"What's wrong with you, are you stupid?" Listening to the biographical narratives of adults with dyslexia

Abstract:	Little research has been conducted, understanding the impact of educational-inclusion and workplace anti-discriminatory policies on lived-experiences of people with dyslexia. This paper consequently analyses qualitative-biographical accounts of 15 adults with dyslexia; applying the social relational model of disability to conceptualise these. Findings illustrate, the embodied-experiences of dyslexia defined within a disabling-educational system and discriminatory-workplace; culminating in psycho-emotional impact on participant's self-esteem leading them to pathologise experiences of failure through an individualistic deficit-explanation of self. The article concludes suggesting these lived-experiences must be acknowledged in education to develop inclusive practices adequately preparing individuals for adulthood, not just for the workplace.

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Points of Interest

- This article draws on the social relational model of disability (i.e. recognising both the social and the biological) and applies it to the experiences of people with dyslexia.
- Participants discussed the psychological and emotional impact of experiences of exclusion throughout their life histories.
- Participants discussed painful school experiences during childhood which had a lasting emotional impact.
- Even though legislation requires 'reasonable adjustments' must be made in workplaces, people with dyslexia still experience discrimination
- The research views dyslexia as an alternative reading and writing style which needs to be considered by schools and employers, looking to create an inclusive environment.

"What's wrong with you, are you stupid?": **Listening to the biographical narratives of adults with dyslexia in an age of 'inclusivity' and 'anti-discriminatory' practice**

Introduction

This article conceptualises the lived-experiences of people with dyslexia to comprehend how concepts such as inclusion and anti-discriminatory practices have impacted on participants' biographical journeys. The research defines and applies the social relational model of disability to these lived-experiences; linking micro social interactions to macro social processes. The article presents findings on the educational biographies of individuals with dyslexia, as early adverse incidents fundamentally shape participants' perceptions concerning their 'self-worth' and their own 'competences' in adult life. This study illustrates how oppressive educational practices have a significant psycho-emotional impact on individuals diagnosed with this condition throughout their lives. Thus, the concept of 'failure' becomes a dominant narrative which emerges in education and shapes a participant's 'self-esteem' and 'self-confidence' throughout their biographical journeys. This article will present evidence on how perceived 'failures' in education are mirrored by perceived 'failures' within the contemporary workplace.

The article will argue that anti-discriminatory policies, such as the Equality Act (2010) which legally requires employers to make reasonable adjustments, can have a minimal impact on people's employment experiences. For individuals in this study discriminatory, or anti-discriminatory, practices often result from relationships that are formed between participants and their managers. The paper concludes by suggesting that although UK inclusion and anti-discriminatory policies have had a positive impact at an organisational (mezzo) level, this is

1

often not the case at a micro-level. Thus, this study suggests that future research must explore

how the concept of 'inclusive' and 'anti-discriminatory' practices in education and

employment operate at the micro-level from the perspective of individuals with dyslexia.

Inclusive Policy and Practices

To conceptualise the biographical journeys of individuals with dyslexia there must be

recognition of how practices, both in education and in the workplace, have shaped

participants' perceptions of 'self-worth' in adult life. The concept of inclusion has become a

much used educational and employment discourse both in professional practice and in a

social policy context. The inclusion agenda was developed in the Warwick Report (1978),

which advocated that children with 'special' educational needs should be educated within

mainstream schools rather than in specialist institutions (Cole 2005). The Warwick Report

(1978) significantly influenced the *Education Act* (1981), and later the *Education Act* (1996),

with its advocacy for inclusive-practice within mainstream education. In conjunction with the

1980s educational reform, the Conservative and, later, New Labour governments developed

an anti-discriminatory agenda that was initially applied in employment and then education

legislation. So, the first wave of legislation aimed at reducing discrimination against disabled

people came in the form of the *Disability Discrimination Act* (DDA) in 1995. It attempted to

confront disability inequality by developing a civil rights approach for people with a range of

impairments including dyslexia. Although this Act was intended to *remove* discriminatory

barriers in employment, the terminology used in the policy referred to 'reasonable

adjustment'. The DDA (1995) was subsequently expanded to education, in the *Special

Educational Needs and Disability Act* (SENDA) 2001, which made it illegal for schools and other

educational establishments to discriminate on the grounds of disability (Konur 2006). The

2

2001 Act amended the *Education Act* 1996 and aimed to enable more disabled students to successfully access mainstream education; introducing the concept of 'reasonable' adjustment within an educational setting.

Due to growing criticisms that the DDA (1995) was being systematically ignored by employers due to the concept of 'reasonable' adjustment, the Act was updated and expanded in 2005 to cover public transport and public authorities within its remit (Roulstone and Warren 2006). This was subsequently replaced with the *Equality Act* (2010) which gave disabled people, including people with dyslexia, legal rights in employment, education, services and housing.

