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## Studying Medicine with Dyslexia: A Collaborative Autoethnography

Sebastian C.K. Shaw

*Brighton and Sussex Medical School, sebastian.shaw@doctors.org.uk*

John L. Anderson

*Brighton and Sussex Medical School, j.anderson@bsms.ac.uk*

Alec J. Grant

*University of Brighton, alecgrant32@yahoo.co.uk*

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## Studying Medicine with Dyslexia: A Collaborative Autoethnography

### Abstract

The topic of this article is the experience of the impact of dyslexia on medical studies, explored using a collaborative autoethnographic methodological approach. The study was prompted by an initial and ongoing full search of the literature, which revealed an absence of autoethnographic research into the experiences of medical students with dyslexia. It has four aims: to provide an in-depth, multi-layered account of the impact of dyslexia on a UK undergraduate medical student; to help other students and academic support staff in similar situations; to outline improvements that could be made to medical and other educational curricula and examination procedures, globally; finally, to call for further qualitative research to test out, possibly enhance, and qualify the cultural transferability of our study.

### Keywords

Dyslexia, Medical Students, Collaborative Autoethnography, Undergraduate Medical Education, Medical Curriculum

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## Studying Medicine with Dyslexia: A Collaborative Autoethnography

Sebastian C. K. Shaw and John L. Anderson  
Brighton and Sussex Medical School, Brighton, UK

Alec J. Grant  
University of Brighton, Brighton, UK

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**28<sup>th</sup> October 2014**

**John:** *How do you see yourself?*

**Seb:** *I think... when I'm supported appropriately... I think I'm pretty good. I tend to think outside the box. I can come up with answers to things that other people can't... because I'm able to verbally communicate and think things through, and have my methodical structure... But I think, if I'm not supported... If I wasn't supported, I would have been long gone by now...*

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### **A Brief Introduction to Dyslexia**

Dyslexia is a well-known Specific Learning Difficulty (SpLD) that impairs people's abilities around reading texts despite them having normal intelligence (National Institute of Neurological Disorders and Stroke, 2011). There is no universal consensus in defining dyslexia; however, there is agreement that it is a learning difficulty that primarily affects the skills involved in spelling, and accurate and fluent word reading. Best conceptualised as occurring in terms of a continuum rather than as a distinct category of learning difficulties, there seems to be an absence of clear cut-off points in the demarcation of dyslexia (British Medical Association, 2009). Its prevalence among medical students was given by the British Medical Association (2009) as 1.7%.

Our review of the existing international literature found five research articles about medical students with dyslexia. Two studies compared exam scores of those with and without dyslexia (McKendree & Snowling 2011; Ricketts et al., 2010). Another focused on the

diagnostic rates of medical students and physicians referred for assessment (Banks et al., 1995). One case study discussed a medical student referred to its author for dyslexia diagnostic assessment (Guyer, 1988), and the final article focused on dyslexic medical students' performance in written compared with clinical performance examinations (Gibson & Leinster, 2011). No work was found that described the subjective lived-experiences of medical students with dyslexia, and so our current study addresses this significant gap in the literature.

### **Method**

In the context of an absence of autoethnographic research in this topic area, we employed a multi-stage collaborative autoethnographic approach in the preparation of this article. First, Sebastian (Seb), a UK student with dyslexia in his penultimate year of studying medicine, wrote a 3000 word autobiographical account of his experiences of the impact of dyslexia on him and his studies, in September 2014. He re-called those experiences from memory as a medical student over the previous four years, from first applying to enter undergraduate medicine through to his clinical years of study.

His initial purpose in writing this account was to complement his MSc dissertation study, which used interpretive phenomenological methodology to explore the topic of dyslexia impacting on medical studies more generally. On the basis of the account, John, his dissertation supervisor, then explored these experiences with him further in an in-depth recorded interview, which was transcribed verbatim (quotations from this interview appear throughout this article in italicised type, either as a dialogic exchange between John and Seb or as a response from Seb taken out of its dialogic context for narrative impact).

Then, Seb and John subjected the autobiographical account and interview transcripts to thematic content analysis. This revealed the following theme clusters: My Dyslexia; Coping Strategies; Awareness and Realization; Diagnosis; Emotional Impact; Impact on Studies and Career; and Unexpected Strengths. They subsequently added thematic narrative content to the emerging manuscript over six increasingly refined drafts, on the basis of supplementary discussions between them, which took place over a year, from October 2014 to November 2015.

John then approach Alec, because he was the most experienced autoethnographer, in early February 2016. Alec agreed to work with the manuscript-in-progress, to further develop, shape and expand it through regular dialogue with Seb and John. Alec's aims were to help Seb expand more on the emerging themes, in emotional and embodied rather than overly-rational ways. Alec also took overall responsibility to shape the structure of the article and Seb's narrative (and to a lesser extent John's), which is organised in the theme clusters. Finally, he aimed to help Seb develop the levels of reflexivity, cultural critique and thick description in his narrative; and position the study in its critically reflexive autoethnographic genre context.

We shared the developing manuscript regularly among all of us. This resulted in successive, developing iterations, to the point at which we agreed that it was ready to submit for peer review for publication.

### **Ethical Issues**

We have shown above how we observed relational ethical principles In the methods section above. Procedural ethical approval from the Brighton and Sussex Medical School Research Governance and Ethics Committee was secured for the study before its commencement in 2014.

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### **Seb**

I have always struggled with reading and writing, from a young age. For example, at the age of five, when starting Year 1 of Primary School, I was the only person in my school year who could not read. My grandmother helped me to overcome this hurdle by visualising the process for me. What I mean by this is simple: she taught me to see images within the words. For example, the first word that learnt to read was "look," because it had two eyes in the middle of the word, looking out of the page at me.

As the years progressed, I became increasingly good at school work. Whilst I always disliked reading (largely due to being so slow at it), I became accustomed to achieving the highest grades in all examinations. This continued unchallenged until I reached the age of sixteen, when I was revising for my GCSE (the UK's General Certificate of Secondary Education) exams. I found that I would struggle to understand what the exam questions were asking of me. Because of this, I would write information that was correct but did not answer the particular question. I found that this, along with a strong dislike of reading, lowered my grades relative to those I had expected.

