An Exploration of Meanings Attributed to a Dyslexic Diagnosis.

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Abstract
This article investigates meanings attributed to the label dyslexia and a dyslexic diagnosis. Its purpose is to provide a critical perspective of the dyslexic diagnosis by reviewing existing information on dyslexia and applying relevant information on other contested illnesses/conditions to dyslexia. Findings show that the meaning of the label dyslexia is not settled in public consciousness. It means different things to different people and professionals and is subject to change. The dyslexic diagnosis has both costs and benefits for the dyslexic person. Its meaning and impact can vary in different situations. Interviews conducted provide personal accounts of the experiences of people with dyslexia and highlight the impact that the dyslexic diagnosis can have in them.

Keywords: Dyslexia; ADHD; labelling; diagnosis; medicalisation; contested illnesses/conditions; disclosure.
Introduction
The need to achieve a deeper understanding of issues involved with the dyslexic diagnosis led me to seek more answers than I could find in existing literature on dyslexia. Most literature on dyslexia focuses on dyslexia in education and associated learning difficulties. My focus is different from this. My third year Social Science research project provided me with the opportunity to explore meanings attributed to dyslexia and its diagnosis. This article comprises a snap-shot of that project. My research uses both primary and secondary data.

I step away from the topic of dyslexia in order to develop a critical and interpretative perspective of its label. To do this I look at concepts in other areas, i.e. contested illnesses/conditions, and apply their conceptual frameworks where relevant. I explore the changing shape of the dyslexic diagnosis and what meanings it holds for people. I do not know of any other study like this and believe it is needed to fill a gap in existing literature on dyslexia.

It is only in recent times that dyslexia has become recognized as a complex learning difficulty that affects each person differently. However, as of yet there is no definition of dyslexia that all the professionals agree upon. Various constructions of dyslexia as well as social forces affect how it is understood. I consider both the advantages and disadvantages to having a dyslexic diagnosis and how it is both a friend and foe for the dyslexic person.

Literature Review
The shift from medical to psycho-medical constructions of dyslexia
Medicalisation is a concept that gained importance through the work of Ivan Illich (1975). It refers to a process where more and more aspects of everyday life become medical issues. This is shown to have both benefits and costs. Conrad (1992) declares that medicalisation is about the management of ‘problems’. Early literature on dyslexia was medical in origin. Neurologists became interested in it in the early 1900s. Shortly afterwards, dyslexia became connected to the reversal of letters and ‘twisted symbols’.
By 1968, The Research Group on Developmental Dyslexia from the World Federation of Neurology recommended two definitions of dyslexia which are still in use today. The first is: “Specific Developmental Dyslexia is a disorder manifested by difficulty in learning to read despite conventional instruction, adequate intelligence, and socio-economic opportunity. It is dependent upon fundamental cognitive disabilities which are frequently of constitutional origin” (Pumfrey and Reason, 1991, p. 14). The other states that dyslexia is “a disorder in children who despite conventional classroom experience, fail to attain the language skills of reading, writing and spelling commensurate with their intellectual abilities (Pumfrey and Reason, 1991, p. 14). Both definitions constructed dyslexia as an inability to achieve to a ‘normal’ standard. Tests for dyslexia started to develop in the 1970s. From this emerged the idea of having an official diagnosis for dyslexia.

By the late 1940s the study of dyslexia became of interest to psychologists, sociologists, and educators who contributed to the proliferation of new theories about the causes and symptoms of dyslexia. However, psychological theories dominated. Sousa (2005) states that today there are several potential causes of ‘developmental dyslexia’ that have been identified by psychological studies, including phonological deficits, differences in auditory and visual processing speeds, varied sizes of brain structures, memory deficits, genetics, brain lesions, and word blindness. “It is possible that several of these causes are related to each other and can coexist in the same individual” (Sousa, 2005, p. 122). The term ‘developmental dyslexia’ conjures up images of a difference in how a person develops. The studies suggest an interplay between the ideas of difference, defect, and disability. The dyslexic label is one of deviance, the dyslexic learner constantly been compared to the ‘normal’ learner.

The history of dyslexia highlights a proliferation of theories and studies and its meaning is surrounded by great uncertainty and debate. The construction of dyslexia is not static and new ‘facts’ are constantly changing our understanding of it. To be diagnosed by the psychological profession a dyslexic person must fit a certain
mould/criteria. For instance, the person’s reading skills must be below what would be expected from IQ scores.