 Yet, because the label of dyslexia has obtained growing recognition in equality social policy, the condition has recently received increased criticism where scholars have questioned its usefulness in contemporary educational practice (Elliott and Place 2002; Elliott and Gibb 2008; Elliott and Grigorenko 2014; Arnold 2017). Elliott and Gibb (2008) suggest dyslexia is a social construct that could not be distinguished from children who have general literacy problems because of sociocultural factors. Due to growing criticisms from within education of the dyslexia-label, the New Labour government commissioned a review of the condition by Sir Jim Rose (2009). The 'Rose Review' (2009) accepted dyslexia as a useful term, reinforcing the inclusion agenda within mainstream education and illustrating the need for targeted support for these children. However, it stopped short of advocating for a diagnostic legal right for children and adults with this condition, and adult services were not referred to at all in the report.

In 2010 the Conservative-led government replaced existing educational policy with the *Education Act* (2011), the *Children and Families Act* (2014) and developed a new Children and Families Act Code of Practice. This new framework states children are to be supported by a wide range of professionals for conditions which are recognised by health services through a multi-agency approach; bringing together education, health and social care (i.e. Health, Education and Care Plans). It should be noted that implementation of these policies has also led to the reduction of funding of special educational needs in mainstream education. Although it is too early to assess the impact of these plans, Macdonald (2013) suggests Health, Education and Care plans have the potential of decreasing access to a diagnosis and educational support, as dyslexia is conceptualised as an educational rather than a medical condition.

Dyslexia in Disability Studies

Dyslexia as an impairment has been a somewhat controversial concept, particularly concerning its neurobiological origins (Elliott and Place 2002; Elliott and Gibb 2008; Elliott and Grigorenko 2014). Academic research, which dominates debates concerning dyslexia, is primarily entrenched within two perspectives: neurocognitive sciences (Snowling 2000; Snowling and Maughan 2006; Peterson and Pennington 2012) and pedagogical interventions (Hall 2009; Elliott and Grigorenko 2014; Grünke and Leonard-Zabel 2015). Research in the neuro-cognitive sciences predominantly focuses on mapping the neurological 'deficits' resulting in children and adults experiencing phonological decoding problems. It is these that are theorised to cause difficulties in reading, writing and language for the **duration** of a person's life (Snowling 2000; Peterson and Pennington 2012). The intentions of these studies

4

are to improve early detection rates so that specialised interventions can be administered within an educational setting (Snowling 2000; Peterson and Pennington 2012).

Pedagogical research, from a critical perspective, has begun to question the validity of dyslexia as an impairment (Elliott and Place 2002; Elliott and Gibb 2008; Elliott and Grigorenko 2014). As Elliott and Place (2002) suggest, educational practice incorrectly assumes that all children learn in a universal manner and cognitive abilities are achieved at similar key stages throughout a child's educational progression (Elliott and Place 2002; Mortimore & Dupree 2008). This critical approach suggests that when some children struggle to learn, and do not achieve what is expected based on their age, the education system incorrectly conceptualises this problem as an indication of a pathological deficit. Elliott and Grigorenko (2014) suggest these learning difficulties often result in a dyslexia diagnosis to vindicate this problem rather than recognising that children learn and progress in diverse ways (Elliott and Place 2002). From this perspective the solution is not to label children but to develop early pedagogically targeted interventions that include multiple teaching and learning styles situated within an educational environment (Elliott and Grigorenko 2014).

Hence, the vast majority of research on dyslexia either focuses on diagnosis, neurocognitive explanations, or childhood pedagogical interventions (Snowling 2000; Peterson and Pennington 2012; Elliott and Grigorenko 2014). Although these perspectives appear fundamentally diverse, they both individualise or pathologise the experiences of this disabled minority group. Hence, from a neuro-cognitive perspective, problems experienced by people with dyslexia are due to a neurological 'deficit' that disrupts 'normal' educational participation (Snowling 2000; Peterson and Pennington 2012); whereas from the pedagogical

5

perspective, literacy difficulties wrongly identified as dyslexic traits can be overcome entirely by specific individually designed pedagogical interventions (Elliott and Grigorenko 2014). Yet, these perspectives are based on research conducted with children in an educational setting and they do not include the impact that dyslexia has in adulthood.

Barbara Riddick was one of the first to publish a critique into these two dominant perspectives of dyslexia by applying a disability studies approach (Riddick 2000; 2001). She critiques the pedagogical perspective for individualising, and often denying, the existence of this impairment. Riddick applies the work of Mike Oliver and Colin Barnes to the experiences of children with dyslexia and proposes the conceptualisation of dyslexia from a social model perspective. Rather than pathologising dyslexia as a 'deficit' which impacts on learning, she offers an analysis that focuses on disabling barriers in education which discriminate against dyslexic learners (Riddick 2000; 2001; 2010). Since Riddick's initial assertion that it was time to apply the social model to the experiences of dyslexia, a growing body of knowledge has emerged attempting to understand these lived experiences (Madriaga 2007; Tanner 2009; Macdonald 2009; 2012; Collinson and Penketh 2010; Skinner and MacGill 2015). As can be observed in the work of Madriaga (2007) and Tanner (2008), they illustrate how dominant narratives of academic failure and passive disablist attitudes significantly construct barriers which affect the future life choices for adults with this condition. Although Riddick and her advocates are endorsing a classical social model approach, they are essentially referring to how people with dyslexia experience particular disabling barriers.

