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Dyscalculia: An Autobiography of my Invisible Learning Disability.

Abstract

There is a dearth of Sociological literature on people living with learning disabilities and more specifically, there is a lacuna when it comes to Dyscalculia. Research into Dyscalculia has remained the preserve of bio-medical discourses thus it is timely to explore Dyscalculia from a Sociological perspective with autobiography as a unique Sociological method. In this article, I use autobiography as a conceptual space to explore Dyscalculia as an invisible disability. I limit my discussion to my interactions with health care providers, power dynamics and stigma. I reveal how stigma has contributed to my psycho-emotional disablism. However, as I illustrate, medical power is situational and I thus comply with and/or resist it. I put forward a nuanced perspective that challenges the concept of the docile learning disabled patient. Rather, I advocate for a theoretical approach that recognizes how the learning disabled exercise power in the face of damaging enacted stigma. However, in so doing, I caution that resilience is related to intersectionality and in my case, may have been largely possible due to my positionality as a middle class person with access to medical insurance, my education and profession.

Keywords: learning disability, health care professionals, Dyscalculia, autobiography, agency, stigma

Introduction

There is a hiatus of Sociological literature on learning disabilities. In this article I explore a learning disability that I am afflicted with, Dyscalculia. To do this, I use autobiography and I focus on my interactions with health care professionals locating them within literature on the medical encounter and stigma. Rather than positioning myself as a passive patient, I see myself as a survivor. Survivor is a politicised term used by Faulkner (2012: 39). It refers to groups who make use of health care professional services and are hence subject to the potentially disempowering effects of such services but still exercise resilience. Below, I illustrate how I have experienced psych-emotional disabilism but also enacted project stigma to counter the negative impact of medicalization and stigma. This is with the caveat that this may have largely been possible because of my positionality as a middle class person with access to medical insurance, my level of education and my profession.

Selected Review of the Literature

Dyscalculia affects a large number of the population, approximately 3% - 7% (Butterworth et al., 2011: 1049). It is a neurobiological disorder that cannot be explained by low intelligence, socio-economic factors, inadequate schooling or low motivation. It manifests, inter alia, as a poor ability in maths and abstract concepts of time and direction although PLDys (People living with Dyscalculia) have normal or accelerated language acquisition that extends into the verbal, reading and writing sphere and they are usually creative (Gillum, 2012: 289).

Research into Dyscalculia has not been located within Sociology, but has remained the preserve of education, social work, psychiatry, psychology and other bio-medical disciplines. Thus it is timely to explore Dyscalculia from a Sociological perspective with autobiography as a novel way of doing so. Dyscalculia is an invisible disease and the unique needs of those with invisible learning disabilities has received little attention (Mullins and Preyde, 2013).

'Invisible disabilities can be considered an umbrella term to refer to disabilities that interfere with day-to-day functioning but do not have a physical manifestation. Although some of the symptoms of the disabilities may be exhibited behaviourally, the cause of the disability cannot be seen' (Mullins and Preyde, 2013: 148).

The lack of the visible sign of disability may present challenges for example, questioning the validity of the disability (Mullins and Preyde, 2013: 149). Storytelling about invisible disabilities can make them visible and locate them in the public sphere, thus transcending personal troubles to become public issues (Mills, 1959: 8). Autobiographies take storytelling one step further by turning the gaze inward to explore the researcher as storyteller. Autobiographies are '[H]ighly personalized accounts that draw upon the experiences of the author / researcher for the purposes of extending Sociological understanding' (Sparks, 2000: 21). Autobiography allows the '[Of]ten silenced voices of the stigmatized to be heard' (Liggins et al., 2013: 105) and locates reflexive voices in social experiences and processes (Mykhalovskiy, 1996: 141, 147). This enables the emergence of 'subjugated knowledge' that has been excluded from the hierarchy of the body of 'official' science (Foucault, 1980: 1). Further autobiography, according to Garland-Thompson (2007: 121), performs 'cultural work. They frame our understandings of raw, unorganized experience, giving it coherent meaning and making it accessible to us through story'.