Dilemmas of diagnosis

Dumit (2006) suggests that medicalization, like dyslexia, is itself a contested process. It involves collective organizing and strategic claim making across multiple areas and the influence and acceptance of a wide array of social actors. “Medicalization studies have demonstrated that agents such as self-help and advocacy groups, social movements, health-related organizations, pharmaceutical companies, academic researchers, and clinicians can be central in creating specific diagnosis” (Conrad and Potter, 2000, p. 560).

According to Dumit (2006) only a diagnosis gives recognition/acceptance to a condition by the medical, psychological and educational professions. In today’s society it is needed to prove that a person’s difficulties are real and legitimate and to entitle them to supports. “A key concern in research on contested, uncertain illnesses is the intense interplay between diagnosis and legitimacy: without a diagnosis and other forms of acceptance into the medical system, suffers are at risk of been denied social recognition of their very suffering and are accused of simply faking it” (Dumit, 2006, p. 578). If the condition is not accepted a person can doubt their own suffering/difficulty.

Arguments for diagnosis

Medical diagnosis brings with it both acceptance and constraints. Writing about ADHD, Conrad and Potter (2000) declare that it can transform an ‘unorganized illness’, an agglomeration of unconnected symptoms and complaints into a more understandable ‘organized illness’. Dyslexic people are often revealed by their diagnosis. “The ADHD diagnosis provides a medical explanation for their underperformance, allows for a re-evaluation for past behaviour, and by shifting responsibility for problems reduces self-blame” (Conrad and Potter, 2000, p. 573). Without a diagnosis a dyslexic person may be seen as stupid or making excuses for lazy behaviour (Pollock, Waller and Politt, 2004; Hornsby, 1995).
The authors suggest that a diagnosis of ADHD puts the individual into the larger category of having a disability which allows access to certain accommodations and benefits. They say that there are social advantages to a medical definition - mitigation of personal blame, medical excuse, and disability benefits. It can be argued that a dyslexic diagnosis allows a person to re-evaluate who they are. “In some instances a diagnosis can be a kind of self-labelling that provides a new public identity as having a particular illness or disorder (Conrad and Potter, 2000, p. 560). Dyslexic people may seek a diagnosis as it can give them a new understanding of their ‘problem’ and thus, a new type of identity.

In schools today, the dyslexic label is seen to give equality of opportunity to students. It has become a tool for the empowerment of dyslexic people as it allows them to access certain ‘accommodations’ and provides supports which many commentators stress are needed in the school environment (Hornsby, 1995; Pollock, 2004; McCormack, 2002; Murphy, 2004). It is felt that when supported, dyslexic students are made level or equal with other students. In this way it can be seen in contrast to the psycho-medical model where the difference is seen in terms of not being able to achieve to the level of non-dyslexic learners.

Studies have shown time and time again that dyslexic people learn differently to others (Shaywitz and Shaywitz, 2002; Sousa, 2005; Burden, 2005). The question is if people with dyslexia want this difference to be acknowledged - to be accorded different treatment - or do they want to be treated equally, the very same as everyone else. There is an assumption that to be seen as different means that one is not equal, to be dyslexic puts one at a disadvantage. A dyslexic label results in a dyslexic person being seen as ‘different’, a reason for learning differently to others. Why strive to be seen as different? For many dyslexic people a diagnosis is liberating. They can see themselves in a different way. It allows them to tell others, if they choose, that any apparent learning difficulties are not due to lack of intelligence but something else, the affects of which can be overcome. In this way, dyslexic people strive for the dyslexic diagnosis. It is through this same label that fairness and equality are thought
to be restored. Therefore, the dyslexic label provides the status of difference and
disadvantage but, paradoxically, is also thought to allow for sameness and equality.
This explains why many dyslexic people seek the label while in education. Ott (1997)
says that for dyslexic people, the benefits of being diagnosed far outweigh the
disadvantages of not knowing.

**Arguments against diagnosis**
In contested conditions ‘facts’ can function differently and provide very different
reactions. Carey (2005) says that while some argue that labels allow children to
receive extra/‘special’ help when needed, others suggest that they limit opportunity
and carry with them a life-long stigma. Thus, fear is an element of having a dyslexic
diagnosis- fear of being ‘found out’ by the wrong person. Therefore, keeping secrets
is part of the experience of being dyslexic for many people.

In addition to professional discourses the media’s portrayal of dyslexia impacts upon
how society sees it. Some representations within newspapers construct it negatively.
For instance a piece written for the *Irish Times* (2008) links dyslexia to a psychiatric
condition and murder. Constructions such as this may create fear towards dyslexic
people and fear among dyslexic people in owning their difficulty. Another article that
appeared in *The Sun* (2006) was titled ‘BARMY Royal Mail bosses have hired a
dyslexic postman who sees door numbers the opposite way round’. This article links
dyslexia to the loss of millions of letters and parcels. This construction of dyslexia
may affect dyslexic people’s ability to obtain jobs in the future and a reason why
some dyslexic people are afraid to tell others of their dyslexia. This can be seen as
another negative consequence involved with the label dyslexia. What I suspect was
written for entertainment purposes for *The Sun* readers can have detrimental effects
for people with dyslexia.

