a diagnosis of dyslexia, but, regardless of that, would you consider yourself to have dyslexia?"

"If you wanted to describe yourself to someone, would you describe yourself as dyslexic, or is there another term you prefer to use?"

"If you weren't dyslexic (or other term), what would you be?" - Create construct with two poles:

Dyslexia -----?????

Explore these constructs further and what it means to have dyslexia vs. not have dyslexia.

"Now I would like us to think about the pros and cons of term dyslexia, this is not about your literacy skills, but just about the way that they are described. We are going to imagine two different worlds, one where you find X and Y difficult and people describe you as having dyslexia. The other is world where you still find X and Y difficult, but you are no longer described as having dyslexia. So imagine that a dyslexia teacher came along tomorrow and assessed you, and told you that now you do/don't meet the criteria for dyslexia. In one world you have dyslexia and in the other world you are a person who finds literacy difficult."

## Appendix G

Create ABC model (B) with two poles:

Dyslexia -----Literacy Difficulties

Explore the advantages of the dyslexia label and advantages of having the label taken away (using a description instead, e.g. “literacy difficulties”)

Create ABC model (C) with two poles:

Literacy Difficulties -----Dyslexia

Explore the disadvantages of the dyslexia label and disadvantages of having the label taken away.

Prompt Questions for ABC modelling:

“In this world...

“How would you interpret that?”

“How would you feel?”

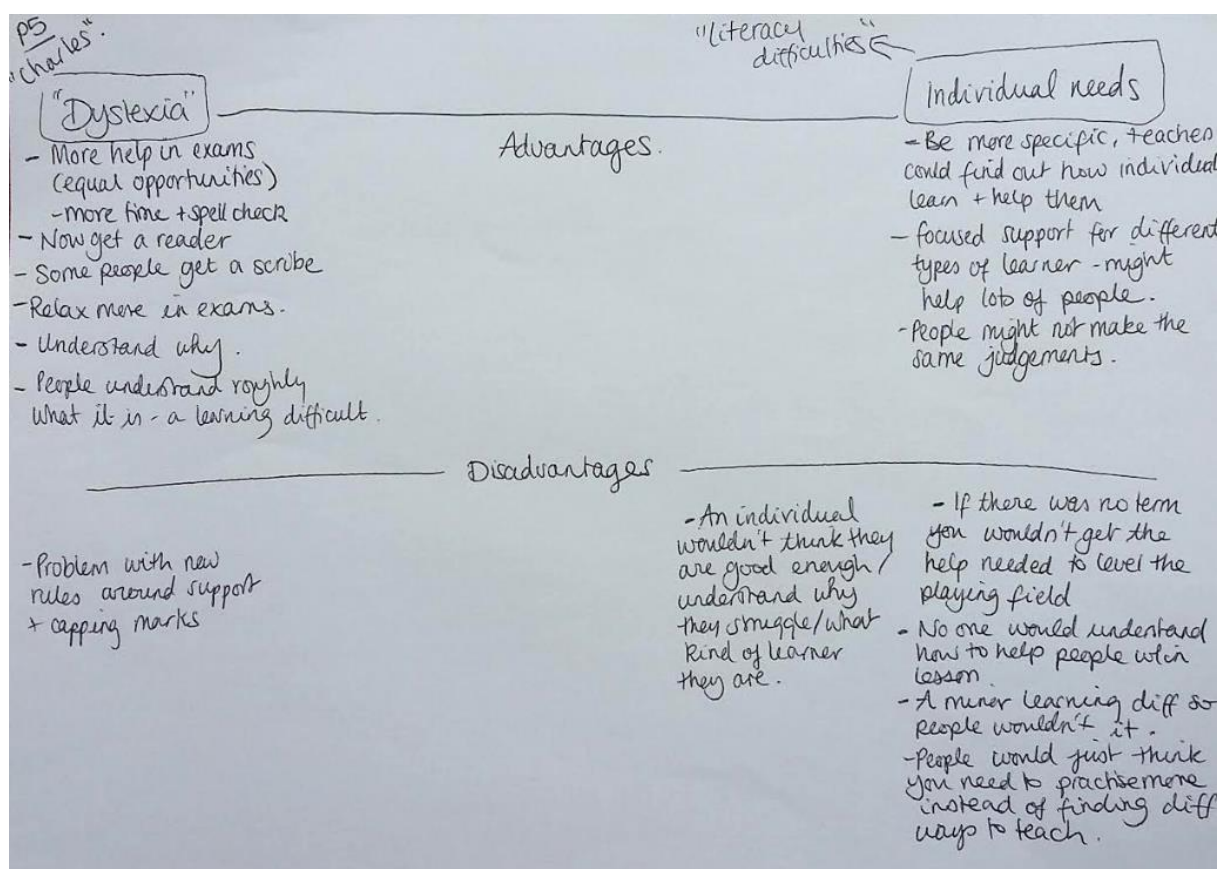
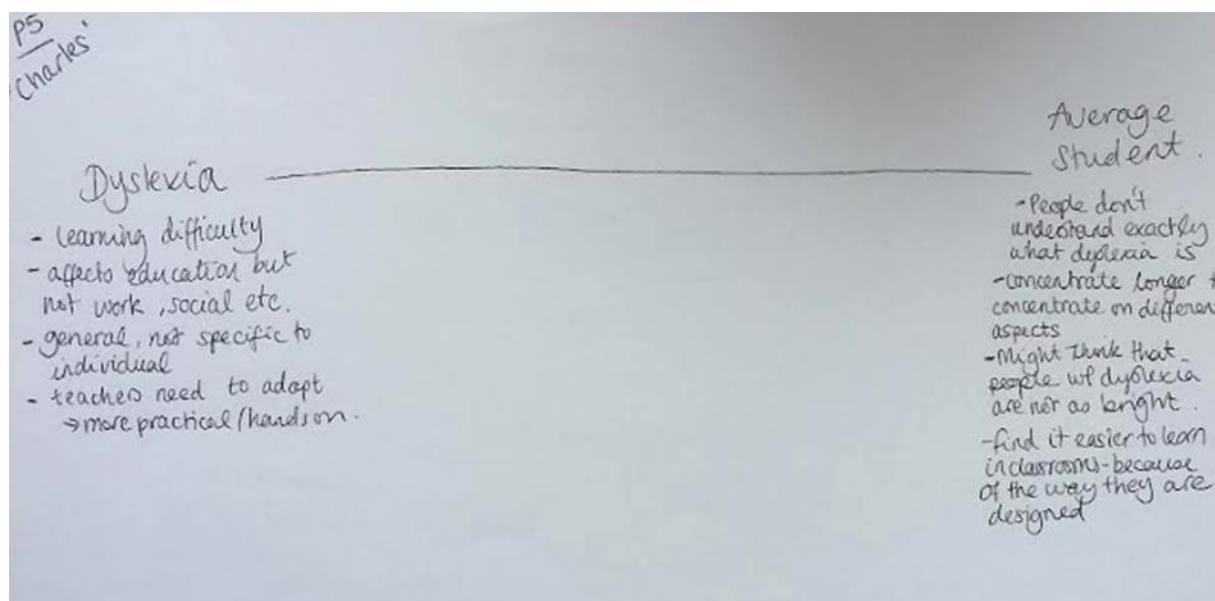
“What would be good about that?”

“What would not be so good about that?”

“How would things change for you?”

“On a scale of 1-10, how much do you believe that statement to be true?”

## Appendix H Example Use of Note Taking and ABC Technique in Interviews







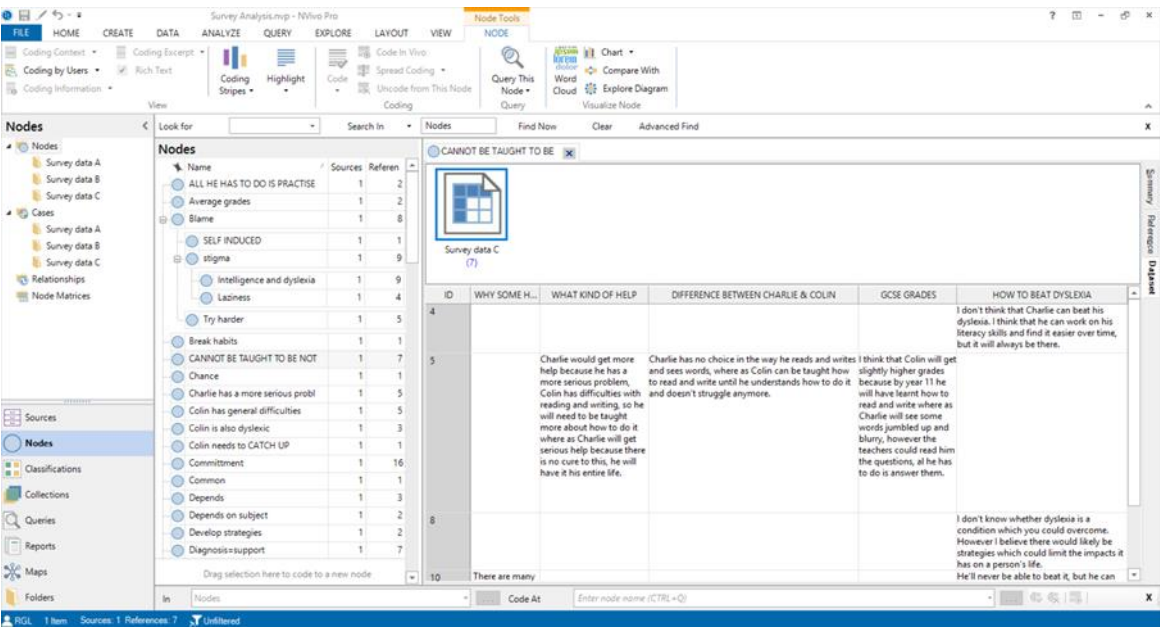
# Appendix I      Records of Survey Data Analysis

## I.1      Example of initial notes and codes recorded manually

ID	GENDER	YOUR EXPERIENCE	WHAT IS DYSLLEXIA	"LEARNING DIFFICULTY"	WHY SOME HAVE DYSLLEXIA	WHAT KIND OF HELP
2564349	Male	I am dyslexic, my sister is also dyslexic. It is me	Dyslexia is a learning difficulty that impacts many different aspects of learning, whether it's reading, writing, numbers, letters and spelling. Dyslexia can also come under processing problems and through memory as well.	RWS numbers "PROCESSING PROBLEMS" "MEMORY" Individual differences	I think that it is through genetics, but it can also happen because of an environment. GENETICS (or) ENVIRONMENT	Both Colin and Charlie will be helped by their teachers, but Charlie would be given a colored book mark when reading to make it easier for him and he would be given extra allocated time to do work in and in exams Charlie would be given a computer and an electronic reader and extra time, whereas Colin would be given a scribe or a computer for exams, he would be given extra time and would be able to have an electronic reader or a reader in exams. They need the same. Time Exams Technology Reader/Scribe
2566596	Fem	It is me I am dyslexic, I was tested out side of school by a person who helps kids with dyslexia. I was first told I had it when I was 9/10. I struggle reading, spelling, and I have a slow righting time. I've been going to this person who helps with dyslexia since I was 10. It was not picked up on in primary school. It was in high school but not much. From going to my tutor I have improved, but I still struggle.  struggling with reading meant I find it hard to finish a book, so I started to read Barrington Stoke books (books for kids with dyslexia). reading these books gave me confidence to start to read proper books again.	I think dyslexia is something that most people have, just different levels. Continuum Some people have low dyslexia and some have strong. Individual differences  Dyslexia is that someone struggles with reading, righting or spelling. RWS some kids who are dyslexic might be really good at reading and not at righting. Or good at spelling and not good at reading. Individual differences	well people might have a parent who is dyslexic and you got it from them. Or people struggle to remember things so struggle with reading and righting. Memory other people from a young age properly started to read, or just find it easy to read or right. GENETICS (or) ENVIRONMENT	Charlie might get a reader or righter for working in class or when taking a test. But Colin could get the same treatment as Charlie. Reader/Scribe Exams They need the same	
2575440	Male	I do have dyslexia, I struggle with reading sometimes. I write really slow.	Where you struggle with your learning.	I don't know. "IDK"	Individualised support Colin would probably get help with his literacy and spelling.  Charlie reads slowly and he would get help with how to say the words correctly.	
2575470	Fem	I have dyslexia.	dyslexia is when you have trouble spelling and reading. And when you can't construct as in the words move or something.	I don't know. "IDK"	Charlie would have help in tests he might have someone read for him, and as his teachers are aware that he has dyslexia he would get more help to get better with his reading and writing whereas for Colin he wouldn't get as much help, he would have to just get on with it. Exams Reader Diagnosis = awareness = support.	

DIFFERENCE BETWEEN CHARLIE & COLIN	GCSE GRADES	LIVES	BEAT DYS	BEAT LIT	HOW TO BEAT DYSLLEXIA	HOW TO BEAT LITERACY DIFFS
They are pretty similar, but Colin has a bigger spelling difficulty. Colin would find it harder to write and put sentences together and to use a wider range of vocabulary, but neither would have a broad vocabulary. PRETTY SIMILAR	English would be a lot lower than other subjects. Both of them would do better in Maths than English. In general the results would be the same as other students if the Charlie and Colin are given the materials that they need in exams. Maths - better grades Similar grades for both It all depends on what subjects they take. If they are more practical subjects they might do really well. Where as if they do more reading and righting subjects they might struggle. It also depends on how had they try and how much effort they put in to there work. Depends on subject Effort Practical subjects - better grades Literary subjects = lower grades	Successful. It would be the same as anyone else but it would take a little longer to do stuff than others. Slower "SUCCESSFUL" "Same as anyone"  "NORMAL LIVES" I think they will normal lives no different to anyone else. Have dyslexia or literacy difficulty's doesn't effect your social life. Maybe they might get a more practical job, so they are doing stuff instead of righting. "PRACTICAL JOBS" "no impact socially"	4	3	Charlie would have to read a lot more books and practice spelling lots of different words that he finds hard. practise effort	Colin would take longer to beat his literacy difficulties, but he could beat it by reading a lot more books and practice spelling lots of different words that he finds hard and by practicing long passages of writing. Practise effort
Charlie is dyslexic so might struggle with other things not just literacy, where as Colin just struggles with literacy. Dyslexia = "NOT JUST LITERACY"			5	6	He will always be dyslexic but could make it weak dyslexia. You CAN'T beat it, BUT "MAKE IT WEAK DYSLLEXIA"	As long as he has help and keeps trying he could d it. Support effort
Individual differences Charlie's difficulties are that he reads quite slowly and struggles with saying the words. Colin's would be how to spell the words out correctly and how to write faster.	I think they would be getting about the same grades. Similar grades for both	I think they'll just keep trying as much as they can and they might be able to get a good job. maybe get a good job	6	6	Just keep trying and don't give up. Effort.	Same as Charlie. Effort
There aren't a lot of a difference, just that one is a bit dyslexier. Not much different Just one has dyslexia - diff. cause / label?	In English they would both get low grades as a lot of the marks are on spelling. English = low grades	they may have trouble getting jobs, as employer aren't interested in people who have trouble with reading and writing. trouble getting jobs due to literacy skills	3	7	I don't know. IDK	more help in school maybe. Support

I.2 Using NVivo to analyse survey data



### I.3 Reflexive note taking alongside reading of survey transcripts

Q4. What help is needed? Charlie (dyslexia) and Colin (literacy difficulties)

#### YP w/ Dyslexia

- Charlie would get more support, Colin “would have to just get on with it”
- Colin SHOULD get help
- They need the same things, but Charlie would probably get more
- Lots of mention about support for tests

#### YP who struggle w/ literacy

- “Charlie might improve but there would still be some difficulties” “Charlie would be more difficult to help”
- “Both would get aid in reading and writing
- Charlie would also get “mind exercises” or something additional/specialist (e.g. “yellow see through card”)
- Charlie would “get more help because he has a diagnosed problem”
- Colin needs general help in class - *his needs are more generalised?*
- Charlie needs help in every class, Colin just in literacy – *opposing view*
- Colin’s difficulties could just be because he struggles or distractions occur – whereas Charlie’s genuinely isn’t his fault – *link to biological origin?*
- “Colin ... should also be encouraged to get better, as there have been no genetic based handicaps for him to overcome.” *So Charlie should not be encouraged to get better?*

#### YP without any literacy difficulties

Again, participants are mentioning the importance of diagnosis, suggesting that without that recognition, Colin will be left “to the same standard as the rest of the class” – *does that mean that we lower standards for Charlie?*