When I progressed onto sixth form college at the age of sixteen (where UK students are prepared for "A" or Advance Level examinations, necessary for applying for entry to university), I found myself having exactly the same problem within exams. This resulted in me having to engage in multiple retakes to get the three A levels required to get into Medical School. To this day, that is the hardest I have had to work - fighting to overcome my, as then, undiagnosed dyslexia.

I did, thankfully, achieve the grades required to get into medical school. I then found myself struggling, but surviving. When I was diagnosed with dyslexia in my second year, this came as a big relief.

I successfully completed my "Academic Years" - the first two years at Medical School, which are primarily spent in a lecture theatre learning theory. I subsequently progressed into my "Clinical Years" - years three, four and five. In these years, medical students are primarily based within clinical settings - learning on the job. Between the third and fourth year, I was allowed to take a year away from the medical degree to study a Master of Science degree (MSc) in Medical Education (September 2014-August 2015).

During this year, I came into my own. I found a supportive supervisor (John), whom I met on the Research Methods module in my MSc. His teaching style resonated with me and I experienced him as engaging and facilitating in a way no other tutor had been. I asked him to supervise my dissertation and he agreed. I felt that I had found my current and future place within my profession - as a researcher and educator. This year was a challenge, but also highly enjoyable and rewarding. It consisted of a 16,000 word phenomenological research dissertation ("The experiences of medical students with dyslexia") and four 3,000 word essays. Due to adequate support, I found this year significantly less challenging than the more general stress of medical school, despite the heavy reliance on essays and written work.

Following my MSc, I returned to medical school and, in June 2016, am now my last month of my fourth year of studies. I will then progress into my final year of my medical degree in September, and on into the working world from August 2017.

### **John**

When I met Seb on the Research Methods module I teach, he impressed me with his open-ness and enthusiasm. In retrospect, I also probably responded to a vulnerability which hooked into the Rescuer in me (Stewart et al., 2012). There was a meeting of minds. I liked

Seb's ideas and introduced him to appropriate approaches. I am a fan of Interpretive Phenomenology and Autoethnography (which Alec introduced me to).

Working with Seb is like being on a roller coaster. I was bombarded by ideas, projects and drafts. The autoethnographic focus grew out of the deep reflexive aspect of the phenomenological study – it was a natural extension of it and Seb took to it immediately. Because of my training in Transactional Analysis psychotherapy, I felt confident to help Seb deal with any demons from the past and refer him to Student Support if necessary – it wasn't.

My suggestion to conduct an interview with Seb to facilitate the introspective process was probably informed by both the researcher and the therapist in me.

It was both fascinating and harrowing – for both of us. Seb has lived with his dyslexia long enough to have come to terms with it – but I had not. I found myself getting enraged on his behalf at some of the ways he had been dealt with by “the system” and by other people. The academic setting provided a defence – more tissues would have been necessary in therapy! It is difficult not to get caught up in the intensity of the experiences Seb was re-visiting. I was aware that I could escape by letting him get on with his tasks, but maintained close contact during the study. We met several times each week. I believe that there was a high degree of therapeutic benefit for Seb as he went through the process of expressing and documenting his experiences from the past.

I was crucially aware of the potential conflicts in my role as we worked very closely together through this journey. Was I teacher, mentor, therapist, colleague, father-figure, or friend? All of these, I guess. It was a very intimate process which demanded an engagement in which I believe we truly fulfilled Rogers' “core conditions” of honesty and open-ness, positive regard, and empathic understanding – on both our parts (Rogers, 1967) I saw Seb grow and change as a person. He responded to events and other people in a more genuinely “Adult” way (Stewart et al., 2012)). He seemed to me to grow in confidence in relationships with other people. I maintained appropriate professional boundaries – these, to me, do not mean being cold and aloof, but we kept to task. We only met in the office, and I did not attempt to therapise Seb! Now I warmly view him as a protégé, a colleague, and a friend.

The work was demanding for both of us and we each had to deal in our own way with the emotional and academic issues involved. We supported each other.

### Alec

I was very pleased when John approached me to ask if I would join the author team to craft this autoethnography. I have co-researched aspects of social and cultural life using the autoethnographic approach over the last two decades. Autoethnography is a contemporary qualitative research approach that combines first person autobiography with cultural critique, given that the researcher/s and the researched are normally the same people (Grant et al., 2013; Holman Jones et al., 2013).

A longstanding attraction of the approach for me is that it demands unusually rigorous, multi-layered levels of strong researcher reflexivity (Grant et al., 2013; Sparkes, in press; Turner et al., in press). “Strong reflexivity” can be understood as a deeper, more explicit and obviously self-consciously displayed form of the level of reflexivity conventionally associated with ethnographic and other qualitative research approaches (Anderson & Glass-Coffin, 2013).

The conventional use of reflexivity in qualitative inquiry describes the reciprocal ways in which knowledge of, and experiences among, participants is employed to expand the self-knowledge of researchers, in turn conveyed in their writing. In this context, the identities of participants and researchers are often regarded as coherent, complete and faithfully captured and represented. In contrast, in my own work and the work of many other autoethnographers, particularly those with critical and poststructural paradigm leanings (Grant et al., 2013;

Sparkes, in press), the use of strong reflexivity undermines assumptions of representational and identity coherence and completeness. (These abstract concepts will be clarified in more detail below).

The production of strong reflexivity can be achieved in a number of ways. A common strategy, and one used by Seb in this study, is to describe and reflect on one's shifting and emerging experiences of self-in-culture at different points in time and place, not necessarily in chronological sequence. Seb does so while using "thick description," to vividly tell description, context-, detail- and emotion-rich stories as a series of illustrative vignettes, common to the practices of autoethnographic writing (see e.g., Holman Jones et al., 2013; Short et al., 2013).

Along with others, I have argued recently that autoethnography informed by strong reflexivity achieves its critical edge through such challenging of mainstream, normative qualitative research assumptions and practices (Grant et al., 2013; Kincheloe & McLaren, 2008; Sparkes, in press). The criticality of such work is further underscored in the assumption that co-researcher subjectivities are always intimately connected with, and often pitted against, dominant cultural norms.

