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## Should 'developmental dyslexia' be understood as a disability or a difference?

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### Abstract

This paper questions current views of the phenomena of 'developmental dyslexia', and offers a discussion of the various models of disability that are currently used in society, and whether they are suitable to use when discussing 'dyslexia': The Medical model, the Social model, the Affirmative Model, the Psych-Emotional model, the Psych-Social/Bio-Psycho-social model, the Social-Relational model are all discussed, each with their own perspectives. Valeras's model (2010) is offered as an alternative to understand 'hidden disabilities' like dyslexia, diabetes and epilepsy etc. The term 'bi-abilities' is introduced to understand how such groups can have strengths in both the disabled and non-disabled worlds, and that such groups often reject any affinity with disability as they argue they are 'able-bodied'. The paper then investigates how dyslexic individuals whilst experiencing trauma at school can also experience growth from such experiences, through a discussion of 'Post-Traumatic Growth-PTG' to understand positives coming from experienced trauma e.g. school-based trauma, arguing Valeras's 'bi-ability' model to be more relevant to the dyslexic experience. The paper concludes by applying the 'bi-ability' model to dyslexia. The main themes are:

- ◆ Disability is a strong word – rejecting an infinity to a term that has negative public perceptions
- ◆ I'm more than in the middle – falling in the middle of two identities but rejecting both
- ◆ We don't have a box – traditional social groups do not describe who they are
- ◆ I didn't want to be different – it wasn't their choice to be born this way
- ◆ Not even consciously. But it's so hardwired – survival instincts naturally kick in
- ◆ To Tell or not to tell, it's the elephant in the room – the stress of not disclosing to others
- ◆ It's a piece of my identity, but it's not my identity – being different is not all consuming

**Keywords:** Dyslexia, Disability, Ability, Success, Post-Traumatic Growth, Bi-ability

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## INTRODUCTION

This paper investigates the phenomena of 'developmental dyslexia' (specific reading disability), defined by Rose (2009) as a specific learning difficulty that primarily affects the skills involved in accurate and fluent word reading and spelling. Whilst there are many characteristic features of dyslexia, these focus on difficulties with phonological awareness, verbal memory and verbal processing speed. As dyslexia occurs across the range of intellectual abilities, it is best thought of as a continuum, not a distinct category, with no clear cut-off points. A good indication of the severity and persistence of dyslexic difficulties can be gained by examining how the individual responds or has responded to well-founded intervention. Whilst there are many theories to the cause of developmental dyslexia, many believe phonological deficits are a core function (Snowling, 2000; Thomson, 1996).

The author questions how this phenomenon should be defined in society, whether it is a disability and by understanding this question, how it should be understood in society. Later parts of this paper introduce both a 'bi-ability' (Valeras, 2010) model to argue that those with 'hidden disabilities' can reject a disability model, and use 'Post-Traumatic Growth-PTG' (Calhoun, Cann & Tedeschi, 2010) to understand that post-school success can come 'despite' and not 'because' of mainstream educational experiences.

### What is a Disability? What is 'Normal'?

The World Health Organisation's International Classification of Disease (WHO, 1980, p.29) separates the concepts of Impairment and Disability as follows:

**Impairment:** Any loss or abnormality of psychological, physiological or anatomical structure or function.

**Disability:** Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

Individuals are perceived to be 'normal' in society when they are: male/female, able-bodied, heterosexual, and these are believed to be the default membership for all in the absence of any visual/behavioural cues that would alert them otherwise (Abberley, 1993; Davis, 1995). Goffman (1963) has called this 'virtual social identities', however some individuals do not fit into this category and are the subject of this investigation.

### Disability in UK Schools

Education systems in the UK and most western countries are based on standardisation and whilst this may be suitable for the great majority of children, for groups of Special Educational Needs and Disabilities-SEND, estimated by Warnock (1978) to be 20% of

children (who will experience impairments at some point in their school career), it is argued is not. National Statistics (2017a) indicate the level of SEND in mainstream education has fallen from 21.1 to 14.4% in the last 7 years (2010 to 2017), however this must be understood to reflect the 'level of provision and funding by schools' not the actual 'level of need' (SEND Code of Practice, 2015). Such groups are perceived as being 'abnormal' and according to the 'Medical Model of Disability' (World Health Organisation, 2002), where individuals are defined as having 'impairments' causing barriers to their learning and limiting their access to services, they are segregated and provided with interventions to achieve according to their peers.

Runswick-Cole and Hodge (2009) argue the SEND term is an administrative label in current educational policy and legislation, and continues to locate the problem within the child, using the Medical Model of Disability. Cole (2004), Hodge (2006) and Runswick-Cole (2007) argue that SEND pupils are excluded within school practices and that the 'SEND' term contributes to such exclusion, as they are classed as the 'other' group supported by professionals and specialists; and thus, other children perceive children with SEND being 'different and deficient' (Rorty, 1989). Cole (2008) counters this by arguing pupils are only limited by the abilities of their teachers to adopt teacher and school flexible approaches to learning, teaching and assessment, rather than the child being expected to fit into pre-existing structures. Recent UK government reports highlight an 'unfit for purpose' SEND educational policy in schools resulting in a 'postcode lottery' of inconsistent support for pupils with SEND in mainstream schools (OFSTED, 2010; Bercow, 2011; Scott, 2016).

