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Experiencing Dyslexia Through The Prism of Difference

According to research by AHEAD (2021), students with specific learning difficulties (SLD) are accessing third level education in greater numbers than ever before. Within the body of research conducted few studies have focused on the overall experiences of students with dyslexia studying in third level education. The current study addresses this gap in knowledge as it provides an insight into how students with dyslexia, as an SLD, navigate third level education. Ethnography was used as the principal method of research in this project, and 17 participants, ranging in age from 20 years old to mid-40 years old, took part. The research found that when students identify dyslexia as a limitation, it becomes a barrier to successful learning and has a negative effect on their identity, which impacts them socially and academically. When viewing dyslexia as a difference and studying through a neurodiverse approach, participants in this study achieved academic success, not despite their dyslexia but in partnership with it.

Keywords: *Dyslexia, higher education, difference, inclusion.*

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INTRODUCTION

Dyslexia is a specific learning difficulty (SLD), under the umbrella term of neurodiversity and according to both the Dyslexia Association of Ireland (DAI) and the European Dyslexia Association (EDA) a person with dyslexia is viewed as having a disability (DAI, 2018; EDA, 2019). Exploring dyslexia as a difference rather than identifying it as a deficit helps to unravel what society can often perceive as the complications surrounding dyslexia and how identifying with a diagnosis of dyslexia can carry cultural and societal expectations. Identifying dyslexia as a difference and viewing dyslexia through a neurodiverse approach does not lessen

dyslexia and/or its affects, it helps to conjure up very different societal perceptions and expectations.

This new idea positions dyslexia in the realm of difference and encourages people with dyslexia in higher education (HE) to use a growth mindset, build resilience, make use of the supports that are available and develop strategies that work for them. Having dyslexia and being in HE is an experience that is very individual, experienced in many ways and influenced by many internal and external factors, therefore, using the metaphor of a prism is a perfect way to imagine the complexity of the experiences. This 'prism' also became a tool in the hands of the research participants, who, after years of struggle, learned to analyse their own experience as multifaceted and many-shaded, involving not just ordeals and shame, however, empowerment and self-discovery also.

This article thus shows how students experience dyslexia through multiple 'selves' and identities, in terms of other aspects of difference. It highlights the experience of dyslexia from the inside out and challenges the notion that difference is a binary system comprising rigidly dichotomous entities, arguing instead that it is 'multifaceted, complex, always changing, and infinitely sociocultural' (Slesaransky-Poe and García, 2009, p. 204).

LITERATURE REVIEW

Following some consideration of the term dyslexia and of the nature and prevalence of dyslexia, below is a brief review of the literature relating to viewing dyslexia beyond ableism, dyslexia and culture and the importance of growth mindset theory foregrounding a brief consideration of dyslexia in HE.

Dyslexia Through Time

Dyslexia falls under the umbrella term, Neurodiversity which was coined by Judy Singer in 1998 and is a range of different neurological challenges (Clouder, Karakas, Cinotti, Ferreyra, Fierros and Rojo, 2020). It is recognised that like a person's fingerprints, no two brains, not even those of identical twins, are exactly the same (DeMello and Gabrieli, 2018), indicating there is no normal standard brain that exists to which all other brains can be compared to. The word 'Dyslexia' originates from the Greek word (dɪsˈlɛksɪə) meaning 'difficulty with words' (Cambridge Dictionary, 2023). However, dyslexia's appearance in society is by no means a recent phenomenon. Dyslexia was identified as early as the 19th century

(Kussmaul, 1878), as word blindness, which was first replaced with the word ‘dyslexia’ a decade later (Berlin, 1887).

Dyslexia is also regarded as a neurological condition that is genetic in origin, and a child with an affected parent has a risk of 40–60% of developing dyslexia (Hudson, High and Otaiba, 2011). Dyslexia affects approximately 1 in 10 people and occurs on a spectrum with some people mildly affected and others more severely (Dyslexia Ireland, n. d). Therefore, Dyslexia is not an illness or disease that can be treated medically, nor is it something that comes and goes. Everyone with dyslexia is different but there is a commonality of difficulties with reading, spelling, writing, related cognitive/processing difficulties, memory retention and articulating information verbally or in writing.

Viewing Dyslexia Beyond Ableism

Dyslexia is often viewed through an ableist lens and ablism is a perspective on disability which assumes that disability is inherently abnormal; it is a perspective which leads to and naturalises various forms of discrimination based on ability (Bottema-Beutel, Kapp, Lester, Sasson and Hand, 2020). It operates from a belief system revering ‘a particular kind of self and body, which is portrayed as the perfect, species-typical, and therefore essential and fully human’ (Campbell, 2009, p.5) and this concept can portray disability as a diminished state of what it means to be a ‘human being’. This article advocates for a framework that avoids ableism and encourages us to look at dyslexia without internalised and externalised ableism. This then takes the view that all brain differences are normal, not deficits and that everyone experiences and interprets the world in unique ways. It also acknowledges that in some environments, dyslexia may manifest as a disability as opposed to highlighting talents, however, this paper calls for an alternative view of ‘human being’ to conceptualise disability and ability as part of the human condition (Ellis, Garland-Thomson, Kent and Robertson, 2018).