This facilitates the inter-subjective development of collaborative autoethnographies, such as this one, which are based on each author's relevant and accumulated lived experiences. These experiences are valued, privileged and explicitly connected with cultural practices (Grant et al., 2013; Sparkes, in press). In this context, I have defined "culture" as broadly referring to mundane and taken-for-granted, time- and place-specific socially constructed meanings and practices (Grant et al., 2013).

From a poststructural perspective, the production of culture is immanent in life and relationships because people are simultaneously constituted by and constitute culture, and can never occupy a position outside of it. Cultural production thus constitutes a perpetually enacted performance of, often mutually contradictory, discourses – time and place bound meanings and related practices – within which people are simultaneously inscribed and help shape in dynamic and nuanced ways. In writing, speaking and doing, our interpersonal exchanges accord us subject positions within these discourses, and these serve to guide the moral direction of our individual and relational lives (Davies & Harré, 1990; Harré, 1991). In this context, all three of us have written this collaborative autoethnography in keeping with what we regard as the moral purpose of our lives. For Seb and John, this has been to find a way through the problems of dyslexia, to benefit them as student and tutor respectively, consolidate and deepen their working relationship, and to help current and future dyslexic medical and other students. For me, it is to use my autoethnographic expertise helpfully in this endeavour.

As critically engaged writing, autoethnographic work aims to unite its authors with its readers in the following ways: in challenging received, dominant, and often insufficiently unscrutinised aspects of culture, autoethnographers compel responses from their audiences (Holman Jones et al., 2013). These shifting and dynamically developing writer provocations and reader responses thus extend the dialogue around the autoethnographic topic, as a perpetually open-ended conversation.

Since autoethnographic inquiry is a vitally important resource for tackling insufficiently scrutinised aspects of cultural life, it is eminently suited to an in-depth inquiry into the lived experience of a student of medicine who has dyslexic problems. In this regard, a key purpose of our study is to speak truth to power (Holman Jones et al., 2013; Sparkes, in press) through displaying Seb's dyslexic subjectivity in thematic narrative form. By this means, and with a focus on one site of UK undergraduate medical education, we hope to make a small but significant contribution to troubling the silence that normally attends such a hidden and sensitive cultural topic.

## Seb's Themes

### My Dyslexia

**28<sup>th</sup> October 2014**

**John:** *OK. I'm going to ask you to complete a sentence. "Dyslexia is..."*

**Seb:** *Quite an integral part of me... that causes me to struggle with academia... but... allows me to make use of diagrams, and unexpected methods... to let me flourish in other areas...*

**2<sup>nd</sup> March 2016**

On several occasions in my medical degree, I have been left feeling stupid, slow, stressed... and eventually depressed. Throughout this time however, the educators and support staff at my university have been incredibly helpful. Some have even acted as rocks for me when times were hard.

When you are struggling with academic requirements, your self-image and your very brain, it is easy to feel like the world is against you. Throughout my first three years at medical school, I often found myself low or even crying about this. I felt that those around me were fed up with me, thought I was inept or, even, hated me. My continuing isolation (to keep up with work) fed this situation, separating me from my peers. This remains a struggle for me to this day. My segregation from my peers has never been greater. Having focused so hard on survival and keeping up with work, I find myself able to talk to less than 10% of my cohort. For this reason, I often look at university timetables and panic when I see that I will be "alone," with people I never took the time to get to know or maintain friendships with. Their collegiate and social groups have already formed and solidified.

For this reason, in a roundabout way, my dyslexia has led to me being "the grey man" - the person in the room who people don't really know, or perhaps don't really like. While this upsets me greatly, I find my studies are becoming increasingly challenging as final exams approach. This means that I cannot rectify the consequences of my work-life balance mistakes made in the earlier years. It is never the right moment, as there is never complete "down time."

Due to a troubled home life, I also find added stresses from current family situations regularly impacting and adding to my emotional workload. Throughout my time at the medical school, the Student Support department has kept me level headed and allowed me to see the sense in carrying on, in graduating. They have been there for me when I was struggling to confide in others about my academic struggles.

Unfortunately, this has not always been the case with regard to clinicians or allied health professionals. Due to the apprenticeship-style education of healthcare, we are regularly attached to healthcare professionals who have nothing to do with the university or education. They are simply doctors, nurses, pharmacists or other healthcare workers who are asked to teach us on top of their already manic schedules. Whilst the majority are beyond lovely and helpful, some may not be. This is a difficult situation to tackle, as medicine is, at its very core, an apprenticeship.

In retrospect, I am now confident that my dyslexia played a part in the development of these feelings. In the following few paragraphs, I outline and comment on two examples – to allow you, the reader, to see, and perhaps feel, things from my point of view.



**18<sup>th</sup> April 2012**

It's a warm spring morning in sunny Sussex, in the south of England. I am sitting at a long table in the large-windowed medical school foyer. My friends – fellow medical students – are with me and we are anxiously awaiting our exam results from the last term to be emailed to us. I am feeling confident for the first time, but do not want to get my hopes up too much. The last term focused on endocrinology, a subject that I was especially interested in, so I had found it much easier to learn. I am hoping to (finally) be “above average” on this exam.

The email arrives. I read that my grade is “B” and am excited. We discuss our results – slowly exploring the willingness of the others to impart more information. We all leave this conversation feeling fair happy with ourselves. Getting a “B” is not bad, I think to myself. Later, and now alone, I glance back down at the email on my phone to read the additional information to see that, like usual, I fall well below average. My heart sinks and my stomach tightens... it's happened again... My best simply wasn't good enough... “below average,” despite working for weeks longer than many of my peers. I know that the longer this pattern goes uninterrupted by success experiences the more I have to fight an internal battle to not let negative thoughts take-over and demotivate me entirely. These go through my mind over and over, and I obsess and worry about what this will mean for my future career and my overall grade decile profile (this term refers to the ten, percentage range categories, where the first decile contains students graded overall in the top 10%, with the tenth graded in the bottom 10%).