Sociological autobiographies facilitate insights into micro-sociology against the backdrop of macro- sociology. Locating subjective experiences within social structures, allows autobiography to avoid the trap of narrow biomedical models of disability as well as the dichotomy between individual lived experience and theoretical social models of disability (Rauol et al., 2002: 5). It is further critical to note that while autobiography goes beyond biomedical explanation, the physical biological effects of impairments are constructed within social and cultural meta-narratives that vary depending on time, place and socio-political

contexts. It is for this reason that autobiography is well placed methodologically within Bhaskar's Critical Realism (1989) with its realist ontology and relativist epistemology. This allows for an understanding that takes the biological, physiological, material as well as socio-cultural and linguistic factors into account.

Due to restricted word length, I have limited my autobiography and discussion on Dyscalculia to medicalization and stigma with reference to health care professionals.

Medicalization has allowed for the growth of the power of health care professionals. This power does not reside in individual health care professionals but is rooted in social structures and the historical institutionalised power attributed to health care professionals (Gilbert et al., 2010: 14-18). Medicalisation subjects PLDys to the clinical gaze and the coding of the PLDys subjecting them to stigma. Link and Phelan (2001: 365) point out that most research on stigma has been 'from the vantage point of theories that are uninformed by the lived experience of the people they study', thus the need to hear voices of those who live with stigma.

Focusing on health related stigma, Scambler (2009: 441) defines stigma as:

> '[A] social *process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from* experience, perception or reasonable anticipation of an adverse social judgement about a person or group. The judgement is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgement is in some essential way medically unwarranted'.

Scambler and Paoli (2008) cited in Scambler (2009: 451) conceptualise three types of stigma namely; enacted, i.e. discrimination by others on grounds of 'being imperfect'; felt, i.e. internalised sense of shame and immobilising anticipation of enacted stigma and project, i.e.

strategies and tactics devised to avoid or combat enacted stigma without falling prey to felt stigma. Stigma is inextricably linked to labelling and stereotyping. In understanding these concepts I lean on Postructuralists and, while avoiding linguistic imperialism, I recognise how language functions to structure and challenge constructs. Thus health care professionals may linguistically classify and code and use binaries to fix the mutually exclusive categories of those who are perceived as 'normal' or 'abnormal'. For example PLDys may be labelled with normative ascriptions assigned to them with different values associated with different codes. Hence, those classified as learning disabled may be devalued leading to 'othering' and stigma. This may result in psycho-emotional disablism, described by Thomas (2007: 72) as 'hurtful' actions or words, both intended and unintended, by non-disabled people in interpersonal engagements with people with impairments. These may lead to 'barriers to being' and negative self-esteem, low confidence and stigma.

Medical power is situational and exists in a dialectical interplay with agency. This is exemplified in models such as those discussed by Speed (2006) and Szasz and Hollender (1956). In Speed's (2006: 29) study of mental health service user discourses, three Weberian ideal types are discussed. At the most passive extreme, there is acceptance of the medical diagnosis and the adopting of a patient discourse concluding 'I am schizophrenic'. Those who are situated within the consumer discourse exert more agency and negotiate and resist as they partially accept the diagnosis while also seeking information about the diagnosis and diverse treatments. Those who are located within the survivor discourse resist diagnosis asserting 'I am a person who hears voices'. Szasz and Hollender (1956 as cited in De Maio, 2010: 589 - 590) focus on the medical consultation and develop a typology which is more realistic than the view of absolute power of health care professionals and complete passivity of patients. In the Activity-Passivity ideal type, doctors act as perfect agents with almost total control in the medical encounter. In the Guidance – Cooperation model, both elements of domination and

submission exist and the patient takes a more active role in decision making. In the ideal typology of Mutual Participation the patient is well informed and an equal participant in decision making. These typologies illustrate that there are various complex relationships between health care professionals and patients / clients.

