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‘It’s been taken away’: an experience of a disappearing dyslexia diagnosis

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ABSTRACT

This research explores the experiences of Beth, a university student in the UK, as she comes to be labelled as ‘dyslexic’, and as she has her diagnosis taken away. Through use of Interpretative Phenomenological Analysis (IPA) and discourse analysis, the research seeks to understand how Beth made sense of these experiences, and to explore the discursive ‘life’ of dyslexia within this sense-making. The discussion in this paper proceeds chronologically through Beth’s story, from ‘struggle’, to ‘legitimation’ to ‘derogation’, and concludes with a call to recognise the role of diagnosis in the field of special educational needs (SEN) from a social constructionist and relational perspective.

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Introduction

Dyslexia: a ‘Pathology of Superiority’. (Geshwind 2010, 15)

The debate about the validity and value of the label ‘dyslexic’ to identify a sub-group of people who have difficulty with aspects of literacy is decades old (Stanovich 1996; Siegel 1999). The debate centres upon the question of whether or not most people who have persistent reading difficulty can be divided into two groups: those for whom difficulty reading is explained by a specific neurological condition (i.e. dyslexia); and those for whom difficulty reading is not explained by a specific neurological condition, but is instead ‘expected’ either because it is commensurate with other ‘abilities’ (i.e. part of a pattern of general learning difficulties), or because there has not been adequate opportunity to learn to read (so-called garden variety poor readers Elliott 2020, 563). There has long existed a belief that the reading difficulties experienced by dyslexic people are special because they are ‘unexpected’ and exist as one part of a ‘spiky’ profile of abilities and difficulties (Stanovich and Stanovich 1997). This conception of dyslexia as a distinct category, connected to ideas of ‘average or above intelligence’, has remained in the public imagination and within some diagnostic practice in the UK (Ryder and Norwich 2018), despite the rejection of the discrepancy model in much of the literature and in assessment guidance (Elliott 2020). Indeed the value of the discrepancy model altogether remains controversial. For example, whilst falling short of

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calling for a return of the discrepancy approach, Snowling and colleagues appear nostalgic for its simplicity and utility (Snowling, Hulme, and Nation 2020).

This paper does not set out to reproduce the scientific debate about the existence or not of a subgroup of 'poor readers' who might be named 'dyslexic'; this has been done thoroughly elsewhere (Elliott and Grigorenko 2014; Snowling, Hulme, and Nation 2020). Rather, it attends to the ways 'dyslexia' can act upon a person's life, not as a neurological difficulty, but as a socially constructed category (Cameron and Nunkoosing 2012; Cameron and Billington 2015a, 2015b; Collinson and Penketh 2010). This research asks how the dyslexia diagnosis (or, indeed, its absence) comes to *mean* in one person's life; how it *acts* and *interacts* with an individual's storied self. This work is an exploration of a single student's experiences: a university student called Beth (not her real name), who received a diagnosis of dyslexia, and then had it taken away. The research explores the ways in which 'dyslexia' can function to legitimise, as well as to provide access to resources. It will also highlight the fragility of legitimation, particularly when self-worth becomes dependent upon the truth of dyslexia as a distinct, neurological, but value-laden, condition, walled off from the other 'kinds' of learning or reading difficulties which are arguably less desirable as explanations.

Dyslexia: the journey so far

Dyslexia, as a recognised category of difficulty with learning, is approximately 120 years old. Since its construction as a distinct and remarkable condition, 'intelligence' has played a consistent role in its definition. Doctor Pringle Morgan's statement in 1896 of 14-year-old Percy as a 'bright and intelligent boy' who has persistent difficulties with reading (Pringle Morgan 1896, 1378) is echoed still in the dyslexia literature, in assessment guidance, and in the public imagination. Dyslexia's association with average or above intelligence has arguably given it an elevated position in the diagnostic hierarchy of learning differences, difficulties and delays. That there is a hierarchy may be a controversial claim, but the existence of books such as 'The dyslexia advantage' (Eide and Eide 2011) certainly do not help to quash this perspective. This book opens (as do I, but for rather different reasons) with the telling inclusion of Norman Geschwind's proclamation of dyslexia as a 'pathology of superiority' (Eide and Eide 2011, xii after Geshwind 2010). Furthermore, the litany of references to dyslexic men of genius (Eide and Eide 2011; and Geshwind 2010, are prime examples) and celebratory advertising of dyslexic people as holding a 'brilliant potential' (e.g. Microsoft 2018) is notable, particularly when compared to the distinct lack of such narratives for 'Learning Disability' or 'Developmental Delay'. 'Dyslexia' as a diagnostic label does more than describe relative difficulties: it can act as a moral currency (Cameron and Billington 2015a), and can hold a certain kind of cachet for certain groups in particular (usually western), neoliberal, cultural contexts (Cameron and Billington 2015b; for an exploration of intersections between dyslexia, race and gender, see Cameron and Greenland 2019).

