Dyslexia or Literacy Difficulties: What Difference Does a Label Make? Exploring the Perceptions and Experiences of Young People

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This study explores the views of young people (YP), with and without self-reported dyslexia or literacy difficulties, focussing on the impact of labels. Qualitative data were gathered through an online survey and individual interviews. The study highlights how the presence or absence of a label can impact people's perceptions. Dyslexia was perceived as biological in origin; therefore, YP with the label were seen as not to blame for their difficulties. However, more negative judgements were made about YP without the label but with the same difficulties. Participants viewed the label as important for gaining support, yet highlighted the potential for discrimination in terms of access to diagnosis and resources. What was important to participants with dyslexia was not necessarily the label but the support that they received and how they were viewed by others. Implications for school professionals are discussed in terms of ensuring that YP feel empowered by the way they are described.

Keywords: dyslexia, literacy, labels, perspectives of young people, personal construct psychology

Literacy Difficulties and Dyslexia

Although overall literacy levels are rising in the UK, young people (YP) leaving school (aged 16 to 18) have been ranked as having the lowest levels of literacy out of eighteen, mainly European, countries (Department for Business, Innovation and Skills, 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 three to ten per cent of the population (Snowling, 2013).

Educators, psychologists and researchers have debated dyslexia for many years, and various definitions are utilised, with little consensus (Elliott & Grigorenko, 2014a). More than ten 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 identified by a significant difference between an individual's cognitive "ability" (determined by IQ testing) and their performance in literacy assessments (Siegel, 1992). This model, however, has been largely discredited (Elliott & Grigorenko, 2014a; Snowling, 2013). There is general agreement that the primary symptoms of dyslexia include difficulty in acquiring literacy skills, but, Elliott and Grigorenko argue, 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 British Psychologyical Society (BPS) (British Psychological Society Working Party, 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, which is relevant as the same challenges appear to underlie both (British Psychological Society Working Party, 2005; Elliott & Gibbs, 2008). One might argue, therefore, that the terminology is inconsequential. However, the BPS acknowledged that

the term dyslexia is within the public domain and requires consideration from a social psychological standpoint (2005, p. 16).

Labelling

Although most would agree that special educational needs (SEN) should be recognised and supported, the labelling of these difficulties is contentious. Changing attitudes towards SEN labels have seen an increase in the number of publications exploring both the benefits and the drawbacks (e.g., Lauchlan & Boyle, 2007).

Researchers looking specifically at the impact of the dyslexia label have identified a number of advantages and disadvantages. Gibbs and 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). Indeed, Glazzard (2010) has described the diagnostic process as replacing accusing, unhelpful labels (e.g., "lazy") with one that is perceived as helpful and accepting (i.e., "dyslexic"). Qualitative research suggests that there are individual differences in response to the label; some resist it, whilst others accommodate it into their sense of self (Armstrong & Humphrey, 2009). 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). There is, therefore, a need for research that offers a better understanding of the perceived advantages and disadvantages of the dyslexia label in terms of exploring the lived experiences of those directly affected by it.

This study aims to explore the views of YP, with and without experiences of dyslexia, with a particular focus on the impact of labels. It uses qualitative methodology to address five research questions, outlined in Table 1.

Method

Design

The participants were purposively sampled to represent YP with and without literacy difficulties and/or dyslexia (LitD/D). Two data collection methods were used: (a) an online survey exploring the perspectives of YP with and without LitD/D, and (b) one-to-one semi-structured interviews with YP who identified themselves as having dyslexia. 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.

Table 1

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?	

Survey Participants

A total of 88 YP completed the online survey, out of 150 who were invited to take part. Of these 88, 36 were randomly selected for data analysis, as illustrated in Table 2.

Table 2

Survey Participants

Self-Identification	N	Gender	Age
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, twenty opted to provide details to be contacted about interview. Six of these YP followed through with making appointments, giving consent and completing interviews. See Table 3 for participant details.

Table 3

Interview Participants

Pseudonym	Gender	Age at Interview	School Year at Interview	School Year at Diagnosis
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

Procedures

Survey

The online survey consisted of two sections with predominantly open-ended, structured questions. The first section explored participants' own experiences and understanding of dyslexia; the second required participants to answer questions related to two vignettes: one about a pupil with dyslexia and the other about a pupil with literacy difficulties (Figure 1). 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.

Figure 1

Survey Vignettes

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.

