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‘I didn’t want to face another day of failing’

The emotional wellbeing of young people with severe dyslexic difficulties in state mainstream education: social and discursive constructions

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A thesis submitted for the degree of

Doctor of Philosophy in Childhood and Youth

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Declaration

I hereby declare that this thesis has not been and will not be, submitted in whole or in part to another University for the award of any other degree.

Signature:

Date: 27 September 2021
This thesis is dedicated with love to my family,
Mark, Tom and Dexter and to the
memory of my parents, Betty and Lauri
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Abbreviations and terms explained

**BDA**: the British Dyslexia Association, which aims to promote a dyslexia friendly society which allows people with dyslexic difficulties to reach their full potential.

**EHCP**: Education, Health and Care Plan is a legal document which entitles children and young people aged up to 25 to support beyond what is available through special educational needs support.

**ITT**: Initial Teacher Training.

**DfE**: Department for Education.

**DHSC**: Department of Health and Social Care.

**Parents**: parents and carers.

**Primary School**: state, mainstream school between 5 and 11 years.

**RTI**: Response to Intervention.

**SATs**: Standard Assessment Tests are taken twice during primary school – at the end of Key Stage 1 and 2 (years 2 and 6).

**SEN**: Special Educational Needs.

**SENCo**: Special Educational Needs Coordinator.

**SEND**: Special Educational Needs and Disability.

**SpLDs**: Specific Learning Difficulties is a term used to describe a group of difficulties which frequently co-occur: Dyslexia, Dyspraxia / Developmental Coordination Disorder (DCD), Dyscalculia, Attention-Deficit Disorder (ADD)/Attention-Deficit Hyperactivity Disorder (ADHD). SpLDs also co-occur with difficulties on the autistic spectrum.

**State school**: a school funded by the government, which provides education free of charge to pupils.

**Secondary School**: state, mainstream school between 11 and 16 years.
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Abstract

In this thesis I focus on the lived experience of young people with severe dyslexic difficulties in state, mainstream education in England. In considering school as a space where difference is constructed and stigma can be experienced, I draw on sociological theory to explore the kinds of emotional labour (Hochschild, 1979) that school demands from young people, when they have to explain their needs, as well as hide, downplay and negotiate their difficulties. Working with conceptual resources drawn from symbolic interactionism and the work of Foucault and Bourdieu, I explore how discursive and cultural practices form part of the institutional and relational contexts created by policy-makers, parents, teachers and peers and the implications of these for young people’s emotional wellbeing and identity. The study contributes to a very small body of existing literature about those whose dyslexic difficulties are most severe and broadens the conversation about young people’s experiences at school to consider the wider influences that shape their identities. The empirical basis of the research includes a mixed methods online survey with 474 parents and qualitative research with 15 young people aged 10-19 and their mothers.

The findings of the study echo those within the existing literature, suggesting that access to early, evidence-based intervention in primary school makes it possible for young people to move on from a dyslexic identity and progress alongside their peers. However, my research presents a landscape of inconsistency in terms of the distribution and quality of provision, with parents holding government accountable for a lack of investment and varying levels of awareness and understanding of dyslexia among educators. Parents’ ability to negotiate access to support was also uneven, reflecting an unequal distribution of economic, cultural and social capital.

Mothers emerge as central actors in the management of their children’s emotional states, playing a key role in scaffolding them away from notions of deficit towards ideas of difference. Drawing on Reay’s interpretation of emotional capital, I also consider classed cultures of parenting as having relevance to an understanding of young people’s emotional wellbeing. The role of teachers and trusted adults within the
school is also examined, including the vital part they play in mediating institutional discourses through micro interactions with learners.

On the basis of these findings, I argue that educators would benefit from opportunities to learn about the emotional impacts of living with severe dyslexic/literacy difficulties, challenging them about normative assumptions regarding difference and deficit. By amplifying positive stories about school, it becomes possible to understand the importance to young people of having their challenges recognised and their abilities and achievements acknowledged, as well as the importance of being able to express their agency, feeling cared for by staff, and a whole-school ethos supporting inclusivity and neurodiversity.
Chapter 1. Introducing my research

The time at which my youngest son started school marked an important point of change, described by Thomson et al (2002) as a critical moment, in both his and my own biography. He became aware of his specific learning difficulties (SpLDs) and began to feel a sense of otherness, and I was thrust into the role of advocate and forced to challenge his teachers about his special educational needs provision. After several years of confrontation with his school and still no nearer effective support and a happy child, I had so many questions. Why did literacy difficulties have such a profound impact on the way he felt about himself? What could teachers do to better support young people like my son? Why are some teachers opposed to the term dyslexia? How could my family and I support him better? This thesis sets out to answer these questions and many more.

In this first chapter I outline the background and context for my research, as well as my motivation and desired goals. I position myself in the research, explaining why I came to be interested in this subject area, what my experience has been and how it has affected me. In sharing this information about my identity as a researcher there is an acceptance that my presence in the research has had some effect on the process through which knowledge is created and that my interpretation of the findings will be value-laden (Harrington, 2005). However, by remaining reflexive and transparent throughout the research I hope to produce an account that is authentic, stands up to scrutiny and contributes to an understanding of an under-researched area.

1.1 From advocate to academic

I believe it is important to summarise how I came to be interested in this subject and recount a little of my own, and my family’s story. In 2005, when my youngest son started school with a moderately severe speech disorder, I knew that communication and social interaction would be challenging for him and that his literacy may be

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1 Provision is ‘different from or additional to that normally available to pupils or students of the same age’ (the SEND Code of Practice, Department for Education [DfE] & Department of Health and Social Care [DHSC], 2014, p. 16) and when effective ‘improves long-term outcomes for the child or young person’ (ibid, p. 94).

2 My family has agreed to me telling a very concise account of this aspect of their lives.
impacted. What I did not anticipate was the shame, sadness and self-loathing he would feel as he struggled to read and write to the standard expected of him at school. At this time, I could not have imagined the impact his difficulties would have on him and us as a family.

A chance encounter for my husband, at this point in his 40s, led him to consider that the difficulties he had experienced all his life could be related to dyslexia. When our eldest son fell behind with reading and writing we were concerned, however he seemed to take it in his stride and his sense of self was not negatively affected at this stage; this unfortunately changed as he got older, in particular when he went to university. However, our youngest son’s difficulties were very severe and he seemed consumed by them, often crying before and after school. Hearing the words ‘my life is not worth living’ when he was 7 years old was heart-breaking. As a family, our lives became dominated by the unhappiness he experienced at school and by the time we spent advocating for him and trying to secure effective provision.

At the beginning, turning to the school for help seemed clear and straightforward. I never doubted that they would not help us. By contrast, what we found was not only a lack of understanding of his difficulties but also a lack of awareness, which meant that the help we hoped for was not forthcoming. Perhaps the biggest barrier to securing the right support for him was the lack of recognition that, in the context of school, he was significantly restricted and that his profound difficulties meant that he required greater levels of support than those identified as having less severe dyslexic difficulties. There was a clear tension between our understanding of his needs and the school’s lack of recognition. This led to the school and local authority being defensive towards us and for us to become embroiled in conflict with them for several years, including two special education needs and disabilities (SEND) tribunals. We were always sympathetic to the pressures that schools were under and were deeply uncomfortable at having to challenge teachers’ professional integrity, however, our son’s declining mental health meant that confronting the school was the only option available to us. Yet, in spite of our relatively privileged position – my husband’s role as a teacher and our level of education – it was only in sixth form that he started to
receive support that enabled him to access the curriculum and begin a long journey to address his negative sense of self.

Writing this at the end of a long research process I am able to reflect on this period with greater perspective. No doubt, with the greater understanding that I now have, I would have done things differently. However, like the parents in my research, I could only act according to what I knew at the time and what I thought was best for my child. It was through this lack of understanding about the causes of my son’s unhappiness surrounding his literacy difficulties and a concern for social justice that formed the basis of my research.

Studying for a Master’s in Childhood and Youth Studies between 2014 and 2016 provided an interdisciplinary framework with which I could explore the broader issues affecting childhood and make sense of my son’s experience. It encouraged me to move beyond linear, universal understandings of childhood development towards viewing youth as ‘a changing and varied social phenomena’ (McLaughlin, Coleman-Fountain and Clavering, 2016, p. 15), framing children as active beings who are involved in shaping their own world. The research that I undertook for my Master’s dissertation (Durrant, 2015) was about the emotional wellbeing of children with severe dyslexic difficulties in mainstream school and comprised in-depth biographical narrative interviews with two parents. It confirmed that my son’s experience was not unique and that the wellbeing of children and parents are closely entangled. The research was small-scale and exploratory and did not include the voices of children themselves, yet it raised questions that I felt justified further research at doctoral level. It also prompted me to think beyond the classroom to the wider causes of the distress that both my son and the children in my Master’s research had experienced. I found myself questioning the value placed on literacy over other kinds of competencies and skills and began to think more critically about the discourses around dyslexia, wondering how the ways that the phenomena of dyslexia is produced by experts and shaped by parents may unwittingly have an impact on young people.

A discourse analysis, conducted for my MSc in Social Research Methods, on newspapers’ representation of dyslexia over a seven-year period (1 April 2010 to 31 March 2017), also made me more aware of the extent of the discourse of deficit and
the limited amount of coverage about social barriers. This made me think about the implications for young people, in particular the impact of the media on how they perceive themselves and how they are regarded by those around them, including parents, peers, teachers and policy-makers. Of the five UK national newspapers sampled, the Sun, Mirror (and Sunday Mirror) and Daily Mail (and Sunday Mail) reinforced the discourse that dyslexia is an individual deficit and not something to which society should adapt. The broadsheets (The Guardian and Daily Telegraph) were more likely to represent dyslexia in terms of social barriers. I also found there to be a recurring theme of individual misfortune, particularly in the tabloids. Much of the representation of dyslexia in these newspapers was in the form of narratives about celebrities, entrepreneurs, sportsmen, and less often, people who are not in the public eye, who have ‘overcome’ their difficulties but ‘suffered’ and ‘struggled’ because of them. In addition, the newspapers sampled rarely commented on the social implications of dyslexia.

In trying to secure effective provision for my son, I had to navigate my way through the SEND system. In this process I learned a great deal, understanding the bureaucratic system but also gaining awareness of how inequalities and privileges are reproduced through its mechanisms. Reflecting Ong-Dean’s (2009) work on parents, privilege and special education, I began to think about how my own advocacy had contributed to this inequity – what Reay describes as middle-class mothers ‘simultaneously acting against the interests of the children of other, less privileged, mothers’ (2005, p. 114). I was very aware of how different my son’s story could have been if we had not known anything about dyslexia ourselves and had not been able to afford for him to have an assessment. Macdonald (2009a) suggests that the children of middle-class families are more likely to be assessed as having dyslexic difficulties than those from working class families. The inference here is that this is due not only to middle-class parents’ greater educational power/knowledge and economic capital (Skeggs, 2004) but also to ‘institutionalised attitudes within education’ (Macdonald, 2009a, p. 158), which make assumptions about the intellectual capacity of working-class children. Other authors talk of the advantage that middle class parents have in securing additional support for their children at school. For example, Riddick (1996) suggests that dyslexia is often only
identified when parents carry out their own research and pay for diagnostic assessments; these parents are often middle class because of the process of completing forms and liaising with professionals. The role of advocate was personally challenging and extremely stressful and I began to think about how much harder it would have been if I had not been white and middle-class. Knowing that support had only been secured for my son because of our relatively privileged position made me uncomfortable and raised issues for me around social justice. This has almost certainly changed the lens with which I have looked at my research and has encouraged me to think more widely about the social implications of dyslexia.

My journey has involved an engagement with critical theory that has problematised many of my taken-for-granted views about the world. Through the writings of scholars like Foucault, Bourdieu and the Symbolic Interactionists, I began to see that my son’s experience was the result of the interaction between many factors – family and community, socio-cultural and institutional. I also came to understand that he was not only influenced by the SEND provision he received and his relationships with teachers, peers and family and their unique ways of communicating with him, but also by the discourses surrounding him, such as the way in which literacy has been constructed as important in post-industrial societies. Burden describes this as ‘culturally imposed assumptions that (a) literacy is important, and (b) everyone should find it (relatively) easy to learn to read’ (2012, para’ 5).

The landscape for understanding my son’s experiences had expanded beyond a focus on the classroom to include wider impacts on identity construction and emotional wellbeing. This recognition that people are labelled ‘through the identification of the difficulties that have been imposed by social and educational barriers (assumptions, systems and expectations) mediated through social interactions’ (Cooper, 2010, p. 11) led me to explore dyslexia through a sociological lens. In framing the experience of the individual in this way I have tried to make space for the active role of the young person by acknowledging that although they live in social worlds that are restricted by structures, they also exist as agents able to operate creatively in and upon structure (Prout & James, 1990).
1.2 Setting out my research

My PhD research prioritises the voices of young people, whilst also recognising that these need to be understood as situated within their families. It emanates from a genuine aspiration to prevent others from having to experience the kind of trauma that my son endured and improve the everyday experience of those with similar difficulties in state, mainstream education.

Much of the research on dyslexia focuses on the young person and their interaction with their immediate environment. In order to contextualise the experiences of the young people explored in this thesis, I have used Bronfenbrenner’s Ecological Model (1979) to provide a framework to scaffold my thinking about the different layers of influence at play and consider where attention should be paid. A similar model was used by Poole to enable a wider interpretation of the child within their ‘life-context’ (2003, p. 177) that goes beyond a within-child definition of dyslexia. In my adapted version of Bronfenbrenner’s model shown below, I conceptualise the micro-system of parents, school, peers etc., and the interrelations between these (known as the meso-system), as well as indirect environmental factors (exo-system), for example, SEND law, government and local authority policies, and the larger cultural and social structural elements of the environment (macro-system). A model such as this is static and it is important to consider the temporalities involved, including how the term ‘dyslexia’ is constantly being renegotiated, as well as the ways in which children and those in relation to them engage and shift in response to lived experience over time. For example, what is constructed (and experienced) as an impairment at one point in time may be viewed differently at another because cultural norms and attitudes constantly change or technology (and competence) improves, rendering dyslexia no longer so relevant as a classification.
By focusing attention on experience within an environment, Bronfenbrenner’s model provides a framework for exploring questions of influence and agency. In choosing to take a self-consciously child-centred approach, this research takes the perspective of agency as relational, distributed and contingent - engaging with young people’s experience and recognising their agency, yet at the same time tracing and understanding the constraints and incitements that shape their imaginations and actions (Ansell, 2009). In chapter 3 I outline my approach to agency as social and relational, as a collaboration and negotiation with adults, rather than as an inherent quality of each young person.

Working with a framework derived from the work of Bronfenbrenner (1979) allows me to understand young people and their environment in relations that ‘continually influence one another in a bio-directional, transactional or mutual manner’ (Poole, 2003, p. 173). This framework also serves as a scaffold for the three different bodies of theory drawn on in the thesis. Each has been used previously within the fields of education and disability research, for example, Allan (1996) and Morgan (2005) use Foucault as a framework for studying SEN, Holt, Bowlby and Lea (2018) and Gillies (2005) draw on Bourdieu’s work on cultural and economic capitals to study how parents access provision for their children with SEND and Lithari (2018) uses Goffman’s (1963) concept of stigma to theorise the findings of her qualitative study about how
children with dyslexic difficulties transition from primary to secondary school. However, deploying these different theoretical possibilities together is more unusual, perhaps because theoretical pluralism can give rise to epistemological contradictions or awkward joins between deconstructive and constructive frameworks. Yet, like Bronfenbrenner, I am keen to move between scales in my analysis and this has led me to utilise theoretical resources strategically. My contention is that theoretical pluralism enhances my account of how dyslexic selves are created and changed through time because each theory provides a different lens or angle with which to consider action and the interplay of different actors, as well as context and constraints. Throughout this thesis, I have thought with these different theoretical resources, stimulated by the different perspectives that they enable, including distinct understandings of agency and its limits.

Both Foucault and Bourdieu share the perspective of social constructionism and the view that people are historically structured agents. However, they differ in how they conceptualise this relationship. Bourdieu’s concept of the habitus is characterised as ‘a subjective but not individual system of internalised structures, schemes of perception, conception, and action common to all members of the same group or class’ (1977a, p.86). He sees power as continuously re-established through the interplay of structure and agency and understands agency as always gaining meaning in particular fields and cultural contexts. In terms of this study, we may think of how the advocacy of parents exists within formations of social class and the re-production of privilege. Foucault, on the other hand, makes less space for the individual, understanding power as ubiquitous and visible in its effects on ‘docile bodies’ (1977) and embedded in discourses (1970). For Foucault, both objectification and subjectification are the effects of power, and agency itself needs to be understood as produced within discourse. However, although Foucault did not believe that absolute freedom was a possibility or that it was possible to find a new self, he suggests that individuals ‘might find moments of freedom or of otherness’ (Albrecht, 2006, p. 1555). In my research we can appreciate how the notions of progress and development shape the forms of subjectivity available to children and how this can be objectified through practices and forms of measurement, but also internalised and experienced in terms of notions of
normality and fulfilment. Symbolic Interactionists, on the other hand, focus attention on ‘how people are made up day by day, within an existing institutional and cultural structure’ (Hacking, 2004, p. 299. This emphasises that people are not ‘free agents’ but that ‘their cognitions and behaviors are controlled by the larger community’ (Ritzer and Stepnisky, 2017), making them active, although not always knowing, agents in the production of their social worlds. Mead (1934) argued that human beings are reflexive and made the distinction between the ‘I’ and the ‘Me’, where the ‘Me’ is the social self and where the attitudes of others are assumed and the ‘I’ is the response to these attitudes. In highlighting this he is suggesting that human action is based on the meaning they assign to an object. Goffman contributes to this discussion through his metaphor of the actor and the stage and the notion of total institutions in which a person’s self can be mortified by processes that damage their ‘civilian selves’ (1961, p. 24), disrupting their ability to show any command over their world.

It is my contention that thinking with these three theorists allows me to utilise different tools for different tasks, illuminating particular dimensions of my analysis and data and generating a multi-dimensional account that locates the children that are my focus in the context of institutions, practices, discourses and relationships. Hacking (2004) suggests that Foucault’s ‘top-down’ (p. 277) approach, which examines complete ‘systems of thought’ (p. 277) and structures within society under-emphasises individuals’ motives and falls short of examining how discourses are incorporated into our lives and the effects they have on us. Hacking points to Goffman and symbolic interactionism as a way of understanding the ‘bottom-up’ (2004, p. 278), everyday way in which we interact within institutions, for example, schools, and uses his theories to complement and supplement Foucault’s work, describing it as a ‘counterweight to … Michel Foucault’s archaeologies’ (p. 281). Both Foucault and Goffman studied extreme cases of the human condition and published works on madness and institutions – Foucault’s ‘Histoire de la folie’ and Goffman’s ‘Asylums’ (both 1961). Both were also interested in stigma: Foucault in terms of normalisation and bio-power; Goffman in terms of the day-to-day way in which people interact within institutions. Combining scholarly traditions allows me to understand the findings of my research in terms of how and why norms become entrenched and endorsed within educational institutions.
and how people are involved in this process of negotiation and interpretation and ‘play a role in larger scale dynamics of power, regulation, marginalisation and discrimination’ (Coleman-Fountain and McLaughlin, 2013, p. 135). By also engaging with the work of Bourdieu, I provide a lens with which to further consider structural limitations and the extent of unequal access to the resources that parents draw on to access provision for their children. The case for addressing micro, meso, exo and macro contexts of the experience of young people with severe dyslexic difficulties is supported by Bronfenbrenner’s framework. This in turn allows me to draw strategically on these three sociological theories in a pluralistic approach, enabling me to reveal different kinds of knowledge and insight arising from my data about the individual and their social context.

As the title of this thesis suggests, my focus is on understanding emotional wellbeing, which Keyes describes as ‘the presence or absence of positive feelings about life’ (2002, p. 208). This term reflects my broad, interactive perspective, acknowledging the importance of taking into account ‘environmental, management, biological, cognitive and behavioural factors’ (Bailey, 2012, p. 7). It also implies that responsibility for good emotional wellbeing lies with the whole of young people’s environment, or the whole ecological system. My understanding of emotional wellbeing begins with young people’s social and collective construction of identity (Lawler, 2014) and includes the ‘interrelationship between the “inside” and the “outside”, the personal and the social’ (Woodward, 2002, p. 20). Informed by the contributions of Mead, Cooley and Goffman, my research is focused on studying an interactive self that constructs an identity through the interface between self and society, with emotions arising from social relations and socio-cultural processes. Underpinning this is the work of Foucault who describes identity as fluid, historically specific and shaped through discourse (Woodward, 2002). From this perspective emotional wellbeing is not simply a personal possession but is connected in important ways to wider structural processes that reveal access to provision as a site of classed contestation with implications for life chances. Inequality of access to educational provision, a discussion informed by scholarship drawing on the work of Pierre Bourdieu (1986) and his conceptualisation of capitals, is discussed in chapter 5.
Despite my landscape expanding, the lived experience of school continues to be a focus for this research. Gilligan describes school as having the potential to be:

‘an ally for children, a guarantor of basic protection, a capacity builder, a secure base from which to explore the self and the world, an integrator into community and culture, a gateway to adult opportunities and a resource for parents and communities’ (1998, p. 13)

Ultimately my thesis aims to understand how schools can achieve this for young people with severe dyslexic difficulties, within economic and political constraints and a context shaped by inequality.

1.3 Why is the dyslexia debate important?

So far in this introduction I have sketched my own journey into and through this research. A key part of this has been my need to engage with the ongoing debate over dyslexia. Over recent years understanding of dyslexia has polarised into two opposing groups, which broadly represent disability rights on the one side and rights for everyone with literacy difficulties on the other. This section will explore both conceptions of the term and will be explicit about my position within the debate.

There is now general agreement that reading is predominantly a linguistic skill and that the most significant cause of difficulties in learning to read is ‘in establishing connective bonds between a word’s spoken and written counterparts’ (Vellutino et al 2004, p. 30), known as phonological difficulties. Shaywitz and Shaywitz describe how reading requires phonological awareness, in particular awareness of the smallest units of sound, or phonemes, that link to the letters – the ability to convert the print on a page into ‘a linguistic code’ (2004, p. 6). They describe dyslexia as a weakness in accessing the sounds of spoken language.

The British Dyslexia Association (BDA) (2012) estimates that up to 10% of the UK population are affected by dyslexia and approximately 4% experience it severely, regardless of intellectual ability, socio-economic status or race (Badian, 1984). However, there is significant disagreement about how to define dyslexia (or what is defined through the term), as well as debate about the diagnostic tools available for identification, educational interventions and even on the value of dyslexia as an
autonomous category. With this level of uncertainty, Hayes (2018) suggests that it is virtually impossible to assess the actual number of people impacted by it.

Snowling (2014) contends that there is a significant amount of agreement within the discipline about the key characteristics of dyslexia, however, Rice and Brooks (2004) discuss the lack of agreement about the causes and Brown Waesche and colleagues lament the absence of a single definition:

‘Without an agreed-on definition that can be implemented reliably and validly, understanding the nature, causes, and best treatments for reading disability is unlikely. Similarly, an agreed-on definition is essential for practice.’ (Brown Waesche et al., 2011, p. 296)

Scientific research into the aetiology of dyslexia spans many different fields including psychology, medicine, genetics and neuroscience and crosses countries and continents. On the disability-rights side of the dyslexia debate, there is a degree of shared understanding that there are differences in ‘the brains of people with this information-processing disorder, either in structure or function or an interaction between the two’ (Hayes, 2018, p. 66). There is also some agreement that this difference can lead to good big-picture processing skills (Shaywitz, 2005). On this side of the debate, it is accepted that dyslexia has genetic correlates and can be accurately diagnosed by an Educational Psychologist (EP) or dyslexia specialist. Another area of consensus is around the importance of dyslexia being identified early and interventions being put in place as soon as possible, ‘before a downward spiral of underachievement, lowered self-esteem and poor motivation sets in’ (Snowling, 2013, p. 7). In terms of interventions, it is agreed that they should be evidence-based and evaluated through randomised controlled trials (RCT) – something that is rare for ethical and practical reasons in education (Hayes, 2018). However, based on the evidence that does exist, it is agreed that well-founded interventions for dyslexia should involve training that has explicit and rigorous instruction in phoneme (being able to hear, recognise and manipulate the smallest observable speech sounds) awareness and analysis. Importantly, this intervention is often seen as being different from the support needed by other poor readers whose difficulties are often perceived as being due to poor teaching or low intelligence.
On the other side of the argument, there are those such as Elliott and Grigorenko, who have highlighted the ‘conceptual, definitional, and diagnostic dilemmas’ (2014, p. 110) surrounding dyslexia. Elliott concedes that there are certain areas of the brain that can be linked to reading difficulty but denies that there is an available test that can determine whether a difficulty is biologically or environmentally based (2016). In addition, he argues that making such a distinction is pointless because whatever the origin of the condition, they require the same interventions (ibid). Elliott and Grigorenko (2014) therefore suggest that the term ‘dyslexia’ should no longer be used and that there should be greater focus on individual difficulties and more emphasis on understanding and addressing ‘literacy problems across clinical, educational, occupational, and social policy contexts’ (Elliott and Grigorenko, 2014, p. 4). Their questioning of the value of the term and assertion that there should be no distinction between people with dyslexia and other poor readers has been highly debated and often misrepresented by the media. Headlines such as those shown here from the Daily Mail may have served to damage perceptions of dyslexia:

- The Dyslexia Deception (Daily Mail, 3 April, 2014)
- Why Pushy Parents Insist their Children are Dyslexic (Daily Mail, 24 February, 2017)

Elliott (2016) suggests that early reading failure has a negative emotional effect when the difficulties are severe and enduring, however, he argues that understandings of dyslexia do not stand up to scientific analysis and that identification does not help to inform effective interventions. He also highlights that without a definitive, internationally agreed definition of dyslexia it is not possible to undertake scientifically valid research and claims that assessments for dyslexia are unable to differentiate between dyslexic and other poor readers. Dorothy Bishop, a Professor of Developmental Neuropsychology at the University of Oxford, agrees that:

‘it is, of course, possible that one day we may hit upon a new diagnostic test that does clearly differentiate a dyslexic subgroup from other poor readers, but many of us in the field are dubious as to whether this will ever happen’. (Bishop, 2014, para 2)

She likens dyslexia to other neurodevelopmental disorders, such as autism, saying that
they:

‘are all beset by the same issues: there is no diagnostic biomarker, the condition is defined purely in terms of behaviour, different disorders overlap and there's no clear boundary between disorder and normality.’ (Bishop, 2014, para 7)

Bishop (2014) likens the complexity and contention surrounding the concept of dyslexia to that of mental disorders, such as schizophrenia and depression, where people cannot agree on how to differentiate them from other disorders or who justifies the diagnosis. Kendall and Jablensky (2003) studied the usefulness of psychiatric labels and concluded that despite most of them not being ‘discrete entities with natural boundaries that separate them from other disorders’ they have ‘high utility by virtue of the information about outcome, treatment response, and aetiology that they convey’ (2003, p. 4). Bishop (2014) believes that the same is true of the construct dyslexia and that it still has utility because it ‘carries connotations of causation, blame and responsibility’ (2014, para 19). In a 2001 paper published in International Studies in Sociology of Education, Riddick also argues that the term is useful because it allows children to access support in school.

By way of compromise, Elliott suggests that those who have received ‘systematic, substantial, evidence-based intervention over a lengthy period of time and whose reading skills continue to be highly problematic’ (2016, p. 111) could be identified as ‘dyslexic’; everyone else could be described as a poor reader. However, this would depend firstly on everyone agreeing about what is ‘systematic, substantial, evidence-based intervention’ (ibid) and secondly on schools having the resources and staff to deliver it.

The dyslexia debate shows no sign of resolution and, if anything, the two sides are growing even further apart. In 2018 two local authorities – Warwickshire and Staffordshire – trialled a model of assessment through teaching (ATT) which did not differentiate between children with dyslexic and literacy difficulties. In doing so they stopped using the classification ‘dyslexia’. When they experienced very strong opposition from dyslexia organisations and advocates, both local authorities dropped
the scheme. Since then, the local education authority of Cambridgeshire has taken the middle ground and retained the word dyslexia in policy guidance but has not differentiated between those with dyslexic and literacy difficulties in teaching literacy. They describe the term ‘dyslexia’ as firmly embedded in the public domain and use it interchangeably in their policy documents (Cambridgeshire, 2018). They have adopted an approach called Response to Intervention (RTI), a dynamic model of assessment and instruction which emerged in the United States around 2004. It stands in sharp contrast to the more common method whereby assessment and identification only comes after a period of failing (Cambridgeshire, 2018).

With two such opposing arguments, it is important that I establish my own position, both at the onset and at the end of this research. Before I began my studies, I treated dyslexia as a self-evident category and moreover was invested in it through my advocacy, which involved networking with other parents through the category of dyslexia. However, through my research I have started thinking about dyslexia, not as a learning difficulty, but as a diagnostic category that came into existence at a point in history in keeping with the social and political atmosphere at the time. Industrialisation in Britain required a literate population which, in 1880, led to compulsory schooling and the capitalisation of the population by the government. Changing expectations of its citizens’ literacy skills gave rise to the problematisation of poor readers (Campbell, 2013) and the first identification of developmental dyslexia in 1896. Bearing this in mind, I believe that the conversation, initiated by Elliott and Grigorenko in 2014, has been useful because their views have challenged established discourses of dyslexia. I agree with their socio-political argument that the term ‘dyslexia’ often serves those with greater resources and concur with their view that schools should focus on individual differences rather than diagnostic categories. I will return to this subject in the discussion chapter.

1.4 Defining dyslexia: a critical analysis

Despite supporting a model of SEND that gives equal rights to everyone with literacy difficulties and does not privilege those with dyslexia, I nevertheless use the terms ‘dyslexic’ and ‘dyslexia’ in my research and throughout this thesis. I do this because it is a category in common use by policymakers, schools, parents and, most importantly,
young people themselves. In this section I describe the definition of dyslexia used most often in schools in England which was developed in 2009 for an independent report by Sir Jim Rose to the Secretary of State for Children, Schools and Families called ‘Identifying and Teaching Children and Young People with Dyslexia and Literacy Difficulties’. In the following sections I explain my reasons for focusing on those with the most severe difficulties and discuss my use of terminology.

Rose’s 2009 report states that ‘dyslexia is a learning difficulty that primarily affects the skills involved in accurate and fluent word reading and spelling’ (2009, p. 10) and includes difficulties with phonological awareness, verbal memory and verbal processing speed. Rose (2009) also states that dyslexia occurs across the range of intellectual abilities and often co-occurs alongside other difficulties, for example, ‘in aspects of language, motor co-ordination, mental calculation, concentration and personal organisation’ (2009, p. 10). Rose describes dyslexia as a continuum, as opposed to a distinct category and states that ‘a good indication of the severity and persistence of dyslexic difficulties can be gained by examining how the individual responds, or has responded, to well-founded intervention’ (2009, p. 10). Rose’s definition recognises that there are different levels of severity of dyslexia and in the full report he talks about how ‘a small proportion will need more intensive support and long-term assistance’ (2009, p. 35).

Rose (2009) suggests three levels of intervention for dyslexia: core classroom instruction in phonics; small group intervention targeted at children who are falling behind; specialist, individual intervention and a more extensive assessment for children who are showing little progress. This approach uses the principles of RTI and is based on the assumption that children who do not respond to well-founded interventions require further assessment in order to understand their difficulties better (Snowling, 2019). Criticisms of this method tend to focus on children with severe difficulties who, it is argued, should not have to go through each stage and fail, before they are fully assessed (ibid).

Rose’s (2009) conception of dyslexia was criticised by the House of Commons, Science and Technology Select Committee as being ‘so broad and blurred at the edges that it is
difficult to see how it could be useful in any diagnostic sense’ (2009, para 71). In spite of this, Rose’s (2009) interpretation is still upheld by the BDA, although in recent years they have added visual and auditory processing difficulties and there has been a movement to identifying and promoting the strengths of dyslexia.

In my view, Rose’s definition is inclusive and comprehensive for the purposes of those working in schools. It is not based on a discrepancy between intelligence and literacy skills, which distinguishes it from historical definitions, but acknowledges that dyslexia can affect anyone, regardless of age, gender and cognitive ability (Reid, 2016). There are, however, aspects of it with which I disagree. Firstly, and in my view most importantly, Rose’s definition perpetuates the deficit model of disability, ignoring the view that dyslexia has been constructed by the central discourse within education which supports and endorses literacy as a social norm. Gardner (1983) was the first person to suggest that dyslexia may be a different way of learning and therefore a difference rather than a deficit; he believed that linguistic ability was just one of several ways of expressing intelligence (ibid). Secondly, I believe that the recognition that severity is based on the response to well-founded interventions is too open to interpretation – what is well-founded in one school could be completely different in another. Thirdly, in my view, the word spectrum is more appropriate than Rose’s (2009) continuum because it moves away from seeing dyslexia as being on a straight line and moves towards dimensions in which individuals vary and have their own strengths and challenges. Hayes (2018) describes this as particularly important because dyslexia is very individual and manifests itself in numerous ways.

1.5 Why my research focuses on severe dyslexic difficulties

It is notable that practitioners and assessors rarely discuss severity in relation to dyslexia. This is likely to be because dyslexia, as mentioned above, is regarded as being on a continuum, and, as Hayes states:

‘... it is almost impossible to allocate a cut-off point on that continuum or normal distribution curve to distinguish the borderline dyslexic from the severe’ (Hayes, 2018, p. 40).
However, for the purposes of my research, I am interested in creating knowledge with, and about the lived experience of, those whose dyslexic difficulties are most severe. This is unusual, with most existing studies focusing on the broader term ‘dyslexia’. Arguably this could lead to the differing challenges and support needs of those with the most severe difficulties being minimised and misrepresented and contribute to their needs not being fully recognised, represented and accommodated.

Evidence from the autistic community suggests that:

‘we cannot sensibly expect one single word “autism” to be the only word used to describe this hugely complex condition. Autism is far too diverse and its degree of impact on those who manifest its symptoms is enormously wide’ (Kenny et al., 2016, p. 456)

The same study reports that parents also express their concern that the term ‘autism spectrum disorder’ leads to those children on the more severe end of the spectrum being neglected. Clearly, the needs of autistic people who need high levels of support are very different to someone with severe dyslexic difficulties, however, I believe that the same argument stands.

In an interview with the Times Educational Supplement in 2018, Snowling talks about severity existing but says that it needs to be considered in conjunction with other factors, such as parental and school support, as well as the temperament of the child. She argues that the impact of dyslexia on everyday functioning is an important measure and cites the possibility that someone with mild dyslexia may experience a severe impact. Although there is a scarcity of research among people with severe dyslexic difficulties, of relevance to my research, a few academics have acknowledged a possible link between the severity with which dyslexia is experienced and self-perception. Burden (2008) points out that, in societies where literacy is seen to be of importance, there is a greater likelihood of people with severe dyslexic difficulties experiencing poor general self-concept. Macdonald also states that ‘severity obviously plays a central role in forming self-perception in relation to dyslexia’ (2009a, p. 158). My own experience of seeing the very different ways in which my two sons on opposite sides of the dyslexia spectrum responded to their difficulties at school, has led me to believe that research among young people with more severe dyslexic
difficulties is justified. Research for my Master’s dissertation (Durrant, 2015) supported this view. Both of the boys whose mothers participated reached a stage of such unhappiness that their parents withdrew them from mainstream school and won legal cases for the local authority to fund places at independent specialist dyslexia schools.

1.6 The politics of disability

In recent years, proponents of disability rights have attempted to change perceptions of disability towards the social model, which recognises that people are disabled by barriers in society rather than by their impairment or difference. In order to facilitate this change they have encouraged the use of language that fosters independence and generates more positive images for those being portrayed (Kenny, et al., 2016). To begin with this involved a campaign to promote the use of language that referred to the person first and then the disability (Blaska, 1993), for example, ‘a young person with dyslexia’. However, some disability communities disagreed with this campaign because they believed that it undermines the experience of living with a disability and prevents them from taking pride in their identity (Vaughan, 1997); supporters of this view would use the descriptor ‘dyslexic young person’.

Kenny and colleagues (2016) conducted a large survey to increase understanding of the terminology that the UK autistic community prefer to be used. They concluded that most autistic adults and their families preferred language that put identity first, while professionals favoured person-first language. There has not been a similar survey about dyslexia, however, I found myself needing to find a suitable way of describing the young people in my study. When advocating for my son, in order to access support, we had to focus on his deficits or difficulties. It was a necessary, but uncomfortable, way of thinking and talking about him, which made me uneasy at the time because, as Hunter-Carsch and Herrington state: ‘We know that the “disability” associated with dyslexia is largely constructed from the perceptions and social practices of others’ (2001, p. 129).