It is likely that there is a significant portion of the population who have a neurological predisposition to difficulties with what Psychology has called phonological processing (Snowling 1995), processing speed, working memory, automatic learning (Nicolson and Fawcett 2008) or verbal communication (Stackhouse 2006; Cameron 2016). In social contexts where highly regularised forms of reading, writing and speaking are the central pillars in conventional educational ‘success’, these predispositions become particularly visible. It is not in doubt that people diagnosed with dyslexia have significant difficulties with certain kinds of learning and academic performance (Mortimore and Crozier 2006; Cameron 2016), that they battle with disablism (Madriaga 2007), nor that support is experienced as valuable (Pino and Mortari 2014). What is in doubt is the assumption that children and young people who have similar cognitive difficulties and learning experiences, but who do not receive diagnosis of dyslexia or specific learning difficulties, would not equally benefit from both the support and the legitimisation that the dyslexia diagnosis can bring (Elliott and Grigorenko 2014; Stanovich 1996).

Dyslexia in UK higher education

Students in UK higher education who have been identified with Specific Learning Difficulties (SpLDs – subsuming dyslexia) form the largest sub-group of students classed by the Higher Education Statistics Agency (HESA) as disabled, and form just under 6% of student enrolment (with a small proportional year-on-year increase: HESA 2019). Higher education students in the UK who have a diagnosis of SpLDs, including dyslexia, are usually eligible to apply for Disabled Students’ Allowance, which typically funds non-medical support. The student is also eligible for a full Needs Assessment which results in specific recommendations for the student and for the institution. The latter will receive recommendations for putting in place ‘reasonable adjustments’ such as additional time in exams, additional time with a tutor, and alternative assessment; they may also be able to label their assessed work with a (virtual or material) sticker so that the marker is aware they may have specific difficulties with literacy. Reaching a decision upon which adjustments are ‘reasonable’ can be very challenging, both for the institution and for individual departments and assessors (see Cameron et al. 2019); but for any adjustment justified because of a specific learning difficulty like dyslexia, a diagnosis is essential. There are no formal adjustments for students who miss the threshold for diagnosis, or for those who choose not to undergo assessment.

Beth’s journey: a case study

Aims and approach

Beth’s situation came to my attention via my professional networks, and I was already aware anecdotally that her experience was not uncommon in the UK. Beth, like many dyslexic students, was assessed for dyslexic-type characteristics at college in order to justify adjustments to assessments and other ‘access arrangements’ but required a full diagnostic assessment (undertaken by a named educational psychology service external to the university) once in higher education. Because there is a gap in time between arriving at university and arranging for a second assessment to be undertaken, universities can put in place adjustments to ensure the student is participating on a par with other students before the diagnosis is (re)confirmed. Stories of students being told they did not reach the threshold for diagnosis the second time were not unusual. Beth did not reach the threshold for dyslexia diagnosis in the full assessment she received after her first university semester, and as such, all of the adjustments she had received were removed. She was no longer entitled to apply for DSA, nor to make use of specialist tutors, stickers, additional time in exams, and adjustments to assessments. To clarify, the university assumes previous test results, including the less extensive testing undertaken at UK Further Education level, can be used as the justification for the provision of reasonable adjustments at Higher Education up to the point at which the results of the updated tests are received. Tests used at the Further Education level include those made available to qualified specialist teacher-assessors and educational psychologists (such as the Wide Range Achievement Test, WRAT, Pearson Education Ltd 2017) as well as tests anyone may use (such as timed writing exercises, digit span tests, and miscue analysis tests). The Further Education Level testing tends not to include a full I.Q.type test. Tests undertaken in Further Education for access arrangements are often administered by qualified specialist teacher-assessors, whereas assessments in Higher Education can be undertaken by qualified teacher-assessors with an assessment practice certificate (APC) or by educational psychologists (and in some cases by qualified clinical psychologists). In Beth's case, the latter assessment was administered by an educational psychologist.

Beth expressed interest in sharing her experiences with the researcher via her specialist tutor, and so, following ethical approval for the study,[1] was given some information about the study, and consented to participation. I did not know Beth before this research took place, nor did I have any influence over her assessment, diagnosis or academic progression.