This social model perspective was further developed by Macdonald (2009) who suggests universal disabling barriers operate at a macro-level but specifically influence people with

6

dyslexia's social experiences at a micro-level. Diagnosis is not completely rejected by both Riddick (2000) and Macdonald (2010) as, they argue, it can be a useful way to understand people's specific experiences. The importance of diagnosis not only impacts on the type of support received, but also on the type of disabling barriers people encounter. There is still a rejection of the biomedical approach, which implies that people with dyslexia cannot do certain tasks because of their impairment type, but Macdonald substitutes this with the concept of dyslexia as a 'neurological variation' which is systematically devalued in contemporary society (Macdonald 2013; 2019). Thus it is this neurological difference which interacts with the social environment, as experiences are different depending on specific conditions. Although Macdonald (2009) focuses entirely on disabling barriers he states these barriers are experienced differently by different impairment groups, e.g. a person with schizophrenia will experience different disabling barriers to a person diagnosed with dyslexia or ADHD (Macdonald 2019).

From this perspective his focus remains on disabling barriers, as it is not about pathologising dyslexia but transforming social environments. Yet, although he recognises that certain disabling barriers are universal, these barriers are often experienced at a micro-level and so there is an interaction between the impairment type and the disabling barriers. Macdonald therefore identifies how labelling is an important element for people to gain access to support; as well as to recognise and confront specific disabling barriers. Thus, this approach focuses on an interaction between disability and impairment at a micro-level (Shakespeare 2013). To understand people's experiences of dyslexia, we must therefore conceptualise them both individually and structurally to comprehend the impact of disabling barriers for this specific group of people.

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Models of Disability

Recent debates in disability studies have been somewhat dominated by theoretical

discussions around defining disability and impairment. These have been broadly summarised

into three distinct theoretical approaches consisting of materialism, post-structuralism and

critical realism (Shakespeare 2013; 2015). In this research, the authors have applied a critical

realist perspective and have been significantly influenced by the work of Roy Basker, Tom

Shakespeare and Carol Thomas. Although there have been meaningful debates concerning

disability studies that give the impression that critical realism and the social model are not

theoretically interchangeable (Shakespeare 2013), the authors of this study dispute this

assumption (Macdonald 2013; Macdonald and Deacon 2019). Within disability studies, critical

theoretical perspectives are somewhat summarised by distinct models of disability, i.e. the

social model, the social relational model and the affirmation model. The authors of this study

suggest that from a critical realist perspective these models can be interchangeable, and

therefore the researcher must apply the model which best fits their data findings. From this

perspective the authors would suggest that these models operate at different levels and are

aimed at different forms of analysis. For example, the social relational model focuses on the

interplay between impairment and disabling factors at a micro-level; whereas the affirmation

model focuses on cultural constructs of disability which are predominantly constructed at the

meso-level. Thus, the authors suggest that the social model operates at the macro-level

focusing on structural disabling barriers which affect all impairment types. Consequently,

from a critical realist perspective, models can be interchangeable and used for a layered

approach to understanding the social experience of disability (Macdonald 2019; Macdonald

and Deacon 2019).

8

Within this study the authors apply the social relational model to conceptualise the experiences of participants with dyslexia in terms of 'disability' *and* 'impairment'. As Carol Thomas argues, when exploring the lived-experiences of disabled people 'disablement' should be at the forefront of the analysis within disability studies. Yet, she argues that this analysis must also incorporate disabled people's 'experience of impairment and impairment effects' in order to capture a reality of these lived-experiences (Thomas 2007: 180). From Thomas' perspective, in order to conceptualise disability and disablism, an analysis should be produced that incorporates the embodied experiences of disabled people encapsulating the social, the biological and the psycho-emotional. From this perspective, these interact at the micro-level where biological variations are interconnected with structural experiences of oppression and can subsequently have a significant psycho-emotional impact on a person's life. As Reindal (2008) suggests, by applying a social relational model to the experiences of disabled people, this does not need to reject the social model of disability but can complement the structural aspects of this approach.

Social model writers in the field of dyslexia have long acknowledged this interactionist approach within their writings. Both Riddick (2001) and Macdonald (2009) illustrate the importance of recognising neurological variations/learning styles which have been labelled as 'dyslexia'. Although both writers are arguing for a social model approach to be adopted in the field of dyslexia, a key disabling barrier identified by both scholars relates to concerns over a lack of diagnosis and recognition of the condition within an educational and employment context. Furthermore, even after this condition is acknowledged they suggest there are still significant disablist attitudes and a lack of support/adjustment in education, employment and

9

in adult services (Riddick 2001; Macdonald and Deacon 2015). Hence, it is these key concepts

of identification, inclusion and discrimination, which are framed by an age of 'inclusivity' and

'anti-discriminatory' policies and practices, that will be examined in the findings section of

this article.

Methodology

The aim of this project was to explore experiences of a range of adults with dyslexia living in

the UK, particularly relating to education and employment. The study aimed to explore

whether socio-economics was still a factor for adults with dyslexia (Macdonald 2009); even

after policies specifically aimed at inclusion were implemented. A mixed-methods approach

was taken and participants from the quantitative phase were accessed by means of an online

survey. This was sent out to organisations across the UK supporting adults with dyslexia; and

appeared on a number of social media websites used by people with dyslexia. The study took

place from 2015–2017, producing a sample size of 442 participants. The quantitative data was

analysed using the social model of disability, thus presenting the macro experiences of

participants, i.e. structural barriers. The analysis illustrated that socio-economics and dyslexia

had a significant impact on the macro experiences of adults in the study (Anon 2019).

