The Dyslexia Experience: Difference, Disclosure, Labelling, Discrimination and Stigma

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Abstract

This paper reports on a qualitative/quantitative adult dyslexic study of 22 dyslexics who presently or have in the past suffered from a depressive disorder, and 7 control dyslexic adults. It compares depressive to non-depressive dyslexics, with gender and academic success variables. Interpretive Phenomenology Analysis was used to investigate dyslexia and stigma.

Many perceived dyslexia as positive and gave them unique skills, but made them feel different. This difference was perceived to come from having to work harder than their non-dyslexic peers to achieve in life, as dyslexia affected many aspects of their daily life. Interestingly most would not seek a cure if it was offered - suggesting they perceived their dyslexia to be integral to whom they were, and losing their dyslexia would be as great as losing a limb.

Evidence suggested that dyslexics experience discrimination due to their disability, whether they perceive it as a disability or not. They felt there was a lack of public domain information on dyslexia and its effects, as many of their peers perceived it being negative. Recent legislation in the US and the UK aims to protect dyslexics in the workplace, however to gain protection they need to disclose their hidden disability to the world, making them vulnerable.

Many dyslexics have survived the last twenty, thirty or more years in the workplace and school without their difficulties being highlighted, one participant noted that they had felt successful in hiding for so long, with many feeling unhappy about disclosing their difficulties as they may fear this would firstly go on their record and

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secondly it might have a negative effect on promotion and career prospects.

Many felt dyslexia was a disability when they were children, as school was seen as an inflexible environment with no escape from reading and writing, along with unfair comparison with age appropriate peers - 'I'm only disabled by my dyslexia when you put me into a classroom' (Natasha). It was felt as an adult there was more flexibility to choose professions that play to a dyslexic's strength and use supportive technology (e.g. computers and spell-checkers). However, a minority withdrew from a society when they felt ill-equipped to function effectively within it.

Stigma due to dyslexia was highlighted as many camouflaged their difficulties at work, attributing their difficulties to quirkiness (positive) rather than being disabled (negative). Implications for the Asia Pacific area are discussed.

Keywords: Dyslexia, Difference, Disclosure, Discrimination, Labelling, Stigma

Introduction

The aim of this study was to pose a semi-structured interview script to a range of UK adult dyslexics to investigate how they coped, their reactions to success/failure and a review of their childhoods. Adult dyslexics were chosen as they would have the ability to review their childhoods for the origins of their coping strategies, and could give a data rich explanation of any emotional damage. Four groups were sought: dyslexics with and without a clinical depression diagnosis, degree-educated and non-degree-educated dyslexics. This research aimed to support a hypothetical 'Dyslexia Defensive Mechanisms' model as first proposed in Alexander-Passe (2009).

Empirical Review

What is Dyslexia?

'Dyslexia' first coined by Berlin (Wagner, 1973) described word blindness, defined through Greek roots: 'Dys' difficulty and 'Lexia' with words. In 1886 Morgan first documented the term and condition in the British Medical Journal (Snowling, 1996). Since then numerous medical and educational professionals have sought to understand the condition, its origins, its cause or causes, and its treatment.

Whilst the origins of the condition concerns difficulty with words, modern definitions are broader and this forms disagreements in the field. Symptoms include difficulties in: short-term memory, phonology, rapid naming, balance, motor skills, and organisation.

Based on the disparity between the original definition and modern symptom lists, a number of alternative names have been proposed to describe the condition better: Specific reading retardation, reading difficulties, specific reading difficulties, reading disability, learning disability, unexpected reading difficulty, and Specific learning difficulties. 75% tend to agree the

difficulty is with words, with the remainder noting a broader difficulty with learning.

Reflecting this disagreement, the draft revision to the 5th version of the American Psychiatric Association's 'Diagnostic and Statistical Manual (DSM-5)' originally suggested the term 'learning disorder' to be replaced with 'dyslexia' to *'render APA terminology consistent with international use'*, describing *'difficulties in reading accuracy or fluency that are not consistent with the person's chronological age, educational opportunities, or intellectual abilities'* (Cowen & Dakin, 2013).

However its final version (APA, 2013) now uses 'Specific Learning Disorder', based on a reasoning that the international conceptions and understandings of dyslexia (and other conditions) exist but disagree on its definition (Tannock in Elliot and Grigorenko, 2014). Elliot and Grigorenko argue that attempts to find a single definition have been hampered by factors of inclusivity, some criticised as being too inclusive and others too exclusive. Rice & Brooks (2004) and Fitzgibbon & O'Connor (2002) agree that a universally agreed definition and explanation remains elusive, and that definitions to date have been subjective and too broad, and serve self-obsessive purposes.

Fletcher & Lyon (2010) offer three primary reasons why dyslexia is hard to define:

Dyslexia is an 'unobservable construct'

meaning that attempts to measure it are imperfect and people suffering from the disorder cannot objectively report it.

Dyslexia is 'dimensional' meaning that there are varying degrees to which individuals may experience difficulty, from minor, severe and in between the two.

There is great disagreement from practitioners and psychologists about what characteristics to include and exclude.

The lack of an agreed definition and assessment route has meant that dyslexia is misunderstood which can lead to low identification rates, with many only being diagnosed in adulthood. It is argued that the majority of dyslexics leave school without diagnosis, and suffer at school through unsuitable and discriminatory teaching methods by teachers lacking special educational needs (SEN) training to identify children with learning difficulties (Hartley, 2010; OFSTED, 2010; Rose, 2009). Whilst current UK education policy states that all classroom teachers are teacher of all pupils including SEN, the lack of SEN training of teachers remains a concern (OFSTED, 2010; Driver Youth Trust, 2013).

Dyslexia affects both children and adults, but as children they are less able to hide their difficulties or differences (e.g. reading aloud, having their writing critically assessed etc.) as much as in adulthood where assisted adults or technology can be utilized. However many dyslexics experience discrimination on a daily basis (Dale &

Aiken, 2007; Michail, 2010). Scott (2004) and the Alexander-Passe (2004, 2006, 2010), Riddick (1996) and Willcutt & Pennington (2000) note the frustration and anger that can build up inside dyslexics when faced with tasks that highlight their inabilities, causing stress and anxiety (the fear of an already experienced negative event or task).

Alexander-Passe (2010), Scott (2004), McNutty (2003) agree that dyslexics generally camouflage their difficulties, with advanced coping strategies, so a sense of normality can be projected. Dyslexics are very conscious of their differences, so create a secondary persona to operate in the wider community (Alexander-Passe, 2010, 2012; Scott, 2004). However when cracks occur in this persona, it can be highly embarrassing, demonstrating how vulnerable they can be, and confirming their otherness compared to their peers.

There is however a shortage of research concerning dyslexia, disclosure, discrimination and stigma and this paper aims to shed light on this subject.