In the absence of definitive information, I have opted for person first language. In the initial stages of my research with parents I mostly referred to ‘young people with dyslexia’ but then started using the descriptor ‘young people with dyslexic difficulties’.
This was a conscious decision because I believe it to be more inclusive, embracing everybody who experiences these particular kinds of difficulties, regardless of whether or not they have had a formal diagnostic assessment or not. In doing this I have referred to discussions about the use of the words ‘differences’ or ‘difficulties’. Pollak (2009) describes how in recent years there has been greater use of the word ‘differences’ rather than ‘difficulties’ and in 2005 the BDA described dyslexia as a learning difference, which included both strengths and weaknesses. They justified their use of this term by saying that it ‘places the focus firmly on how all lessons are planned, resourced and taught and also on the way teachers are supported through school policy, practice and ethos’ (2005, p. 1). It is interesting however to note that the term difference is no longer used on the BDA website and dyslexia is once again referred to in terms of difficulties. The idea of brain difference being seen as normal rather than a deficit and greater value being placed on human diversity is attributed to Judy Singer in the late 1990s and she was one of the first to use the term neurodiversity (2017). Although originally applied to the autistic community, the term has been adopted by other groups, including those with SpLDs. In 2016 the Department for Education (DfE) used the word neurodiversity to describe SpLDs, encouraging people to ‘view neurological differences such as autism, dyslexia and dyspraxia as natural and normal variations of the human genome’ (DfE, 2016, p. 3).

On the one hand, I like the word differences because it moves away from the deficit model, however, as Walker and Shaw point out, ‘for those with more severe SpLDs, calling it a difference may leave them feeling as though the challenges they face are not acknowledged or validated’ (2018, p. 2). On this basis, I have chosen to use the term ‘difficulties’ in this thesis. Importantly, however, as I discuss in chapter 3, I tried throughout the interviews with young people to reflect the terminology they used.

Finally, I acknowledge that in using the term ‘young person with severe dyslexic difficulties’ as a shorthand, there is a potential for missing the uniqueness of individuals and stigmatising the whole person (Burden, 2008). However, I ask the reader to understand that my reasons for doing so are pragmatic; to describe those who are experiencing the most difficulties in participating in a specified range of school functions.
1.7 Thesis Structure

In the next two chapters I will contextualise my research within a wider literature. Following my discussion in section 1.2 about how I have used Bronfenbrenner’s Ecological Model (1979) as a scaffold for employing three different bodies of theory in this thesis, I introduce Foucault in chapter 2 and Bourdieu and Symbolic Interactionism in chapter 3. The literature review also provides context and locates my study within existing research on dyslexia and identity and emotional wellbeing. Chapter 4 details my research questions, as well as the theoretical perspective for my research and the epistemological underpinnings of the mixed methods research design that I have chosen to use. It also considers my positionality in relation to my research participants, reflexivity as a researcher, the ethical issues of researching a potentially vulnerable group and my approach to data analysis.

My findings will be presented across three chapters, which seek to answer my research questions and provide greater understanding of the lived experience of young people with severe dyslexic difficulties in state, mainstream schools in England. My first analysis chapter (chapter 5) focuses on provision in schools, asking why variation occurs and reflecting on how the category ‘dyslexia’ has been constructed in discourse over time. It analyses participants’ support in school, seeking to understand what effective provision is and its relationship with young people’s emotions. In addition, through the lens of Bourdieu’s (1986) capitals, I examine equality of access to provision. Chapter 6 focuses on the influence of relationships with parents, peers and teachers and explores how micro interactions reinforce discursive and cultural practices that are internalised by young people. Chapter 7 presents the findings relating to young people’s identity and emotional wellbeing, which are developed in terms of the interrelationship between discourse and social interaction. I consider how some young people experience stigma and feel shame, while others create their own narrative and experience feelings of pride. I also examine how participants protect themselves from prejudice and stereotyping. Chapter 8 draws the thesis together, reflecting on, and discussing the findings, while the final chapter identifies my contribution to knowledge and the implications of my findings for both policy and practice.
Chapter 2. Reviewing the literature: situating young people within the wider environment

In chapter 1 I set out my intention to focus on young people with severe dyslexic difficulties and situate them within a wider environment that extends outwards from the home and classroom. I also explain how Bronfenbrenner’s Ecological Model (1979) provides a framework for thinking about the different influences at play in young people’s lives, for exploring questions of structure and agency and for taking an approach based on theoretical pluralism. My aim is to maintain a closeness to participants’ lived experience while locating them within a larger world. In this first of two chapters reviewing the literature I highlight the socio-cultural, institutional, economic and policy context and introduce the theories of Michel Foucault, which have been an important influence on my work.

Details of how I went about my literature review are shown in Appendix ii.

2.1 Policy context

In locating young people within the wider environment, it is important to consider the policy context in which they experience their dyslexic difficulties, both locally and internationally.

2.1.1 UK government policy

I will firstly examine how dyslexia sits in relation to the legislation around SEND, disability and equality. In 1970 dyslexia was recognised by Parliament in the Chronically Sick and Disabled Persons Act and in 1995 it was acknowledged under the Disability Discrimination Act. Since 1997 dyslexia has also been recognised as a SEN, which means that there is DfE recognition that dyslexia can affect young people’s ability to learn. It is also explicitly mentioned in the 2010 Equalities Act, which means that schools have an obligation to make reasonable adjustments to ensure that people affected by dyslexia are not disadvantaged in comparison to their peers.

More recently, the Children and Families Act 2014 and the SEND Code of Practice (DfE & Department of Health and Social Care [DHSC], 2014) have brought health, education and care into one plan. Statements of Educational Need were replaced with Education,
Health and Care Plans (EHCP) and 'School Action', 'School Action Plus' and 'Individual Education Plans (IEPs) were replaced with 'SEN Support', which is the level of support that most pupils with dyslexia receive (BDA, 2017). In practice, only those with more severe and complex dyslexic difficulties, usually with co-occurring difficulties such as Attention-Deficit Hyperactivity Disorder (ADHD) or autism, receive an EHCP, which entitles them to greater levels of support. However, the 2014 reforms have received criticism. For example, the 2019 report by the House of Commons Education Committee describes them as necessary and ambitious but is critical of their implementation, describing them as resulting in:

‘confusion and at times unlawful practice, bureaucratic nightmares, buck-passing and a lack of accountability, strained resources and adversarial experiences, and ultimately dashed the hopes of many.’ (House of Commons Education Committee, 2019)

The Local Government and Social Care Ombudsman’s 2019 report on EHCPs suggests a ‘system in crisis’ (p. 2), citing severe delays, poor planning and anticipation of needs, inadequate communication and preparation for meetings, a lack of partnership working and oversight from senior managers. The report states that in 2018-19 they received 45% more complaints about EHCPs than in 2016-17 and have upheld close to nine out of ten investigations – a situation that is unprecedented.

Despite acknowledgement of dyslexia in key UK government policy described above, it has been argued that policies on spelling, punctuation and grammar in schools discriminate against those with dyslexic difficulties (Collinson, 2018). Specifically, Collinson (2018) discusses how the 2015 Interim Teacher Assessment Frameworks at the End of Key Stage 2 and the Key Stage 2 English Grammar, Punctuation and Spelling Tests disadvantage learners with dyslexic difficulties because they are unable to access certain marks allocated exclusively to spelling. Another policy change, which impacts those with dyslexic difficulties, is the 2015 reform of GCSEs. The amendments not only reduce the amount of continuous assessment and increase the number of exams but also penalise spelling, grammar and punctuation mistakes in subjects such as English, Geography and History, even for those with dyslexic difficulties (Office of Qualifications and Examinations Regulation, 2015).
2.1.2 School accountability

The 1988 Education Reform Act led to local education authorities having to relinquish power to central government in what was seen as a radical shift in the structure of the education system. Schools and governing bodies were given greater autonomy and the teaching profession became more regulated and controlled in the form of testing and league tables and the introduction of the National Curriculum, a situation that still exists today (Elkins and Elliott, 2004). Perryman and Calvert argue that over time this concern for higher academic standards has meant that schools have become more and more attentive to improving exam results, leading to a ‘performativity culture in education’ (2019, p. 6). Rogers argues that the pressure on schools to raise standards has implications for children with SEN, leading to schools needing to:

‘eliminate anything that may interfere with the “efficient” running of the education process, which has a negative impact on the inclusion of children with SEN.’ (2007, p. 58).

Docking (2000) describes this as a tension between inclusion and the pressure on schools to perform.

2.1.3 Budget cuts

Funding for SEND provision in schools is from two sources (Provision Map, 2021). Firstly, local authorities (maintained schools) or the Education Funding Agency (academies and free schools) receive money from government to fund SEND specific support; allocation to schools is based on a formula, which is slightly different in each area and this notional budget is not ring-fenced to SEND (ibid). Secondly, local authorities receive money from government for additional, or top-up funding that can be requested by schools for children needing more expensive provision (ibid).

At the time of writing, government spending cuts in education have placed school budgets under severe pressure, with the support of those with additional needs causing the most stress on resources (National Association of Head teachers [NAHT], 2018). The Institute for Fiscal Studies (2018) reported that between 2009/10 and 2017/18 total spending in England fell by 8% per pupil. A recent report by the Institute for Public Policy Research (IPPR) North (2019) claims that cuts to education and local government have resulted in high needs funding for pupils with EHCPs being reduced
by 17% across England between 2014/15 and 2018/19. They also found a significant decrease in the amount of support available to those with less complex needs who do not have an EHCP (the majority of those with severe dyslexic difficulties).

In 2016 the United Nations (UN) Committee on the Rights of the Child (2016) said that recent spending cuts in the UK have had an adverse effect on children’s rights, including in education. Within their 150 recommendations they urged that efforts should be made to:

‘reduce the effects of the social background or disabilities of children on their achievement in school and to guarantee the right of all children to a truly inclusive education.’ (UN Committee on the Rights of the Child, 2016, p. 19)

Perhaps reflecting a strain on resources, in 2019 Ofsted produced a report about home education in which it states that, according to children and their parents, special educational needs, alongside medical, behavioural and other wellbeing needs, are the key reasons for children leaving school to be home educated. They also cite a breakdown in the relationship between schools and children or parents and describe it as a ‘last resort’ (2019, para’ 3).

2.1.4 Teacher training and SEND

The 2009 government commissioned Rose Report recommended that the Training and Development Agency for Schools and the Initial Teacher Training (ITT) sector increase coverage of SEN, including dyslexia. It also recommended the training of dyslexia specialist teachers and improving awareness of dyslexia among all teachers. The British Labour government accepted all of the recommendations of the Rose Report. In 2010, however, the Coalition Government refused to make SEN and SpLDs, including dyslexia, a compulsory part of ITT on the basis that individual training institutions should be able to make their own decisions on this issue. Instead, as part of the 2014 reform of SEND provision, the government developed some online dyslexia training for teachers which they were under no obligation to access (Earey, 2013).

The Carter Review, an independent evaluation of the quality and effectiveness of ITT courses by the DFE (2015), found considerable variability and significant gaps in ITT
courses in terms of the teaching of SEND and SpLDs, including dyslexia. The Review recommended that:

‘Special educational needs and disabilities should be included in a framework for ITT content. This should prepare all new teachers to support SEND in their classrooms, providing a solid grounding in the most pertinent issues and setting an expectation for on-going high-quality professional development’ (Carter Review, p. 58).

The Government accepted this recommendation and independent working groups developed an ITT Core Content Framework (2019a) and an Early Years Framework (2019b) in which differentiation and SEND awareness are key, mandatory components of ITT. Although they both include broad guidance on SEND content, the amount of time allocated to training of this nature is not stipulated.

2.1.5 Accommodating difference in schools: understanding inclusion

Inclusion is an important subject in the context of young people with severe dyslexic difficulties and one that I refer to throughout this thesis. Inclusion supports diversity and schools ensuring that they accommodate all learners in the way they teach. An examination of policies and agreements will inform my exploration of how young people experience inclusion in their everyday lives.

Arguably the most important international documents that have influenced SEND are the Salamanca Statement and Framework for Action on Special Needs Education (UNESCO, 1994) and the United Nations Convention on the Rights of People with Disabilities (UN, 2009). Both have had a significant influence on international attitudes, policy and practice in the field of inclusion. However, 25 years on from the Salamanca Statement, Ainscow, Slee and Best suggest that there is still uncertainty about its legacy and that it signifies ‘movement in a clear philosophical direction’ (2019, p. 676) but also requires similar shifts by wider society.

The 1981 Education Act enshrined in law many of the recommendations of the 1978 Special Educational Needs Report, which was chaired by Baroness Mary Warnock. The Report suggested that separate, ‘special’ schools should only be for those who have long-term, severe disabilities and that mainstream schools should be for everyone else. In 2002 the government issued the ‘Index for Inclusion’ booklet (Booth and
Ainscow, 2000) to all schools in England, a resource aimed at supporting the development of inclusive schools. However, in 2005, Warnock challenged her own recommendations by saying that children who were moved back into mainstream education from ‘special’ schools had been marginalised in schools that were not equipped to deal with their needs. Masschelein and Simons (2005) endorse this view, saying that the UK government’s drive for inclusive education gives the impression of self-determination when children with SEND are actually often less well supported in mainstream education.

Critics such as Fuchs and Fuchs, writing in the journal ‘Exceptional Children’ in 1994, suggest that the reality of inclusion is less about mainstream schools making changes to accommodate learners’ needs and more about learners having to adapt to the learning styles and curriculum of the school itself. Hegarty calls for a different approach of ‘fitting schools to pupils, not socialising pupils to pre-set norms of learning and behaviour’ (1991, p. 90) and Riddick (2001) adds that proper integration should be about reforming schools to embrace difference. Inclusion is spoken of as a process – ‘a never-ending search to find better ways of responding to diversity’ (Ainscow, 2005, p. 118). While this process is still evolving, inclusion advocates such as Slee (2011) argue that the ideologies of inclusion should not be abandoned because of the maladministration of inclusive education.

Slee (2011) argues that it is not inclusion when children have all, or some, classes in learning support units or rooms which are grafted on to mainstream schools and describes students as being ‘locked out’ (p. 160). Holt (2004) calls it segregation, where academic achievement is not prioritised and, what she describes as, mini-institutions spatially ‘contain and reinforce difference’ (2004, p. 26). Very occasionally, some young people with the most severe dyslexic difficulties, and often co-occurring difficulties as well, may attend specialist provision, located away from the mainstream. O’Brien’s (2019) small study of six children aged 10-12 attending a special reading school in Ireland reflects McPhilips’ and Shevlin’s (2009) findings that children in specialist reading schools (in Ireland) do better academically and have a better image of themselves. On this basis, O’Brien (2019) suggests that it is the environment of
mainstream school that causes young people to experience low self-esteem, not the difficulties associated with dyslexia. Burden’s (2008) study of the dyslexic identity of 50 adolescent boys at an independent specialist residential school in England also found there to be feelings of ‘dyslexic pride’ among his participants.

2.1.6 The rights of young people’s voices to be heard in school

Article 12 of the United Nations (UN) Convention on the Rights of the Child (UNCRC) (UN, 1989) lays down the right of children and young people to express their views freely on all matters that have an impact on them, according to age and maturity. In addition, it says that children have the right to be heard in judicial and administrative proceedings that affect them. Article 3 of the UNCRC requires that the best interests of the child are always considered and specifies that the views of the child must be taken into account. In addition, the UN Committee on the Rights of the Child (2016) advocates a human rights approach to disability, in particular respecting the right of children with disabilities to express their views in decisions that affect them ‘including on access to and choice of personal support and education’ (UN, 2016, p. 14).

In spite of these international agreements, the voices of children with SEND are still usually heard second hand, through the advocacy of parents and carers (McKay, 2014). In 2011, the UK Children’s Commissioner’s report articulated concern about children’s participation in educational settings:

‘The mainstreaming of children’s participation has yet to happen and children have repeatedly reported that their views are not sought, listened to or acted upon consistently.’ (The Children’s Commissioner, (2011, p. 7)

Riddell (2018), in her review of the autonomy and rights of children with special and additional support needs, highlights the tension between the rhetoric of celebrating children’s voices and the reality of involving them in educational planning. Lundy (2018) describes participation in schools as tokenistic and says that children’s rights activists believe it to be of little value. McKay (2014) describes the participation of children with SEN as driven by context and relationships. She draws on the work of Foucault to argue that children and young people’s participation is framed by restrictive policies that:
‘subjugate children within disciplinary technologies that determine a regime of “truth” about effective and appropriate participation’....where children are observed, (ab)normalized, classified and thus governed.’ (McKay, 2014, p. 760)

The literature makes a distinction between merely consulting children and actually involving them in decision making. Wearmouth describes children as often ‘impotent at the hands of powerful others’ (1999, p. 19) and O’Brien (2019) calls for meaningful participation by citing Freire:

‘Attempting to liberate the oppressed without their reflective participation in the act of liberation is to treat them as objects that must be saved from a burning building’ (Freire, 1972, p. 41).

Lansdown (2006) suggests a range of measures that should be taken for participation to be worthwhile. This includes children understanding what the process is for, what it is about and what their role is. She also identifies making power relations and decision-making structures explicit, involving children early on, giving them equal respect regardless of their age, ethnic group, abilities etc., establishing ground rules and making participation voluntary.

2.1.7 A postcode lottery of SEND provision
A report for the Department for Children, Schools and Families (DCSF) (Lewis et al., 2010) acknowledges local variation in both the number of children with SEN and the level of support they receive. This disparity was highlighted by the House of Commons Education and Skills Select Committee (House of Commons, 2006), which described it as a ‘postcode lottery’ or a ‘lottery of provision’ (para 129). Several years later, Hayes also argues that ‘it depends upon where you live as to the type and impact of the assistance that those with dyslexia are likely to receive’ and goes on to use the words ‘postcode lottery’ to describe this idea (2018, p. 20). The DCSF report (Lewis et al., 2010) suggests that this can be explained by several interacting factors. Firstly, population size and the structure of the local authority, alongside differences in the speed local authorities are able to respond to changes in policy or practice development. Different interpretations of ‘inclusion’ by local authorities and different approaches to multi-agency working, information sharing and partnership working with parents and families were also identified. Finally, the report highlighted different
ways of handling identification and assessment, EHCPs, and access to specialist support and training.

2.2 Understanding the discursive production of self through the work of Foucault

Michel Foucault was a French historian and philosopher associated with the post-structuralist movement of the 1960s. His theories challenge supposed scientifically grounded truths and expose them as having been affected by historical influences and as being a reflection of the politics and ethics of a certain epoch. Foucault contends that knowledge is never objectively created but is delineated in a specific place and at a specific time as a consequence of our cultural, institutional and personal communications (Thomas, 2006) and under conditions of power.

Foucault did not explore the discourse of disability directly, however, his work on the social construction of madness, punishment and sexuality, and his later work on the relationship between power and knowledge, provide a useful framework for studying disability (Tremain, 2001) and SEN (Allan, 1996, Morgan, 2005). Power is an important theme of Foucault’s (1977) work. He contends that, rather than obvious repression, modern societies control and limit by means of ‘disciplines’, or standards of behaviour which are monitored by institutions (Foucault, 1977). He recognises that discipline operates as a mechanism of power in ‘local centres of power/knowledge’ (1978, p. 98), for example in education.

A key theme of Foucault’s (1978) work was the shift in the 18th century in the way the body was conceptualised and acted upon. He highlights a shift from sovereign power to bio-power which refers to government regulation of its subjects through techniques of control aimed at maximising its capabilities, while at the same time making the population more passive (ibid). He draws attention to the introduction of technologies of government, which influence and control the population, such as birth and mortality rates and life expectancy figures. This has important implications for an analysis of dyslexia, not least because it creates the conditions that make the diagnostic category of dyslexia possible. Foucault (ibid) discusses how the population was re-figured as a
resource that can be improved and optimised and Campbell (2013) argues that this led to programmes such as compulsory schooling, designed to create a literate population. Foucault (1978) contends that contemporary society is established on medical notions of the norm which ‘has caused the contemporary disabled subject to emerge into discourse and social existence’ (Tremain, 2005, p. 5) and ascribe identities such as physically impaired, deaf, mentally ill, autistic and dyslexic. Rajchman (1991) explains Foucault’s ideas on normality as the means by which individuals are identified and are made to identify themselves, with the intention of making them docile and governable. In terms of education, the changes associated with bio-power established a norm of educational standards and problematised anyone who did not conform (Campbell, 2011). This had the effect of individualising children ‘by making it possible to measure gaps, to determine levels, to fix specialities and to render the differences useful by fitting them one to another’ (Foucault, 1977, p. 184). This led to the birth of special educational needs programmes and special schools.

In Foucault’s (1977) study of power and docile bodies he identifies three forms of surveillance, which could be said to affect the experiences of children with dyslexic difficulties in the institution of school. The first of these is hierarchical observation, which likens the way pupils are observed and regulated in school to Bentham’s Panopticon, designed to provide comprehensive and uninterrupted surveillance by having a metaphorical central watchtower surrounded by metaphorical cells containing children (Foucault, 1977). Allan (1996) relates this hierarchical observation to children with special needs who are subject to increased scrutiny at school. The second technique of surveillance is normalisation, which imposes ‘new delimitations’ (Foucault, 1977, p. 184) and leads to greater individualisation of need by measuring children in relation to the norm. The third form of surveillance is the examination, which Foucault (1977) sees as an amalgamation of hierarchical observation and normalisation in that it provides a mechanism with which people can be differentiated and is the key instrument for constructing them as objects of power and knowledge.

Much of Foucault’s (1997a) later work is about ethics and is focused on individual agency and the ‘technologies of the self’. His idea of transgression is particularly useful
in this regard. Allan (2011) posits that transgression allows disabled people to influence their own identities by challenging the norms that constrain them. In her qualitative research among students with special needs in Scotland, Allan (2011) expected to find that young people were limited and contained by the discourses and procedures within special education. However, while she discovered ‘significant disciplinary effects on the young people and their families’ (Allan, 2011, p. 157), she also found examples of subtle transgression among the students.

2.2.1 Discourses operating within SEND

Foucault’s archaeologies (1970) and genealogies (1977) can be used to examine the complex discourses functioning in special education and dyslexia. Archaeology, which he drew upon in his earliest works (1970), is about examining the past to understand the present and highlights the structure of thought and knowledge (‘epistemes’ or ‘discursive formations’) which function at the unconscious level. Genealogy on the other hand, which was first employed in Discipline and Punish (1977), was intended to demonstrate that a system of thought, exposed by archaeology, is the outcome of political and economic concerns (Shumway, 1989) and can be differentiated by mechanisms of power. Foucault (1977) points out that governments create the illusion that practices and policies have a natural origin in order to justify and legitimise them. Tremain (2001) relates this to disability by saying that impairment persists in being described as a natural deficit so as to legitimise the government practices that created it.

If we begin the process of contextualising the individual child with dyslexic difficulties within the wider environment, it is necessary to deal with the broadly based formations of knowledge through which dyslexia gains its meaning – the kinds of debates within science and educational policy explored in chapter 1. A key concept for capturing this dimension of meaning is ‘discourse’, which can be understood as ‘a group of statements which provide a language for talking about... a particular topic at a particular historical moment’ (Hall, 1992, p. 291); discourse functions through epistemes, which describe the unconscious rules and processes within a certain epoch. The following two sections describe the key discourses impacting those with dyslexic difficulties in school.
The discursive construction of literacy

Donald (1983) studied how, in the late eighteenth and early nineteenth centuries, illiteracy was produced as a problem, and often linked to criminality. He tracks it to the advent of state-provided education, which was seen (in part) as a solution and what he describes as a way of keeping surveillance over the children of the labouring poor. More recently, the introduction of the National Curriculum in 1988 marks a strong emphasis on reading and writing, leading to new norms of educational standards and the problematisation of those who do not conform (Campbell, 2011). Riddick (2001) describes how ‘the notions of being “educated” and being “literate” have become inextricably bound together in many European cultures’ (2001, p. 224). As mentioned in chapter 1, Burden (2012) writes about how literacy has been culturally constructed as something that everyone should be able to do and argues that people with dyslexic difficulties often have difficulty coping with these culturally imposed assumptions.

Cameron and Billington (2015), in their qualitative study among dyslexic students in higher education in England, describe how their participants constructed dyslexia and being dyslexic as a moral issue. They highlight how the students:

‘drew upon discourses which produce high literacy and academic success as moral goods, while also managing discourses which reproduce historical associations between learning difficulties and low moral or social status.’ (Cameron and Billington, 2015, p. 1227).

Although they found that the dyslexia label provided ‘an escape from accusations of moral and intellectual inferiority’ (Cameron and Billington, 2015, p. 1237), they argue that how the term is conceptualised, and by whom, determines whether or not students chose to disclose their difficulties.

Stromquist (2008) highlights the central role of literacy in modern society as being fundamental to being a socially engaged citizen:

‘... literacy skills are fundamental to informed decision-making, to active and passive participation in local, national, and global social life, and to the development and establishment of a sense of personal competence and autonomy.’ (Stromquist, 2008, p. 14)
With the dominance of service industries and a knowledge-based economy and a sharp decrease in the number of jobs requiring little or no literacy, others link literacy skills to job and employment prospects. Macdonald (2012) describes the barriers that exist in education for young people with literacy difficulties as disabling, leaving them unprepared to participate in the modern-day workforce and more likely to experience disadvantage and unemployment. A range of studies have estimated that up to half of ‘offenders’ may be described as ‘dyslexic’ (Kirk and Reid, 2001) and that just under 50% of people in prison have a literacy level at or below that expected of primary school (Shannon Trust, 2017). The National Literacy Trust highlights the ‘prominence of poor literacy in the profile of disadvantaged adult lives’ (Dugdale and Clark, 2008, p. 3), but calls for caution in terms of linking literacy and criminal behaviour. Instead, they justify the need to increase literacy levels as a human right rather than in terms of reducing crime levels:

‘the potential for restoring to society those people who are excluded from full citizenship because they have yet to attain functional literacy. In short, reading interventions for offenders are justified not by reference to human wrongs but by reference to human rights.’ (Rice and Brooks, 2004, p. 2)

**Medical notions of the norm**

Arguably, the dominant discourse within education is the medical model of disability, which situates children’s differences within individual pathology and prioritises treatment of the ‘deficit’. The ‘problem’ is seen to be located within the child, and endured by them. Rieser (2012) describes the medical model of disability as still deeply embedded in education today. Its prevalence reflects the influence of neo-liberal ideology within SEND – difficulties and challenges are one’s own concern and not the responsibility of the state (or the educational institution) (Cameron and Billington, 2017). This has implications for young people with severe dyslexic difficulties in terms of where responsibility lies for providing support and interventions.

Mike Oliver (1983) developed an alternative model – the social model of disability. The social model rejects individualism (Macdonald, 2009b) and argues that disability arises from the attitudes of society, which produce ‘environmental, organisational and social
barriers’ (Walker and Shaw, 2018, p. 2). This is the model favoured by the disability movement and disability theorists in the UK.

Macdonald (2009b) suggests that schools tend to construct dyslexia in terms of the meeting of the medical and educational models of disability. The medical model categorises dyslexia as a neurological impairment, which leads to limited educational participation (Morton, 2004) and the educational model relates it to cognitive dysfunction, which is associated with specific processing deficits but recognises that it can be surmounted through educational intervention (Macdonald, 2009b). This means that barriers to learning are acknowledged but there is still a focus on individual deficit and the wider social and situational factors that reinforce discrimination (Barton & Armstrong, 2001). This model has consequences for how people respond to the category of dyslexia and how schools shape provision.

2.3 Discussion

My research takes place at a time when there is policy level acknowledgement of dyslexia in the UK, yet at the same time education policies exist that discriminate against those with dyslexic difficulties in school. In sketching the current landscape within which young people are located I have found criticism of the 2014 SEND reforms, an under-resourcing of SEND in schools and a lack of teacher training on the learning difficulties associated with dyslexia. I suggest that using a Foucauldian approach to discourse permits an understanding that most schools operate within a discourse of deficit and a culture of literacy norms, which means that young people are increasingly subjected to an ‘educational gaze’, whereby they are measured and tested to assess deficit, and those who do not keep up can be segregated from their peers within mainstream settings. I have also contextualised this area of policy and practice within wider social discourses, including the internationally agreed rights of children and young people to express their views. I have found that participation in schools has a long way to go, with the voices of those with SEND still usually heard second hand through parents.
Chapter 3. Reviewing the literature: the co-construction of identity and emotional wellbeing

In this chapter I focus on the literature most closely linked to my topic and into which I seek to make a contribution. This will involve reviewing the wider research literature in order to provide a context for the study and identify a space for my own contribution to knowledge. Based on my research aim to focus on an interactive self and understand how young people’s identity and emotional wellbeing is co-constructed through relationships, I present a summary of existing research relating to the roles of the people around the child and introduce the key theorists that shape my work. I also consider how the main concepts framing my research, such as stigma, recognition, care, capitals and emotional labour, are discussed in the literature.

3.1 Understanding relationships through Symbolic Interactionism

Parents, peers and teachers play independent roles in young people’s lives and support from each of them is ‘additive rather than compensatory’ (Wentzel, 1998, p. 207). I therefore start my examination of the relevant literature and theory by examining how relationships with social actors influence the lived experience of young people with severe dyslexic difficulties. I will use a symbolic interactionist lens for this, focusing on understanding human experience through the interactions of individuals.

Interactionism is considered to have developed from the work of psychologist George Herbert Mead in the 1930s. His work on reflexivity of the mind/self laid the groundwork for identity theory and provides a framework for conceptualising a process through which individuals develop a self-image in dialogue with the responses of others and larger socio-cultural structures (Mead, 1934). Herbert Blumer (1969) developed this further, highlighting how interaction is mediated by symbols, or interpretation, and coining the term ‘symbolic interactionism’. Symbolic interactionism concerns itself with ‘language, communication, interrelationships and community’ (Crotty, 1998, p. 8). Its central tenet is that meaning occurs through the process of social interaction and that individuals ‘act on the basis of their interpretations and understandings’ (Atkinson and Housley, 2003, p. 9). Importantly, this means that the definition of ‘self’ is not fixed and that there is an element of agency involved.
As early as 1902, Cooley described how, through social interaction, we internalise other people’s attitudes and behaviour towards us, leading to a process of self-categorisation. He called this the ‘looking-glass self’, emphasising that people incorporate the attitudes of both those who are valued and those who are not and that much of this process is based on what we imagine others think of us (ibid). Cooley described how social actors evaluate themselves from the perspective of others and respond to external judgement in the form of feelings ranging from pride to shame:

‘A self idea of this sort seems to have three principal elements: the imagination of our appearance to the other person; the imagination of his [sic] judgment of that appearance, and some sort of self feeling, such as pride or mortification’ (Cooley, 1902, p. 184).

Woodward (2002) describes Cooley’s (1902) notion of self as based more on instinct, compared with Mead’s (1934) approach which is more about social interaction. Goffman (1922-1982), who extended Mead’s (1934) interest in roles to analyse how we present ourselves to the world, is also an important figure in terms of identity theory. His work on dramaturgy, impression management, the self, and stigma form a backdrop for much of my analysis.

3.1.1 Exploring the role of parents

The role of parents is clearly important. We know from John Bowlby’s theory of attachment that early childhood experiences of parenting function as the basis for the development of positive self-esteem and adjustment throughout a person’s life (Bartholomew, Kwong, & Hart, 2001). Furthermore, children regard their parents as the most important source of support until middle childhood when relationships with peers tend to become more significant and those with parents are taken up more with behavioural and time management issues (Erwin, 1998).

Mothering a disabled child

Reay’s (1998) work on the gendered nature of parenting has been extended to include research on dyslexia by, for example, Buswell-Griffiths, Norwich and Burden (2004), who conducted a two-year qualitative study of seven families in the south-west of England on parent-professional communication. In this study they outline how the additional work related to having a child with dyslexic difficulties tends to be
associated with mothers. Reay (1998) describes this kind of additional work as an extension of their mothering duties and responsibilities.

Rogers (2011) writes about how the mothers of intellectually disabled children must develop a range of skills so that they can set out on an ‘unanticipated mothering journey’ (p. 565). She also describes how mothering a disabled child ‘merges with the public and political social world, in a way that is often costly – emotionally, practically and financially’ (Rogers, p. 578). In particular, the mothers of disabled children find that their capability as a parent becomes very visible and, in their contact with professionals and statutory bodies, often under surveillance (Ryan and Runswick-Cole, 2008).

Ryan and Runswick-Cole (2008) argue that the mothers of disabled children feel, directly and indirectly, the discrimination and stigma experienced by their children. They often seek to protect their children by pursuing a diagnosis which prevents others from perceiving them as ineffectual and inadequate parents (Ryan and Runswick, 2008) and which also leads to greater information and support (Avdi, Griffin, and Brough, 2000). Singh (2004) describes this as a particularly positive step for the mothers of children with invisible disabilities, where citing brain difference is preferable to being blamed themselves for their child’s difficulties, something they are more likely to experience from professionals than fathers (Read, 2000).

In order to negotiate a complex world on behalf of their disabled children, mothers adapt and develop their skills over time (Green, 2001). Ryan (2005) describes how mothers grow into their role and change significantly in terms of how they manage public interactions concerning their children. She reports on how a mother characterised the mothers of disabled children as moving from ‘worriers’ to ‘warriors’ (Ryan, 2005). These skills arise because of their responsibilities as advocates and mediators for their children, a role often requiring them to challenge social structures (Read, 2000).

Providing emotional support

Several studies have researched the significance of the emotional support provided by parents for their children with dyslexic difficulties. Hellendoorn and Ruijsenaars’
research among 27 Dutch adults with dyslexic difficulties describes the support they received from their parents in primary school as a ‘powerful protective factor’ (2000, p. 237). More recently, in an American study, Nalavany and Carawan (2011) draw on psychodynamic theory and the work of Palombo (1985) to highlight the positive role of family support in providing protection from the negative impact that dyslexia can have on self-esteem. They make the point that this support is critical in both childhood and early adulthood. A small quantitative Swedish study (Daderman, Nilvang and Levander, 2014) of young women with dyslexic difficulties aged 16-30 endorses this finding, suggesting that family have an important role in terms of increasing ‘self-esteem’ and maintaining ‘positive self-image’.

In providing this support, however, some parents have to contend with feelings of guilt associated with their belief that dyslexia is hereditary and feelings of anxiety if they themselves have had difficult experiences of schooling (Rose, 2009). Earey’s study comprising in-depth, semi-structured interviews with seven parents in England (2013), explored this further. She suggests that parents can also feel guilty if, in the past, before they knew about their children’s dyslexic difficulties, they accused them of not trying and even being lazy.

The relationship between parents and schools

Reflecting on her narrative research among 15 practitioners involved in SEN and 12 parents of children with a high functioning autism spectrum condition, Thackray refers to the SEN system in Britain as ‘problematic and adversarial’ (2013, p. 1). She cites the 2011 Green Paper, describing it as a domain where:

‘parents feel they have to battle for the support they need, where they are passed from pillar to post, and where bureaucracy and frustration face them at every step’ (DFE, 2011, p. 2).

Although this research was conducted before the 2014 reform of SEND, there is evidence that the situation has not improved. Writing in 2020 and using academic studies and grey literature to explore parents’ experiences, Ross suggests that parents still have to fight what they call ‘a battle’ to access provision for their children. Among the ten parents taking part in her 2019 study of a school in the north of England, even
those who were able to access the habitus of the educational establishment, did not know how to make their voices heard and felt disempowered. Ross (2019) cites a tension between the promises of public policy and the local reality. Furthermore, an American narrative study (Valle, 2018) describes how the mothers of children with SpLDs associate meetings to discuss their child’s Individual Education Plan (IEP) with fear, guilt, shame and dread, as well as public scrutiny.

Riddick, in considering dyslexia, highlights the importance of the relationship between parents and teachers (1995), arguing that schools often treat parents as clients and not partners. Although the SEND Code of Practice (DfE & DHSC, 2014) and the Children and Families Act 2014 aim to afford children and parents more control over the provision required to meet their needs, Ross (2019) argues that it is left undefined as to how exactly this should be achieved and consequently varies by local authority area. In her 2017 qualitative study among teachers in an English secondary school, Ross notes that the sharp contrast between teachers’ institutional position and their lack of autonomy to distribute resources can create tension with parents who have expectations that they have control over budgets. All of this leaves some questioning whether the increasing emphasis on parental involvement is actually empowerment or rather a move from compliant parent to compliant partner (Cribb & Gewirtz, 2012).

Buswell-Griffiths, Norwich and Burden (2004) describe parents as at a disadvantage in respect to teachers who have greater status and power based on their expert knowledge. They question the likelihood of the partnership between parents and teachers ever being equal and speak of how expectations are different for parents and teachers; parents prioritise the needs of their child and teachers have to be cognisant of the needs of all children, as well as the needs of their school.

Reid (2011) suggests that parents are often the first to speculate that their children may have dyslexic difficulties and recognise that they need extra support. He (2003) also raises the issue of parents sometimes knowing more than teachers about dyslexia and the support required for their child. This is explored further by Thackray who explains that when parents know more, practitioners can feel threatened and wish to ‘restore the status quo in placing them in a position of superiority over a parent, sometimes to the detriment of the child’ (2013, p. 5). In addition, Lawrence (2009)
argues that not all schools are willing to acknowledge dyslexia and the Rose Report (2009) states that parental anxiety is caused by a perceived lack of urgency to meet their needs. Furthermore, in her interview study in Britain of children with dyslexic difficulties and their families, Riddick (1995) observed negative framings of parents by teachers. For example, parents who enter into conflict with the school over the needs of their child with dyslexic difficulties were characterised as ‘overambitious’, ‘overanxious’ and ‘unrealistic’ (ibid, p. 465) in their expectations for their child. When this happens, the partnership between schools and parents becomes complicated and causes anxiety for parents (Lawrence, 2009). Biggar and Barr (1996) also suggest that children can be sensitive to any disagreement between their parents and the school.