The survey was developed specifically for this research. Vignettes have been successfully used in similar research exploring the impact of labels (e.g., Gibbs & Elliott, 2015; Ohan et al., 2011). The vignettes were designed to have a typical Year 6 reading level. All participants were offered support to help them access the survey (headphones, voice recorders, reader and/or scribe). A quarter of participants utilised some kind of support.

Interviews

An interview schedule was used flexibly to guide discussion (see Appendix). It incorporated techniques from personal construct psychology (PCP) (Kelly, 2003), including 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. 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.

Data Analysis

Interview and survey data were analysed using an inductive approach and following the six steps of Thematic Analysis (TA) outlined by Braun and Clarke (2006); however, analysis was dynamic and recursive within this process.

Survey Analysis

To make comparisons between the different groups, data was divided into sets A (YP with dyslexia), B (YP with literacy difficulties) and C (YP with no literacy difficulties). Initial TA took place for one dataset at a time, before bringing codes and potential themes together across all datasets.

Scaling Questions

To specifically address the issue of prognosis, two scaling questions were included in the survey, with participants asked to rate, on a scale of 1 to 10, how likely it was that the pupil in the vignette would overcome their difficulties.

Interview Analysis

Interview transcripts were analysed using a combination of computer-assisted and handwritten note taking and arrangement of potential themes.

Results

Online Survey

Participants were asked to self-identify into one of three categories: dyslexia (Group A), literacy difficulties (Group B) or no literacy difficulties (Group C).

The thematic map (Figure 2) 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 and relevance to research questions and practice. This section addresses one research question at a time, presenting each theme in turn (Table 4). 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.

Figure 2

Thematic Map for Online Survey Findings
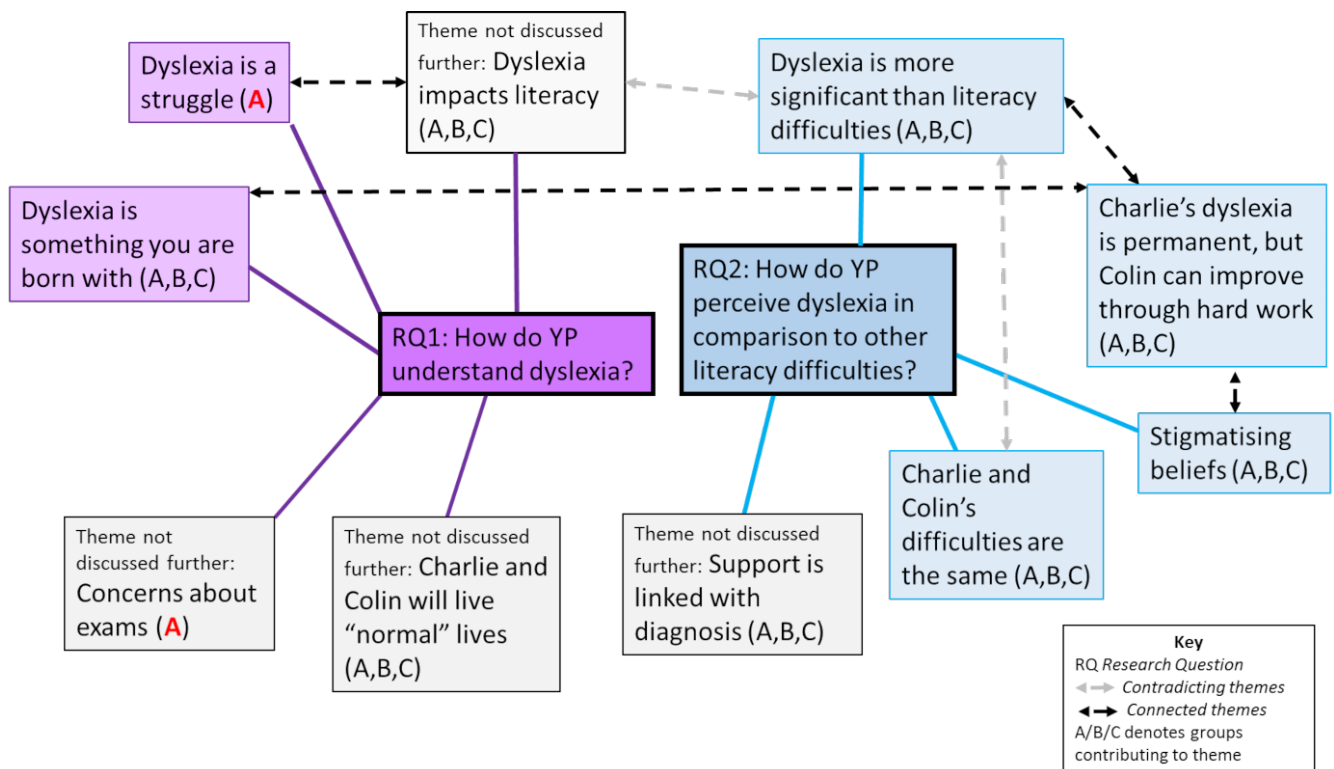
Quotes have not been edited and original spelling has been retained. Quotes are denoted with a letter to indicate how the participant self-identified: dyslexia (A), literacy difficulties (B) or no literacy difficulties (C).