Disclosure

Dale & Aiken (2007, p.14) note in a recent study of dyslexic nurses *'many have gone to considerable lengths to hide their difficulties'.* Morris & Turnbull's (2006) study found dyslexic student nurses experiencing widespread concealment of student disabilities in clinical settings, as one student nurse noted *'when they (staff) find out they withdraw from you and make out you're not on the same level...they try to rubbish you and make you feel you've got*

nothing in your brain' (p.38). However without disclosure no *'reasonable adjustments'* and mentoring can be possible, to deal with the task-based difficulties experienced – so a double-edge sword

The need for disclosure is complicated by many dyslexics not perceiving themselves as being disabled (Blackfield, 2001) or not being recognised by others as being disabled. However the legal and bureaucratic position of dyslexia (in employment legislation and law) defines it as a disability. Also to gain additional support in the workplace individuals would need to disclose their dyslexia within the first 6 weeks of UK employment, to gain reasonable adjustments.

To disclose dyslexia at a work interview may mean that you may not be offered the post. Is it a risk worth taking? If you avoid disclosure until you start, your employer could argue you withheld disclosure of an important aspect relating to your ability to fulfil the post - thus you could be fired for non-disclosure.

Nalavany, Carawan and Sauber (2013) investigated dyslexia as a hidden disability. They note that adult dyslexics face complex decisions over disclosure. Hellendoorn, and Ruijssenaars (2000) found most participants felt dyslexia impacted on their daily life, experiencing many educational and career related problems. Nalavany, Carawan and Rennick (2010) noted that from 39 adult dyslexics, nine distinct cluster themes were identified, including: Why can't they see it?; Pain, Hurt, and Embarrassment

from past to present; and Fear of disclosure.

Barga (1996) studied the experiences of nine university students with learning disabilities (another term often used for dyslexia in the USA). Over a six-month period, students experienced labelling and stigmatization, which they considered to be a barrier to their education. Whilst all participants were selective when disclosing information about their disability to others, 6 of them reported deliberately using avoidance behaviours and concealment to hide their disabilities, fearing ridicule and stigmatisation. They feared rejection, ridicule and stigmatisation, so adjusted their lives to avoid the likelihood of perceptions of difference. Dyslexic participants noted regular examples of clinical misunderstanding and often misinformed ignorance and hostility by staff in regard to their dyslexia. Barga argues that dyslexia continues to attract an unwarranted stigma, which in some individuals can adversely influence the development of a constructive relationship with their mentor. Goffman (1964) defined stigma as the perceived deviance of personality or characteristics from the norm, within a particular context.

Rao (2004) reported that many undergraduate students avoid reporting their disability to avoid negative social perceptions, although admitting that their academic achievement may suffer as a result.

Empirical evidence suggests that dyslexia is similar to invisible differences such as religious orientation, in that there is no obvious appearance of disability (e.g. being in a wheelchair or exhibiting so called abnormal behaviour). Such invisible groups according to Beatty and Kirby (2006) have difficulty forming group awareness, because people are reluctant to publicly claim a potentially damaging identity in the workplace and socially.

Being visible means declaring one's hidden identity and 'coming out' to employers, friends and family. Such disclosure is weighed up for its advantages and disadvantages, before the plunge to openly disclose. Thus in many ways being dyslexic and sexual preference are similar as they are both (incorrectly) perceived to be negative in the workplace and 'coming out' is required to gain protection by discrimination legislation. Gordon and Rosenblum (2002) note that ironically the laws that protect people with invisible identities also creates and reinforce stigma by naming and categorizing groups.

This points to the lack of power by certain minority groups to advocate for themselves e.g. being black or a woman in the last century or being gay in this century, along with dyslexics these groups may find it hard to advocate for themselves as many lack the skills. In the UK, the main national charity protecting the rights of dyslexics (British Dyslexia Association) was set-up and run for many years by parents of dyslexics for school-aged dyslexics. Unintentionally they supported the argument that dyslexics were unable to voice their concerns and were incapable of fending and campaigning for themselves.

Hover, The BDA has evolved from this model with dyslexics being involved, especially at the top, and a developing focus on adult dyslexics.

In a personal relationship when should you disclose dyslexia? If you say it on your first date, then will there be a second? If you leave it until a relationship has settled, then you could be perceived as lying e.g. not admitting that you are a drug addict or addicted to gambling. Alexander-Passe (2012) found that some dyslexics disclosure on the first date as a discussion point, such as wearing glasses for reading, whereas others waited several dates into the relationship, as they wanted to secure the relationship before dropping the bomb-shell. Alexander- Passe concluded this depended on how dyslexia is perceived by the individual. Is it a strength or a weakness?

Disclosure has risks in the workplace; however it can have also its benefits. In the UK and the US disclosure brings access to support required to do the job well. As noted earlier, 'Access to Work' and the 'Disability Support Allowance' can mean the difference between succeeding at work or in your studies. These issues are particularly pertinent for the Asia Pacific region where adult support and legislation may be in its infancy.

What is Stigma?

Susman (1994) defines Stigma as an adverse reaction to the perception of a negative evaluated difference. It is not the attribute of the individual who bears the difference, but rather it resides in the interactions between the person with the difference and others who evaluate the difference in negative terms (Goffman, 1964). Critics of stigma argue it is too broadly conceived (Cahill & Eggleston, 1994).

Schulze & Angermeyer (2003) suggest that stigma adds a dimension of suffering to the primary illness – a second condition which may be more devastating, life-limiting, and long-lasting than the first.

Link & Phelan (2001) define Stigma as having five main components:

- Labelling – the recognition of differences and the assignment of social factors to those differences e.g. recognising that the individual may have different biological/ neurological traits to the norm.

- Stereotyping – the assignment of negative attributes to these social factor differences e.g. differences that matter and are deemed by others to be undesirable.

- Separation – occurring when the reactions to others leads to avoidance of those with the undesired difference (felt stigma).

- Status Loss – when the individual with differences is not allowed to fully participate in society or a community, thus the value of their place is reduced e.g. net worth is devalued by other people's views. This is perceived as 'enacted stigma'.
- Discrimination – when those with

the differences are viewed negatively and they are barred from certain jobs or tasks in society. Not based on abilities but perception (enacted stigma).

- Power differential – occurs when those with the authority use their position to bar or reduce those with the difference from taking full roles in society e.g. a company boss who feels negatively about disability may not shortlist a person with a disability for a vacant job.

- Stigma comes from making a conscious choice to discriminate against another individual, be it at school, walking down the street, at work, or socially. Within the medical model of disability, stigma can cause families to send a disabled or sick person away 'for their own good' but really to protect families from social stigma.

Stigma and discrimination go hand in hand as part of the medical model of disability (a disability that needs medical intervention to be cured). It has meant that disabled individuals, such as those with dyslexia are unable to get jobs, based on an incorrect perception that if a person can't read or write that they were 'stupid', and 'unintelligent'. In schools children may avoid making friends with those on the slow table, or make nasty remarks when a dyslexic child is made to read aloud in class and stumbles over their words.