Colin needs to “catch up” *he is behind - due to his experiences?*

- Charlie would get more help because of his diagnosis/severity
- Charlie would get “a professional” one-to-one or specialist type support
- Charlie would get specialist equipment (coloured overlays) – *idea that diagnosis informs intervention*
- Both would get extra help
- Colin should be assessed for dyslexia
- Extra time in exams for Charlie
- Colin would get more help as he has a learning difficulty, which requires more treatment than dyslexia – *mixed views about who has the more significant need*

## I.4 Recording thoughts on theme development

**Themes YP w/ dyslexia: "I struggle"**

- Primarily w/ reading, writing, spelling (all)
- Memory (2)
- Visual disturbances/sequencing (5)
- Slower at writing/learning; things take longer (5)
- Generally negative, only 1 comment about potential positives of thinking differently (1)
- Individual differences in symptoms/severity (2) - Link w/ "Struggle"

**YP w/ w/out literacy difficulties: "I don't have dyslexia but I know a lot of people who do"**

- Family member w/ dyslexia or friends (14) said they know people w/ dyslexia
- Own experiences of literacy dips (7) 4 in group B described their own dips, although had self-identified as not having dyslexia, 3 in group C also (even though said they had no difficulties)
- No experience (5): 4 from C.
- Disclosure: 5 participants commented on disclosure of dyslexia, w/ varying ideas (faking/being v. common + not necessarily obvious, some people may choose not to disclose)

**Q2. How do YP understand dyslexia?**

**AU: "Everyone's brains are different"**

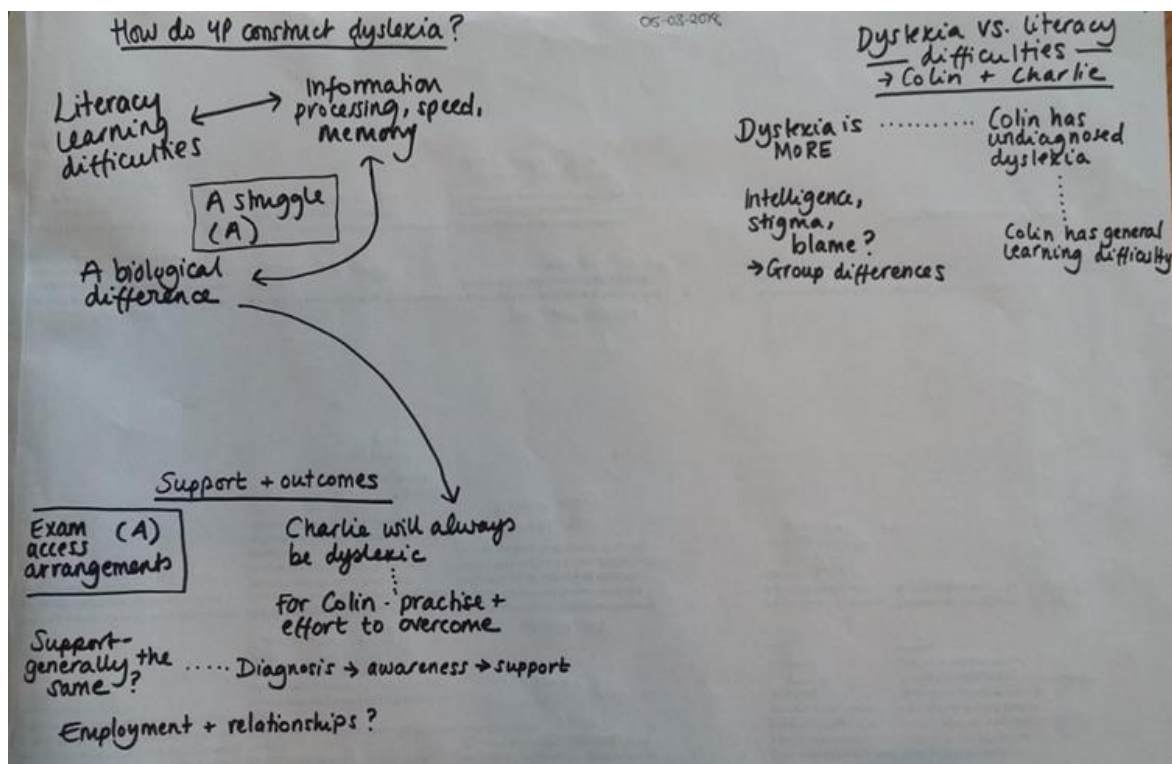
- My brain is a bit different "Ideas of neurodiversity, something physically different in the brain, perhaps formed differently"
- "He still has to fight his biology" → something genetic, hereditary - nothing to do with environment
- Nature and nurture, mostly from group C, considering impact of environment as well as genes
- "Just born with it" Nothing anyone can do - participants thought it is not something that develops (B+C)
- Information processing - Difficulties w/ the brain processing info that causes confusion w/ words/slowly down/see things differently

**AM: "He will always be dyslexic"**

- "Dyslexic people cannot be taught to be 'not dyslexic'" (11 - all groups) Charlie will always have dyslexia and there is little that can be done. No cure, no choice. Groups B+C often qualified this by saying strategies/improvements are possible to reduce the impact. Link to ratings
- "There is a difference between finding stuff hard and having dyslexia" (14 - all groups) Dyslexia is different, it's not just literacy - always there, see things differently. Link to ratings
- harder to help Charlie, "Colin just struggles" "Charlie has a condition". Picked up on Colin making slow progress Charlie has difficulties in multiple areas. Even though many acknowledge that their difficulties are basically the same.

**YP w/ dyslexia: Concerns about exams**

- Exam access arrangements (10) seen as important for Charlie and some mentioned as part of own experiences - reader/scrubber, extra time (5) and technology (4)
- "It all depends on what subjects they take" (18) Likely to get lower grades on English/English dependent subjects, but higher ones in maths/practical subjects, most of high proportion of course work (for Charlie + Colin too).
- Assessment: Given the emphasis placed on exam support, participants w/ dyslexia were quite pessimistic about Charlie + Colin's ability to pass their English GCSE, or, in some cases, any of their GCSEs. Only 1 participant said they would be fine w/ their exam support.





## I.5 Table of themes, with contributing codes and examples of quotes

**RED = A (YP with dyslexia) GREEN = B (YP who struggle with literacy) BLACK = C (YP with no literacy difficulties)**

Main theme	Sub themes	Codes	Examples from survey
<b>How do YP Construct Dyslexia?</b>			
<b>Dyslexia is a struggle Group A</b>			
		“Struggle”, Pros and cons	<ul style="list-style-type: none"> <li><i>i have it and its be a rill struggle all of my life</i></li> <li><i>From going to my tutor i have improved, but i still struggle. struggling with reading meant i find it hard to finish a book, so i started to read Barrington Stoke books (books for kids with dyslexia). reading these books gave me confidence to start to read proper books again.</i></li> <li><i>it is really irritating because it makes things harder for me than for other people and it makes it hard if we are doing some sort of assessment i might be hard for me to wright i will have the ideas of what to wright but i cant do it sometimes but i think dyslexia also helps me in crective subjects and i cna think diffrent ley from other people.</i></li> </ul>
<b>Dyslexia impacts literacy All groups</b>			
	“Dyslexia is that someone struggles with reading, righting or spelling”	Literacy Skill, Reading, writing, spelling, Dyslexia affects literacy	<ul style="list-style-type: none"> <li><i>Dyslexia is that someone struggles with reading, righting or spelling. some kids who are dyslexic might be really good at reading and not at righting. Or good at spelling and not good at reading.</i></li> <li><i>its when someone struggles with spelling and writing and literacy in general</i></li> <li><i>you may not have the best writing or wording to make teaches understand what you are saying in exams you may need more help in some of your subjects and help in the exams like readers and scribes. may find spelling hard you may see words in a strange way.</i></li> <li><i>i think it is something where people suffer to read and write and brake word up.</i></li> </ul>

## Appendix I

			<ul style="list-style-type: none"> <li>• <i>I think dyslexia is when someone struggles to do things that others would find easy or natural, such as reading or writing.</i></li> </ul>
	Information Processing Differences	Memory, Visual differences, Information processing, Ordering, Dyslexia = word confusion	<ul style="list-style-type: none"> <li>• <i>Dyslexia can also come under processing problems and through memory as well</i></li> <li>• <i>A condition that makes the brain misread or swap letters and words around in the brain.</i></li> <li>• <i>I think dyslexia is where letters and numbers get jumbled up in a persons head to the point where they cant understand it</i></li> <li>• <i>It's something where when you are reading something and you go upwards where you already read or you read backwards as well. Sometimes you see the writing blurry.</i></li> <li>• <i>When reading it can sometimes seem like the words are muddled and when writing you muddle up the letters in words.</i></li> </ul>
	"Takes a little longer"	Speed of processing, Slower,	<ul style="list-style-type: none"> <li>• <i>I write really slow</i></li> <li>• <i>It [life] would be the same as anyone else but it would take a little longer to do stuff than others.</i></li> <li>• <i>I find it difficult to keep up with the rest of the class.</i></li> <li>• <i>A condition which impairs the speed of cognitive processing of letters/ words symbols.</i></li> </ul>
<b>Dyslexia is something you are born with All groups</b>			
	"My brain is a bit different"	Neurodiversity, "My brain is a bit different", Brain	<ul style="list-style-type: none"> <li>• <i>my brain is a bit different from other peoples and i think diffrentley it makes things hard for me sometimes?</i></li> <li>• <i>because we cant all be the same uther wiseit will be boring</i></li> <li>• <i>because everyones brains are diffrent</i></li> <li>• <i>you have a mind of that if a letter is in a wrong place it wont tell you to correct it thats how ive always seen it as.</i></li> <li>• <i>There's a difference between self induced and actual physical learning issues.</i></li> <li>• <i>just have brains that work differently</i></li> </ul>
	"He still has to fight his biology"	"Genetics", Genetic or hereditary, Hereditary, Biological differences,	<ul style="list-style-type: none"> <li>• <i>im not really sure it might be a thig of if one of your parents have it you might have it</i></li> <li>• <i>Dyslexia is caused by the genes of their parents witch has been passed down over the years in the genetic DNA.</i></li> <li>• <i>Charlie's difficulties are the result of his genetics, and so whilst his upbringing and his parent(s) style of support may have been good, he still has to fight his biology.</i></li> </ul>
	Nature and nurture	Genetics or environment,	<ul style="list-style-type: none"> <li>• <i>I think that it is through genetics, but it can also happen because of an event</i></li> <li>• <i>Because it is in their genes or people have different upbringings which may affect this.</i></li> </ul>

			<ul style="list-style-type: none"> <li>• <i>We are all different physically. Some may argue it depends on the nature and nurture of your upbringing which in effect it does.</i></li> </ul>
	“Just born with it”	“Just born with it”, Born with it	<ul style="list-style-type: none"> <li>• <i>Some people have dyslexia and some don't because depends on how you were born</i></li> <li>• <i>It's how they were born it's not their fault.</i></li> <li>• <i>some are just born with it and some others are not</i></li> </ul>
<b>How do YP Perceive Dyslexia in Comparison to Other Literacy Difficulties?</b>			
<b>Dyslexia is more significant than literacy difficulties</b> <i>All groups</i>			
		Dyslexia is different, Dyslexia is “not just literacy”, Charlie “has a more serious problem”, Colin “just finds it hard”	<ul style="list-style-type: none"> <li>• <i>There is a difference etween finding stuff hard and havnig dyslexia because dyslexia is like having something always at the back of your mind and stopping you from doing things and your not always awarif it</i></li> <li>• <i>charlie has dylexia where as colin just stuggles</i></li> <li>• <i>Charlie is dyslexic so might struggle with other things not just literacy, where as Colin just struggles with literacy.</i></li> <li>• <i>one of them sees things in a different way and the other they find it hard to read but both could have difficulties in spelling.</i></li> <li>• <i>Charlie's difficulties are more apparent then Collins because he has dyslexia which is a known problem which he cannot help with as much where as Colin just has difficulties within literacy which teachers may just think its normal</i></li> <li>• <i>Charlie has got dyslexia whereas Colin just finds it hard to read and write.</i></li> <li>• <i>I think that Coin will get a higher level in his GCSE because he doesn't suffer from dyslexia. Colin could possibly get a B-, but because Charlie suffers from dyslexia he might get a C- or even a D.</i></li> <li>• <i>charlie can't raed and spell and colin is making slow progress.</i></li> <li>• <i>Colin only finds learning new words hard whereas Charlie finds lots of things hard.</i></li> <li>• <i>Charlie would get more help because he has a more serious problem</i></li> </ul>
<b>Charlie and Colin’s difficulties are the same</b> <i>All groups</i>			
		Charlie and Colin are the same,	<ul style="list-style-type: none"> <li>• <i>there aren't a lot of a difference. just that one has a got dylexiyer</i></li> </ul>

## Appendix I

		“it is the same”, Label is the only difference	<ul style="list-style-type: none"> <li>• <i>It would take the same time and effort as Charlie's Dyslexia to beat it because it is the same but may be considered less serious then his when in reality it isn't</i></li> <li>• <i>I think that they have the same difficulties, but Charlie has a diagnosis and Colin doesn't. I think this is the only difference.</i></li> </ul>
		Colin has dyslexia too, Diagnosis is the difference, Colin is also dyslexic,	<ul style="list-style-type: none"> <li>• <i>one noes her has dislex ier and the other one dosent</i></li> <li>• <i>the teachers are not aware that he [Colin] may have dyslexia .</i></li> <li>• <i>Colin to begin with needs to be tested for dyslexia then the appropriate route of action taken.</i></li> </ul>
<b>Stigmatising beliefs All groups</b>			
	“Colin has difficulties with learning”	Coin has learning difficulties, Colin has general difficulties, Intelligence	<ul style="list-style-type: none"> <li>• <i>They are pretty similar, but Colin has a bigger learning difficulty.</i></li> <li>• <i>Charlie has problems with reading and Colin has difficulties with learning</i></li> <li>• <i>I think that Charlie's difficulties is because of a genetic disorder whilst Colin's may be because of his intellect.</i></li> <li>• <i>Charlie has dyslexia which only affects literacy where as Colin has learning difficulty's which may be autism autism affects the brain and thinking processes where as dyslexia only affects literacy</i></li> <li>• <i>many people might find it hard to understand his [Colin's] situation and may quickly assume that he doesn't put enough effort in.</i></li> </ul>
	Intelligence and dyslexia (C)		<ul style="list-style-type: none"> <li>• <i>A condition which impairs the speed of cognitive processing of letters/ words symbols. Also I know it doesn't affect intelligence.</i></li> <li>• <i>I think that dyslexia is a misunderstanding inside the process between what you are seeing and the process of your brain. However some people can be very smart but still have dyslexia.</i></li> </ul>
	Stigma	Stigma, Awareness, Employment	<ul style="list-style-type: none"> <li>• <i>they may have trouble getting jobs. as employer aren't interested in people who have trouble with reading and writing.</i></li> <li>• <i>it will be hard to get jobs but people those dayas are more aware of it</i></li> <li>• <i>I would believe that Charlie and Colin's lives wouldn't differ that much as they would through hard work be able to get anywhere but i would believe that Charlie would find it harder to find a job as he is dyslexic.</i></li> <li>• <i>I think that Dyslexia and learning difficulties shouldn't have any effect with relationships, success, or happiness, as long as these fields have nothing to do with literacy. Job wise, it would be naive to say that their conditions would mean that they would have less access in the job market.</i></li> </ul>