### **'Medical' vs 'Social' Models of Disability**

The 'Medical' model suggests that those with a disability have dysfunctional bodies that require medical intervention to return to society's concept of normality (Finkelstein, 1980). By contrast, the 'Social' model suggests that it is the environment that causes any disability and this needs to be modified to be inclusive to all needs (Oliver, 1996; Barnes, 2003). Interestingly Barnes and Oliver (1993) suggest that the 'medical' model was created by non-disabled researchers to understand abnormal populations and the 'social' model was created by disabled researchers to make sense of 'normal' populations as part of 'social oppression theory', as it is argued that *'non-disabled researchers have consistently failed to address the question of disability as perceived by disabled people whether young or old'* (p.3). Lang (2001) notes the 'Social' Model was born out of the disability movement finding a means to create a political platform to secure the 'rights of disabled people in society. Lang goes on to suggest the 'Social' model *'should not be considered as a monolithic entity, but rather as a cluster of approaches to the understanding of the notion of disablement'* (p.2). Lemert (1962) and Goffman (1963) talk about disability as a social deviance causing a stigma, mark or blemish to describe a 'moral inferiority'.

The empowerment and politicisation of disabled people is a defining principle in the social model, making it a force for 'social action' (Finklestein, 1996; Oliver, 1997; Swain, Griffiths and Heyman, 2003), as it emphasises social oppression and barriers which limit what a disabled person can 'be' and 'do' (Thomas, 1999; Reeve, 2004), in a society that discriminates against people with impairments and excludes them from involvement and participation. Additionally, that all people have a unique set of strengths and weaknesses that society needs to recognise, empower and utilize (Union of Physically Impaired against Segregation, 2009). This is also reflected in the 'Positive Dyslexia' model advocated by Nicolson (2015), making use of the 'Positive Psychology' movement (Seligman, 2011).

Charlton (1998, p.27) argues that the oppression experienced through the medicalisation of disability; has '*prevented people with disabilities from knowing: their real selves, their real needs, and their real capabilities and from recognising the options they in fact have*'. Barton (1996, p.8) furthermore suggests disabled people have historically been oppressed through institutional discrimination by: '*horror, fear, anxiety, hostility, distrust, pity, over-protection and patronizing behaviour*'. However, there are other models of disability that should also be considered.

The 'Affirmative Model of Disability' (Swain and French, 2000) develops the 'Social Model', from a deficit to a positive stance, to be '*essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle of being impaired and disabled*' (Swain and French, 2000, p.569). The 'Affirmative Model' argues that '*far from being necessarily tragic, living with impairment can be experienced as valuable, interesting and intrinsically satisfying. This is not to deny there can be negative experiences resulting from impairment, but to make the point that this is not all that impairment is about*' (Cameron, 2011, p.110).

Lastly, the 'Psycho-Emotional Model of Disability' (Thomas, 1999) offers an understanding of the emotional impact of disability, '*being made to feel of lesser value, worthless, unattractive or disgusting*' (Thomas, 2004, p. 38), that the oppression individuals with impairments experience from society is internalised/absorbed, and this affects their self-belief about what they can do - a form of 'learned helplessness' (Seligman, 1991), defined as a condition in which a person suffers from a sense of powerlessness, arising from a traumatic event or persistent failure to succeed. It is believed to be one of the underlying causes of depression.

The above definitions of disability have been argued to be largely based around those with physical disabilities (as expanded versions of the Social' model), however as will be discussed, dyslexia and other conditions such as Diabetes, ADHD, and Epilepsy, are not based on physical barriers, and this can create a perceived hierarchy to the term disability in both disability groups and in the public arena (Reeve, 2004; Shakespeare and Watson, 2002).

### Critics of the 'Social' Model of Disability

Morris (1991) suggests the 'social' model effectively denies any physical, emotional pain, and suffering experienced by disabled people due to their impairments having an impact upon their practical daily living, hence the model is perceived as 'lacking' by commentators in the disability community (Hughes and Paterson, 1997; Crow, 1996).

Adding to this, Shakespeare and Watson (2002) argued that the 'social' model is outdated as it was created in the 1970's, and nearly 50 years later society has developed, and 'by arguing against the social model we are not denying that for much of the time the priority remains to analyse and campaign against social barriers, merely that we require a more sophisticated approach to disability' (p.24). They offer three reasons why it is outdated:

- (1) Impairment and disability are not dichotomous, but
- (2) Disability should not be reduced to a medical condition. It should not be overlaid with negative cultural meanings. Neither should it be reduced to an outcome of social barriers alone, however important these might be in people's lives.
- (3) Intervention at physical, psychological, environmental and socio-political levels is the key to progressive change, yet one cannot be a substitute for the other. Social change remains the most expedient measure to remove the problems presented by impairment and its consequences.

Lastly, arguing any 'failure to follow a social model line, or join with the disability movement, may be less of a failure of particular individuals, and more a limitation of the model or movement itself' (p.25).

Lang (2001) notes that Crow (1996) and Morris (1991) along with Hughes and Patterson (1997) argue that the 'Social' model has focussed on social change over that of the experience of those with disabilities, and 'denies' the physical and emotional pain, and suffering experienced by disabled people in their daily lives. Reeve (2004) argues that there is a public perception of what a disabled person 'looks like' and how they should 'act', focussed on physical impairments, and that those individuals 'without' physical impairments are frowned upon if they try to gain allowances for their needs: leaving them 'feeling ashamed, vulnerable and invalidated' (p.87). Morris (1991) argues that disabled people are surrounded by myths and stereotypes which underpin prejudices, with terms such as 'too blind to see', 'out of your mind', 'words falling on deaf ears', 'haven't got a leg to stand on' that support the concept to be of value one must be physically, psychologically and mentally fit (Thomas, 1995).