Unfair advantage

Green, Davis, Karshmer, Marsh & Straigh (2005) found that those with an invisible disability were perceived by others as 'faking it' to gain special privileges or advantages, comments such as *'what's the matter with her? She's not in a wheelchair!'*

Lisle (2011) argues that there is growing evidence that a stigma exists towards those with a learning difficulty (LD) e.g. speaking of LDs as being intellectually inferior (McNulty, 2003; Denhart, 2008; Gerber, Reiff & Ginsberg, 1996). Interestingly, Snyder, Carmichael, Blackwell, Cleveland & Thornton (201) found those with non-physically visible disabilities reported more negative experiences than those with physical disabilities, questioning the validity of invisible disabilities in public perceptions (are they really disabled? Are they just trying to gain an unfair advantage).

The use of a label that identifies dyslexia was found to affect teachers perceptions and actions, many felt sorry for the students (Frymier & Wanzer, 2003), some perceived them as not only more difficult to teach but also less intelligent (Gersten, Walker & Darch, 1988; Frymier & Wanzer, 2003). Frymier & Wanzer found that many negative perceptions by teachers were due to the negotiation between student and teacher about reasonable accommodations, and the teacher questioning the validity of a non-visible disability.

Lock & Layton (2001) found some college professors held beliefs that the label 'learning disabilities' was an excuse to get out of work and laziness/not trying hard enough. Even though studies suggest dyslexics/LDs work themselves to exhaustion and illness to achieve at the level of their peers (Barga, 1996; Denhart, 2008; Reiff, Gerber & Ginsberg, 1997; Rodis, Garrod & Boscardin, 2001).

What drives stigma towards dyslexics

Lisle (2011) argues that stigmatisation of those with dyslexia/learning disabilities persists for the following reasons:

- Lack of Knowledge – Duchane, Leung & Coulter-Kern (2008) found that teachers stigma towards those with dyslexia comes from misunderstanding or a lack of knowledge about disabilities. Roe (2004) found educators with better knowledge of disability legislation had a more positive attitude towards those with learning disabilities.

- Invisibility of disability cues – Upton, Harper & Wadsworth (2005) found that perceptions of accommodation deservedness was greater for disabilities that are more visible and have more obvious educational implications; thus the visibility/invisibility of disabilities is an important influence on the formation of disability perceptions. The lack of physical cues hinders non-disabled individuals from understanding any educational difficulties. It is still perceived that those with

dyslexia/LD have lower IQ, so performing on par or better than peers and claiming extra accommodations can be misunderstood as cheating by both educators and students (Winters, 1997; Field, Sarver & Shaw, 2003; Elaqua, Rapaport & Kruses, 1996).

- Self-fulfilling prophecies – Jussim, Eccles & Madon (1996) and Hornstra, Denessen, Voeten, van den Bergh & Bakker. (2010) discuss the correlations between teachers expectations of LD/dyslexic students and their resulting student achievements, with those treated as having low ability accordingly believing such perceptions and acting/achieving in line with these beliefs. Evidence suggests that students with dyslexia/LD are more likely to drop out of college and university than those with LD/dyslexia and this will lead to social and economic disadvantage, argued to lead many such individuals into criminality (Mishna, 2003; Morrison & Cosden, 1997; Kenyon, 2003)

- Confirmation of bias – It is argued by Nickerson (1998) that educators will interpret information in a manner consistent with existing beliefs or explanations. Thus once a view of dyslexia/LD has been formed, maybe from teaching a single individual with such learning differences, then they will tend to ignore individual characteristics and treat all with a single definition and give a single type of

accommodation (Higgins, Raskin, Goldberg & Herman, 2002). However as noted earlier, all dyslexics are different and the differences are along a continuum, thus all dyslexics need tailored accommodations.

- Out-group homogeneity – it is argued that dyslexics/LDs are viewed by others as being of lower intelligence than themselves, they tend to be grouped together and ignored in social settings. This is based on convenience, rather than treating all people as individuals.

- Abelism – Hehir (2007) explains that there is an assumption in society that those without disabilities are more capable than those with disabilities, and in society groups tend to socialise with likeminded individuals. Thus as seen in school playgrounds, those who like football socialise together, and those with disabilities socialise together. It is also argued that in schools the use of withdrawal for intervention groups will mean that some groups are viewed as incapable and abnormal, and thus can be shunned and barred from joining certain high achievement social groups. This can create an unwelcoming and inaccessible environment for individuals with disabilities.

The effect of labelling with dyslexia

Several studies in the US and UK have investigated the impact of labelling in schools. These range from historical studies drawn from the 1970's and 80's to more recent studies.

Foster, Schmidt & Sabatino (1976) showed a film of a non-disabled child to two groups of 22 primary/elementary school teachers. One group was told the child was normal (control), other group (experimental) was told the child had learning disabilities. The study found the experimental group rated the child more negatively, which led to researchers to conclude the label generates negative expectations in teachers affecting their objective observations of behaviour and may be detrimental to a child's academic progress.

In a larger study of 88 teacher Foster & Salvia (1977) similar results were found *'teachers perceived more deviance when the child was labelled learning disabled than when he was labelled normal'* (p.533). Moreover, Gillung & Rucker (1977) found similar outcomes with 176 regular and 82 special education teachers in seven urban and sub-urban educational districts/ authorities *'teachers apparently perceived a child described with a label as having more severe academic or behavioural problems and required more intensive special services than the same child described without a label'*.

More recently, Bianco (2005) in a study of 247 general and special educational teachers were more willing to refer non-labelled students to gifted and talented programs (91%) than the same student labelled with emotional/behavioural disability (70%) or labelled as having a

learning disability (63%). Some of the teachers remarked that they wanted disabled students to be in a less pressured environment.

The focus now turns to student peers, are they affected by labels? Bak, Cooper, Dobroth & Siperstein (1987) investigated how non-disabled peers viewed students being removed for intervention sessions without the use of labels for difficulties. Two scenarios were investigated, removal to the 'resource room for 25% of the school day' and removal to the 'special needs room for 80% of the school day'. Results indicated that students were sensitive about students who leave classrooms during the day, the authors noted (p.154) *'the absence of formal labels did not prevent children from forming negative (although realistically pessimistic) expectations based on their own experiences with special class children's academic limitations'.* Those students were aware of the differences of where students were being taught for long periods, and negatively perceived removal for intervention.

Sutherland, Algozzine, Ysseldyke & Freeman (2001) suggests students were not rejected by their peers based on a disability label, but were more likely to be rejected by their actions. However, those who were informed about the positive attributes of the learning disabled students were held in higher regard by their non-disabled peers. The authors argue teachers need to inform the classes of positive-strengths rather than purely focus on negative-weaknesses.

Labels seem to have both negative and positive affects in education. Knowing a child's label, especially those of mental retardation, emotional/behavioural difficulties and learning difficulties tends to affect teacher perceptions and expectations for student success (Bianco, 2005; Foster & Salvia, 1977), with teachers also highly influenced over student behaviour over labels (Levin, McCormick, Miller, Berry & Pressley, 1982).

More recently, studies point to labelling of dyslexia having a positive effect by mitigating the effects by providing an acceptable explanation for a student's difficulties in reading, spelling, or writing effectively, compared to negative concepts of laziness or having a low IQ (Solvang, 2007; Riddick, 2000; Taylor, Hume & Welsh, 2010). This may reflect greater awareness if dyslexia through advocacy groups and the media, and a recognition that there can be strengths as well as weaknesses in dyslexia.