			<ul style="list-style-type: none"> <li>Relationships, they may struggle to make friends and maybe be called 'stupid' or things like that by other kids because they take a longer process.</li> <li>The stigma of being dyslexic may make Charlie fare slightly worse than Colin. I think Charlie will be less happy because he has to accept that he has dyslexia and there is a stigma associated with that that he has to accept.</li> </ul>
	“they may not believe that they are good enough”	Self-views, “Self-esteem issues”, Confidence	<ul style="list-style-type: none"> <li>struggling with reading meant i find it hard to finish a book, so i started to read Barrington Stoke books (books for kids with dyslexia). reading these books gave me confidence to start to read proper books again.</li> <li>It might affect their happiness because they wish they were like other people but they are happy to have friends and family and a life.</li> <li>Charlie and Colin's lives may be really good or really bad because if they don't bother trying the may end up with an extremely terrible job because they may not believe that they are good enough or they are also good sides is that yes you will always have but if you work really well.</li> <li>Happiness, sometimes it can make them feel sad when everyones getting good grades etc. and they just really struggle.</li> </ul>
	Blame	Blame	<ul style="list-style-type: none"> <li>Charlie might have a tiny bit more trouble but he'll also be able to talk to people and have a reason, where they might think Colin is not trying.</li> <li>I think Charlie would get a bit more help then Colin because Colin only seems to have literacy difficulties not dyslexia which some teachers may help more with because it genuinely isn't his fault where as difficulties could be just because he struggles or distractions may occur</li> <li>It's how they [people with dyslexia] were born it's not their fault.</li> <li>Colin's may be the result of a different upbringing where his carers weren't as involved or his family(ies) wasn't as stable, thus his literacy skills either haven't properly formed and/or they have suffered as a result of his disorganised past. He may not have a biological issue.</li> <li>I need to know their back stories whether Colin is a hard worker or if he's showing no improvement because he's being lazy.</li> </ul>

Charlie's dyslexia is permanent, but Colin can improve through hard work All groups			
	<p>"Dyslexic people cannot be 'taught' to be 'not dyslexic'"</p>	<p>"He will always be dyslexic",          "You can't beat dyslexia",          Fixed,          "Cannot be 'taught' to be 'not dyslexic'"          "Charlie would be more difficult to help"</p>	<ul style="list-style-type: none"> <li>• <i>nothing as you cant get rid of it [dyslexia]</i></li> <li>• <i>Charlie has a condition which as far as we know cannot be treated</i></li> <li>• <i>there both quite simalar but charlie might struggle more because he might not be able to overcome his dyslexia, where as colin can practise and get better as he learns something everyday and get better. charlie will also learn how new things and practise but he might be a bit slower at learning and understanding.</i></li> <li>• <i>Colin has difficulties with reading and writing, so he will need to be taught more about how to do it where as Charlie will get serious help because there is no cure to this, he will have it his entire life.</i></li> <li>• <i>There are many external factors that can influence however dyslexic people cannot be 'taught' to be 'not dyslexic'.</i></li> </ul>
	<p>"You can learn along the way"</p>	<p>"Easier over time" (dyslexia),          "You can learn along the way",          Dyslexia can be reduced</p>	<ul style="list-style-type: none"> <li>• <i>you cant BEAT dyslexia you can just make it easier for your self.</i></li> <li>• <i>He will always be dyslexic but could make it weak dyslexia.</i></li> <li>• <i>A lot more research and money put into cures and medication for the condition</i></li> <li>• <i>i dont think dyslexia will get better but you can learn along the way to try and help it. i think its something that is always there but you can get a round it.</i></li> <li>• <i>Charlie would be more difficult to help out. As Colin would improve less aid would be given whilst Charlie may need a person to help out. Charlie also might improve but there still would be some difficulties.</i></li> <li>• <i>He'll never be able to beat it, but he can improve on the symptoms with a lot of hard work.</i></li> <li>• <i>I don't think that Charlie can beat his dyslexia. I think that he can work on his literacy skills and find it easier over time, but it will always be there.</i></li> </ul>
	<p>"All he has to do is practise"</p>	<p>Practise to improve,          "All he has to do is practise",          Practise</p>	<ul style="list-style-type: none"> <li>• <i>Charlie would have to read a lot more books and practice spelling lots of different words that he finds hard.</i></li> <li>• <i>it would take Colin to beat his literacy difficulties by learning new words but also he could read more which might help beat it.</i></li> <li>• <i>[For Colin] To read more books, starting with small books and then getting bigger.</i></li> <li>• <i>All he [Colin] has to do is practice and this will allow him to read and right well, this could take anytime from a couple of weeks to a year or two, I don't think he will still struggle after a couple of years help.</i></li> </ul>
	<p>"Hard work throughout his life"</p>	<p>Commitment,          Effort,          Overcome,</p>	<ul style="list-style-type: none"> <li>• <i>try and try again [Colin]</i></li> <li>• <i>if he [Colin] studies hard and continues to practise allowing him to progress and evenly be smarter.</i></li> </ul>

		Dedication, Determination, Hard work, Try harder, Overcoming difficulties	<ul style="list-style-type: none"> <li>• <i>I would believe that Charlie and Colin's lives wouldn't differ that much as they would through hard work be able to get anywhere but i would believe that Charlie would find it harder to find a job as he is dyslexic.</i></li> <li>• <i>Through hard work and dedication, Colin should be able to get better unless there is some unnoticed condition that prevents him from doing so.</i></li> <li>• <i>Colin could beat his literacy difficulties with a lot of hard work.</i></li> <li>• <i>Help and support and extra time and commitment from him [Charlie] to work out strategies to help get around the difficulties he faces.</i></li> </ul>
--	--	--	--



## Appendix J Records of Interview Data Analysis

### J.1 Reflexive note taking

Reflections noted following interviews:

Reflections 19-01-2018

P1

- Helpful to have the construct to draw out - something else to focus on.
- Experiences of those around her impacted her own path - mother's desire to protect her from the school exp. that she had had.
- Observation of her friend who struggles more than she does → no diagnosis = no help, fewer opportunities.
- Did not describe any particularly negative exp. or feelings.
- Wanting to protect her independence + autonomy as a learner, but also some impact of the reactions of others → not wanting to be seen to be different.
- Only perceived advantages of the label.

P2

- Felt he had got off lightly w/ his dyslexia - comparison to others who are worse off, said he wanted to be able to help by doing research.
- Again, exp. of family had impacted own path.
- V. determined, excelling in other areas - motivation + protection of self-esteem.
- Very eloquent + reflective.
- Some recollection of negative exp. pre-diagnosis but not blaming of school - they didn't know.
- Felt pros + cons of label. Medical/weight seen as a pro - people to take it seriously.
- Quite a lot of support received - good schools /

fairly affluent area / high achievement in general.

P3

- Felt that there was a difference b/w LD + dyslexia - but not sure what.
- Spoke about biological 'brain' differences.
- Memories of pre-diagnosis not very good → 'not trying hard enough'.
- Diagnosis of dyslexia - 'no different' but described advantages.

P4

- Had experienced life up + about the label at different times + had only received support when he disclosed his label. even though his difficulties still persisted.
- All these participants seemed to be doing fairly well academically exp. sixth form students who wouldn't be here if they hadn't got good grades - had been able to overcome to a sig extent, but still felt definitely dyslexic.
- Like others, not confident in what dyslexia actually is - never fully explained but I sensed would appreciate an explanation.

### *Reflexive note taking alongside initial readings of transcripts:*

#### ***Violet – Participant 1***

- Reading, writing and spelling are trickier and slower. Some other people have issues with speaking.
- Not liking to use the computer/laptop in class because other pupils would talk about it – not wanting to be singled out. Also did not like it when they tried to put an adult with her in class – wanting to be more independent and to do things privately, did not feel she needed the help. Not initially asked about having the TA.
- “Extra classes” – being taken out of normal class with other students who had “similar disabilities” to get help with spelling and English. This was in primary school and at beginning of secondary, but no longer compulsory in year 9 – not offered - No longer feels she needs the extra support – talk about overcoming of difficulties
- “I think I *have* overcome a lot of it [my dyslexia].” Just slower at reading, but felt she had made a lot of progress since primary school.
- Uses the term dyslexia to describe self and it is something that friends etc. know because it cannot be hidden – “I have horrendous spelling” – if there is a choice, someone else will always do the writing
- Mum also has dyslexia. Parents did English exercises at home and Mum helped her to cope e.g. through teaching skills and strategies
- Mum as a role model – she still has difficulties with her dyslexia but just gets on with it, will ask for help when needed and acknowledges her difficulties (*feeling supported*)
- Mum understands and knows how to help, how to explain things e.g. understanding what to do in coursework. She has had similar experience so knows what helps.
- Feeling happy with the support that she has received, that it has helped her.
- “[I] just get on with it” agreed that she had worked hard, although put emphasis on how others had helped her. Felt that she would continue to improve, would be close to “not dyslexic” but would not ever be fully there. Would always be slower with reading and writing.
- At the beginning of the year had been assessed for exam access arrangements to have a computer and word processor in exams – came out as “below average”. If next year she was average, she wouldn’t believe it “I’d think it was wrong.” Without the word processor exams would be “very distressful, especially in English.”
- If I was an average reader and speller etc. then “I probably wouldn’t say I had dyslexia anymore, but I probably would still be slow with things.” It wouldn’t be necessary to tell people anymore, but it wouldn’t ever be completely gone.
- Not perceiving any impact of dyslexia in the future other than with tasks such as having to fill out a form or something.

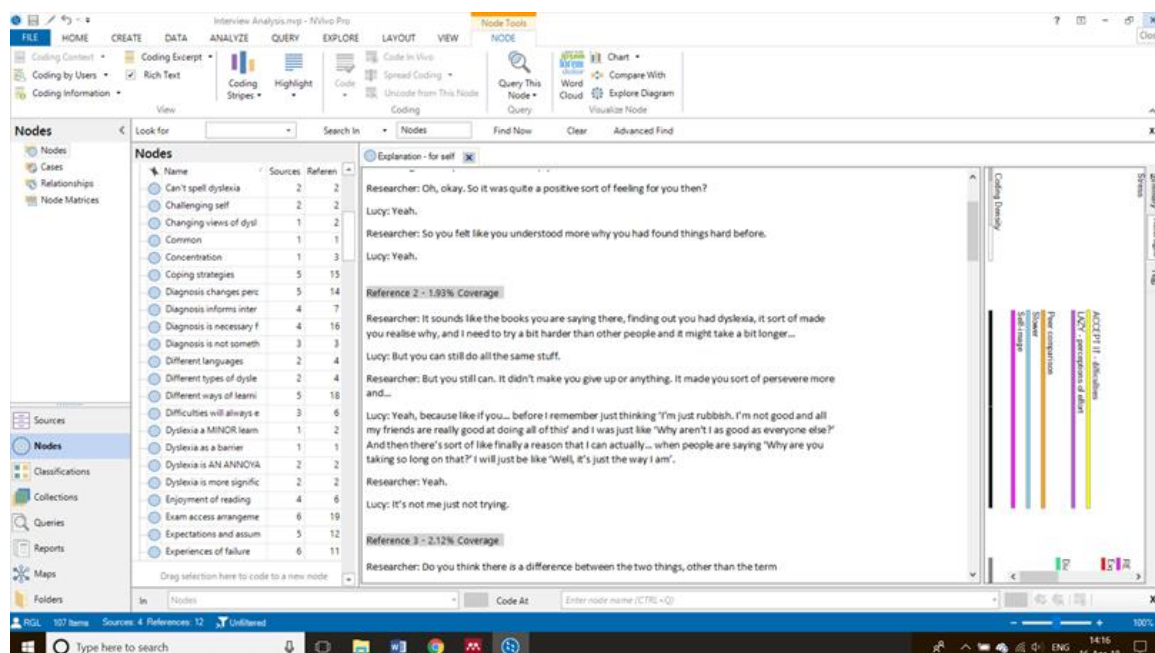
### Advantages of the dyslexia label

- “People understand me more” Without the diagnosis people would not understand.
- If I didn’t have the label, “people would just assume that I was a bit dumb”.
- Mother’s experience – school was horrible because teachers thought she was stupid.
- Diagnosis is definitely better.
- The label leads to getting extra help with learning and to support for exams
- Without the diagnosis, there would be no exam help, without the exam help I would be “failing” “definitely”
- Mum had already mentioned dyslexia and highlighted difficulties, but the perception was that a diagnosis should be made so that “now I can get extra help and that’s a good thing”
- Was not getting any support pre diagnosis - as far as she remembers/was aware
- People who struggle with reading and spelling probably would also prefer to have a dyslexia diagnosis, because then they would get more help (this happened to a friend) “Because she wants the test to make sure... to get the extra help because she doesn’t get very much help at the moment.” “She’s a lot worse than I am, yes. She just hasn’t been tested”. She has not received help at this school and is going to another college specifically because they have said they will test her for dyslexia. – *not always fair in terms of who gets diagnosis and therefore support*
- “The school is reluctant to provide [extra support] unless you are dyslexic or with a different disability” but not everyone gets the test.

### Disadvantages of the label

- No disadvantages – *but then reflected on her friends situation and access to support*
- If the label was taken away “I would be really annoyed. Especially if like the exam help and everything got taken away with it. That would be really annoying.”
- “Yeah, I wouldn’t really be fussed. As long as I still got the help I needed, I wouldn’t care what it was called.”
- Would be happy just to say “I can’t spell” rather than “I have dyslexia”
- Support is the most important thing – might not really matter what we call it?

## J.2 Using NVivo to analyse interview data



### J.3 Interview codebook

*Capitals indicate in vivo coding (using participants' own words)*

Code	Description	Sources	Refs
ACCEPT IT - difficulties	Acceptance of difficulties associated with dyslexia, e.g. "it's just the way I am" and feeling comfortable with that	5	5
Access to assessment	Recognition of the fact that not everyone would have access to a formal assessment that could result in diagnosis	3	6
Accuracy of label	Reference to how accurate either a diagnostic or descriptive label would be for each individual person	3	8
Additional English classes	Mention of being offered support from school through additional lessons/teaching to develop literacy skills	4	12
Assessment	Memories of the diagnostic assessment that was carried out	5	9
Assessor	Memories of the person who carried out the diagnostic assessment	5	5
Being informed about diagnosis	Comments about how much they knew about their diagnosis, how they were informed and what they were told	5	14
Being seen as different	Comments about being seen as different from their peers, things that might make them stand out	4	6
BEYOND LITERACY	Mention of difficulties associated with dyslexia that extend "beyond literacy", suggestion that dyslexia is more than just having difficulties with literacy	4	9
Can't hide the support	Comments about other people being aware that participants have difficulties because it is obvious that they are receiving some support e.g. because they are using a computer	2	4
Can't hide the symptoms	Comments about the 'symptoms' of dyslexia being easily observed by others - other people noticing participants' struggles	5	5
Can't spell dyslexia	Issues with being able to spell the word 'dyslexia'	2	2
Challenging self	Comments about participants challenging themselves to improve and to do more	2	2
Changing views of dyslexia	The way that dyslexia is viewed by the general population has changed over time	1	2
Common	Belief that dyslexia affects many people	1	1
Concentration	Mention of concentration/attention difficulties associated with dyslexia	1	3
Coping strategies	Mention of coping strategies that they have developed in response to their dyslexia, ways that they are able to manage their difficulties	5	15



Diagnosis changes perceptions	Participants' experiences or beliefs that receiving a diagnosis of dyslexia changes their own or others' perceptions of them and/or their difficulties	5	14
Diagnosis informs intervention	References to the belief that diagnosis of dyslexia will inform the type of support/intervention that is required	4	7
Diagnosis is necessary for support	Specific references to how diagnosis of dyslexia is necessary to receive support with it, and participants experiences of this	4	16
Diagnosis is not something to hide	Being open about dyslexia and not hiding it from others	3	3
Different languages	Comments about learning different languages	2	4
Different types of dyslexia	Comments about the heterogeneous nature of dyslexia - different people experience it differently and have different 'symptoms'	2	4
Different ways of learning	Talk of dyslexia being associated with different learning styles and requiring different types of teaching to other students	5	18
Difficulties will always exist	Suggestion that certain aspects of dyslexia will always remain, even if the 'symptoms' can be improved - it is not possible to fully overcome dyslexia and no longer have it	3	6
Dyslexia a MINOR learning difficulty	Idea that dyslexia is a "minor" learning difficulty in comparison to others kinds of learning difficulty or disability	1	2
Dyslexia as a barrier	References to how dyslexia impairs school work/functioning in any way	1	1
Dyslexia is AN ANNOYANCE	Reference to "annoyance" or irritation related to the 'symptoms' of dyslexia	2	2
Dyslexia is more significant	Suggestions that dyslexia is more significant than other literacy difficulties	2	2
Enjoyment of reading	Comments about enjoying reading	4	6
Exam access arrangements	Any mentioned of exam access arrangements	6	19
Expectations and assumptions	Comments made about other people's assumptions or expectations of participants in relation to their difficulties and/or label	5	12
Experiences of failure	Any comment related to experiences of failure or predictions of failure at school	6	11
Explanation - for others	Comments about how the dyslexia label/process of diagnosis provides an explanation for other people, to help them better understand the participant	5	8
Explanation - for self	Comments about how the dyslexia label/process of diagnosis provides an explanation for the participants' previous experiences	4	12
Fairness and equity	Comments about what is fair and equal in terms of support, expectations and exam access arrangements	3	10