For the qualitative phase of the study, an in-depth biographical interviewing methodology

was used (Wengraf 2001) and participants were initially selected based on social class (Savage

et al. 2013), then subsequently organised into different gender groups (Skinner and MacGill

2015) and then ages; which are known to transform the experiences of people with dyslexia.

This was in order to ensure access to a wide range of views and experiences to produce a

detailed analysis. In total, 15 individuals were selected; of these nine were female and six

10

male (pseudonyms); ages ranged from 23 to 64; and 13 identified as White British, one African Caribbean and one declined to answer. The wide age range enabled the inclusion of participants from both pre- and post-*Education Act* 1981. Their socio-economic status was as follows; elite (1); established middle class (2); technical middle class (2); new affluent worker (2); traditional working class (2); emergent service worker (4); and precariat (2) (Savage et al. 2013). Their qualifications ranged from none through to postgraduate level. In describing their dyslexia, ten identified it as 'moderate', four as 'mild' and one as 'profound'.

According to the biographical method (Wengraf 2001), participants were each asked the same single question to induce narrative: *'Can you please tell me your life story, with all the events and experiences which you feel relevant, concerning your life? I will listen without interrupting you'* (Wengraf 2001: 119). The interviews stopped when participants made it clear they had nothing else to say concerning their life story. This interview transcript was then analysed to produce a set of questions for the second interview. After this, the transcript was analysed again and another set of questions was produced drawing on existing research. After interviewing was complete, the data themes were organized using a phenomenological approach (Macdonald 2009; Oliver 2012). The importance of this form of interviewing is that participants were allowed to start their life story at any historic point they chose. This enabled them to speak freely about their position in relation to dyslexia. It also allowed them to translate their own events, themes and meanings within their own biographies to produce a narrative form. In reporting data, this is achieved by presenting dense description and analysis (Patton 2002) in the Findings, rather than personal perspectives. Geertz (1973) refers to this as *thick description* whereby the beliefs and meaning of participants are presented as they are observed; a significant concept in the presentation of disability research (Thomas 2007),

11

enabling researchers to 'understand and [absorb] the context of the situation' (Ponterotto 2006: 539).

The qualitative data has been analysed from the social relational perspective to understand the individual (micro) experiences of adults with dyslexia. Findings will show that, although socio-economics was significant at a macro (quantitative) level (Anon 2019), at a micro level, issues of disability were at the forefront of experiences of exclusion. Thus, the findings are structured around specific disabling barriers relating to dyslexia rather than experiences of social class.

Findings: Educational Narratives of 'Failure'

Negative schooling experiences dominated the biographical narratives of participants in this study regardless of when they attended school, i.e. pre-1981 Act (aged 46 and over) or post-1981 Act (aged 45 and under). All participants reported experiences of 'difference' compared to other pupils and most conceptualise these from a 'deficit' perspective, i.e. lacking intellectual ability. Dominant discourses used in these narratives referred to themselves as 'stupid', 'thick' or 'not academic'. Often these stigmatised assumptions about a participant's academic ability came from other pupils, but on a number of occasions these labels were reinforced by teachers, e.g. Martha (21) suggests a teacher stated in class *'what's wrong with you, are you stupid?'*, and Zach (47) recalls being told *'you're thick'*. For most participants, labels such as 'laziness' and 'stupidity' were attached to them *before* they were diagnosed with dyslexia, yet these early experiences shaped their self-perception.

12

> …the pain of getting it wrong is like torture. So other kids might get a spelling
>
> wrong and they kind of just laugh it off. I would be sobbing for days and not
>
> wanting to go back into school and the dramatics and everything… all because I
>
> got one thing wrong and that's stayed with us probably my whole life. (Eve, 36)

Even students who reported having a predominantly happy childhood excluded their schooling experiences from this description. As Melissa (29) said, *'I had a very happy life but I hated school purely from an educational point'*. Participants suggested their notions of being a 'low achiever' were reinforced at school by their peers and teachers. As participants struggled to achieve the same educational goals as their peers, this reinforced their own self-perception of them as being in 'deficit'.

> …in the back of your head you always know that you're not as good as everybody
>
> else, there's just things that other people are doing a lot quicker than you and you
>
> notice it so then subconsciously you become aware of the fact that perhaps you
>
> can't do things very well. (Melissa, 29)

This was particularly the case with reference to their literacy skills. For many participants (regardless of age) education focused entirely around reading and writing. As all participants struggled with expected literacy levels throughout their educational careers, this had a direct impact on teachers' perceptions, and subsequently their own views, on the intellectual capability concerning other subjects. Zach (47) remembered a teacher suggesting *'You can't read and write, you're thick, that's it'*. As literacy underpins the assessment of most other subjects (DfE 2014) participants conceptualised their struggles with literacy as an indication

13

of their own ability and intellect. Participants reported they were discouraged to take subjects

such as languages or humanity-based subjects due to teachers' assumptions about their

abilities. Melissa (29) describes being laughed at by a teacher in primary school.