Taylor, Hume & Welsh (2010) investigated self-esteem levels in three groups of students: with a dyslexia label, with a general special educational needs label, or no label at all. The authors noted '*being labelled as having a general need negatively affected children's self-esteem, because unlike the label dyslexia, this label offers very little in the way of an explanation for the child's academic difficulties, and because targeted interventions are not as available for those with a less specific label*' (p.191). Riddick (2000) also found the dyslexia label was preferred by children, than a general 'special educational needs' label. In

Norway, Solvang (2007) also found that discovering they had the label *'dyslexia, many students were relieved that their difficulties were not their fault, removing the status of lacking motivation or having a low IQ'.* However it did suggest a greater problem for the parents based on the implication that they had given the child the neurological difficulties through their genes.

Acceptance of labelling

Dyslexics and their parents commonly have issues over labelling, which come from the acceptance of difference. The perception is that a label can confirm a difference so severe that it warrants a label. Early screening and intervention is seen by many educationists to be the key to helping the dyslexic to achieve their potential at school (Johnson, Peer & Lee, 2001; Lyon, Fletcher, Shaywitz, Shaywitz & Torgesen, 2001), as leaving screening/identification until late in primary school or early secondary school will mean negative concepts of difference will be established, with possible secondary emotional manifestations as a consequence.

Riddick (1996) and Zetterqvist-Nelson (2003) discuss the use of labelling and also whether such a label is a suitable definition of a person made up of combinations of strengths and weaknesses. Alexander-Passe (2010) noted a research participant labelled as a young child, who found the label a negative badge or 'noose around her neck'. It limited her ability to attempt subjects as they were known to be difficult for dyslexics, her curriculum was reduced, and she concluded the label was a negative factor in her life, especially at school. Zetterqvist-Nelson (2003) found similar findings, in that dyslexics preferred non-labelling as they did not want to stick out amongst their peers. However participants did find the label useful on a personal level as a relief and explanation for their difficulties, along with a moral relief that their difficulties were not their fault; but not on a public level, as it could be a cause of bullying or weakness in the eyes of others (as also found by Singer, 2005). Both Zetterqvist-Nelson and McNulty (2003) agree that the positivity of the labelling comes from individual's understanding of their diagnosis. This places an onus on diagnosticians, teachers and parents to ensure that dyslexic children and adults understand their profile of abilities and disabilities.

Stigma and Disability

Relating to this paper's topic of Stigma, it is argued that the lack of a single agreed definition of dyslexia, as per the lack of a single identification measurement instrument, has meant that dyslexia is broadly misunderstood. It is this lack of understanding that creates difficult situations for dyslexics at school as children and in the workplace as adults. In the majority of cases the stigma has come from lack of public knowledge and the inability to see that all individuals have skills and abilities to aid society. Stigma has caused problems such as social exclusions and religious persecution, however it is more subtle influences which underlie the problems that stigma causes, being turned down for jobs and treated as unable to mix in society which can have

lasting effects on countless generations.

Empirical knowledge in the field of stigma suggests that the experience of stigma (Byrne, 2000) includes the following: shame, blame, secrecy, being the black sheep of the family, isolation, social exclusion, stereotypes and discrimination. He then suggests there is a cycle to stigma which begins with the initial condition (e.g. disability) which leads to stigma, then discrimination, then disadvantage, leading to lower self-esteem and more disability as a result. This then leads to less resistance and then triggers and reinforces the initial condition. Such a cycle is self-perpetuating and leads to greater stigma as no understanding is added to society. In the workplace Stuart (2004) suggests a cycle starting with the initial condition (e.g. disability) leading to social stigma, then unemployment, then under employment due to feeling too inferior to their peers to work, leading to self-stigma by viewing yourself as less worthy by internalizing the social stereotypes which again leads back to reinforcing the initial condition. Both models suggest that unless intervention is made both cycles are self-perpetuating and society cannot develop.

There are four main definitions of disability (Kaplan, 2008) which is relevant to the discussion of stigma and dyslexia. The first is the 'moral or religious' definition of disability, where the individual is regarded as disabled by sinning against God. The second is the 'medical' definition where the person is disabled by being born defective or they develop a condition which makes

their body ineffective. The third is the 'rehabilitation' definition that comes to the fore in that until such a fix is made with medical intervention they are not a complete person without the medical fix. The last is the social definition, which believes that difference is part of society and that everyone has something to give to society. It celebrates difference compared to the other three definitions which sees difference as something to be feared and to be avoided.

Dyslexia and Stigma

Little research has been undertaken to study dyslexia and stigma. The author's earlier work on 'Dyslexia and Depression' (Alexander-Passe, 2010) was the first, looking at adult dyslexics through an investigative qualitative study; this paper is based on this investigation.

Riddick (2000) in an interview study of 27 children and 16 adults, all dyslexic, argued that although labelling can lead to stigmatisation, this is not always the case. It is argued that stigmatisation can take place in the absence of formal labelling, and stigmatisation can precede labelling, thus Riddick sees a greater gain from labelling, than not.

MacDonald (2010) argued that in a study of dyslexia in prisons, dyslexic inmates felt stigmatised by their literacy inabilities by not having a dyslexia label. In fact the stigma of restricted reading and writing ability had an indirect impact on offenders' self-confidence. MacDonald concluded (p.95) that *'the data in this study suggests it is not the label causing the stigma, but the*

symptoms. Removing the label only reduced the educational support and prohibits their legal rights'.

Morris and Turnbill (2007) with a sample of 87 trainee nurses during their clinical placements in hospitals, argued that dyslexia continues to attract an unwarranted stigma and can adversely affect the learning experience. The need for disability awareness training in the workplace and improved education/ service partnerships to support these students is considered crucial, one noted *''I overheard heard him (my mentor) tell another nurse that I wouldn't make it as a nurse because I'm dyslexic.'.* Co-workers too, often discriminate and stigmatise, by only seeing the perceived negative aspects of dyslexia, thus an biased focus on negatives (McLaughlin et al., 2004).

Rice & Brooks (2004) and Elliott & Place (2004) argue that using the label of dyslexia can be counter-productive as it stigmatise individuals, however Elliott (2005) argues the lack of a label will stigmatise poor readers who lack the dyslexia label – damned if you do, damned if you don't!

The Dyslexia Debate

Recent debate has focused on the effectiveness of using the term 'dyslexia' in educational settings. Elliott & Grigorenko (2014) argued in a recent controversial book 'The Dyslexia Debate' that the term is not only misleading (as it can cover more than just difficulty with reading and writing), but as intervention for dyslexics is no different to that for poor readers, that dyslexia is not a distinctive learning disorder and as such the term should be discontinued. They also note that using the term dyslexia can 'reduce the shame and embarrassment that are often the consequence of literacy difficulties. It may help exculpate the child, parents and teachers from any perceived sense of responsibility'.