## Appendix J

Family with dyslexia	Mention of having family members with dyslexia or similar, undiagnosed, difficulties	5	7
Feelings around time of diagnosis	Any feelings that were expressed in relation to experience of diagnosis	4	6
Finding school difficult	Any references to finding any aspect of school difficult	4	6
FRUSTRATING difficulties	Comments about frustration with difficulties	2	2
Give up	References to giving up and not trying	3	4
Good amount of support	Comments about school support that indicate participants felt that they were receiving the right amount, or a good amount of support	5	16
Good enough	References to aiming for an "acceptable" standard, or doing just "enough" to keep up with others	2	2
Hard work	Participants' references to the amount of hard work they have had to put in to deal with their dyslexia	5	15
HAVE TO WORK HARDER than others	Comments about having to work harder than other people, without dyslexia	3	5
Humour	Use of humour in relation to dyslexia and associated difficulties	2	2
Identifying with dyslexia	Reference to participants identifying themselves as 'dyslexic' or having dyslexia, or choosing to use that term	6	12
Inappropriate support	Participants' experiences of having received support that they felt was inappropriate	4	8
Independence	Participants' thoughts about their own level of independence in managing their difficulties	4	4
Insufficient support post diagnosis	Participants' experiences of not being offered the support that was required/requested/appropriate, post diagnosis	2	6
Intelligence	Any comments relating to intelligence	2	10
JUST GET ON WITH IT	Participants talking about the need to "just get on with it" despite their difficulties	2	3
LAZY - perceptions of effort	Any reference to participants' own or others' perceptions of the effort that they put into their work or overcoming their difficulties e.g. "he's just lazy"	4	14
Limited knowledge of other people's dyslexia	Feeling isolated or having little knowledge of other people with dyslexia or their experiences	1	1
Literacy as an important skill	Recognition that literacy is an important life skill	1	1
Literacy difficulties	Any mention of difficulties associated with dyslexia that are specifically related to literacy (reading, writing and spelling)	6	19
Medical label	The idea that the 'dyslexia' label is more of a medical label	1	1

Memory	References to memory difficulties as an aspect of dyslexia	4	9
MESS AROUND	Reference to participants preferring to "mess around" rather than do their work	1	2
MILD dyslexia	Participants' beliefs that they have a "mild" form of dyslexia	1	3
Misconceptions about dyslexia	Reference to other people's misconceptions around dyslexia	1	2
More time	Participants talking about needing, or being given, more time to do things, compared with other people, without dyslexia	5	9
Motivation	Participants talking about the things that motivate them to work hard	2	5
Muddled	Talk about things getting muddled or "jumbled" up in one's head	2	3
Neatness	Difficulties with doing things neatly and precisely, as an aspect of dyslexia	1	1
Need to label	Idea that people need to label things	1	1
No impact on opportunities	Comments suggesting that dyslexia will not impact participants' opportunities in life	4	5
No support prior to diagnosis	Participants' experiences of not having been given sufficient support, prior to receiving their diagnosis	6	15
Non-disclosure	Participants choosing not to tell people about their dyslexia	2	2
Organisation	References to difficulties with organisation, as an aspect of dyslexia	1	4
Overcoming difficulties	Participants experiences of having made progress, or overcome some of their difficulties	6	16
Parental support	References to participants being supported by their parents, either at home or through school	4	9
Parents' experiences	Any talk of participants' parents' experiences of difficulties with dyslexia, or similar	4	8
Parents' experiences impacting on own diagnosis	Mention of how participants' parents' experiences with dyslexia, or similar difficulties, impacted how/whether they got a diagnosis and the experience of that	5	9
Peer awareness	Comments about peers' awareness of participants' dyslexia and/or difficulties	5	12
Peer comparison	Comments in which participants make comparisons between themselves and their peers	3	7
Perception of words	Participants' experiences of struggling to accurately perceive written text - difficulties with the visual perception	1	2
Perceptions of others prior to diagnosis	Comments about how participants were perceived prior to their diagnosis	2	3
Perseverance	Comments about persevering in the face of difficulties, persevering to succeed in school etc.	4	9
Positive aspects of dyslexia	Any mention of positive differences associated with dyslexia	3	7

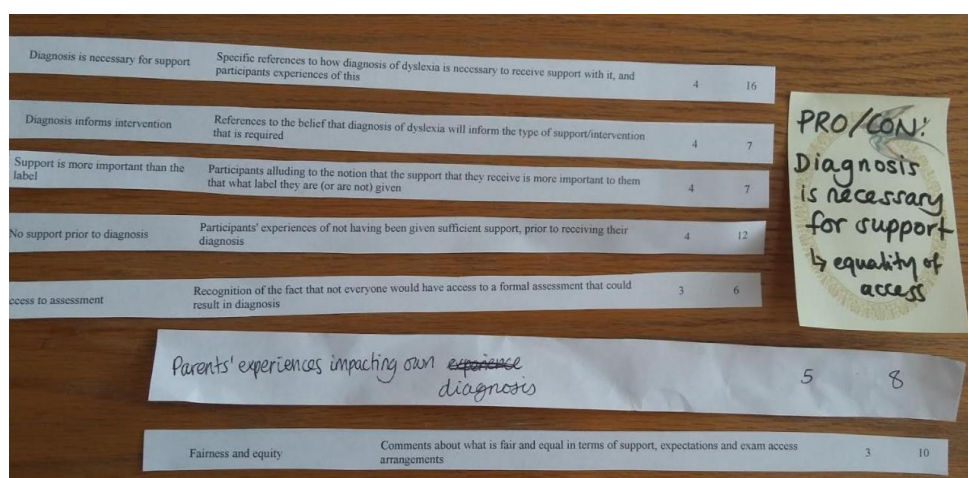
## Appendix J

Preference for certain types of information	Comments about how information is presented and needing it to be done in a certain way to aid understanding and processing	1	2
Processing	Comments about processing differences as an aspect of dyslexia	2	5
Proving self	References to the desire to prove one's capability, either to prove it to yourself or to another	4	5
REASON INSIDE YOUR HEAD	Dyslexia as a biological reason for any difficulties experienced	1	2
Self-image	Comments relating to how participants see themselves and their self-esteem	5	13
Sensory sensitivity	References to participants experiencing sensory sensitivities	1	1
SHAPE OF THE WORD	Recognising words through their shape rather than decoding, as an aspect of dyslexia	1	1
SHEER BLOODY-MINDEDNESS	Participants' references to wanting to go against the grain, do things just to prove a point, do things that they know will be difficult and exceed expectations	2	6
Slower	Any comments relating to participants' being slower than their peers, taking longer to do things or being behind	5	17
Specific nature of difficulties	The idea of dyslexia being associated with certain specific difficulties - impacting certain cognitive functions, but not others	1	1
Stigma of the difficulties	References to their being a "stigma" around having difficulties associated with dyslexia	2	3
Stigma of the label	Reference to a "stigma" being attached to the dyslexia label	3	8
Stress	Comments about feelings of stress in relation to difficulties/diagnosis	3	4
STUPID	Any reference to derogatory comments around intelligence or beliefs that a person with dyslexia and/or literacy difficulties is perceived as "stupid"	5	10
Subject choice	References to choice of school subjects being influenced by participants' difficulties	3	5
Success	Comments about successes experienced at school, or with learning in general	5	12
Support from school	References to support offered by school, that do not constitute additional literacy/English lessons or exam access arrangements	4	11
Support is more important than the label	Participants alluding to the notion that the support that they receive is more important to them than what label they are (or are not) given	4	7
Teachers' understanding of how to help	References to teachers' level of understanding of participants and how to support them	3	8
Technology	Any reference to the use of technology as a way of supporting difficulties	6	23
Terms that are easier to understand	Comments about how easily different terms (i.e. diagnostic vs descriptive terms) are understood	4	9

Thinking differently	The idea that individuals with dyslexia "think differently" to others, without dyslexia	1	4
Traditional methods of learning	Comments about different methods of teaching and learning and how traditional methods may not work for individuals with dyslexia	4	8
UNDER PRESSURE	Comments about feeling pressure related to school work or achievement	2	2
Understanding and comprehension	References to difficulties with understanding and comprehension of written text, as an aspect of dyslexia	3	3
WEIGHT of the term dyslexia	The idea that the term 'dyslexia' has a credence, a weight, that makes it more impactful than a descriptive term	3	3
WORK AROUND THE PROBLEMS	References to the idea that difficulties associated with dyslexia are something that you can "work around" even if it will never fully go away	3	8

## J.4 Manual arrangement of codes into themes

*Stages 3-5 of thematic analysis, done by manually arranging and editing codes*



Appendix J



Stress	Comments about feelings of stress in relation to dyslexia diagnosis	3	4
FRUSTRATING dyslexia	Comments about frustration with dyslexia	2	2
Dyslexia is AN ANNOYANCE	Reference to "annoyance" or irritation related to the 'symptoms' of dyslexia	2	2
Dyslexia is a barrier	Reference to how dyslexia impacts school work/functioning in any way	3	6
Finding school difficult	Any references to finding any aspect of school difficult	4	6
UNDER PRESSURE	Comments about feeling pressure related to school work or achievement	2	2
Experiences of failure	Any comment related to experiences of failure or predictions of failure at school	6	11
No impact on opportunities	Comments suggesting that dyslexia will not impact participants' opportunities in life	4	5

Dyslexia makes school more stressful, (but does not necessarily impact on life opportunities)

### J.5 Table of themes, with contributing codes and examples of quotes

<i>Main theme</i>	<i>Sub themes</i>	<i>Codes</i>	<i>Example quotes from interviews</i>
<b>What are YP's Experiences of Having a Dyslexia Diagnosis?</b>			
<b>Dyslexia can make school stressful</b>			
	Difficulties within education	Stress, "Frustrating" difficulties, Dyslexia is "an annoyance", Dyslexia as a barrier, Finding school difficult, "Under pressure", Experiences of failure	<p><b>Lucy:</b> <i>Because like lots of lessons I found hard, like Maths I found particularly hard, so I would always be happy to come out of that.</i></p> <p><b>Theo:</b> <i>Yes. It's not just I'm struggling in that subject. I am struggling in that broader school sense.</i></p> <p><b>Moon:</b> <i>And my writing was always messy and my spelling was always terrible. So those who could write neat, could write in a nice line and had brilliant spelling, were rewarded.</i></p> <p><b>Charles:</b> <i>No, I wouldn't say pressure. I think it's just... well, I suppose it is pressure, but not from other people. I would say it's more from, like myself.</i></p> <p><b>Charles:</b> <i>I was glad that I'd got the extra time and stuff because I had never finished an exam before. Whereas it allowed me to actually finish some exams, which was quite good.</i></p> <p><b>Researcher:</b> <i>[The computer is] very helpful. What do you think it would be like if you didn't have that?</i></p> <p><b>Violet:</b> <i>Very distressful, especially in English. I get it for all the subjects except for Maths, so...</i></p>

## Appendix J

			<p><b>Oz:</b> Yes. And it has allowed me to put across what I know. Because otherwise I would be constantly worrying about spelling and how long is this going to take? You know, and all those other things which would just limit your ability to actually do the work, if you will.</p> <p><b>Oz:</b> So um an example, and even after it was picked up, we did a spelling test in RE. Ah, I think I got one right. But it's not because I couldn't, well, I obviously can't spell but it's the fact I got three words right in the whole test, including the title and yeah</p> <p><b>Oz:</b> My languages I was the worst in the class. I probably say in the lower 25%, you know worst in the year probably, easily. And it was kind of, I was getting no higher than primary school grades. And they were kind of meh primary school grades, if you will.</p>
	Dyslexia is not a barrier to future success	No impact on opportunities	<p><b>Charles:</b> Learning difficulty. It mainly affects education. It doesn't... I'd say it doesn't really affect like in life jobs because everything is done on a computer nowadays, so the only thing it really impacts is education.</p> <p><b>Researcher:</b> Okay, so not work, not like social aspects or anything like that? It isn't going to make any difference?</p> <p><b>Charles:</b> No, dyslexic doesn't. No.</p> <p><b>Lucy:</b> Well, sort of like maybe... I think some teachers... I'm not really sure to be honest. Because I don't think it affects you really, to get sort of like the dyslexia label. In like... it's not going to, I don't think it would stop me from doing anything. Like for some people it may not help them, but I don't feel like it would stop me doing anything but it's almost like... I'm just like different. It doesn't mean I can't follow this career or I can't do that. It's just I'm different.</p> <p><b>Lucy:</b> So it's not going to sort of... it's not going to affect your life loads because you are still going to have the same stuff. It's not going to affect you in that sense. It just means you are going to get more help for it.</p> <p><b>Researcher:</b> So you can... I feel like you don't see any particular barriers in terms of what you can and can't do?</p> <p><b>Moon:</b> Yeah.</p>
<b>Difficulties are diminished, but not defeated</b>			
	Making progress	Overcoming difficulties	<p><b>Violet:</b> I think I have overcome a lot of it. It's just if we're reading in class I am always a page or two behind.</p> <p><b>Oz:</b> So I have to work quite hard to organise... I have to set like times and stuff for me to do things. My organisation of notes, even once they are taken down, is sometimes sub-par. And I even had, in Year 10, or I think it was Year 10,</p>



			<p>maybe Year 11, I had help with organising. Because that was generally a problem. ... ..And we've kind of found ways around it and we've... they took, shall we say it took some work.</p> <p><b>Lucy:</b> Because like at the moment I have been trying sort of a bit more challenging sort of books. And now I feel like I can, like even though I have got reading dyslexia, I enjoy reading. Like it just makes it slightly different and like maybe like with reading I have to think really hard, like really concentrate on it, but I can still enjoy reading. Because in class we have read <i>Of Mice And Men</i>, and on my own I have read <i>To Kill A Mockingbird</i>, which like some of the words are quite difficult in it, but it's quite helpful just having sort of, if you keep reading then it sort of...</p> <p><b>Theo:</b> There is quite a lot of reading and writing, and I was really struggling at first but I've sort of managed to cope with it.</p> <p><b>Charles:</b> Yeah, even... like it helps me if I've heard it. I quite like a video because I will watch a video through, then I will watch the video through and I will make notes. And it will just help kind of if I can hear it, and then see it and hear it and see it, then it will help me be like 'Okay, I can get that right', by like one letter of something, which helps a lot in exams.</p> <p><b>Moon:</b> I... spelling is... so some words I can spell and some words I can't, and actually I've found a way that I can improve my spelling a lot.</p>
	Dyslexia is permanent	Difficulties will always exist	<p><b>Violet:</b> I will definitely still be a little slow with reading and writing, stuff like that. But...</p> <p><b>Researcher:</b> Yes. So you don't think you will ever completely get to the other end of the pole, of just not having dyslexia?</p> <p><b>Violet:</b> Yes.</p> <p><b>Researcher:</b> But you can definitely make improvements in your reading and spelling skills so that you are very close to...?</p> <p><b>Violet:</b> Yes.</p>

			<p><b>Theo:</b> <i>I don't know but I would probably find a way to get over sort of some of the symptoms. ... Like words would always still seem jumbled up but grammar and spelling would get easier.</i></p> <p><b>Researcher:</b> <i>So there maybe are some aspects of it that you don't think are necessarily changeable, like the kind of like visual, the confusion when you look at like a big block of text.</i></p> <p><b>Theo:</b> <i>Yeah.</i></p> <p><b>Researcher:</b> <i>But in terms of your skills, like your actual spelling skills and grammar skills, those could be improved so that they were kind of just the same as everyone else's?</i></p> <p><b>Theo:</b> <i>Yeah. ... I think I would still have it but it just wouldn't affect me in the same way.</i></p> <p><b>Researcher:</b> <i>You could improve on it if, what, if you did what?</i></p> <p><b>Moon:</b> <i>If I just practised. I have got my own style of writing.</i></p> <p><b>Researcher:</b> <i>Yeah. And what about these things? Memory and processing. Do you think those are things that you could improve on? Or do you think those are things that are just...?</i></p> <p><b>Moon:</b> <i>I think I could improve on them to a certain extent, but I don't think they are something I can suddenly overcome.</i></p> <p><b>Researcher:</b> <i>No. Do you feel like they are more, I don't know, permanent? More part of... just how you are made up?</i></p> <p><b>Moon:</b> <i>Yeah. Anyone can have bad handwriting.</i></p>
	Accepting and working around it	“Accept it” – difficulties, “Work around the problems”	<p><b>Oz:</b> <i>But it's not because I couldn't, well, I obviously can't spell but it's the fact I got three words right in the whole test, including the title and yeah... so it was, and it was the fact that phonetically everything was correct but it just didn't fit into the patterns and stuff. And you kind of just, um, you accept it to be honest. You can't... you learn how to spell the words because you constantly correct yourself.</i></p> <p><b>Oz:</b> <i>Um, I was offered other ways, especially when I came to secondary school and there was a lot more writing and stuff, um, but I kind of... I had already started to work round the problems so I thought rather than stop I would use the help to help me work round the problems, in the way I had already kind of had to start doing it. And that's what used to help at primary school really, to kind of help me get round the first couple of problems that I had encountered.</i></p> <p><b>Lucy:</b> <i>Yeah, because like if you... before I remember just thinking 'I'm just rubbish. I'm not good and all my friends are really good at doing all of this' and I was just like 'Why aren't I as good as everyone else?' And then there's sort of like finally a reason that I can actually... when people are saying 'Why are you taking so long on that?' I will just be like 'Well, it's just the way I am'.</i></p>