The aims of this study were as follows:

- To come as close as possible to understanding what it was like for Beth to 'be' dyslexic for the period during which a quasi-diagnosis had been attached to her
- To come as close as possible to understanding what it was like for Beth not to be dyslexic (whilst experiencing literacy difficulties but before dyslexia was considered a possibility) and to be 'not dyslexic' (after the label was taken away).
- To attend to how 'dyslexia' the absence of 'dyslexia' and 'literacy difficulties' are discursively produced by teachers, family, psychologists and peers, both via Beth's narrative and in diagnostic and related paperwork.
- To consider the relationship between the discursive construction of 'un/intelligence' or 'dis/ability' and constructions of the in/human and sub/human

The longer term objectives of the study are to widen the argument about the neuropsychological existence or not of 'dyslexia', to question the fairness of specialist provision, and to build an understanding of the potential implications of the label for those who are either not-diagnosed dyslexic, or diagnosed not-dyslexic (under which categories Beth has fallen at different points in her life); and also to highlight the ways in which the discursive work of a diagnosis is always tied to social and cultural context which has implications for the globalisation and marketisation of diagnoses like dyslexia (Tomlinson 2012).

Interpretative phenomenological analysis (IPA: Smith, Flower, and Larkin 2009) was chosen as the methodological approach best suited to the first two aims; and an analysis of discourse (after Gee 2005, 2011) was included to address aims three and four. IPA asks, 'what is it like to experience this?': in interview, therefore, the aim is to follow the speaker's experiences and perspectives to enable them to give as much detail as possible about their feelings, their reflections on those feelings, and their sense making of those reflections. The analysis is circular in that it asks the researcher to go round and round from the whole to the parts, from my broad in-a-nutshell interpretations of Beth's feelings back to the detail in specific utterances, and back again. In undertaking discourse analysis (following Gee 2011) I asked questions of the data such as 'how is dyslexia being constructed?', 'why this construction and not that one?', 'what is not being said that could be said?', 'what assumptions about learning, il/literacy, dis/ability/ in/humanity are being reproduced here and via which broader discourses (for example professional psychological discourses)?' (see Gee 2011 for detail on the stages of analysis followed). The analyses are brought together in the following section.

Discussion

'Struggle': being 'one of those'

Before dyslexia appeared as a possibility for Beth, school was not easy for her. For as long as she can remember, she has known there was something 'wrong'. However, it is her recollection of her mum's communication with her school teachers about her 'struggle' which appears to set the scene for later developments in Beth's sense of herself as someone who 'struggles', and after that, as someone who is dyslexic. Beth recall's her mum going 'behind my back' to let her teachers know she struggled, so that they might 'keep an eye' on her, without her knowledge. The way in which Beth recalls this is interesting in that it appears to assume that open naming of 'struggle' with Beth is better avoided, and that any school action which separated Beth out from her peers would be undesirable (three dots indicate removal of my interjections).

> … and my mum went behind my back, not in a bad way, to let my lecturers know that I struggle … so that, I think because when you're young, at school, you don't really want to be in to be in a room separately, do you? 'Cause all your peers like look at you as if like, where's she going?' So she told all my lect, all my er teachers that I er struggle with like grammar and writing and all of that erm and so then they kept an eye on me but without me knowing … but I actually never really knew until like a couple of years later because I used to think I think my English teachers used to spend a bit more time with me, but I never knew

In the extract above, Beth is subject both to her mother and to her teachers' secret, but kindly gaze. Beth constructs this secrecy as positive ('not in a bad way') and the additional attention as preferable to the stigma she perceived may have resulted from separation from her peers at that age. Would Beth's 'struggles' have been constructed as such, or attracted extra attention, had her Mum not let her lecturers 'know'? One interpretation of the desire for secrecy is the knowledge that difficulties with academic literacy have a moral dimension (Gee 2005; Cameron and Billington 2015b), and children who are separated out into special classes, are often those considered to be less 'able', less 'intelligent', less 'good'. 'Struggle' in mainstream educational contexts has come to carry an ideological load beyond its metaphorical conjuring of battle against adversity: it produces a particular passive identity for a student which comes into being in the relations between them and their teachers in particular institutional spaces at particular times (Triplett 2007). 'Struggling' was attached to Beth without her knowledge, and so without her resistance; and was used as justification for careful watching and extra attention.