Regarding individuals without physical barriers, who could be classed as having 'hidden/invisible impairments'; they constantly risk their disability status being publicly revealed,

forming the basis for their *'negative psycho-emotional reasons for concealment'* (Thomas, 1999, p.55). Reeves (2004) found that those who *'passed'* disclosing their impairment were seen as *'traitors by others within the disabled people's movement'* (p.92) as they were actively rejecting their disabled identity (Kanuha, 1999). It suggests there is a perceived *'hierarchy of impairment'*, as found by Reeve (2004, p.92) *'one of my participants did not feel she was seen as a 'real' disabled person because she was not a wheelchair user and did not have one of 'the biggies' like cancer, arthritis, multiple sclerosis or visual impairment. Consequently, her identity as a disabled person was challenged by other disabled people in the organisation'*.

Grewal, Joy, Lewis, Swales and Woodfield (2002) identified that just over half of people with impairments surveyed did not identify themselves as disabled. Reasons varied: they did not think they were ill or incapacitated enough to count as disabled, their health problems were part of an illness or getting older. The negative images they associated with disability caused many to be too embarrassed to identify as disabled, as they felt it was believed to be connected with a physical impairment: typically affecting mobility, was visible, led to dependency, incapacity issues, and was a permanent condition. They also dismissed their own impairment as they felt they were mobile and capable, and they saw themselves being *'normal'* (Watson, 2002). It is argued by Reeve (2004) that the *'Psycho-Emotional Model of Disability'* offers a more sophisticated tool to understand the breadth of experiences from disability and any associated issues of disability identity.

The *'Psycho-Social/Bio-Psycho-social Model of Disability'* (interactional) proposed by Erikson (1959), talks about a psycho-social crisis in the development of the identity in a disabled person, which causes them to recognise and face the barriers of their impairment through their interaction with their social (e.g. cultural understanding of *'normality'*), biological (e.g. having an impairment that needs medical intervention e.g. insulin) and psychological factors (e.g. the stress or anxiety caused by bullying at school by peers or being misunderstood by teachers).

The *'Social-Relational Model of Disability'* (Shakespeare and Watson, 2001; Crow, 1994) asserts that *'to accurately comprehend disabled people's experiences, there needs to be a focus on how both disabling barriers and impairment interact with each other'* (MacDonald, 2017, p.11). That individuals are disabled by their bodies and social barriers, and by recognising/focussing on the impact of one alone (e.g. their bodies) without the other (e.g. their environment) would be wrong. Shakespeare (2013) argues that *'reality'* exists in four domains (sociological, psychological, biological and molecular) and any theory of disability must acknowledge all four domains. Thus the *'Social Relational Model of Disability'* refers to disabling barriers from structural exclusion, social oppression, and impairments that affect a person's life course.

As the Medical, Social, Affirmative, Psycho-Emotional models of disability could be argued as focussing on the negative aspects of impairment and disability (oppression in

society and their impacts), it is such concepts which are problematic for many with invisible disabilities/differences such as those with dyslexia who question if they are actually disabled, and reject a disabled identity.

As Sutherland (1981) argued, '*a more radical approach is needed: we must demolish the false dividing line between 'normal' and 'disabled' [meaning impaired] and attack the whole concept of physical normality. We have to recognise that disablement [impairment] is not merely the physical state of a small minority of people. It is the normal condition of humanity*' (p. 18). A new paradigm shift is needed to understand those with hidden disabilities/differences such as dyslexia.

To conclude, it could be argued that neither the 'Social' or 'Medical' models of disability encapsulate the experience of those with non-physical and non-visible differences/disabilities, therefore such groups may reject a 'disabled' label, as they would find it hard to argue that the environment (e.g. school, workplace, society) is disabling to them.

### **A New Perspective**

Valeras's (2010) paper 'We don't have a box: Understanding hidden disability identity' offers a new perspective to understand those with 'hidden disabilities', which dyslexia falls into along with individuals with Diabetes, Coeliac Disease, Juvenile Rheumatoid Arthritis, Epilepsy etc. Her paper investigates individuals that might look normal but also have impairments that can affect their lives, investigating six individuals with borderline identities that contradict, interact, inform and implicate each other; as they have the ability to transcend and travel between two worlds - the disabled and the non-disabled. '*They live on the edge of social, cultural, and political lines and adapt to any situation that they encounter to emphasise or de-emphasise various aspects of their identity depending on the pressures of the social context*' (p.16). Whilst her sample is small, other researchers support this concept (Yee, 2013; Burke Valeras, 2007; Gillespie, 1996; Roman, 2009; Stone, 2005; Sturge-Jacobs, 2002). As Gabel (1999) suggests '*If... I experience my body as a disabled body, regardless of what others think of me, then I am disabled. In contrast, if I do not view my body or myself as disabled, then I am not disabled, even though others may disagree*'. (p.42).

Higgins, Raskind, Goldberg, & Herman (2002) found any labelling for a disability was for many individuals a lengthy process that often resulted in conflicting diagnoses, with individuals confused as to which labels to accept and which to reject. In response, some individuals simply reject any label as inaccurate, offering their own explanation for their challenges (e.g. emotional problems that interfered with learning). Furthermore, Santuzzi, Waltz, Rupp and Finkelstein (2014) argue that a clinical diagnosis of a condition may not be sufficient to warrant a legal definition of disability in the employment contexts; therefore, even if you identify with a disability you may not be covered by disability/equality legislation.