Dyslexia and Culture

Macdonald (2019) suggests research in the field of dyslexia has begun to use a range of models to interpret the social experiences of people living with this condition. In some countries, ‘conditions such as dyslexia are not recognised as disabling, whilst in others, they are considered to be a mental disability suggesting that disability is culturally determined’ (Clouder et al., 2020, p. 759). This highlights how dyslexia can be culturally embedded within thought and language and is an example of the intersection between language as an evolved behaviour and literacy as a cultural invention (Pennington and Olsen, 2005). Dyslexia as a social construct depends on socially generated interpretations as ‘society through

language and its use continues to construct people, especially those perceived to have a lack or disability' (Leshota and Sefotho, 2020, p. 6). This is mediated by sociocultural factors and how 'various social actors interpret and then define their academic abilities' (Kabuto, 2016, p. 301). Dyslexia is not obvious to society, as it is a hidden disability, however, the difference between someone who has dyslexia, and its characteristics are exposed within the cultural settings of HE and its assessing methods. Some of the difficulties for students with dyslexia can be around pronunciation, memory retention, certain attributes around language, reading, writing, and articulating skills, both written and verbally.

Growth Mindset Theory

One strategy being advocated for is leaving behind the concept of a fixed mindset and engaging with the concept of a growth mindset. Dweck (2012) and Daeun (2015) state that students with fixed mindsets adopt the idea that intelligence is fixed, feedback is criticism and understand intelligence and ability as static whereby success can only come from talent. If a student thinks they have a perceived low ability and chance of success, this can evoke 'learned helplessness' (Daeun, 2015), which is a fixed mindset. However, the opposite happens when a student perceives they have a good proficiency in the task and they have a high chance of success when completing that task, this is known as a growth mindset.

Dyslexia in HE

In HE, students with a SLD such as dyslexia, may suffer from difficulties with their academic work leading to anxieties, and internalised ableism according to research by Couzens, Poed, Kataoka, Brandon, Hartley & Keen (2015). Disabling and disablist attitudinal barriers can be the societal and cultural attitudes towards people with dyslexia (Byrne, 2018). These, and similar perceptions, can be held by someone within university admissions, and/or academic staff. Cameron (2016) states that prior to a potential student with dyslexia even thinking about HE, barriers are often unwittingly created by teachers, parents, careers advisers and others who assume that certain professions and/or HE is not for them (Cameron, 2016).

METHODOLOGY

This article is based on ethnographic research which was carried out in four different HE institutions during the academic semesters in 2018. This method was chosen as it is concerned with 'learning about people' (Jones and Smith, 2017, p. 98). This project had a total of 17 participants, of which 14 identified as female

and three as male. The gender ratio is obvious to the researcher however, gender is not the focus of this study. There were four participants from the 40+ age range, three from the 30-40 age group and the rest, ten, were in the 19- to 30-year-old age range. The researcher sent out an expression of interest in this project via four HE institutions access offices. The disability services officers sent out an email about the research project to all their students who were registered with them as having a diagnosis of dyslexia. This email contained an introduction, a brief overview of the research project, and what their role as a participant would entail for them. No specific variable arose, or no rationale was discovered for the very low participation in the project by the male student population, as the only inclusion or exclusion to participation was having a diagnosis of dyslexia and being registered with the access office in the institution.

Meetings were arranged with the students who had self-selected to be participants on an individual basis to gain a small insight into their educational journeys. They were informed of the nature and the purpose of the research and their right to withdraw before a specified date. It was agreed that they would be sent a copy of their transcript to allow them to confirm what was said and gain their consensual participation and to protect their identities and that real names would not be used or any material which could identify them. The research study was approved by the ethics committee at the institute of the researcher.