Classed cultures of parenting

Considering the role of parents includes examining how they relate to their child as a learner. In order to help understand how inequality mediates advocacy, Reay (2000) draws on the work of Helga Nowotny (1981) and her notion of emotional capital, a variant of social capital as utilised by Bourdieu (1986). Reay (2000) interprets emotional capital in terms of the emotional resources made available, and handed on, by women within the domain of the family. In her analysis of a study of 33 mothers of Year 5 children in England, Reay (2000) reveals how some middle-class mothers prioritise their child’s happiness as an adult, which they perceive as educational success, over happiness as a child at school. She also suggests that the only mothers who are not affected by feelings of anxiety about the insecurity of state education are wealthy middle-class mothers who are able to buy in additional support for their children, such as tutors, or working-class mothers who privilege their child’s happiness over educational achievement. Reay points out that those mothers who prioritise educational success and involve themselves intensely in their child’s education can transfer their anxiety to their child, causing ‘extensive negative emotional fall-out’ (2004, p. 71). Gillies argues that working class families understand the significance of education as much as anyone else but, with limited ‘capitals’, have to prioritise enabling ‘their children to survive school without being emotionally crushed’ (2006, p. 285). She argues that working class mothers generate ‘significant levels of emotional capital’ (p. 292) which is ‘focused on keeping their children safe, soothing feelings of
failure and low self-worth, and challenging injustice’ (p.281). She suggests that Reay’s definition of emotional capital inflicts middle class principles on working class lives.

The implications of capitals on parents’ capacity to access provision

Pierre Bourdieu’s (1986) theory of capitals also frames my research, reflecting my interest in social equality and the subtleties of power within education. Morrow (1999) emphasises that capital theory avoids focusing on the resources that people lack and instead concentrates on what is required. Bourdieu’s (1986) theories therefore provide a framework for understanding what resources parents require when communicating with schools to access educational provision for their children. In doing this, structural limitations and the extent of unequal access will be highlighted.

Bourdieu’s notion of the ‘field’ refers to the structure of social relations within social and institutional arenas:

‘The field as a whole is defined as a system of deviations on different levels and nothing, either in the institutions or in the agents, the acts or discourses they produce, has meaning except relationally, by virtue of the interplay of oppositions and distinctions.’ (Bourdieu, 1991, p. 185)

He noted that context, or type of field, is important in terms of how people experience power (Gaventa, 2009); for example, parents may behave differently in the field of education than they do in other contexts. Bourdieu’s (1974) work challenges assumptions about schools being places of equality and social reform and re-positions them as places of social reproduction. His notion of habitus, or socialised norms, can also be used to understand the social class/socio-economic nature of schools, in which the values of the middle classes are imposed on the majority, and social inequality is reproduced (Bourdieu & Passeron, 1990).

Bourdieu’s theory of capitals locates people in social space and takes the emphasis away from monetary exchange and focuses it on ‘accumulated labor (in its materialised form or its “incorporated” embodied form)’ (1986, p. 241). He identifies three types of capital that are relevant to my research – economic, social and cultural – and highlights the interaction that takes place between them and how one type of capital can be converted into another. These three types of capital will frame an
exploration of how they combine, or act separately, to influence parents’
communication with schools.

Bourdieu defines economic capital as material assets that are ‘immediately and
directly convertible into money and may be institutionalized in the form of property
rights’ (1986, p. 242). While economic capital is generated through interactions
between an individual and the economy, social capital is produced through ‘social
processes between the family and wider society and is made up of social networks’
(Reay, 2000, p. 569). Social capital originates from having social status within a social
network.

Bourdieu describes cultural capital as:

‘…linguistic and cultural competence and that relationship of familiarity with
culture which can only be produced by family upbringing when it transmits the
dominant culture.’ (Bourdieu 1977b, p. 494)

Cultural capital can only be understood in relation to other capitals ‘that together
constitute advantage and disadvantage in society’ (Reay, 2000, p. 569). Bourdieu
(1986) identifies three types of cultural capital: the embodied state which relates to
values, skills, knowledge and tastes; the objectified state which refers to cultural goods
such as books, dictionaries, instruments etc.; the institutionalised state which is about
educational attainment.

Since the 1980s and, as mentioned earlier, particularly since the 2014 reform of SEND,
there has been an increasing expectation by government for parents to become ‘active
partners in the production of educated children’ (McNamara et al., 2000, p. 474). Reay
(2002) argues that this is a response to disinvestment in the public sector – when
schools have insufficient funds and performance targets to achieve, parents are
expected to take on more and more of school’s work (Reay, 2004). She describes this
as leading to an increase in inequality (ibid). Reay’s (1998) qualitative research of
mothers whose children attended two London secondary schools found that working-
class participants’ own experience of education and their level of self-assurance led
them to be more tentative and self-reproachful than their better-educated, middle-
class counterparts and to feel that their voices were not heard. This approach builds on
the influential work of Beverley Skeggs (1997) who, like Reay, combines feminist and Bourdieusian theory to conceptualise the intersections of class and gender in shaping ideas of care and respectability. Reflecting on the working-class female participants in her ethnographic research study in Britain, Skeggs characterises them as never having ‘the certainty that they are doing it right, which is one of the main signifiers of middle-class dispositions’ (1997, p. 90). These feelings of self-doubt arguably make working class parents more likely to follow the school’s lead and accept the status quo (Reay, 2004). In other research on class and education, Crozier (1997) discusses how interpretations of partnership differ according to social class, with working class parents more trusting of professionals and middle-class parents being less compliant. Middle-class parents are also generally more able to support their children at home and challenge teachers when necessary (Reay, 2004).

In their analysis of the intersection of SEND, social class and capitals, Holt, Bowlby and Lea (2018) conclude that although children and young people with SEND are disproportionately from poor families, those with SEND labels tend to be more affluent. They also argue that cultural and economic capitals combine to improve the likelihood of accessing what parents believe is the most suitable provision for their child (ibid). Similarly, Gillies points to identification as an important ‘bargaining chip’ (2005, p. 847) and links a diagnosis of dyslexia to middle class cultural capitals. Holt, Bowlby and Lea (2018) also propose that middle-class parents who become frustrated with the SEND process use their greater economic capital to speed the process up by paying for their own assessment and intervention.

Data from the Millennium Cohort Survey (MCS) Wave 6 (University of London, 2015) shows that the parents of young people described as having dyslexic difficulties are significantly more likely to have a degree or higher qualification (54.2%) than the parents of those who do not have dyslexic difficulties (48.2%). Parsons and Platt consider whether these findings indicate ‘an over-identification of dyslexia among advantaged socio-economic groups or rather an under-identification among socio-economically disadvantaged groups’ (2013, p. 20). They suggest that early identification of dyslexia is more likely among children who present as bright or who have engaged parents, while children who have behavioural difficulties or parents
experiencing greater socio-economic disadvantage are less likely to be identified. Parsons and Platt (2013) link this to teachers’ expectations, saying that they often perceive learning difficulties among children from socio-disadvantaged families as related to behaviour rather than something else, for example, dyslexia. This leads to under-identification ‘if children are thought to be working at or near expected levels’ (p. 21).

Macdonald uses Bourdieu’s (1986) work on capitals to understand the resources that middle-class parents of children with dyslexic difficulties draw on which gives them ‘the knowledge and financial capital to challenge and control educational discourse’ (2009a, p. 133). Morgan and Klein (2000) highlight cultural capital, suggesting that the parents of dyslexic children from lower socio-economic groups lack the understanding required of their child’s legal rights in relation to legislation to obtain equal rights. Reay’s work on cultural capital and education (2004) endorses this and provides a vocabulary for understanding the negotiations over schooling and the part played by cultural capital in reproducing advantages and disadvantages in society.

3.1.2 Positive and negative impacts of relationships with peers
In order to understand the experiences of young people with severe dyslexic difficulties it is also important to consider peer relationships and friendships. Research has shown that preschool age children make social comparisons with other individuals (Mosatche & Bragonier, 1981) and by the age of 7 or 8 begin to assess their competence in relation to their peers (Ruble et al., 1980). This culminates in early adolescence when young people become more sensitive to the feedback of peers (Dweck, 2002) and declines in later adolescence (Steinberg & Silverberg 1986).

An increase in social comparison occurs for two reasons. Firstly, children become better at interpreting and understanding comments about their performance and develop a more refined and realistic sense of how they are doing in comparison to their peers (Dweck & Elliot, 1983). Secondly, the changes in the ‘organisational, instructional and evaluation practices that children are exposed to in school induce a greater level of comparison between peers’ (Stipek and Mac Iver, 1989). These changes refer to the transition to secondary school, where there is an increased emphasis on testing, grades and comparison. Dweck and Elliot point out that this often
coincides with a decline in young people’s perception of their own competence (1983); as they compare themselves against their peers, those who experience a decline in perceived competence may develop feelings of negative self-worth.

Chatzitheochari, Parsons and Platt (2016) use longitudinal, large-scale data from the Millennium Cohort Study and the Longitudinal Study of Young People in England to explore experiences of bullying among children and young people with SEN and long-term limiting illnesses (LTLI). Their analysis corroborates small-scale, qualitative research on disability and bullying by concluding that both SEN and LTLI are likely to increase the likelihood of bullying and that the impact is greatest for those with a Statement/EHCP. Chatzitheochari, Parsons and Platt (2016) suggest that bullying negatively influences social and psychological outcomes, including destabilising ‘self-efficacy’, the term coined by Bandura (1997) to describe an individual’s expectation of what they can achieve in a given circumstance.

There is a small amount of literature on how peers may influence the self-perception of young people with dyslexic difficulties. Eaude (1999) suggests that they are less likely to be accepted by their peers and are even sometimes bullied. Riddick (1996), in interviews with 22 children aged 8-14 with dyslexic difficulties and their mothers in Britain, proposes that children with dyslexic difficulties respond to bullying or unkind comments from their peers by trying to hide their difficulties, which can make them more isolated. This kind of information control is discussed further in section 3.3 below in relation to Goffman (1959) and impression management.

However, there is also research suggesting that perceived support from peers is a significant coping strategy for disabled children, which helps them to be more socially and academically adjusted (Wallander and Varni, 1998). Here Goffman’s concept of in-group alignment is very relevant (1963), suggesting that some people experiencing difference or stigma turn towards ‘fellow-sufferers’ (1963, p138) rather than away. He describes them as ‘like-situated individuals’ (1963, p. 137).

3.1.3 The significance of the teacher-learner relationship
In 2015 the European Agency for Development in Special Education produced a report called ‘Empowering teachers to promote inclusive education’ in which they recognise
the significance of teacher understanding of learners’ challenges and the impact they can have on self-esteem. O’Brien (2019), in writing about those with dyslexic difficulties, also highlights the significance of the teacher-learner relationship. As part of understanding the context for young people living with severe dyslexic difficulties it is therefore important to consider interaction between young people and their teachers.

Analysis of my research findings draws on two key concepts – recognition and care. There is a long tradition in philosophy of the notion of recognition being key to human relations. Hegel (1991) suggests that inter-subjective recognition is crucial for society’s moral development and that it increases individuals’ self-awareness. Honneth (1995) takes these ideas further and, using symbolic interactionism, contends that mutual recognition is a requirement for optimal self-realisation. He argues that when recognition is present in the form of love or care, when individuals are able to assert their rights and have their abilities and achievements validated in social settings, which makes them feel like they belong to a community, they are more likely to feel self-confident, have self-respect and self-esteem (Honneth, 1995).

Houston (2010) applies Honneth’s (1995) ideas around mutual recognition and self-realisation to social work, discussing social work practice as symbolic interaction, care, respect and validation. This notion of recognition can be applied productively to the classroom and relationships between teachers and learners. Huttunen and Heikkinen describe the work that a teacher does as a ‘process of receiving and giving recognition’ (2004, p. 164) and suggest that it should be at the heart of education. They describe recognition as a central part of social interaction and vital for the development of a person’s identity.

Noddings (2005) discusses the notion of care in relation to teaching, advocating a relational sense of caring and highlighting the significance of teachers paying attention to learners and being willing to listen. She emphasises the importance of attention, or what she calls ‘engrossment’, and the significance of the cared-for (ie. the learner), responding in a way that is detectable. Laurent (2013) uses Noddings’ (2005) relational ethics of care as a framework for her research among disengaged secondary school children, in which she explores using caring relations as an intervention and highlights
that even small acts of care by teachers are memorable and revered by young people. Rogers, who also studies care within educational institutions in England, in particular in terms of those with learning disabilities, describes care and compassion, as well as socially just practices, as essential for ‘human development, social inclusion and inclusive education’ (2013, p. 988). She states that ‘learning should take place within and through relationships and that these relationships are important in developing a healthy sense of self’ (2013, p. 988). Lithari and Rogers emphasise the importance of ‘care-full spaces’ (2016, p. 259) at school and at home, which avoid marginalisation and enable ‘healthy identity construction’ (2016, p. 259).

Gillies and Robinson, however, suggest that a government agenda of greater regulation and management of caring practices in schools, has led to ‘the documenting of “due care” rather than towards seeking the understandings and relationships that would enable more realistic evaluations of pupil welfare’ (2013, p. 52). They talk of ‘professional care’ (2013, p. 46) and suggest that adherence to educational objectives often precludes teachers from demonstrating ‘emotional commitment, compassion and respect for the different experiences and identities of pupils’ (p. 46). Luff (2013), referring to her ethnographic research with ten newly-qualified early years practitioners in England, describes the informal caring that occurs in early childhood education but discusses how it can be in tension with educational requirements, procedures and frameworks.

**Teacher awareness, understanding and attitudes**

Recognition and care is however more likely to occur in the context of school if teachers are aware of, and understand, the learning difficulties experienced by the young people they teach. As discussed in chapter 3, although SEND is now a mandatory part of initial and early years teacher training, the government does not stipulate the time allocated to it and the guidance on content does not specify teaching on individual learning differences, such as dyslexia. In 2017, a survey of Newly Qualified Teachers (DfE) found respondents to be generally positive about their ITT. However, views were more negative about monitoring the progress of learners with SEND and training in teaching reading and comprehension in secondary school. Gwernan-Jones and Burden, in their survey among 408 student teachers in England
(2010), found that only a small proportion claimed to know how to support learners with dyslexic difficulties.

A mixed-methods study by Taylor and Coyne (2014) in England, comprising 30 online questionnaires and three face-to-face interviews, found that teachers’ lack of understanding can contribute to them feeling less positive towards young people with dyslexic difficulties. A recent survey by the Driver Youth Trust (2019) among 5,775 teachers in Britain found that 26% think that the term ‘dyslexia’ is useful but have concerns about its validity; headteachers expressed the greatest level of concern (33%).

In contrast to the literature on the significance of awareness and understanding of dyslexia, Ross (2017), in her qualitative research among teachers in an English secondary school, found that negative perceptions of themselves as teachers of learners with dyslexic difficulties often led them to have better relationships with their students. This happens because teachers do ‘not view themselves as experts on dyslexia and, as such, do not place themselves in a fully dominant position over young people’ (2017, p. 199).

Teacher expectation of learners’ academic potential has been shown, on many occasions, to have a small but significant effect on school attainment (e.g. Madon, Jussim, & Eccles, 1997) and having stigmatising attitudes towards certain groups can influence how teachers react to individual learners (Jussim & Harber, 2005). This happens because teachers’ expectations can lead them to interrelate differently with, and provide different opportunities for, students who they believe can perform less well at school (Alvidrez & Weinstein, 1999, Paterson, 2007). It is worth bearing in mind that teachers may lower their expectations for young people with dyslexic difficulties.

Allowing young people’s voices to be heard

The previous chapter outlines the internationally established rights of young people with SEND to have their voices heard in school. However, Harris and Davidge’s 2019 qualitative study of 21 stakeholders in the field of education in England found that young people still have to rely on their parents to have their voices heard. They also argue that the 2014 reform of SEND has not produced any significant shift towards
increasing young people’s agency.

Giddens describes agency as not referring ‘to the intentions people have in doing things, but to their capability of doing those things in the first place’ (Giddens, 1984, p. 9). Prout and James (1990) were among the first sociologists to consider that children and young people have agency, referring to them as being constrained by structures but also being social actors in their own right. In ‘Asylums’ (1961), Goffman discusses the construction of self through total institutions, which are characterised by ‘the bureaucratic control of the human needs of a group of people’ and operate ‘through the mechanism of the mortification of self’ (Goodman, 2013, p. 81). Goffman (1961) suggests that total institutions interrupt people’s capacity to have some kind of command over their world, leading to a lack of autonomy and self-determination.

The interplay between structure and agency is interesting in the context of relationships between teachers and young people. On the one hand, young people are affected by broader social processes, which highlight power differentials (Morrow, 2011), but on the other hand they are active agents operating in and upon structure (Prout and James, 1990). For example, in Allan’s (2011) research among disabled students discussed in the previous chapter, she expected to find that young people were limited and constrained by the discourses and procedures within special education. Instead, she found some perceivable signs of transgression. Furthermore, in my Master’s research (Durrant, 2015), I found examples of children with severe dyslexic difficulties demonstrating agency and challenging norms, alongside parents confronting their child’s school and local education authority.

In this thesis I conceptualise the agency of young people with severe dyslexic difficulties as simultaneously personal, social and collective, acknowledging Esser et al’s (2016) argument that children’s agency can have both ‘a reproductive and transformative effect on the generational order’ (p. 8). In this respect my work sits within a movement in childhood studies (for example, Esser, 2016, Prout 2000) that is rethinking children’s agency, from an essential quality of each individual child, towards an understanding of it as ‘assembled, infrastructured and networked’ (Spyrou, 2018, p. 117). Importantly, this shift takes account of the different ways children express their
agency and moves away from ‘a model in which privileged children will be accorded more agency than those who do not display rationality and choice in conventional ways’ (Valentine, 2011, p. 347). It also ensures that agency is understood within the context of social relations because the capacity to act may be driven by vulnerability rather than being individually created (Mizen and Ofosu-Kusi, 2013) and it is important to acknowledge the difference.

3.2 Forming an identity

There has been considerable debate about the degree to which the self is able to influence its own destiny and act as an agent in the construction of identity (Woodward, 2002). Different accounts of identity emphasise, to varying degrees, the relationship between ‘the “inside” and the “outside”, the personal and the social’ (Woodward, 2002). My research engages with the work of Mead (1934) and Cooley (1902) and highlights the interactive self through which identity is constructed in dialogue with society. Moreover, through engagement with Foucault’s (1970) work I attempt to locate identity within historically situated discursive formations.

According to Gecas, identity focuses ‘on the meanings comprising the self as an object, gives structure and content to self-concept, and anchors the self to social systems’ (1982, p. 4). Dyslexia has emerged as an educational issue impacting young people’s ability to reach certain developmental goals. This is experienced in terms of a sense of self, or what might be termed an academic self-concept, which in turn shapes the construction of their identity as a learner with implications for wellbeing and esteem. It is considered that people can have a good opinion of their competence in some areas (eg. sport) but a low opinion in other areas, eg. schoolwork (Elbaum & Vaughn, 2001). Global self-concept describes perceptions of self in broader areas.

3.2.1 Using Goffman to understand how young people with dyslexic difficulties construct an identity

While much of the research literature in this area is in the field of developmental psychology, I have drawn on more sociological resources to conceptualise the situation

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3 Rosenberg defines self-concept as ‘the totality of the individual's thoughts and feelings with reference to [the] self as an object’ (1979, p.7).
of the individual child that is the focus of my research. In particular I have engaged with
the work of Goffman, which, as previously mentioned in chapter 1, acts as a
counterpoint to a Foucauldian approach. Both Goffman and Foucault studied extreme
cases of the human condition and published works on madness and institutions –
Foucault’s ‘Madness and Civilisation’ (1965) and Goffman’s ‘Asylums’ (1961). Both
were also interested in stigma: Foucault in terms of normalisation and bio-power
(1978); Goffman in terms of understanding the ‘bottom-up’ (Hacking, 2004, p. 278),
everyday way in which we interact within institutions, for example, schools.

In developing Mead’s (1934) work, Goffman, who did not consider himself an
interactionist but did draw extensively on their work, engaged with the notion of the self as occurring through social interaction:

‘The self, then, as a performed character, is not an organic thing that has a specific location, whose fundamental fate is to be born, to mature, and to die; it is a dramatic effect arising diffusely from a scene that is presented...’ (Goffman, 1959, p. 245).

Using theatrical metaphors Goffman (1959) marks out the difference between the performed, or public, self and the private self. He referred to this as dramaturgy (1959),
suggesting that most of the time we are not conscious of the roles we play. Hacking
discusses how Goffman uses the notion of performance to suggest that ‘the roles become aspects of the person, some more owned, some more resented, but always an evolving side of what the person is’ (Hacking, 2004, p. 290). Lawler summarises this as ‘constantly playing various parts, but what those parts add up to is ourselves’ (2014, p. 121). An example of this is when young people’s behaviour differs significantly
between home and school, or in Goffman’s (1959) terms, the front and backstage. Riddick (1996) suggests that young people with dyslexic difficulties may show anger and frustration in the home setting while seeming withdrawn and detached at school. She argues that this difference in appearance can make it hard for parents in their discussions with teachers.

In this thesis I have taken up Houston’s (2010) call to look to Goffman’s work on stigma and ‘faulty personhood’ (1963) as a way of understanding how a discredited attribute, such as a disability, can impact identity construction. Goffman (1963) distinguishes
between evident/known and not evident/not known attributes or, in his terms, discredited and discreditable (1963). Dyslexia is invisible and is therefore a discreditable attribute in which there is potential for people to find out. Arguably, in the context of school, the likelihood of people finding out and it becoming a discredited attribute, is high.

In his theory of the mortification of self, Goffman (1961) links the labelling and stigma that occurs in total institutions directly with shame, humiliation and lack of self-respect. He describes stigma as when a person’s social identity – their category or attributes – is perceived as different or even undesirable. This ‘social identity’ is contrasted with personal identity and ego, or felt identity. Personal identity comprises the unique characteristics that each individual possesses and is based on the value structures of those with whom a person interacts (Hitlin, 2003). Ego identity on the other hand, is defined by Goffman as ‘the subjective sense of his own situation and his continuity and character that an individual comes to obtain as a result of his various social experiences’ (1963, p. 129).

Goffman (1963) argued that people who are stigmatised differ in some way to the expected social and cultural norms of a society and that difference and otherness are constructed through social interaction. He describes the body as belonging to the individual but given meaning by society (Woodward, 2002). The space between the two is where the tension lies for young people with severe dyslexic difficulties, who can experience stigma because of their academic difficulties and poor literacy skills – two culturally derived marks of achievement in the school environment. Goffman (1963) describes the way that other people react to difference as creating a spoiled identity. He talks about ‘normals’ as those ‘who do not depart negatively from the particular expectations at issue’ (1963, p. 15) and describes the social expectations determining how we understand situations as ‘frames’.

An important part of Goffman’s (1963) work was to sketch the ‘moral career’ of those who are stigmatised. In this he explains how people manage their stigma through ‘learning experiences’, and changes in their understanding of self (ibid). Goffman (ibid) details the ways in which people with a stigma manage social interactions by adopting fronts that are regarded as socially acceptable. He speaks of mechanisms of
impression management (1959), or information control, in which people with a stigma try to pass as having a particular identity and manage situations to help them cope (1963).

3.2.2 The dilemma of difference

There is tension between treating all children the same and providing for their individual differences. The former risks the child not being supported in a way that is effective for their individual needs, while the latter risks them being discriminated against and experiencing stigma. This contradiction was highlighted by Warnock (2005) and forms an important part of the debate in special and inclusive education. Terzi (2005) coined this ‘the dilemma of difference’.

Riddick (2000), in her interview studies of 27 children and 16 adults with dyslexic difficulties in Britain, argues that stigma occurs even before a label is attached to their difficulties. Macdonald (2009b) concurs, saying that it is the difficulties associated with dyslexia that cause stigma and not the label itself. Based on his qualitative biographical research of 13 adults with dyslexic difficulties in Britain, he argues that the label brings with it support, in this case assistive technology, that may not otherwise be available (ibid). Gillman, Hayman and Swain (2000) also suggest that a label can provide opportunities, mostly in terms of additional resources that may not otherwise have been secured. Others suggest that labelling leads to increased awareness and understanding of SEN and may lead to ‘increased adult tolerance . . . that helps teachers and carers understand why the child [has particular difficulties]’ (Gross, 1994, p. 105). On the other hand, Ogilvy (1994) describes the label as only of use if it leads to effective interventions.

In a systematic review of the literature about children and young people with literacy difficulties and dyslexia, using 19 papers from around Europe between 2000 and 2017, Gibby-Leversuch, Hartwell and Wright (2019) discuss the extent to which the label ‘dyslexia’ impacts self-perceptions. The review found the research to be inconclusive, with responses to identification differing and lying somewhere between resistance and accommodation; they recommend further research on this subject. Fulgeri and colleagues (2014), on the other hand, studied how being identified as having dyslexic difficulties can be a turning point in the construction of young people’s identity. Their
research among primary school children in Italy highlights three elements that shape identity: understanding in terms of the meaning given to dyslexia; acceptance; and psychological compensation, which they relate to self-efficacy.

3.2.3 Literature on identity and dyslexia

In the previous section, I discussed the importance of considering labelling in relation to self-identity. Here I look more closely at the ways that dyslexia and identity are linked in the literature. Barnes, Mercer and Shakespeare (1999) suggest that people with visible disabilities are more likely to identify themselves as disabled than those with hidden disabilities such as dyslexia. Chanock (2007), however, proposes that people with dyslexia form their identities through the discourse of impairment rather than through the lens of societal barriers and an appreciation of the influence of cultural values. She adds that well-intentioned educational models to eliminate barriers to learning actually compound the sense that literacy is crucial in today’s society, and that identification may increase the feeling that something is wrong. Thompson, Bacon and Auburn state that ‘cumulatively, these experiences can contribute to a disabled self-identity and feeling of powerlessness in the face of society’s failure to meet their needs’ (2015, p. 1330). They found three dyslexic identities in their research with young people aged 15 and over on an English speaking online dyslexia discussion forum: learning-disabled, which they say is particularly predominant in educational settings; socially-disabled by a society that prioritises literacy; and differently-enabled, which focuses on strengths rather than deficits. They found that there was considerable overlap between a socially-disabled identity and a learning-disability identity.

Armstrong and Humphrey (2009) highlight the importance of acceptance. In their qualitative research among twenty 16-19 year olds at a Further Education College in the north of England, they suggest that young adults who accept their identity as ‘dyslexic’ are more likely to agree to educational support, are more motivated and perform better at college. They also found that young people are better able to form a positive perception of self when they have been assessed early and received early intervention, at least pre-/early teenage.

Barden (2014), in his UK research on social media among five young people with
dyslexic difficulties in a sixth-form college in the north-west of England, highlights how issues of identity become most important during the teenage years when identities are particularly unstable and most liable to be influenced by peers and role models. Vezzoli, Vasalou and Porayska-Pomsta, who also conducted a qualitative study about British teenagers’ use of social media, describe how young people who ‘struggle with literacy’ have to negotiate their perceived differences against the need to fit in. They found that their participants entered this stage of life with a history of:

‘academic avoidance and rejection of reading and writing that can have negative long-term effects on their sense of identity, and more broadly on their educational and life chances’ (Vezzoli, Vasalou and Porayska-Pomsta, 2017, p. 4).

Other research focuses on the shame experienced by young people in education when they have poor literacy skills and academic difficulties. For example, Lithari (2018) uses Goffman’s (1963) concept of stigma to theorise the findings of her qualitative study about the transition from primary to secondary school in England. She describes how the difficulties experienced by young people in achieving literacy norms lead to feelings of being defective and having a spoiled identity. Lithari concludes that ‘dyslexia has a profound effect on identity construction, since it fractures academic attainment, which is a cultural expectation’ (2018, p. 292). She explains differences in young people’s identities by pointing to the support received at school and from teachers, parents and peers. She also found that participants were able to repair their ‘fractured academic identities’ (2018, p. 280) when they left compulsory education and the focus was taken off literacy and academic attainment.

There is another body of research, and a growing movement among dyslexia organisations, such as Made by Dyslexia (2021), that suggests that people with dyslexia may be particularly able in other areas. These include artistic and creative endeavours (Aaron and Guillemond, 1993), visuospatial awareness (Attree, Turner, and Cowell, 2009) and visual thinking (Grant, 2010). Bacon and Bennett (2013) argue, in their research with thirteen art students with dyslexic difficulties in England, that participants were able to construct a positive sense of identity because their abilities were appreciated and their weaknesses were accepted. Elliott and Grigorenko (2014),
however, dispute these claims, citing personality and motivation as more likely causes.

3.3 Young people’s emotional worlds

The government recognises that neuro-diversity, which they define as ‘neurological differences such as autism, dyslexia and dyspraxia...’ (DfE. 2016, p. 3), is a high-risk factor for children and young people developing mental health issues. The BDA also states in a resource pack for schools that:

‘Paying attention to empowerment, emotional intelligence and self-esteem may prove to be more valuable than a detailed knowledge of a learner’s neurological makeup’ (BDA, 2005, p. 3).

Since around the turn of this century there has been increased interest in, and concern about, emotions in the classroom. The Children Act 2004, which has been important in terms of service provision by local authorities and other agencies, reflects this interest in emotions and refers to improving mental health and emotional wellbeing, alongside physical health. However, Gillies describes the measures taken as ‘specific and highly regulated’ (2011, p. 187), designed to teach ‘emotional skills’ within the curriculum and create learners who are ‘rational, detached and physically subdued’ (p. 186). The focus has been on the young people themselves and giving them the tools to improve their social and emotional literacy, treating them as skills that can be learnt. My research, reflecting Gillies (2011) work, takes a holistic approach and aims to take the emphasis away from young people as a psychological project towards social, cultural, interpretative processes and wider structural issues.

Therefore, my research takes a sociological, rather than psychological, perspective of emotions, seeking to understand both the context and social interaction. Within symbolic interactionist theory, positive emotions, such as pride, are experienced when the self is validated by others and negative emotions, such as shame, anger and anxiety, are felt when it is negated (Turner and Stets, 2005). Foucault (1980) locates emotions in discursive practices, where discourse determines what can be felt. In Foucauldian terms, emotions may be viewed as formations of strategies that incorporate discourses, institutions and technologies of power – ‘the said as much as the unsaid’ (Foucault, 1980, p. 194), which ‘penetrate the body, the psyche, the emotions’ (Doyle McCarthy, 1994, p. 273).
Goffman (1959) relates emotions to his theories of dramaturgy and impression management by suggesting that people attempt to avoid shame and embarrassment in their interactions, or performances, highlighting the emotional dimension involved in managing stigma. He suggests that there are psychological implications of the mortification of self and that ‘the study of stress and of encroachments on the self will often be tied together’ (1961, p. 48). Arlie Hochschild (1979) developed Goffman’s (1961) work by considering the influence of cultural norms and vocabularies on how emotions are felt and expressed, specifying feeling rules, framing (context) rules and display rules, which determine how we manage and express emotions. She coined the term ‘emotional labour’ to describe the work required by an individual to ‘induce or suppress feelings in order to sustain the outward countenance that produces the proper state of mind in others’ (Hochschild, 1983, p. 7). In the context of school, it could be argued that all children are expected to engage in emotional labour, but those with SpLDs and other forms of disability may have to engage in even more, in an effort to explicate their support needs and requirements, as well as hide, downplay and negotiate their differences.

Since the mid-1990s there has been an increase in psychological studies focusing on the relationship between self-perception and dyslexia, as well as its emotional impacts. Much of the work is rooted in a positivist paradigm and involves making connections between dyslexia and many different measures of self-perception and affect, including self-worth, self-esteem, self-concept, externalising and internalising problems, affective issues, emotional challenges, school stress, emotional impacts, self-efficacy, and depression. My exploration of this area will focus on two reviews of the literature that were conducted eleven years apart. Burden’s review covers the period between 1988 and 2008 and includes literature from around the world. As mentioned previously, Gibby-Leversuch, Hartwell and Wright’s systematic review (2019) covered Europe-based literature between 2000 and 2017. Both reviews discuss how it can be problematic to compare studies in this complex area because of the definitional
difficulties associated with the concept ‘dyslexia’ and the lack of appropriate definitions provided within the literature of self-esteem⁴ and self-concept.

Both studies agree that the evidence demonstrates that children and young people with literacy difficulties or dyslexia are more likely to perceive themselves as having lower academic ability than their peers who attain normally. Burden (2008) points out that this situation is not fixed and that improving literacy skills can lead to a more positive academic self-concept. While Burden holds back from saying that there is a clear relationship between dyslexia and how someone perceives their abilities overall, he suggests that there may be a link between dyslexia and global self-concept when literacy is perceived as being of vital importance to someone’s life, for example, for those with severe difficulties living in a society where literacy is highly valued.

The two studies disagree about the extent to which dyslexia impacts global self-esteem, or how it makes people feel generally. Burden (2008) found, among the studies reviewed, that children and adults with dyslexia experience lower global self-esteem than those without any difficulties. Gibby-Leversuch, Hartwell and Wright (2019), on the other hand, did not find a consistent relationship between the two.

Burden (2008) also discusses how young people with dyslexic difficulties may seek to avoid any activity at which they are likely to fail: Seligman and colleagues (1979) describe this as learned helplessness and suggest that it can in some cases lead to chronic depression. Later, in 2012, Burden argues that people with dyslexic difficulties are as likely to require an ‘empathic listener with counselling training’ as they are ‘intensive remedial input, study skills training, laptops with spellcheckers and extra examination time’ (last paragraph). He cites Covington (1992) to emphasise the importance of building self-efficacy:

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⁴ Self-esteem is regarded as a measure of how a person’s self-image matches up to their ideal self. James’ theories of self-esteem (1890) make the link between how we feel about ourselves (pretensions) and how well we actually do.
‘When the belief in personal efficacy flourishes, so does imagination, flexibility, and compassion; and when this belief is compromised, so is a major share of humanity’ (Covington, 1992, p. 73).

Gibby-Leversuch, Hartwell & Wright discuss the protective factors that help children and young people to deal more effectively with their difficulties, including ‘supportive family, teacher and peer relationships, and recognition of their successes in other areas’ (2019, p. 14). They also conclude from the evidence that children and young people with dyslexic difficulties are more likely to believe they do not have control over what happens in their lives. They suggest that this makes them susceptible to developing negative self-attributions – attributing failure to a lack of core ability and lowering expectations because they think that they cannot influence the outcome (Bernard Weiner, 1979). Gibby-Leversuch, Hartwell & Wright (2019) cite research in the general population that suggests that negative self-attribution can lead to lower levels of self-esteem, which impacts motivation and academic performance (Chodkiewicz and Boyle 2014).

An outcome of Burden’s systematic review (2008) is that, like Humphrey (2004), he questions the worth of simply making connections between dyslexia and measures of self-perception and advocates a more attributional approach to the study of emotions and dyslexia. He also suggests that more research should be undertaken on dyslexic young people’s developing sense of identity, as well as research broken down by gender and age. Furthermore, Gibby-Leversuch, Hartwell & Wright conclude that there is a need for more research ‘to explore the impact of attributional style and the potential for intervention’ (2019, p. 1).

None of the studies in either of the systematic reviews described above differentiate their findings by severity of dyslexic difficulties. In fact, I have only found one study that focuses on severe dyslexic difficulties and emotions. This is a questionnaire study from Norway among 70 children and young people with severe dyslexic difficulties (Dahle, Knivsberg and Andreassen, 2011) plus their parents/carers and teachers. They report that children and young people with severe dyslexic difficulties are more withdrawn, nervous and unhappy than the control group without literacy difficulties. They also found them to have more somatic disorders and to present with more anti-
social and violent behaviour, although these were less significant. Nine out of the seventy participants with severe dyslexic difficulties had suicidal thoughts, compared to none in the control group (ibid).

3.4 Discussion

With most existing studies focusing on the broader term ‘dyslexia’, this chapter suggests that my research has a distinct place within the literature because it focuses on the identity and emotions of young people with the most severe dyslexic difficulties. This is something that Burden would have approved of, when in 2008 he advocated that future research should explore how the extent of a person’s literacy difficulties relates to their self-perception.

Much of the existing literature about the parents of young people with dyslexic difficulties focuses on the importance of parental support, the parent/teacher relationship and the experience of parents having to advocate in an adversarial SEN system. There is also some research about the impact of social class and capitals on parents’ ability to negotiate provision; my research will contribute to this. By writing this chapter I have identified that there is a lack of research about the influence of classed cultures on how parents respond to their dyslexic child as a learner.