**26<sup>th</sup> July 2015**

It is late at night and I am sitting alone in my grandmother's countryside kitchen, preparing to move back to medical school, working on my laptop. I am flicking through the “Virtual Learning Environment” – an online website used in my university, where students can access lecture content, module information and general course information – when I stumble across an un-advertised questionnaire in my announcements. This is in the form of a Word document template – to be downloaded, filled-out and emailed to our exams office. I notice that it is about medical students with SpLDs, but also aimed at those without them. Naturally, this intrigues me, so I download the document to have a read. Downloading... Opening... Question one asks whether or not I have a Learning Support Plan (which is essential if, like me, you have an SpLD). It invites me to continue, regardless of my answer... Question two asks if I feel that students given support in practical exams might have an advantage over other students... At this stage I begin to feel uneasy, maybe even hurt. I feel winded in my stomach and my face drops. How can someone who is at a natural disadvantage, who is simply supported, have an “advantage”? Nevertheless, I read on... Question 3 asks me if I think that students with an agreed learning support plan should have adjustments made to practical exams. At this point I despair. All of these questions in combination evoke in me a sense of utter betrayal by those who would claim to support us. After all, surely they cannot revoke all support on the grounds that students without SpLDs do not like us receiving it – through jealousy, innocent ignorance or any range of reasons.

People all have preconceptions and fantasies about dyslexia. With *my* dyslexia, my spelling is often as accurate as anyone else's. My weaknesses can be summarised within four domains: slow reading speed; slow writing speed; difficulty in assimilating large chunks of verbal information; and an inability to retain written information if attempting to read quickly.

If I read something slowly I'll take it in, but it's *insanely* slow. If you want me to read out loud, I can read at the speed of a normal person... If you ask me what I just read, when I read at that speed, I wouldn't be able to tell you if it was about astrophysics or gardening.

I have, however, one blessing – I am, thankfully, a very fast typist.

## Coping Strategies

I have been able to compensate by adding my fast typing to the additional ways of working I have serendipitously discovered, which I use to bolster my own coping strategies, and which I rely heavily on to this day. These includes techniques such as talking concepts through with teachers on a 1-on-1 basis, driven by an absolute need to know the grounds on which information presented to me was factual. In doing this, I was able to make use of my non-written learning skills to gain a deeper underpinning of the knowledge. If I can create logical explanations and chains within my head, I can make myself retain the information.

People with dyslexia often develop other abilities in much the same way as I have done (Guyer, 1988; Rosebraugh, 2000). I felt challenged to the limit by the demanding environment of medical school. On the basis of my anecdotal impressions, I believe that such constant pressure pushes us dyslexic medical students to adapt and develop these compensatory skills at a significantly faster pace compared with dyslexic students in less-pressured degree programmes. After my first week I knew there was too much content, and I'd never been taught using PowerPoint before. I always had a teacher with a whiteboard and a marker pen. That's how I was taught and that's how I learn better, now, still – with diagrams, and with teachers who can talk you through things.

Throughout my time at primary and secondary school, teachers would stand in front of the class and write on a whiteboard as they explained information. I experienced this as helpful, and not resulting in me wasting time working out where we were had they been using slide presentations. I also found the adaptability of the more traditional whiteboard method beneficial in enabling visually-assisted additional time for discussion. Since commencing university, I have noticed that almost every single large-group teaching session in the past five years has consisted of a PowerPoint with overlying discussion. Generally speaking, this is simple, cheap and gets the job done. In contrast to this, however, I teach a research methods lecture using no PowerPoint at all. This is consistently praised in my feedback – medical student learners are even shocked by it, reflected in the comment "wow! No PowerPoint!"

One of the strategies I used during my early years at medical school was to create a "backbone" of knowledge to attach information to (Figure 1, below). The academic modules contained a daunting quantity of relatively abstract information to memorise. I handled this by learning the relevant "core drugs" used to treat the anatomical systems in question – creating my "*backbone*." I then used this structure to attach clinical conditions, and then I attached symptoms and diagnostic tests relevant to those conditions.

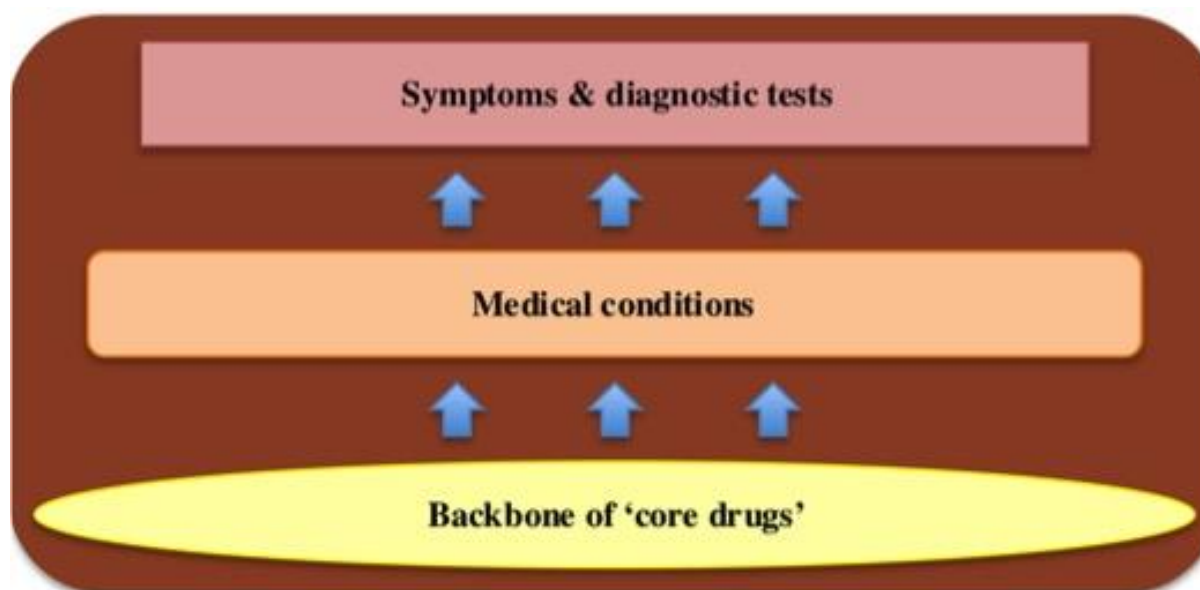


Figure 1: SS's method for learning systems-based, academic medicine.

By doing this, I managed to assimilate sufficient information during the non-clinical years of the course... and survive!

### Awareness and Realization

My family background was far from normal. I was taken into care by the age of four. After leaving care, I was called to interview by every medical school I applied to – contrary to what I believe is the norm. I have constantly been told over the years that it is rare to see someone from that type of background applying to university at all, let alone medical school.