			<p><b>Theo:</b> But for me I sort of, it felt I struggled but I didn't really know why. Then I got told why and thought, okay, so it's not just that I'm stupid. There is a reason. ... ..And I can work around it.</p> <p><b>Theo:</b> Yes. Nowadays I just feel comfortable with it [dyslexia].</p> <p><b>Charles:</b> But then once I understood 'Oh, okay. I do have this' and this, because I won't be able to kind of finish everything at the same time as, say, my friends will. So I'm a little bit slower and it allowed me just to relax and be like 'Oh, okay. If I can get the help that I need then I will be able to finish the exams'.</p> <p><b>Moon:</b> No. It <u>is</u> harder for me to learn Korean. I just have to persevere.</p>
What do YP with dyslexia perceive as the advantages and disadvantages of the dyslexia label?			
The label changes others' perceptions			
	Diagnosis changes people's negative judgements	Perceptions of others prior to diagnosis, Diagnosis changes perceptions, Intelligence, Self-image, "Stupid", Expectations and assumptions, Explanation – for others,	<p><b>Violet:</b> If I didn't have the diagnosis, people would just assume that I was a bit dumb. I know my mum didn't get it until she was... she had left school so her school experience was horrible because her teachers just thought she was stupid. ... So it would definitely be better if I had the diagnosis.</p> <p><b>Oz:</b> I suppose that's much more preferable to being... either one is, if people understand that you have them it's better than nothing. Because otherwise you are just assumed to be lazy and stupid.</p> <p><b>Oz:</b> I have vague memories of... because I moved school in Year 3, because my dad's job moved and we all moved as well – but I have vague memories of really not liking my old school. It was quite a small school and I can't remember much but I have a memory of being labelled as lazy and...</p>

		<p>“Lazy” – perceptions of effort</p> <p><b>Oz:</b> Well, prior [to diagnosis] it was kind of just... I think I was one of those students who is kind of, I was seen as hardworking but didn't necessarily get it, but reasonably clever. Um, and we wanted to learn but we couldn't quite grasp it.</p> <p><b>Lucy:</b> I'm not really sure. I just remember my mum getting very annoyed because they wouldn't give, like they... it took her ages going in to them, 'Can we have this test done?' And then they said 'She probably just needs to try more' and stuff.</p> <p><b>Researcher:</b> If we think about the term 'dyslexia' and having had that diagnosis, what do you think are the advantages of having had that? If any?</p> <p><b>Lucy:</b> People don't just think you are not trying. People sort of understand that you do do stuff differently and it's not that you don't care and you're not trying. It's just that you're slightly different in the way you do it.</p> <p><b>Lucy:</b> No. Definitely only afterwards. I never had any help before. Basically our primary school would be like 'Well, there's no reason so they just need to try harder'.</p> <p><b>Theo:</b> Teachers will treat you differently, yeah. They sort of are more inclined to help you. I had a French teacher who was always really willing to help, so...</p> <p><b>Researcher:</b> Yeah. Do you have any idea why they felt like they... why would they be more inclined to help the person who has this diagnosis than the person who doesn't?</p> <p><b>Theo:</b> There's a different sort of idea around it. Because someone might think that [person without a diagnosis] is lazy and they are just like that.</p> <p><b>Researcher:</b> How do you think you would feel if someone came along and said 'Oh, we're not going to use that term anymore' and you stopped being able to use the term 'dyslexia'?</p> <p><b>Theo:</b> Then people would probably just perceive me as not being as smart.</p> <p><b>Researcher:</b> Yes. So how would you feel then?</p> <p><b>Theo:</b> I would probably struggle a lot in class with paying enough attention, because if I'm labelled with something I'm more likely to just go with it than fight it.</p> <p><b>Charles:</b> So if there wasn't the term 'dyslexia' around, then people would be like 'Oh, you just can't read. Start reading loads of books', instead of going like 'Okay, we've got to find different ways of trying to help you read'. Or to...</p> <p><b>Researcher:</b> So they would just think you need to practise more?</p>
--	--	---

			<i><b>Charles:</b> Yeah. Which probably wouldn't help students.</i>
	Diagnosis may lead to negative judgements	Diagnosis changes perceptions, Intelligence, Self-image, "Stupid", Expectations and assumptions, Explanation – for others, "Lazy" – perceptions of effort	<p><i>Researcher:</i> So then are you describing the potential disadvantage of that label is that if somebody hears 'Oh, Oz is dyslexic' before actually meeting you, that they might then make assumptions about you that would be inaccurate?</p> <p><i>Oz:</i> Yeah. Or they will go looking for the proof, if you will.</p> <p><i>Researcher:</i> Yeah?</p> <p><i>Oz:</i> It becomes a bit of a... so it can become a bit of a self-fulfilling prophecy. So if you're told you're bad at something by everyone you meet, it's very difficult to then decide you are going to go out and work at it. Um, and it took me... ..For me to go out and really work hard on my English, which affected my English and my History, and it kind of, it was... I started kind of right back end of Year 10, and it didn't really reap rewards until kind of just at the right time. And it was kind of, it was one of those things that took an awful lot of work and didn't seem to give much out. So if you are told you are stupid, um, shall we say it's not brilliant for your self-esteem.</p> <p><i>Researcher:</i> Yeah, okay. So maybe that is reflected in the fact that you initially didn't want anybody to know, because actually you'd rather they know you than...</p> <p><i>Theo:</i> Yeah. Or they'd just sort of think that I'm just stupid.</p> <p><i>Researcher:</i> What do you mean by that?</p> <p><i>Theo:</i> Well, at that time I just thought if I can't do a subject very well it makes me look stupid or something. So...</p> <p><i>Researcher:</i> Okay. So did you feel that if they knew you had dyslexia they would think that you were stupid?</p> <p><i>Theo:</i> Yeah.</p> <p><i>Charles:</i> Okay. So you'd kind of think that more, like dyslexic kids, are normally dumber because they can't do as much.</p> <p><i>Researcher:</i> So people who haven't experienced dyslexia might think that people with dyslexia are not as bright?</p> <p><i>Charles:</i> Yes, bright or... because I know that I have experienced people going 'Oh, you're stupid' just because I'm dyslexic.</p> <p><i>Moon:</i> No. I think people see you as dumb.</p>

			<p><i>Researcher: Okay, so people might equate having dyslexia with being dumb?</i></p> <p><i><b>Moon:</b> Yeah, and unintelligent. And actually we could be more intelligent than you are.</i></p> <p><i>Researcher: Yeah.</i></p> <p><i><b>Moon:</b> We just have a different... we're just different.</i></p> <p><i><b>Moon:</b> Yeah. But then possibly if I didn't have dyslexia people might have not expected me to do badly. I don't know.</i></p> <p><i><b>Oz:</b> It's not something I usually take out on the first meeting. Because I've found it's easier to explain to someone you are dyslexic once they know you are clever, than to explain to someone you are clever once they know you are dyslexic.</i></p>
<b>The label does justice to the significant of the difficulties</b>			
		<p>Dyslexia is more significant, "Beyond" literacy, Medical label, "Weight" of the term dyslexia</p>	<p><i><b>Oz:</b> But within kind of a... the diagnostic, the fact it's been diagnosed as a label, gives it some credence if you will. So maybe if you had, you know, the dyslexia but then you had an equivalent term, would probably be the best way of going round it. Because just dropping the label in its whole would, I think, remove the validity of whatever label took its place if it wasn't as... because the word 'dyslexia' doesn't sound English. ... It has a, shall we say, it has a rather un-English, almost medical feel to it. ... And that, even before you go away and look it up, adds some almost weight to the term.</i></p> <p><i><b>Oz:</b> It's just that you suffer with... shall we say you have a long running feud with the written word. So kind of if I was given that [a descriptive term], honestly that, I don't think it would quite explain all the difficulties I have, because my organisational difficulties extend beyond literacy.</i></p> <p><i><b>Theo:</b> I probably would prefer 'dyslexia' because 'difficulties' makes it sound more like you are just struggling for a little bit and that you can get over it. But I think it takes a bit more effort than just a little bit of work.</i></p> <p><i>Researcher: Okay. So do you think 'dyslexia' is a bit more like, um, it makes it sound more... I don't know, it's like a stronger word I suppose.</i></p> <p><i><b>Theo:</b> Yes.</i></p> <p><i>Researcher: So 'literacy difficulties' sounds a bit like...</i></p> <p><i><b>Theo:</b> It sounds like a short-term sort of thing. Like you are struggling in class for a bit. ... Yes. It's not just I'm struggling in that subject. I am struggling in that broader school sense. ... Maybe this is for people which struggle more, but this is like they are still struggling.</i></p>

			<p><i>Researcher: Yes, okay. So, you would put yourself firmly at the end of someone who has dyslexia because that's kind of how you see yourself really.</i></p> <p><b>Lucy:</b> Yes.</p> <p><i>Researcher: And it's more of a one or the other for you, rather than a continuum of...</i></p> <p><b>Lucy:</b> I suppose like sort of people who would have literacy sort of differences would be sort of there-ish.</p> <p><i>Researcher: Okay, so they would be closer to the 'normal' end.</i></p> <p><b>Lucy:</b> Yes. They would be closer to that, I would say. In this half, or maybe it the third sort of quarter.</p> <p><b>Moon:</b> Oh, I would feel like... I would kind of feel like I was just... because everyone else had a label and I didn't, I would kind of, I would feel, I don't know, left out. I would feel like those with dyslexia have a label so this must be worse, but it's actually the same.</p> <p><i>Researcher: So is there something about the label that makes it more serious? Like people take it more seriously?</i></p> <p><b>Moon:</b> Yeah, because this is like, you know, that illness which hasn't been proven, kind of like the allergy to the synthetic world or whatever, and then they go and live in like the Texas desert or something.</p> <p><i>Researcher: Okay.</i></p> <p><b>Moon:</b> And they never touch a book. I just... if everyone else had a label and you didn't, I would feel like it was kind of, I don't know, fake. And it didn't actually kind of feel like I was...</p> <p><b>Moon:</b> And also I feel like a lot of people think dyslexia is just about reading and writing.</p> <p><i>Researcher: Right, yeah.</i></p> <p><b>Moon:</b> But it's more than that.</p>
<b>The label does not give enough information</b>			
	'Dyslexia' does not describe an individual	Terms that are easier to understand,	<p><b>Moon:</b> Yeah. It's also... we tend to be a society that likes to label things. You're straight, you're asexual, you're dyslexic, you're intelligent... because we think it's simpler for everyone, but...</p> <p><i>Researcher: Yeah. Do you think it is simpler?</i></p>

		<p>Accuracy of the label, Need to label, Different types of dyslexia, Misconceptions about dyslexia</p>	<p><b>Moon:</b> I don't know. Well yeah, I think it's simpler if we can just label everything and try to understand the world, but there's no kind of claim to be able to. I don't think it's possible.</p> <p><b>Moon:</b> I think people are less likely to think you're dumb if you have dyslexia because I think a lot of people probably don't understand what the word means. But I'm pretty sure everyone knows what the word 'dumb' means.</p> <p><b>Researcher:</b> Okay. So actually maybe that's another disadvantage of dyslexia, is that not everyone knows what it means?</p> <p><b>Moon:</b> Yeah. I think it's better now than it has ever been, but...</p> <p><b>Researcher:</b> Okay. So not everyone knows but, like, it's increasing. People's awareness is increasing.</p> <p><b>Moon:</b> Yes, awareness is increasing. Yes.</p> <p><b>Moon:</b> No, they are definitely not. They are individual people who have a personality.</p> <p><b>Researcher:</b> So obviously they are all individuals, but do you think the things that they find difficult due to their dyslexia are also all different? Or are they more...?</p> <p><b>Moon:</b> I think, yeah. For everyone it's different. Everyone has got a different experience of dyslexia.</p> <p><b>Moon:</b> Because instead of being the umbrella term it's actually...</p> <p><b>Researcher:</b> It's more specific?</p> <p><b>Moon:</b> Yeah, it's less of a label.</p> <p><b>Researcher:</b> Okay. So it's more specific rather than an umbrella term, and also it's less of a label.</p> <p><b>Moon:</b> Yeah.</p> <p><b>Researcher:</b> Why is that a good thing?</p> <p><b>Moon:</b> Well, I think it's the same, it's similar to the point before. It's just... it's like dyslexia and then people will have their own understanding of what dyslexia is, but actually I think if I gave this explanation to my friends, they wouldn't connect it at all with dyslexia.</p> <p><b>Oz:</b> Well, within the... I think it would not be nice to have a slightly more to the point label, if you will.</p> <p><b>Researcher:</b> A descriptive label do you mean?</p> <p><b>Oz:</b> Yeah, a more descriptive label, because you kind of have to go 'what is dyslexia?' Go away and look it up a bit, and then come back.</p> <p><b>Oz:</b> Yes, however it [the descriptive term] is very effective at describing people whom it encompasses. And it's very difficult to get the best of both worlds.</p>
--	--	---	--



			<p><b>Theo:</b> Well, if you don't give it a term as such, if you say 'they struggle with this' but if you have dyslexia a lot of people don't really know what it is a hundred percent. Because I don't really know what it is a hundred percent and I have it, so...</p> <p><b>Researcher:</b> Yeah, okay. So this [descriptive term] maybe is a bit easier to understand for people?</p> <p><b>Theo:</b> Yeah.</p> <p><b>Researcher:</b> Like 'literacy difficulties' they sort of know what that's going to mean. Whereas they might not necessarily know what that means.</p> <p><b>Theo:</b> Yeah.</p> <p><b>Charles:</b> I would say that was, um... so people normally don't understand exactly what dyslexia is.</p> <p><b>Charles:</b> So in lessons they can apply their lessons to the generalised dyslexic person, but obviously if that doesn't work for that... like say there's two dyslexic people in the room but it doesn't apply to their dyslexia types, then those two could be worse off.</p> <p><b>Charles:</b> Well, yeah. I would say that it's... it would be... Having dyslexia used as a general term is good because it helps teachers and other people understand, 'okay, it's a learning difficulty'. But it would be, I'd say that with individual needs it's kind of neater than dyslexia itself. It would help teachers understand if it was broken down into different kind of sub-sections, I guess. ... ..If it was broken down into like different sub-sections then teachers would know, 'Okay, this is what I can do to help <u>this</u> student. This is what I can do to help <u>this</u> student. And this is what I can do to help <u>this</u> student'. So if there are different ways in which they find it easier to learn, then maybe the teacher can, like during lessons, can go and help those students just with... like put it into terms where they will be able to learn a little bit better.</p>
	Lack of information at time of	Being informed about diagnosis	<p><b>Theo:</b> I didn't know what it was so I just thought... no. So I just got on with it and just didn't really think too much about it.</p> <p><b>Researcher:</b> Did you have no idea what it was? Did you know it was something to do with...?</p>