Bishop (2014) tends to agree that the term is incorrect but concludes that there are other conditions such as depression and schizophrenia which are also 'massively problematic in terms of validity and reliability' (Kendell & Jablensky, 2003). However Bishop suggests that for each term whilst being incorrect and misleading, the strongest argument for retention comes not from science but public perception. That 'some of the most passionate defenses of the dyslexia label come from those who have built up a sense of identity around this condition, and who feel they benefit from being part of a community that can offer information and support'.

Also the term 'poor readers' leads readers to assume that such difficulties could be fixed through more effort and quality teaching, whereas 'dyslexia' suggests something different, long-term, and requiring specialist intervention. Bishop interestingly concludes that 'at present we are between a rock and a hard place. The rock is the term 'dyslexia', which has inaccurate connotations of a distinct neurobiological syndrome. The hard place is a term like 'poor readers' which leads people to think we are dealing with a trivial problem caused by bad teaching'.

The recent 2010 OFSTED review of special educational needs (SEN) and disability in UK schools found that pupils were often incorrectly identified as having SEN when they were not, and that good or outstanding teaching would remove such a barrier to learning, '...as many as half of all pupils identified for School Action would not be identified as having special educational needs if schools focused on improving teaching and learning for all, with individual goals for improvement' (p.5). However it also noted that identification was generally inconsistent and many SEN pupils were not identified, that children with similar difficulties were treated differently; and lastly that parents views of inconsistency were well-founded. The review also found that parents pushing for a statement of SEN (now replaced with 'Educational Health Plans') may not be enough to guarantee the high level of specialist interventions required. They noted that many schools misidentified pupils with SEN to cover up for their poor quality teaching and that by diagnosing them as having SEN they were assisted in removing their GCSE results from school result league table data, and gaining additional government funding.

The Bercow Report (2011) for the UK's Department for Education supports OFSTED's view that SEN is inconsistently supported in the UK, and that even having a statement of SEN does not guarantee the specialist support needed, noting 'the current system is characterised by high variability and a lack of equity. (It) is routinely described by families as a 'postcode lottery' (p.14)'. It again stresses the need for early screening and intervention in schools,

something that has been noted for several decades in UK schools. This lack of 'early screening and intervention' has meant millions of dyslexics in the UK have lacked the specialist intervention they need to reach their potential, and can be argued to lead to many dyslexics ending up in prison.

Hewitt-Mann (2012) suggests that up to 50% of the prison population is dyslexic, a figure not dissimilar to similar studies from the UK, Sweden and the USA (Mottram, 2007; Rack, 2005; Alm & Andersson, 1995; Kirk & Reid, 2001).

Tony Blair, the then UK Prime minister commented that *'many of those people in the prison population did not have the educational opportunities [that most of the population received] – often because they are dyslexic, had not been diagnosed properly, or did not get the extra help they needed'* (Hansard, 2007).

To conclude, dyslexia is contentious in its definition, diagnosis and intervention. It is generally misunderstood, but as a term it is accepted and those with the identification gain assistance in managing the difficulties they face. Incorrect public perceptions of dyslexia are misleading, and being an invisible disability many find it hard to accept which can lead to discrimination, stigma and bias in many environments.

However gaining the help required at school is highly problematic (high variability and a lack of equity), not only in schools screening and identifying policies, but once an identification has been made, receiving the specialist

support needed. As adults, many dyslexics lack diagnosis so face stigma and discrimination in the workplace, whilst coping with their difficulties, and will tend to use a number of defensive mechanisms to camouflage their difficulties, but these can result in negative mental health manifestations (Alexander-Passe, in press).

Methodology

Sample

Participants were recruited in three ways: (1) emails to UK dyslexia newsgroups, (2) adverts on dyslexic web-forums, (3) inclusions on dyslexia associations' websites. Four dyslexic sample groups were requested (with/without depression, degree/non-degree educated), with dyslexic adults with depression being the largest group recruited.

All participants were required to provide evidence of: (1) formal diagnosis of dyslexia evidence (e.g. educational psychologist reports), (2) depression (e.g. a clinical depression diagnosis or at least one course of physician/GP prescribed anti-depressants). Whilst mild depression is common in society, only severe cases tend to be referred for clinical diagnosis.

See Tables 1-3 for sample details. The mean age of dyslexia diagnosis data indicated that non-depressives tended to be diagnosed earlier, however in both groups they were mainly diagnosed post-school and after leaving university.

Apparatus

An investigative semi-structured interview script was used with 31 main themes (See Figure 1). Interviews lasted between an hour and three hours.

Table 1. Sample data: Size, mean age and standard deviations

	N	Mean age (years)	Standard Deviation
All	29	40.56	12.67
Depression diagnosis	22	42.32	13.0
No depression diagnosis	7	35,14	10.89
Depressed - females	15	38.8	11.71
Depressed - males	7	49.86	11.32
Non-depressed - females	3	18.0	1.63
Non-depressed - males	4	43.5	6.54
Depressed - dyslexia diagnosis	22	28.09	11.83
Non-depressed dyslexia diagnosis	7	22.28	14.77

Table 2. Sample data: Depressed participants

Depressed	Age	Diagnosed age of Dyslexia	Male or Female	Degree Educated	Non-Degree Educated	Depressed at school
Adrian	45	32	M	X		
Brian	70	35	M	X		X
Jasper	59	45	M	X		
Norman	40	33	M	X		X
Anita	47	45	F	X		
Emma	36	25	F	X		X
Maureen	34	27	F	X		
Rachel	40	32	F	X		X
Shelley	61	50	F	X		X
Susan	27	20	F	X		X
Trixie	58	11	F	X		X
George	54	40	M		X	
Ronnie	33	15	M		X	X
Samuel	48	19	M		X	
Andrea	41	39	F		X	
Karen	56	40	F		X	
Kirsty	23	16	F		X	X
Lara	25	20	F		X	X
Milly	37	7	F		X	
Natasha	40	25	F		X	
Norma	29	23	F		X	X
Phoebe	28	19	F		X	X

Table 3. Sample data: Non-depressed participants

Non-depressed	Age	Diagnosed age of Dyslexia	Male or Female	Degree-educated	Non-degree educated	Depressed at school
Zara	26	8	F	X		
Harry	52	45	M		X	
Jordan	34	33	M		X	
Malcolm	46	36	M		X	
Peter	42	8	M		X	
Izzy	24	5	F		X	
Jean	22	21	F		X	

Book Interview Questions:

1. Please describe how you are feeling today? (Are you taking any depression medication at present?)
2. Please describe your life/yourself? (I need to create a description of you e.g. age, education, job, character, personality etc.)
3. Do you enjoy life?
4. Please describe your childhood? Was it happy? (e.g. with your family)
5. Do you have any siblings? Do you think you were treated fairly/unfairly to your siblings?
6. Please describe your time at school? Was it enjoyable?
7. Did you ever get frustrated from your learning difficulties?
8. What does dyslexia mean to you?
9. **Is dyslexia something positive or negative?**
10. **How does dyslexia affect your daily life?**
11. What classic dyslexia symptoms to you have?
12. Do you think your hobbies help you? Giving you self-confidence?
13. Do you ever blame your dyslexia for things?
14. Do you/have you ever resented your teachers at school for not seeing your difficulties?
15. **Do you ever feel rejected? Please explain?**
16. **Have you ever encountered stigma towards your dyslexia?**
17. **Have you ever tried to hide your dyslexia?**
18. **Why might people try and hide their dyslexia?**
19. **Do many people know you are dyslexic? How did they find out?**
20. **Did you tell them? What was their reaction to your disclosure?**
21. **How do you feel about disclosing your dyslexia to other? Friends or at work, university?**
22. **Do you think dyslexics are discriminated against at school, university, at work, socially?**
23. How does failing or getting things wrong affect you?
24. Do you ever say why me? Why am I dyslexic?
25. Do/Did you self-harm? Why? What are the triggers?
26. Have you ever thought about or tried to commit suicide? Why? What were the triggers?
27. Do you think dyslexia and depression are correlated (linked)?
28. Did you ever truant/run away from home?
29. How do you feel going into schools now, what triggers any negative emotions?
30. Do you enjoy being you? Please explain?
31. Would you call yourself a successful dyslexic?

*Figure 1. Book Interview Script 31 items. (Items in **BOLD** are included in this paper.)*

The Interview Process, Confidentiality, Informed Consent and Personal Disclosure

All participants were sent details of the study before the interview, and all verbally confirmed participation before the start of each recorded interview. Participants were also advised that they could avoid any questions that were too emotional to answer and to halt the interview and their participation in the study without reason; fortunately, no participants took this option. As avoidance was noted in several interviews, further investigative questions were required.

Confidentiality was assured at several points: (1) in the original study advert; (2) in email confirmation/requests for basic details (name, age, education etc.); (3) at the start of each interview, (4) advising participants that pseudonyms names would be used.

Each participant was also reassured that they would receive a copy of their transcript which they would have the opportunity to check and modify. As the interviews concerned participants disclosing emotionally painful or frustrating events it was felt best that the interviewer (the author) also disclosed, where required, that he was diagnosed dyslexic at fourteen years old and understood and had experienced many of the difficulties at school that they may have encountered.

Analysis

Each interview was recorded on audio tape, transcribed, spell-checked with minimal grammar changes; lastly a check was made for readability. The transcript was then emailed to each volunteer for them to check and amend if required, with the opportunity for them to add additional notes or post interview revelations, as interviews can commonly trigger post-interview thoughts. Interviews were then subjected to IPA analysis.

Interpretative Phenomenological Analysis (IPA)

IPA is a relatively recent analysis model but has its historical origins with the phenomenology and Husserl (1970) aiming to return to studying living things. This refers to "to return to the things themselves is to return to *that* world which precedes knowledge, of which knowledge always speaks" (Merleau-Ponty, 1962). Husserl was very interested in the life-world, which comprises of the objects around us as we perceive them and our experience of our self, body and relationships.

Whilst there are many forms of phenomenology in use (*Idiographic, Eidetic, and Transcendental*), IPA using Idiographic ideals is used in this study. Smith developed Interpretative Phenomenological Analysis (Smith, Harré and Van Langenhove, 1995; Smith and Osburn, 2008) to analyse elements of the reflected personal experience - the subjective experience of the social world. Giorgi (1994) argues that phenomenology avoids the reductionist tendencies of other research methodologies, and uses the researcher's assumptions/divergent links to inform new insights from the data,

rather than forcing data to fit pre-defined categories. Such intuition in the researcher allows 'outside the box' thinking. The researcher is an interpretative element to understand themes and body language, compared to Discourse Analysis (Potter, 1996) which relies on precise analysis of the words used.

IPA has been used in many research studies (Duncan, Hart, Scoular, & Brigg, 2001, Thompson, Kent, & Smith, 2002; Clare, 2003; Biggerstaff, 2003; French, Maissi, Marteau, 2005).

IPA is suitable for this sample due to: (1) Being 'social model of disability' and inclusion friendly, aiding understanding in special need samples; (2) Allowing flexibility and the ability for themes from initial participants to inform an investigative interview script; and (3) Dyslexic friendly as it does not rely solely on discourse.

Analysis Methodology Used in this Study

This study predominately uses IPA methodology for analysis of data; however the results from the transformations (themes) were then used to create quantitative data, thus mixing qualitative and quantitative methodologies. Nineteen main themes were identified from transformations in the third stage of IPA and two-hundred feelings or aspects were identified for these nineteen themes, displayed in quantitative percentages. The quantitative data was then used to create tables along with interview evidence in the form of quotes (from

mean units from the second IPA stage) are used to form each argument/topic for the results.

Results: Profiles

Profile results from this study are drawn from Table 4.

Overall the sample found dyslexia to be positive (57.7%) and to give individual unique skills (76.9%), but dyslexia makes them feel different (76.9%). Most (61.5%) agreed that not only does dyslexia affect their daily lives but they feel the world is unfair to dyslexics. Many agree that they must work harder in life (38.5%) but only a small percentage would want to take a magic pill to rid themselves of their dyslexia (11.5%).

Males seemed unsure if dyslexia was something positive or negative (both 36.4%) but most agreed that it gave unique skills, made them feel different, but the world was unfair to dyslexics (all 72.7%). Most felt dyslexia affected their daily lives (54.5%) but only a fraction would want to get rid of their dyslexia (9.1%). Interestingly females saw dyslexia as more positive (61.1%) and like the males, felt it gave them unique skills and made them feel different (66.7%).

Unsurprisingly, the depressed sample found dyslexia to be mainly negative (72.7%) but most agree that dyslexia is a social construct (55.6%), gave unique skills (63.6%), made them feel different (68.2%), affected their daily lives (59.1%), however few would want to be cured (9.1%). Compared to this the non-depressed sample, who felt dyslexia

Table 4. Perceptions of Dyslexia

What is Dyslexia?	All Participants			Depressed					Non-Depressed		
	All	Males	Females	All	With degree	Without degree	Males	Females	All	Males	Females
	N=29	N=11	N=18	N=22	N=11	N=11	N=7	N=15	N=7	N=4	N=3
Its positive	57.70%	36.40%	61.10%	54.50%	45.50%	63.60%	28.60%	66.70%	42.90%	50.00%	33.30%
Its negative	26.90%	36.40%	16.70%	72.70%	27.30%	27.30%	42.90%	20.00%	14.30%	25.00%	0.00%
Dyslexia is a social construct	50.00%	27.30%	55.60%	45.50%	36.40%	54.50%	28.60%	53.30%	42.90%	25.00%	66.70%
Dyslexia gives me unique skills	76.90%	72.70%	66.70%	63.60%	63.60%	63.60%	57.10%	66.70%	85.70%	100.00%	66.70%
Dyslexia makes me feel different	76.90%	72.70%	66.70%	68.20%	63.60%	72.70%	71.40%	66.70%	71.40%	75.00%	66.70%
Dyslexia affects my daily life	61.50%	54.50%	55.60%	59.10%	63.60%	54.50%	57.10%	60.00%	42.90%	50.00%	33.30%
I feel the world is unfair for dyslexics	61.50%	72.70%	44.40%	50.00%	45.50%	54.50%	71.40%	40.00%	71.40%	75.00%	66.70%
I must work harder because I'm dyslexic	38.50%	45.50%	27.80%	31.80%	36.40%	27.30%	42.90%	26.70%	42.90%	50.00%	33.30%
I would take a pill to cure myself of dyslexia	11.50%	9.10%	11.10%	9.10%	18.20%	0.00%	0.00%	13.30%	14.30%	25.00%	0.00%
I'm disorganised due to my dyslexia	30.80%	27.30%	27.80%	31.80%	45.50%	18.20%	28.60%	33.30%	14.30%	25.00%	0.00%
I blame thing on my dyslexia	19.20%	27.30%	11.10%	13.60%	9.10%	18.20%	14.30%	13.30%	28.60%	50.00%	0.00%