This chapter also discusses a small body of work on the negative impact of relationships with peers. However, there is a gap in the research about how peers can provide support for young people with dyslexic difficulties, in particular an exploration of in-group alignment. This chapter has also shown that much of the existing literature on the teachers of learners with dyslexic difficulties is focused on their awareness and understanding of, and attitudes to, dyslexia and has exposed the need for more research on the relationship between them and the young people they teach. It has also highlighted a gap in the research on the agency and participation of young people with dyslexic difficulties at school.

There is a small, but growing body of research exploring identity development and dyslexia, which suggests that young people’s identity can be negatively affected when they are not able to meet the norms and expectations of school. Existing literature also establishes the connection between dyslexia and measures of self-perception by
referencing a significant number of studies, many rooted in a positivist paradigm. There is, however, less interpretivist research focusing on lived experience and relating emotions to wider social, cultural and structural issues which provides understanding of the interplay between shame and pride and the emotional labour required to engage in information control and impression management.

As the next chapter will explain, my methodology is designed to address the gaps that I have identified by prioritising the voices of young people, as well as exploring the perspective of their parents.
Chapter 4. Methodological framework

In this chapter I outline my logic of enquiry and the methodological assumptions underpinning my research endeavour. My overall aim is to show how the methodology employed in the study is suitable for the objectives of my research and consistent with my epistemological orientation. I will also explicate my positioning and reflexivity as a researcher, establishing, within the context of my theoretical perspective, where I locate myself in relation to my research participants. Finally, I will describe my research method, including ethics, and data analysis.

4.1 My epistemological and ontological perspective

The difficulties associated with dyslexia are socially embedded and this informed the development of my theoretical position and research design. My epistemological perspective is social constructionism, which emphasises that knowledge of the world and truth are created through human relationships, rather than discovered from an external reality or created by reason, separately from such a reality (Blaikie, 2007). Knowledge is therefore constructed by people through active and purposive interaction (Morcol, 2001), is constantly interpreted (Esland, 1971) and will differ between societies and cultures. Importantly, this approach acknowledges the role of people in creating knowledge and recognises that the process of ‘assigning meanings to things in different settings on particular occasions’ entails ‘situating encounters with the world in their appropriate cultural contexts’ (Bruner, 1996, p. 3).

Influenced by the work of Alfred Schutz (1899-1959), the notion of social constructionism was introduced in the 1960s by Berger and Luckmann. They defined the difference between objective reality (things that exist independently of the human mind, such as the natural world) and subjective reality which is socially constructed through interaction with other people, or socialisation (1966). They spoke of reification in terms of the way in which ‘the products of human activity’ are understood as if they are something else, ‘such as facts of nature, results of cosmic laws, or manifestations of divine will’ (1966, p. 106).

My ontological standpoint reflects my understanding of the nature of existence and my view of the form that reality takes, while epistemology is more focused on how we
come to have knowledge of the world. Social constructionism is associated with the ontology of relativism, which proposes that the external world does not exist independently of experience (Blaikie, 2007). From the position of a relativist, reality is indistinguishable from the subjective experience of it (Guba & Lincoln, 2005). This presumes that there are multiple realities that are formed socially and experientially and are reliant on individuals for their shape and content. Relativism’s questioning of an objective reality raises important questions for my own research, which involves a methodology that values interactive processes and the shared construction of social reality, but at the same time is interested in understanding the lived experiences of young people with learning differences. While I agree with Guba and Lincoln (1989) that, as a researcher, I am not separate from my research participants, such that knowledge is a co-construction, I do not adhere to the argument that the external world does not exist outside of my experience of it. My research is about learning difference and I believe it is important to acknowledge that our bodies function differently while also recognising that these differences are subjected to examination against culturally derived norms that inform social interactions. Dyslexia is a classification that has been constructed in response to a post-industrial society that values literacy. For most of the 19th century the term did not exist and this may be the case again in the future if assistive technology is able to overcome many of the difficulties associated with it. Hacking (1999) talks about how the notion of social constructionism can be liberating, however he moderates this through the example of anorexia – ‘a transient mental illness, flourishing only in some places at some times. But that does not help the young women and girls suffering’ (1999, p. 2). While it may be a relief for some people to understand how their learning differences have been constructed, on a daily basis in school or at work, their difficulties feel very real to them. McLaughlin, Coleman-Fountain and Clavering argue for the importance of retaining the notion of the body, saying that it is inconceivable that the body does not influence ‘the edifices of power, or the lived experience of having a body differently abled than the norm’ (2016, p. 23).

This is where Symbolic Interactionism becomes of value to my research because of the way it explores how ‘meaning and selfhood is constructed through our embodied
interactions with the social world that we inhabit’ (McLaughlin, Coleman-Fountain and Clavering, 2016, p. 24). As a body of knowledge, it recognises that the way we live our lives is influenced by the bodies we have and our experience of those bodies (Denzin, 1992). Blumer describes the nature of an object as consisting ‘of the meaning that it has for the person for whom it is an object’ (1969, p. 11) and says that this meaning is relationally constructed through interactions. Blumer (1969) speaks of an empirical world that resists, talks back, has an obdurate character, is fluid and changes over time. Although I accept that SpLDs, such as dyslexia, only make sense within an institutional framework that values literacy skills and that in other cultural contexts they have no meaning (Dudley-Marling, 2004), for the young people with whom I conducted my research, dyslexic difficulties are very real.

4.2 Social Constructionism and my role as a researcher

Proponents of social constructionism argue that all research replicates the perspective of the researcher and that it is impossible to make observations and produce knowledge that does not refer back to existing theories (Denzin and Lincoln, 2000) and the values of the social scientist. This raises important questions around the issue of objectivity and the researcher/participant relationship. The positivist researcher’s absolutist, scientific stance is to position herself as removed from the participant and outside of the process as an objective observer. By contrast, the role of a researcher who adopts a social constructionist perspective is less detached and perceives that her role as a researcher is to understand social actors’ lived experience from their own perspective. These two methodological orientations are described in metaphorical terms by Kvale (1996) as the miner, who represents the positivist researcher, and the traveller, who represents the interpretive researcher. In following the traveller’s path there is an acceptance that the researcher’s presence will have some effect on the process and the knowledge created and that their interpretation of the findings will be value-laden (Harrington, 2005). Positivists would argue that this will impact validity. However, while social constructionists may not present their research findings in objectivist, definitive terms, they would contend that positivist researchers are far from neutral. Aguinaldo proposes a move away from the binaries of valid or not valid
to assessing research claims made through a social constructionist lens in terms of ‘What is this research valid for?’ (2004, p. 130).

Social constructionism de-emphasises what are generally regarded as the norms of childhood and prioritises children and young people as social actors that interrelate with, and confront, the norms around them (Hardman, 2001). My research frames children as social actors (e.g. Prout and James, 1990) who are involved in shaping their own world. My philosophical position in relation to researching young people is also influenced by a rights-based framework and the assumption that young people with dyslexic difficulties should be able to participate in society on an equal basis. By using participatory methods, my research seeks to make the young people active participants in the creation of knowledge, which means being cognisant of issues of accountability, power, and ethics. Kesby argues that participatory methods ‘access and valorise previously neglected knowledges and provide more nuanced understandings of complex social phenomena’ (2000, p. 423).

4.3 My positionality and reflexivity

In this section I reflect on my relationship with the participants in my research and how I positioned myself with respect to them. I will also examine how reflexivity has helped me to critically reflect on my role in the research (Braun and Clarke, 2013), stand back from it, provide evidence of an ‘internal dialogue’ and take ‘a metacognitive stance’ (Moon, 2004, p. 25).

I am a white, middle-class mother in my 50s from the south of England. I went to a private school but was the first person in my family to go to university. I have a strong sense of social injustice, perhaps borne out of my childhood spanning two worlds – a world of relative privilege and opportunity at school with an insight into another world of disadvantage and lack of opportunity among my wider family. As described in chapter 1, this sense of unfairness was amplified when I had a child with SEND and struggled to navigate the SEND system on his behalf. It is, therefore, with a heightened political awareness and sense of injustice that I designed my research. There is no doubt that I have shaped my research to investigate the themes that I am interested in and which I want to know more about.
Milligan (2016) emphasises the importance of researchers reflecting on their ‘status sets’, described as the collection of social statuses that an individual has (Merton, 1972), in order to uncover how participants may perceive them. My statuses include being white, an older adult, a mother of two children with dyslexic difficulties, from the South of England and a (PhD) student. Each of these identities signify different things to different participants and reminded me of the potential power implications and ‘the potential pitfalls of the illusions of being an insider’ (Milligan, 2016, p. 241).

As the mother of a young person with severe dyslexic difficulties with a similar narrative to some of the parents that participated in my research, I am an insider in the research. With this come several challenges. Being an insider means that I am conducting research among a group of people of which I am a member (Kanuha, 2000). This membership means that I share experiences, language and an identity with the people taking part in my research, which affords me both benefits and drawbacks. Adler and Adler discuss how the ‘the greater involvement and overlap between researchers’ personal lives and research role invoke methodological, epistemological, and ethical issues’ (1996, p. 40). As I will describe below, most of the time I was able to combine my two roles, but with a recognition that ‘the parental role served as the base and the research flowed out of it’ (Adler and Adler, 1996, p. 47).

As I will explain in detail below, I posted a link to my online survey on the public BDA page on Facebook and on the Facebook page of two support groups for people with dyslexic difficulties, which I would not have had access to if I had not already been a member. My previous involvement meant that I was familiar with the groups’ norms and language (Brannick & Coghlan, 2007), which allowed me to be accepted by participants. It may also have meant that participants were more likely to share their stories because they trusted that I would represent them properly (Berger, 2013).

However, being an insider can be problematic because it involves ‘operating in complex territories’ (Humphrey, 2007). Brannick and Coghlan (2007) argue that when a researcher is similar to participants, she can struggle between her two roles and her objectivity can be hindered. Mills (2002) suggests that researchers can miss what respondents tell them if they pay too much attention to their own agenda and Fay
(1996) proposes that sometimes it is easier for outsiders to make connections and see a wider view.

Based on the assumption that complete objectivity in research is not achievable (Crotty, 1998) and that ‘There is no neutrality. There is only greater or less awareness of one’s biases.’ (Rose, 1985, p. 77), I have used reflexivity to enable me to highlight and explore ‘personal feelings and preconceptions’ (Ahern, 1999, p. 408) and illuminate the values and interests that may intrude on my research. Braun and Clarke (2013) describe reflexivity as the process by which a researcher critically reflects on her role in the research and Moon (2004) describes reflective writing as ‘standing back from an event’, providing evidence on an ‘internal dialogue’ and taking ‘a metacognitive stance’ (p. 25). Given my dual role as researcher and parent/advocate, it is imperative that I make explicit my ‘taken-for-granted assumptions, values, prejudices, personal and theoretical positions’ (Lyons and Roulstone, 2018, p. 21). In chapter 1 I locate myself in the research and state from the outset that my experiences and interests will have shaped my research design and my interpretation of the findings. Within my analysis chapters I am open about the thoughts and emotions that the interviews generated and report on how they may be influencing my understanding of the research findings. In particular I pay attention to the times when I felt angry, anxious, sad or empathetic, which Walkerdine, Lucey and Melody (2001) suggest can be the starting point for understanding my personal investments in the research and the kinds of knowledge enabled by this (which they liken to the phenomena of counter-transference in a psychoanalytic relationship). Finlay describes this structured process of reflexivity as:

‘full of muddy ambiguity and multiple trails as researchers negotiate the swamp of interminable deconstructions, self-analysis and self-disclosure’ (Finlay, 2002, p. 209)

In spite of this, I believe that reflexivity has allowed me to provide a richer, more developed understanding of the lived experience of young people with severe dyslexic difficulties and has made my arguments more persuasive.

For me, being an insider has also meant that I have had some strong emotional reactions to my research. The first time I experienced this was when I was analysing
the findings of the open-ended questions in the online survey and was reading about children’s experiences at school and their reactions to them. Some of these stories reminded me of my own and made me feel very sad and also angry at the injustice of their situation. After a few days I worked out how to concentrate on what respondents were saying, without relating it to my own experiences; I still felt sad at some of the experiences that children have had but was better able to de-personalise it. However, these feelings returned during the narrative case studies – for some participants more than others. In order to alleviate these feelings, and to maintain the integrity of the research, I wrote field notes during data collection. I also met with my supervisor at least a couple of times during fieldwork for a debriefing and to access support.

As an insider I needed to consider how much of myself to reveal to participants. The first time I thought about this was when I was writing the introduction for the online survey. Believing that at this stage there was no benefit to saying that I was the mother of a child with dyslexic difficulties, I decided to simply describe myself as ‘a PhD student at the University of Sussex’. However, when it came to contacting those participants who agreed to take part in further research, I wanted them to know that I had shared experiences but did not want them to think that this meant they should disclose less (Hellawell, 2006). It was important that I found a balance between these two positions. I therefore described myself as ‘the parent of two children with dyslexia’ and referred to knowing ‘how difficult it is to get your, and your child’s, voice heard’. I signed the email with my name and ‘PhD student’. By doing this I reminded them that I am a doctoral researcher, while at the same time showing understanding of the struggles that they and their children may have experienced. When I visited families’ homes, I decided to be more open in my conversations with parents either side of the interview with their child. I also opened my interviews with young people by saying ‘I am a mum to two boys, both of whom have dyslexic difficulties. I live down on the south coast, near Brighton, and I am currently a student at the University of Sussex’. Within the interview itself I only referred to my son’s experiences if I felt that showing empathy and understanding would help them to relax and speak more openly to me.
Being a member of a particular group does not mean that there is total uniformity within that group and not being a member does not mean absolute difference (Corbin Dwyer & Buckle, 2009). On this basis, Corbin Dwyer and Buckle (2009) argue that researcher status is not a binary issue, citing Acker (2000) who suggests that researchers should strive to be both and crossover between the two. Humphrey (2007) describes this as triggering the hyphen between insider and outsider. Despite my position as an insider researcher I have therefore tried to recognise the heterogeneity of the human experience and remember that ‘There is no self-understanding without other-understanding’ (Fay, 1996, p. 241). In other words, it is important to be aware of both the ways in which we are the same as others, as well as the ways in which we are different.

4.4 Method

4.4.1 Research questions

My doctoral study and the methods used were guided by three research questions, each of which reflects my experiences and research interests as described in chapter 1 and in the section above on positionality and reflexivity. As my research developed, the focus of my research questions shifted, settling on the following:

RQ1. How do young people in state, mainstream education who experience what is described as severe dyslexic difficulties construct their identities?

RQ2. What are the factors influencing how young people respond emotionally to their severe dyslexic difficulties?

RQ3. How equal is access to SEND provision for young people with severe dyslexic difficulties and what resources do parents require in order to acquire support?

Each of these questions seeks greater understanding of how young people with severe dyslexic difficulties experience school, with the ultimate aim of finding ways to support them better.

Social constructionism has informed my research design, framing young people as social actors who are active participants in the research and using narrative methods to co-construct their stories, while situating them within social structures and cultures.
I made a pragmatic decision to use an online mixed methods survey with parents to find a sample for my parent/child narrative case studies. This mirrors my own research journey of using both quantitative and qualitative methods and helped me to locate myself within the field, before moving on to the narrative case studies which broadened and deepened my understanding. I have employed an iterative design, whereby the online mixed methods survey not only provides a sample for the parent/child narrative case studies but also shapes what is asked and explored in it. My original intention was to include a third stage of research comprising a focus group with young people at a specialist dyslexia school and an interpretive panel with educators. However, having completed the online survey and case studies with young people and parents and being happy with the richness of the data collected, I decided to postpone the last stage of my research to a later date.

4.4.2 Online mixed methods survey with parents

The main purpose of this initial stage of my research was to provide a population of parents and young people for sampling for the following qualitative phase. In addition, I also saw it as a way of creating a community for my research to which I could feed back my findings.

Studies have suggested that the heritability of dyslexia is around 50% (Dyslexia Research Trust, 2020); this means that some parents are likely to have dyslexic difficulties themselves and it was important that the layout, font and language of the questionnaire reflected this. The questionnaire, which can be found in Appendix ii, comprised 24 questions, including five which were open-ended. The closed questions were mostly information gathering about their child, including details of their dyslexic difficulties, school, age, gender etc., but there were also questions to establish geographical area, level of education of parents plus their own, and their child’s, willingness to participate in further research. The open-ended questions were designed to elicit parents’ perspective on the positive and negative effects of dyslexia, the impact of dyslexia and their child’s support at primary and secondary school in their own words.

The questionnaire was written using Qualtrics software and on 25 June 2018 posted in three places on Facebook (the ‘post’ is shown in Appendix iii):
• the BDA Facebook page (a UK-based charity with nearly 14,000 followers)
• the Operation Diversity Community (a UK-based closed Facebook group with 9,000 members, which supports people with dyslexia, as well as their parents, carers, educators and employers
• the Operation Diversity Academy (a UK-based closed FB group with around 300 members who pay a fee to join).

I had been following each of the Facebook pages shown above for a couple of years prior to my research. I was not an active participant, preferring to observe rather than post anything myself or comment on other people’s posts. Nevertheless, this afforded me familiarity and understanding and, particularly in the case of Operation Diversity, meant that I was perceived as part of the group.

I reposted the questionnaire another two times on the Operation Diversity pages (28 June and 9 July, 2018) and once more on the BDA page (4 July, 2018) (this ‘post’ is shown in Appendix iv). Consent was built into the first page of the questionnaire as follows: ‘By taking part in this online survey you are consenting to me using anonymised information for the purposes of research only’. I closed the survey to responses on 13 July 2018.

I received responses from a total of 474 parents. Everyone was included in the analysis, although they did not necessarily complete every question; the findings exclude those who did not answer but include those who coded ‘don’t know’. This relatively large number of responses has allowed me to identify relationships between attributes and generalise them to all those who were involved in the three Facebook groups that I used as my sample frame. Notably, they cannot be generalised to the wider population but are illustrative of what can and does happen.

Earlier discussions about the lack of agreement on a definition of dyslexia (see chapter 1) and the social construction of classifications such as dyslexia (see section 4.1) led me to let parents opt into the online survey if they have a child who they identify as having dyslexic difficulties. This could be through a screening test, which is designed to give an indication of possible dyslexic difficulties or a full diagnostic assessment but neither was a necessary requirement for participation. Similarly, I did not define what
emotional wellbeing means in the context of the questionnaire – the term is socially constructed and therefore will mean different things to different people.

**Limitations of the Online Survey**

The achieved sample size means that it is possible to identify patterns and raise issues that justify more detailed research. Yet the nature of the sample (being neither randomised nor representative) means that I need to be cautious about making generalisations from the findings beyond the survey itself.

I recognised from the beginning that the sample of people who participate in the online survey may not represent the wider population of parents with a child with dyslexic difficulties for three reasons. Firstly, parents who follow these pages/groups are already engaged in finding out more about how to support their child. Secondly, they tend to be looking for support and advice, which suggests that their experience of dyslexia may not be wholly positive. Thirdly, the people who participate in my survey will be a self-selecting group which may create bias. In Appendix v I have also compared the demographic profile of my sample with Wave 6 of the Millenium Cohort Survey (MCS) and 2011 Census (Office for National Statistics, 2011) data and found that black and minority ethnic families are under-represented and those with higher qualifications are over-represented.

**Selecting a sample for the narrative case studies**

A key objective of the online survey was to provide a population of parents and young people who might take part in the qualitative phase of my research. Therefore, a question asking about willingness to participate in a further stage of research was triggered if the parent said that they live in England and had a child aged 10 or over. Interestingly, all of the 137 who gave me their name and contact details were women. Among this group there were 41 parents who said their child had been assessed as having severe dyslexic difficulties and I selected my sample from these.

In selecting the sample, I have made judgements based on wanting to achieve a sample that, within the limits of the online survey described above, broadly represents young people with severe dyslexic difficulties in England and would help me to achieve my research aims and answer my research questions. Given the under-representation
in the online survey (see Appendix v) of black and minority ethnic parents and the over-representation of those with a degree or higher, I wanted to ensure that the sample for the narrative case studies was as diverse as possible. I therefore started by selecting those with qualifications lower than degree or who did not pay for a full diagnostic dyslexia assessment. In order to represent different school experiences, I also wanted to make sure that the sample included not just young people currently at local authority/academy schools but also those who had left to be home-educated or attend a specialist dyslexia school or independent school. I purposively selected young people who had an EHCP in order to be able to contrast their experience with those who do not. In addition, I thought it was important to not just interview those whose emotional wellbeing was severely and moderately impacted by dyslexia. I therefore selected all three of the respondents in my pool of 41 parents who said that their child is only mildly emotionally affected. I hoped this might show me where support had gone well.

Using these criteria, I selected 34 possible respondents and grouped them into four areas: north, midlands, south and south west. I also checked that they included a range of ages and that girls were not significantly under-represented. When I checked for ethnic origin and found that all of my original pool of 41 respondents were White I tried to redress this imbalance. I looked beyond young people with severe dyslexic difficulties to any non-White respondents who described their child’s emotional wellbeing as severely impacted by dyslexia. This constituted 2 people, neither of whom were able to participate in the study.

Among the 34 selected respondents I looked for geographical clusters within the four areas and in this way narrowed my initial selection down to 17. The email that I sent to parents asking them to participate in the narrative case studies is shown in Appendix vi.

After I had interviewed 11 young people and received 11 accounts from their mothers of their child’s story, I reviewed my sampling strategy and decided that I should conduct four more interviews and at least three of them should be with girls. On this basis, the final completed sample of 15 young people and their parents is as follows:
Figure 1: Sample of young people and parents for the narrative case studies

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Type of School</th>
<th>Other SEND/health issue*</th>
<th>EHCP</th>
<th>Parent highest qualification</th>
<th>Parent’s narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Georgia</td>
<td>F</td>
<td>19 State</td>
<td>Being tested for autism, dyscalculia</td>
<td>No</td>
<td>Degree or above</td>
<td>Written in advance</td>
</tr>
<tr>
<td>Gina</td>
<td>F</td>
<td>18 State</td>
<td></td>
<td>No</td>
<td>A’ levels</td>
<td>Written in advance</td>
</tr>
<tr>
<td>Arthur</td>
<td>M</td>
<td>17 State</td>
<td>ADHD</td>
<td>Yes</td>
<td>5+ GCSEs</td>
<td>Written during interview</td>
</tr>
<tr>
<td>Nina</td>
<td>F</td>
<td>16 State</td>
<td>Dyspraxia, dyscalculia</td>
<td>No</td>
<td>Professional qualification</td>
<td>Written in advance</td>
</tr>
<tr>
<td>Harvey</td>
<td>M</td>
<td>16 State</td>
<td>Attention deficit</td>
<td>No</td>
<td>NVQ Level 3</td>
<td>Written in advance</td>
</tr>
<tr>
<td>Trevor</td>
<td>M</td>
<td>14 State &amp; home education ADHD</td>
<td>No</td>
<td>NVQ Level 3</td>
<td>Written in advance</td>
<td></td>
</tr>
<tr>
<td>Pia</td>
<td>F</td>
<td>14 State</td>
<td></td>
<td>No</td>
<td>Degree</td>
<td>None</td>
</tr>
<tr>
<td>Spy</td>
<td>M</td>
<td>14 State</td>
<td></td>
<td>No</td>
<td>Degree</td>
<td>None</td>
</tr>
<tr>
<td>Matthew</td>
<td>M</td>
<td>13 State &amp; independent mainstream</td>
<td>-</td>
<td>Degree or above</td>
<td>Written in advance</td>
<td></td>
</tr>
<tr>
<td>Todd</td>
<td>M</td>
<td>12 State</td>
<td></td>
<td>No</td>
<td>NVQ Level 4-5</td>
<td>Written in advance</td>
</tr>
<tr>
<td>Ella</td>
<td>F</td>
<td>12 State</td>
<td>Dyspraxia, dyscalculia, dysgraphia</td>
<td>No</td>
<td>Degree</td>
<td>Written in advance</td>
</tr>
<tr>
<td>Adam</td>
<td>M</td>
<td>12 State</td>
<td></td>
<td>No</td>
<td>Professional qualification</td>
<td>Written in advance &amp; Educational Psychologist report</td>
</tr>
<tr>
<td>Toby</td>
<td>M</td>
<td>12 State</td>
<td>Eating disorder</td>
<td>Yes</td>
<td>NVQ Level 2</td>
<td>Sent local authority &amp; SEND reports</td>
</tr>
<tr>
<td>Jack</td>
<td>M</td>
<td>11 State</td>
<td>ADHD, dyspraxia</td>
<td>No</td>
<td>1-4 GCSEs</td>
<td>In person</td>
</tr>
<tr>
<td>Sid</td>
<td>M</td>
<td>10 State and independent dyslexia school</td>
<td>Autism, dysgraphia</td>
<td>Yes</td>
<td>Degree</td>
<td>Written in advance</td>
</tr>
</tbody>
</table>

* Other SEND as specified by parent in online survey. These have not necessarily been formally assessed.

4.4.3 Narrative case studies

Case studies provide a ‘closeness ...to real-life situations’ and ‘the development of a nuanced view of reality’ (Flyvbjerg, 2006, p. 223). In terms of my research, they are also important because they illuminate the interactions and relationship between parent and child. The issues associated with case studies, such as confidentiality and conflicting accounts will be discussed in section 4.4.5 below.

Narratives are a universal form of communication that provide a way for people to understand their experiences and make sense of themselves as individuals. Barthes asserts that narrative is ‘present in every age, in every place, in every society; it begins with the very history of mankind .... narrative is international, transhistorical, transcultural: it is simply there, like life itself’ (1993, pp. 251-2).
My approach to identity is based on an understanding of narrative, which situates people in ‘social structures, processes and discourses’ (Coleman-Fountain, 2014, p. 2) and focuses on interpretation and meaning (Blumer, 1969). Situated at the heart of social constructionism, this storytelling approach highlights how identity is constructed within historical, cultural and social contexts and is revised over time as circumstances change. Hammack describes how people engage with and reframe ‘master narratives’ – ‘a story which is so central to the group’s existence and “essence” that it commands identification and integration into the personal narrative’ (2011, p. 313). As we tell our stories we decide which aspects of the master narratives to appropriate and which to reject. In looking for opposing narratives that challenge existing representations (Ronai and Cross, 1998), people are ‘artfully agentic and culturally circumscribed’ (Holstein and Gubrium, 2000, p. 12)

In October 2018 I emailed and posted information packs to 17 mothers and young people. The pack included two information leaflets and two consent forms (one for mothers and one for young people; these can be seen in Appendices viii-xi). I also sent them a link to the study website (https://cdurrant2.wixsite.com/website) on which there was a video of me describing the research and explaining what the interview would involve (screenshots of the webpage are shown in Appendix xi). I clearly explained my motivation for doing the research and my hopes and aspirations for it. I was also careful to ensure that I did not raise participants’ expectations unrealistically of what the research could achieve, making it clear that it was unlikely to make any difference to their lives in the short-term (Kellett, 2010). Families were able to discuss their participation and contact me by telephone or email if they had any further questions.

4.4.4 Mothers narrating their child’s story
Parents who agreed to participate were asked to tell their child’s story, in particular their time at school, including all the experiences and events which have been important for her/him, up to now; the instructions I sent to mothers can be seen in Appendix xii. They were given the option of doing this with me on the telephone/Skype or as a written narrative. Ten parents sent me their story in advance of the interview with their child, one sent me copies of local authority and school SEND
reports, one wrote it during her son’s interview and one asked me to arrive early for her son’s interview so that she could relate his story to me and I could take notes. One parent, representing twins, did not provide a written narrative but she contributed to her children’s interviews. If I needed to clarify any biographical information or probe for more detail, I spoke to parents when I was at their home.

Although the parents’ brief was kept purposively very open, as expected, parents did not just relate a sequence of events but also conveyed information about how they occurred and the meanings they had. I undertook some initial analysis before starting interviews with young people which helped me to not only understand the parents’ perspectives, but also to put the child’s experience into context.

Throughout this thesis, unless otherwise specified, all quotes made by mothers are from their written story or the discussion I had with them after their child’s interview. Any comments made by parents in the online mixed methods survey are clearly marked as such.

4.4.5 Semi-structured interviews with young people

This section details how I set-up and conducted semi-structured interviews with young people, focusing particularly on ethical considerations.

My aim for this part of my research was to ensure that the young people involved in my research did not respond passively to a series of questions but were able to produce knowledge through active participation that aimed to give them a feeling of ownership of the research. At all times I treated them as capable, articulate and autonomous, prioritising creating a non-hierarchical, friendly environment in which they could be active agents, speak freely about their experiences and express their opinions. From my previous experience of research with children and young people I knew that this can be difficult to achieve; for example, they may not be familiar with having their views listened to (Einarsdottir, 2007) and may frame their answers in terms of what they think the researcher wants them to say (Robinson and Kellett, 2004). I have provided details below on how I managed issues of power and tried to create a non-hierarchical environment.
Fals-Borda (2001) describes participatory methods as based on mutual learning, social justice and equality and presents them as transformative. The extent to which I was able to empower and emancipate my participants depended on the degree of responsibility I gave my young participants to make decisions. Gallacher and Gallagher assert that:

‘...what matters is not so much the methods used, but the ways and the spirit in which they are used: the methodological attitude taken’ (Gallacher and Gallagher, 2008, p. 513).

My intention throughout my research with young people was to enable them to participate in decision-making, rather than take responsibility for it. It was also important to me that they felt they had agency and were able to withdraw from the research whenever they wanted to; this is described in the next section.

Mauthner (1997) contends that there are important distinctions in the way ethics is managed with children and young people compared with adults. I was very aware when setting up my research that asking young people to reflect on their experiences of severe dyslexia could cause them distress, discomfort or embarrassment. It was therefore important that I took measures to prevent them from experiencing any harm and at all times balance my own research objectives with my participants' potential vulnerabilities.

As an acknowledgement of young people’s competency and role as co-collaborators in my research, I involved them as reflexive and critical agents, asking them to think about their education and broader issues relating to participation and models of disability. I was interested in their views and opinions on the support they received at school for their SEN, the degree to which they were involved in decisions concerning them and, for older participants, the social model of disability (see Appendix xiii below). I was aware that they were being asked to reflect on subjects that they may not have given any thought to before the interview and were being asked to consider them in ways that may not have happened before, or would not have occurred without my prompts. To facilitate some of these discussions and enable joint meaning-making, I used creative techniques which are described in the section ‘My discussions with young people’ below.
The Ethical Review Board at the University of Sussex approved my research as a high-risk project. I was committed to upholding the highest possible standards of research practice by taking account of the consequences of my work and safeguarding the interests of my participants, as well as protecting myself and the institution I am associated with and making sure that my research attends to the interests of society as a whole. Shaw says that when we ask someone to tell their story ‘we become characters in those stories, and thus change those stories’, which has ethical consequences (2008, p. 408). I was very aware of this when conducting my research and, as mentioned earlier, kept a reflective journal throughout, in which I was transparent about my experiences, values, interests and motivation for conducting my research; I also reflected on the choices I made in terms of the research design.

**Giving young people a sense of control**

As mentioned above, in order to gain informed consent, I sent an information pack in the post and via email to both parents and young people aimed at preparing them in advance and to allow them to feel more in control of what was happening. I also worked with young people throughout the research on their informed consent for data sharing under agreed terms and conditions. This was particularly important as young people may be less likely than older participants to be aware of the full implications of consent for data sharing.

Before beginning the interview, I talked face-to-face with young people about what was required of them and allowed plenty of time for questions. We discussed how they had the right to withdraw from the research at any time without needing to give a reason and I rehearsed with them how to go about informing me that they no longer wished to take part or did not want to answer certain questions. I reassured them that their wishes would be respected and that they would not be asked questions about why they did not want to take part. I also continually checked throughout the research process that they were not distressed in any way and that they wished to continue to participate; this included taking note of non-verbal cues suggesting discomfort. In addition, I made participants aware that they could withdraw from the research up until one month after their interview had taken place.
Another measure taken to ensure that young people felt a sense of control was to check with the young person at the beginning of the interview that they were happy for me to take notes and record the session. If they initially agreed and then changed their mind, I would cease recording/note-taking immediately.

**Maintaining confidentiality**

I conducted interviews with young people after I had completed my research with their parents, which reassured them of the confidentiality of what they told me. In some cases, I chatted to parents before leaving but was careful not to reveal anything about their child’s interview. However, three mothers (Adam’s, Sid’s and Nina’s) sat in on my interviews with their children and the mother of the twins, Pia and Seb, was in the same room making dinner and occasionally made a contribution to the conversation. In each case it seemed to be the young person’s choice to have their mother there, which I respected, and I observed them to have a very easy and open relationship. At no point did I notice any tension and in fact found the mothers’ involvement useful in terms of encouraging their child to talk honestly to me.

In order to protect families’ anonymity and respect the researcher/participant relationship, as well as giving participants pseudonyms and changing the names of identifiable places, I have also consciously avoided including certain personal details, which may make participants recognisable. I am less concerned about parents recognising their children’s words and finding out something they did not previously know. All of the mothers taking part were already advocating for their children and were interested in their wellbeing. All of the young people taking part talked to their parents about their experiences at school in relation to their dyslexic difficulties and in most cases mirrored what their parents said about them. I will discuss this further in the section below on data analysis.

It was also important to bear in mind the issue of child protection and the need to be explicit with young people that I would not disclose the content of our discussions with anyone else, including their parent, unless I had concerns about something they told me, either about themselves or someone else coming to harm in some way (Williamson et al., 2005). My reassurance to them was that I would talk to them first about anything that I thought needed to be passed on; I told them that I would
encourage them to talk to a trusted adult before securing their agreement for me to talk to the adult myself.

The interviews generated audio and transcripts, supplemented by the parents’ written narratives. This data was anonymised, encrypted, and stored on my own password protected computer/hard-drive. Any hard copies were anonymised and kept in lockable storage. Personal information about participants, for example, names, ages and email addresses, is kept securely and in compliance with the Data Protection Act 1998.

**Shifting the balance of power**

Participatory research helps to ensure that young people feel that they can engage in the research in a meaningful way and have opportunities to exercise their agency. A key principle of participatory research is that it generates knowledge with, rather than about, those who are the subject of the research. It assumes that children are defined as ‘beings’ rather than ‘becomings’ (James, Jenks and Prout, 1998) who are already competent, coherent and autonomous and able to be actively involved in research rather than passively responding. It also makes the assumption that people are knowable to themselves.

With the aim of shifting the balance of power between the researcher and participant, I involved my young participants in deciding on the mode of communication that we used for our discussion. I offered participants the opportunity to talk to me and/or use creative methods that did not highlight their literacy difficulties but permitted full participation in the research and the chance to articulate their experiences and feelings. This consisted of pens and paper, playdoh, magazines and glue for collage. In the event most participants chose to talk to me rather than use creative methods to express themselves, although a few liked to play with the playdoh to help them concentrate.

I paid attention to the suggestions made by Alderson and Morrow (2011) for creating a comfortable and non-hierarchical environment in which young people felt able to express their agency. I arranged the room where the interview took place so that I was sitting at the same eye level as the young person and not too close or too far away. I
allowed young people to listen to their own voice on the tape if they wanted to. I reassured and emboldened young people by paying attention to how I spoke, trying at all times to talk slowly, clearly and not too loudly. I also made sure that they could see I was interested in what they said in terms of my facial expressions and what I asked in response and provided affirmation for the points they made by reflecting them back to them.

My discussions with young people

The findings of the online survey helped me to understand where I needed to focus my attention in the interviews with young people in order to understand more about their lives, feelings and attitudes. I chose semi-structured interviews because of their flexibility, giving participants the opportunity to focus on the issues most important to them. The discussion guide, which can be seen in Appendix xiii, comprised open-ended questions, follow-up questions asking them to elaborate, as well as a range of devices aimed at facilitating well-developed and rich data. I used metaphors to enrich meaning and to access a different type of conversation ‘away from the normative discourse that both participants and interviewer have in common’ (Thomson and Østergaard, 2020). I asked young people to bring to the interview photographs, objects or images that represent them and their world or things or places that are important to them (see email reminding them to do this in Appendix xiv). These object metaphors were a useful tool for encouraging conversation at the beginning of the interview and for providing opportunities to uncover what Bourdieu et al call an ‘extra-ordinary discourse, which might never have been spoken, but was already there’ (Bourdieu et al. 1999, p. 614). My approach also involved the active use of metaphor as a strategy for capturing the complexities of how young people understand and experience dyslexia. Following the work of Burden (2005) I asked participants to imagine dyslexia as some kind of ‘thing’ or ‘picture’ in their mind. If they were struggling with this concept, I followed the question up by asking them what dyslexia would look like if it was an animal or a colour. As well as employing metaphors, I also used other strategies to understand young people’s lives. I asked them to tell me about any significant events in their lives or important memories and together we filled in a timeline (see Appendix xv.). This gave them the opportunity to talk about the things that they
perceived as memorable and central to their lives. Some also filled in a relational map (see Appendix xvi.) at the beginning of the interview which helped me to understand their relationships with family, friends and teachers and situated them in their micro-environment. In order to encourage young people to talk about themselves and what makes them happy and sad, if necessary, I offered packs of cards on which I had written various descriptors and rainbow/suns to express positives and clouds/raindrops to illustrate negatives. I showed them two videos, one by the BDA (https://www.youtube.com/watch?v=11r7CFK2sc), which discusses how everyone’s brain is different and how dyslexia not only affects the way the brain handles information but also impacts how people feel about themselves, naming emotions such as anger, sadness and frustration. The second video is about famous dyslexics (https://www.youtube.com/watch?v=FrOvfIgiDZc). I asked young people what they thought of both videos and how they made them feel, generating conversations about both the positives and negatives of dyslexia. I also asked older participants to reflect on the Word Clouds that had been generated by the online survey about the positives and negatives of dyslexia (see figure 5, section 6.1 and figure 9, section 7.3). In addition, I asked young people to respond to a vignette about a young girl with dyslexic difficulties who was unhappy about the way she was being treated by her teachers (see Appendix xvii). We talked about what they thought the girl should do and what advice they would give to her. Lastly, in order to introduce the idea of the social model of disability to older participants, I read out a comment by Benjamin Zephaniah (see Appendix xiii), which suggests that society disables people with dyslexic difficulties, rather than dyslexia itself. I asked them what they thought of this concept and how it made them feel.