## Appendix J

	assessment and diagnosis		<p><b>Theo:</b> <i>I knew it was something to do with English but that's about it really.</i></p> <p><b>Researcher:</b> <i>Yeah, okay. So there wasn't like a proper explanation for you of what that meant?</i></p> <p><b>Theo:</b> <i>No. Not that I can remember.</i></p> <p>...</p> <p><b>Researcher:</b> <i>Okay. So were you aware at that time what they were doing?</i></p> <p><b>Theo:</b> <i>Not really. They just told me to write a paragraph about myself and copy the words, and stuff like that. ... Well, when I found out I didn't really know what it was so I just thought everyone, you know, people said that. And so... I thought it was more derogatory then. Then I found out what it is.</i></p> <p><b>Researcher:</b> <i>Do you know who diagnosed you?</i></p> <p><b>Oz:</b> <i>No. I just kind of sat in a room with a person and he did some tests, questions and like, I don't know, it was quite a long time ago and for me, as a Year... I can't remember. Anyway, to me at that age it wasn't really that important.</i></p> <p><b>Lucy:</b> <i>I don't really think so because they never talked to me about it, they were just talking to my mum while I was sitting on the floor going, 'Oh, okay'.</i></p> <p><b>Researcher:</b> <i>Oh, right. You were quite little.</i></p> <p><b>Lucy:</b> <i>Yes.</i></p> <p><b>Researcher:</b> <i>So actually they didn't involve you that much.</i></p> <p><b>Lucy:</b> <i>Yeah, I don't really know what dyslexia like properly is because I was never really told about it.</i></p> <p><b>Researcher:</b> <i>So do you still feel like that now?</i></p> <p><b>Lucy:</b> <i>Yeah. I sort of... I like know a tiny bit I think, like roughly. But like I was never really told what it was.</i></p>
<b>The label is necessary for support</b>			
	Diagnosis leads to support	No support prior to diagnosis, Diagnosis is necessary for support, Diagnosis informs intervention,	<p><b>Researcher:</b> <i>So your mum had already noticed when you were quite young that you were having similar difficulties that she'd had?</i></p> <p><b>Violet:</b> <i>Yes. It was more of the 'now I can get extra help and that's a good thing'.</i></p> <p><b>Researcher:</b> <i>So as far as you know you weren't getting any extra support before you'd had that diagnosis?</i></p> <p><b>Violet:</b> <i>Not really, no. Yes.</i></p> <p><b>Violet:</b> <i>I'm not sure, it's just I've got a friend who is getting tested when she goes to college.</i></p> <p><b>Researcher:</b> <i>Oh, okay.</i></p> <p><b>Violet:</b> <i>Because she wants the test to make sure... to get the extra help because she doesn't get very much help at the moment.</i></p>

		<p><i>Researcher: So is this a friend who doesn't have a diagnosis?</i></p> <p><b>Violet:</b> <i>Yes, she's not diagnosed dyslexic.</i></p> <p><i>Researcher: But she also is struggling?</i></p> <p><b>Violet:</b> <i>Yes.</i></p> <p><i>Researcher: Do you think she is struggling as much as you have done in the past?</i></p> <p><b>Violet:</b> <i>She's a lot worse than I am, yes. She just hasn't been tested.</i></p> <p><b>Oz:</b> <i>Well, prior [to diagnosis] it was kind of just... I think I was one of those students who is kind of, I was seen as hardworking but didn't necessarily get it, but reasonably clever. Um, and we wanted to learn but we couldn't quite grasp it. But then they worked out why I didn't quite grasp it and they were able to deal with the problems. It wasn't so much me understanding it but telling other people that I could and showing to other people that I could understand it.</i></p> <p><i>Researcher: Yeah, sure. Do you remember... I suppose although it was a long time ago and you would have been very young, do you remember getting any extra help before you had your diagnosis?</i></p> <p><b>Lucy:</b> <i>No.</i></p> <p><i>Researcher: So it only came afterwards?</i></p> <p><b>Lucy:</b> <i>No. Definitely only afterwards. I never had any help before. Basically our primary school would be like 'Well, there's no reason so they just need to try harder'.</i></p> <p><b>Theo:</b> <i>You are more likely to get help if you have dyslexia.</i></p> <p><i>Researcher: Okay. And I suppose that has been your experience, hasn't it, in terms of when the school didn't know you had it, they didn't give you that extra help.</i></p> <p><b>Theo:</b> <i>Yes.</i></p> <p><i>Researcher: So in Year 7 and 8 when you were here and they didn't know that you had dyslexia, do you think they knew that you were struggling? Do you think they would have described you as having difficulties with literacy?</i></p> <p><b>Theo:</b> <i>Yes. My English grades were always quite low compared to all my other grades.</i></p> <p><i>Researcher: But they still didn't actually offer you help until you...?</i></p> <p><b>Theo:</b> <i>I had never been helped as such. I think they did some things but I'm not really sure.</i></p>
--	--	---

			<p><i>Researcher: Okay, so they do maybe try and help. Maybe you weren't that open to the help?</i></p> <p><b>Theo:</b> <i>Erm... yeah.</i></p> <p><i>Researcher: Or they just didn't do very much?</i></p> <p><b>Theo:</b> <i>I don't really remember. I don't remember being offered any help, but...</i></p> <p><i>Researcher: You don't remember being offered help?</i></p> <p><b>Theo:</b> <i>No.</i></p> <p><i>Researcher: And in Year 7, although you weren't told the outcome of the test, are you aware if anything happened as a result of that? So you were flagged up as a maybe. Did you then get any extra support?</i></p> <p><b>Charles:</b> <i>No, I didn't get any extra support or help. Because I wasn't told or my teachers weren't told. So it was just carrying on with how they normally did every lesson.</i></p> <p><b>Charles:</b> <i>Obviously if there wasn't the term of dyslexia, which helps students, then you wouldn't get all the required... well, the help that you need to essentially kind of level the playing field.</i></p> <p><b>Moon:</b> <i>I think if they got this description from you, I think they would be able to. But if they were just told you were dyslexic, I would... if I was told someone was then I would be providing them with yellow paper, I would be providing them with the scribbler that goes down the page, which is actually quite helpful. But it's a different colour so it's not helpful. And then I don't think, no, I think everyone is different.</i></p> <p><i>Researcher: So in Year 6, you can't remember exactly what the assessment was but the outcome of it was that you got more time?</i></p> <p><b>Moon:</b> <i>I got extra time. I got a reader, which I didn't need, but the school just provided it and I just was like 'No, I don't want it'. I got a scribe and... yeah... I think they might have tried to provide me with yellow paper but I hate yellow paper I think yellow paper is the most infuriating thing ever.</i></p>
	Equity of access to diagnosis	Access to assessment, Parents' experiences impacting on own diagnosis,	<p><i>Researcher: Do you think she is struggling as much as you have done in the past?</i></p> <p><b>Violet:</b> <i>She's a lot worse than I am, yes. She just hasn't been tested.</i></p> <p><i>Researcher: Okay. Do you have any idea why she hasn't been tested? Or...</i></p> <p><b>Violet:</b> <i>I just don't think the school did it. This school doesn't do it.</i></p> <p><i>Researcher: Okay.</i></p> <p><b>Violet:</b> <i>And she obviously didn't do it in her primary school, so...</i></p> <p><i>Researcher: Okay. So what did... so you think that she would like to have that diagnosis?</i></p>

		<p>Fairness and equity</p> <p><b>Violet:</b> Yes.  <b>Researcher:</b> Like to have that test, but she just hasn't had the opportunity.  <b>Violet:</b> Yes.</p> <p><b>Violet:</b> If I didn't have the diagnosis, people would just assume that I was a bit dumb. I know my mum didn't get it until she was... she had left school so her school experience was horrible because her teachers just thought she was stupid.</p> <p><b>Oz:</b> Because he kind of understood and had experience of it, and he didn't want it to affect me and my brother.  <b>Researcher:</b> Okay. Do you think that then was a motivator behind him making sure you got that assessment?  <b>Oz:</b> That was, I think, the main reason he made us actually take it.</p> <p><b>Lucy:</b> I'm not really sure. I just remember my mum getting very annoyed because they wouldn't give, like they... it took her ages going in to them, 'Can we have this test done?' And then they said 'She probably just needs to try more' and stuff. I honestly don't know. They have changed head teacher quite a few times now so it might have been down to that teacher.</p> <p><b>Theo:</b> Yeah, and I think it's because I was struggling in class. I might have been older but I'm not actually sure. I was struggling in class and my mum asked if – because someone else was getting tested – and my mum asked if they could test me. And so they said that I... yes.</p> <p><b>Charles:</b> Yeah, okay. Well I would say that that's good then. Obviously not everybody can go and have a test done. When you're in a school like this it's a lot better because they test every child, which is good, because it means that every child, they know exactly what each child needs. But in certain schools it is not possible to do that. So if you can give a child the help that they need to succeed, then you should do it. But then obviously there's a problem on whether they are just, schools are going 'Oh, yes, have this. Have this' just to help the students get extra time.</p> <p><b>Moon:</b> I always knew I had dyslexia. My dad is a head teacher and he had experience working with people, and my mum was dyslexic but it hadn't been diagnosed until she was much older so she didn't get any help at all at school, and she</p>
--	--	--

## Appendix J

			<p>was kind of... labelled a failure. And then, in Year 6, they wanted me to have extra time for my SATs so they got me tested, and then again I got tested in Year 10 because they were like 'No, you don't get extra time anymore'.</p> <p><b>Moon:</b> Everyone is given extra time or you're given extra time on your own. It all depends on the lesson you're in. But most of the time everyone is given extra time, which is not helpful.</p> <p>...</p> <p><b>Moon:</b> I understand that it's hard for them to give me extra time because it's within a lesson setting, but I could come back at lunch, I could... yeah. I don't think it... but if everybody gets extra time, I don't think that's fair but I've told the teachers and they said 'But you're still getting your extra time'. So...</p>
	Support is more important than the label	Support is more important than the label	<p><b>Researcher:</b> How do you think you would feel if [your dyslexia diagnosis] was taken away?</p> <p><b>Violet:</b> I would just be annoyed. Especially if like the exam help and everything got taken away with it. That would be really annoying.</p> <p><b>Researcher:</b> What if you still had all the extra help, you just didn't have the label?</p> <p><b>Violet:</b> Yeah, that would be fine.</p> <p><b>Researcher:</b> Then you wouldn't really...?</p> <p><b>Violet:</b> Yeah, I wouldn't really be fussed. As long as I still got the help I needed, I wouldn't care what it was called.</p> <p><b>Lucy:</b> But... and then it's sort of like people would get sort of the help easier. Because I suppose if you don't have dyslexia but you find a lot of things hard, people may just not be as inclined to give you help, which I think... it's not so much different. I think there should be the same help available if you have dyslexia or if you find it hard, if you find stuff hard. Because in essence you are still both finding stuff hard.</p> <p><b>Lucy:</b> Yeah. Because even though you haven't got this thing [dyslexia], you still find it hard. So in essence it's a very similar thing. And so you should still get the help for it if you...</p> <p><b>Charles:</b> I don't think it would really impact me. I don't really see dyslexia as a label that impacts like the way in which I succeed. It's more, it just helps me understand how I've got to use it, like within my limitations. Like how I can succeed. Which way that I have to learn to succeed. There's no... I don't see that it would impact me. If I got the same help, I would do the same and it doesn't, I wouldn't say it impacts the way in which I would have done.</p> <p><b>Researcher:</b> So, correct me if I'm wrong, but a good school would notice the students who were struggling, try and find out more about why that is...?</p>

			<p><b>Moon:</b> Yeah. But I do think there is a funding issue. There is not enough funding in schools.</p> <p><b>Researcher:</b> Yeah, okay. But I mean in an ideal world.</p> <p><b>Moon:</b> Yeah.</p> <p><b>Researcher:</b> And it's not necessarily that they need to then give you a diagnostic label like dyslexia?</p> <p><b>Moon:</b> No.</p> <p><b>Researcher:</b> But they will need to give you the support that is necessary?</p> <p><b>Moon:</b> Yeah.</p>
<b>Understanding led to perseverance</b>			
	Diagnosis helped participants to understand their difficulties	Explanation – for self	<p><b>Lucy:</b> I sort of felt like that... because like lots of other people would be like 'Oh, this is really easy' to do something and I would be like 'well, why isn't it easy for me to do it?' And it sort of feels a bit sort of like... it's quite sort of, so you know that it's not just you being stupid. It's actually that you actually have something and they will be able to help you with it now.</p> <p><b>Lucy:</b> And with dyslexia there's this like, this reason inside your head and it just makes you like different. I don't really know much about it, but it's sort of... there's sort of like an actual reason. But literacy issues, you just find stuff hard. Maybe for some other reason, it just... I think if I didn't get that help, it would be almost like I wouldn't definitely be... because I am definitely doing a lot better now in school compared to how I did in primary school. So if I didn't get help I would, I would be doing a lot worse in school I think, because I just think there's no point in me trying because I'm just going to be worse than everyone else.</p> <p><b>Theo:</b> But for me I sort of, it felt I struggled but I didn't really know why. Then I got told why and thought, okay, so it's not just that I'm stupid. There is a reason.</p> <p><b>Charles:</b> So probably another disadvantage of that would be that an individual might not think they are good enough, if there wasn't the term dyslexia where you obviously help the individual know what's kind of... like what they need to do or why they struggle with certain tasks. So it would help them understand, even if the teacher didn't really, they would</p>

## Appendix J

			<p><i>be like ‘Oh, okay. I would be better off learning in this way. So if I can do it this way then I will be able to learn the material better’.</i></p> <p><i>Researcher: So if we imagine that there was just no label, no diagnosis or anything, what would that be like? Can you imagine? Like how do you think it might have been for you if nobody had ever assessed you for dyslexia or said that you had dyslexia?</i></p> <p><i><b>Moon:</b> Um, I don’t think I would be as stubborn as I am now. I do not think I would have passed any of my GCSEs.</i></p> <p><i>Researcher: Okay.</i></p> <p><i><b>Moon:</b> I don’t think I would be where I am now if there was no label.</i></p> <p><i>Researcher: If there was no label. So do you mean if there was no label and nobody had noticed?</i></p> <p><i><b>Moon:</b> If I’d had no support or had... or not just support but like just... yeah. I’d have felt like I was a failure.</i></p> <p><i>Researcher: Yeah. So having the label of dyslexia did help you... to understand that?</i></p> <p><i><b>Moon:</b> Yeah.</i></p>
	Diagnosis helped participants to persevere	Perseverance, Challenging self, “Just get on with it”, Hard work, “Have to work harder” than others,	<p><i>Researcher: I feel like you have had an integral role as well in making that kind of improvement. What do you think it is that you have done or... I don’t know, how would you describe your approach to making that improvement?</i></p> <p><i><b>Violet:</b> I don’t know. It wasn’t really an approach. Just get on with it.</i></p> <p><i>Researcher: Just get on with it?</i></p> <p><i><b>Violet:</b> Yes.</i></p> <p><i>Researcher: Would you say that you’ve worked hard?</i></p> <p><i><b>Violet:</b> Yes.</i></p> <p><i><b>Oz:</b> And so I went ‘I really want to do Further Maths because I don’t want to do Chemistry as much’, and the result of that kind of realisation was I worked really, really hard in Maths, because I had to get quite a high grade in that to do it, and I worked really, really hard with my writing and English. Because it meant that I would have, shall we say, casus belli for doing. You know, there’s a reason I show that I am clever enough that I can do it, so you can’t not let me do it.</i></p> <p><i><b>Lucy:</b> Yeah, because I really didn’t want to read. And sort of after that, like I was given more help with it and I was... because I remember like the old, I remember talking to one of the old teachers about dyslexia and it was like ‘Oh, you’ve just got to keep trying. You will get it one day’. So I thought, I just sort of thought if I keep trying I will get it, and in the end I slowly started to like it a bit more. It must have been sort of end of primary school, start of secondary school when I finally sort of felt... when I just found reading a lot easier.</i></p>



			<p><b>Theo:</b> I would probably struggle a lot in class with paying enough attention, because if I'm labelled with something I'm more likely to just go with it than fight it.</p> <p>...</p> <p><b>Researcher:</b> Yeah, okay. So do you think then having that diagnosis of dyslexia has stopped that from happening? It's stopped you from just giving up?</p> <p><b>Theo:</b> I think so, yes. Because my dad had a similar thing and he was never really diagnosed. And then he wished... ..and didn't do great in class. ... ..But, um, I feel I have done better.</p> <p><b>Researcher:</b> So whereas he didn't have that diagnosis and really struggled, you feel like having it has made you actually like work a bit more.</p> <p><b>Theo:</b> Harder, yeah.</p> <p><b>Charles:</b> I felt quite dumb because I thought 'Oh, I'm clearly not as good as everybody else. I clearly can't read as well as everybody else. I'm clearly not as fast. I clearly can't spell very well compared to everybody else'. So I thought 'I am just really dumb. I can't do it'. Whereas then when I found out that I did have dyslexia I was like 'I'm not dumb. I just need stuff to facilitate my learning and can help me in exams'. And that's how everything kind of changed my point of view. Because I wasn't... I thought I was just dumb or wasn't particularly gifted in education or... but then when I found out that I was dyslexic I was like 'Oh well, I can actually do this. I might not be dumb. It's just that I might not have received the help that I needed over the years'. And then you see, when I got the help in the exams, it helped me to get better grades.</p> <p><b>Moon:</b> I didn't start to learn to read until I was in Year 3 and until I moved to a better school where there was kind of more provision for people with dyslexia. It wasn't a special school, it was just a new primary school. But yeah, I kind of just forced myself to read and I just persevered, and I was like... and then I just enjoyed reading. Because it's kind of an escape to a different world.</p> <p><b>Researcher:</b> But do you feel like you do things differently because of having that knowledge, that you have dyslexia?</p>
--	--	--	--