Beth eventually became aware that she is someone who 'struggles'. Her mum 'always commented' on her grammar and helped her with it; and as well as being observed by teachers, she also began to receive additional support from a 'lady' at school who 'used to take me out'. This lady was from 'a separate department … for children that needed extra support'. However, despite additional support, Beth continued to experience school as highly challenging, and a place where she was notably behind her peers. She talked about going straight from top to bottom set and her grammar being 'all over the place and so it just went a bit wrong'. At this point, dyslexia had not yet been offered as an explanation.

Before dyslexia appeared as a robust explanation for her difficulties, and, indeed, after it disappeared, Beth was left searching for reasons why she has such a hard time. One of the ways she did, and does, this is via self-construction as a particular kind of person, as 'one of them who … '. She was and is variously 'one of them who has to put the effort in'; 'one of them that would be at the table every night'; someone who is 'more of a person when I'm like, I'm more active … kinaesthetic'. Beth also explains:

> if I'm not engaged, you've lost me …
> if I don't understand, I'm gone … .
> if my attention's not grasped, I just lose concentration …

Beth attempts to explain her struggles by attributing them to her character as a certain kind of person, and a certain kind of learner. By doing so, she resists the readily available individualist and meritocratic discourses which link difficulties with reading and writing to lack of intelligence and laziness. Her 'if' clauses and situate the blame for her struggles in the environment around her, rather than in herself. The responsibility in the 'if' clauses above is implicitly handed to the unnamed individuals who might have been more engaging. In the subsequent main clauses, Beth's responsibility is also minimised: someone else loses her; she is 'gone' (subtly different to deciding to leave, as it arguably suggests a sudden disappearance without considered intention); and she 'just' loses concentration – the 'just' indicating a simple and unavoidable occurrence over which she has no control. It is also interesting to hear the discourse of learning styles woven in to her talk via 'kinaesthetic'. Regardless of the validity of their claim to truth, 'learning styles' discourse arguably offered a possibility of escape from being simply 'not very academic'. Furthermore, Beth draws upon the neoliberal discourse of 'hard work' as the counter to the implied moral lack attached to those who struggle with literacy. Her hard work is an important signifier of worth in a system which equates a person's value with their place in the academic hierarchy. Emphasising her hard work: having to put the effort in 'ten times more than other people' is a strong thread in Beth's self sense-making. In the interview conversation, Beth worked hard to construct a positive identity for herself even though she had had a history of being placed on the bottom rungs of the academic ability ladder. But this identity-construction was hard work, compared to the comparative ease of self-understanding and self-rationalisation through use of the soon-to-be-gained dyslexia label.

Legitimation: becoming (almost certainly) dyslexic

Beth's self-sense making shifted as the possibility of dyslexia transformed into a probability and then an assurance as she moved through her A-levels. The first time dyslexia appeared as a possibility from a perceived trustworthy source was when a school teacher read through one of Beth's essays and named dyslexia as a possibility. This appears as a transformatory moment in Beth's story (underline – spoken emphasis):

> 'Cause I'd never really had that, someone <u>actually</u> say to me, 'I've read your assignment, and this is what I'm <u>actually</u> getting from it' because, I, probably, she'd seen multiple of them before she came to me.

The repeated use of emphatic 'actually' in the statement of Beth's above tells both of the relief connected to a direct naming of dyslexia in relation to her work, and to the importance of the point at which the actuality, the truthfulness of her dyslexic identity was made visible to Beth. She had 'never really had that'. Her final line 'because, I, probably, she'd seen multiple of them before she came to me' is discursively validating the professional opinion of the teacher via reference to their extensive experience in reading student assignments and spotting dyslexic-type patterns in them.

At A-level, Beth continued to 'struggle', but this time, with the knowledge of the strong possibility of dyslexia, Beth was given access to additional study support. She was also invited to undertake a 'quickscan' test for dyslexia. This is a very short, online test, not diagnostic, but instead used to indicate whether or not the taker may benefit from further testing. In other words, it is a first step along the route to diagnosis. Interestingly, the quickscan test did not suggest dyslexia, but it did suggest dyspraxia as a possibility. The wording of the quickscan test (as reported in the later test for 'Access Arrangements', see below) was as follows:

> [Beth] completed the quickscan screening on [date]: the resulting profile was not consistent with that normally associated with dyslexia, although there were some indicators normally associated with dyspraxia (these are similar conditions and sometimes overlap or 'co-occur').

In our interview conversation, Beth skated over this wording. She misremembered the suggestion within the quickscan that she was probably not dyslexic, but perhaps dyspraxic; instead she emphasised the outcome of the subsequent Access Arrangements test, which did imply that dyslexia was a strong likelihood.