I was concerned that some participants may find it upsetting to discuss their experiences with me and was aware that research can have a lasting impact, beyond the actual interview (Joanou, 2009). As described above, before starting our discussion we talked about their right to withdraw from the research at any time. We also talked about their support networks and I provided them with the Childline telephone number. I am pleased to say, however, that I saw no indication of our discussion being anything other than positive, and on the basis of my experience, concur with Hollway
and Jefferson that ‘it can be reassuring and therapeutic to talk about an upsetting event in a safe context’ (2000, p. 87).

Where appropriate, at the end of some interviews I drew on my experience to offer participants a few ideas of what has worked for my son, and sign-posted parents to resources. I feel that it was a very simple way of giving something back to them and making the research relationship more equal.

*Creating rapport*

Before sending out information in advance of the interview I checked the answer to Q14 of the online survey, which asked parents to confirm that their child used the term ‘dyslexia’ or ‘dyslexic’. In the event every participant described themselves in this way, which meant that I was able to mention dyslexia in the advance information and talk openly about it in the interview.

The majority of young people who I visited at home between November 2018 and January 2019 were keen to participate in my research. In fact, some seemed positively excited at my presence. An extract from my fieldnotes recalls the welcome I received when I arrived at Matthew’s house on a cold wintry evening in November 2018:

> ‘Having taken a few wrong turns off the dark country lanes I was glad to finally arrive at Matthew’s house. He seemed to live on the edge of a village but it was hard to tell in the dark. The drive was long and very dark and seemed to be attached to a large country house. I didn’t know which way to go and drove straight past their house once before circling round and coming back. Matthew had clearly been watching out for me because this time he was outside the house waving excitedly and welcoming me in. He politely waited while I got out the car and accompanied me to the front door. He seemed happy to see me and his mum immediately told me that he wanted to show me something. He proceeded to do an aerial somersault in the hallway, proudly telling me that this was how he had chosen to respond to my request to bring something along to the interview that he felt represented him. I felt very pleased that he had reacted so positively to my visit.’

Fieldnotes November 2018

Todd was similarly welcoming, looking out the window in expectation of my arrival. I feel that I managed to create a good rapport with all of my young participants, with the possible exception of Toby who seemed reluctant to talk. Others seemed relieved
to have someone interested in them and to be listened to. I worked hard at making them feel relaxed and when they told me things that I found upsetting or shocking I made sure that I stayed neutral in my language. However, I did find myself responding in an empathetic, maternal way towards them. This was an authentic reaction as a mother and an ‘insider’. Indeed, experiencing my kindness and understanding seemed to comfort them, put them at ease, facilitate dialogue and encourage reflection. To thank young people for their time, I sent them a thank you card, which is shown in Appendix xix.

Throughout this thesis, all quotes by young people, with the exception of those from Trevor’s note that he emailed me in advance, are from the semi-structured interviews.

4.5 Data Analysis

The focus of my three findings chapters emerged from my data analysis process. In this section I show how I analysed my data and combined the findings of my multi-method research design. Social constructionism has informed how I have analysed my data. My analysis is based on a subjective construction of the findings in interaction between myself and my participants and reflexivity during the analysis process reveals how I have critically explored my own emotions and values.

Data from the online survey was transferred from Qualtrics to SPSS and explored using descriptive analysis. Percentage frequency distributions and cross-tabulations were utilised to describe the basic features of the data. Analysis took place immediately after the online survey had taken place and some of the key findings formed part of a blog publicised on Twitter, as well as the Operation Diversity Facebook pages that I used for my research. I made decisions about how to analyse each of the open-ended questions on a question-by-question basis. I felt that Q6 would benefit from descriptive statistical analysis using SPSS, so drew up a code frame and analysed it against key variables. For the remainder I felt it was more useful to use NVivo to look for patterns and themes and create Word Clouds. Throughout this thesis, I have woven the online data with the findings from the narrative research where context is required to highlight an issue or by way of introduction to a new subject.
Interviews with young people were transcribed and analysed manually, alongside some initial coding using NVivo. Data from parents’ narratives was analysed in the same way. After this initial analysis using a grounded theory approach, I wanted to move away from the process of sorting participants’ stories into categories towards a data analysis method that would strengthen my attention to their words and voices. Before classifying and making judgements and interpretations, I wanted to really listen to what my participants had told me. For this I used a voice centred relational data analysis framework called the Listening Guide, which originates from the analysis that Carol Gilligan conducted in 1982 for her research on identity and moral development. It is a systematic method for focusing on the multi-layered voices encapsulated within participants’ expressed experiences (Gilligan et al., 2003), obliging the researcher to listen attentively to the voice relating the story and demanding researcher reflexivity (Brown & Gilligan, 1991). It attempts to recreate the listening that took place during the actual interview, allowing the participants’ own sense of self to emerge before the researcher makes her own interpretation: ‘how she speaks of herself before we speak of her’ (Brown and Gilligan, 1992, p. 27–8). ‘I’ poems capture participants’ sense of self and trace how it ebbs and flows across the course of the interview. However, the implication of the emphasis on the notion of the ‘I’ is that there is a voice or sense of self that can be accessed through participants’ words. Furthermore, there is the suggestion that by following the framework, researchers can come to understand subjectivity. Edwards and Weller (2012), however, reject the idea that ‘I’ poems access an inner self and suggest that they are characterised by ‘a produced account and produced analysis’ (p. 215), with the researcher ‘standing alongside’ (p. 215) the participant and ‘constructing an interpretation of her/him and her/his social reality’ (p. 215).

Having selected eight interview transcripts that I thought required further analysis, I read them at least four times, with each ‘listening’ focusing on a different feature of the participant’s voice. Firstly, I listened for the plot, noting any recurring words, images and metaphors and reflecting on dominant themes. With the aim of understanding how my presence in the research could impact my analysis, I also documented my own emotional response to their narrative and how I located myself
socially in relation to the participant; the reflective diary that I wrote during fieldwork was used at this stage to strengthen my understanding of my role in the research. I then read for the voice of the ‘I’ (respondent) and constructed ‘I’ poems (Gilligan et al., 2003) as a way of uncovering how young people spoke about themselves. In order to do this, I looked for and then underlined each first person singular ‘I’ pronoun and associated verb or text which provided meaning. I did this intuitively and tried not to include too many words around the ‘I’ so that the participant’s ‘voice’ stood out. I then copied these phrases into a separate document, making stanzas based on breaks in the topic being discussed. Going through this process focused my attention on how the participant spoke of her/himself and helped me to identify changes in their ‘voices’. I have included ‘I’ poems in each of my findings chapters to animate young people’s words and to highlight how they spoke, thought and felt about themselves. The next stage of analysis involved listening for contrapuntal, or contrasting, voices, noting dissonance and tension. Finally I related different layers of the participants’ expressed experience to the research questions and composed an analysis of ‘the entirety of data generated in each step, namely, incorporating, synthesizing, and considering all interpretations and reflexive notes’ (Petrovic et al., 2015).

I found the Listening Guide to be a useful analysis tool because it strengthened my attention to the words and views of the participants (Petrovic et al., 2015) and ensured that I attended to my own subjective thoughts. It also highlighted the multi-dimensional nature of my participants’ thoughts and experiences and the interface between ‘self and relationship, psyche and culture’ (Gilligan et al., 2003). Together with the coding that I did on NVivo I feel that I have undertaken a thorough analysis of the narrative findings.

In spite of all of the efforts I made to make young people active participants in the creation of knowledge, there were times in the interview where they clearly did not want to engage in conversation with me about something or simply gave me a short answer. An example of this is where Arthur talked about school making him unhappy, mentioning some fairly strong emotions and then playing them down. I have therefore filled in the gaps in my understanding about his emotions by triangulating the findings
with his mother’s written narrative. There is no doubt that parents’ narratives have enhanced my findings about young people’s lived experience and that the case study approach has produced useful thematic connections. However, there were also points of disagreement between parents and young people, which I discuss in the analysis chapters. Throughout I am also careful to distinguish between the voices of young people and their parents, while still treating them as family case studies, which together form the threads of a story.

Finally in terms of data analysis, I must consider how the co-occurring difficulties experienced by young people (shown in Figure 1) may have influenced the findings. With six out of fifteen parents identifying their children as having other SEND, such as autism, ADHD, dyspraxia and dyscalculia, all of which may affect their experience of school, it is difficult to unravel the influence of severe dyslexic difficulties in isolation. Whilst my research aims to focus on the impact of the difficulties associated with severe dyslexic difficulties, it is not productive to assume that participants were able to separate them out from other SEND they may experience.

4.6 Discussion

This chapter has laid out the philosophical assumptions supporting my research, described how I position myself within it and explained my research methods and approach to data analysis. With this understanding I can now proceed to present the findings of my research.
Chapter 5. My findings: how provision is conceptualised and accessed

In this first analysis chapter, I focus my attention on the provision of SEND support for young people with severe dyslexic difficulties and engage with urgently expressed concerns about distribution and quality that characterise the accounts of parents in particular. In considering ideas of fairness and equality I seek to both hear and understand the stories of those advocating for young people, while also thinking critically about the way in which support is conceptualised as a limited resource that must be struggled for.

I begin the chapter with an analysis of SEND provision, reflecting on how dyslexia is mobilised as a category within distinct discourses by key social actors. Drawing on conceptual resources from Foucault I attempt to shift attention from dyslexia as located within the individual towards understanding the wider discursive formations through which notions of ‘falling behind’ emerge. I explore how this construction of dyslexia comes to frame the way that schools and teachers respond to the needs of young people and examine how the focus is on catching up or keeping up, eclipsing other possibilities that might be possible through a conception of SEND that accommodates or values neurodiversity.

Turning my gaze towards the young people themselves and the support they have received, I explore the extent to which timely and effective provision can combine to improve and maintain good emotional health. I describe individual cases, my analyses of which seek to bring to life the complex and nuanced relationship between emotional wellbeing and provision and reveal the aspects of provision that are particularly salient.

Towards the end of the chapter, I focus on how support has been accessed, attempting to understand the influence of power and capitals in families’ narratives. As I begin to explore the findings throughout this chapter, I will introduce the young participants of my research, providing a very brief pen portrait of each of them.
5.1 Understanding provision through social constructionism and discursive practices

When Foucault’s theories are related to dyslexia within educational settings, an individualising of young people and a problematising of those who do not conform is revealed. In this section I draw on Foucault’s (1970) work to help understand how dyslexia is constructed as a category within distinct discourses, which shape policy and provision. Controversially this position suggests that we cannot understand dyslexia simply as a natural phenomenon waiting to be revealed, but rather as a problem that has been constructed in discourse over time (Thomas, 2006).

5.1.1 National and local government’s influence on provision

As described in chapter 4, social constructionism is used to describe how social actors create their own reality by conceptualising and understanding their own, and others’, experiences (Blaikie, 2007). As this reality becomes shared, it is experienced as objectively factual and subjectively meaningful (Berger and Luckmann, 1966). What we perceive as social facts are the outcome of discursive practices that have promoted one view over another, making them seem natural and preordained (Schwandt, 1998). An example of this is the medical model of disability. My understanding of it as a discourse and not a social fact has raised my consciousness (Hacking, 1999) about dyslexia and literacy difficulties and has allowed me to challenge knowledge that has been shaped, institutionalised, embedded and taken for granted. Using social constructionist and poststructuralist theories, in particular those of Foucault, I question ‘essentialized meanings, final representations and fixed identity categories’ (Khoja-Moolji, 2014, p. 1).

In chapter 2 I outlined how the medical model of disability is still firmly ingrained in education today (Rieser, 2012), in spite of a small shift towards the social model which recognises that disability is caused by the way society is organised, rather than by a person’s impairment or difference. The government policies that frame SEND – the Children and Families Act 2014 and the SEND Code of Practice (DfE & DHSC, 2014) – despite claiming to ‘present a holistic, biopsychosocial, and multidimensional approach to disability’ (Castro and Palikara, 2016, para. 3), actually situate SEND within a
medicalised model of disability (Ross, 2017). EHCPs, which necessitate assessments by multi-disciplinary professionals, further strengthen this medicalised position. However, while policy may be framed by the medical model, Ross (2017) suggests that current government discourse locates dyslexia in relation to social factors around the child, such as poor teaching and parenting. She (2019) cites the DfE’s 2011 consultation document on the reform of SEND that recommends high quality teaching as a way of ameliorating the impact of dyslexia. This implies tension between government policy and discourse and could be interpreted by schools as suggesting that young people with dyslexic difficulties can be supported without recourse to SEND budgets, even though dyslexia is acknowledged under the Disability Discrimination Act 1995 and has been recognised as a SEN since 1997. The following section discusses how schools respond to this lack of clarity.

Access to provision can also be understood as premised on a particular construction of dyslexia which is aligned with, rather than disruptive of, an approach to education that is based on developmental norms and testing. An integral part of this approach, since the 1988 Education Reform Act, is government policy around tracking and testing learners, which I describe in chapter 2 as creating a performance dominated culture (Perryman and Calvert, 2019). A participant in the online survey linked this greater focus on improving exam results with a loss of creativity:

‘The system focuses on SATs results and not on developing creative skills. (Parent, id145, online)

Many parents participating in my study were aware of the pressure that this cultural shift has put on teachers in the classroom and some parents said that teachers are themselves frustrated by the lack of support they are able to offer children with SEND:

‘Totally overwhelmed teaching staff trying desperately to help everyone. Poor teachers trying still to reach all the children and their needs.’ (Parent, id451, online survey)

Referencing the need for schools to show progress, a parent who participated in the online survey claimed that her child received help from a teacher during her Standard Assessment Tests (SATs). Trevor, a boy of 14 who lives in a town in the north of
England with his mother, stepfather and older brother, told me that he too received assistance. He was very candid both in a one-page typed note that he emailed to me in advance of the interview and during the interview itself. He described what a teaching assistant had said to him before he started his SATs:

‘And then if—if you’ve done a question right and you—if you’re still on it for a couple of minutes, I’ll cough and that either means you’ve got it right or you know...’ (Trevor, 14)”

While Trevor appreciated this help, his mother condemned it and told me that his school may have also exaggerated the progress he was making because his teachers were under so much pressure to perform:

‘I knew he was nowhere near the level he should be. I also know the pressure teachers are under to show progress, which is what was happening year after year – imaginary progress’ (Trevor’s mother)

Trevor’s mother highlighted a situation that teachers can find themselves in, particularly with young people with SEND: the need to prove progress when there has been little. On this theme, Tomlinson suggests that the privileging of exam results has led to teachers becoming ‘a technical workforce to be managed and controlled rather than a profession to be respected’ (2001, p. 36). Trevor’s mother’s experience of working in a school as a teaching assistant means that she understood this high-stakes environment of accountability and would be aware of how measures of achievement are often used to criticise schools that are performing less well than others (Ragusa and Bousfield, 2017).

Parents also commented on the pressure that SATs places on their children, in particular through the additional interventions put in place prior to the tests to help those with SEND pass. They spoke of the impact of teachers’ very public concern about SATs and the impact this has on some children. The mother of Todd, a 12-year-old boy who lives in a village in the north of England with his parents and younger brother,

5 Unless otherwise specified, all quotes made by young people are from the semi-structured interviews
6 Unless otherwise specified, all quotes made by mothers are from the narrative case studies, either their written response or the discussion I had with them after their child’s interview
recalled him having panic attacks prior to SATs. She described this as ‘due to the extreme pressure placed on teachers in that school year to focus purely on getting pupils through with a pass’. Consequently, she withdrew him from sitting the exams.

Another issue related to exams and referred to by one young participant, is the greater emphasis on spelling, punctuation and grammar at GCSEs, which was discussed in chapter 2 as discriminating against dyslexic learners (eg. Collinson, 2018). Harvey is 16 years old and lives on the outskirts of London with his parents and autistic sister. As well as severe dyslexic difficulties Harvey has severe Irlen’s syndrome, which is described as a visual processing difficulty (Irlen Institute, 2019). Approaching his GCSEs, Harvey was critical of the policy of marking learners down and was concerned about the impact it may have on him:

‘You can’t get marks in some questions with spelling, punctuation and grammar so that’s like, so like 10 to 15 marks off.’ (Harvey, 16)

Chapter 2 also described SEND budgets, showing that there has been a decrease in funding over recent years. Some parents raised the issue of central government cutting SEND budgets, linking it with lack of adequate provision and ‘damage’ done to young people:

‘With government cuts he now has no support just extra time in exams’ (Parent, id249, online)

‘Our feeling is the problems we experienced were down to budget constraints and the restriction imposed on the school and how they could teach by the national curriculum. Central government is failing our dyslexic children and in my opinion society will live to regret this when these kids are damaged adults in need of support due to experiences in the current education system’ (Parent, id229, online)

A few parents went as far as to suggest that schools do not want to recognise dyslexia because they do not have the budget to do anything about it. They laid the blame for this firmly at the door of the local authority and government:

‘In our local authority, all the councillors are telling them not to spend money so they don’t look at ways of actually helping. They’re just like, oh we don’t want to diagnose it, if we’ve got a diagnosis then we’ve got to help them’ (Arthur’s mother)
‘In our experience... schools do not accept dyslexia as apparently the government won’t fund it. It is slightly better when you move up to secondary school’ (Parent, id101, online)

With schools and governing bodies having greater autonomy and independence, as discussed in chapter 2, SEND provision is also likely to be affected by the policies of individual schools. This is discussed in the next section.

5.1.2 Schools’ influence on provision

We have seen in chapter 2 that Macdonald (2009b) describes schools as constructing dyslexia in terms of the meeting of the medical and educational models of disability, which has implications for how schools and teachers respond to the category of dyslexia and organise provision. Within this model of disability, provision is mostly seen in terms of interventions (eg. one-to-one and group teaching, as well as in-class support) ‘done’ to young people rather than the curriculum being made accessible to everyone under a conception of SEND requiring classrooms to accommodate neurodiversity. It could be argued that provision formed through this model is likely to be more vulnerable to budget cuts than that conceived through the social model, which addresses the needs of all learners within the classroom.

The overall picture of provision that emerges from parents in the online survey with a child with severe dyslexic difficulties suggests variation in distribution and quality. As Figure 2 illustrates, although parents’ attitudes towards primary provision were mostly negative (62.3%), over a third (36.8%) expressed a positive view. Attitudes to secondary school were, on the other hand, more divided, with 48.2% saying that their child had been not very or not at all well supported and 48.3% giving a positive view.

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7 These findings are based on Q10 and Q12 of the online survey: ‘Overall, how well would you say your child’s dyslexia has been supported in primary/secondary school? Parents’ attitudes are likely to combine their views on both the quantity and quality of support provided and be based on their views of their child’s progress in literacy/narrowing the gap with peers and assessment of their child’s emotional wellbeing.
Participants were aware that provision varies between schools and talked about moving their children, particularly at primary level, to access better support. In some cases, this strategy seemed successful, with one parent explaining:

‘His initial 2 primaries were not supportive, reluctant to assess and without any strategy to help him. He was moved to a different school for Years 5 & 6 which provided excellent support and massively bolstered his confidence’ (Parent, id024, online)

Holt (2004) explains that there is variation in the way schools interpret norms of childhood development, which leads to an inconsistent diagnosis of disability. Research by the Driver Trust (2015) suggests that the extent to which schools prioritise, and improve outcomes for, young people with SEND can be dependent on the school’s leadership. They recommend that the ‘notional SEND budget’ should be ring-fenced to prevent schools from spending it how they choose (ibid), creating an inconsistency in provision.

Parents and young people alike were also very focused on how awareness and understanding of dyslexia among school staff varies greatly:

‘I feel it really depends on the teacher, which it shouldn't. His teacher when he was diagnosed was amazing but then the three after weren't, so didn't feel he got anywhere’ (Parent, id298, online)
‘His dyslexia was missed by teachers, labelled lazy and “will always be slow”. Even with us getting him a full assessment, his middle primary years were so difficult for him due to lack of true awareness by teachers’ (Parent, id183, online)

The mother of Sid, a 10-year-old boy who lives in a village in the south-east of England with his parents and younger brother and sister, actually used the word ‘lottery’ to describe the lack of certainty:

‘Mainstream feels like a bit of a lottery…You can’t guarantee…’ (Sid’s mother)

Many parents attributed teachers’ lack of awareness and understanding to inadequate teacher training in dyslexia and called for it to be made a compulsory part of ITT. The mother of Matthew, a 13-year-old boy who lives in a village in the north of England with his parents and two older brothers, was one of many who were critical of the inconsistency of provision, citing lack of training as a reason:

‘Throughout his primary school years Matthew had no consistency in reading schemes or interventions, well-meaning teachers or TAs would try things out, however they had no specific dyslexia training, resulting in poor outcomes’ (Matthew’s mother)

‘I think most schools and teachers are also frustrated by the lack of training and support available.’ (Parent, id148, online survey)

A couple of young participants also questioned why teachers are not taught more about dyslexia. The quote below from Arthur, a 17-year-old, who lives in a village in the south west of England with his parents and younger brother and is now at Further Education College, identified lack of training as the reason why his teachers did not recognise his needs. He believed that their perception of him as ‘stupid’ was a consequence of their lack of training:

‘The teachers weren’t trained to pick up on dyslexia and stuff like that so they just, “Well, he’s stupid, isn’t he?”’ (Arthur, 17)

These views mirror the literature reviewed in chapter 2 (DfE, 2017) suggesting that newly qualified teachers leave ITT without the necessary knowledge of the range of learning difficulties that children may experience or the skills to support them. I would
also suggest that teachers’ lack of focus on SEND may also be indicative of a discourse of deficit within education, where the ‘problem’ is seen to be located within the child and the solution is to provide educational interventions that are perceived as outside of the remit of class teachers.

The attitudes of schools and teachers towards dyslexia as a SEND may also influence provision and the decisions that are made around the distribution of resources. Included in this are broader views on disability and the extent to which they believe learners’ difficulties to be permanent or something that they can affect (e.g., Jordan, Schwartz and McGhie-Richmond, 2009), as well as their philosophy of education and attitudes to SEND, inclusion, labelling and dyslexia itself. Each of these will be influenced by historical, economic, political, social and cultural contexts, as well as current educational policy and discourse. Gwernan-Jones and Burden (2010) apply Ajzen’s Theory of Planned Behaviour (1985) to explain the variance in the way attitudes influence teachers’ behaviour. They assert that teachers start their career aiming to follow normative attitudes towards dyslexia, ones that are common within their profession, however, over time these views are influenced by their own values and beliefs, the opinions of others and how able they feel they are to have an impact on the learning of young people with dyslexic difficulties. Ernest (1989) also relates knowledge, beliefs and attitudes to the practices of teachers. A few parents referred to how some schools and teachers appear to be in opposition to the concept of dyslexia, saying that they refer to it as a middle-class problem or that it does not exist:

I still believe that some teachers don’t think it exists or that we are just making it up’ (Harvey’s mother)

‘At his first primary school it was horrendous. Head teacher told him he was lazy and he had a middle-class disease and I couldn’t be bothered as a mother and she thought dyslexia had been eradicated’ (Parent, id026, online)

Some parents sensed actual resistance by schools to change their teaching to accommodate the needs of those with dyslexic difficulties:

‘... am coming to the conclusion that rather than ignorance of dyslexia/dyspraxia etc., there is an actual resistance to adapting teaching methods’ (Matthew’s mother)
‘I was even told by one teacher that dyslexia isn’t recognised anymore and that pushy parents like me just try to get extra time for their children as they aren’t academic!’ (Parent, id249, online)

In reflecting on teachers’ treatment of him, Trevor told me that he ‘always felt like teachers didn’t believe in dyslexia’ or did not want to go to the effort of understanding it. His mother supported this when she said:

‘Well, it was if the word dyslexia is a swear word! It wasn’t allowed to be used’ (Trevor’s mother)

As well as discussing teachers’ awareness, understanding and attitudes to their children’s dyslexic difficulties, parents also discussed the provision itself. Reflecting Snowling’s (2013) work, discussed in chapter 1, many parents seemed to value early intervention and frequently referred to the emotional consequences of not receiving it. They described the situation where children only receive support once they have failed, as too little too late:

‘A total lack of acknowledgement of his difficulties until he was two full school years behind his peers. By this point he believed that he was “stupid”’. The damage was done’ (Parent, id241, online)

‘They have waited for her to fail and then they have supported her, if they had assessed her earlier (diagnosed at age 9), the interventions would have been more effective and she wouldn’t have needed to fail to get help’ (Parent, id059, online)

Responses also document concern among parents about the effectiveness of the support that is provided, often by untrained teaching assistants, and the lack of evidence provided to show the progress of interventions:

“We have no evidence that the interventions are helping. We are not sure if the interventions happen as they should. Teachers do not have formal training in dyslexia. She has two teachers and two TAs spread over the week so it’s not consistent which does not help with focus’ (Parent, id169, online)

I will take a more detailed approach to the provision received by my young participants in the following section.
5.1.3 Summary of section

This section set out to understand the distribution and quality of provision for young people with severe dyslexic difficulties through the lens of social constructionism and discursive practices. It highlights a tension between government policy and discourse and focuses on parents’ concerns relating to the unevenness of provision, awareness and understanding of dyslexia, as well as teachers’ attitudes towards it. Participants identify increased resources, early intervention and better training for teachers and teaching assistants on dyslexic difficulties as possible ways forward.

5.2 Showing the complexity of individual cases

Starting with a finding from the online survey about attitudes to the support provided, this section explores the complexity of the relationship between provision and emotional wellbeing. As Figure 3 below shows, two in three parents (65.2%) whose child has severe dyslexic difficulties and reported a severe emotional impact described her/him as being not very well or not at all well supported in primary school. However, more than a third (34.8%) expressed a more positive view, suggesting that some young people can be severely emotionally impacted even when they have had acceptable levels of support in primary school.

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8 Q5 in the online survey: Overall, how would you describe the impact of dyslexia on your child’s emotional wellbeing?
In this section I seek to better understand the role of SEND provision by drawing on the findings of my narrative case studies, in which I engaged with 15 families where a child had been assessed as having severe dyslexic difficulties. In the following chapters I ask the question: Other than provision, what influences young people’s emotional wellbeing?

In order to explore the part played by provision, I have mapped young people within a field that allows me to distinguish participants’ reported perception of the quality of provision and parents’ reported understanding of their children’s emotional wellbeing, gaining insight into how the two axes might relate. I have positioned them on the map according to my young participants’ experience in state mainstream education – if they have moved on, I have indicated that this may have changed. In doing this I acknowledge that it is difficult to interpret the findings relating to SEND support, given the part played by timing and the nature of the provision involved, as well as individual perceptions of it. In addition, it is important to bear in mind that I did not observe young people in school and have positioned participants’ provision on the map on the basis of the information provided by them and their parents. The only exception to this was Toby, whose mother sent me several school and local authority reports about his SEND provision instead of a written narrative.

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**Figure 3: Attitudes to primary school provision among parents whose child has severe dyslexic difficulties and has experienced a severe emotional impact (online survey)**

<table>
<thead>
<tr>
<th>Attitudes to Primary School Provision</th>
<th>All parents answering with a child with severe dyslexic difficulties and severe emotional impact (46)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very well supported</td>
<td>4.4</td>
</tr>
<tr>
<td>Fairly well supported</td>
<td>30.4</td>
</tr>
<tr>
<td>Not very well supported</td>
<td>23.9</td>
</tr>
<tr>
<td>Not at all well supported</td>
<td>41.3</td>
</tr>
<tr>
<td>Don’t know</td>
<td>-</td>
</tr>
</tbody>
</table>

* 73 parents (61.3%) said that their child had severe dyslexic difficulties but did not have a severe emotional impact
By highlighting the wide range of experience as reported by young people and their parents, the diagram above (Figure 4) shows the nuanced relationship between effective support and emotions, cautioning against any simplistic correlation between effective provision and good emotional wellbeing. In seeking to understand their provision and how it relates to emotional wellbeing, I have grouped my young participants into the four categories described below.

5.2.1 Thriving in spite of dyslexia: the benchmark for support

The possibility of thriving despite dyslexia is something that is discussed in the research literature, often in terms of the importance of early intervention (Snowling, 2013), in particular to help young people form a positive perception of self (Armstrong and Humphrey, 2009). Reflecting this, the accounts of the twins, Pia and Seb, and their mother, suggest that when appropriate and timely support is made available, young people can flourish in a state, mainstream school setting.

When I met Pia and Seb they were 14-years old and lived in inner London with their...
parents. The twins were interviewed separately. Their parents anticipated that they might have difficulties with reading and writing and sent them to a local state mainstream primary school with a dyslexia unit. On investigation I found that the local authority in which the twins lived, and the primary school they attended, had been part of the 2007/8 ‘No to Failure’ initiative (Dylexia SpLD Trust, 2009), which took place in three local authority areas and was funded by the DCSF. The project aimed to increase awareness and understanding of dyslexia and provide whole-school training, including training for some teachers to become dyslexia specialists.

From Year 2 until the end of Year 6, Pia and Seb were taken out of class twice every week for 1:1 sessions with a specialist teacher. Pia described the dyslexia unit as ‘like kind of a second home’. She felt valued there and enjoyed the shared identity she had with the other children who attended:

‘Yes, the dyslexic kids...I remember, they were so nice. They were all ages. Eliza was dyslexic and I made friends with her because we kind of shared something.’ (Pia, 14)

Goffman (1963) refers to this as in-group alignment, where people experiencing difference find relief in being around ‘fellow-sufferers’ (1963, p. 138). Arguably, reflecting Vygotsky’s (1978) zone of proximal development, in which he suggests that children learn new skills and understanding when they work in collaboration with others, the older children within the dyslexia unit may have also provided the twins with a better sense of how to thrive in spite of dyslexia.

The dyslexia unit was framed positively within the whole school, with all children encouraged to be accepting of difference:

‘...the cool kids were dyslexic at their primary school....they got to go to radio club. Yeah, they did all these really cool kind of things. They would often go on trips.’ (Pia’s mother)

Pia concurred with her mother’s view and explained that class teachers gave her the same work, with differentiation, as everyone else but frequently checked in with her to see if she needed help; there was also regular liaison between the specialist and classroom teachers. Their mother told me that the twins not only left primary school with a reading age beyond their chronological age but felt fully prepared for secondary
school. Although they both continue to have exam accommodations and Seb uses a laptop at secondary school, they have no other support, a situation with which they seemed happy and able to function effectively. In fact, they told me that dyslexia is nowadays not a big part of their lives. Pia said that ‘it’s almost like I’m just not dyslexic anymore’ and Seb talked about having ‘overcome dyslexia’.

By contrast, before the twins received recognition and effective specialist support for their dyslexia in early primary school, their mother reported that they both regularly cried on Sunday evenings about having to go to school the following day. The following two ‘I’ poems trace Pia’s changing voice, from someone who was unhappy about her difficulties to almost forgetting them. I note her repeated use of the word ‘felt’ in the first poem when she was feeling vulnerable and contrast this with her use of more descriptive language in the second poem in which she explains how she is affected now:

‘I felt
I felt really useless at everything
I felt like upset.’
(Pia, 14)

‘I would not say it affects me
I’ve had a lot of help
I’ve gotten over most of the things that troubled me
I remember I’m dyslexic
I’d almost forgotten’
(Pia, 14)

Having never met anyone before who had made such progress, I was taken aback. In my fieldnotes I noted that it was the astute and timely intervention of their parents and some good fortune that made it possible for them to attend a school where there was greater understanding of dyslexia among mainstream teachers and specialist intervention was available. I started to consider that with early intervention and inclusive practices in primary school, it may be possible for young people to move on from a dyslexic identity, progress in convoy with peers and require minimal additional support at secondary school. I would describe Pia and Seb’s experience of primary school as the benchmark against which to consider other participants’ provision because it suggests that early effective support can protect against the emotional
impact of dyslexic difficulties. However, dyslexia units in state-funded mainstream primary schools are extremely rare and local authority funding for the one Pia and Seb attended has now been removed. In fact, this kind of provision is unimaginable in the current climate of SEND budget cuts and underfunding described in chapter 2. Perhaps the support received by Toby and others, described in the next section, is a more realistic and pragmatic proposition.

5.2.2 Getting by with dyslexia: good enough support?

There is also a group of young people whose provision, although not comparable with Pia and Seb’s, is nevertheless discussed in fairly positive terms by participants, particularly parents. I do not have any information on how well they are doing at school in comparison with their peers, however, they all have in common relatively early recognition of their difficulties through an assessment, followed up by some intervention and support. The title of this section is therefore a question, raising the suggestion that there may be a category of support that is below the benchmark described above but may be good enough.

When I met Toby, he was 12 years old and in the first year of secondary school. He was living on the edge of a town in the south of England with his parents and older brother; I interviewed him alone and he was very shy and withdrawn. With an EHCP secured in Year 4 by his parents, Toby received 25 hours a week of in-class one-to-one support for the last two years of primary school. Now at secondary school, he has a Learning Support Assistant to help him in mainstream classes and spends 6 hours a week in Resource Provision – some 1:1 with a specialist teacher and some working in small groups. I can confirm from the paperwork his mother sent me that his support seems to be of relatively good quality. Neither Toby nor his mother were critical of his schools’ provision since receiving an EHCP and in fact, in the online survey, his mother described him as being fairly well supported in primary school and was even more positive about his provision in secondary school. While describing his emotional wellbeing as having been severely impacted, she does not attribute his suffering to the provision he is receiving, but rather to his dyslexic difficulties themselves. In doing this she is individualising his difficulties and taking a deficit approach. Chapters 6 and 7
explore other reasons why Toby continues to struggle emotionally in spite of what I would categorise as good enough provision.

None of the other young people that I have grouped into this category have an EHCP. However, they have all benefitted from having their difficulties identified relatively early and have attended primary and secondary schools that recognised their difficulties and have had the skills and expertise among their teaching staff to be able to introduce some interventions and make accommodations for them in the classroom. Although the overall picture is positive, the level and quality of support is not comparable with that of Pia and Seb’s in primary school and is less prescriptive and formalised than Toby’s.

Each of Todd, Gina and Ella’s mothers wrote in the online survey that their children have been overall very well supported in both primary and secondary school. This level of positivity is qualified by what Todd, Gina and Ella themselves said about their provision, indicating a tension between the views of young people and their parents. This dissonance suggests that while their provision, particularly in secondary school, may have been better than some, it was not as good as their parents believed.

Todd’s mother made a direct link between her son’s emotional wellbeing and provision, describing him as despondent, forlorn and anxious before he started to receive appropriate support for his difficulties at school. This forms part of a narrative that takes him from a position of chaos/anxiety through assessment/provision into some kind of managing and sense-making. However, although Todd’s provision is clearly better than most, he was nonetheless critical of aspects of it. He admitted that he would like more support from teaching assistants in class and complained about the lack of differentiation in his work, for example, he is given the same spellings as the rest of the class:

‘Yeah. I have to do spellings every week......So, I don’t really see the point of, because it’s really hard and I struggle with spellings.’ (Todd, 12)
Nevertheless, in spite of this dissonance between Todd and his mother’s opinion of his provision, as later chapters demonstrate, he has a positive self-image, suggesting that other factors have also influenced how he feels about himself.

Gina, who is 18 years old and from a town in the east of England where she lives with her parents and two older brothers when she is not at university, was positive about primary school but described secondary school provision as dependent on individual teachers. She was particularly critical of some teachers’ lack of understanding of her difficulties and the lack of teaching assistant support in class at secondary school:

‘I had spelling tests and they’d almost say to me “You need to be better.” I’m like, what do you expect?’ (Gina, 18)

Her mother, on the other hand, presented a more positive view of her daughter’s provision. Later chapters suggest that Gina’s outward resilience and confidence may be hiding the pressure she feels to not let herself and her family down. Her description of inconsistent provision in secondary school may have deepened this stress.