The methodological tool employed was participant observation and interviews, which are the distinguishing features of ethnographic research, as it aims to describe life as it is lived, 'by a people, somewhere, sometime' (Ingold, 2017, p. 21). Ethnographic methods are diverse and that enabled the researcher to utilise a range of approaches which are based on participation and observation, in-depth interviews, and detailed writing analysis. The participants were informed that the researcher would be a passive observer in their lectures and tutorials and no brief was given before the participant observation took place. During the interviews, the lectures, tutorials, and group work sessions arose as often there was relational incident to one of the findings. Chiseri-Strater and Sunstein (1997) developed a theory on taking, analysising and writing up field notes from participant observation. This includes documenting dates, times, places, facts, participants, smells, and sounds. The researcher followed these guidelines 'it is the detail and completeness of these records that provides the richness and texture of the written product (DeWalt and DeWalt 2002, p. 148). Each participant was shadowed for at least one two-hour lecture and/or an hour tutorial at least once a week, over two semesters, as well as their bi-weekly group work sessions, field notes were taken, and these were used later during the writing-up process. Interviews were

also conducted which took place in 'natural settings' (Creswell, 2013) chosen by the participants. A recording device (LiveScribe pen) was used to ensure all data was saved and documented and these were transcribed later. This enabled me to read and re-read the transcripts several times to tell the stories of the participants.

The questions asked were around family history of dyslexia, brief experiences of formal school and how they experienced HE with dyslexia, in relation to teaching, learning, assessment and supports. They were also asked about how they understood their dyslexia and how they thought others understood it, what the disclosure process was like, the discourse and identity experienced, and the cultural perceptions and prejudices surrounding dyslexia. A limitation of this project is that the data collected represents a small snapshot of the population with dyslexia studying in HE.

Research Questions

The research study sought to answer the following research questions:

- How did the participants experience and navigate HE education in Ireland?
- How did they understand their dyslexia in the context of an environment so heavily reliant on text-based learning and assessment?

By answering these questions, the study provided a deeper knowledge, insights and understanding into how learning is experienced by those operating within an environment and culture that champions the very issues that hinder people with dyslexia such as reading, writing, short-term memory retrieval both in an oral capacity and in final written examinations. The findings discussed below are drawn from the wider study and relay participants' experiences of having dyslexia while studying in HE. The aim is to give an insight into participants' experiences of the barriers encountered with having dyslexia in HE. Nonetheless, this paper highlights, in spite of all these barriers, when the right inclusive learning environment is enabled and provided, students with dyslexia can achieve success on a par with their peers. The findings presented and discussed relate to three themes namely i) awareness of dyslexia, ii) voice suppression and iii) the 'self'.

DISCUSSION

Awareness of Dyslexia

The medical model of disability can focus on the person's disability and what a person cannot do as opposed to how we can support a person better in that task. In HE in Ireland a student with dyslexia needs a psychological diagnosis. This

perpetuates the nature of the medical model and associated negative connotations and pre-conceptions.

One of the main issues identified by participants was the lack of knowledge around dyslexia and how it affects their learning. The deficit view and discourse (Rappolt-Schlichtmann, Boucher, and Evans, 2018) they encountered around dyslexia was described as loaded and confusing and centred around constructions of able-bodiedness (Bone, 2017).

> 'I think people's perception on dyslexia is so different. People don't know how to handle it' (Kitty Kat).

> 'If anyone has got dyslexia [in school], they kind of look at them as if they are stupid, they look at them like they can't think' (Joy).

> 'I always just thought like I was the class clown and stuff, because that's what they [teachers] told me' (Smithwick's).

This allows for dyslexia to be then viewed as a deficit or 'something wrong with someone' as opposed to, nothing is wrong, it is just a difference. The deficit view can then create a certain perspective or allow a particular attitude to develop and thus, a barrier is created. This enables the creation of institutional and attitudinal barriers and ableism. Currently, there is very little research on 'lecturers' awareness of dyslexia and of their attitudes towards and opinions about dyslexic students' (Ryder and Norwich, 2019:162). Students with dyslexia pose a particular challenge to academic staff because their difficulties are hidden, according to Pino and Mortari (2014). These findings also highlight the need to provide adequate training for HE education staff around dyslexia as the research highlighted how some teaching staff 'identified major problems in recognizing dyslexia, estimating the severity of the disability, and uncertainty about what would be the best form of support' (Schabmann, Hans-Christoph, Schmidt, Hennes and Ramacher-Faasen, 2020, p. 275).

> 'Yeah, I think there are intolerant lecturers that I've found very difficult, I was a stranger to them, and they didn't know I was trying or things like that' (The General).

The knowledge lecturers had on dyslexia, and its impacts appeared to come from personal experience of family, friends, or students with dyslexia. When teaching staff had any awareness of dyslexia, with this awareness it usually connected to a more positive experience for students with dyslexia and created a learning environment more willing to accommodate them.

> ‘I don’t know if they had a good knowledge, but they really went out of their way to make my learning, my life a little bit easier’ (Heffo).

> ‘Most the [good] lecturers, they seem to know about it [dyslexia] already like’ (Ali).

This further highlights the need for training to help raise awareness of dyslexia for all HE staff and in particular what dyslexia is and what dyslexia is not.