was more positive (42.9%) than negative (14.3%). However agree that dyslexia gave unique skills (85.7%), made them feel different, but the world was unfair to dyslexics (71.4%). Many agreed it was socially constructed, affecting their daily lives and that they needed to work harder because of their dyslexia (42.9%). Interestingly more non-depressed individuals wanted a cure than depressed (14.3% to 9.1%), however both are minority views.

Looking at the largest sample, depressed individuals. Those without a degree felt dyslexia was less positive (45.5% to 63.6%) with both group agreeing to the same level of it being negative (27.3%). Interrogating the interview data, degree-educated depressive dyslexics noted that by going to university they truly understood the barriers involved, whereas before such education they had an insular impression of their learning difference.

This was confirmed by them understanding that dyslexia was socially constructed and compared to non-degree educated individuals; they would take a cure pill (18.2% to 0%).

Results and Discussion: Interview Evidence

Stigma or Lack of Knowledge?

Have you encountered any stigma towards dyslexia? Not really, I think I have encountered more that people do not know what it is, especially at work, that people misunderstand it, but I have never really encountered any stigma about it, but I'm working with people who know what the problems are. (Anita)

Have you ever tried hiding dyslexia? Yes. Why do you think you tried to hide it? Because sometimes I don't want to answer questions on it, I don't want to have to explain why I do things and how I feel about it, and then when I kind...if I do answer questions I want to do so eloquently or properly or so that people understand or in a way that people understand, so that they are accepting of it. I know I try and hide it when I know I can't answer the questions. (Emma)

How were your parents concerning your learning difficulties? The problem with me was they knew there was a problem but they thought the solution was me putting in more effort and more hard work, without admitting it was there. If they admitted there was a problem then they have to talk about it, about it, they thought if I worked harder, all of this will go away. **Did that cause friction with you?** I was talking about dyslexia years later to my mum and she would not discuss it, it was still a stigma thing then. (George).

The interview evidence suggests that there has been a void of information in the public forum that truly describes the dyslexia experience, thus disinformation creates situations where dyslexics choose to hide their differences, as they themselves cannot fully explain how and why they do things. As each dyslexic has a different combination of difficulties, one single profile would be misleading.

Work Discrimination

Do they know you are dyslexic at work? Yes. I kind of decided when I changed my job, because of the role it was, I was going to be very clear all the way through the recruitment process and when I got into the team. To be very explicit to what the problems were and to get support there. I felt a bit coerced into telling people, like the manager saying 'you will tell everybody, won't you?', so that began with, then 'when will you tell them, what are you going to tell them, you need to tell them soon', so I think in the end I found the most comprehensive description of the problems a dyslexic might have and emailed everybody that. I think they thought I had all of the problems I wrote about, all I really wanted them to know was I was dyslexic and dyspraxia and I might need some adjustments made for me and to be understood. I felt I was pushed a bit to send out that general email, having done that I felt exposed, as I wasn't given the support by my employer, so I had to fight for it and get the union involved. It got messy and fraught. So I got stress from their lack of adjustment (Norman).

It sounds surprising for a social work job; you got no support and needed to be protected from the people who were not only paid to know better but to help others. So you needed your own social worker really? The irony for me was I was working for an NHS (National Health Service] mental health team in the UK as a social worker, but they didn't identify that I was getting unwell there, getting extremely stressed and losing the plot. So that's when I talked to the union person and she was the one that told me to see a doctor, she said 'you look like you're at the end of your tether', but no one at work had picked it up. Which is worrying. (Norman).

Whilst some dyslexics are open about their differences, most are not (Passe, 2010, 2012) as they feel they would be treated poorly in the recruitment process. In the UK there is 'Access to Work' a government funded program to put in place reasonable adjustments (training and software etc.) so that anyone with a disability can be assisted to reach their potential as per their peers. However many argue that this only comes after the recruitment process and as many dyslexics attain poorly academically they can be seen as under-qualified for the post and are not even interviewed. As Norman notes there is little support for those who need to educate colleagues to their learning difference and this can cause emotional trauma.

Social Construct: Is it Only a Disability at School?

Do you ever get frustrated/annoyed by your learning difficulties? Reading and spelling did annoy me at school; I think that it only annoyed me at school. Therefore, you think dyslexia is mainly about school, a disability at school, not as an adult? It depends on what line of work you go into, it is not a disability in my area. I mean I am really good at what I do, but I am not in an area of work where you have to write things down and to be organised, but why would you go into a job like that, if you

were not going to be good at it. (Izzy)

Do you think the problem is us (dyslexics) or the world around us? No, I do not believe there is a problem. To hear some people say [things, or] to receive certain reactions, if it can be agreed that we have difficulties in learning, which doesn't make us inferior or worse than others, then why can't it be agreed that in a situation where people don't have a condition, that won't act or respond, not as relative to our class as the norm (as normal). I do not think it is a problem, I do not see it as a problem with them or us, and it is just a lack of understanding. If they understood dyslexia and the implications of dyslexia there would be less problems encountered. **You were talking about 'normal', do you feel normal?** What is normal? **Do you feel normal?** Well, what is normal? (Jordan)

I don't regard myself as disabled by it, I regard myself as disabled by how other people see it and whenever I meet dyslexics I sort of tell them that, especially kids who are feeling...don't know how to feel about it and I can kind of see something switching in their face when I put it to them like that, it is quite a state of mind – another coping strategy. (Milly).

As Milly notes 'I don't regard myself as disabled by it, I regard myself as disabled by how other people see it'. Many dyslexics believe dyslexia is socially constructed and until the social model of disability is used in the workplace, difference will be perceived as negative. Whilst few professions openly recruit dyslexics (e.g. computer graphics), most see it negatively which will affect productivity. Normality is noted by Jordan, to explain how dyslexia is perceived in the workplace.

Is it a Taboo Subject?

But probably taking to you is the most honest I've felt or at ease talking about my problems for a long time. **I don't think people really talk about how they feel about their difficulties; it's like a taboo subject.** Yes, the same as the homosexual was 20 yrs ago. It's similar to how I feel; it astounded me thinking back about it. **You are right there are similar themes to it.** Yes. **I guess coming out is similar to coming out that you are gay?** Yes. **It's a fascinating link, fascinating.** I'll wait for the how dyslexics are homosexual link next. I used to work out that it is the same occurrence. They said that it was one in five is gay and also they say that one in five could be dyslexic. I should put a patent on that. (Ronnie).