An 'Access Arrangements' assessment is undertaken with students in further education in order to identify the degree of 'risk' of specific learning difficulties/ dyslexia so that decisions might be made about the provision of learning support and additional time. Although these assessments are not legally accepted as formally diagnostic, they include some of the same tests used in a full diagnostic assessment, and they are considered sufficiently reliable and robust that they are used to justify substantial adjustments to the student's learning environments; and indeed are sufficient for the student to describe themselves as 'dyslexic' with greater confidence. In this report, Beth's difficulties with reading, writing and attention were detailed in a way which formalised the conclusions Beth had drawn following communication with her teacher(s) and mum, beforehand. The construction of Beth as a student with particular difficulties, via the printed word, in a formal report, is arguably very powerful, and plays a role in Beth's experience as someone with difficulties or differences that are being given formal, professional attention; or in other words, legitimised. Importantly, in the second half of the document, the Access Arrangements report presented the results of a number of norm-referenced tests used in the identification of dyslexia (or dyslexia potential). Key amongst these was the Dyslexia Adult Screening test (DAST) (Nicolson and Fawcett 1998) which produces an ‘At Risk Quotient’ or ‘ARQ’ score for dyslexia according to the test-taker’s performance. The conclusions drawn from these test results were worded as follows in the report:

> On the DAST test Beth’s scores indicated some difficulties associated with reading accuracy, speed of working, phonological processing, short-term auditory memory, nonverbal reasoning, spelling and verbal fluency. A score (ARQ) was recorded which demonstrates strong evidence of Risk of dyslexia.

The ‘strong evidence of risk’ discourse persists in the report with the additional conclusion that for eight out of the ten subtests ‘which test skills associated with dyslexia’ Beth was labelled ‘At Risk’. ‘[T]hat’s all the things that I struggle with’ Beth explained in interview; the dyslexia as described in the report appeared to Beth to exactly match her educational experiences and thus made most sense as the correct explanation. Beth referred to the specifics of the test profile, identifying positively with the descriptions of her abilities, for example, in phonological processing. The report made recommendations for significant adjustments to Beth’s learning environment on the basis of this ‘strong evidence of risk’ for dyslexia. These adjustments included 25% extra time in exams, and a separate exam location; alternative assessments; additional time to complete tasks; guidance for teaching staff to teach ‘visually, practically … and by auditory means’. Teachers were also called to ‘be aware of her long standing difficulties with the maintenance of concentration and attention and be prepared to make relevant allowances and adjustments, as necessary’ and ‘[m]arking should take into account any difficulties with spelling, grammar and punctuation, wherever possible … ’. From this point on, as far as Beth was concerned, she was, and always had been, dyslexic. She identified herself with the label, and shared the knowledge with others, assured by the language of the report, and confident in the conclusions which helped her to make sense of her experiences in education thus far.

> Harriet: so, at that point … did you feel that you were dyslexic.
> Beth: yeah, I think I’ve always known, I’ve always thought I was [because] of the way … I’ve struggled with things

The specific adjustments recommended, and the language used to communicate them, are of note: Beth confirmed that many of the recommendations made a significant difference to her educational participation. The language used to make these recommendations presumes the ‘strong evidence of risk’ is equal to a full positive diagnosis, which may, under the 2010 Equality Act (Gov.uk. 2010) constitute a disability, and thus confer institutional obligations for ‘reasonable adjustments’. The language of recommendation is very similar to the language used in recommendations given in Needs Assessments following full, positive diagnostic assessment in dyslexia. It draws upon the language of learner styles and kinds (as Beth does in self-description, see above); it places responsibility for Beth’s learning and fair assessment with the teachers, and asks they 'be prepared to make … allowances' and 'adjustments'. The instruction to 'be prepared' creates a past in which teachers may not have been prepared, or one in which they need not have been prepared. The direction of instruction flows from the author of the report to the educators who are constructed as thus far having not, for example, taught visually, practically, nor by auditory means. For a student, like Beth, who has for years felt unrecognised as academically competent, this wording may be seen as a powerful validation of her experiences, and builds a history in which she has been unfairly penalised for difficulties with grammar and punctuation, narrow teaching methods, insufficient study and exam time, and has not received the recognition for her specific difficulties that she was entitled to. It is understandable that a quasi-diagnosis like this was a very welcome one, when the absence of diagnosis meant the absence of any legitimate explanation for her 'struggles'. There is an unavailability of language with which to talk about difficulties with literacy which does not become attached to talk about 'intelligence', 'merit', 'stupidity', and 'laziness' (see Cameron 2017), as such, what remains is a baffling confusion, or absence of explanation, as highlighted by the extract below.