1. How Do YP Understand Dyslexia?

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. 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.

"*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). In describing their own experiences, many participants in Group A used the term *struggle* to describe dyslexia, and just one participant mentioned potential positives. 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)

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 have been told that he has "dyslexia" and Colin and his teachers say that he has "literacy difficulties".

Dyslexia Is More Significant Than Literacy Difficulties. Almost half of the participants implied 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)

"*Charlie would get more help because he has a more serious problem.*" (C)

The majority of participants suggested that both Charlie and Colin would attain lower than average grades because

Table 4

Research Questions and Relevant Themes, With Source Groups in Brackets

Research Questions	Themes
1. How do YP understand dyslexia?	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's 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).

of their difficulties. However, several suggested that Colin would do better because he does not have 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's and Colin's Difficulties Are the Same. In contrast, some of the participants described little difference between Charlie's and Colin's needs. Several participants explicitly stated that this was because Colin also has dyslexia but is undiagnosed, meaning that the only difference is "*one noes her has dislex ier and the other one dosent*" (A).

A few 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. This was perceived as 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)

This perception of dyslexia offers little sense of control over the associated difficulties, but participants across groups did feel that, whilst dyslexia will always be present, the symptoms improve over time.

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

The 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 to Charlie.

"*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)

Stigmatising Beliefs. All groups had varied views on intelligence in relation to dyslexia and literacy difficulties. 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)

Some participants interpreted Colin's lack of dyslexia label as indicating that his difficulties were not specific to literacy. Furthermore, participants suggested that, unlike Charlie, Colin 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 across participants around whether there is a stigma associated with dyslexia. However, the stigma was not necessarily linked to the label; prejudices

could be attached to difficulties with literacy, regardless of the label:

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

A small number of participants in each group mentioned potential "*self-esteem issues*" for both Charlie and Colin, suggesting that "*they may not believe that they are good enough*" (B).

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 based solely on the difference in label.

3. Does Choice of Label Affect Perceptions of the Permanence of Difficulties?

Table 5 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 to 10 (with 0 being not at all likely and 10 being very likely).

Table 5

Mean Scores Assigned to Scaling Questions and Difference in Mean Score

Group	Mean Score for Charlie (*Range*)	Mean Score for Colin (*Range*)	Difference in Means
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, Colin was seen as being more able to overcome his difficulties than Charlie, and participants in Group A had less belief in Charlie overcoming his dyslexia than participants in Groups B and C.

Interviews

Table 6 outlines how each interview participant described their own experience of dyslexia and the specific characteristics or symptoms they identified in themselves.

All participants identified themselves as having dyslexia and used this term to describe themselves in interviews. All participants talked about family members with dyslexia or similar difficulties. All were succeeding academically; either completing A-levels or on track to do well in GCSE exams.

This section addresses research question five only, due to limitations of word count. The themes derived in relation to research question four can be seen below in the thematic map (Figure 3). All themes are outlined in the thematic map; however, only those deemed most resonant are discussed.

5. What Do YP Perceive as the Advantages and Disadvantages of the Dyslexia Label?

Figure 4 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.

The Label Changes Others' Perceptions. Participants described how their dyslexia label altered others' perceptions of them, in both advantageous and disadvantageous ways. Two conflicting views existed across, as well as within, participants' dialogues. 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, they felt the term dyslexia could set up the expectation that a person is unintelligent or will not succeed academically, which could become a "*self-fulfilling prophecy*". 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.

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

Lucy and Oz spoke of how they were perceived differently by different people, both before and after they had their dyslexia label. This highlighted the idea that the label itself is less important than the assumptions or judgements that people make and that the label does not enable an accurate prediction of others' responses.

Oz: "*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.*"

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. The majority of participants suggested that dyslexia is more than just literacy difficulties; they felt that their difficulties were more significant and extended beyond literacy, that is, 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 "*literacy difficulties*".