According to Valeras's (2010) 'bi-ability' model, such individuals found:

'Disability is a strong word' and isn't a term they feel encapsulates them, as they are more than a disabled person. They believe they are able-bodied, and that '*disability has negative connotations*'.

'I'm more in the middle' defines more of what or who they are, and that they can empathise with both groups equally. This is based on a perception that the need by society for clear demarcation between people with visible markers (perceived as disabled) and people without visible markers (perceived as non-disabled) is a defensive strategy and denies the human frailty that we all have (Davis, 2005). This denotes a perceived stigma towards those with physical disabilities, as having a greater human weakness than they have (Nussbaum, 2004).

'We don't have a box' describes that they feel that they are an 'other' group, but there isn't an 'other box' featured on forms. They believe they have the ability to tick both boxes if they felt like it - having the ability to 'pass' and look normal to those around them. This ability to 'pass' can be found in many instances of race, class, gender and sexual orientations. (Ginsberg, 1996; Schlossberg, 2001; Leary, 1999).

'I didn't want to be different' describes that they want and do look 'normal' but in their need for accommodations they also need to disclose a disability, something they do not recognise being a part of their identity, resulting in others questioning their 'disability-ness'. The requirement to be alert to the 'impressions and reactions' to others means that they are hyper-alert to avoid situations that would highlight any behaviours or situations that might reveal a symptom of any disability.

'Not even consciously, but it's so hardwired' describes the ability to pass or disclose their ability to others that can be both a 'blessing and a curse', resulting in a constant private struggle to sustain both a private and public self (Cavet, 1998). This means that such individuals may be reluctant to access accommodations, people, places, situations because they might draw attention to their disability (Cavet, 2000; Fitzgerald, 2000) and at times suffer pain and impairment to uphold an identity of the 'non-disabled' person (e.g. by polio sufferers walking).

'It's always that elephant in the room' argues that many such individuals are reluctant to disclose their disability to maintain their self-esteem/self-identity, and any needs are constantly forgotten by others as they maintain zero visual clues to remind others that they might need accommodations. Goffman (1963, p.57) describes the dilemma '*to display or not to display, to tell or not to tell, to let on or not to let on, to lie or not to lie*'. The sharing of such information means that their invisible condition become visible and so would be their 'differentness' to others.



'It's a piece of my identity, but it is not my identity' describes the dilemma many experience as having an impairment but not recognising it as a disability; and that such an impairment is only a small part of who they really are. Likened to wearing glasses, they argue that they are 'a person with a disability or a disabled person'. Many choose the former as it describes 'a part or piece of their identity, not who they are' (p.15).

These individuals have flexible identities which are argued cannot be 'squished into a box....they exist in the space between, travelling in and out of two juxtaposed identity categories' (p.16). Valeras along with Darling (2003) argues that a 'bi-ability' exists because of such individuals that can exist in both disabled and non-disabled worlds, and that neither category is a perfect fit.

### **The Social Model of Dyslexia and Neurodiversity**

A question can be posed, is 'bi-abilities' the same as 'neurodiversity' (Cooper, 2008, 2009, 2011; Pollak, 2009; Walker, 2014), what are their similarities and differences? It could be argued that 'neurodiversity' embraces disability and whilst it aims to diversify labels so that an individual could be 'dyslexic with ASD ADHD traits', the author argues it is very much centred on the biological elements of disability. In locating the many aspects of a person's difficulties or disabled profile, as an educational professional (a SENCO in a mainstream primary school) it makes planning targeted interventions extremely hard and whilst teachers are now finally gaining a handle on what dyslexia is, to bombard them with a multiple of sometimes conflicting impairments, best conceptualized as a 'fruit salad' of impairments can make their jobs much harder.

Neurodiversity like the concept of bi-abilities promotes the strengths of individuals, however Neurodiversity differs from bi-abilities in its biological basis that aims to combine many learning difficulties into a collective force for political gain, with strong support from the 'Autism Rights Movement' (Soloman, 2008; Autistic UK, 2017) to advance the needs of autistic individuals. Therefore, it is argued by the author that the Neurodiversity movement is a 'social' model concept that aims to deliver environmental change, whereas the 'bi-ability' concept rejects the concept and label of 'disability' as they see such individuals as neither 'dis-abled' or 'abled-bodied' as no label currently exists that best describes them, but able to use a number of strategies to work successfully in many environments.

### **The Dyslexic Experience and Hidden Disability**

In the case of the dyslexic individuals encapsulated in the authors previous works (Alexander-Passe, 2010, 2012, 2015a, b) one finds that many do not recognise they have a disability and try very hard to camouflage any difficulties to promote a sense of 'normality'. The constant hyper-alertness for situations that might highlight any deficiency is seen as highly stressful and adds a secondary stress to that of their primary difference/impairment.

The school-aged young person with dyslexia recognises they look normal but are impaired at school (e.g. reading, writing, spelling), however many also recognise their strengths (e.g. drawing, drama, debating) which is confusing, an oxymoron, as if they were actually disabled they would firstly according to society have a physical indication of disability and secondly such an impairment would affect all areas of their life with no apparent strengths.

This dilemma or paradox causes many young people with dyslexia to question their place in their families and see themselves as being 'abnormal', as their parents, sibling and peers do not have this strange selection of strengths and weaknesses. This causes them to question their identity and their 'otherness' causing them to isolate themselves as a form of self-protection, some relate to the 'Spock' character in Star Trek (Alexander-Passe, 2010).