Because of the need for UK universities to fill their quota of positive discrimination tick boxes, and because competition for university places is so great, most applicants from settled, non-separated families wouldn't get interviewed by more than one university. These interviews allowed me to show my *passion* for medicine without the daunting constraints of doing so in written form. Had it not been for my troubled childhood, I might not be here today.

Having had to retake many exams in the past, I had always known there was *something* holding me back. I realise this is often the case with dyslexic peers, many of whom, like me, were diagnosed during the medical course. As a secondary school student, I used to regularly misunderstand questions and subsequently performed poorly in exams. I had, however, never explored or considered the reason for this. This was particularly evident within my A-Level Mathematics exam, where my mathematic ability was sound, but unfortunately did not match what questions were asking of me.

I would put flawless mathematics, that wasn't in the slightest related to what the question wanted.

I strategically chose to apply to medical schools with an entrance assessment that I hoped would not highlight my poor literary skills. I chose medical schools making use of the UK Clinical Aptitude Test (UKCAT). This is a multiple choice on-line test, which was different from other tests that might require me to write answers or even essay sections. Although I performed weakly within the literacy section, my other strengths allowed me to achieve a reasonable score overall. I had a particular love for biology. This spurred me to keep

working and my success in this topic led to me applying to medical school. (In the UK, medical undergraduate studies do not require applicants to have a prior first degree.)

## Diagnosis

In my first week at medical school, a member of the Student Support department gave a brief talk on the symptoms of dyslexia and other SpLDs (Specific Learning Difficulties), and explained that it may be common for people to get as far as medical school without knowing they had these difficulties. We were told that these difficulties were common among medical students, and it was suggested that if any of us felt that we might have them we should contact the Student Support department and not feel ashamed to ask for help. Subsequently, I self-referred to them, after realising that the symptoms list they described largely applied to me. They arranged for me to be screened and subsequently tested for dyslexia.

When first tested, the educational psychologist who tried to diagnose me told me that it was unclear whether or not I was dyslexic. She said: “you are *so* borderline, I need to think. I don’t know what to do with your results”... She looked at me and asked “do you want to be dyslexic?” despite knowing I was desperate for support, because I was finding myself falling behind more and more with the sheer content that I was expected to be learning. I said “no, I don’t think I need the stigma”... She then went away for a few weeks and this left me kind of stewing.

This neutral result left me confused. The Disability and Dyslexia Team and the university interpreted this to mean that I was not dyslexic. This left me without the answers I needed, which were if I had dyslexia, or whether it was just me – stupid, thick and slow, and beyond help. I challenged the result. The second assessor confirmed I was “very dyslexic” and, following my formal diagnosis on the 26<sup>th</sup> July 2012, I was given explanations to help me understand my problems and how they might differ from what is considered normal for people without dyslexia.

## Emotional Impact

I decided “I absolutely don’t want to be dyslexic.” I was sort of afraid of the stigma and what people would think...

The thought of being diagnosed with a condition that is not immediately visible to others was abhorrent. I was concerned that people, even friends, might think less of me if they found this out.

I might not necessarily want you to be my doctor if you can’t read the drug chart.

My uncle said this to me in a light-hearted joking manner at one point, but it made me worry that others might genuinely feel that way about me. It was not until I thought logically about the situation that I appreciated the benefit of the diagnosis. I realised that, with or without the label, the problem would still be there, but, with the label, I could receive appropriate support to help me deal with it head-on.

...But when I actually got the diagnosis... I think I was relieved... I knew that I wasn’t just stupid.

A strong theme that runs through my story – as can be seen from the preceding text – is that of negative effect, exemplified by expressions such as “depressed,” “disadvantaged,”

“disappointing,” “disheartened,” “hopelessness,” etc. This is accompanied by my sensitivity to stigma – being suspected as or identified as somewhat “freaky” by others.

**25<sup>th</sup> May 2011**

It is the second year of my medical degree, and I am sitting at my desk trying to revise biochemistry and metabolic medicine – definitely not the part of medicine that I eagerly signed up for. This consists of rote learning long cycles and flowcharts of complicated words and letters – “beta hydroxybutarate,” for example. These are completely mind-boggling and are making me extremely frustrated with myself.

As I sit reading the words, one syllable at a time, I get more and more annoyed. I have to put so much time into just reading each word that I lose sight of the bigger task at hand. At the same time, I hear my flatmates leave to go shopping in town. They ask me to go with them, but I can’t – I’m not efficient enough. As this progresses for several hours, I become extremely upset and just want to crawl into my bed, switch the lights off and cry as a result of my ineptitude, my stupidity.

### **Impact on Studies and Career**

I wouldn’t change where, or what I study for the world. We have a small year size, a modular-based structure and follow a systems-based programme. A modular-based structure means that we are assessed internally within modules, or discrete topic-specific courses, throughout the year, rather than in exams at the end of a year. In a systems-based programme students learn all about the system in question (for example the cardiovascular system), in terms of its anatomy, physiology, associated clinical conditions and diagnostic and treatment procedures. This contrasts with programmes where students learn all the anatomy of the body at once, then all the physiology, then all the conditions, diagnoses and treatments. So a systems-based syllabus is more integrated, with students learning a little of everything at once, to match a specific part or system of the body. All this has made studying here a wonderful experience. The small year size, combined with the approachable demeanour of the staff, has meant that I have rarely felt lost.

I found that the early clinical integration within my course allowed me to continue to build upon my compensatory learning strategies. I honestly believe that, without the regular exposure to clinicians in a clinical setting, I would not have been able to complete the first two years. I used my monthly visits to a General Practitioner (GP) surgery to talk through the basic concepts of my academic modules with the GP – much like at school, with teachers who knew me personally and had the time to talk things through with me. This provides me with enough of a clinical perspective and overview to be able to slowly build my other learning around this.

At the point at which I was formally diagnosed with dyslexia, I was a full year into my degree – an essay-heavy year, full of low scores and disappointing grades.

I am really decompensating. Things are going to hell.

I was disheartened to hear that there was nothing anyone could do to compensate for my uncharacteristically poor grades in this year. This made me feel helpless, but what was done was done. It is only through sheer determination that I keep working as hard as I do. Otherwise, I would let this upset me even more and likely give up and quit while I am behind.