Oz: "*the fact it's been diagnosed as a label, gives it some credence if you will.*"

The Label Does Not Give Enough Information. Four participants felt that using a single diagnostic term to de-

Table 6

Participants' Descriptions of Their Dyslexia

Participant	Age	Characteristics of Dyslexia
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 the 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 from those of other people, and she sees things and thinks about things differently, which can be beneficial at times.
Theo	16	Theo finds that his dyslexia impacts 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. Charles was diagnosed when he was assessed for exam access arrangements for GCSEs, much later than all the other participants.
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. Moon said that she always knew she had dyslexia, but this was confirmed through assessment in year 6 to ensure that she got exam access arrangements.

Table 7

Research Question and Relevant Themes

Research Question	Themes
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.

scribe their experiences was not always effective; it can be difficult to understand and is not sufficiently accurate or informative.

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

The Label Is Necessary for Support. All of the participants felt that their diagnosis had been a necessary step in getting the support they needed. Five participants reported not receiving any support 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'.*"

Charles and Theo both felt that their teachers were well aware of their difficulties prior to diagnosis, but it was the label that led to support being offered. Moon and Charles highlighted that knowing a person has dyslexia does not necessarily equate to knowing what kind of support they need.

Violet, Charles and Lucy reflected on differing levels of

Figure 3

Thematic Map for Interview Findings
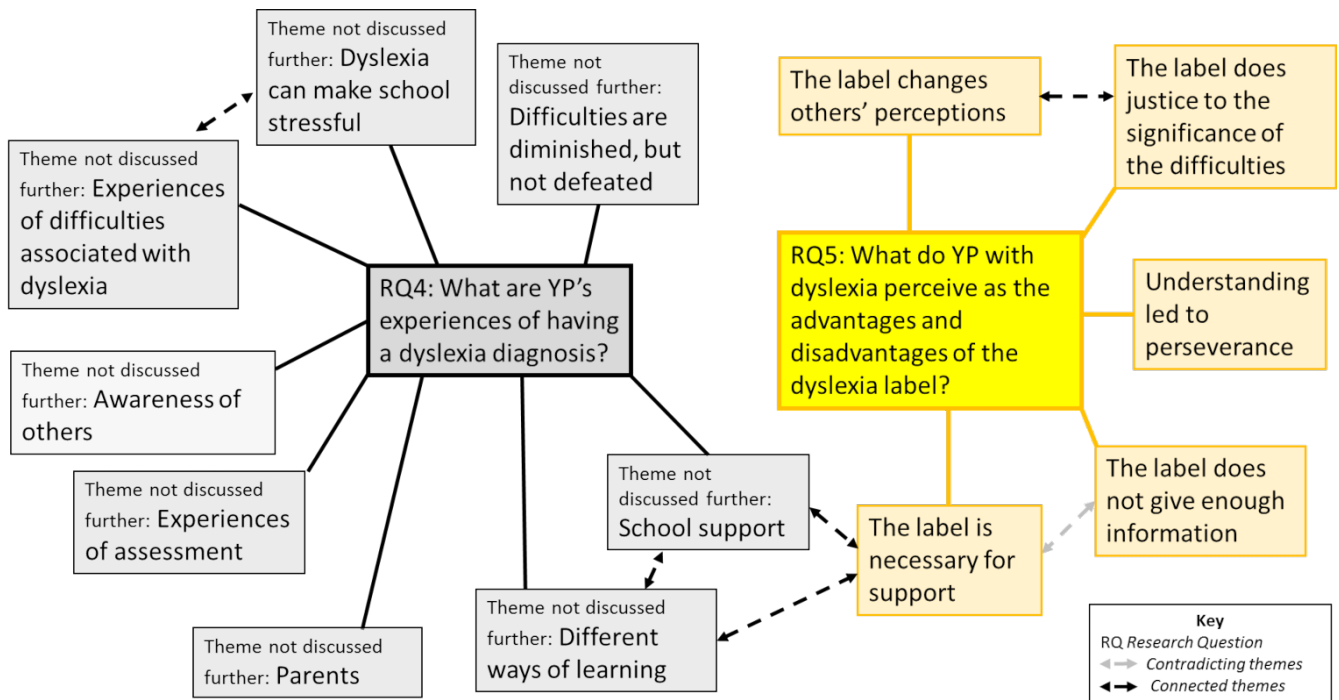
access to assessment and how this may influence support and outcomes.

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.*"

Although participants' experiences led them to feel their support was inextricably linked with their label, ultimately it was support that they really cared about, not the label they were given.