> …my teacher would laugh at me because obviously my English was so bad, my
>
> handwriting was so bad erm… it's one of those upsetting things when you're a
>
> small child where you learn the sort of reality that actually you can't do anything
>
> you want, there are certain things which you are limited.

For participants, once their literacy problems were identified this usually resulted in them

either being moved onto a table with other children who were having difficulties adapting

(primary school) or being moved into a specialist class (secondary school). Interestingly this

seems to be a universal response no matter what timeframe participants were in mainstream

education. For participants this led to further feelings of isolation and reinforced their notion

of 'deficit'. As Susan (53) discusses her experiences in primary school:

> This involved being put on what was described as the 'thick table'. You were put
>
> on a table which was where all the… It was known as the 'thick table', you were
>
> there with other children who were not doing as well in the classroom and I was
>
> on that table.

Similar experiences can be seen at secondary school as Martha (21) recounts her feelings

about being moved to a special needs class:

14

It was a 'little room'… while everyone else would do their Maths lesson, and then

I'd go into this support group and we'd sit there and count blocks. I was with the

kids that were deemed naughty or kids who were seen to have special needs and

things.

As many participants discussed significant feelings of loneliness and isolation throughout their

educational experiences, a number of participants referred to 'drifting off' during classes or

becoming extremely shy or quiet at school. Other participants confronted their difficulties

with more rebellious and disruptive behaviours when in education. However, the vast

majority report experiences of bullying. Interestingly, participants describe direct bullying

from other pupils, but also indirect bullying from some classroom teachers. Leroy (58)

illustrates this point by suggesting teachers would discipline him by humiliation; '*being told

to stand up in front of the class and, I was told to read out loud and I just couldn't do it*'. From

his perspective teachers could use this as an instrument to control his disruptive behaviours.

When their inability to perform an educational task was recognised, they felt they were then

the 'perfect target' for other pupils to single them out. Participants also recognised that their

literacy difficulties were widely known by teachers and pupils; hence their stigmatised

position in education became a key target of name-calling or even violence for many pupils.

As Leroy (58) reports:

… once when I'd left school I bumped into what I called "school mates" erm and

they would start taking the "piss" and I would get into a punch up then particularly

if I was sort of not in a very good mood anyway.

15

Concepts of failure were significant throughout participants' early educational experiences; and these were still seen as *painful* in adulthood. However, a number of participants discussed the positive impact being diagnosed with dyslexia had on their self-confidence during education. Within this study 11 participants were diagnosed during education, from a range of socio-economic backgrounds. For many who were diagnosed in secondary school, or later, they discussed feelings of 'relief' when discovering that they had dyslexia as it meant, to them, they were not intellectually restricted. However, it also led to mixed feelings with reference to the idea that there was 'something wrong' with them. Many participants were also concerned about having a label which they considered as inherently socially stigmatised. As Lucy (23) suggests, the label:

...was positive in a sense, that I finally had an explanation of why everything was so hard erm... that I no longer had an intelligence thing it was genuinely I had a problem and that was good, erm, I did worry briefly that other people might think of me negatively of having the label of dyslexia.

For participants who were diagnosed early in education the concept of dyslexia became an internally stigmatised term as they associated the label with failure. As Jenny (36) states:

I was devastated (laughs), I think my parents were happy but I don't think I was overly impressed by the fact that I've now got this label, erm, so it just proves I'm thick.

16

However, especially for participants who were diagnosed in secondary school, this led to some form of educational provisions being put in place. Reports of being labelled as 'lazy' or 'stupid' by teachers also declined after a diagnosis took place for post-1981 Act participants. For many participants the label led to support at home from their parents. For participants who had recently graduated from the schooling system they reported their parents were relatively active in gaining knowledge on the condition and accessing support outside of schools. Charitable organisations played a significant role in support with both children and adults once they were diagnosed.

However, participants reported mixed feelings about their educational experiences after diagnosis took place. For some participants very little changed however, within the narratives, certain teachers were illustrated as having a significantly positive impact on individuals' lives due to knowledge of dyslexia. As Melissa (29) stated *'I do remember the definite change when I had a new Special Needs Teacher come into my school and who is Mrs Fawcett and who is fantastic.'* Although a number of teachers had a positive impact, for the vast majority of participants their overall schooling experiences, both before and after diagnosis, were described as negative, which significantly impacted on their self-esteem and self-confidence when leaving mainstream schools; thus impacting on their aspirations. As Melissa (29) suggests:

> We were supposed to write down a diary of what we would like to be when we are older and I do remember getting a bit upset and not wanting to put down what I wanted to be because it was a writer. Because I had all these lovely stories in my

17

head… my teacher would laugh at me because obviously my English was so bad,

my handwriting was so bad…

Disabling Barriers and Technologies

Thirteen participants in this study discussed in great detail the impact that literacy difficulties

had throughout their entire lifecourse. When discussing literacy difficulties in adulthood, 14

out of 15 participants discussed the importance of using assistive technologies to overcome

these. For younger participants, technologies such as personal computers, laptops and later

smart phones/tablets were used increasingly earlier in their lives. For some of the older

participants there were a number of discussions concerning early, less effective forms of

technologies which used spellchecks. As Leroy (58) reminisces:

The first thing I ever had was what they call a Spelling Ace… it was a keyboard on

a small, like a little calculator, like an old fashioned calculator. Basically what you

did was you spelled the word and if it was correct a star would come up by the

side of it so you would know you got it right.