> Harriet: yeah. (if the test) hadn't of told you that it was something like dyslexia going on, how would you then have felt about it … ?
>
> Beth: I think I would have been really confused in terms of like why I haven't understood, and why I, nothing's improved, 'cause you know you go through the years of school … and you kind of, you get better … and your understanding gets better, but I feel like if my understanding didn't get better I'd be like, why? … Like, am I missing something? … Am I not like taking things in that the lecturers are saying compared to what my friends are understanding? … I wouldn't really understand it, because the effort is always there, but it's never, I've never had to put less effort in, if that makes sense.

At the end here, Beth makes a nod to the discourse around 'effort', perhaps to dismiss 'laziness' as a possible explanation. However, notably missing, understandably, is the hovering-in-the-wings spectre of 'low academic ability'. This possibility is not as easy to caste off as the idea of 'laziness' is. '[A]cademic ability' is socially constructed via school and university grades. It cannot be convincingly self-proclaimed or demonstrated in the way that 'hard work' may be. The historical development of schools and universities as the ultimate deciders, and bestowers of 'cleverness', according to a particular (white, usually male, usually upper middle class) mould can be difficult to articulate as a defence against accusations of 'stupidity' for many outside the field of critical theory. Instead, Beth is left 'really confused', wondering 'why?' and 'Am I missing something?'. Ironically, perhaps, it is another product of that same historical development, psychometric testing, which here promises Beth an escape from the taint of 'low intelligence'. 'Strong evidence of Risk' of dyslexia, in print, following psychological testing, offers Beth a new position (for the moment) apart from any debate about intelligence.

Beth's story shifts at this point from A-level study and 'access' course, to the embarkation of her university degree. As is the case more broadly across higher education in the UK, students must undergo a full diagnostic assessment for specific learning difficulties in order that they may access a set of adjustments to which disabled students may be entitled under the law (Equality Act, Gov.uk. 2010). Full diagnostic assessment involves a larger number of tests and, some may argue, adheres to more systematic administration and rigorous analysis in comparison to the test for Access Arrangements, and must be done by either a specialist teacher or by an educational psychologist. However, as there is often a waiting list to undergo full diagnostic tests, the system in place at Beth's university worked on the assumption that the conclusions of 'strong risk' given in students' Access Arrangements tests were sufficiently predictive of future positive diagnoses that 'reasonable adjustments' could justifiably be put in place prior to diagnostic confirmation. As such, on visiting the Disability Support Services at her university Beth was immediately entered into the disability support system as if she had received a full diagnosis. Beth reported that the disability advisor examined her Access Arrangements report, confirmed there would be no problem, agreed that she clearly was dyslexic, referred her for weekly one-to-one support with a specialist teacher within the institution, and put in place a number of additional adjustments including 25% extra time in exams and 'SpLD' stickers to place upon her assignments. All of this was a great relief to Beth. The need to undertake a confirmatory diagnostic assessment was understood as a formality.

Derogation: losing dyslexia – back to 'one of those'

For most of the first semester of her university course, from the university's perspective as well as her own, Beth was 'dyslexic', and she made as much use as she could of the adjustments provided. Beth found the specialist one-to-one tutorials, delivered by an experienced and highly qualified in-house SpLD tutor, to be particularly useful. Her specialist tutor not only helped her to improve her academic reading and writing, but also to improve her confidence and engagement with her work. Beth took her exams with other dyslexic students in a separate location, and with more time; and here she felt a camaraderie; a belonging; part of a 'we'. By placing 'SpLD stickers' onto her work she received useful and considerate comments upon her writing, minus the feeling of judgement; and she felt less afraid to approach teachers to ask for help when she needed it.

As soon as she completed the full psychological test for dyslexia, Beth had a strong feeling she would not come out as 'dyslexic': she felt she had completed some subtests too quickly, and too well:

> I am quite competitive, and they were games to me … I like matching shapes. I wanted to do it as quick as I can, that's like my type of personality, anyway … I think I just knew that they wouldn't diagnose me after that, so I was feeling a bit, I guess, disappointed in a way, like, should I have done it slower, just to get it, should I have done this? Should I have arrived a bit late?, type of thing.