Ronnie makes parallels to homosexuality which he perceives as a similar difference to be self-conscious about in the workplace and with friends. The notion of coming out as a dyslexic was fearful to many in the study, with most avoiding telling their employer for fear of being made redundant or passed over for promotion.

Disclosure of your Dyslexia

So you feel you are very open about it so they blamed the dyslexia not you? It's one of the first thing I say, but I suppose I use it as an excuse. I do not mind telling people I am dyslexic, as it is

who you are. I would be lying if I said I do not use it as an excuse. I guess it is because I have been told I am stupid a lot growing up, you are quite eager to tell people the reason why you cannot do things. **How do people normally react to you telling them you are dyslexic?** Most people say 'really, you don't look dyslexic', because I think a lot of people have this perception of dyslexia and disability, they have this idea about people with a disability, and because I'm quite well-spoken I can get through day-to-day life quite well, I'm quite good at hiding all the little things I do to get me through it. (Kirsty).

Kirsty comments on the dilemma that most dyslexics face. Do they disclose and face unhelpful and negative comments, or do they stay silent and use coping strategies to get by.

Labelling

You were talking about not telling people you were dyslexic, being 'in the closet'. You see the thing about it was, I had not been formally assessed, although I screened positive when I was 15 years old, and they turned round and said that I had poor visual and hearing memory, but refused to label me because it was deemed to be inappropriate, it was in 1976, labelling wasn't the done thing. So although it was a brief thirty minute chat with a psychologist, nothing really happened from it. It was not a formal assessment and I was not aware of how much help was available then and what I could have been getting. It was only when I was struggling with assignments at Oxford University that I finally thought I

would do something about it and it could make a difference. (Anita).

I guess you are the first person I know who was diagnosed at five year old stage. It is fairly interesting how you view the situation. Do you know what it is, I can't remember a single time in my life when I haven't been told that I'm dyslexic. It has been a constant word in my life. I can only vaguely remember the test, at the time I wasn't sure why I was being tested, being taken out of class for it...It has always been this word, I'm angry that in my whole life I have been labelled, just because the educational system didn't fit into my strengths, that I didn't fit into a mould, my brain isn't like yours, we are all different, you know. I guess if you test my whole class, most would have a similar IQ, a few would have a high IQ, and others might have an IQ a bit lower. We all have our strengths and weaknesses, it's a spectrum. If you don't fit into the mould with creativity, artist ability and original thought, maybe they should be labelled creative or something. Now I'm in the real world, and in what I'm doing I'm brilliant at it. I'm starting my own business, I know what my strengths are, and I have proven I'm good at things. (Izzy)

Anita and Izzy see labelling from different perspectives. Anita sees labelling in a positive way, as a means to explain what is going on. Izzy on the other hand has found it a heavy weight around her shoulders, as other quotes from Izzy suggested that it had a negative impact on her education as it prevented her doing things, as teachers had a stereotypical perception of what

dyslexics could and couldn't do, which prevented her from creating her own dyslexic profile (of strengths and weaknesses).

Conclusion

The quantitative data in this study painted a picture of different perceptions amongst depressive and non-depressive adult dyslexics, along with sub groups of degree and non-degree educated, and gender splits.

There were high frequencies that perceived dyslexia as positive and gave them not only unique skills but made them feel different. This difference was seen to come from having to unfairly work harder to achieve in life, with dyslexia affecting their daily life. Interestingly most would not seek a cure if it was offered, which suggests they see dyslexia as integral to who they were, and losing their dyslexia would be as great as losing a limb.

The interview evidence in this study suggests that dyslexics experience discrimination due to their disability, whether they perceive it as a disability or not. There seems to be too little information about dyslexia and what it affects in the public domain, thus many perceived dyslexia as something negative and not something they feel able to help with. It is hoped that recent legislation in both the US and the UK will protect dyslexics in the workplace, however as noted earlier, to gain protection by such legislation they will need to disclose their hidden disability to the world. However many dyslexics have survived the last twenty, thirty or more years in the workplace and school without their difficulties being highlighted. Other extracts of Passe (2010) asked 'Do you feel successful', with one participant that they had felt successful in hiding for so long, with many feeling unhappy about disclosing their difficulties as they may fear this would firstly go on their record and secondly that it could have a negative effect on promotion and career prospects.

Many in this study perceived that they only felt dyslexia was a disability when they were at school, as it was an inflexible environment with no escape from reading and writing along with unfair comparison with age appropriate peers. As one participant in this study noted 'I'm only disabled by my dyslexia when you put me into a classroom' (Natasha). There is much more flexibility as an adult to choose professions that play to a dyslexic's strength and one that limits the need for reading and writing, with greater use of technology (e.g. computers and spell-checkers). Whilst a minority, it should be noted that some dyslexics may withdraw from a society which they feel ill-skilled to participate in (Scott, 2004).

The author in this study who is dyslexic, has at time chosen to hide his difficulties, creating situations where his sometimes strange range of skills was attributed to quirkiness (positive), rather than being disabled (negative). This camouflaging was a common feature in his research with other dyslexics.

Until the social model of disability is used more widely in the workplace,

there will always be instances of discrimination against those who do not fit into the perceived 'norm' model. Thus, further research is needed to understand dyslexia, stigma and discrimination in the workplace.

Labelling was lastly discussed. This is a contentious issue as many parents incorrectly feel a label is negative with life-long longevity (post school and into the workplace). However in education the lack of labels may prevent teachers from making sense of their child's strengths and weaknesses, and denying their child can prevent access to suitable interventions. Whilst the author agrees that a label is only as good as the diagnosis given with it, it relies on starting educational intervention discussions rather than ending them; as non-SEN teachers commonly rely on incorrect stereotypical views on the strengths and weaknesses of individuals with dyslexia, and these need to be challenged.

Limitations

Whilst 29 participants took part in the study, 22 were diagnosed as depression and only seven had no depression diagnosis. The author took the viewpoint that the vast majority of the participants suffered one or more depressive symptoms, and that the study would not label any quotes as from a depressive and others from a non-depressive, as this might be misleading and lead the reader to make assumptions. However, a slightly different pattern of responses might be found from a group of participants who were not suffering from depression.

Finally, it should be noted that the material here is drawn from adults who received their education when less awareness of dyslexia and the pattern of strengths and weaknesses was available. It could be argued that within the Western world, the situation for children going through the educational system will be vastly different in 2015. This study has particularly strong implications for some Asian-Pacific countries, where public awareness of dyslexia may still be in its infancy. The onus is on those with expertise in the area, dyslexia associations and trained teachers, to ensure that this knowledge is shared and the strengths in dyslexia are recognised, in order to ensure that up to 10% of the population can no longer be stigmatised. With greater recognition and early structured support, dyslexic children and adults will have every opportunity to overcome their weaknesses and express their strengths fully

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