For these participants there was recognition of how technologies had significantly

improved over the past 10 years. The most effective intervention which allowed

participants to confront difficulties in adult life, particularly within the workforce, was

situated around the use of assistive technologies such as dictate software, text-to-speak

software and electronic calendars. As Simon (54) suggests:

18

I got quite a lot of assistive technology to use which has helped enormously. I use

Dragon dictate, which was a bit strange at first speaking to a microphone, dictating

your work when you're not used to it, but I had quite a bit of training. I use Read

and Write Gold, erm, I got a Dictaphone.

Participants acquired these technologies in numerous different ways; some bought their own

technologies, others gained access through their employment agencies and some acquired

these through a university disability grant. As one male participant reports, it was his

employer that purchased the relevant equipment for him when he was promoted to a new

role. It should be noted that some participants trained themselves, and for others practice,

perseverance and having access to support were central to them using these new

technologies to assist their reading and writing. However, a number of participants indicated

that technology alone was not enough to overcome many of the barriers they face in the

workplace. Although technologies offered a solution for many participants, technology as a

tool to remove barriers was often misinterpreted by employers offering these 'reasonable

adjustments'; offering a laptop with dictate and text-to-read software was often the only

'solution'. As Simon (51) illustrates:

I walked into the office and saw the computer and said "What the hell's that?",

they hadn't even mentioned it at the interview and they said "Ah it's easy, it even

puts your spelling right" and then when I thought well it puts your spelling right if

you know what the spelling should look like to start with.

The range of technologies varied depending on the employer, and a number of participants

suggested that although they got access to a laptop with assistive technologies, they were

unable to connect this laptop to their employers' internal system for security reasons.

Individuals would have to transfer information back and forth from their laptop to their work

desktop. Some participants also reported that although they got access to assistive

technologies, either at university or when starting a new job, these technologies quickly

became out of date and out of sync with other technologies in the workplace. When this

happened employers very rarely updated their assistive technologies in line with the

technological changes in the workplace. This led to many employees having to purchase their

own updates, which were often very expensive. When assistive technologies were integrated

into a work-based system there was also a lack of support within the workplace on how to

use these technologies effectively with their employers' systems. Hence, employers' work-

based technicians very rarely had expertise in supporting these technologies.

Interestingly, although participants discussed the importance of assistive technologies in

adult life, these skills were not taught or encouraged during mainstream education. Although

half of the sample reported that these technologies were not around when they were in

education, a number of younger participants had access to these technologies outside of

education but could not use them at school. As Melissa (29) reports:

I remember my Mum buying loads of equipment for me at home as well, some

really nice… erm… speak and spell things which were really cool… erm…. and you

clicked on the word and it said the word to you and the school had actually bought

the equipment for me as well but I didn't actually get to use it because it was a

reward for finishing off your work.

This participant is somewhat representative of the younger group of participants where

these assistive technologies could have been used within an educational setting, but

were not. In Melissa's (29) narrative she does not suggest that her teacher was engaging

in this practice out of malice, in fact she describes this teacher with very fond memories,

but the education system did not consider integrating assistive technologies into

dyslexic students' educational curriculum. Students were not taught or supported in

using assistive technologies within schools, although many students used these outside

of the schooling environment to assist them in completing their coursework. As Leroy

(58) states:

Dyslexic children [are] not even in a different school, you know [they are] in

mainstream school in separate classes, no one can teach them correctly, you know

how they should be taught so just spend a bit more money on that [assistive

technologies]

For Leroy (58), assistive technologies should be integrated into the mainstream schooling

system for pupils with dyslexia. Within the narratives of participants it appeared that assistive

technologies were viewed in education as a coping strategy for students. Yet, based on adult

experiences in the workplace, it seems that these technologies were used as an alternative

form of engagement with literacy. Rather than viewing these technologies as a coping

strategy, adults appear to substitute the traditional technologies of a pen, paper and book

21

with a laptop, tablet computer and/or smart phone. Thus, the findings seem to illustrate that people with dyslexia, rather than develop coping strategies by engaging with assistive technologies, had developed an alternative reading and writing style by engaging with these new digital technologies.

Employment Narratives of Discrimination

Within the data, participants' employment and unemployment histories were often explained based on their perceptions of their educational 'successes/failures'. When discussing adulthood, a number of participants discussed the initial impact of leaving education without any qualifications. For these participants the experiences of being excluded in education had a significant impact on their self-confidence and self-esteem. As Jane (48) suggests, *'I didn't come out of it [school] with any qualifications. I didn't particularly want to be anything'*. For these participants low self-esteem often resulted in a combination of short-term contracts and periods of unemployment. As Leroy (58) states, '*I tried to get a job, not everybody wants to give a kid that can't read and write a job'.* These participants report lacking direction and career ambitions, thus for some this resulted in low paid temporary contracts with little promotion opportunities. For participants who had experienced periods of unemployment, they also illustrated significant barriers in job centre support. When Leroy (58) informed his job agency that he had dyslexia he was required to attend an English course as part of his unemployment allowance to improve his employability. Unfortunately, he suggests that this particular course made no provision or support for dyslexia, which resulted in him struggling and reinforced his negative self-belief in his own skill set and employability:

22

…there is a lack of recognition to what dyslexia is and how it is experienced. They

don't realise how hard it is… just trying to find work it's all hard cause everything

has to do [with] reading and writing.