In this part of the conversation Beth reaches again for a description of her personality type to make sense of what happened, and questions whether she should have been less honest in approaching the test. Her words here suggest she does not feel the test was a good measure of her learning, and she resists its conclusions. Beth questions the assessment validity further via her dismay that the assessor had not included consideration of a piece of her academic writing, where she felt the dyslexia related difficulties would have been obvious:

> I was so confused with it, because noone actually reads your work.
>
> I just said to someone, ‘I’ve brought an assignment, please read it’, and they said they can’t.

After her test results are emailed to her, Beth continues to push back:

> [Y]eah I just got an email like um, here’s your results, it’s come back as er no need for extra support, then I got another email from the gentleman at the dyslexia support, like ‘please bring your (SpLD) stickers back, um, it’s been taken away’, so I emailed back and was like, ‘hi, um, please will you just look an assignment? please?’ and they’re like, ‘no2. and I was like, ‘but how, how can you compare that to this, it’s 2 different things,’ like I know that you have to write, but the style of writing is completely different.

The phrase ‘it’s been taken way’ leaves the taker unnamed and powerful. It is not clear to Beth whom she should appeal to. Beth appeared desperate and perplexed: why were the plentiful examples of her academic writing not considered? What had changed? Beth continued to experience the same literacy difficulties, but they were no longer seen in the same light. Her sympathetic specialist tutor and disability advisor were held back by the same diagnostic line. Beth was asked to hand in her ‘SpLD stickers’ which became symbolic for her as a metaphorical and shameful handing back of her dyslexia; no longer permitted her additional exam time, and her space amongst fellow dyslexic students, she was also robbed of the ‘we’ she had become a part of. Over the next few months, Beth’s grades dropped significantly (by a whole classification – from an upper second-class to a lower second-class degree level) which she considered to be a consequence of her loss of specialist tutorials. Lecturer comments about her grammar returned, this time without the consideration the sticker had helped to ensure.

The language of the psychological report here is notable for two reasons: firstly, the assessor appears to have mis-read the former quasi-diagnostic ‘access arrangements’ report by inaccurately reporting that it stated Beth’s ‘profile is not consistent with dyslexia’. In fact this report stated that Beth was at ‘stong risk’ for dyslexia. The ‘not consistent with dyslexia’ line was reported in an earlier, and much less in-depth quickscan questionnaire. It is possible that this mis-reading informed the assessor’s interpretation to some degree. Secondly, the assessor makes repeated reference to Beth’s flat cognitive profile, and to the lack of discrepancy between Beth’s scores on literacy-specific tests and scores for overall ‘ability’, strongly implying that the out-of-date discrepancy criteria for diagnosis were applied in Beth’s assessment. Had Beth’s overall ‘I.Q.’ score, or at least sub scores for ‘verbal intelligence’ or ‘fluid intelligence’ been significantly higher, it is possible that the assessor would have diagnosed dyslexia because this would have displayed the apparently necessary ‘spiky profile’ or discrepancy. This highlights the strange and manifestly unjust probability that the students with higher IQs may be likely to receive specialist support than those with lower I.Q.s, despite similar difficulties with literacy.

Of all the outcomes being diagnosed not-dyslexic catalysed, one of the most difficult for Beth to deal with was the return of the question ‘why?’. Why does she finds academic work, specifically reading and writing, so hard? She had not only lost access to a legitimising way of understanding herself, but she had also lost the explanation she had been using to help others understand her difficulties: her mum, her friends, her teachers and her examiners. She no longer felt it was easy approaching others to talk about it:

> I feel like I've got to explain to people why my writing's so bad … now when I say to someone, oh do you mind reading this for me? and it's, it doesn't read right, I feel like then I've got to explain myself as to why I write like that, if that makes sense … cos I don't want people to think … that's really bad for someone that's at university, if that makes sense?

> I guess, it's just everyone commenting, like 'oh yeah, you are dyslexic', from school to now, it's been, how many years is that? Like 15 plus years of being … of saying that, and then it's gone, after that amount of time.

Beth no longer knew quite how to explain to others why she had difficulties; and neither did the university staff know now how to communicate the reasons for Beth's difficulties to one another. There appeared for all to be a return to the rather vague language of 'struggle': '[M]y um module coordinator said she would send an email round to lecturers just to let them know I do struggle', Beth explained. I wondered when re-reading this exactly how the tutor would have phrased this without being able to draw upon 'dyslexia' or 'possible dyslexia'. I wonder at the delicate discursive dance which must be played to avoid the implication that Beth is 'not very bright' or 'a bit lazy' or one of those 'not suited to university' (see Cameron 2017). And, as Beth herself pointed out, there is little lecturers would have been able to do to support her without being open to accusations of unfair treatment to those *with* a formal diagnosis, to those with a *potential* diagnosis, and to those *without* (Cameron et al. 2019).