Similarly, 12-year-old Ella, who lives in a village in the south west of England with her parents and several pets, was also less positive about her provision than her mother. Although ostensibly very confident, she showed vulnerability in relation to school that her mother did not seem to be aware of. In Year 7 she was in a nurture class, where she received a higher level of support and the teacher was aware of her needs. Now in Year 8, Ella expressed uncertainty about having more of her lessons in mainstream and being in the ‘big’ class where some teachers were not aware of her difficulties:

‘Um, sometimes, I have to like tell a teacher, but... She’s like busy with other people, because they don’t know’ (Ella, 12)

The provision of two other participants – Nina, who is 16 years old and lives in a small town in the south west of England with her parents and younger brother and Adam, a 13-year-old boy living in a town in the south west of England with his parents and older brother – started relatively early and was rated fairly positively by their parents. Neither of them was without criticism of aspects of their provision but overall, they seemed to be benefiting from it, both academically and emotionally. In particular, Adam’s mother linked his recovery from quite severe anxiety, which impacted his
attendance and learning, with receiving a ‘tailored programme of support’. Both Adam and his mother discussed how his anxiety used to bring on somatic complaints such as ‘lip licking eczema sores’ and ‘worry tummy’. These findings resonate with the work of Willcutt and Pennington (2000) who link somatic complaints to internalising anxiety and the stress experienced in school by poor readers. Adam also talked about having time off school when he was younger because ‘when I get scared, I feel sick’. He told me that nowadays he only gets anxious when he is asked to speak out loud in class or to be in a school play. Although Adam’s mother made the connection between receiving effective support and feeling less anxious, the following chapters suggest that like Todd, other factors may have also influenced his emotional wellbeing.

5.2.3 Struggling through with dyslexia: lack of support

There was also a group of young people who had their dyslexic difficulties identified later and, on the basis of what participants told me, still seemed to be without effective provision. ‘Struggling through’ seems to describe the situation they find themselves in at school.

The most extreme example of this is Harvey, who had his difficulties identified in Year 10, just a year before we met. His mother wrote in her narrative that he still experiences ‘very low self-esteem’ and is ‘very anxious’. She also expressed concern that although the school had written a SEND plan, there seemed to be no commitment to it – at the time of meeting him he still had no support apart from exam accommodations, including a reader and a scribe, or a computer if he preferred. With GCSEs approaching she was critical of his school:

‘As you can tell I am not very positive about his school. I really feel they have failed him as at home he is verbal, and we have great conversations, he just can’t put his thoughts or answers into words on a paper.’ (Harvey’s mother)

When talking with Harvey’s mother after the interview, with him still present, she made the link between his lack of support in class tests and being moved into lower sets and his subsequent loss of confidence:

‘... because obviously for his exams he is entitled to the extra time and whatever, but when they do class tests throughout the year, he doesn’t get anything. So, he is constantly moved down the sets.’ (Harvey’s mother)
Although Matthew was identified as having severe dyslexic difficulties at a much younger age than Harvey (in Year 5), his mother reported that he was not very well supported at either his primary school or his independent, secondary school. He now benefits from smaller class sizes and two 1:1 sessions each week but she was still critical of his provision. Similarly, Jack, who is 11 years old and lives in a town in the south east of England with his mother, step-father and two older brothers, had a full assessment for dyslexia at the end of Year 6 and now has all of his lessons at secondary school, except ICT, Art and PE, in a small SEND group. When we met, he had only been at secondary school a couple of months and therefore it was difficult for him and his mother to assess the provision he was receiving. Although his mother did not discuss the content of his support, she seemed very happy about him being in a nurture group. I have placed Jack in this ‘struggling through with dyslexia’ group because he was noticeably unhappy about being in the nurture group; whilst recognising that it may support his educational needs better, he expressed sadness at being separated from his friends and longed to be treated the same as his peers. This will be explored further in chapter 6.

5.2.4 Moving on from mainstream education

The following examples are explicitly very critical about lack of support, citing late identification and a lack of well-founded provision. However, for each participant, their struggles eased once they left mainstream school.

Trevor and Sid have both moved away from mainstream school – Trevor to be home-educated and Sid to a specialist dyslexia school. Sid has an EHCP for Asperger’s Syndrome but, when we met, the local authority did not acknowledge his severe dyslexic difficulties, despite an assessment and even though his mother believed that they have the most significant impact on him at school. This is known as ‘diagnostic overshadowing’, when someone receives inadequate or delayed support or treatment because their symptoms are wrongly attributed to another condition (Jones, Howard and Thornicroft, 2008). Sid’s parents had recently started paying to send him to a specialist dyslexia school and were planning to take the local authority to tribunal for funding. After years of not having his dyslexic difficulties recognised or supported in
primary school, echoing Burden’s (2008) and O’Brien’s (2019) research, Sid is thriving in his new specialist school where he feels like ‘an equal member of a group’ (Sid’s mother). Once again, the theme of the relationship between emotions and provision is evident. Prior to attending the specialist school, his mother described his self-confidence as ‘a very fragile thing’ and told me that he had suicidal thoughts in Year 5. When his anxiety worsened and he became a school refuser, he was signed off by a doctor. His mother reported that he spent Sunday evenings crying in anticipation of school and told her that ‘this world is not made for me’ and that he wished himself dead; on the most serious occasion he talked about standing in front of traffic. Sid talked about his primary school as ‘so stressful and there wasn’t really that much help’ but enthused about his new school, telling me about the smaller class sizes, having his own desk and insisting that I ‘write that Fulton [the specialist school] is good’.

With his difficulties unrecognised at primary school, Trevor was assessed for dyslexia before moving to secondary school. There his difficulties were acknowledged and his mother told me that she felt hopeful because he had weekly interventions and some support in class. However, after a period of absence in Year 8 due to illness, he struggled to cope and was placed in the lowest ability classes, including a period in learning support. It was here that he started to have panic attacks and became a school refuser one or two days a week:

‘It’s too hard. I get stressed and angry. I suffer anxiety and panic attacks. I started refusing to go to school.’ (Trevor, 14)

His mother described why she deregistered him from school in Year 8:

‘He had no way up and no one to aspire to. He was missing 1 or 2 days of school each week due to his anxiety. He cried all the time and he was so sad.’ (Trevor’s mother)

When I interviewed Trevor, he was still primarily being home-educated but was also attending college a couple of times a week where he had support in class and was working towards his GCSEs. The following ‘I’ poem (in this case he also used the third person to talk about himself) describes how he felt alone with his difficulties at school:
‘I would explain it like
You’re living on your own
You’ve got to figure everything out for yourself
You don’t get the right support
You don’t know how to do it’
(Trevor, 14)

Trevor made the link between provision and his emotional wellbeing, recognising that his recovery was dependent on him getting SEND support, but at the same time acknowledging that it will be slow:

‘As soon as you get that help, which I didn’t get any help until I was in college... eventually you get that help, it’s a slow process to get back up’ (Trevor, 14)

Even though Trevor had been home-educated for over a year when we met, he still experienced the residual effects of anxiety. He wrote in his advance note that despite no longer going to school and not having the constant worry of failing ‘I still get anxious when I leave the house’. His mother explained that they focused entirely on his anxiety when she de-registered him from school, but nevertheless he still struggles:

‘We didn’t do much academic work for 6 months...He’s still under CAMHs and his anxiety is still there.’ (Trevor’s mother)

At 19 and 16 years of age, Georgia and Arthur were amongst the oldest participants. Their experiences echo the findings of Lithari’s research, which characterises how after leaving school young people with dyslexia can start to repair their ‘fractured academic identities’ (2018, p. 280). Both reported very emotionally challenging times at school and failed most of their GCSEs. However, since leaving school and moving on to Higher and Further Education, they have both received support and are now more accepting of their difficulties.

Arthur was identified as having severe dyslexic difficulties relatively young (end of Year 4) and received a Statement of Educational Need just before his transition to secondary school. However, he received very limited support, despite his mother being given assurances that his secondary school could support his needs and that he was meeting targets. Arthur failed all of his GCSEs apart from Science and Photography. His mother has since found out that he did not even have his entitlement of a reader and a
scribe at GCSE. Arthur is now at Further Education College where he has since passed Maths with a reader and scribe and intends to take English GCSE next year.

Georgia is 19 years old and lives in a large northern city with her parents and younger brother. She received no support at school and has never had a full assessment for dyslexia, or for the other difficulties she experiences, which she believes may be autism and dyscalculia. Around the time she started secondary school her father was seriously ill and subsequently still requires Georgia’s mother to care for him. This life-changing event meant that her parents were prevented from following up on a dyslexia screening test that was completed in primary school but was not passed on to her secondary school. In 2017, Georgia herself required a major operation. In Year 9 she asked her school for support and had another screening test. Although she went on to receive extra time in exams, Georgia told me that what she really needed was a reader and a scribe; she failed English, Maths, History and some Science GCSEs. Georgia’s experience of school is framed by anxiety, which seemed to centre around being bullied; this will be discussed in the following chapter. She is now at a local university studying Art, an environment where she told me there is less pressure to read and write and where she feels more emotionally supported:

‘I'm not used to them being like, “Are you okay? Is everything alright? You can always talk to me” (Georgia, 19)

5.2.5 Summary of section

Participants’ written and spoken narratives confirm a significant variation in the provision made available to young people. I have shown that some received very effective support while others received nothing, making this a matter of equality. Although some parents explicitly linked effective provision and emotional wellbeing, my findings suggest that the picture is more complex and nuanced.

Analysis of the different types of provision led me to group young people according to how well they are doing in relation to their difficulties and the support received. In considering Pia and Seb’s benchmark of support and the notion of provision that may be good enough, a few factors emerge as particularly salient. Firstly, early identification and early intervention, where my research suggests that ‘early’ means
before the end of Year 3 of primary school and ‘intervention’ includes both instructional 1:1s, group learning and teaching assistant support in class. Secondly, Pia and Seb’s experience also suggests that whole school awareness and understanding of dyslexic difficulties and an ethos of inclusivity is significant. The following chapter will build on these ideas and also highlight the importance of the social context of school.

5.3 What resources do parents draw on to support their children?
Reflecting the literature, parents reported having to advocate for their children and challenge their school about the SEND support provided. I concur with Buswell-Griffiths, Norwich and Burden (2004) that this is gendered and that it was mostly the mothers of the young people in my research who seemed to take on this role. This section explores how they mobilised their resources to support their children at home and challenged their school in order to gain access to SEND classifications and additional support to provide them with what they determined to be the “best” education. When reading the findings below it is important to be mindful that the parents participating in my study were already engaged with an online dyslexia community, suggesting a level of organisation not necessarily always found elsewhere.

5.3.1 Education as a resource
I will start by reporting on a couple of findings from the online survey, which suggest that young people may be more likely to receive good provision when their parents have higher levels of education. Highest level of education achieved is often used to operationalise social class when it is not possible to ask a more detailed set of questions about income and occupation. Connelly, Gayle and Lambert describe education as ‘a powerful explanatory factor influencing a number of economic phenomena, most notably both participation and success in the labour market’ (2016, p. 1). Galobardes links education with having a ‘richer source of knowledge’ (2006, p. 7).

When asked about the type of support their child had at school⁹, among parents participating in the online survey, those who do not have a degree or higher were

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⁹ Q8 Which of the following type of support, if any, does your child have at school?
slightly more likely to say that their child received no support (18.2% compared with 11.4% of those with a degree or higher). Those without a degree or higher were also more likely to say ‘not at all well’ when asked\textsuperscript{10} how their child had been supported at primary school (45.5% compared with 33.2% of those with a degree or higher). Findings for secondary school follow the same trend.

There is also evidence from parents’ narratives of mothers going to great lengths to support their children at home with schoolwork, which in turn requires them to have a certain level of education, as well as the time available. Pia and Seb’s mother recognised the additional burden of parents having dyslexic difficulties or being unable to read themselves and how this could impact their ability to support their child at home:

‘It’s like a cyclical thing. That parent wouldn’t be able to sit with that child and encourage them to read or read to them because their level of literacy is really small’ (Pia and Seb’s mother)

Before Georgia’s father became ill, her mother, who is educated to degree level, spent a year working with her daughter after school, trying to help her catch up with her Year 3 spelling and mathematics schoolwork. In addition, Gina’s mother, who went on to specialise in dyslexia for her Learning Support Assistant role, spoke of spending years working with her daughter at home. This is a list of just some of the things that she told me she did:

‘Listening to Gina read for 15 minutes every night and asking questions about the text; helping with spellings...; assisting with any literacy homework activities if necessary...; encouraging neat handwriting and presentation; encouraging Gina to check her work for a variety of different sentence openers; spellchecking; organising her schoolwork’. (Gina’s mother)

Clearly, not all parents have the time or the expertise to supplement formal teaching in this way, suggesting inequality. However, parental support does not necessarily mean that it is always informed support. For example, only one parent (who was a teacher) mentioned the usefulness of assistive technology – computer software that supports

\textsuperscript{10} Q10 Overall, how well would you say that your child’s dyslexia has been supported at primary school?
and assists with reading and spelling, which is not commonplace in schools – despite evidence that this is something that can be enormously helpful to young people (DfE, 2020a). This reinforces the importance of teachers being trained in how to support young people effectively.

5.3.2 Power and capitals

In reflecting on parents’ involvement with their child’s school about their SEND needs, it is important to consider elements of power. Foucault describes power as ‘a whole series of particular mechanisms, definable and defined, which seem likely to induce behaviors or discourses’ (1997b, p. 51). A distinctive feature of this is disciplinary power, which, as described in chapter 2, guides and sets limits on conduct and is regarded by Foucault (1977) as the most effective type of power because it is not the most repressive in nature. For example, Morgan (2005) relates disciplinary power to the process by which parents of children with SEN decide which school they want their child to attend; parents are given a list of schools but power is firmly located with those who compile the list. Morgan (2005) states that this apparently liberal act of government – giving parents choice – is actually an illusion. Power remains disciplinary as long as parents are made to “want” what the system needs and do not show dissent. Relating this to the parents of young people with severe dyslexic difficulties, paying for an assessment might be understood as channeling parental resistance into doing something that makes sense within a set of options framed by the medical/educational model. A Foucauldian framework enables us to understand the limits of choice and the way that the pursuit of equality takes place within a discursive frame. However, in order to develop a nuanced understanding of advocacy within the field of education, I have also considered Bourdieu’s theories of symbolic power (1984) and capitals – economic, cultural and social (1986).

Bourdieu’s concept of symbolic power, which he defines as power based on recognition – ‘renown, prestige, honour, glory, authority’ (1984, p. 251) – can also be studied in relation to hierarchies of expertise between teachers and parents. In the remainder of this section, I explore how parents are differently equipped when they advocate for their children (Ong-Dean, 2009) and document how the parents in my research used the symbols of capital available to them to attempt to secure provision.
In doing this, however, I observe that they were only effective when schools were willing to listen to parents, acknowledge their child’s difficulties and provide support to meet their needs.

Todd’s mother summarised the views of many parents when she described the significant role of a full diagnostic assessment in accessing provision:

‘A full diagnosis assessment report is invaluable and helps you to get the school to meet your child’s specific needs. Otherwise, they will try to use a one size fits all approach which may not be suitable’ (Todd’s mother)

However, full diagnostic assessments are not equally available to all parents. The picture emerging from my research suggests that parents, rather than schools, are often paying for full diagnostic dyslexia assessments themselves. The online survey shows that although almost half (44.2%) of young people had completed a screening test at school and 21.6% had a full diagnostic assessment paid for by their school/local authority, three fifths of parents (59.9%) paid for a full diagnostic assessment themselves. Parents with a degree or higher qualification were more likely to have paid for a full diagnostic assessment (67.7%) than those who did not (50.4%).

Reflecting the online survey, six out of fifteen young people in the narrative case studies (Jack, Trevor, Harvey, Arthur, Todd and Sid) had a full diagnostic assessment paid for by their parents. Three of these – Jack, Trevor and Harvey’s parents – prioritised a full assessment in spite of fairly low economic resources. Among the remaining nine young people, an assessment was either paid for by their school or effective provision was put in place on the basis of a screening test. The exception to this was Georgia, who had never had a full assessment because her school did not offer it and her parents could not afford it; as shown in section 5.2.4, she has also never had any support.

A further expense for some parents who have access to economic resources and were concerned about the lack, or quality, of the support received, is the cost of a private tutor, who either works with young people at home or sometimes at the school itself:
‘I still think that having a specialist home tutor was the most successful intervention for our daughter as it taught her to read, spell and write in a way that worked’ (Parent, id459, online)

Whilst Todd’s provision at school was described as ‘good enough’ in section 5.22, it is notable that it has been supplemented by four years of weekly private tuition with Dyslexia Action and later the Dyslexia Institute, which was paid for by his parents. It is difficult to know how much difference this tuition made to his academic progress and confidence, but his mother felt that it benefitted him. Matthew’s parents also paid for tuition, which his mother described as having a positive impact on his confidence.

In considering the advantages of parents’ greater economic resources, in particular how it can secure a SEND label, it is interesting to note that five out of six of the young people whose parents paid for an assessment (Trevor, Harvey, Arthur, Jack and Sid) did not go on to receive what I have referred to earlier in this chapter as a benchmark level of, or ‘good enough?, professional provision. This suggests that parents may need other resources. I have therefore drawn on Bourdieu’s (1986) three forms of cultural capital: *institutional*, for example, educational attainment; *objectified*, such as the possession of cultural goods; *embodied*, such as knowledge, values, skills and tastes. I also consider Reay’s adaptation of Bourdieu’s (1986) concept of cultural capital which particularly focuses on mothers, and goes beyond level of education and ‘participation in high status activities’ to include:

‘... confidence, ambivalence or a sense of inadequacy about providing support, the amount of expertise women feel in the educational field, and the extent to which entitlement, assertiveness, aggression or timidity characterize women’s approaches to teaching staff’ (Reay, 1998, p. 32)

Buswell-Griffiths, Norwich and Burden (2004) describe parents’ knowledge of dyslexia as a key factor in understanding the parent–school relationship, citing the acquisition of knowledge as the key to increased confidence. With nine out of fifteen parents in the narrative case studies having to inform their child’s school about their dyslexic difficulties themselves, it is clearly important to consider the impact that awareness and understanding can have on parents’ ability to secure support. Several parents also highlighted the significance of having knowledge of the SEND system.
All of those who had to challenge their child’s school expressed a lack of self-confidence and anxiety about the process they had to go through. They acknowledged the challenges they have faced in navigating a complex and adversarial SEND system and worried that other parents could struggle. Some alluded to cultural capital, without mentioning it by name and, reflecting my own concerns, suggested that middle class parents may be more likely to know how to navigate the system:

‘It’s been a nightmare. And I’m articulate, educated, confident. I was chair of governors of the school and I became a director of a multi-academy trust. I knew education. I was talking to people that I worked with and even for me, it was really difficult’ (Arthur’s mother)

‘The vast majority of pupils receiving the support are from middle class families that shout the loudest. Dyslexia affects all social classes. Would indicate more a problem with how school fails to identify children’ (Parent, id204, online)

‘A parent really shouldn’t have to have an MSc in SpLDs in order to know how to support their child’ (Parent, id336, online)

However, the following examples demonstrate that there is no simple relationship between cultural capital and provision accessed. Harvey is an example of a young person who has been impacted by his mother’s lack of awareness and knowledge of dyslexia and understanding of the SEND system. In fact, she trusted her son’s school to support him appropriately and did not question what they were doing until Harvey was 15 years old. It was only at this point that she realised she needed to pay for an assessment to help her challenge the school and access much needed support. Even then, however, Harvey’s mother did not seem aware that she could have asked for help with his literacy to catch him up with his peers.

Trevor’s mother, on the other hand, had a job as a teaching assistant and some awareness and understanding of dyslexia and the SEND system. Although she recognised the need and paid for an assessment, she was still unable to secure effective support for her son in both primary and secondary school. Whether this was because of the power differentials that existed between her, a teaching assistant, and teachers, or the resistance of the school to supporting Trevor, is unknown.
Jack’s mother is an example of someone who started off with no knowledge of how to access support and navigate the SEND system but learnt through the experiences of her two older autistic sons. Over time she came to understand the importance of paying for an assessment. She also gained confidence – enough to access support for Jack in the nurture group of a state secondary school. Although Jack does not like being in this SEND group, it has been a notable achievement for her after the initial struggle she had to secure support for him in primary school:

‘He is in the smaller group (SEND group) and is getting help. The new SENCo there is very good. He has taken Jack under his wing’ (Jack’s mother)

Arthur’s mother, on the other hand, is an example of someone who had considerable cultural capital but was still unable to access support for her son. She described herself as having experience of education as a chair of governors and director of an academy trust. However, she explained that once she had paid for an assessment and successfully obtained an EHCP, she mistakenly assumed that her son’s secondary school would support him as they had agreed. She expressed shock when they did not and he failed most of his GCSEs:

‘We were reassured that the local secondary school could handle Arthur’s SEND. In fact, the Head had been Head of SEND for another county and the SENCo had extensive experience, so we felt happy to send him there and we trusted their judgement.’ (Arthur’s mother)

Among the remaining parents who challenged their child’s school there have been varying levels of success. Adam’s mother is a teacher and had a relatively high level of knowledge, which she continues to draw on when interacting with her son’s school. She has been able to access what she described as good support, while acknowledging that she must constantly monitor what the school is doing. Sid’s mother, on the other hand, who over time has acquired some awareness and understanding of dyslexia, at the time of talking to her, had not managed to access the type of provision that she wanted for her son in mainstream school; as mentioned earlier, Sid is now educated in private, specialist provision. Finally, I refer to Georgia, who is an example of someone whose parents had significant awareness and knowledge of dyslexia but life events, economic circumstances and a lack of recognition by both her schools prevented them
from securing appropriate support. I reflected upon Georgia’s situation in my fieldnotes because it highlighted to me the significance of both parental advocacy and assessment. With neither of these, young people are reliant on their school identifying their needs and being willing to support them:

> Georgia’s experience is indicative of what I suspected may happen when schools do not offer provision and families have low incomes and/or their life circumstances prevent them from challenging their child’s school. It makes me sad that the system has not supported her when she most needed it. Even now she is at university she told me that she still can’t apply for DSA (Disability Support Allowance) without an assessment – she’s stuck in a vicious circle.’

Fieldnote, November 2018

Georgia’s situation is indicative of any family that has their own challenges to deal with. This could be physical or mental health difficulties, or SpLDs, as pointed out by Sid’s mother,

> ‘We are quite happy to try and sort things out but there are families where the parents are also dyslexic…it must be so overwhelming’ (Sid’s mother).

Finally, from what Toby’s mother told me, she secured an EHCP and fairly good support by converting social capital, in the form of the advice and support of a relative who worked in education at the local authority, into cultural capital. She was very open about how this allowed them to successfully navigate their way through the SEND system and acknowledged that their situation was fortuitous but unusual.

Nevertheless, she recognised that even with this help the process was extremely difficult for them:

> ‘The terrifying thing is... ... my family are all teachers...my sister runs support provision for this area...so really excellent support at home. And even then, we’ve not found it easy.’ (Toby’s mother)

5.3.3 Summary of section

This section suggests that when schools do not provide access to provision there is no simple relationship between parents’ ability to advocate effectively on behalf of their children and their economic, social and cultural capital. However, the evidence suggests that families are not equally positioned to negotiate access to the provision that they are made to “want” and which they deem necessary within the current
education system and require different resources at different stages. Firstly, parents may need awareness and understanding of dyslexia to recognise their child’s difficulties in the first place, if the school does not. Secondly, having identified a need, parents may need to pay for an assessment in order to get their voice heard. Finally, if schools are resistant to providing effective additional support, then parents need the resources to challenge their child’s school. For this they either need knowledge of the SEND system (or know someone who does) and communication skills to confront the school, local authority and even a tribunal, or economic resources to pay for a professional to negotiate for them.

5.4 Discussion

Participants’ appraisal of SEND provision suggests local inconsistency, inequality and unfairness. I have highlighted how discourses around dyslexia have implications for the ways in which policy-makers, schools and teachers respond to the category of dyslexia and how they shape provision. In particular, the medical/educational model found in most schools has led to intervention being favoured over classroom modifications, which is less inclusive, arguably reinforces the idea that SEND is outside the remit of class teachers and is more susceptible to budget cuts. I have also noted a tension between the way that SEND policy has been constructed through a medical model of disability, while government discourse on dyslexia implies a social model approach, in particular that young people with dyslexic difficulties can be supported without recourse to SEND budgets.

My findings suggest a dependent but nuanced relationship between effective educational provision and emotional wellbeing. In considering the benchmark of support accessed by Pia and Seb and the idea that some other types of provision may be good enough, a few factors emerge as particularly salient: early identification and intervention, as well as whole school recognition of dyslexic difficulties and an ethos of inclusivity. However, it is also important to note that good provision does not always lead to positive emotional wellbeing, opening up space in the following chapters to explore the other factors influencing how young people feel about themselves.
Parents are subject to disciplinary power in the way they are made to “want” a model of provision that prioritises individual intervention over one that values neurodiversity. However, schools are the gatekeepers to unlocking resources for young people with SEND and not all of them respond to the needs of young people and put support in place. My findings suggest that this is where social inequality occurs, with parents requiring economic resources and cultural and social capital to persuade schools to support their children. However, although I argue that those with access to capitals stand a better chance of successfully challenging their child’s school, this chapter has also shown that some parents with these resources still failed to access appropriate provision.
Chapter 6. My findings: the role of relationships in co-constructing the dyslexic self

This chapter seeks to understand more about how young people’s ‘hierarchical identity positionings’ (Holt, 2010, p. 26) are not only reproduced through norms and values but are also co-constructed through relationships within social networks. To support my argument, I draw on Symbolic Interactionism as a framework, anchored in Mead’s (1934) idea that young people internalise their interactions with others and use imagination to act out roles. This is a model of the self as reflexive and agentic and interacting with significant others, such as parents and family, peers and teachers. Utilising Cooley’s (1902) concept of the ‘looking-glass self’, I set out to capture how young people interpret the reactions of others and how in turn this impacts their emotional wellbeing and identity construction.

Holt (2010) describes how young people with disabilities construct their identities as they move through social space, such as school. She uses the notion of embodied social capital to explore how social networks confer value on young people, which in turn influence ‘their subjectification and self-identification (eg. as ‘disabled’ and whether an individual perceives this as a positive or a negative attribute)’ (2010, p. 26). We can think of this in terms of social interaction, what Mead describes as the:

‘internalisation and inner dramatization by the individual, of what is happening outside which constitute.... (the) chief mode of interaction with other individuals belonging to the same society’ (Mead, 1934, p. 173).

Honneth’s (1995) theory of mutual recognition, described in chapter 3, arguably complements a social interactionist approach and directs our attention to the significance of recognition in young people’s lived experience of severe dyslexic difficulties. By approaching this as an intersubjective process, I will focus on the importance of being accorded rights and having achievement validated by a community of interest, in particular teachers.

In chapter 3 I discussed what I mean by identity in this thesis. In this chapter I examine how the identity of my young participants is co-constructed through interaction with their families, before moving into the environment of school, where participants’
difficulties are most visible, and they interact with both peers and teachers. Towards the end of the chapter, I turn my attention to understanding how young people exercise agency through their interactions at school.

6.1 Relationships with parents and family

Every parent participating in the case studies was already involved in a range of caring and supportive activities aimed at understanding, helping, encouraging, reassuring, and standing up for their child, as well as advocating for them. Lynch refers to these activities as ‘love labour’, or ‘emotionally engaged work that has as its principal goal the survival, development and/or well being of the other’ (2007, p. 557). Clearly, these are roles that most parents take on anyway, however, as the following sections suggest, for those who have children with severe dyslexic difficulties, it becomes even more important that they can provide support in these ways.

6.1.1 Additional emotional work of parents, particularly mothers

Reay (2004) identifies women as most likely to take on the extra work of being responsible for managing their child’s emotional states and responding to their distress. This has been referred to as easing ‘their child’s passage’ (Buswell-Griffiths, Norwich and Burden, 2004, p. 429) through school. All of the parents taking part in the case studies and every respondent in the online survey who gave me their name were women. Reflecting the literature, the suggestion here is that mothers take on much of the additional work involved in accessing provision and providing reassurance and reinforcement. The following three sections describe how parents perform this role and the effort required to fulfil it.

Parents at the forefront of the battle to access provision

The notion of partnership between schools and the parents of children with SEND is not new, however with the introduction of the Children and Families Act in 2014, which promised greater participation in decisions, parents’ expectations were raised. With parents assuming that professionals will welcome their involvement, it is not surprising that they sometimes become dissatisfied and frustrated when they encounter disinterest in their attempts to be included in decisions impacting their children (Rogers, 2011).
Ross (2017) also refers to the gap between parents’ perception of how teachers allocate resources and the level of autonomy that teachers actually have within the structural restrictions that exist, which causes conflict between teachers, parents and the government:

‘...between parental perception of teachers as powerful “state functionaries” (Bourdieu, 1989), teachers’ ability at a pragmatic level autonomously to negotiate structural constraints relating to provision for young people’s dyslexia, and governmental expectation that the needs of young people with dyslexia will be met in the classroom’ (Ross, 2017, p. 199).

Ross (2019) found in her research that parents tend to initially locate their child’s dyslexic difficulties within the medical model of disability but, as they learn more about their difficulties and the system surrounding it, they start to consider the social structures that impact its effects. Without referring directly to the medical or social model of disability, parents interpreted their own experiences in a way that suggests some understanding of the issues:

‘Children that are not neurotypical are failed just because they need a different approach to learning... Teachers put too much blame on the children for not progressing instead of looking at new ways to teach.’ (Trevor’s mother)

‘Her school is a selective school and recognised intelligence over the importance of spelling.’ (Parent, id082, online)

Although parents may have some awareness and understanding of the principles of the social model of disability, as discussed in previous chapters, disciplinary power ensures that parents are made to “want” a model of provision which prioritises individual intervention over a conception of SEND that accommodates or values neurodiversity. In pursuing this type of provision for their children at all costs, there is an argument that parents are unintentionally reinforcing the very framework that rendered their child, through a deficit model, as ‘behind’ in the first place.

As described in chapter 2 some parents find the SEND system in Britain adversarial (Thackray, 2013). Tension between schools and parents can turn to mistrust and lead to parents challenging their child’s school; in Foucauldian terms this can be described
as a point of resistance (Foucault, 1978). Morgan (2005) likens the SEND system to Bentham’s Panopticon (Foucault, 1977), which was designed to provide comprehensive and uninterrupted surveillance without the occupants knowing. However, he cautions against equating power with repression, suggesting that power can be creative because it forces some parents to resist and ‘actively challenge the panoptic structure/system of special education by explicitly contesting its mechanism of power’ (2005, p. 343). This was the case for many of the parents in my research when they encountered a lack of awareness and understanding of, or opposition to, dyslexia, or when their child’s school did not provide effective support. Participants in both the online survey and the narrative case studies used combative words like ‘battle’ and ‘fight’ to explain the antipathy they experienced when trying to access provision for their child. Included in this is the implication of struggle and hardship. These are familiar words, used by several other researchers writing about dyslexia (eg. Ross, 2020) and other SEND (eg. Rogers, 2011):

‘I was faced with a battle trying to get staff to realise it wasn’t just more ‘practise’ that was required!!’ (Parent, id139, online)

‘I discussed my concerns about his reading with his teacher. Armed with evidence that Trevor is a very bright boy and he shouldn’t be struggling with his reading and writing as he clearly was... That’s when the battle began.’ (Trevor’s mother)

Reflecting this confrontational stance, one parent reported that she was actually told by a SEND officer to be a ‘nuisance, because it’s the people who are nuisances that get what they ask for...You have to find that grrr’ (Toby’s mother). Trevor’s mother said that ‘by SATs I’d been in and out of that school almost daily to discuss support for Trevor’, and Arthur’s mother described the process of having to threaten her local authority with tribunal as ‘incredibly stressful’.

Several young people acknowledged the effort their mothers had made to secure appropriate support for their children. For example, Harvey talked about his mother sending emails to his school and Trevor and Todd told me of the times they had been distressed and their mothers had challenged the teachers who had not supported them in class.
The level of commitment shown by parents to challenging their child’s school is noteworthy, however, it is also important to refer back to the previous chapter and remind ourselves that this kind of undertaking requires resources that not every family has. I am reminded of Georgia’s parents, who were prevented from challenging their daughter’s school by a significant life event occurring just as she started secondary school and Harvey’s mother who did not know how to access support for her son until he was in Year 10. Arguably, in the general population, rather than a sample of already ‘active’ parents, families like Georgia’s and Harvey’s may be more common, once again pointing to inequality.

**Providing reassurance and reinforcement**

In coming to know how young people understand their dyslexic difficulties it is important to consider the part played by the adults around them who may scaffold them towards ideas of difference and away from notions of deficit or fault. This can be seen in the interview with Adam and his mother where she prompts him towards this explanatory framework when describing his dyslexic difficulties:

‘Mother: Brain. Works in a...?  
Adam: Different and harder way’.

Todd’s parents talked about the things they did before their son received support at school, and still do, to raise his confidence:

‘We tried to encourage him in the things he was good at, like his creativity and ability to make anything, out of anything, but he was getting more and more down, and more behind in his school grades.’ (Todd’s mother)

This kind of reassurance and reinforcement can be understood as part of the work of parenting a child with SEND. Parents’ active engagement in labour to reframe how dyslexia is understood, alerts us to the relational character of the emotional underpinnings of how dyslexia is narrated by young people. Supporting this view, in a document that Adam’s mother sent me in addition to her narrative, her local SpLD Support Centre states:

‘The most important job of his family is to protect and nurture his self-esteem, so he is happy to continue doing battle with the written word!’
Reflecting the growing campaign, mentioned in chapter 3, of dyslexia being associated with advantages as well as disadvantages, the following diagram captures the words most commonly used by parents in the online survey to describe the positives of dyslexia. These are words that, as chapter 7 will show, were echoed by some young people when describing themselves, suggesting that they may have been influenced by their parents’ efforts to change how they perceive their dyslexic difficulties. ‘Creativity’ was mentioned the most often (more than a hundred times). Other commonly used words relate to thinking differently/laterally/outside the box, being good at problem solving and seeing patterns, being determined, having a good imagination and being empathetic. Fewer mentioned resilience, being practical and a thinker/thoughtful. It is possible to understand these words as part of a positive account of dyslexia that is co-produced between parents and children, and that is underpinned by recourse to biological explanations of brain difference and wider sources, such as celebrities coming forward to talk about their strengths.

Figure 5: Key words used by parents in the online survey to describe the positive effects of dyslexia on their children:

Parents’ function as a source of positive affirmation resonates with my own experiences and aligns with much of what the parents in my study were already doing. Part of wanting to protect their children from feeling ‘stupid’ led Todd and Trevor’s mothers to want to tell them as early as possible that they were dyslexic. They believed that this helped with their confidence ‘which has probably been knocked for years’ (Todd’s mother). There was also a strong feeling among many parents that their
role was to focus on ‘the things they excel in and praise non-stop’ (Todd’s mother), thereby repairing their child’s confidence after it is dented in the classroom to a lesser or greater extent. Many used superlatives to describe their children and their skills and provided them with opportunities to try new things and take part in activities they are good at. For example, Adam’s mother gave him positive affirmation throughout the interview and praised his woodwork skills and riding ability. She suggested that parents should find activities their child enjoys and is good at and ‘shout it from the roof-tops’. Although she described Adam’s confidence as having improved since receiving a programme of support at school, she still expressed concern that:

‘His daily life at school is a struggle, therefore we have a constant battle to keep his self-confidence raised.’ (Adam’s mother)

Nina’s mother was keen to tell me during the interview about how her daughter had taught herself to knit from watching a video on the internet, saying to both Nina and myself, ‘which I’m in awe of’. Sid’s mother encouraged her son’s imagination, and confidence, by helping him to make comic books, ‘power’ cards and toys based on the characters he has created (see Figure 10, section 7.4.2) and Todd proudly told me that his parents would describe him as ‘kind’, ‘polite’ and ‘funny’, but also ‘talented’.

Trevor’s mother, reflecting her understanding of how her son was made to feel at school, talked with pride and emotion about how he surprised everyone when he played piano in a concert:

‘No one at school knew how good he was at playing the piano until they put on a music concert. A day I will never forget and still gives me goosebumps! He sat at that piano after 6 months of lessons and played ‘the entertainer’ for the whole school. His teacher’s jaw hit the floor. He was amazing! He blew everyone away.’ (Trevor’s mother)

As well as providing positive affirmation, all parents were involved in protecting their children and bringing comfort to them. Adam told me about how his mother provided reassurance when she told him that the purpose of his Year 6 SATs was to test the teacher not him. She was also very kind and patient with him when he was trying to write during the interview, creating somewhere safe for him to be himself:
‘Don’t worry about your spelling. That’s fine. You just write what you think it is, and then we can write it.’ (Adam’s mother)

Gina and Georgia also referred to how understanding their families had been. Although Gina’s mother had spent many hours supporting her daughter with her schoolwork at home, it was the emotional support that she highlighted to me:

‘Yeah because she’s the one, since I got diagnosed, mum’s been there. She’s put up with the screaming matches because I said I couldn’t read. She’s put up with, when I was in primary school especially I had so many temper tantrums because of my dyslexia….’ (Gina, 18)

A couple of parents went to extreme lengths to support their children when they were unhappy at school and resorted to withdrawing them. Georgia was taken out of school six months before her GCSEs and, as previously mentioned, Trevor was de-registered and has been home-educated ever since. These were not decisions that were taken lightly.