I knew this would always depress my overall position within my year-group and disadvantage my chances of getting a good work placement when I qualify.

Unfortunately, we are assessed overall in a complex ranking system and it was deemed unfair on those without disabilities to adjust the marks of those with them *retrospectively*. This was, a local, medical school decision; internal ranking policy is done differently between different institutions. It was deemed that no change could be made within our system and many of my dyslexic peers were diagnosed while at medical school. This left me feeling both upset and defeated. I was extremely anxious about the effect this would have on the rest of my career. This led to me obsessing over my decile ranking for years – kind of ageing me. My peers developed (and still maintain) the joke of "grandpa Seb."

Some of us dyslexic medical students have experienced a sense of hopelessness towards our already disadvantaged careers. If my decile is low, then I am less likely to be allocated a good location in the UK for when I qualify. This may result in me having to work somewhere far away for this time and would likely cause me to become very low and homesick. Subsequently, this might impact on the next application hurdle, and the next...

### 15<sup>th</sup> April 2012: Conversation with Another Dyslexic Student

Seb: I'm getting really upset about my deciles now. I mean, I just don't know what I can possibly do to overcome this...

Peer: I know what you mean. I don't even want to think about it. I can't do what you do. I can't even try to plan to overcome it. It makes me to upset thinking about any of it. I'll just accept what's coming to me I guess, as it lets me avoid upset.

Seb: I know what you mean. Like, if I'd been diagnosed before I got here... If I'd had the support in place... I don't think I'd have done anywhere near as badly last year. Like my current grades are testament to that I think.

Peer: Yeah, I totally agree. I mean, I got diagnosed more recently than you did, so imagine how I feel – a whole extra term of poor grades to go against my future career. (My grade is combined with other academic indicators, for example, published papers in MedLine Indexed journals, to allocate me to where I work in the UK for my first two year. I am then sent where I am sent. So, in its own way, it has a huge impact on my career - geographically and emotionally.)

Seb: Yeah, I can't believe that of many of us have been left to struggle for so long, only to be diagnosed whilst already here. It seems so unfair that, despite struggling alone for longer, we don't get any backdated help or consideration.

Peer: Yeah, but I guess there's not much was can do about it now. We just have to accept it.

For this reason, I believe our own procedures, and perhaps those in other institutions, need reconsideration. I do however accept that, within the current system, retrospective compensation cannot be awarded.

On receiving my report, the medical school implemented all the recommendations made by the educational psychologist who formally diagnosed my dyslexia. These were extra

time in exams, being allowed to audio-record lectures and take exams on a computer. I was also allowed extensions for assignments and allowed access to a dyslexia tutor.

I now sit written examinations at a computer with 25% extra time. Since then, my confidence and my attainment have greatly improved. This has helped me shift much closer towards my true academic potential – and to come out of my shell personally. Although the relationship between the medical school and myself may be different to that of a student without a Learning Difficulty, I have never felt treated like “the special one.”

I do however feel that some areas are over-supported, whereas others may be lacking. I feel over-supported in the provision of “dyslexia tutors” who have been very hard to get in touch with and, because they did not know anything about our degree, really couldn’t help in any case. A further example of over-support is in the provision of dyslexic support equipment that isn’t necessary as it is not medicine-specific – for example dictionary software access. That said, since receiving support, my grades within essays, for example, have increased from an average of C to A-grades. But, because of my earlier grades, I am still located within the 7<sup>th</sup> decile. This means that I remain in the bottom 30-40% of my year, based on the assignments that my medical school chooses to include in their ranking system.

I have witnessed many of my non-dyslexic peers writing entire assignments just hours before deadlines. I would work weeks ahead, carefully articulating my thoughts and transcribing them into the essay. Even with this painstaking approach, I would usually get lower grades. I found this extremely frustrating. The course relies heavily on written assignments such as reflective essays. After many such disappointments, I expressed my concerns and met with someone from the teaching staff. They highlighted issues in my writing style and flow of thought. This helped me do further work to develop techniques to deal with this.

However, my inability to work at the fast pace of my peers meant that I missed out on some of the “university experience.” On many occasions I have found myself sitting in my room writing essays whilst my classmates have been out living their lives. It is good to have an extension, but this does not help much when assignments occur in quick succession. I have, therefore, never requested an extension – to avoid the nightmare of a *backlog* of assignments.

I have struggled with the *colour* of PowerPoint slides and hand-outs. Both my speed of reading and eyestrain are greatly improved when reading black text on a pastel yellow background. I now own a yellow filter to place over pages that I need read. This helps me read them at a pace more representative of “normality.” This issue appears to be poorly understood by many educators who use a wide variety of colour schemes for both slides and text – making it very difficult for me to read. (John has now changed all his beautiful dark blue slides to pastel yellow!) Another difficulty I have is called Irlen Syndrome (Figure 2, below). This term refers to the visual disturbances – colloquially known as “rivers” – that are experienced by 46% of people with dyslexia (Uccula et al., 2014).