For participants who had a career plan after leaving education the process of being

interviewed, and for some being tested, created a significant barrier. A number of participants

reported how during interviews, once they informed their potential employer they had

dyslexia, they felt their attitudes changed. Participants reported that they knew as soon as

this happened that they were not going to get the job. In Tony's case when leaving school, he

desired to join the Fire Brigade. In order to do this, he had to pass the selection process which

included a written test. As Tony (42) reports:

I started to think about what I wanted to do and the one job I always wanted to

do was join the fire service and I tried a few times and part of the test was

dictation, I passed every other test but I couldn't pass that… [For a] two-year

period I applied for ten brigades and I failed.

Tony persevered with the selection process and finally got accepted after informing the Fire

Brigade that he had dyslexia. Yet during training his colleagues discovered that he had been

rejected from ten other brigades which, he reports, led to high levels of stigmatisation by

recruits/staff: '*I was always ridiculed about it [previous rejections] throughout my training*'.

Tony (42) reports that when serving as a firefighter he had a relatively successful career but

things changed when he was promoted to a management position, which led him to leave the

service. Stigmatising attitudes by managers and colleagues were reported by participants

23

from a whole range of professions. Participants often reported that colleagues either presumed that having dyslexia meant they were entirely illiterate or that their impairment was an excuse for 'incompetence' or 'laziness'. Participants reported having to deal with people who suggested that dyslexia was not a 'real' condition, or not a 'real' disability. Amahle (22) suggested that senior staff often made statements like '*You know that dyslexia is not a real disability*'. For Tony, colleagues associated dyslexia with the concept of low intelligence. Hence, there was a dismissal that he even had dyslexia, as he was not perceived to be of low intelligence.

> They'd all say the same thing, "How can you have dyslexia and be in the job cause
>
> you don't come across as being thick?" and that was the stigma.

Participants also reported that although dyslexia was seen as 'not a real disability' other colleagues would also make assumptions about a person's perceived skill set. Hence these colleagues would presume a complete lack of literacy skill, as Leroy (58) suggests: *'Some of the staff particularly the old guard, it was a case of you know, this boy can't write so, let him clean the trolleys.'* These attitudes were also mirrored by family and friends when participants were successful in obtaining certain employments. For one male participant friends questioned whether he was capable of doing a job due to his dyslexia. As Simon (51) reports:

> I've got a new post with the NHS, as a call advisor and they say "Well how can you
>
> do it you can't read?" I said "Well who said I can't read?" I said "Just because
>
> you're dyslexic doesn't mean to say that you don't read, it's just the way that you
>
> process information".

Yet a significant barrier experienced within employment was due to attitudes concerning

managers. For participants in this study it was how accepting or unaccepting senior staff were

about dyslexia that had a significant impact on individuals' employment experiences. Leroy

(58) illustrates that the attitude of his manager changed when he discovered he had dyslexia.

Until this point, he reported having a relatively positive relationship with this senior staff

member. As Leroy reports:

> I had a problem with one of my managers... I did my level two and she was fine
>
> and was pushing me to do my level three ... I said, "I'm going to need extra help"
>
> and she said "What do you mean" and I said "well I'm dyslexic" and she went "Oh"
>
> and she might as well turned her back on me at that point and said; go away

However, for a number of participants key issues emerged within the workplace when there

was a change in management structure. Susan (53) reports how she had particularly enjoyed

her job working within an educational organisation. However, due to a restructuring to make

the organisation more efficient, new managers were brought in. She reports:

> We had a new manager and he was from the Council side, so all the colourful
>
> creative [practice] ... went and ... it was more structured and a total different way
>
> of working, now I was starting to feel anxious and ... [the] feeling I was back at
>
> school

She reported this manager significantly impacted on her self-esteem in this particular role. As

she suggests it *'was just like putting a knife and twisting it and I was so upset'*. Similarly, Jenny

(36) was asked to write a report which took her three hours outside her normal working day.

When giving this to her new manager, she returned the report having corrected her literacy

mistakes with red pen: *'she'd written all over it in red pen which was like "Red – see me" all*

over again and I just flipped'. For Jenny (36) this led to her experiencing mental health

problems in the form of panic attacks. She felt that her new senior managers were trying to

undermine her ability to do her job. As she reports:

> They were trying to find me out, they're trying to find out I can't do this job and
>
> they're putting me in situations where I'm going to fail and it was just too much
>
> and my mind exploded and I had another breakdown.

This led to Jenny (36) taking significant time off work and ultimately resigning from her job. A

number of the participants identified how although managers used the language of equality,

they enacted oppressive working conditions; that whilst the law might state organisations

should make 'reasonable' adjustments, at the ground level this appeared to depend on the

senior staff who participants had contact with. Susan (53) suggests that inclusive policies do

not change the perceptions of managers in her experience.