Counting the emotional toll on mothers

As shown throughout this thesis, mothers often have to identify need in the first place, become advocates, take on the additional work of managing their children’s emotions and navigate an education system where provision is inconsistent. In conducting my analysis, it became clear that mothers are often uneasy and worried about their ability to fulfil these roles and for some it has taken its toll and become an emotional burden.

The additional emotional work of the mothers in my research has affected some more than others. The emotional impact on those who have had to challenge their child’s school over a long period of time has been significant, however perhaps not as burdensome as the emotional stress and worry of watching their child suffer emotionally. Arthur’s mother recounted the impact of her son’s unhappiness at secondary school on her:

‘He disappeared into his own little world and it wasn’t until the end of it all that we realized just how hellish that world actually was. I didn’t have a nervous breakdown but I got very close to one’ (Arthur’s mother)

Furthermore, Harvey’s mother talked about experiencing guilt for not realising sooner
that her son required support. This has made her feel anxious and unhappy, believing that she should have taken action earlier:

‘I am not sleeping well now as I feel I’ve left it too late for this school to get help and have let him down. His sister who is 13 and was so behind at primary. I applied myself for an EHCP, which I got... I feel so bad that I haven’t done one for Harvey as the school have never told me how far behind he is’. (Harvey’s mother)

The emotional weight of managing a child’s difficulties also includes concern for the future. Many parents related poor academic performance to lack of opportunity, believing that access to provision is the only way for their children to reach their potential:

‘Sorry, this is very negative but halfway through his mocks now and he feels they are going very badly. I worry for his future and am annoyed at myself for not hassling the school enough as I have for my daughter.’ (Harvey’s mother)

Sid’s mother revealed that before she sent Sid to an independent, specialist dyslexia school she worried that her son’s life chances would be limited. She reflected on this by talking about her experience of working in social housing and coming across people who ‘have been failed by the education system’. She summarised why she has persisted in challenging her son’s school and local authority:

I honestly believe that people who are failed in the education system often have a crappier .... I used to see people stuck in these flats...and they were really interesting, like I met an amazing pianist...all these things they had made and created but they had no sense of purpose. They were on benefits and had mental health issues, smoking and drinking too much and not looking after themselves...they felt...I really think it sets them up ...that was what I was worried about more’. (Sid’s mother)

6.1.2 Classed cultures of parenting: the influence on young people

As discussed in chapter 3, Reay’s (2004) work on emotional capital is a useful framework for understanding what can happen when parents prioritise educational success and are very involved in their child’s education.

Two cases come to mind in my research where parents may have transferred their own anxiety to their children by focusing on their education. Firstly, Gina’s mother is
an example of someone who may have prioritised her daughter’s happiness in the future over her happiness in the present. Her strong focus on helping her daughter with her schoolwork at home, which was discussed in section 5.3.1, may have inadvertently created pressure for Gina. It is worth bearing in mind that this may have happened anyway, even if she had not had severe dyslexic difficulties, however, I was struck by the force of her assertion that dyslexia:

‘Doesn't stop her achieving...However, she doesn't let it hold her back and has never used her dyslexia as an excuse’. (Gina’s mother)

Gina presented as proud to be ‘dyslexic’ and echoed her mother’s words, saying that it ‘doesn’t hold me back’ several times in the interview. In mirroring her mother’s words in the quote below she suggests that the responsibility to achieve is in her own hands:

‘Yeah. It was knowing that nothing can hold me back except myself.’ (Gina, 18)

Although Gina initially seemed like someone who was well-adjusted to her learning difficulties, as the interview progressed, I found myself wondering about the pressure she might feel to not ‘let her family, and herself, down’. She talked about wanting to be as ‘good’ as her brothers, suggesting that this feeling originated from her:

‘Yeah, to be that better person especially because I’ve, some reason in my head I’ve always got to be just as good as my brothers. It sounds stupid but I don’t want to be less than them.’ (Gina, 18)

While on the one hand explaining that she used her desire to please her family as her ‘motivation to keep going, to be just as good as the next’, she also admitted that this puts pressure on her:

‘...that’s probably one of my biggest enemies that I don’t want to fail because it puts a lot of pressure on. But I think if I didn’t have my dyslexia I don’t necessarily think I’d be like that. But because of it, I think I’m more harsh on myself.’ (Gina, 18)

By the end of the interview, I felt concerned about the pressure she was putting herself under. I wondered if any of this burden emanated from her mother’s response to her, in which she acknowledged that some of Gina’s difficulties were hard to overcome but still placed responsibility on her to defeat them.
Toby is the second example of how parental anxiety over education may have had an impact, in particular the way in which his parents pursued effective provision and the confrontation between them and the school, which was not hidden from him. He was the most withdrawn of my participants and despite what seemed to be reasonably good support at school, was very uninformed about dyslexia and the impact it may have had on him. He was also very closed off when talking to me about it. His mother did not write a narrative but sent me six official school/local authority documents relating to Toby and his learning difficulties and the EHCP that they put in place for him. I stayed after my interview with Toby to talk to his mother and began then to understand the amount of effort and stress that has gone into acquiring support for her son. Her anxiety was still palpable, even though she had gained an EHCP and chosen a secondary school where the provision seemed to be good. She talked very openly in front of Toby, both about the struggle they had to secure provision for him and the extent of his difficulties, recounting how a SENCo told her that he must have ‘really profound needs’ in order to have an EHCP. Toby interrupted and said ‘Is that what I’ve got?’, to which his mother explained that if the range of difficulties of dyslexia was a pack of cards, then he has a hand that you would least want, what she described as ‘the most difficult bits’ of dyslexia! As mentioned in chapter 5, in doing this she was individualising her son’s difficulties and focusing on deficit rather than difference. She also talked openly to Toby and myself about how she has mobilised a group of teachers and teaching assistants to what she called ‘Team Toby’:

‘So we gather the team around us and we try and really work as a team. And we’ve recruited Mrs Spreckley to Team Toby – that’s the SpLD unit lead.’

(Toby’s mother)

I found it interesting that Toby knew so little about his difficulties and wondered why his mother had not told him more. In thinking about this it made me consider whether he might benefit from hearing about the so-called positives of dyslexia, whether they are scientifically proven or not (Elliott and Grigorenko, 2014), or at least have a more informed view of his difficulties.

I noted at the time that the way she talked in front of him about his difficulties and the school’s initial reluctance to help made me feel uncomfortable. I recognised the
language she used about the school as similar to my own and it made me reflect on how my anger and anxiety may have transferred to my son. Reflecting Biggar and Barr’s work (1996), I also thought about how my confrontation with the school may have led my son to perceive it as an unsafe and unreliable authority and to feel that he needed to side with us, his parents. These were thoughts I have had before but seeing another parent react in a similar way, highlighted it and made me feel regretful. The following extract from my journal illustrates this point:

‘In examining parents’ responses to their children’s difficulties, I have had to look back and question my own role and ask myself if I may have unintentionally contributed in some way to my son’s distress. This has not been an easy process but it has made me more analytical and accepting of myself and other parents – whatever we did or did not do, we acted on the information and knowledge we had at the time and from a place of love.’

Note written during analysis of parents’ narratives, February 2019

Toby’s mother also seemed very concerned when he expressed agency and showed transgression (Foucault, 1997a) at school by writing on a test question “I need a scribe”. She was worried that this could be construed as bad behaviour, even though Toby explained that he was responding to having his hand up for 5 or 10 minutes and being ignored. There is no doubt that Toby’s mother has gone to extraordinary lengths to support her son. However, in the course of doing so, she may have become preoccupied with his difficulties and the process of acquiring the best provision available – a process that has involved much conflict with the school, as well as personal stress and anxiety. As someone who has had very similar experiences to Toby’s mother I empathise with her and hope that as time passes he grows to understand his difficulties better and appreciate his strengths.

Both of the cases described above highlight the complexity of the role of parents with a child with additional needs and how difficult it is to achieve a balance between encouraging academic achievement and not creating additional pressure. Overall, I would argue that, although the mothers who participated in the narrative case studies were mainly middle class, for most of them, happiness for their child in the moment was perhaps the first, and the most significant, motivation for them to challenge their child’s school. This is not to say that concern for educational development was not
important, but that they have prioritised their child’s happiness first. Gillies would describe this as focusing the emotional capital they have generated on protecting their child and easing their ‘feelings of failure and low self-worth, and challenging injustice’ (2006, p. 281). As I have analysed my findings, however, I have started to consider the possibility that even those parents who were motivated by happiness in the moment may have passed anxiety on to their children if, as was very common, their strategy to improve their child’s emotional health was to seek effective provision. If young people interpreted this approach as prioritising educational success, it may have led to further stress and anxiety for them.

6.1.3 Support from wider family
A couple of the young participants spoke enthusiastically about the time they spend with their grandparents, seeming to enjoy pursuing interests they perceive themselves to be good at and appreciating the positive affirmation they receive. For example, Todd talked about making a go-kart and a basketball net with his grandad and baking with both his grandparents. He also enjoyed walking in the countryside with his grandad and described them as having a good relationship. Adam also seemed to benefit from a similar relationship with his grandad and enjoyed doing a lot of woodwork with him. This culminated in him making small wooden reindeers to sell at Christmas, which seemed to make him extremely proud. Both boys seemed to benefit from the time they spend with their grandparents and the encouragement and reassurance they receive from someone other than their parents.

6.1.4 Summary of section
This section has highlighted the additional emotional work that parents, in particular mothers, take on when advocating for their children at school and managing their emotional states. Having to challenge the school, a task that can turn into what was often described as a ‘battle’, adds to this emotional burden and I note that this kind of undertaking requires resources that not every family has. The findings also suggest that parents, and the wider family, can play a significant part in helping young people to understand their difficulties and scaffold them away from notions of deficit towards ideas of difference. However, I also observe that occasionally parents’ anxiety about their children’s education and the conflict they may have with the school can cause
young people to experience stress too.

6.2 Relationships with peers

Peers have an important role to play in how young people shape their identity. As shown in chapter 2, children as young as pre-school age make social comparisons with each other and around middle childhood start to regard their relationships with their peers as more significant than those with parents. When parents participating in the online survey were asked to reflect on the impact of dyslexia on their child, 11.4% cited issues with peers, including feeling isolated and being bullied. Furthermore, among those taking part in the narrative case studies, there was much negative discussion in relation to peers, including teasing, belittling and even bullying. There is also a theme of separation and how young people with severe dyslexic difficulties are often educated apart from their friends. However, there are also some positive reflections, which I will highlight first.

6.2.1 The support of peers

Research by Wallander and Varni (1998), discussed in chapter 3, describes peer support as contributing to coping strategies for children with disabilities, and several young people in my study talked appreciatively about the support they received from friends who helped them at school. Pia spoke about a primary school friend who helped her with reading and Ella mentioned friends supporting her with writing. Group identity is also important. Trevor talked about finding a group identity with two friends in primary schools who also had dyslexic difficulties. He spoke as though he found comfort in these friendships:

‘(chuckles) Well, it’s quite cringey, but me and Barney called each other dyslexic buddies.’ (Trevor, 14)

He went on to tell me about how his friend Ben, who also has dyslexic difficulties, won a scholarship to an engineering school. He spoke generously and with genuine pride about his friend’s achievement, as well as a touch of envy, wishing that he had taken this path himself:

‘Because he’s dyslexic just like me and he’s very badly dyslexic. And he’s actually gone to, uh, an Engineering school and it’s...So I just—and I’m so happy for him that he’s done it’. (Trevor, 14)
Sid’s mother described how her son, who had recently started attending a specialist dyslexia school, now felt part of a group for the first time and enjoyed the fact that everyone there had dyslexic difficulties. When I asked Sid, what were the good things about being ‘dyslexic’, he referenced his new school and friends:

‘I think like you got all the cool friends... there's something in common and it’s very big...Yes so yeah because you’re like each other...It’s just a big, it’s a big deal if you have it common...You're really close if you have it in common with someone.’ (Sid, 10)

The relief that both Trevor and Sid found in being around others with similar difficulties ties in with Goffman’s (1963) concept of in-group alignment, as discussed in chapter 3. This highlights how people facing difference or stigma can find solace in turning towards people having a similar experience.

6.2.2 ‘They quite literally pointed and laughed’

From a symbolic interactionist perspective and Cooley’s (1902) concept of the ‘looking-glass self’, peers are likely to internalise the attitudes and behaviour of teachers towards young people with severe dyslexic difficulties. Georgia recognised the impact that one of her teachers, who she described as a bully, may have had on her relationship with her peers:

‘Then she’d (the teacher) picked on me because I didn't do it properly in front of the whole class...So it was very much the class had an opinion of me due to the teacher (Georgia, 19)

In addition, it could also be argued that peers embody the discourse of dyslexia that focuses on deficit and reaching cultural and educational norms. For example, peers who belittle a young person with severe dyslexic difficulties for not being able to read and write are reinforcing a cultural belief that everyone should be literate. If peers internalise these views, then, arguably, they are more likely to make insulting and hurtful comments.

As mentioned in chapter 3, research conducted by Chatzitheochari, Parsons and Platt (2016) proposes that children and young people with disabilities are more likely to be bullied at school than those without a disability. The DfE defines bullying at school as
‘behaviour that is repeated and intended to hurt someone either physically or emotionally’ (2020b). In my research, I found that in almost every interview with young people there was an underlying feeling, to a lesser or greater extent, of their vulnerability in relation to their peers. Indeed, many of them spoke of name-calling, being made fun of and worse. The accounts provided by parents supported these stories.

Sid’s mother told me that he was regularly called ‘lazy’ and ‘rubbish at reading’ by his peers and that this name-calling led him to identify himself in this way. Arthur actually used the word bullying to name interactions that took place in both primary and secondary school. He admitted to being upset by it at the time and said that being called ‘stupid’ and ‘freak’ made him believe that he was inferior. His attitude to the bullying now that he is older is to minimise it by calling it ‘pathetic’, ‘childish stupidity’ and ‘not important’.

Georgia referred to a few cases of bullying, some of which were long-term and very damaging to her personally. In particular she told me about a group of girls who ‘quite literally pointed and laughed’ at her and physically hurt her. She believed that this was largely attributable to the girls being in the same classes as her and seeing her struggle. The following ‘I’ poem captures her frustration and sadness at the attitude of her peers:

‘I just have no tolerance left
I couldn’t cope with any of it
I just didn’t understand’
(Georgia, 19)

Similarly, Jack spoke about the hurtful language that his peers have used, and continue to use, against him. He told me that they talk to him in this way because he is in the learning support unit and because the ‘less intelligent kids’ are easier to pick on. This was not the only time he referred to himself as being part of a group of less able people:

‘People calling me names a lot. A lot of the time...the people who pick on me, always call me like ‘retard’ and ‘spastic’ and stuff’. (Jack, 11)
In response to these words, he said that he gets upset and runs away so that he can calm down.

Likewise, Gina talked openly about how her friends at school used to ‘take the mickey out of her’. She described it as relentless, naming it ‘bullying’ and explaining that it had taken its toll on her. She told me about how her friends at school used to joke about the things she said and how she said them. When this happened again recently on a WhatsApp chat, she demonstrated her frustration to me by saying ‘I’m done. I’m done with this’. She added, however, that being bullied by her friends has contributed to her being more resilient.

Although Ella did not specifically mention her peers in a negative light, she talked generally about people being unkind when they know that someone has dyslexic difficulties. She focused on people’s potential negative reaction to her if they do not understand her difficulties, which has led her to hide them from people she does not know. She was reluctant to cite any particular incidences of unkindness towards her at school, but did talk about occasions when children on her estate were ‘mean’ to her.

Even Todd, who seemed one of the most resilient among the young people I spoke to, talked about being bullied by a boy in his learning support class. The boy’s actions led to Todd’s wrist being broken:

‘Um, but he’s saying it weren’t him and bullying me and calling me names. And this other kid keeps slapping me’. (Todd, 12)

When I asked Todd why he thought he was being bullied, he simply said ‘just bad luck’ and because he was defending his friend who was being singled out by the same boy. He made no link whatsoever between his dyslexic difficulties and the bullying he was experiencing, which may well be true but also reflects his confidence in himself and the pride he feels about his dyslexic difficulties.

6.2.3 Relating to peers with similar difficulties

In contrast to in-group alignment described above, Gina displayed identity ambivalence when she was critical of some of her peers for using dyslexia as an
excuse. She also had no time for people who do not accept support from teachers. Goffman describes identity ambivalence as when someone:

‘obtains a close sight of his own kind behaving in a stereotyped way, flamboyantly or pitifully acting out the negative attributes imputed to them’ (Goffman, 1963, p. 131)

Gina was clearly incensed by the behaviour of her fellow students and went out of her way to encourage younger learners with dyslexic difficulties at school to not give up, show determination and accept help. She described what she said to younger children when she was still at school:

‘I'm like you know, I've been called, you know, I've been called stupid and you know things like that. But it’s what you do with it.’ (Gina, 18)

Gina was not the only participant who was annoyed by people using dyslexia as an excuse. Pia talked about a girl who blamed everything on her dyslexia and Trevor mentioned a boy who used his dyslexia to his advantage, often to avoid doing schoolwork that he found difficult. Trevor recognised how the boy felt, but disagreed with his strategy of avoidance:

‘He just doesn’t want to do it because he struggles so much with it and it makes him upset ...I know how he’s feeling and I know he doesn’t want to do it...but one day he’s going to have to do it...And he’s better off doing it now...’ (Trevor, 14)

6.2.4 Summary of section

While some young people recounted ways in which peers had been supportive or talked about how they had found comfort in others facing difference or stigma, many expressed vulnerability. In seeking to understand the reasons why young people talked of being picked on and bullied, this section discusses how peers may internalise the views and behaviour of their teachers and embody a discourse of dyslexia that focuses on deficit and achieving cultural and educational norms.

6.3 Relationships with teachers

This section focuses on teachers but also refers to teaching assistants when participants mentioned them. It is important to capture views on teaching assistants,
as well as teachers, because they are responsible for much of the support of children with SEND. The Lamb Inquiry into Special Needs and Parental Confidence suggests that the teaching and support of those with SEND has been largely ‘handed over to TAs’ (Lamb, 2009, p. 29).

Reflecting the existing literature, discussed in section 3.1.3, my findings leave me in no doubt about the significance of the role of teachers in supporting young people to develop a positive sense of self. The previous section discusses the way that peers internalise the attitudes and behaviour of teachers, while this section focuses on the significance of teachers’ relationships with young people with severe dyslexic difficulties themselves. Once again, Cooley’s (1902) ‘looking-glass self’ perspective frames my findings.

I explore both the positive and negative stories about interaction between young people and the adults at school. Relationships are examined through the lens of recognition and care, in particular Houston’s (2010) interpretation of Honneth’s (1995) ideas on self-realisation, referred to in section 3.1.3, in which he suggests four dimensions which together make up recognition. The first of these dimensions is *symbolic interaction* which acknowledges that meaning derives from social interaction (Blumer, 1969). The second is *care* which is conceptualised as a significant component of any relationship which affects self-confidence. The third is *respect* in terms of ‘the recognition and realisation of the citizen’s comprehensive, legal rights’ (Houston, 2010, p. 851) and the fourth is *validation* in which individual strengths are recognised. Each of these elements of recognition can be seen as relevant to an examination of participants’ interactions with teachers.

### 6.3.1 Positive stories of teachers

It is important to highlight the positive stories that participants recounted about their relationships with teachers and learn from them. Almost every young participant had somebody in school, at some time during their school life, who helped in a particular way and who they trusted and valued. However, these relationships were mostly fleeting and perceived as a matter of luck rather than something on which they could rely. Many of participants’ positive comments centred around the theme of
recognition, in particular, Houston’s notions of care, respect and validation described above. They also reflect Laurent’s (2013) research in which she highlights the significance of even the smallest acts of care by the adults at school and Lithari and Rogers’ (2016) research about the importance of school being a ‘care-full’ space for children with SEND.

Parents were keen to point out the impact that individual teachers and teaching assistants can have when they show empathy and are open-minded about learning difference:

‘His SENCo was amazing!! Quiet and calm when needed and funny and motivating when needed. She focused on what he was good at... he had time alone for extra help every single day with his SENCo or a teaching assistant... he is so lucky he had so much help from the age of 7’ (Parent, id158, online)

Sid’s mother also described a teaching assistant in mainstream primary school with whom her son formed a close bond. She not only said that the teaching assistant seemed to understand Sid but also everything she said to her about Sid:

‘...she could finish my sentences when I was talking... some of the other times, you’d feel like people maybe didn’t quite get what was going...’ (Sid’s mother)

Those with personal experience of dyslexia (either their own, a family member, friend or another learner) were described as especially understanding. This insight is supported by Sahin (2018), who suggests that teachers’ previous experience of SEND has an impact on their attitude towards young people with learning differences. Gina really appreciated one of her teachers telling her that he had dyslexic difficulties, particularly because she thought it made him ‘vulnerable’ – something she deemed to be a good thing. Although Georgia reported no positive experiences with teachers at school, she mentioned a lecturer who identified as ‘dyslexic’ himself. She not only found his teaching more accessible but described him as understanding:

‘He was very much like, “Don’t worry about it. I’m dyslexic. I’ll do my best to help you out. If you need any help just ask.” He was very, very understanding with it.’ (Georgia, 19)

Nina and Adam’s mothers also talked about the positive impact of having teachers
who have dyslexic difficulties themselves, highlighting the greater understanding it offered and how it made teachers more caring. Adam’s mother described one of these teachers as someone her son could talk to about how he was feeling, who met him at the school gate if he did not want to go into school and sorted out problems for him. She told me that this relationship helped to raise her son’s self-esteem. Adam hesitantly agreed, saying ‘Mm-hmm, mm-hmm’, suggesting that he may not have felt quite as supported by her as his mother thought.

Similarly, Todd spoke about one teacher in particular who also had dyslexic difficulties and who he valued for the support she offered. She did not teach him but ‘...she takes me out of class and talks to me about things...Just about like dyslexia...and everything.’ Todd’s mother also appreciated the attitude of his primary school head teacher and SEND teaching assistant who realised the stress that SATs was causing him and talked to him about how bright he was and how proud they were of him.

Pia, whose teachers had greater awareness of dyslexia due to their involvement in the 2007/8 ‘No to Failure’ (Dyslexia SpLD Trust, 2009) initiative discussed in chapter 5, spoke positively about her teachers, emphasising the impact of one particular specialist teacher in the dyslexia unit who made her feel cared for:

‘And every time I came to our lesson, we have these little like rituals or traditions ... we’d get the magic box and get a toy every time we got enough points or something. I can’t remember what it was...she had stickers and we could decorate our own drawer where we kept all our work’. (Pia, 14)

However, teachers and teaching assistants do not necessarily require personal experience of dyslexia in order to recognise and care for young people. Gina praised a teacher who had no particular training in dyslexia but still showed compassion and stayed with her when she was upset about her schoolwork. She also spoke about how she felt when her mother started working in the learning support unit at her school, highlighting the importance of having a trusted adult to turn to:

‘I had her to go to
I was in Year 11
I felt a lot more comfortable going
I needed an overlay
I had forgotten mine
I felt much more comfortable
I felt like I knew them
I knew it was the safer place to go’
(Gina, 18)

Sid’s mother emphasised that teachers who do not have training can still form a good relationship with young people if they have an open-minded attitude to neurodiversity and inclusion:

‘He’s had some teachers and TAs that have been fantastically supportive and even if they haven’t had training, they are open-minded enough to accept that not everyone is the same….and he’s had a lovely relationship with those teachers.’ (Sid’s mother)

Young people also identified particular adults at school who had been kind and helped them. Trevor talked very positively about his form tutor in Year 7. He clearly valued her support and recognised the difference it made to his life for that one year. He talked about how he ‘...just felt so happy that someone actually...wants to help me for once in my life’ – highlighting how abandoned he must have felt otherwise, something that made me feel extremely sad. Harvey, who showed little enthusiasm for his teachers, mentioned a couple who he said ‘help’ him. He told me that his English teacher spoke to him ‘like a person, not just a student’. After 10 years at school when his needs were not identified, respect seemed to be very important to him. His mother later clarified that this teacher had a Master’s in SEND. Finally, Georgia highlighted the greater emotional support that her tutors at university have offered her, which was in sharp contrast to her experience of school:

‘Probably it’s the emotional support actually for me because I’m quite an emotional person. I think if I didn’t have the emotional support from my tutors, I probably would have left by now.’ (Georgia, 19)

6.3.2 ‘They gave up on me’: negative stories of teachers

Sadly, good and caring relationships between teachers and young people illustrated in the section above do not always happen. The following quote from Georgia, once again references teachers’ lack of recognition and care and summarises experiences that are typical of other accounts from young people in my research:
‘Some of my teachers didn’t care or didn’t want to understand why I didn’t understand. They didn’t try and help me…they were kind of funny about it because they didn’t understand it.’ (Georgia, 19)

This section recounts the negative stories of young people’s interaction with teachers and teaching assistants and draws on Trevor’s experiences to understand the influence they have on emotional wellbeing and identity construction.

Reflecting the literature discussed in chapter 3 about teacher expectations (e.g. Madon, Jussim, & Eccles, 1997), some parents took issue with teachers’ perception that young people with severe dyslexic difficulties are less able to achieve in an academic context, suggesting that this makes them complacent and willing to accept lower grades. This is illustrated in the words of Trevor’s mother, once again highlighting the discourse of deficit and being less than:

‘Some teachers just don’t acknowledge SEN children can achieve and thrive like their peers.’ (Trevor’s mother)

Nina’s mother was disappointed by a primary school teacher’s reaction to her daughter’s difficulties, saying that she would never learn to read and write. Other parents commented on this issue in terms of their children being prevented from reaching their potential:

‘There is a definite sense that if he is functioning as a ‘middle ability’ student (despite being in top 2% for intellectual ability according to his private psychological assessment), then he is doing well enough.’ (Parent, id403, online)

Sometimes these low expectations by teachers led to young people feeling patronised. Gina spoke of a recent occasion when she felt belittled, unsupported and criticised by her learning support assistant at university, which led to her becoming ‘touchy’:

‘… she was trying to teach me like, I felt as if I was a year four. And I was like, “No, no, no”… It’s when they started treating me as if I’m a bit stupid or they try to, it’s like teaching me in a childish way, that I get peed off …’ (Gina, 18)

Arthur’s account is typical of several young people when he described how his teachers made him feel ‘stupid’. Although his parents tried to convince him otherwise, he started to believe the teachers’ narrative:
‘I mean my parents always told me, no you aren’t. But like when you see those TV shows and stuff and they say, “Oh god. No, Jimmy you’re not stupid.” But then you realise you just see like, “Yeah, he is.” So, I thought I was Jimmy to be honest but….’ (Arthur, 17)

Similarly, Gina was critical of how several teachers treated her. This included one who suggested she was exaggerating her difficulties and another who undermined her abilities:

‘I always felt that my teacher hated me, even looking back. (Laughter)...I always got the impression that she thought that I wouldn’t amount to anything.’ (Gina, 18)

In thinking about the influence that teachers may have on young people’s identity construction and emotional wellbeing, it is interesting to focus on Trevor’s experiences at school, which ultimately led to his mother deregistering him. It is very noticeable in both Trevor’s and his mother’s accounts that teachers did not understand him and assumed he was lazy. In his interview he explained that he mirrored their perception and gave up trying:

‘Teachers didn’t understand me. They just thought I was lazy and can’t be bothered but that’s not true. I just gave up trying because they gave up on me. What’s the point in trying, I’m going to fail anyway. Being told daily “that’s not enough work Trevor, that’s not good enough Trevor, I’m disappointed in your efforts Trevor, do it again Trevor, stay in at break, finish it at home, that’s a detention.”’ (Trevor, 14)

Trevor’s mother even suggested that teachers blamed him for his difficulties and expected him to resolve them by trying hard:

‘I was told by the headteacher that Trevor wasn’t ‘playing his part’ and he needed to try harder. I threatened to pull him out of school several times because I was concerned about the effect it was all having on his mental health.’ (Trevor’s mother)

Trevor also talked candidly about being humiliated in front of his class because he did not finish his SATs paper in primary school. When we met, he explained that on his return to the classroom from the separate room where he had taken the exam his teacher singled him out. He spoke with indignation and emotion in his voice:
‘And then he personally said my name (coughs) sorry, and then...oh, and then...yeah. He, um, he said, um, my name personally (clears throat) and then he said that he was told that I didn’t try very hard and I didn’t try my best and that I was not going to go anywhere if I didn’t try.’ (Trevor, 14)

Trevor described how upset this made him feel and how unfair he thought it was of the teacher to talk to him in this manner in front of the whole class:

‘I just felt like crying, I just felt so upset...that he would say something like that to me.’ (Trevor, 14)

This confrontation may be indicative of wider issues relating to dyslexia. Firstly, the teacher showed a lack of awareness and understanding of how, within the current education system, dyslexic difficulties impact young people, demonstrating a lack of recognition. Secondly, the teacher followed the dominant discourse within education that it was Trevor’s fault and the deficit was his to deal with and not that of the teacher. Thirdly, the teacher confronted him in front of the whole class, showing a lack of care and making it likely that his peers, as discussed in the previous section, would take on the same view. As I will go on to argue in the next section, Trevor experienced mortification of self (Goffman, 1961), being effectively silenced by the power dynamic between teacher and learner and his own lack of agency.

6.3.3 Summary of section

A key finding from this section is the significance of the role of teachers in modelling how young people (and their peers) perceive difference and themselves. Participants’ stories illustrate the positive impact that individual teachers and teaching assistants have when they show recognition and care. Awareness and understanding of young people’s difficulties and the challenges they bring in the context of school is helpful in this regard, however, the findings also suggest that compassion and open-mindedness about learning difference goes a long way to supporting young people’s self-image and emotional wellbeing.

6.4 ‘If you need help, ask for help. If you feel scared, go tell someone’

In chapters 1 and 3 I outline my approach to agency as relational, connected and interdependent and draw on the work of scholars such as Spyrou (2018). By thinking
about agency in this way it prompts us to consider the constraints and challenges experienced by children and highlight their vulnerabilities as they navigate their way through school.

In viewing young people as social actors in their own right, this section explores the extent to which they are able to operate in and upon structure (Prout & James, 1990) and exercise agency within the environment of the school. Given the power differential between teachers and young people, the capacity for agency is likely to be dependent on schools’ and teachers’ ethos of participation, which is described in chapter 2 by the Children’s Commissioner as still yet to happen in schools (2011). I am also interested in noting any points of transgression (Foucault, 1997a), as discussed in chapter 3, on the part of young people.

In this section I explore different experiences of agency, from those who consistently showed agency at school to those who were agentic around certain teachers or not at all because they spent their entire time trying to cover up their difficulties and not draw attention to themselves. I illustrate how respect and trust are important and that young people need to be sure they will be listened to before they speak up for themselves.

Todd and Adam were the only participants who seemed able to speak up for themselves in most situations relating to their dyslexic difficulties. Todd talked about being comfortable putting his hand up in class to ask the teacher for help when he was struggling; he did not always actually get the help he required but he showed agency in asking for it. He also went to see the head teacher as soon as he started being bullied by a couple of boys in his core support class:

‘Yeah, because he started bullying me. So, I thought, “Right, I’m going to go and talk to the head teacher” So, I did.’ (Todd, 12)

Todd’s mother endorsed her son’s claim by saying that he can deflect criticism, including by teachers:

‘He is quick to shut down anyone, teachers included, if they try to make him feel bad or lazy if he’s struggling with something.’ (Todd’s mother)
Echoing Mckay’s (2014) work on the participation of children being driven by context and relationships, this show of agency by Todd suggests that the environment of school is perceived by him as a safe place where he can express his views. It may also reflect the quality of the relationship he has with a teacher at school who identified as ‘dyslexic’ (see section 6.3.1 above).

When I asked Adam for his advice for younger children with severe dyslexic difficulties, he was very clear in saying:

‘Speak out to people...If you need help, ask for help. If you feel scared, go tell someone. If you need help with something, put your hand up.’ (Adam, 12)

He conceded that he has only been able to do this for the last four years since his mother convinced him that people at school were listening to him and there to help. Adam described how his mother encouraged his agency and reassured him that he should speak up at school if he needed help:

‘If you speak up you’ll get help...And you’ll be able to...you’ll be able to do what other people are able to do.’ (Adam, 12)

Although he needed his mother’s encouragement, the response he had from school was clearly positive, suggesting once again that the school has created an atmosphere in which he feels comfortable to express his views and ask for help.

Others related their agency to particular teachers who they trust and with whom they felt able to be honest. Luhmann (1979), who has made an important contribution to trust theory, suggests that people decide who to trust or distrust based on experience and risk. He says that trust only exists when there is risk and if risk is not present, then there is confidence or anticipation rather than trust (Luhmann 2005). Ella told me that she is cautious about asking for help from teachers she did not know but was happy to share her difficulties with those she trusted. Gina said that she did not speak up until a particular SENCo made her realise she would be taken seriously and even now, at university, she is reticent about being assertive around lecturers she does not know very well.
Other acts of agency include Georgia asking her school in Year 9 for support which led to her having a screening test for dyslexia and receiving extra time in her GCSEs. Jack made a YouTube video, with his mother’s encouragement, in which he talks about his severe dyslexic difficulties, his eye condition and the possibility that he might also have dyspraxia and ADHD. He initially showed the video to his teacher and his class and then shared it with the rest of the teachers in the school. He is extremely proud of the video and enjoyed showing it to me. I recognise the act of making the video as agentic but also acknowledge the support of his mother in motivating him to make it and his teacher in encouraging him to share it.

However, some young people – Matthew, Arthur and Jack – described themselves as unable to speak up for themselves at school. Arthur was very clear that he spent the whole of his time at school trying to cover up his difficulties and therefore would not draw attention to himself by asking for help. Matthew’s reticence was due to embarrassment about his dyslexic difficulties, as well as shyness, while there is a sense that Jack has tried to speak up for himself but has been silenced. He recounted the times he has given his dyslexic difficulties as a reason for not being able to do something at school and his teachers have told him that he should not use dyslexia as an excuse. He spoke about how he does not say anything back to them but preferred to run away, explaining that he no longer speaks up for himself because ‘they will think that I’m not a nice person’.

Some participants described teachers as not listening to them when they do share something. Both Georgia and Jack talked about this in relation to being bullied and teachers not taking them seriously. Jack told me that he believed the teachers think he is a liar, while Georgia compared the response of teachers at school with those at college and university who ‘treat you more like a person’ who is entitled to an opinion. Trevor was emotional about the way he was not empowered to speak up for himself at school. He talked with regret about not standing up to teachers who accused him of not trying or being lazy. On one occasion when he spoke up by telling the teacher that he had tried his best, he was told not to answer back and the teacher threatened to call the head teacher. This incident has clearly had a big impact on Trevor because his mother also talked about it. When he looked back he was still shocked and angry.
about what happened. He wished he had said more to defend himself but understood that he was only young at the time:

‘If I could go back now and he said that to me, I would actually tell him to call her down so I could tell her what he’s just said to me. And I’m just shocked that he’d say something, I think I was just shocked like someone would actually say that to a little boy.’ (Trevor, 14)

Finally, I have observed some small acts of transgression (Foucault, 1997a) on the part of a few young people in their interactions and relationships with teachers. This is an important issue in maintaining or reclaiming agency in a school space. Trevor felt picked on in secondary school by a teacher who, he said, singled him out. In this case, he sometimes retaliated and was given regular detentions. On his last day at school before leaving to be home educated he was supposed to go for a detention but refused, saying ‘No, I’m not going. I’ve done more work than everybody here so why should I go?’ Ella and a friend, who were both supported by a teaching assistant in Science, had complained to the teacher that the teaching assistant did all the work for them in experiments. In doing this, Ella recognised an injustice and spoke up. Finally, as mentioned in the previous chapter, Toby, the quietest of all my participants, wrote on a test paper “I need a scribe” and did not attempt to answer the question. He had asked for help and none was forthcoming so he decided to make his point in his own way.

6.5 Discussion

The findings in this chapter demonstrate the lengths that parents, mostly mothers, are prepared to go to in order to advocate for their children and manage their emotions, including scaffolding them away from notions of deficit towards ideas of difference. Arguably, there is tension between these two roles – seeking a label and intervention through a system that treats learning difference as a deficit, while encouraging their children to move away from understanding their difficulties as individual shortfall. My findings also suggest that fulfilling these roles can be emotionally burdensome for some mothers in my research. Whilst noting that challenging school is not something that is open to everyone as it requires resources that not every family has, I suggest that parents have to negotiate a fine balance between prioritising their child’s
happiness in the future, which is often associated with educational success, and ensuring their happiness in the moment. Arguably, a strategy that combines challenging school with a concentrated effort to shield their children from any conflict with themselves and teachers, as well as building their child’s confidence through out-of-school and family activities and focusing on the things they excel in, is more likely to avoid the negative impact of emotional capital.