As can easily be seen, the label dyslexia can mean very different things- often on
opposite ends of the spectrum. Within education, its benefits are seen to outweigh its
costs. However, declaring that one is dyslexic can be harmful to the dyslexic person.
“Whilst negative stereotypes dominate the media, it is easy to see why admitting to
having a learning difficulty may therefore be perceived as a high-risk strategy” (Morris and Turnbull, 2006, p. 36).

**Research Approach**

I used a qualitative, phenomenological approach to explore and understand subjective information addressing and explaining the nature of the diagnosis. This allowed me to develop a deeper understanding of the phenomenon. A rigidly structured approach would not easily accommodate this type of analysis. Creswell (1998) says that a phenomenologist seeks out the perception of participants to see how they live the phenomenon and how it affects them. The main method of data collection for phenomenological research is interviews. Participants can fully express their views on a phenomenon allowing the interviewer to really understand their experience or perspective. I used semi-structured interviews. I prepared specific questions in advance but also asked unprepared questions that emerged during the interview. This allowed the interviews to follow a certain path and enabled me to obtain a degree of uniform information. The method allowed me to easily compare the collected data but also provided a degree of flexibility. I was able to follow up on relevant points if interest brought up by the interviewees.

In addition, I used purposive sampling (Kumar, 2005). This means that I only went to people who were likely to have the information I was looking for and may be willing to share it. My interviewees came from two types of sources. The first is from professionals who have gained relevant knowledge for my research question by working on the ground with dyslexic people. This provided broad, generalized knowledge about how dyslexic people experience dyslexia and its diagnosis. More specific information was then gathered from people who have a dyslexic diagnosis (adults/18 years old and over), the very people who have experienced this issue. To assess this information I engaged in open coding and pulled meaningful statements from it. This allowed me to compare and contrast the experience for different people.
Findings

To ensure anonymity I have changed the names of all the interviewees. Two of my interviewees are professionals who work with people with dyslexia. Claire is a member of the educational profession and Emma is a careers advisor who is connected to a support service for people with disabilities. They provided me with a good overview of the issues about diagnosis and the perceptions of the dyslexic experience for dyslexic people. The other three interviewees, Greg, Kate and Paul, are people who have a dyslexic diagnosis.

Perceptions of dyslexia

In my research I found both similarities and differences in how dyslexia is understood and what it means to people. All participants accepted dyslexia to be a reality in itself and expressed no uncertainty about its existence. Everyone associated it with difficulty in learning. However, variations in the perception of dyslexia were evident.

The interviewees with a diagnosis of dyslexia used a range of terms to refer to it. Kate suggests that it makes her “different” to her friends who do not have any known learning difficulties. Paul refers to it as a “problem”. He suggests that he used to shy away from certain things, e.g. public speaking. “I would think…this is going to expose my problem here now. I really don’t want to be doing this so I never did any of them”. He also refers to it as a “condition” and later as a “weakness”. Greg and Emma refer to it as a “disability”. Not alone are current debates about dyslexia happening in the professional sphere but varied interpretations are also evident in discourses used by dyslexic people themselves. This could be a reflection of dyslexic people applying social understandings of dyslexia to their experience of it. The meaning of dyslexia has not been categorically decided upon.

Dyslexia is associated by all of the interviewees with a struggle or a fight. Paul declares that “I can see from my own situation that if you can that you can fight it and it is a fight because you have to carry a dictionary under your oxtail every day…”. Greg says “I wouldn’t even apply for a job where dyslexia would make me struggle”. Kate states that she “struggled in school. Being dyslexic means that you have to fight
harder for good marks”. Paul was the only dyslexic person to express his belief that dyslexia has associated advantages. He says”...I have great spatial intelligence and things like that...”. When asked about his feelings about dyslexia being seen as a gift he says “...it can be and I know that that’s what I have benefited from it”. This theme also emerges in interviews with the professionals, Emma and Claire. When speaking of dyslexic people Claire states: “generally speaking, this is a general finding, we would find in the department that the dyslexic students are some of our stronger students. I would say of the nine years that I have been teaching the two best students I had had dyslexia”.