Schools are generally bemused by students who can look and act normally, but struggle in learning settings. As they show strengths/focus in many subjects (commonly vocational), many teachers believe such a student is being lazy and not applying such strengths/focus to their subjects (commonly core subjects of English, Maths and Science). The lack of substantial impairment means many such students are overlooked for diagnosis of underlying difficulties, however the examination access arrangements (Joint Council of Qualifications, 2016) for formal school examinations (e.g. GCSE) adds to this confusion by allowing students to receive allowances (e.g. extra time, use of a laptop to overcome handwriting difficulties) without any need for a formal diagnosis. This demonstrates an 'other' group who have impairments but are not disabled at school.

This dilemma is also seen in UK schools where children are added to the school's Special Educational Needs-SEND Register when they are receiving additional interventions, however without the actual diagnosis of a disability or a SEND (SEND Code of Practice, 2015), this change reflects the provision being provided by schools rather than the actual needs of pupils. Therefore, children with a known disability (e.g. high functioning autism) are not added to the SEND register as they are not actually receiving any intervention/provision. Also, if a school is unable to fund enough SEND provision, then they will only record the frequency of SEND in school that they can actively provide, which could be argued to camouflage the actual frequency of SEND need.

The young dyslexic adult is faced with leaving school lacking the academic results of their siblings and peers. Their lack of perceived impairment (commonly perceived as physical) means they are misunderstood as being lazy and unfocused, rather than struggling with 'hidden impairments'.

The ability to look and act 'normally' means they are overlooked as having underlying difficulties. However, they are faced with a dilemma, the application forms they must complete ask about disabilities, ask a range of questions: Do you have a disability?

Do you believe you have a disability? Do you have a disability covered under the United Kingdom's Equality Act (2010)?

This causes them to question if they actually have a disability, do they believe they have a disability, and what advantage/disadvantage a disclosure might bring? It also poses other questions: Will I have a better chance to get through the first round of sifting of applications if I disclose or not? At what point should I disclose their dyslexia or difficulties? At the application, interview, when offered the role, or after starting the role? (Alexander-Passe, 2015, 2017, Scott, 2004)

As mature adults, many adults with dyslexia have developed a sense of their strengths and weaknesses, and use these to develop careers that are fulfilling, but interestingly they do not recognise such strengths as a disability but a learning or working difference. In these situations, using the term disability would be alien to them and might have negative connotations.

To conclude, it is argued that using a 'model of disability' to describe the experiences that many dyslexic and individuals with 'hidden disabilities' undergo may be inappropriate, as they can be argued to be negative and deficit models, focussing on what individuals 'can't do, rather than what they can'. The 'bi-ability' model (Valeras, 2010) offers a positive model that many 'hidden disability' individuals can relate to, while allowing the conceptualization of an identity that is both 'disabled' and 'non-disabled' and the internal emotional struggle that come from sitting in both camps and not truly being comfortable in either.

### **Successful Dyslexics – Where does this fit into 'Bi-abilities'?**

Alexander-Passe (2016a, b) investigated successful individuals with dyslexia and two theories were suggested 'The Disability Paradox' and 'Post-Traumatic Growth-PTG', to understand individuals who were successful in their post-school careers achieved through:

- ◆ Demonstrating strengths that others do not have (many found as children/teenagers).
- ◆ Not indicating their dyslexia to others – passing.
- ◆ Demonstrating exceptional resilience and motivation.
- ◆ Developing a healthy attitude towards failure – that it is part of the journey towards mastery or success.
- ◆ Success came post-school, and after facing adversary, trauma and negative schooling

All the above could be argued to fit into the 'bi-ability' model as they all indicate the ability to take strengths where they exist, some coming from their dyslexia and others from their non-dyslexic abilities. Again, being dyslexic is only part of who they are, so the

ability to harness the strengths from each part of their personality means they can bring unique skills and abilities to problems and the workplace.

Exceptional resilience and motivation could be argued to come from always being on the lookout (having sensors) for situations that might highlight their difficulties, and the ability to bounce back from set-backs (forced disclosure of difficulties) and the motivation to avoid such forced disclosure in the future.

Interestingly, the ability to see 'failure as part of the journey to mastery' is part of their unconscious coping or defence mechanisms developed at school, and linked with resilience, the ability to play the 'long-game' and recognise that they will need longer to gain certain skills, and that knowledge learnt through failure can be as good or better than that learnt first time (as argued through the 'Growth Mindset' by Dweck (2012). If a machine never fails, there would be no need to develop a better model, so if one always gets things right first time there would be no motivation to question if it's the best model for the job. The inquisitive mind is more likely to make leaps of faith to solve problems, asking the 'what if' questions.

### **Growth from Shattered Lives**

For many decades, the concept of trauma derived from incidents related to neurosis and negative manifestations requiring interventions as per the 'Medical Model of Disability' (World Health Organisation, 1992) e.g. stays in mental asylums and electric shock treatment (Mind, 2016). More recently the 'positive psychology' movement spearheaded by the esteemed Professor Martin Seligman has aimed to rethink trauma. This movement aimed to understand any positive manifestations that might come from trauma, and several theories have developed under this umbrella (Seligman, 1991, 2011). Nicolson (2015) is now developing such themes within the realms of dyslexia, called 'Positive Dyslexia' along with other researchers who campaign for the recognition of the strengths that can come from dyslexia (West, 1997; Alexander-Passe, 2016a, b).