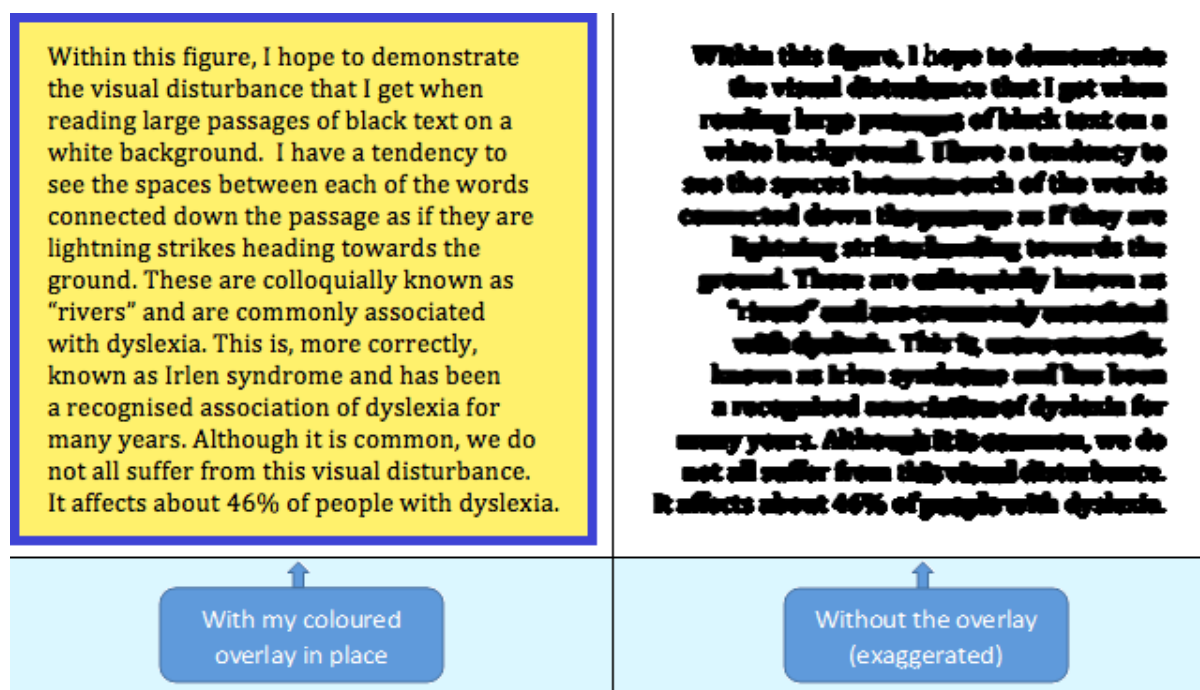


Figure 2: My Irlen visual disturbance. Created using information from Uccula et al. (2014).

Even with all of the support in place, I still do not feel able to compete with ‘normal’ students within the current assessment methods. I have excelled on many occasions where we were assessed practically or verbally. However, apart from Observed Structured Clinical Examinations (OSCEs) which are graded, these assessments have all been formative, therefore not graded. In the first two years of medical school, I often felt that the harder I tried, the more I was told that I was “average” at best.

... That’s where I flourish... Academic areas I struggle more... Clinical areas is my niche.

As I progressed into the clinical years, I have experienced a substantial improvement in my medical knowledge. I have *flourished* in the practical environment where I have been able to make use of my skills as a *kinaesthetic* (learning through doing) and *verbal* (learning through talking and listening) learner. Not only this, but I have been able to make use of the heightened communication skills that I had to develop whilst growing up. Over the years, I became “a friendly face.” I have learnt what it is like to struggle, so am easy to talk to (so I am told) and empathetic. My difficulty with reading and writing has also led to me having to focus more on verbal communication - thus the development of this as a strength (much like using a muscle more leads to it strengthening). I believe that all of this has helped me develop good relationships with my patients – arguably more easily than many of my colleagues:

I’m so methodical, that my notes writing (writing within patient notes) is much better than the average as well... because, although I’m a bit slower at it, I have an exact system and I know what goes where... I keep everything very logical and simple.



### 22nd October 2013

It is a cloudy winters day, and I am on the wards. I am sitting with “Janet,” a 72 year old woman who is in hospital with diabetes. She has been struggling to understand lots of the terminology used about her since her admission – “thiazolidinedione... hyperglycaemic control.... “ She has asked me to help her make sense of it all. As I sit with her, I can empathise with her situation. I too know what it is like to feel lost in a sea of information, not really understanding any of it enough to begin swimming my way to the top. As it sit with her, I am able to discuss what everything means and to clarify the points that she did not understand.

However, assessments that contribute towards my grades for this period are still mainly essays and examinations based on reading and writing. So, however much I have shone in the working environment, I continue to feel that I let myself down with assessment grades. I have spent many hours along the way emotionally “beating myself up” because my best was just not good enough. For example, I regularly sit and think about my grades, stressing over why they don’t correspond with the clinical feedback I’m receiving. This causes me to become increasingly frustrated. Why am I not able to perform the way people think I should? Why do I perform so badly at the time it matters? What am I doing wrong? These thoughts often haunt me following results.

### Unexpected Strengths

As described earlier, I took one year out to study for a *Master of Science in Medical Education* during my studies. I could have gone for ether a Bachelors or Master’s degree during this year, but chose to challenge myself with the latter. Achieving the qualification has enabled me to regularly teach undergraduate medical students – primarily those in their first clinical year. I repeatedly receive positive feedback about the way in which I am able to explain difficult topics in simple and easy-to-follow steps. I have my dyslexia to thank for this strength. Feedback from others through the years continually tells me that I explain things in simple ways. I just teach things how understand them – which is in a simple and straightforward form, because I have to find other ways of learning things. I thank my dyslexia for that!

I can teach things in such simple, methodical ways, which the students like... that they don’t get from other people...

### 15th September 2014

It is a sunny afternoon, and I have been asked to meet with a student in order to help them with their studies. "Michael" is wanting help with his dissertation. He does not really understand the differences between Grounded Theory, Phenomenology and Ethnography. While he knows that they are all qualitative approaches, he does not know which he should use for his project. I sit and explain, briefly, what each of the methodologies is, and how they differ. We then discuss his project and what he hopes to achieve. By taking the time to do this, and explaining everything in a simple manner, I am able to get him back on track.

Over the years, I have been forced to learn concepts in inventive and unexpected ways. In having to work around my dyslexia and find weird and wonderful approaches to learning things, I consistently find that, after time has passed, I know everything I've learnt in great detail, when others who cram for exams do not. The only downside of this is that, because it takes longer to learn this way, I do not achieve the same exam grades. Thus, I develop a broader understanding of *Medicine as a whole*. Outside of the examination-room, this has already become strikingly apparent compared to some classmates who relied on "rote-learning" to gain remarkable grades throughout the course. It is *this* broad and deep understanding that helps me teach in an innovative and effective manner.

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### **Seb, John, and Alec: Concluding Comments**

Throughout Seb's time at medical school he has been forced to accept his dyslexia in several ways, including at the deep emotional level, as evidenced by the negative impact the problem in its cultural context has had on him. However, he has developed strategies which have helped him survive. As argued above, what he may lack in literary skills he gains in practical abilities, problem solving and communication skills. Medical school is tough – for all students – but being dyslexic has some positive aspects which are easy to overlook in an exclusive focus on its negative effects as an SpLD.