Voice Suppression

For my research participants, internalising doubts about their academic ability manifested as a fear when in a lecture hall or tutorial class, notably around when they were asked a question or encouraged to articulate their thoughts on a particular topic. This developed into a fear of appearing a bad academic or unintelligent, or ‘looking stupid’ (General) in front of one’s peers and lecturers. This becomes what Carrithers (2009) describes as vicissitude, which is an unfavourable event or situation that occurs by chance, usually beyond one’s control. This ordeal becomes a moment, unanticipated and beyond routine, and invokes what Basso (2009) terms as voice suppression. To be, or to imagine oneself as being under surveillance, triggers mechanisms of self-suppression and silencing (Meek and Rogers, 2014) and this can then create ‘self’-oppression through fear, shame, and experience, arising out of a moment and thus, initiate what I term as academic imprisonment. For participants, this moment occurs as a ‘performance’ in an educational setting and/or involving peers and educators:

> ‘Whenever I was asked a question in class, I just froze, I wouldn’t answer questions in class, I think I’m just slow’ (Smithwicks).

> ‘No, no [shaking her head, nervous laugh and making a funny face] I wouldn’t really answer questions in class, after school, no way’ (Calloway).

> ‘I overthink it and then I panic like I know the answer and then I just sit there’ (Turbo).

Voice suppression (Basso, 2009) inhibits the learning experience and initiates internal conflict between the individual in their private realms and public realms (Carrithers, 2009) through lecture halls. Conflict can then occur between one’s own thoughts, feelings, emotions, and subjectivity in the lecture halls and tutorial rooms and this brings shame and introduces a humiliating relationship between the student and their dyslexia.

> ‘Even though I know I want to say it I just cannot say it, even if I have the right answer, I just don’t say it and I just sit [in lecture hall/tutorial room] there awkwardly while everyone stares at me’ (Ali).

> 'I'm just like oh my god, oh no, I don't know anything and when they do ask me a question I just sit there and don't say anything' (Anne).

This will then lead to a rise in emotions and the negative development of ideals about the 'self', which are developed from false perceptions by the self of 'the self'.

The 'Self'

A host of emotions were used by participants to describe their educational experiences with dyslexia including disappointment, frustration, embarrassment, shame, sadness, depression, anger, and low self-esteem.

> So, I don't know if I have this ingrown thing that I think being dyslexic is awful, to be honest with you I think em you're a dyslexic person is very degrading (Summertime).

> I could be also afraid to tell people that I am dyslexic because the horror of being [identified] thought of as stupid (Winehouse).

> You lose your self-esteem; your self-esteem becomes so low because you lose interest (Joy).

Participants views and construct of the self were often not based on actual performance but upon perceived performance and these can influence their construct of self and impact on their experiences in HE. When students developed a negative association with their dyslexia (Gee, 2014) the challenge was then to dis-identify with the developed limited sense of self. This can in turn affect confidence on every level, which leads to students with dyslexia often using this persona of their 'self-esteem' for judgements of their self and self-worth. When participants identified and made a connection between a positive view of dyslexia and a positive identity with self-esteem, it helped to improve their cognition about their dyslexia which led to improved perceptions of self. One strategy developed by participants was leaving behind the concept of a fixed mindset and engagement with the concept of a growth mindset (Dweck, 2012). When participants recognised the concept of a fixed mindset and understood that intelligence is not fixed, they were able to embrace all the positive outcomes from using a growth mindset.

CONCLUSION

This research has highlighted how students with dyslexia experience HE as individuals with what is termed as a disability. It has also examined what are some-

times negative societal connotations, cultural perceptions and how education can sometimes view and 'deal' with dyslexia. The limited awareness and understanding of dyslexia were highlighted, thus, the need for the implementation of a state-wide awareness and educational campaign around dyslexia is recommended. A vital part of this research is that it demonstrated how people with dyslexia can and will succeed in HE, regardless of encountering the barriers identified. Analysing the data and participants' personal experiences of studying in HE shows how one can succeed with dyslexia, not despite dyslexia or the systemic barriers in place, but in partnership with their dyslexia. The research has shown how studying with dyslexia is not all bad and by moving out of a pre-existing fixed mindset to a more growth mindset will allow one to view dyslexia and studying in a new light and to do things in a different way. This will then increase the opportunities for people with dyslexia and enable them to achieve on par with their peers.

One of the challenges for students with dyslexia is to dis-identify with a fixed mindset which promotes a limited sense of 'self'. This can be created by the destructive emotions associated with dyslexia and how it impacts on the educational experience. It is also imperative to work alongside disability advocates, disability study academics and disability activists to maintain awareness and to embrace the belief that there is nothing wrong with having a disability.

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