Post-Traumatic Growth-PTG (Calhoun, Cann & Tedeschi, 2010) argues that growth can be triggered by a single or multiple highly stressful life event/s that poses a significant challenge to an individual's assumptive belief about the world. Beliefs that the world is predictable, controllable, and ordered that to that point have been relied upon to guide behaviour and to make sense of the world. PTG is argued to come from the impact of these 'shattered' beliefs and how individuals choose to piece them together or interpret them. It is argued that using an analogy of a shattered vase, individuals can try and piece together their shattered pieces but will fail as they can't return to how it originally was (perfection), and develop depression/withdrawal when they see their efforts are pointless; alternatively, they can reuse the pieces to construct something new and different - not trying to replicate the former vase's beauty, but to create something new, maybe a sculpture or a mosaic. The 'growth' comes from using a trauma positively and the

motivation to become more engaged in life e.g. being resilient to future trauma, to help others who have been through trauma, change careers, take a trip or course that was always put off, or to have a new lease of life etc. Thus, making sense of the trauma and developing new characteristics and strengths as a result.

Organismic Valuing Theory-OVT (or adversarial growth) is a more developed PTG theory (Joseph & Linley, 2005). It argues that following a significant trauma, humans have an inherent tendency to try and comprehend and integrate such experiences in a meaningful way while striving towards emotional and psychological well-being. The theory proposes three outcomes:

1. 'Assimilate' the trauma-related information by 'integrating' the experience into their beliefs they held before the trauma – they recover but return to their pre-trauma state
2. 'Accommodate' the trauma-related information by 'modifying' the beliefs they held before the trauma: (a) if accommodated in a negative way (e.g. bad things happen and there is nothing I can do about it) then they can develop helplessness/depression.
3. But (b) if they accommodate in a positive way and modify their beliefs appropriately (e.g. life is unpredictable, so it should be lived to the fullest) then they can experience psychological growth following adversity.

In this model, positive benefit-finding and psychological growth is facilitated by many factors (the need for affiliation, autonomy and competency) along with supportive social environments.

### **Pulling the Discussion Together**

Pulling the two aspects together (models on disability and models from trauma) to form a theoretical basis for this paper. The concept of 'bi-ability' (Valeras, 2010) stands out in offering an explanation of the following: how individuals with dyslexia can function and succeed in both the dyslexic and non-dyslexic worlds (disabled and able-bodied worlds), why individuals with dyslexia suffer from mental health issues and self-doubt, and how they can choose when, where and with whom they disclose their dyslexic difficulties, which allows them to develop successful careers despite suffering in educational environments.

The Psycho-Emotional Model of Disability is useful in expanding the dyslexia experience, in how the public perception of disability (being mobility and incapacity-based) has meant that many individuals with dyslexia reject a 'disability label' and this causes problems when accessing services designed to assist them in gaining employment, causing secondary stress and anxiety.

However, the 'Organismic Valuing Theory' (Joseph & Linley, 2005), an advanced version of PTG is also very helpful in understanding the reasoning dyslexics make from their experienced school-trauma/educational neglect and their personal journeys using 'assimilation' or 'accommodation' in changing their values and beliefs, and how this has allowed many to find new meaning in what they do, embracing risk, and creating successful careers as a result. However, others have accommodated their school-trauma negatively and have developed helplessness leading to depression and withdrawal as a result.

### **Applying the Bi-Ability Model to Dyslexia**

The 'Bi-Ability' model has the following main themes which will now be discussed to see if they are relevant to the dyslexic samples as found in this research. The main themes are:

- ◆ Disability is a strong word – rejecting an affinity to a term that has negative public perceptions.
- ◆ I'm more than in the middle – falling in the middle of two identities but rejecting both.
- ◆ We don't have a box – traditional social groups do not describe who they are.
- ◆ I didn't want to be different – it wasn't their choice to be born this way.
- ◆ Not even consciously. But it's so hardwired – survival instincts naturally kick in.
- ◆ To Tell or not to tell, it's the elephant in the room – the stress of not disclosing to others.
- ◆ It's a piece of my identity, but it's not my identity – being different is not all consuming

### **Disability is a Strong Word**

When it comes to dyslexic individuals whilst many will associate their dyslexia with difficulties in reading, writing, spelling, organisation and short-term memory, they do not see themselves as disabled by their dyslexia. They do not see dyslexia as a disability, and thus will reject this label. However, they do realise to gain certain allowances at work and at university provide them additional rights, accessible software and training they must identify with a difficulty that is covered under the 'Equality Act' (2010) and US 'Disabilities at Work Act' (Equal Employment Opportunity Commission, 2008). It could be argued that individuals with dyslexia and those with other 'hidden disabilities' reject a disability label, however will claim under such allowances when it is advantageous to them. Thus, a paradox exists.

### **I'm more than in the middle**

It could be argued that many individuals with dyslexia reject a 'disability' label, but many

of them also reject a 'dyslexia' label. They see their difficulties or differences as being 'just how they are' and they feel they don't fit into a 'dyslexia' label as they have learned to read and write, and can function in the workplace with a meaningful job - thus many believe they are cured of their dyslexia as they look and act normally. However, in rejecting their dyslexia, they are also rejecting any help on offer or employment protection. Alexander-Passe (2010, p.250) noted a participant regarding a late diagnosis '*If I managed to gain a degree and a job without diagnosis, how much more could I have gained with a diagnosis and the help it would offer*'. This suggests their own rejection was confirmed by others around them, in that teachers at school and lecturers at university had seen them as 'needing more time and effort to achieve' rather than fighting against a 'hidden disability'.