## Appendix J

			<p><b>Moon:</b> <i>Um, I don't know what I would have done before that. But, um... ..I don't know if I would have had the perseverance to get through all the comments from my teachers.</i></p>
	<p>Diagnosis led to participants wanting to exceed expectations</p>	<p>“Sheer bloody-mindedness”, Proving self,</p>	<p><b>Oz:</b> <i>The problem is that I've existed in a bit of a microcosm because through sheer bloody-mindedness and work I have managed to stay at the top.</i></p> <p><i>Researcher: And perhaps another person in your situation who didn't quite have that level of perseverance or resilience, might have given up?</i></p> <p><b>Oz:</b> <i>Yeah, then my reaction to being told I can't do something is to try and go out and do it.</i></p> <p><i>Researcher: Mm.</i></p> <p><b>Oz:</b> <i>And I'm kind of fortunate that is my kind of stock reaction, to be vehemently told I can't do it. Um, that did bite me in the foot with having to pick History, even though I really enjoyed it, that was enough writing for me.</i></p> <p><b>Theo:</b> <i>Yeah, and around CS as well. Around CS it's more like people went there if they really were struggling.</i></p> <p><i>Researcher: Okay.</i></p> <p><b>Theo:</b> <i>And I thought I was coping so I just got on with it.</i></p> <p><i>Researcher: Okay, so you didn't want to kind of like be lumped in with maybe a group of people who are using the Curriculum Support centre who need... who aren't coping?</i></p> <p><b>Theo:</b> <i>Yeah.</i></p> <p><b>Charles:</b> <i>No, I wouldn't say pressure. I think it's just... well, I suppose it is pressure, but not from other people. I would say it's more from, like myself.</i></p> <p><i>Researcher: Yes.</i></p> <p><b>Charles:</b> <i>Self-induced pressure.</i></p> <p><b>Moon:</b> <i>So I decided to learn Korean because it's considered one of the hardest for someone, an English speaker to learn. And it's also, if you're dyslexic they say 'Oh, you can't learn a language. You would be awful', and actually that's what kind of peps me up and gets me doing things.</i></p> <p><i>Researcher: Yeah.</i></p> <p><b>Moon:</b> <i>So people telling me I can't do something is better motivation than someone saying I can.</i></p>

## Appendix K Extract from a Survey Transcript

*Example extract from the online survey answers of one participant*

What do you think dyslexia is? There are no right or wrong answers, just describe your thoughts.	Why do you think some people have dyslexia and others do not?	Think about Charlie and Colin. What kind of help do you think each person would get?	What do you think are the differences between Charlie's difficulties and Colin's difficulties?	What kinds of GCSE grades do you think Charlie and Colin will get?	What do you think Charlie and Colin's lives will be like? E.g. relationships, jobs, happiness, success.	What would it take for Charlie to beat his dyslexia?	What would it take for Colin to beat his literacy difficulties?
where you struggle with certain areas of language for example reading or spelling	the way there brain has formed	Charlie may get extra time in exams to help him read all the question. they may also get <u>extra curricular support</u> to help them and try to get them to improve.	Collin may have another type of learning difficulty <u>where as</u> Charlie is actually dyslexic.	Charlie may get fairly low scores in English but higher ones in other areas such as maths, Collin may get low scores <u>through out</u> his GCSE's	It is likely that they will both have fairly normal lives and with modern technology like spell check there in ability to spell will become less of a issue however there <u>grama</u> will likely continue to struggle.	i do not know.	if he studies hard and continues to practise allowing him to progress and evenly be smarter.



## Appendix L    Extract from an Interview Transcript

Researcher: So I want to explore the advantages and disadvantages of those. So, let's start with the advantages. So from your perspective, so this is kind of the world we live in at the moment. You *have* been described as having dyslexia.

Moon: Yeah.

Researcher: What would you say are the advantages of having that word to use and to describe your needs, to tell other people about or to have other people...?

Moon: People can understand you better, I think, in some circumstances. But not wholly.

Researcher: So people can understand you better if they... what do you mean? If you told them you had dyslexia?

Moon: Well, yeah. They can... or they can think they can understand how your brain works. But no one can understand how I think someone's brain works.

Researcher: Yeah.

Moon: But if we could our brains would be so simple.

Researcher: Oh yeah.

Moon: But we wouldn't be able to understand.

Researcher: So by being able to describe yourself as dyslexic you think you can let other people know something about how your brain works?

Moon: Yeah.

Researcher: And you think they would understand something about you. Okay. Is there anything else you think that would be an advantage?

Moon: People can understand how they can help you, I think, as well. But... not always because I think a lot of people think it's just reading. And I'm like 'Reading?'

Researcher: Okay. People understand how to help you.

Moon: Also I think my vocabulary is quite... quite good, I think.

Researcher: Uh huh. So...

Moon: Because words interest me.

Researcher: Yeah, yeah. Well, I think that has come across, that you are quite articulate and I mean you are learning Korean, so...

Moon: Yeah.

Researcher: You know, language in itself is not an issue for you.

Moon: No. It *is* harder for me to learn Korean. I just have to persevere.

Researcher: Okay.

## Appendix L

Moon: And there's some people saying 'No, you can't do it' and I'm like 'Yeah, I can. I will'.

Researcher: Okay.

Moon: Which puts a lot of people off, if they're told they can't do it. But if someone tells me I can't do it, even if I don't want to do it in the first place, I will have to do it.

Researcher: Alright. Are there any other advantages to being able to use that word?

Moon: I don't think so. No, I can't think of anything else.

Researcher: Are there any advantages to *not* using that word? So I suppose the words you've used here, like 'dumb' and 'not functioning very well' are...

Moon: I feel like people group you into one category with dyslexia. You are just dyslexic or you're not. And...

Researcher: So maybe that's a disadvantage then?

Moon: Yeah.

Researcher: So people might just lump, what, like lump all people with dyslexia into one group?

Moon: Yeah.

Researcher: And actually they are not the same?

Moon: No, they are definitely not. They are individual people who have a personality.

Researcher: So obviously they are all individuals, but do you think the things that they find difficult due to their dyslexia are also all different? Or are they more...?

Moon: I think, yeah. For everyone it's different. Everyone has got a different experience of dyslexia.

Researcher: Uh huh. So people might not recognise the different experiences people have with dyslexia?

Moon: Yeah, because I think dyslexia is like a kind of little... it's like an umbrella. Underneath dyslexia there's a whole load of things inside... inside there.

Researcher: Yeah. Are there any other disadvantages, do you think, of using that term 'dyslexia'?

Moon: No. Apart from the fact I can't spell it. [LAUGHS]

Researcher: The spelling of the word is not that helpful, is it?

Moon: No. I think people see you as dumb.

Researcher: Okay, so people might equate having dyslexia with being dumb?

Moon: Yeah, and unintelligent. And actually we could be more intelligent than you are.

Researcher: Yeah.

Moon: We just have a different... we're just different.

Researcher: Okay. So people wrongly make the assumption that if you are dyslexic you might not be as intelligent?

Moon: Yeah.

Researcher: Okay. I think we might need to reconsider this, because I feel like that, maybe that's more a description.

Moon: Yeah, it is.

Researcher: Than... so, okay. That's more of a judgment, isn't it?

Moon: Yeah.

Researcher: So, if we didn't have, if we didn't use the term 'dyslexia' to describe people, they might use the term 'dumb' instead?

Moon: Yeah.

Researcher: So maybe for both, so some people might equate dyslexia with being stupid, but equally if we didn't have the term dyslexia, do you think people would be more or equally as likely to think 'Oh well, they are just unintelligent'.

Moon: I think people are less likely to think you're dumb if you have dyslexia because I think a lot of people probably don't understand what the word means. But I'm pretty sure everyone knows what the word 'dumb' means.

Researcher: Okay. So actually maybe that's another disadvantage of dyslexia, is that not everyone knows what it means?

Moon: Yeah. I think it's better now than it has ever been, but...

Researcher: Okay. So not everyone knows but, like, it's increasing. People's awareness is increasing.

Moon: Yes, awareness is increasing. Yes.

Researcher: Okay, let's say... so on this side with this alternative label, instead of saying 'dumb' or 'dyslexia', let's just put a description of how you described yourself in terms of the things that you find a bit more difficult.

Moon: So just the things that we put on that other paper?

Researcher: Yeah, so I think just a purely descriptive term, without any kind of judgment attached.

Moon: Okay.

Researcher: So if I am a teacher and you come to my class for the first time... Oh, hello.

*[interruption]*

Researcher: Anyway, interrupted. We were just getting somewhere. Right, so we were going to put at this end...

Moon: A nice description.

Researcher: A descriptive term. So, what shall I put down?

## Appendix L

Moon: Someone with a... I don't know. It's just a different... oh god. Their brain just works differently.

Researcher: So what I was going to say was if I was your teacher and you were a new student coming into my class, and a teacher you had previously wants to just come and tell me a bit about all the new students that are coming into my class so that I can teach them in the best way that I can.

Moon: Yeah.

Researcher: And they are not going to use the word 'dyslexia' to describe you. What are they going to say?

Moon: She has processing issues and finds it takes longer to remember.

Researcher: Uh huh.

Moon: But is an avid reader?

Researcher: Yes, okay. Right. So that's how we are going to describe you to the teacher.

Moon: Okay.

Researcher: So we've got some processing issues and you find it takes longer to remember things, but you're an avid reader as well. Okay, so that is the descriptive term we are going to use instead of 'dyslexia'.

Moon: Okay.

Researcher: What would be the advantages of a teacher coming to me and telling me that, as opposed to coming to me and saying 'Oh, you're going to meet Moon. She's got dyslexia'?

Moon: I think this is more personal. I think I would much prefer this to be my description of dyslexia.

Researcher: Okay.

Moon: Because instead of being the umbrella term it's actually...

Researcher: It's more specific?

Moon: Yeah, it's less of a label.

Researcher: Okay. So it's more specific rather than an umbrella term, and also it's less of a label.

Moon: Yeah.

Researcher: Why is that a good thing?

Moon: Well, I think it's the same, it's similar to the point before. It's just... it's like dyslexia and then people will have their own understanding of what dyslexia is, but actually I think if I gave this explanation to my friends, they wouldn't connect it at all with dyslexia.

Researcher: Okay.



Moon: If I wrote 'finds spelling and reading really difficult. The words fly around the page' they immediately think 'dyslexia'.

Researcher: Yes, sure.

Moon: But this description, I don't think they would think.

Researcher: No.

Moon: No.

Researcher: So they wouldn't be able to associate it with a specific term?

Moon: Yeah.

Researcher: So if that description, like it might be for another student in my class, what you just said, you know, they find reading and writing really difficult, and spelling and the words fly around on the page, then me on hearing that description, I might just say 'Oh, dyslexic'.

Moon: Mm.

Researcher: So even though you've used a description rather than a single word...

Moon: I don't think they would instantly *say* it's dyslexia. I think they would... they might be thinking it might be.

Researcher: Okay.

Moon: Yeah. It's also... we tend to be a society that likes to label things. You're straight, you're asexual, you're dyslexic, you're intelligent... because we think it's simpler for everyone, but...

Researcher: Yeah. Do you think it *is* simpler?

Moon: I don't know. Well yeah, I think it's simpler if we can just label everything and try to understand the world, but there's no kind of claim to be able to. I don't think it's possible.

Researcher: Okay. So is there anything else you would like to add here about the advantages of using this description?

Moon: Erm...

Researcher: So here, under advantages of 'dyslexia' as a term, so people can understand you better and know something about how your brain works...

Moon: I feel like that's what they think, and I feel like it is to a certain extent, but this is *more* personal and they'd *more* understand you.

Researcher: Do you think then they would know how to help you? So you said that they might be able to help you if they know you have dyslexia?

Moon: I think if they got this description from you, I think they would be able to. But if they were just told you were dyslexic, I would... if *I* was told someone was then I would be providing them with yellow paper, I would be providing them with the scribbler that goes down the page, which *is* actually quite helpful. But it's a different colour so it's not helpful. And then I don't think, no, I think everyone is different.



## List of References

- Alexander-Passe, N. (2006). How dyslexic teenagers cope: An investigation of self-esteem, coping and depression. *Dyslexia*, 12(4), 256–275. <https://doi.org/10.1002/dys.318>
- Arishi, L., Boyle, C., & Lauchlan, F. (2017). Inclusive education and the politics of difference: Considering the effectiveness of labelling in special education. *Educational & Child Psychology*, 34(4), 9–19.
- 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. <https://doi.org/10.1111/j.1467-8578.2008.00408.x>
- Bear, G. G., Minke, K. M., & Manning, M. A. (2002). Self-concept of students with learning disabilities: A meta-analysis. *School Psychology Review*, 31(3).
- Beck, J. S., Beck, A., & Jolly, J. (2001). *Beck Youth Inventories - Second Edition for Children and Adolescents*. San Antonio, TX: PsychCorp.
- Blackwell, L. S., Trzesniewski, K. H., & Dweck, C. S. (2007). Implicit theories of intelligence predict achievement across an adolescent transition: A longitudinal study and an intervention. *Child Development*, 78(1), 246–263. <https://doi.org/10.1111/j.1467-8624.2007.00995.x>
- Bong, M., & Skaalvik, E. M. (2003). Academic Self-Concept and Self-Efficacy: How Different Are They Really? *Educational Psychology Review*, 15(1), 1–40. <https://doi.org/10.1023/A:1021302408382>
- Brante, E. W. (2013). “I don”t know what it is to be able to read’: How students with dyslexia experience their reading impairment. *Support for Learning*, 28(2), 79–86. <https://doi.org/10.1111/1467-9604.12022>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- British Psychological Society. (2005). *Dyslexia, Literacy and Psychological Assessment. Report by a Working Party of the Division of Educational and Child Psychology*. Leicester.