My story

I live in South Africa where very little is known about Dyscalculia and I was diagnosed with Dyscalculia as an adult. This necessitated many interactions with health care professionals. Despite my Dyscalculia, as a child I managed to "escape" health care professionals as I excelled in school. My poor ability in maths when basic geometry was introduced was attributed to 'hanging out with kids from the wrong side of tracks'. I obtained a PhD in Sociology in 2005 and began to lecture at a University in Johannesburg. As my responsibilities increased my invisible disability became visible. Even though it was not inscribed on my body it manifested in being time blind, in lacking a sense of space and place and numeric dyslexia and seeped into all areas of my life. My finances suffered as I struggled to count money and to budget. In the workplace I added up marks incorrectly, could not numerically order the pages of photocopies and took extra long with administrative tasks that demanded any numbers such as working out how many students attended lectures thus interfering with research time. Moreover, my social life was marred by a fear of finding my way to places and getting the date and time wrong. This necessitated continued contact with health care professionals in the hope of legitimating my disability for my employer in order to obtain reasonable accommodation, to mitigate its destructive impact on my life as well as my desire for an official medical label to validate what I sometimes believed to be an imaginary ailment or my inherent incompetence. Many of these consultations lead to stigma, however, I also exerted agency to partly counter this.

In seeking a diagnosis and treatment for my Dyscalculia, I consulted with three occupational therapists. The first occupational therapist increased her voice incrementally for each task that I could not do. It was as if the louder she spoke the more I would miraculously become competent in the assigned tasks. The second occupational therapist advocated that to overcome my problems with dates and times, I should use a 'large calendar', thus overlooking the critical fact that it is difficult for me to read columns even if they are large ones and that I had not consulted her for visual impairments. My assessment with the third occupational therapist included her asking me if I recognised a toothbrush, a coin and a bunch of keys despite knowing my profession and that I had a PhD. A neuropsychologist concluded his report by wondering how I could have obtained my PhD given that I performed well below average on tasks requiring spacial and mathematical competence. In contrast to this, a neurologist could not conceptualise that I had a learning disability precisely because of my post as a lecturer and level of education, proclaiming that I was trying to 'get out of work'. I also had numerous experiences with psychiatrists who, rather than delving further into the realm of learning disabilities, preferred to over-medicate me so that it became very difficult to perform any tasks, let alone the ones related to Dyscalculia. This being said, I have had some positive experiences with health care professionals. For example, I "shopped around", until I found a psychiatrist whose philosophy is that both the health care professional and client are experts with reference to the clients' 'troubles', so that my diagnosis would be co-authored. I am also in a unique position in that I teach health Sociology with a section on Disability to first year doctors, pharmacists and occupational therapists which, as shall be seen further, acts as a buffer against stigma and unequal power dynamics. In my autobiography, it is also important to point out that my disability needs to be read in the context of intersectionality where my middle class position, access to medical insurance, education and the inter-net afforded me a privileged position.

Discussion

Lupton (1979: 379) has emphasized the importance of the 'affective' in the doctor – client experience and the importance of interrogating '[H]ow the patient 'feels' during and after the encounter' (Lupton, 1979: 379). In this regard enacted stigma in many of my consultations contributed to internalised oppression (Barnes et al., 1999: 78) and to the undermining of my psycho-emotional well being (Thomas, 2007: 22).

In linguistically coding me the signifier, learning disabled, was often coupled with signifieds such as infantile and unintelligent, as was the case when asked by the occupational therapist if I could identify a coin and toothbrush. Enacted stigma (Scambler, 2009: 451) also manifested in the patronizing attitudes of the occupational therapist who spoke loudly and the occupational therapist who suggested a large calendar. Further, some health care professionals have imposed my learning disability as a master status. Witness the neuropsychologist who wondered how I could have obtained my PhD thus extrapolating from limitations related to my learning disability to areas where no difficulties existed, thus devaluing my competence in my professional field. However, power is not possessed and is relational (Foucault, 1979: 94), hence the balance of power constantly shifts. In the above consultations, I did not contest the enacted stigma, thus seemingly taking on a passive role. However, this is not akin to taking on Szass and Hollender's (ibid) Activity-Passivity role as I did not venerate the health care professionals as 'perfect agents', but in fact recognised their stigmatising practices. I consciously chose not to challenge these as I needed their diagnosis. This is in line with Parson's sick role whereby the 'patient' must seek out and comply with a licensed physician to receive the 'benefits' of the sick role (Parsons: 1975); in my instance, being exempt from particular job tasks. In consulting with health care professionals, I have intentionally chosen to subject myself to surveillance in 'disclosing discredited information' (Goffman, 1963: 41) about my disability; but in 'choosing' to 'tell', I have enacted agency. I