### **We don't have a box**

According to many job applications and the UK census, you are either disabled or you are not. The questions posing 'do you believe you are disabled' suggests that the person completing the form must take ownership of any difficulties. Answering yes to 'are you disabled under the Equality Act (2010)' would mean that you are covered by such legislation, however it pains many individuals with dyslexia that they need to say yes. To say no, be offered the post and then have difficulties could be argued that you withheld information that might have meant you might not have been offered the post.

The absence of an option 'are you covered by the Equality Act 2010 but do not perceive this will affect your ability to do the role' means a possible employer might shy away from even offering the individual an interview. Alexander-Passe (2015a) found that many individuals with dyslexia avoid disclosure of their dyslexia in the workplace, and those that do are hit by experiencing misunderstanding and unfair treatment/discrimination in the workplace.

### **I didn't want to be different**

It is believed that only a third of dyslexics are diagnosed at school, another third at university or in the workplace, and the last third go through life undiagnosed (Alexander-Passe, 2017). Many individuals go through school being told 'they are slow, lazy or immature, they need more time to get things'. They just need to get used to their siblings and peers overtaking them at school and in the workplace; and they will need to be 'contented' with manual vocational jobs that offer a low salary. They were told early on that this is 'just how they were made' and that it was okay to be different, and in some cases a second-class citizen.

Recent UK government statistics (National Statistics, 2017a, b) found Specific Learning Difficulties, a common educational term to include dyslexia (Rose, 2009) rose from 10.8% in primary school to 23.3% in secondary school, suggesting that their learning difficulties

had been dismissed in primary school as substantial enough for a diagnosis. Alternatively, there is a tendency for teachers to assume that 'it will come' given time, and only in secondary school is it accepted that there is a continuing problem. However, inside most dyslexics are individuals with dreams and passions to 'show the world they have value' and that those around them e.g. parents, teachers, and peers have got it wrong about them. This motivation to prove others wrong is a feature found in successful dyslexics (Alexander-Passe, 2016a, b) and is extremely powerful, however it is only outside the confines of mainstream education that many such individuals can shine.

The countless individuals with dyslexia found in the creative professions (e.g. actors, designers, artists) are able to bring unique skills to the workplace, but are these skills or compensations? Have they developed these skills as a coping strategy or are they hot-wired with them at birth? Are they more kinaesthetic as they can learn 'vocational' education faster than by reading and writing? This was investigated by the author (Alexander-Passe, 2010b) in an edited work with many leading educationalists and artists, however no definitive verdict was reached.

### **Not even consciously. But it's so hardwired**

Alexander-Passe, (2006, 2008, 2010, 2016b) discusses the educational trauma that many teenagers and children with dyslexia experience in mainstream education and the many strategies developed to cope at school, from avoidance or passing, that allow them to survive in mainstream mixed-ability classrooms. This changes school into somewhere to survive, rather than enjoy or demonstrate their potential. Before long, sensors to possible dangers are developed and finely tuned to avoid any form of detection of their difficulties, so that they are spared humiliation at school for their inability to read, write and spell as well as their peers. These become unconscious and they serve the dyslexic well to survive, but at what costs? The cost may be the ability to develop their potential?

### **To Tell or not to tell, it's the elephant in the room**

As mentioned above, individuals with dyslexia develop finely tuned sensors to avoid all situations that will expose them to humiliation and embarrassment in the hands of their peers. However, the need for such sensors make living with a difficulty such as dyslexia very exhausting, as the author (Alexander-Passe, 2010) found in a study of twenty-nine adult dyslexics. This makes many dyslexics believe they are living a double life, like that of a spy, in that they are always keeping up a pretence, and lying constantly to come up with decent reasons to avoid doing many chores (e.g. I have forgotten my glasses so I can't read the menu; I can't find my diary so please tell me the date, sorry; I have a bad memory; did I lock the door, could you go and check please etc.) (Alexander-Passe, 2010; see also Scott, 2004)

In the same study, the author (Alexander-Passe, 2010) found that many participants noted



they had been the most truthful about their dyslexia and difficulties in their interviews, not even telling their parents, siblings and partners the truth. Living a 'double-life' meant living a 'double-lie' and on top of having a poor short-term memory as part of their dyslexia, they were likely to be found out, and this was highly embarrassing. Moreover, some also linked the experience of being dyslexic with that of experiencing being gay in society, where both are stigmatised in the workplace.

### **It's a piece of my identity, but it's not my identity**

Speaking with adults with dyslexia one finds that their dyslexic identity was a contentious issue. Those who disclosed their dyslexia early on in the dating process, normally in the first date, do so to explain why they choose certain paths and why they might do a few quirky things (Alexander-Passe, 2012). However, it is framed as one part of who they are, as per wearing glasses or being tall, short, thin or overweight.

However, those who are reluctant to disclose their dyslexia in the dating process, which also reflected their reluctance in the workplace, perceive their dyslexia as affecting all aspects of their life, and something that can be blamed for their difficulties gaining a long-term partner, employment and a family.

In the case of successful individuals with dyslexia (Alexander-Passe, 2016a, b) they perceive their dyslexia bringing them great strengths and they embrace these as coming from living with dyslexia in mainstream education. The 'chip on their shoulders' developed as a reaction to their experiences, and they use these powerful motivations to bring about career change and enhancement. They have 'dyslexia' but are not 'dyslexic', so could be argued as having the traits without being all-consumed by it.