## List of References

- Burden, R. (2008). Is dyslexia necessarily associated with negative feelings of self-worth? A review and implications for future research. *Dyslexia*, 14, 188–196.  
<https://doi.org/10.1002/dys.371>
- Burden, R., & Burdett, J. (2005). Factors associated with successful learning in pupils with dyslexia: A motivational analysis. *British Journal of Special Education*, 32(2), 100–104. <https://doi.org/10.1111/j.0952-3383.2005.00378.x>
- Burden, R., & Burdett, J. (2007). What's in a name? Students with dyslexia: their use of metaphor in making sense of their disability. *British Journal of Special Education*, 34(2), 77–82.
- Burr, V., King, N., & Butt, T. (2014). Personal construct psychology methods for qualitative research. *International Journal of Social Research Methodology*, 17(4), 341–355. Retrieved from  
<http://www.tandfonline.com/doi/abs/10.1080/13645579.2012.730702>
- Burton, S. (2004). Self-esteem groups for secondary pupils with dyslexia. *Educational Psychology in Practice*, 20(1), 55–73. <https://doi.org/10.1080/0266736042000180410>
- Cassery, A. M. (2013). The socio-emotional needs of children with dyslexia in different educational settings in Ireland. *Journal of Research in Special Educational Needs*, 13(1), 79–91. <https://doi.org/10.1111/j.1471-3802.2011.01227.x>
- Chapman, J. W., & Tunmer, W. E. (2003). Reading Difficulties, Reading-Related Self-Perceptions, and Strategies for Overcoming Negative Self-Beliefs. *Reading & Writing Quarterly*, 19(1), 5–24. <https://doi.org/10.1080/10573560308205>
- Chapman, J. W., Tunmer, W. E., & Prochnow, J. E. (2000). Early reading-related skills and performance, reading self-concept, and the development of academic self-concept: A longitudinal study. *Journal of Educational Psychology*, 92(4), 703–708.  
<https://doi.org/http://dx.doi.org/10.1037/0022-0663.92.4.703>
- Children and Families Act*. (2014). London. Retrieved from  
[http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga\\_20140006\\_en.pdf](http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga_20140006_en.pdf)
- Critical Appraisal Skills Programme. (2017). CASP Qualitative Research Checklist. Retrieved November 1, 2017, from  
[http://docs.wixstatic.com/ugd/dded87\\_25658615020e427da194a325e7773d42.pdf](http://docs.wixstatic.com/ugd/dded87_25658615020e427da194a325e7773d42.pdf)

- Danermark, B. (2001). Interdisciplinary Research and Critical Realism - The Example of Disability Research. *Journal of Critical Realism*, 5(1), 56–64.  
<https://doi.org/10.1558/aleth.v5i1.56>
- Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology & Community Health*, 52, 377–384.
- Dugdale, G., & Clark, C. (2008). *Literacy changes lives: An advocacy resource*. London: National Literacy Trust. Retrieved from  
[http://www.literacytrust.org.uk/assets/0000/0401/Literacy\\_changes\\_lives\\_2008.pdf](http://www.literacytrust.org.uk/assets/0000/0401/Literacy_changes_lives_2008.pdf)
- Elbaum, B., & Vaughn, S. (2001). School-Based Interventions to Enhance the Self-Concept of Students with Learning Disabilities: A Meta-Analysis. *The Elementary School Journal*, 101(3), 303–329.
- Elliott, J. G., & Grigorenko, E. L. (2014a). *The Dyslexia Debate* (No. 14). New York: Cambridge University Press. <https://doi.org/10.1017/CBO9781139017824>
- Elliott, J. G., & Grigorenko, E. L. (2014b, August). The end of dyslexia? *The Psychologist*, 27(8), 576–580. <https://doi.org/10.1136/bmj.i5344>
- Elliott, J., & Gibbs, S. (2008). Does Dyslexia Exist? *Journal of Philosophy of Education*, 42(3–4), 475–491. [https://doi.org/10.1108/S0735-004X\(2010\)0000023013](https://doi.org/10.1108/S0735-004X(2010)0000023013)
- Frederickson, N., & Jacobs, S. (2001). Controllability Attributions for Academic Performance and the Perceived Scholastic Competence, Global Self-Worth and Achievement of Children with Dyslexia. *School Psychology International*, 22(4), 401–416. <https://doi.org/10.1177/0143034301224002>
- Gans, A. M., Kenny, M. C., & Ghany, D. L. (2003). Comparing the Self-Concept of Students With and Without Learning Disabilities. *Journal of Learning Disabilities*, 36(3), 287–295. <https://doi.org/10.1177/002221940303600307>
- Gibbs, S., & Elliott, J. (2015). The differential effects of labelling: how do “dyslexia” and “reading difficulties” affect teachers’ beliefs. *European Journal of Special Needs Education*, 30(3), 323–337. <https://doi.org/10.1080/08856257.2015.1022999>
- Gibson, S., & Kendall, L. (2010). Stories from school: Dyslexia and learners’ voices on

## List of References

- factors impacting on achievement. *Support for Learning*, 25(4), 187–193.  
<https://doi.org/10.1111/j.1467-9604.2010.01465.x>
- Glazzard, J. (2010). The impact of dyslexia on pupils' self-esteem. *Support for Learning*, 25(2), 63–69.
- Griffin, C. P., & Murtagh, L. (2015). Increasing the sight vocabulary and reading fluency of children requiring reading support: the use of a Precision Teaching approach. *Educational Psychology in Practice*, 31(2), 186–209.  
<https://doi.org/10.1080/02667363.2015.1022818>
- Grigorenko, E. L. (2001). Developmental dyslexia: An update on genes, brains, and environments. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 42(1), 91–125. <https://doi.org/10.1017/S0021963001006564>
- Guba, E. G., & Lincoln, Y. S. (1994). Competing Paradigms in Qualitative Research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Thousand Oaks, CA: Sage.  
<https://doi.org/http://www.uncg.edu/hdf/facultystaff/Tudge/Guba%20&%20Lincoln%201994.pdf>
- Harding, C., Romanou, E., Williams, J., Peters, M., Winkley, J., Burke, P., ... Shay, M. (2012). *The 2011 Skills for Life Survey: A Survey of Literacy, Numeracy and ICT Levels in England*. London.
- Harter, S. (1985). *Manual for the self-perception profile for children*. Denver, CO: University of Denver.
- Hinshelwood, J. (1900). Congenital Word Blindness. *The Lancet*, 155, 1506–1508.  
[https://doi.org/10.1016/S0140-6736\(01\)21410-X](https://doi.org/10.1016/S0140-6736(01)21410-X)
- Hornery, S., Seaton, M., Tracey, D., Craven, R. G., & Yeung, A. S. (2014). Enhancing reading skills and reading self-concept of children with reading difficulties: Adopting a dual approach intervention. *Australian Journal of Educational and Developmental Psychology*, 14(SPEC. ISS.), 131–143.
- Humphrey, N. (2002). Teacher and pupil ratings of self-esteem in developmental dyslexia. *British Journal of Special Education*, 29(1), 29–36.
- Humphrey, N., & Mullins, P. M. (2002a). Personal Constructs and Attribution for

- Academic Success and Failure in Dyslexia. *British Journal of Special Education*, 29(4), 196–203. <https://doi.org/10.1111/1467-8527.00269>
- Humphrey, N., & Mullins, P. M. (2002b). Self-concept and self-esteem in developmental dyslexia. *Journal of Research in Special Educational Needs*, 2(2). <https://doi.org/10.1111/j.1471-3802.2002.00163.x>
- Jodrell, D. (2010). Social identity and self-efficacy concern for disability labels. *Psychology Teaching Review*, 16(2), 111–121. Retrieved from <http://ezp-prod1.hul.harvard.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=psych&AN=2011-04420-010&site=ehost-live&scope=site%5Cnhttp://djodrell@dartington.org.uk>
- Jussim, L., & Harber, K. D. (2005). Teacher Expectations and Self-Fulfilling Prophecies : Knowns and Unknowns , Resolved and Unresolved Controversies, 9(2), 131–155.
- Kelly, B., Woolfson, L., & Boyle, J. (Eds.). (2008). *Frameworks for Practice in Educational Psychology*. London: Jessica Kingsley Publishers.
- Kelly, G. A. (2003). A Brief Introduction to Personal Construct Theory. In F. Fransella (Ed.), *International Handbook of Personal Construct Psychology* (pp. 3–20). Chichester: John Wiley & Sons Ltd. <https://doi.org/10.1007/978-1-4419-7400-6>
- Kotecha, M. (2012). Promoting Inclusive practice in mathematics and statistics. *The Journal of Inclusive Practice in Further and Higher Education*, 4(1), 1–102. Retrieved from <http://nadp-uk.org/uploads/JIPFHE/JIPFHE JOURNAL 4.pdf#page=5>
- Laidra, K., Pullmann, H., & Allik, J. (2007). Personality and intelligence as predictors of academic achievement: A cross-sectional study from elementary to secondary school. *Personality and Individual Differences*, 42(3), 441–451. <https://doi.org/10.1016/j.paid.2006.08.001>
- Lauchlan, F., & Boyle, C. (2007). Is the use of labels in special education helpful? *Support for Learning*, 22(1), 36–42. <https://doi.org/10.1111/j.1467-9604.2007.00443.x>
- Lindeblad, E., Svensson, I., & Gustafson, S. (2016). Self-Concepts and Psychological Well-Being Assessed By Beck Youth Inventory Among Pupils with Reading Difficulties. *Reading Psychology*, 37(3), 449–469. <https://doi.org/10.1080/02702711.2015.1060092>

## List of References

- Lindsley, O. R. (1995). Precision Teaching: By Teachers for Children. *Journal of Precision Teaching*, 12(2), 9–17.
- Long, L., MacBlain, S., & MacBlain, M. (2007). Supporting students with dyslexia at the secondary level: an emotional model of literacy. *Journal of Adolescent & Adult Literacy*, 51(October), 124–134. <https://doi.org/10.1598/JAAL.51.2.4>
- Macdonald, S. J. (2010). Towards a social reality of dyslexia. *British Journal of Learning Disabilities*, 38(4), 271–279. <https://doi.org/10.1111/j.1468-3156.2009.00601.x>
- Marsh, H. W. (1990a). A multidimensional, hierarchical model of self-concept: Theoretical and empirical justification. *Educational Psychology Review*, 2(2), 77–172. <https://doi.org/10.1007/BF01322177>
- Marsh, H. W. (1990b). *Self-Description Questionnaire 1*. Sydney: University of Western Sydney.
- Maxwell, J. A. (2010). Using numbers in qualitative research. *Qualitative Inquiry*, 16(6), 475–482. <https://doi.org/10.1177/1077800410364740>
- Mcarthur, G. M., Hogben, J. H., Edwards, V. T., Heath, S. M., & Mengler, E. D. (2018). On the ““Specifics”” of Specific Reading Disability and Specific Language Impairment. *Journal of Child Psychology and Psychiatry*, 41(7), 869–874.
- Morgan, W. . (1896). A case of congenital word blindness. *British Medical Journal*, 2, 1378. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2510936/?page=1>
- Mruk, C. J. J. (2006). *Self-Esteem Research, Theory, and Practice: Toward a Positive Psychology of Self-Esteem* (Third Edit). New York: Springer Publishing Company. Retrieved from <https://ebookcentral.proquest.com/lib/soton-ebooks/detail.action?docID=291344>
- National Heart, Lung and Blood Institute. (2014). Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies. Retrieved October 20, 2017, from <https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort>
- Novita, S. (2016). Secondary symptoms of dyslexia: a comparison of self-esteem and anxiety profiles of children with and without dyslexia. *European Journal of Special*



- Needs Education*, 31(2), 279–288. <https://doi.org/10.1080/08856257.2015.1125694>
- NVivo 11. (2017). Melbourne, Australia: QSR International Pty Ltd.
- Ohan, J. L., Visser, T. A. W., Strain, M. C., & Allen, L. (2011). Teachers' and education students' perceptions of and reactions to children with and without the diagnostic label "ADHD." *Journal of School Psychology*, 49(1), 81–105.  
<https://doi.org/10.1016/j.jsp.2010.10.001>
- Pasta, T., Mendola, M., Longobardi, C., Prino, L. E., & Gastaldi, F. G. M. (2013). Attributional style of children with and without Specific Learning Disability. *Electronic Journal of Research in Educational Psychology*, 11(3), 649–664.  
<https://doi.org/10.14204/ejrep.31.13064>
- Paulesu, E., Démonet, J. F., Fazio, F., McCrory, E., Chanoine, V., Brunswick, N., ... Frith, U. (2001). Dyslexia: Cultural diversity and biological unity. *Science*, 291(5511), 2165–2167. <https://doi.org/10.1126/science.1057179>
- Podsakoff, P. M., MacKenzie, S. B., Lee, J. Y., & Podsakoff, N. P. (2003). Common Method Biases in Behavioral Research: A Critical Review of the Literature and Recommended Remedies. *Journal of Applied Psychology*, 88(5), 879–903.  
<https://doi.org/10.1037/0021-9010.88.5.879>
- Polychroni, F., Koukoura, K., & Anagnostou, I. (2006). Academic self-concept, reading attitudes and approaches to learning of children with dyslexia: do they differ from their peers? *European Journal of Special Needs Education*, 21(4), 415–430.  
<https://doi.org/10.1080/08856250600956311>
- Riddick, B. (2000). An Examination of the Relationship Between Labelling and Stigmatisation with Special Reference to Dyslexia. *Disability & Society*, 15(4), 653–667. <https://doi.org/10.1080/09687590050058233>
- Saday Duman, N., Öner, Ö., & Aysev, A. (2017). The effect of educational therapy on self-esteem and problem behaviors in children with specific learning disability. *Journal of Psychiatry*, 18(1), 85–92. <https://doi.org/10.5455/apd.219208>
- Saldaña, J. (2013). *The Coding Manual for Qualitative Researchers* (Second Edi). London: SAGE Publications. Retrieved from  
<https://books.google.co.uk/books?id=V3tTG4jvgFkC&printsec=frontcover#v=onepage&q&f=false>

## List of References

- Scanlon, G., McEntegart, C., Barnes-Holmes, Y., & Barnes-Holmes, D. (2014). Using the implicit relational assessment procedure (IRAP) to assess implicit gender bias and self-esteem in typically- developing children and children with adhd and with dyslexia. *Behavioral Development Bulletin*, 19(2), 48–59.  
<https://doi.org/10.1016/j.jcbs.2014.08.001>
- Siegel, L. S. (1992). An evaluation of the discrepancy definition of dyslexia. *Journal of Learning Disabilities*, 25(10), 618–629.  
<https://doi.org/10.1177/002221949202501001>
- 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(5), 411–423.  
<https://doi.org/10.1177/00222194050380050401>
- Snowling, M. J. (2013). Early identification and interventions for dyslexia: A contemporary view. *Journal of Research in Special Educational Needs*, 1(13), 7–14.  
<https://doi.org/10.1111/j.1471-3802.2012.01262.x>
- Snowling, M. J., Muter, V., & Carroll, J. (2007). Children at family risk of dyslexia: A follow-up in early adolescence. *Journal of Child Psychology and Psychiatry*, 48(6), 609–618. <https://doi.org/10.1111/j.1469-7610.2006.01725.x>
- Solvang, P. (2007). Developing an ambivalence perspective on medical labelling in education: case dyslexia. *International Studies in Sociology of Education*, 17(1–2), 79–94. <https://doi.org/10.1080/09620210701433779>
- Stampoltzis, A., & Polychronopoulou, S. (2009). Greek university students with dyslexia: An interview study. *European Journal of Special Needs Education*, 24(3), 307–321.  
<https://doi.org/10.1080/08856250903020195>
- Tanaka, H., Black, J. M., Hulme, C., Stanley, L. M., Kesler, S. R., Whitfield-Gabrieli, S., ... Hoeft, F. (2011). The brain basis of the phonological deficit in dyslexia is independent of IQ. *Psychological Science*, 22(11), 1442–1451.  
<https://doi.org/10.1177/0956797611419521>
- Temple, E. (2002). Brain mechanisms in normal and dyslexic readers. *Current Opinion in Neurobiology*, 12(2), 178–183. [https://doi.org/10.1016/S0959-4388\(02\)00303-3](https://doi.org/10.1016/S0959-4388(02)00303-3)
- Terras, M. M., Thompson, L. C., & Minnis, H. (2009). Dyslexia and psycho-social functioning: An exploratory study of the role of self-esteem and understanding.

- Dyslexia*, 15, 304–327. <https://doi.org/10.1002/dys.386>
- Tschudi, F., & Winter, D. (2012). The ABC Model Revisited. In P. Caputi, L. L. Viney, B. M. Walker, & N. Crittenden (Eds.), *Personal Construct Methodology* (pp. 89–108). Chichester: Wiley-Blackwell.
- Tunmer, W. E., & Chapman, J. W. (2002). The relation of beginning readers' reported word identification strategies to reading achievement, reading-related skills, and academic self-perceptions. *Reading and Writing: An Interdisciplinary Journal*, 15, 341–358. <https://doi.org/10.1023/A:1015219229515>
- Von Károlyi, C., Winner, E., Gray, W., & Sherman, G. F. (2003). Dyslexia linked to talent: Global visual-spatial ability. *Brain and Language*, 85, 427–431. [https://doi.org/10.1016/S0093-934X\(03\)00052-X](https://doi.org/10.1016/S0093-934X(03)00052-X)
- Watkins, C. (2010). Learning, performance and improvement. *INSI Research Matters*, 34, 2–15. Retrieved from <http://eprints.ioe.ac.uk/id/eprint/6401>
- Weiner, B. (1985). An attributional theory of achievement motivation and emotion. *Psychological Review*, 92(4), 548–573. <https://doi.org/10.1037/0033-295X.92.4.548>
- Wheater, R., Burge, B., Sewell, J., Sizmur, J., Worth, J., & Williams, J. (2013). *The International Survey of Adult Skills 2012 : Adult literacy , numeracy and problem solving skills in England*. London.
- Willig, C. (2013). *Introducing Qualitative Research in Psychology* (3rd ed.). Maidenhead: Open University Press.
- Zimmerman, B. J. (2000). Self-efficacy: An essential motive to learn. *Contemporary Educational Psychology*, 25(February), 82–91. <https://doi.org/10.1006/ceps.1999.1016>