**Experience of dyslexia**

All three dyslexic people who I interviewed described difficulties associated with dyslexia that they experienced. For instance, Paul says that he had trouble learning to read, his “spellings were and still are appalling today”. He says:

“...in my case I can mix up Bs and Ps, Ds and 9s... I remember being in third class. There was a big spelling test anyway and I remember really learning the spellings, really learning the spellings I’d say for about two weeks and I said that I’m going to get all these right now. I had decided to myself that it was time to get them all right. And, I’d say I got about seventy percent of them wrong. I got nervous and of course that makes my condition worse. Then my teacher said to me ‘you didn’t make any effort to learn these did you?’ And I said ‘I did, I just spent hours and days learning them’. And she said ‘you didn’t’ and that was the end of that”.

**Experience of diagnosis**

At seventeen, Greg received his first diagnosis. He says that it was not followed up to any great benefit to him. There was no follow up treatment or recommendations made by anyone. As he got no assistance or supports in Junior Certificate he could not get assistance for his Leaving Certificate. He says “if you sit one state exam without assistance you can’t get assistance for the next one”. Thus, because he did not get an early diagnosis he was denied access to most supports. At twenty-four he began a Post-Leaving Certificate course. He began to experience difficulties and was told in
order to access supports he would have to be reassessed. Seven years had passed since his last assessment and so it was no longer valid to access supports. This highlights Dumit’s (2006) point that only a diagnosis gives acceptance to a condition by the medical, psychological and educational professionals. It is needed to legitimize difficulties and entitle a person to supports. After obtaining the second diagnosis Greg was able to access available supports: “I got one to one tuition, I got the course broken up into two years, I got a tutor, a computer with voice control and everything”. Therefore, if a dyslexic person does not get a diagnosis at an early age they may find it difficult to access supports and if the diagnosis is not a recent one, he/she must be reassessed in order to access supports.

Conrad and Potter (2000) declare that a medical diagnosis can make an illness more understandable. The dyslexic label can provide a new understanding of problems associated with been dyslexic. Kate states “it gave me an answer for everything. I knew then that I could do something about it”. Greg says that “…being dyslexic doesn’t mean anything really. I am still the same person but I always found it hard. I couldn’t understand how I couldn’t get things when everyone else was getting them but now I know that it is because I’m dyslexic. You know that that you will have to take longer at something to understand it and put it into your way of getting it… So, the diagnosis is not a blessing but it helps you because you can understand how to solve things your own way”.

All my interviewees with dyslexia expressed positive attributes of the dyslexic diagnosis for them. For instance, Paul says that “it was a relief that it wasn’t anything more than I thought it might have been…”. When asked how she felt when she was diagnosed Kate says “…relieved because it meant that it wasn’t something worse. It meant that I wasn’t actually just not bright. It allowed me to be bright and have dyslexia as opposed to not having dyslexia and not being bright”. This highlights how the dyslexic label and diagnosis is seen to dismiss the label of laziness and stupidity as expressed by commentators such as Hornsby (1995) and Pollock, Waller and Politt (2004).
Existing literature on dyslexia expresses a sense of emergency to diagnose as many dyslexic children as possible. Claire expresses her surprise at undiagnosed dyslexic students who have come straight out of secondary school. In existing literature, the lack of a diagnosis is linked to issues of low self-esteem and poor educational achievement. However, Paul’s experience shows that this is not the case for all people with dyslexia. He did not get his diagnosis in school and says “what I’ll say about things is that I knew I wasn’t stupid ever because I could figure stuff out really fast, faster than a lot of guys and I could understand an awful lot”. He explains that when he was nine or ten he thought himself to play chess from a book and by the age of twelve was able to beat his siblings and father in the game. This shows that a dyslexic diagnosis is not the only thing that stops a dyslexic person from thinking they are stupid. Dyslexia does not automatically lead to low self-esteem. Identity is formed by many different things and in many different ways.

Paul does not believe that dyslexia as a significant issue in education for him. He says “…educationally it hasn’t affected me. I mean I did go to college and stuff like that and ya, I did have problems with it and I suppose it affected my marks and things like that but it never actually stopped me from doing anything… My biggest handicap going to college wasn’t points or the fact that I couldn’t spell, it was the fact that I couldn’t afford it”. Unlike Kate, Paul did not need the dyslexic diagnosis to see himself as bright and he did not see it as his biggest challenge. Claire states that some people with dyslexia do not need her to work with them more closely. This shows that not everyone with dyslexia needs special supports, which contrasts with assumptions made in much of the existing literature on dyslexia. The meaning of dyslexia and a dyslexic diagnosis can differ between people.