It could be argued that much that is presumed to stem from dyslexia are the reactions to how society has made them act (as per the 'Medical Model of Disability'). If their workplace is not inclusive, then they must work harder to achieve their goals.

What is important is to compartmentalize any dyslexic difficulties and view these in the arena of an individual's strengths and weaknesses. Only through this can dyslexia be seen as a 'part' and not the 'whole' of a person's identity.

### **CONCLUSION**

This theoretical paper takes an interesting look at dyslexic experience, and asks if the highly politicised 'social model of disability' is valid in understanding the needs of such a group.

Mainstream education is clearly centred on the 'medical model of disability', in that all individuals are taught the same curriculum, expected to attain to the same level, and if

one is found to be unable to achieve this, interventions are given to overcome any deficiencies (in essence so they are fixed or cured). UK and international schools are judged with league tables, which are designed to demonstrate to current and prospective customers (parents) the school's ability to 'add value' to a child, no matter their educational starting points.

Due to the changes in the SEN Code of Practice (2015), the change to record SEND in school from 'provision' to 'need' has resulted in most schools reporting a significant decrease in SEND in pupils over the last 7 years. This is argued to have resulted from many schools only listing pupils on a SEND register when they are actually receiving 'provision', therefore if a school is unwilling to provide sufficient provision for 'vulnerable' pupils, then such pupils simply disappear from school records. This view is supported by Scott (2016), Bercow (2011), OFSTED (2010) and the Audit Commission (2002) of a 'postcode lottery' with 'piecemeal' inconsistent provision in schools.

Whilst schools can be applauded for their aims to be inclusive to all learners through differentiation of lessons and making sure buildings are accessible to those with physical difficulties, there is much to be done to improve the teacher's ability to both screen for learning difficulties and offer effective differentiations. UK teacher standards will next year make differentiation and SEND awareness core elements mandatory in Initial Teacher Training courses following the Carter Review (2015), confirmed by Department of Education (2016).

The 'social model of disability' is often found in the workplace, with schemes such as the UK's 'Access to Work' helping to make workplaces more accessible through assisted software and hardware. However, whilst 'social models' are implemented in the public sectors, this is not often found in the 'private sector', forcing many dyslexic individuals to hide their dyslexia and their ability to 'pass' as non-disabled is essential to their career development.

Various models of disability were discussed and these help to understand the interaction between society and those with disabilities, however arguments against the 'social model' emphasise that it lacks cultural and experiential dimensions, in essence how the disabled individual feels (the 'lived' experience) as a reaction to society's perception of them. It is argued that it is hard to relate aspects of these models to those with 'hidden disabilities' as many with dyslexia and other hidden disabilities reject the concept that they are disabled.

Valeras's Bi-ability model (2010) offers an understanding of the 'hidden disability experience', in that they reject any disability identity and the ability to 'pass' as normal in society means they can achieve more in society. The use of passing has been used by many groups (race, gender, sexual, disability) who feel they would gain more by blending into society (e.g. Polio sufferers walking despite intense pain, a gay person pretending to

be heterosexual, a mentally ill person acting without any symptoms to be accepted by the public). Many powerful examples can be seen over the last few centuries of passing to gain certain freedoms, and it can be argued that the dyslexic child avoiding certain tasks at school (reading and writing) can be identified with 'passing' and this means dyslexic groups can be discussed in a wider disability, gender and race context. It could be also argued that the ability to pass by dyslexic individuals allows them to be successful in industry and entrepreneurship.

This paper finishes by looking at the various elements of the 'Bi-ability' model in the context of dyslexic individuals: Disability is a strong word – rejecting an affinity to a term that has negative public perceptions. I'm more than in the middle – falling in the middle of two identities but rejecting both. We don't have a box – traditional social groups do not describe who they are. I didn't want to be different – it wasn't their choice to be born this way. Not even consciously. But it's so hardwired – survival instincts naturally kick in. To Tell or not to tell, it's the elephant in the room – the stress of not disclosing to others. It's a piece of my identity, but it's not my identity – being different is not all consuming

The strength of Valeras's paper comes in its ability to cross race, gender and disability, and improves understanding the dyslexic experience for both dyslexic and non-dyslexics groups, and it could be argued that 'passing' allows the dyslexic through the 'workplace' front door, and this allows them space and security to demonstrate the strengths and skills which will make them successful.

## **LIMITATIONS**

The author notes that whilst the study of Valeras (2010) was only based on 6 research participants, and therefore conclusions should be treated with caution. However, other researchers have reported similar themes, which the author believes gives weight to Valeras' theory. The author also notes that the field of study that looks at the 'Social' model of dyslexia is extremely broad and only a summary of the arguments can be included in this paper.

## **IMPLICATIONS FOR ASIA**

The author of this article is writing in the UK, where support and recognition for dyslexia is well-established, and there is legislation in place to provide good outcomes, despite recent changes in SEND that have impacted on this. How far is this article relevant for the Asian context, where some countries have no legislation, no provision in education, little public awareness and dyslexia may be seen as a stigma, making the issue of disclosure even more pertinent? Even in Asian countries where dyslexics are now supported within the education system, identification and provision remain patchy and

the numbers identified are far below the predicted levels for the population, suggesting untapped cases that require support. At the same time, there is a growing interest in the region in the strengths of dyslexia, and how these strengths should be understood within the context of disability. The concept of dyslexia as a difference rather than a disability outlined in this article resonates more readily with this movement and with the aims of this journal.

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