have recognized that, paradoxically, even labeling can be constructive, and I have actively sought out diagnosis and a medical label (Broom and Woodward, 1996). This has assisted me to ascertain whether I had a legitimate learning disability so that I did not deem myself as unintelligent. Further, I have constructively drawn on my diagnosis to obtain reasonable accommodation in the workplace for some of the administrative tasks that a PLDys cannot perform, for example, adding up student marks. Thus, as 'consumerist client' and 'reflexive actor', I have been able to calculate, assess and counter medical knowledge to maximise the services of health care professionals (Lupton, 1979: 375).

As a survivor, I have rejected the role of patient hence I do not say 'I *am* Dyscalculic' but rather, I say 'I am a person living with Dyscalculia', as it is only part of my fragmented identity; albeit a large part and one that shapes my life in significant ways. I have refused to be reified to a learning disorder or straightjacketed with labels as although I live with Dyscalculia, I am not it and not defined by it. Further, as an individual with have multiple identities, I have been able to draw on alternate identities rather than on the stigmatized ones, strategically focusing on identities that are valued (Shih, 2002: 179 – 180). To assist me with positive identity work and to deal with my negatively affected sense of self (Thomas, 2007), I have consulted with a psychologist who practices based on participatory principles. In negating the role of passive patient, I have positioned myself as a self-reflexive client and consumer (Speed, 2006). In this regard, upon my dissatisfaction with the over prescribing psychiatrist, I 'shopped around' (Lupton, 1977) until I located a psychiatrist who maintained that we would 'coauthor my diagnosis and treatment' thus encouraging mutual participation (Szasz and Hollender, 1956). This 'collaborative approach' is an example of 'constructive medicalisation' (Broom and Woodward, 1996: 369, 367). I am active in obtaining information about my prognosis and treatment by using online Dyscalculia assessments. I have also joined Dyscalculia forums where other PLDys share advice and coping

mechanisms and to educate myself about Dyscalculia thus narrowing 'the competence gap' (Gilbert et al., 2010: 15). Hence, I have been selective in respecting medical knowledge but I do not revere or fear it.

My position as a Health Sociologist who teaches Sociology to students who are studying to become doctors, pharmacists, nurses, occupational therapists and physiotherapists has also been instrumental in facilitating a view of the health care professional as not 'godlike' and all knowing. I have enacted project stigma, by using lecture time to introduce critical pedagogy (Giroux, 1988) and to challenge students to rethink norms and power dynamics between health care professionals and clients. For example, I have introduced a theme on disability and stigma and I have used provocative covers on my course reading packs. With reference to the occupational therapist who spoke loudly, an experience which is common amongst people with both physical and learning disabilities, I inserted a picture of a women wearing a Tee-shirt that read 'Paralyzed, Hearing is Fine' on the cover of my course reading pack.

Concluding Thoughts

I have offered my autobiography as a powerful analytical space in which to reflect Sociologically on learning disabilities and relations of power in the health care professional - client relationship. People with both visible and invisible disabilities may be subjected to demeaning health care professional interactions and stigma that contribute to internalised oppression, as I have experienced. I have complicated the idea of the passive patient and I have illustrated how I have been a reflexive survivor and consumer of health care services. This is with the caveat that my agency has partly been possible because of my positionality and that my resilience has not precluded the effects of psycho-emotional disabilism resulting from negative health care professional consultations. Autobiographies serve as constructive

methods for people living with physical and learning disabilities to reflect on disabilism and how their micro stories can be located within macro structures. This can be empowering as it encourages a move away from personal tragedy models of disability and while not painting all people with disabilities with the same brush, it can locate their micro lived every day stories within macro social models of disability to inform both practice and policy.

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