A significant amount of effort is made to support dyslexic students in our local medical school. However, this is sometimes misplaced – for example in providing expensive equipment designed to overcome significant problems with the English language, while leaving other potential problems for learning undergraduate medicine untouched. These include the emotional problems that attend the experience of dyslexia; knowledge that is crammed rather than retained in the long-term; and the fact that practical abilities, observed by ward teams in mini-assessments, don't count towards student grades.

This study also raises several other important issues not previously considered anywhere within the medical educational literature. These issues speak to curriculum and student support development in several ways. A strong, negative emotional reaction may accompany a diagnosis of dyslexia in medical students. Therefore, formal or informal pastoral support can be positively life changing. In this paper we have described the forms of such support that were helpful for Seb. These included the constant availability of kind and caring staff within the Student Support department, understanding friends and the support of John – who took him under his wing for the past year.

We have suggested throughout this paper that both support and coping strategies are personal to the individual. They should therefore be tailored and adopted on a person-by-person basis. Support and coping strategies should, as in Seb's case, both enhance existing strengths and encourage creativity in seeking hitherto unexplored learning and adaptation possibilities. In this regard, as evidenced in Seb's narrative, dyslexic students may have untapped potential and hidden strengths – for example as peer educators.

As also revealed in Seb's narrative, dyslexic students may struggle with *more* than just reading and writing. This has clear implications for course and curriculum design and development. Arguably, students with SpLDs need to be more involved in curriculum design. This has been a slightly contentious and sensitive issue locally over the past year, evoking jealousy in non-dyslexic students over the support that dyslexic students receive, which has been relayed to the medical school.

At a broader cultural level, this study raised the question as to whether the current medical educational system in the UK and perhaps other countries is truly inclusive. In the light

of the literature on dyslexia and our study, further consideration arguably needs to be given to the training of dyslexic medical students around the issue of developing further an inclusivity agenda that minimises the risks of segregation and stigma.

In summary, this study has highlighted the significant emotional burden that can result when a student with dyslexia studies medicine. Conversely, it has also explored some potential benefits of being dyslexic, as a peer teacher and clinician. These include the ability to develop a clear, straightforward and accessible communication style, which benefits the development of collegiate peer relationships and therapeutic relationships with patients.

A third important message emerging from this study is the insufficiently scrutinised and questioned cultural norm of favouring written exams rather than clinical assessments, at specific points in medical training. Although the effects of this are not known in a quantifiable way, we have in this article highlighted the potential disadvantages of this for dyslexic students in their clinical years of study.

The nature of autoethnographic inquiry allows readers to take what they will from this paper. However, we propose that further research might build on our study. In keeping with autoethnographic inquiry, we have used the particulars of lived experience to make critical cultural comments and recommendations, but this strength is also potentially a limitation. Some readers may well reasonably question whether these experiences are universal. Further qualitative research might therefore usefully explore the extent to which this study is culturally transferable, in terms of whether Seb's experiences, thoughts and feelings resonate with other medical students with dyslexia in the UK and internationally, and with their tutors. This transferability question will also extend to whether the learning and educational support initiatives undertaken by Seb individually, and Seb and John together, make sense in different educational cultural contexts.

If our study is accepted as a reasonably convincing basis for further work, another area for future inquiry might be in identifying how the ranking system within UK medical schools might be made fairer to dyslexic students. Based upon Seb's strength in this area, the use of dyslexic medical students as medical peer educators might also be usefully explored. Finally, further research could also focus on how the ways in which medical students are assessed during their clinical years of study might be made fairer to dyslexic students, with consideration given to a broader range of assessment methods. In the UK, the current focus of support provided seems to be around trying to help dyslexic students cope with and adapt to assessment methods that are at their core, and by their very nature, harder for them and disadvantage them. This is in the face of the duty call for "Medical educators ... to make sure that a handicapped student is tested in a manner which will indicate what they know rather than what their handicap is" (Rosebraugh, 2000, p. 999).

Our overarching hope is for medical schools and universities to sympathetically respond to all of the above. Doing so will help dyslexic students to better understand and manage their own practical and emotional issues, academic challenges and positive aspects of having dyslexia in the unique and challenging environment of undergraduate medicine and other, similar, professional learning cultures.

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### Author Note

Sebastian C. K. Shaw is a final year medical student at the Brighton and Sussex Medical School. He has an MSc in Medical Education, and as a result of this regularly teaches within both Postgraduate and Undergraduate Medicine – primarily in research methods and “dyslexia in medical education.” He is an Associate Fellow of the Higher Education Academy and a Member of the Academy of Medical Educators. Correspondence regarding this article can be addressed directly to: Sebastian Shaw, Division of Medical Education, Brighton and Sussex

Medical School, Mayfield House, University of Brighton, Falmer, BN1 9PH, UK. Email: [S.Shaw1@uni.bsms.ac.uk](mailto:S.Shaw1@uni.bsms.ac.uk).

John L. Anderson is a medical sociologist. His career has mainly been in teaching and research in medical schools. He is a Senior Fellow of the UK Higher Education Academy and is currently a Principal Lecturer in Postgraduate Medicine, within the Division of Medical Education at Brighton and Sussex Medical School. Correspondence regarding this article can also be addressed directly to: John L. Anderson, Division of Medical Education, Brighton and Sussex Medical School, Mayfield House, University of Brighton, Falmer, BN1 9PH, UK. Email: [J.Anderson@bsms.ac.uk](mailto:J.Anderson@bsms.ac.uk).

Alec J. Grant, PhD is Reader in Narrative Mental Health in the School of Health Sciences at the University of Brighton, UK. He is a Fellow of the UK Higher Education Academy and contributes to narrative social and human science as a qualitative researcher, supervisor, mentor and educator, using dialogical narrative methodologies, including autoethnography. His published qualitative research is underpinned by critical reflexivity in the service of human emancipation and social justice. In this context, he also challenges established onto epistemological assumptions, orthodoxies and related representational practices, around what can and should be known, and how it is known. Correspondence regarding this article can also be addressed directly to: Dr Alec J. Grant, School of Health Sciences, University of Brighton, Robert Dodd Building (RD105), 49 Darley Road, Eastbourne BN20 7UR, UK; E-mail: [A.Grant@brighton.ac.uk](mailto:A.Grant@brighton.ac.uk).

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