Claire believes that with the dyslexic diagnosis, “some students are happy, some students are very concerned about keeping it covered”. As discussed, part of the dyslexic experience is about keeping secrets. Greg says that “I didn’t tell anyone that I had been diagnosed because I didn’t want to give other people ammunition to slag me off”. He also suggests that he would not immediately tell women that he is dyslexic. When asked if he thinks they would not want to date him then he responds
“I can’t see how it would be a turn on anyway”. Fear of felt stigmatization is one of the disadvantages associated with the dyslexic label. In addition, Emma expresses her belief that “labels by their nature put people in boxes”. The perceived dyslexic role affects how someone with dyslexia is seen.

**Issues of disclosure**

A recurrent underlying theme that became apparent through my interviews is that a lack of public awareness seems to prevent people from disclosing their dyslexia. All of interviewees expressed this as an issue. Greg, Paul and Kate declared that they would not want to lie about being dyslexic in interviews, but they just would not offer the information. They are not happy to divulge the fact that they are dyslexia because other people may not understand what it is.

With regards to work colleagues Kate says that she would be careful who she told: “And if you made a mistake people might be thinking or saying oh sure just let her off because she is dyslexic. Sometimes it’s just better not to tell people”. When speaking about disclosing his dyslexic diagnosis Paul supposes that it could “militate against you in lots of ways because irrespective then if they don’t know about it they are going to be thinking like does that mean they are going to take a knife out of the drawer and stab me?”. This is a prime example of the influence of negative media representations, discussed earlier, and the issue of perceived lack of public knowledge of dyslexia. It shows an awareness of negative connotations, assumptions and meanings that others may attribute to the dyslexic diagnosis.

When asked about her experience of the hopes and fears people may have in disclosing a dyslexic label in potential employment, Emma responds “…people hope that the employer will give them a chance…they just want to get in and be the same as everyone else…”. This builds upon a point made in the literature review. Can a dyslexic diagnosis allow for difference and sameness? The hope with disclosing a dyslexic diagnosis is that one’s difficulties and difference are recognized and addressed but that they can still be seen the same as everyone else. They want to be
accorded the opportunity to just fit in. Emma says “people do want to fit in, they don’t want to be seen as the different person, the dyslexic person”.

Conclusion
A diverse array of influences shape and reshape contemporary understandings of dyslexia e.g. medical/ psychological/ educational professions, the media etc. Within and between all these fields dyslexia is debated, agreed and disputed. The term dyslexia means different things to different people and professionals and is subject to change. This is reflected by the many different terms used to describe dyslexia by the interviewees. Particular circumstances determine what effect the diagnosis might have. A commonality that dyslexic people share is the changing nature of the label or diagnosis they carry. From the interviews it became apparent that people with dyslexia can hold similar hopes and fears with regards to the diagnosis. For instance, hope that others will see past negative connotations associated with the dyslexic label but fear that they will not.

For my three interviewees it provided a sense of relief that experienced difficulties are not due to something worse. Some find the diagnosis comforting and liberating and it allows them to reassess their identity. However, the diagnosis may also have disadvantages such as fear of stigmatization and discrimination. A lack of knowledge in the employment sector creates a sense of fear that one may be seen as different and unequal or not as able. This is one of the associated costs with disclosing the dyslexic diagnosis.

Current constructions of dyslexia provide for a label similar to a double-edged sword. This type of sword can inflict injury in two ways. Without the label dyslexia, one may be seen as stupid and lazy, feel self-doubt about one’s abilities and have low self-esteem. This may slice through one’s confidence and limit one’s choices in life. The label then can be a type of reassurance to a dyslexic person and a shield when needed. It is for this reason that people seek the label ‘dyslexia’, even though it is one associated with being different. Within the educational sphere this difference is not associated with inequality but with promoting equality. On the other hand, if society
has a negative attitude towards dyslexic people then the ‘label’ dyslexia can also be damaging. Negative connotations or understandings of dyslexia means that its diagnosis can slice through one’s opportunities in life and may have a negative effect on or injure a dyslexic person’s self-concept. As seen, the media has linked dyslexia to a psychiatric condition, a murder charge and millions of lost letters etc. For this reason some dyslexic people seek a dyslexic label while others reject it. I believe some people may do both, depending upon what circumstance they are in at any time.

Dyslexia is part of who somebody is and how contemporary society understands it has a huge influence on a dyslexic person. The dyslexic diagnosis can provide for a form of identity, one that is determined by its social construction. It is a complex phenomenon which can hold similar and opposed meanings for people. Attributed to it are feelings of acceptance and constraints, power and powerlessness, answers and questions, hope, and for some despair.
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