Beth now felt that she had to 'warn' others that her work might not be very good, and ask them not to 'judge' her. In listening to Beth's use of these words it appeared that her difficulties, once understood, were now embarrassing and a potential source of shame. She no longer had permission to use the same words to explain her 'self'. She resigned herself to 'just having to be an even harder worker' who would describe herself once again as just 'one of those'.

Beth's resistance to the judgement of the diagnostic assessment was present in her reference to the opinions of other professionals and educators who recognised Beth as dyslexic: 'all of my English teachers have commented, saying you have got dyslexic traits' and English teachers 'are the ones that can pick up dyslexia from assignments and things like that'. Beth continued:

> I would say the teachers are right, because they know me, … and if they, and if, from all them years, nothing has changed and I'm still getting the same comments, that's who I believe, because they've read my work, and they understand my process of writing things, and then for that, one, an hour assessment, I'm like, you don't know my kind of writing, you don't know my thinking, you just, it's just, I went on what, I believe what my teachers and my family say, but I guess with teachers, who could compare you to like a whole class of people and think ok these students are at this level and compare their writing to mine …

However, Beth's resistance was not strong enough to overcome submission to the word of the psychologist and the weight of the 'science' it carries. In other words, although she was able to question the 'truth' of the diagnosis when asked directly in the research interview, she was unable to continue to openly label herself dyslexic. The power of the psychologist and the psychological report is not easily broken, and this is particularly true when it was that same 'science' that she had been obliged to invest in when first 'tested'. Beth says later in the conversation that she feels it would have been better if she had not undergone diagnostic assessment, then she would have been able to refer to dyslexia as a potentiality. When I interviewed her, it was not only the dyslexia she had had which had been taken but also any future possibility of dyslexia, and its accompanying ‘forgiveness’.

Conclusions

In this paper, I have interpreted Beth’s story through my own experience as a specialist teacher and, latterly, as an academic in the field, using methodological approaches grounded in social constructionist research and practice. The case study is limited in its narrow focus and small scale. My belief that Beth’s story is a common one is as yet anecdotal; further research which explores how wide spread experiences like Beth’s are is needed. The findings should also be considered as a starting point for further discussion on practice and intervention for children and young people which balances science with sociology, and which centres inclusion for marginalised children and young people. There are a number of possible explanations for the change in professional opinion Beth received: perhaps she had become better at covering her difficulties over time, or perhaps there were errors made in assessment at different stages. Whatever the reasons for a changing diagnosis, the social and educational impact of having a label removed was not taken into account. The concerns raised in this case study are thus likely to have relevance across educational contexts which make use of diagnosis as a key gatekeeping tool.

I agree with Snowling, Hulme, and Nation (2020) that ‘elaborate comprehensive assessments are not required to identify a child as in need of reading intervention’ (508) and that persistent reading and writing difficulties can be indicative of other difficulties and differences in learning which should be investigated. However, I disagree with their perspective that the label of dyslexia has become too broadly applied. Instead, I argue this paper supports a further loosening of the label ‘dyslexia’ so that it is less closely guarded, and accessible to all who experience persistent difficulties with reading and writing (despite engagement with instruction). The conclusions of this paper echo those of an exploration of ‘specific language impairment (SLI)’ (Reilly et al. 2014) as a diagnostic category, which has been similarly dogged by discrepancy debates and arguments about diagnostic cut off points. The authors argue for a dropping of exclusionary criteria and for far greater recognition of the ways in which services and institutions respond to diagnosis in practice (Reilly et al. 2014, 431). I argue for the same in relation to dyslexia.

A scientific approach to the discussion of access to particular labels such as dyslexia is undoubtedly hugely important, but this science should be considered in tandem with a sociological understanding of the way labels come to act on and in people’s lives. An intersectional approach is vital here, particularly where constructions of race intersect with concepts of dis/ability (Leonardo and Broderick 2011; Annamma, Connor, and Ferri 2013). In education, overly narrow access to legitimising labels can support a hierarchy of human value, which, as I hope this paper has shown, is both harmful, and avoidable. In other words, a redrawing of the educational landscape to foreground an understanding of special educational needs as socially constructed and relational may enable some escape from the potential pitfalls of a solely scientific understanding of difference and distress (Cameron 2020).

Note

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