> I mean they were talking about reasonable adjustments but I knew I wasn't going to
>
> go back there because of his attitude cause he had to put reasonable adjustments in
>
> by law but it doesn't change his attitude

26

From this perspective, although organisations might have a policy which focuses on 'reasonable' adjustment, adapting working environments and providing assistive technologies, if the line managers' attitudes concerning disability are oppressive then this will lead to individuals resigning, applying for alternative roles or even being dismissed. For the most part, when participants discussed oppressive practice within the workplace, all but one left their employment voluntarily. However, one participant did report being fired from his employment due to his competency being questioned, which related to issues concerning his dyslexia. Tony (42) reported that he raised a grievance with his employer due to a particular manager's perception of his competence due to his literacy abilities. Whilst the grievance was being investigated, he was suspended. This resulted in him losing the grievance and his employment, which then resulted in a court case. During this case, although he had been assessed 12 years previously, he had to be reassessed in order to confirm that he had dyslexia. Although Tony (42) won his court case and received a financial settlement from his employer, he ultimately lost his employment and has struggled to find suitable employment since.

Discussion and Conclusion

Findings from the authors' quantitative phase demonstrated an intersectional relationship between socio-economics and dyslexia at a macro-level (*see* Anon 2019). Yet data presented in this paper from the qualitative stage of the study revealed that socio-economics (Macdonald 2009) and gender (Skinner and MacGill 2015) did not appear to emerge as a prominent theme at the micro-level. From a qualitative perspective, the entire group experienced some form of stigmatisation and exclusion, as well as discriminatory experiences in education and employment. Participants in this study all articulated painful stories of

27

educational and workplace exclusion based on their perceived 'inability' to engage in

advanced literacy skills. Of these, nine were educated post- and six pre-*Education Act* 1981,

yet within all of these narratives, difficulties participants experienced with literacy led to

assumptions being made about their abilities across other subject areas, thus alienating them

in schools.

What became evident from the findings was that people with dyslexia appear to read and

write in different ways compared with their non-dyslexic peers. To do so, they report using

different assistive technologies to engage in literacy, yet a significant barrier emerged as these

technologies are not integrated in the contemporary education system. For a number of

participants a lack of access to assistive technologies was a key disabling barrier in preventing

them from engaging with advanced literacy skills. From their perspective this is an example

of how education does not prepare children with dyslexia for adulthood and in particular for

the contemporary workforce (also found by Macdonald 2009). So, although educational

inclusion has been a dominant discourse since the late 1970s, the nine participants educated

in the post-1981 *Education Act* era did not report feeling *included* within the classroom or

throughout their educational biographical journeys.

Towards the end of their schooling experiences, perceptions of 'failure' impacted further

negatively on the aspirations of many participants (Madriaga 2007). So, the discourse of

failure became significant and emerged throughout participants' narratives (Tanner 2009).

These discriminatory experiences of education, reported by participants, did not just stop at

the end of school life, but continue to have a psycho-emotional impact throughout a person's

lifecourse, with similar experiences found in the workplace; thus reinforcing the individualistic

deficit view of the condition (Macdonald 2009; Tanner 2009). This deficit perspective is not just reinforced by non-disabled groups but appears to be adopted by the individuals themselves. Thus, in this study the narrative of 'failure' seems to appear and disappear throughout the entire group's life histories (Macdonald 2009; Tanner 2009).

Whilst in adulthood assistive technologies were often used to meet the legislative requirements of 'reasonable' adjustment in the workplace, participants very rarely reported that their employers actively attempted to foster an inclusive working environment. As William (2016) states, employers have the ability to interpret the meaning of 'reasonable' adjustment within their own organisations which leads to an 'implementation gap' for disabled employees (356). Therefore, because of this, participants reported experiencing significant disabling barriers relating to their competency being questioned, as well as being subjected to issues of stigma (Riddick 2000; 2010; Macdonald 2009). In this study, these challenges appear to have predominantly come from lower-level management. Although at an organisational level it could be argued that 'reasonable' adjustment was made for participants in this study in line with the *Equality Act* (2010), it should be noted that the implementation of these adjustments was dependent on how inclusive line managers were. If line managers had negative or discriminatory views of dyslexia, employees reported being stigmatised and excluded in the work place. This led to some participants leaving their jobs, and in the most extreme case, one participant being made redundant.

From a social relational perspective, throughout individuals' lives the experiences of exclusion have had a negative psycho-emotional impact on participants in this study. This has led to participants individualising their experiences of discrimination both within education and

29

employment, i.e. perceiving the problems in education and employment as resulting from a

neurological deficit rather than because of environmental barriers (Macdonald 2009; Riddick

2010). To conclude, these findings illustrate that the embodied experiences of dyslexia are

defined within a *disabling*-educational system and a *discriminatory*-workplace, both of which

have a psycho-emotional impact on a person's lifecourse and personal identity. Thus,

although society constructs the notion that we are living through an age of inclusion and anti-

discriminatory practices, the findings in this study seem to be consistent with previous

research by Riddick (2010) and Macdonald (2009) suggesting that equality legislation has only

had a relatively minor impact on the personal experiences of inclusion in contemporary social

life.

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35