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

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. Having a "*reason*" for the differences between themselves and their peers was helpful and 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: "*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'.*"

Moon and Oz, in particular, reflected on their personali-

ties and their strong desire to exceed others' expectations or prove their assumptions wrong.

Oz: "*Yeah, then my reaction to being told I can't do something is to try and go out and do it.*"

Discussion

This research explored the perceptions of YP with and without LitD/D, alongside the experiences of YP who identified with the dyslexia label. A number of key themes emerged that are important in terms of developing our understanding of the impact of a label from a range of perspectives.

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 8. The participants in this study contribute some additional and contrasting perspectives in relation to Solvang's. 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, such as the idea that dyslexia is characterised by difficulties with literacy but is also more

Figure 4

Participants' Views of the Advantages and Disadvantages of the Dyslexia Label

Dyslexia label

Advantages ———————————————————————————————— **Disadvantages**

- Relief from own or others' perceptions of them as unintelligent or lazy
- The label signifies the significance of the difficulties and helps others to recognise this
- Additional support in school and exam access arrangements
- Understanding of why they have struggled, leading to increased motivation and perseverance
- Protecting self-image and self-esteem

- Lowered academic expectations and others may equate dyslexia with stupidity
- "Self-fulfilling prophecy" may impact beliefs about self
- Individuals with the label are seen as part of a homogenous group
- The label does not tell you how to support the individual
- Not everyone has access to diagnosis or support

No dyslexia label

Advantages ———————————————————————————————— **Disadvantages**

- Others would have to get to know you; not make assumptions
- Descriptive terms provide a more nuanced understanding of strengths and difficulties on an individual basis
- A descriptive term is easier to understand
- Support would be determined based on need

- Others may perceive individuals as unintelligent
- Support may not be provided, leading to disadvantage in terms of academic outcomes
- Lack of explanation for difficulties, leading to lowered self-perceptions, motivation and achievement

than just literacy difficulties, and other participants' belief that dyslexia and literacy difficulties are the same.

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 oversimplifies and misleads (p. 325). Wennås 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, 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.

Table 8

Comparison of Solvang's (2007) Advantages and Disadvantages of Dyslexia Labelling With Those From the Current Research

Positive Aspects	Solvang's Description	The Current Research
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 would still apply to individuals 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.
Negative Aspects		
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 constituting a reason for celebrating diversity and individual strengths and needs.	Interview participants in this study had positively accommodated their dyslexia label, accepted their difference and recognised their strengths.

Interview participants reported that their label changed others' perceptions. They found that others were more understanding post-diagnosis, and, for some, their dyslexia label replaced the negative labels (e.g., lazy/unintelligent) that 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 label. 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 neg-

ative judgements about individuals regardless of label. For interview participants, it was apparent that the problem lay with the negative judgements, not the labels.

The Impact of Expectations and Assumptions

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 la-

bels 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), many participants felt that the dyslexia label was key to specialist and increased 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. Interview participants largely experienced their label as an essential step in obtaining support, as reported in other studies (e.g., Gibson & Kendall, 2010; Macdonald, 2010). However, this was not necessarily seen as being right; 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. However, researchers have cautioned against the risk of services being provided only for those with "exceptional parental support" (Wennås 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 is, 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 Working Party, 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. 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 had a clear sense of agency. Participants reflected on how they had begun to overcome certain difficulties through developing coping strategies, utilising support from school, and hard work. Participants suggested that although they might not be able to "cure" their dyslexia, the label 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 wanted to challenge expectations and show what they were capable of. 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, 2002; 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

This study gathered rich qualitative data from individual interviews, as well as data from a larger group of participants with a more diverse range of experiences. It attended to the

voices of YP currently in education, adding to an existing literature base that is more often focused on older groups. The interviews were person-centred and made innovative use of Tschudi's ABC technique.

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 primarily 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 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, interview data was gained from only six participants, who happened to have had quite similar educational experiences, and were achieving well in school.

Future Research

This study builds on the current literature base by exploring the views of individuals with literacy difficulties but no dyslexia label. However, the method of data collection limited the possibility of gaining more 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' responses to labelling, views of themselves and future educational attainment.

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 strive for environments in which difficulties are accepted, without judgement or blame, and understanding and support are developed through seeking the views of the YP. Teaching around attributions and beliefs of ability and intelligence may support YP 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 YP 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 YP make sense of their literacy struggles and identifying what helps them to persist and make progress is a worthwhile endeavour, whether or not we support the existence of the dyslexia label.

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Appendix
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 is 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 your 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."

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 to 10, how much do you believe that statement to be true?"