Young people’s academic comparisons and relationships with peers can also impact their identity and emotional wellbeing. While some participants cited positive experiences and talked about the comfort they find in being around others with similar difficulties, there were several who described incidents of peers being unkind and even bullying. It was suggested that this negative behaviour may reflect social and cultural norms, as well as the attitudes of teachers towards young people with severe dyslexic difficulties, which are internalised by peers. This ‘looking-glass self’ perspective can also be used to explain how young people with severe dyslexic difficulties can internalise the attitudes of teachers and evaluate and self-categorise themselves on this basis. Therefore, the importance of teachers presenting learning difference in a positive light cannot be overestimated. The findings also suggest that teacher recognition of young people’s difficulties and having a caring attitude towards them is important, in particular having at least one trusted adult at school. However, teachers may be more likely to be able to form this kind of relationship with young people when they have awareness and understanding of dyslexia, which we know from chapter 5 is very inconsistent.

Finally, in thinking about agency as personal, social and collective, I have found that young people are unlikely to show agency at school if they are trying to cover up their difficulties and not appear different, or if they do not trust their teachers. Greater openness and acceptance towards difference may go some way to resolving this.
Chapter 7. My findings: making and surviving a dyslexic identity

In this chapter I explore young people’s self-image – an image that has been developed in dialogue with the responses of others and larger socio-cultural structures (Mead, 1934). I also study the ‘feeling subject’ (Bericat, 2016, p. 495), exploring how feelings feature in participants’ accounts, suggesting that strong emotion marks important moments in the evolution of young people’s identities.

I will consider school as a space where difference is constructed and where some young people with severe dyslexic difficulties experience stigma and feel shame, and others manage to create their own narrative and experience feelings of pride. Clearly, it is my research that frames participants as young people with severe dyslexic difficulties and it is not necessarily the case that this is how they frame themselves. In fact, when I asked them to describe themselves to someone who does not know them, only a couple of young people (Gina and Todd) referred to their dyslexic difficulties. In telling their emotional stories I hope to capture the nuanced, complex and dynamic understandings of their emotional lives, which are not centred on their difficulties all of the time.

It is important to clarify the way that emotion is theorised within my social constructionist approach, rejecting the conceptualisation of emotions as simply physical states or natural objects (Doyle McCarthy, 1994) and viewing them instead as evolving from social relations and socio-cultural processes. The feelings discussed in this chapter are therefore grounded in the notion that most emotions arise from, and are contextualised by, social relations (Kemper, 1978) and are contingent on culture. As young people’s feelings of shame about their struggle to achieve literacy norms overwhelm, Goffman’s (1963) theories on stigma provide a focus for discussion.

Towards the end of the chapter, I examine how participants manage stigma and shore up their identity to protect themselves from prejudice and stereotyping. Finally, I engage with the notion of emotional labour (Hochschild, 1979), highlighting how the ableist environment of the school demands extra forms of emotional work from young people with severe dyslexic difficulties in order to explain their needs and requirements, as well as hide, downplay and negotiate their difficulties.
7.1 Where do participants position themselves in relation to their dyslexic difficulties?

Following in the sociological tradition of using metaphor as a way of enhancing meaning and gaining insight (Thomson and Østergaard, 2020), I asked young people to imagine dyslexia as some kind of ‘thing’ or ‘picture’ in their mind. Those who struggled with this concept were asked to think about what dyslexia would look like if it was an animal or a colour. Using metaphor in this way allowed me to deliberately seek to engage with unconscious as well as conscious sense making of the term ‘dyslexia’ and ‘dig underground into the cryptic life of things’ (Harman, 2005, p. 122). It worked well, with most participants responding enthusiastically. As a method this gives us insight into how young people make sense of their difficulties, allowing feelings and experiences to be condensed, focused and understood – the first stage in dealing with what might otherwise be an overwhelming sense of chaos, impossible to distinguish from the self.

The most common metaphor offered for dyslexia was a wall, although all three young people (Nina, Trevor and Pia) who responded in this way had different interpretations of the image. Figure 6 below shows Nina’s representation. She initially described dyslexia as something ‘chaotic’ and then added that it is ‘like a wall, like one side it’s like chaos and the other side it’s just blank’. She explained that the chaotic side is full of bright colours, shapes and words and the blank side represents how ‘it’s really hard to get stuff from my brain out’. She described the wall as what stops her from being able to make sense of the chaos. The motif of chaos reappears in Georgia’s metaphor for dyslexia as being like a scribble ball, an image of entanglement and confusion. She described it as:

‘Like rhymes and words and letters and all in a little screwed up ball……and all mixed up…And then sometimes when it bounces around in your head, you hear words that aren’t really words you understand but they’re still there.’ (Georgia, 19)
Pia also imagined dyslexia as a wall, yet elaborated the image to show that she sees it as an obstacle within a longer journey. She explained:

‘I just think if you have this wall you need to get over it. But it’s difficult…if you’re someone who’s lucky like me, maybe you have someone to help you up the wall.’ (Pia, 14)

She wrote on her diagram (see Figure 7 below) ‘no one asked for dyslexia’ and ‘help’, with one of the figures pushing the wall out of the way, acknowledging the support she received in primary school. However, unlike Nina, she showed that there is life for her on the other side of the wall, drawing things that make her happy like her hamster and dog and shouts ‘bye’ to dyslexia.
For Trevor, the wall represents a barrier to accessing ‘knowledge and everything you need and everything—everybody has’. His use of the words ‘everything’ and ‘everybody’ point to feelings of exclusion and the idea that the wall is stopping him from accessing vital information that everyone else has. He used the example of when he is texting his friends and is unable to spell what he calls ‘simple words’ because the wall is blocking him. The wall metaphor captures the way that he experiences dyslexia as a barrier that he is unable to overcome. He also likened dyslexia to:

‘a dangerous, big animal’ because ‘it’s big, it’s obnoxious, it’s very annoying and it’s just always in the way really, it’s just always there’ (Trevor, 14)

The animal is a more dynamic image than the wall, conjuring dyslexia as something that is not just overwhelming but frightening. Toby and Harvey also used metaphors that suggest a kind of jeopardy, as well as something that is holding them back. For Toby dyslexia was like a book with teeth ‘and when you go to open it it’ll just… snap’, while Harvey described it as a dark character that is ‘annoying’ and ‘just gets in your way and all… just makes your life harder’. 
Arthur described dyslexia as an immovable obstacle that must be worked around. He illustrated this by talking about a boulder on the top of a hill, which is blocking his way and he has to think creatively about how he is going to get around it. Arthur’s metaphor draws attention to the importance of his own acceptance of dyslexia and recognition that living with it is easier than constantly trying to ‘push it the other way’, referencing his reluctance to show any kind of difference when he was at school. It may be that he is able to portray it in this way because he is, for the first time, receiving support for his SEND at Further Education College. The following quote captures this moment in the formation of his identity as someone living with dyslexia:

‘I think it’s not a problem. It’s just an obstacle to get around. Because I mean it’s always going to be there. And honestly, you’re just trying to push it the other way. It’s a lot harder than working with it.’ (Arthur, 17)

It is notable that in all these discussions of dyslexia as a wall or obstacle, none of the participants directly suggested that these are barriers put in place by society. However, it is possible to discern signs of the emergence of a social model of disability in a couple of the older participants’ accounts. For example, when I described the social model of disability to Georgia, she said ‘I completely understand that. I’ve been making that fight for a while’ and quoted ‘you can’t teach a fish to climb a tree…’. Arthur cited the education system as being the problem:

‘But the problem is that our entire education system is structured in a way for the majority.’ (Arthur, 17)

Mathew’s description of dyslexia typically drew on both the positive and negative aspects, introducing the notion of balance, which is a common theme of his wider interview and operating as a key component of a hard-won sense of self:

‘…like half like rainy and thunder and lightning, and then sunny and nice on the other. Like there’s bad points and then… there’s good sides of it.’ (Matthew, 13)

Matthew also likened his experiences to those of a kangaroo ‘because it has its ups and downs’. He cited the ability to visualise things before he makes or builds them as an ability linked to his dyslexic differences and something which he embraced proudly. The negatives for him were that he felt behind at school.
When Jack was asked to choose an animal to describe dyslexia, he talked about a rabbit, which looks ‘the same as all the other rabbits but is maybe just a bit less intelligent’. This image allows us insight into the tension he feels between appearing similar to, yet being different from, his peers and contributes to his narrative of being less intelligent. This may relate to the frustration he experiences as a consequence of spending the majority of his time in the learning support unit; this will be explored further in the next section. His mother agreed that Jack lacks confidence in his abilities.

By inviting young people to characterise dyslexia as an object (animate and inanimate), it becomes possible to displace the idea of dyslexia as something that is simply contained within them. The metaphor method allows us to see the extent to which dyslexia is perceived and experienced as causing a deficit and as a challenge that they must learn to face and circumvent. The following few sections extend the idea of deficit to consider how young people make sense of, and manage, feelings of difference.

7.2 School as a space that constructs difference

Foucault (1977) makes the link between disciplinary space, institutions and systems of punishment. Campbell (2013) relates this to schools, where children are often organised according to ability, and those with SEND can sometimes be placed in a separate unit or even excluded from joining a particular school in the first place. This section firstly examines how parents perceive difference and then asks the question – how do young people position themselves in relation to deficit and difference?

Several parents wrote in their narratives about their child’s feelings of difference, very much describing this as a negative. This echoes the findings of an open-ended question in the online survey about the impact of dyslexia on their children, in which 56 parents (17.3%) said that their child felt stupid or different. Toby’s mother was worried about her son’s heightened awareness of his differences when he was in primary school, before his needs were identified and support provided. She explained that she wanted to alleviate his feelings of difference and set out to do this by challenging the school about his provision and eventually securing an EHCP. This is indicative of other parents who perceived difference to be something from which they wanted to defend their
child. However, rather than challenging their child’s school about the way they are made to feel different, parents put all their effort and resources into securing an assessment and label where possible, which arguably further demarcates their differences. This once again illustrates how disciplinary power operates to contain parental choice, making them “want” a model of provision that prioritises a label over one that values neurodiversity.

Turning now to how young people themselves talked about school as a space where they make sense of difference. The conversations that I conducted with young people were at home and, in this respect, I was able to engage with their identities in a rounded way, away from the pressures of school and academic work. However, school operates as a vital space within which ideas of disability and learning difficulty take on meaning and, therefore, I explored how participants felt about being in learning support groups or bottom sets, and even in different schools, and how this contributes to feelings of difference.

Most young people reflected on being separated from their peers to a lesser or greater extent because of their dyslexic difficulties, which seemed to reinforce their sense of difference and isolation. Trevor, who is now home-educated, left mainstream education altogether because of its effect on his emotional wellbeing. However, he spoke several times throughout the interview about missing his friends. Despite recognising that he no longer has ‘the constant worry of failing’, he expressed sadness that he does not see his friends as much:

‘...I miss my friends so much...I was away for so long, for a year, and I just miss them so much. And I said if I could go back to school, I would, but I would only go for half a day.’ (Trevor, 14)

Trevor introduced me to his pet snake and explained that it provides reassurance and comfort. This was an indication early in the interview of Trevor’s loneliness and isolation:

‘...you can talk to him, you can play with him, you can do whatever you want with him you know, and he’ll just sit there, wrap around your arm and just listen...Just like the feeling that something’s there so I can talk to him....’ (Trevor, 14)
Separation was also an issue for Toby whose parents chose for him to go to a different mainstream school to his primary school friends because it had a reputation for being good for those with dyslexic difficulties. He admitted to me that he does not have any friends at his new school and beyond playing online and having a WhatsApp group with his primary school friends, he does not see them anymore. Although he did not name his feelings about this situation, his tone of voice and facial expressions suggested to me that this is something that made him unhappy.

Others remained in their local state, mainstream school but were taught separately for some or all of their lessons, or were taken out of class for specialist interventions, emphasising their difference both to those around them and to themselves. When Arthur looked back on his time at school where he spent many of his lessons in a learning support class, he did not talk about missing friends, but told me about the lack of opportunity to make friends outside of this small group. Gina, on the other hand, seemed affronted by being put in the bottom set for English in Year 7 because ‘it made me feel stupid’. Jack illustrated the tension between the relief of having difference acknowledged and the frustrations that arose as a result. He spoke with sadness about missing his friends because he has most lessons in a learning support class but recognised that he needs to be in the smaller classes for educational reasons:

‘If I was allowed to change one thing in a school, I would say that the people with dyslexia, or any other disability, should be allowed with their friends in class. That’s all I ever want to be in my school, is be in the same lessons with my friends’. (Jack, 11)

Jack also talked about being treated differently to his peers, claiming that teachers talk to him as if he is ‘little-minded’ because he is in the learning support class. In this way, teachers’ attitudes towards him could be increasing his sense of otherness:

‘I get treated more like a 7-year-old to me and all my friends who are in the higher groups, they get treated more like a proper year 7.’ (Jack, 11)

From my discussion with Jack, I found a disconnect between his mother’s positivity about the learning support group and his uncertainty about where he wants to learn – the mainstream class or a smaller group. This contradiction between his and his mother’s account suggests that the struggle to forge a liveable identity for young
people may involve resistance to parental support and that the stigma associated with
difference is not simply escaped. This tension between inclusion and exclusion is also
demonstrated by Ella, who explained her uncertainty about where she fits best – the
small learning support group where she has many of her lessons, describing it as ‘more
comfy’, or the mainstream class where she struggles to get the support she needs. A
couple of older participants reflected on this issue, which is referred to in chapter 2 as
the dilemma of difference (Terzi, 2005). Gina discussed how inclusion does not always
mean equality and made the point that being treated the same as everyone else at
school is unhelpful and damaging when so-called inclusive classrooms do not
accommodate the needs of learners with dyslexic difficulties:

‘Because they treat everyone the same. And like it’s good everyone needs to be
treated the same. But there’s different ways around it, I think. And to someone
who’s always at a disadvantage, it’s not fair.’ (Gina, 18)

However, some young participants embraced difference and welcomed being
supported separately. When asked a question about the good things about dyslexia,
Adam immediately said ‘you’re different’. He seemed a little reticent to say it at first
but as soon as he did his mother backed him up, as if this was a well-rehearsed
discussion between them. Even Georgia corrected herself when she started describing
her difficulties as ‘faults’, before changing this to: ‘they are not really faults, they’re
just how it is’. Their decision to embrace their differences concurs with Thompson,
Bacon and Auburn’s research (2015), which suggests that some young people with
dyslexic difficulties identify as differently-abled and focus on strengths rather than
deficits. Gina reinforced this by confidently saying ‘…you’re no different. We just have
something a little bit extra. And everyone is unique in their own different ways’.

Being taken out of class was even viewed positively by a few participants. Pia, Seb and
their mother described how dyslexia was normalised in their primary school and they
felt valued. Consequently, being taken out of class regularly to go to the dyslexia unit
was not perceived as a negative. Pia had strong views on what can happen if young
people are made to feel different:

‘...maybe I'm wrong but if you treat someone like they're stupid because they
have dyslexia they're probably just going to keep acting like that... they just
won’t try. You need to push them and say, you can be just as good as everyone else.’ (Pia, 14)

Reflecting his ease with his dyslexic difficulties, Todd was also not concerned about being taken out of class. In fact, he said he prefers it when he is struggling and likes to return to the classroom when his problem has been resolved:

‘I like the teacher to read the question to show me like the first one or two, um, uh, how you do the answers...and working out and everything...And then...then I have a go.’ (Todd, 12)

If we follow Arthur’s insights as captured in his metaphor of dyslexia being like an obstacle, then we can see how acknowledging difference may be the necessary foundation for working with and around the challenges of dyslexia. Refusing to accept the obstacle (pushing it away) may make this process more drawn out. This resonates with Goffman’s (1963) work on stigma, in which he observes that the demanding work of covering up differences (because of the reaction of others) gets in the way of living with difference. Arthur acknowledged that he spent most of his school life trying to appear the same as everyone else but advised those in a similar position to him to follow their own path and not be concerned about difference:

Don’t follow what everyone else is doing. Because that’s something I tried in school. ... when you get to my age, you don’t care what everyone else is doing. You just care about what you’re doing.’ (Arthur, 17)

In thinking about learning to live with difference, it is important to recognise the influence of the people and institutions around the child. Chapter 6 illustrated the significance of relationships and discussed Cooley’s (1902) ‘looking-glass self’. It also recognised the importance of school context in young people’s decision to express agency. Young people may, therefore, find it challenging to move their thinking away from dyslexia as a deficit and difference as a negative until those around them, in particular schools, begin to normalise difference and value neurodiversity.

7.3 An exploration of shame and stigma

Both Foucault and Goffman were interested in stigma: Foucault (1978) in terms of
normalisation and bio-power and Goffman (1963) in terms of the way in which people interact within institutions and respond to stigma. Chapter 6 discusses how discourse and culturally derived norms of literacy can be reinforced by significant others and internalised by young people. This section focuses on the emotional toll of these interactions. Scheff (1990) conceptualises this in terms of feeling shame when social interactions and connections, which he termed ‘social bonds’, are threatened or broken. He describes how feelings of shame are often hidden or minimised, and manifest in terms of negative emotions. He distinguishes this from feelings of pride, when social bonds are unbroken, and emotions are often outwardly expressed and joyful. In this section I examine shame and its relationship with self-esteem, happiness and anger among young people with severe dyslexic difficulties. In the next section (7.4) I explore how some young people have managed to change the narrative of deficit and shame to one of pride about their difficulties.

In order to contextualise my discussion on emotions, 327 parents (80%) in the online survey described the impact of dyslexia on their child’s emotional wellbeing as severe or moderate (30.1% severe and 49.9% moderate); under a fifth (19.1%) described the impact as mild. As the table below shows, emotional impact was judged by parents to be greatest for those with severe, rather than moderate or mild dyslexic difficulties, justifying my decision to undertake research among those with the most severe difficulties.

Figure 8: Impact of dyslexia on emotional wellbeing

<table>
<thead>
<tr>
<th>Emotional impact</th>
<th>Severity of dyslexic difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Severe (122)</td>
</tr>
<tr>
<td>Severe impact</td>
<td>%</td>
</tr>
<tr>
<td>Moderate impact</td>
<td>40.2</td>
</tr>
<tr>
<td>Mild impact</td>
<td>49.2</td>
</tr>
<tr>
<td>Don’t know</td>
<td>10.7</td>
</tr>
</tbody>
</table>

Base: All answering
The findings of another question in the online survey also point to emotions being foremost in parents’ minds. When asked what five words described the negative effects of dyslexia on their children, almost all cited an aspect of their child’s emotional wellbeing (Figure 9). ‘Self-esteem’ was clearly seen as being the biggest issue and was mentioned 122 times. This was followed by ‘confidence’, which was mentioned 80 times and ‘frustration’ (64 mentions). ‘Anxiety’ was also regarded as a negative effect of dyslexia (mentioned 33 times).

Figure 9: Key words used by parents to describe the negative effects of dyslexia on their children

7.3.1 ‘What’s the point of me?’

The theme of self-esteem that emerges from the online survey findings is based on parents’ observations of the struggle and suffering of their children. The potentially all-encompassing nature of dyslexia in the context of school is summed up by Todd, who said ‘you struggle’ with ‘everything, really’, and Trevor who described it as ‘life-changing’. Parents used the term self-esteem to make sense of, and create meaning from, the emotional toll of dyslexia and their children’s shame-laden notions of self. Todd’s mother wrote about how her son used to describe himself, before he found out about dyslexia: ‘what’s the point of me?’ and ‘I’m rubbish at everything’. This focus on self-esteem reflects the way that the term has become part of popular culture (Dunne, 2008) and integral to individualistic discourses (Hewitt, 1998) common under neoliberal methods of governance (Cruikshank, 1996). It could be described as an
example of the ‘sociology of concept formation’ (Hacking, 1988, p. 54) in which terms such as self-esteem are socially formed:

‘We do not first form a new concept and then discover law-like regularities about the objects that fall under it. Items are grouped because we believe a classification helps with understanding, explaining, judging or predicting features of the items classified.’ (Hacking, 1988, p. 54)

As shown in chapter 3, the literature in this field is dominated by a psychological paradigm that conceptualises self-esteem in particular ways and uses quantitative methodologies both to measure it and to establish associations with dyslexia. My approach, rather than seeing self-esteem as a phenomenon that can be measured, starts from an interactionist position. It uses a constructionist epistemology to listen and understand how ideas of self-esteem are deployed by social actors and how it might help make sense of experience from their point of view.

Scheff describes how ‘low self-esteem might be conceptualised as a tendency towards endlessly recursive shame, spirals of potentially limitless intensity and duration” (1990, p. 93). In 1988 he wrote of an ‘interpersonal feeling trap’:

‘In Goffman’s analysis one becomes ashamed that the other is ashamed, who in turn becomes ashamed, which increases the first person's shame, and so on – an interpersonal feeling trap’ (Scheff, 1988, p. 396).

Scheff (1990) drew on the work of research psychoanalyst, Helen Lewis, (1971) who said that her patients never talked directly about shame but characterised their emotions as feeling stupid or as having low self-esteem. The accounts of young people and their parents reflect this finding.

‘Self-esteem’ was drawn on by Trevor and his mother to capture how his learning difficulties have impacted his wellbeing. Like other young people, Trevor emphasised his lack of self-worth with words like ‘stupid’ and ‘lazy’. As shown in chapter 6, these emotions arose from his interaction with others, in particular teachers, and their judgement of him. Trevor also compared himself academically to his peers, noting that his differences caused him to feel ‘stupid’. In the note he sent me in advance, Trevor wrote:
‘Other children can read aloud to the class and I feel stupid because I struggle to read to myself…I just can’t do it. I’m stupid.’ (Trevor, 14, advance note)

Indicating his despair, in the ‘I’ poem below Trevor said ‘had enough of’ three times in relation to his experience at school, culminating in him saying that he had actually had enough of everything by the time he left school to be home-educated:

‘I think I had enough of being told I can’t do something
I had enough of being told that I’ll fail
I started...
I just completely had enough of everything
I was just like
I can’t do this anymore’
(Trevor, 14 years)

As shown earlier, Trevor described dyslexia as ‘life-changing’. He presented his life as having been significantly altered by it, talked about it as ‘horrible’ and explained that it made every aspect of his life so much more difficult. His mother wrote that when he first left school to be home-educated ‘we just spent time together, building up his self-esteem and confidence’. As previously discussed in chapter 6, parents have an important role to play in protecting and increasing their child’s self-esteem. In providing a positive mirroring experience, she started Trevor on a path towards wellbeing that is scaffolded by a language of self and positive affect. Jack’s mother endorsed this strategy, prioritising building his self-esteem at home:

‘He needs encouragement and nurturing and he will flourish’ (Jack’s mother)

While Trevor, after two years of home education, was beginning to regain his self-belief, Harvey was still at school and in the midst of some very strong emotions. He raised the issue of lacking confidence in relation to his peers and said: ‘Like I don’t feel that I’m as good as the people that are also in my class’. Like Trevor’s mother, Harvey’s mother described her son as having very low self-esteem and as feeling ‘a total failure’, which she attributed to his dyslexic difficulties:

‘He is now in bottom sets mostly. Struggles badly with any exams. Very low self-esteem, very anxious. No bad behaviour as doesn’t really speak in class. Feels a total failure’. (Harvey’s mother)
In response to my request for participants to bring an object along to the interview that they felt represented them or their world, Harvey showed me a trophy that he received from his football club for ‘Clubman of the Year’. He described this as ‘It’s like I have the best attitude and I turned up to most games’. When I looked back on this and remembered what his mother said about his self-esteem and how he longed to find something that he perceives himself to be good at, I reflected on the despondent way in which he spoke about his award. I wondered if football is just another example of something that he perceives he is not good at and the award represents second best to being a good player. This made me feel sad and reminded me of the desperation I felt in the past when my son was so dismissive of my attempts to make him feel more positive about himself.

Harvey’s reaction to his difficulties was to see himself as the cause of the problem. This reflects the literature on attribution theory which suggests that when individuals make self- attributions and blame themselves for loss of status, they feel shame and embarrassment (Turner, 2009). Harvey suggested that it is his responsibility to adapt and try harder, no matter how that makes him feel. When I asked him how he feels about dyslexia he responded in a despairing voice: ‘I just felt like... just got to try and adapt with it and just like try and do my best’. This seemed to be a very typical response for Harvey, who appeared stoic, carrying the burden of dyslexia on his own shoulders and engaging in ‘tortured learning’ (Goffman, 1963, p. 21) – when stigmatised individuals devote large amounts of effort to mastering an activity that seems dauntingly difficult. He seemed to bear no grudge against his school for not supporting him until he was in Year 10. The way in which he was left so vulnerable made me feel angry towards the school on his and his mother’s behalf.

7.3.2 ‘You just sort of feel down’

Self-attribution and self-esteem are closely related to the concept of happiness. Turner suggests that when individuals make self-attributions, their self-esteem is undermined and they can become unhappy and even depressed (2009). Working with an interactionist model of self it is also possible to think about hope in terms of conceptualising resources that enable one to imagine a future beyond the obstacles
and anxieties that overwhelm the present. In this respect, reading the interviews for ‘hope’ has been a productive analytic strategy.

Some young people told me about their specific goals for when they leave education and were enthusiastic about the future. For example, Pia wants to be a biologist and traveller, Seb aspires to work in technical theatre, Todd wants to be a joiner, Adam a carpenter, Matthew a stuntman and Nina hopes to work with textiles. Jack told me that he has lots of ideas, including being a mechanic and Ella described four possible careers:

‘Like some vet work...Training animals like dog training...And then horse riding, because I’m really good at it...And maybe sometimes I might do something musical.’ (Ella, 12)

Reflecting Lithari’s (2018) research suggesting that when young people with dyslexia leave school they can start to repair their ‘fractured academic identities’, Arthur, Georgia and Gina also seemed optimistic about their futures. This is in sharp contrast to how Arthur related the story of his time at school and how the attitudes of teachers towards him made him very unhappy:

‘As a kid you don’t really get depressed. You just sort of feel down instead and just like believe in what they tell you.’ (Arthur, 17)

He told me that school made him ‘upset’, ‘down’ and made him talk of killing himself. His mother also described him as becoming more and more withdrawn at secondary school and spoke of ‘losing’ him. When she briefly joined us in the interview, she was vocal about how badly his school had let him down. Arthur mirrored this, suggesting that he may be beginning to look beyond himself to attribute blame and understand his experiences through the lens of the social model of disability rather than his own deficit:

‘Now I think back and I think about how many other people’s lives have, well not been ruined, but have hit this point and then yeah...because I know there are some people that are worse than me.’ (Arthur, 17)

In the interview Arthur presented as having moved on from the emotional turmoil described above and through the metaphor work I did with him (see section 7.1 above)
I suggested that he was beginning to accept his differences. The ‘I’ poem below, however, suggests that his feelings could be closer to resignation than acceptance:

‘I just don’t care.
I don’t see the point in caring
I’ve always had it
I’m always going to have it.’
(Arthur, 17)

I came away from my interviews with Harvey and Trevor feeling very sad. They are both in their mid-teens and approaching the age when they were starting to consider a future beyond school. However, they both seemed unhappy and lacking in hope. Trevor’s mother went as far as to say that her son suffers from ‘mental health problems because of school ignorance to dyslexia’ and I was struck by how distressed Trevor was about not being able to go to school with his friends. He was also regretful and upset about not applying to go to an engineering school like his friend and talked about dyslexia in terms of it not being ‘something that you can cure…it’s there for your life’. He described why he is now home-educated:

‘I couldn’t get out of bed. I didn’t want to face another day of failing and getting into trouble. I just wanted to stay at home, with my mum, the one person that understands and supports me.’ (Trevor, 14, advance note)

He is resigned to the fact that he will at some point have to go back to school to do his GCSEs but seemed very worried about the impact it may have on him.

While Trevor was particularly open about his experiences at school and his feelings, Harvey on the other hand simply talked about feeling ‘upset’ when he gets bad results or struggles at school. He also said that school makes him ‘miserable’. However, his mother’s narrative and our conversation after Harvey’s interview suggested that he is actually very pessimistic and despondent. She described him as feeling like ‘a failure as he hasn’t found his talent’.

7.3.3 ‘I’m angry with them, because they don’t help me’

Scheff combines Goffman’s (1963) social analysis of shame with Lewis's psychological analysis of shame and anger to demonstrate ‘the extraordinary power of the deference-emotion system’ (1988, p. 396). Lewis suggests that shame can lead to
anger and destroy the social bonds with others and ourselves, leading to further shame.

Parents wrote in both the online survey and their narratives about the anger and frustration felt by their children at school, and with their dyslexic difficulties. A couple of young people said they have become angry and disruptive in class, with Trevor, for example, talking about getting detentions. However, the incidents they talked about seemed to me to be fairly minor and they were more likely to turn their anger inwards. This resonates with the findings of a study discussed in chapter 3 focusing on those who have severe dyslexic difficulties (Dahle, Knivsberg & Andreassen, 2011), which found that anti-social and violent behaviour was less significant than internalised disorders.

Some young people looked for external figures to be angry and frustrated with, such as teachers who do not support them. Turner (2009) describes this as external attributions or blaming others for their feelings of shame. Kemper and Collins (1990) also suggest that anger occurs when individuals want to compel others to show them deference. Todd and Adam reflected this idea, with Todd suggesting in the ‘I’ poem below that what he really wanted was his teacher’s help:

> ‘I get a bit angry
> I feel angry
> I can’t do it
> I’m angry with them, because they don’t help me.’
> (Todd, 12)

Several young people who attributed their difficulties to themselves turned their frustration inwards. Toby’s mother reported that when she tried to help her son with his homework, he ‘cried tears of frustration in response to his difficulty and Harvey talked about getting annoyed and angry with himself:

> ‘I think I get annoyed when I don’t like know what to do or something...I’ll get angry when I see... or upset when I get like bad results and stuff.’ (Harvey, 16)

On the other hand, Gina identified feeling frustrated with both herself and others. When we met, she was in the first year of a Performing Arts degree at university.
Unlike other young people she wove dyslexia into our discussion very early on in the interview and seemed self-aware and analytical in her approach to our discussion. Gina described the frustration she feels when she forgets things or struggles to spell and admitted that she can be ‘temperamental’. She also talked about feeling stressed and upset when others undermine or patronise her, or show a lack of understanding or empathy. She spoke of dyslexia ‘defeating’ her, as though it was an object or something external to herself, rather than part of who she is. The language she used to describe her emotions – ‘upset’, ‘burst into tears’, ‘low mood because of my dyslexia’, ‘screaming matches’, ‘tantrums, ‘meltdown’, and ‘taken its toll’ – suggest that she is deeply frustrated by her difficulties and can become very emotional when she is challenged.

7.3.4 Summary of section
This section conceptualises young people’s emotions in terms of shame and its relationship with self-esteem, happiness and anger. Whilst it reports on some very troubling feelings relating to shame-laden notions of self, feeling like a failure and frustration with external figures as well as with themselves, some young people have managed to maintain a sense of hope about the future.

7.4 An exploration of pride
As mentioned earlier in this chapter, when social bonds are not broken (Scheff, 1990), individuals can experience feelings of pride. In this section, I firstly consider the role of dyslexia assessments and seek to understand how the label ‘dyslexia’ can instil feelings of pride in some young people. I then examine how some participants have found comfort in the growing discourse about the positives of dyslexia and draw together participants’ positive narratives of competence.

7.4.1 ‘He finally understood that he was not “thick or stupid”’
As chapter 3 demonstrates, in the current SEND system, a label is often required before support can be put in place and for this reason many of the parents in this study have worked hard to acquire one for their children. Harvey illustrated this, saying that his teachers have become more understanding and have provided more support since he was assessed as having severe dyslexic difficulties:
‘For me I would say the teachers are more like aware that, like how I work and stuff. So I think they know that they’re going to have to try and help me.’
(Harvey, 16)

In this section I propose that there may be value in the identification of dyslexia in terms of enabling a separation of self from the experience of chaos that young people may feel. However, it is important to make the distinction between having a label and having an understanding of the difficulties associated with dyslexia, which arguably may lead to acceptance. Toby was aware that his difficulties related to dyslexia but showed very little understanding of what that means in practice, perhaps holding him back from developing an identity independent of his dyslexic difficulties.

Although Matthew’s mother expressed caution about identification, saying that ‘the testing and results impacted his confidence’ and Ella’s mother talked about how her daughter did not initially cope well with diagnosis, most parents were positive about it. Reflecting Toby’s mother’s comments in section 7.2, some parents described how they wanted their children to know they were dyslexic because having undefined difficulties was affecting their confidence and self-esteem. Trevor’s mother illustrates this:

‘It was important to me that he understood why he found reading and writing difficult, it wasn’t because he was stupid (which is what he started to believe)’
(Trevor’s mother)

Todd’s mother talked about them both crying tears of relief when he received his diagnosis:

‘There were tears of utter relief all round, not least from Todd who finally understood that he was not “thick or stupid” as he so often referred to himself, but actually that his brain has to work a whole lot harder and he just sees things differently’
(Todd’s mother)

Having received the label and some relatively good support for his difficulties, Todd’s mother described how he now wears his dyslexia like a ‘badge of pride’.

Several young people referred to the suggestion by sections of the scientific community that dyslexia is caused by differences in the brain. The possibility of being able to account for their difficulties in this way seemed to bring an element of relief. It is possible that a discourse of biological difference operates as a positive resource for
Harvey, a justification, or an explanation for his difficulties, with implications for how he feels about himself:

‘Well, it’s the brains are different to other people that don’t have it. Like the way you interpret stuff might be different, or the way you work...’. (Harvey, 16)

Gina talked about her diagnosis as finding an answer to something that she did not know was a problem, implying something of the iterative process through which something becomes an issue. She told me that she believes that finding out that she was dyslexic when she was young helped her to accept it and move forwards with it as part of her:

‘Okay, let’s just get on.” It doesn’t make me any different to who I was 30 seconds ago before I got told. It just means that I've got an answer.’ (Gina, 18)

As previously mentioned, Gina was the only young person who immediately mentioned dyslexia at the beginning of the interview and ‘dyslexic’ was the first thing she said when asked to describe herself. When I asked her if her dyslexic difficulties would always be at the forefront of a description about herself, she said that it would definitely be one of the words she would use:

‘Um...Because I don’t see any point in hiding it because it’s, it’s who I am. And if they can’t accept that, well, they need to accept it basically’ (Gina, 18)

Gina encouraged younger people not to hide their difficulties and talked about ‘wearing it on her sleeve’:

‘Show it how it is. It makes people more aware as well. Because a lot of people still don’t know or understand it’. (Gina, 18)

She contrasted this with some of her peers at school and some of her friends at university who have dyslexic difficulties but do not talk about it:

‘Boys just try to be all hard-core and ignore it I reckon or um...yeah... I think in some ways, I'm very much an exception to the rule.’ (Gina, 18)

However, after initially thinking that Gina’s openness was about her choosing to be honest, I started to wonder if it might be a strategy to seize control of the conversation
and stop people saying something derogatory to her, or bullying her, about her difficulties:

‘Because if you try and hide it people will just take the mickey out of your spelling and not know why, whereas if people know, they do it in a slightly different way. I mean sometimes they do it in the same way and it does get annoying.’ (Gina, 18)

Gina told me that this approach generally disarms people and makes them more accepting and, if they do decide to make a joke of it, they are less likely to be offensive.

In Goffman’s (1963) terms, Gina’s strategy could be seen as an attempt to move her discreditable attribute to a discredited one. He also writes of disclosure etiquette (1963), which, applied to Gina, might mean that admitting to dyslexic difficulties in a matter-of-fact way would encourage the people she has told to be accepting and not to stigmatise her.

7.4.2 Positive narratives of competence
Reflecting the growing movement suggesting that people with dyslexia may be particularly able in other areas (eg. Made by Dyslexia, 2021), several young people discussed the skills they have that they attribute to dyslexia. A few young people told me that people with dyslexic difficulties can be good at finding creative ways to problem-solve. Matthew talked about his ‘ability to see patterns, how things fit together’ which he uses in design and Nina mentioned her ability to see the ‘bigger picture’. Gina referred to the ‘dyslexic brain’ and her ability to make connections:

‘...everyone’s brains will go to this and mine will jump all the way over there... And then I’ll do, well this connects to that which connects to that, which connects to that, which connects back.’ (Gina, 18)

Similarly, Todd and Ella associated dyslexia with being good at designing things and solving puzzles. After watching the BDA video in the interview, even Trevor, who was extremely negative about the impact of his dyslexic difficulties on him, remembered that he is good at working out the answers to puzzles and that ‘once I put up a tent, I can always remember how to do it’. He linked these skills with his dyslexic difficulties.

Ella talked about people with dyslexia as high achievers. In saying this she seemed to
be referring to the determination and resilience that some successful people with dyslexia have, as well as her own optimism about her future.

‘...they can achieve things that people might think is impossible...like some scientist and athletes and stuff’. (Ella, 12)

As mentioned in chapter 3, the scientific basis for these claims is contested (Elliott and Grigorenko, 2014). Over time, however, these strengths have become part of a language surrounding the classification ‘dyslexia’, demonstrating that categories are not ‘definite classes defined by definite properties’ (Hacking, 1985). Hacking (2004) relates this to a ‘looping effect’ in which the commonalities associated with people defined as having a classification, for example, problem-solving or creativity and dyslexia, causes some to change their behaviour, which in turn can lead to the definition of the classification changing.

However, this is not the only language in circulation, nor is it the only way that the young people accounted for their experience. For example, Seb strongly disagreed with the view that people with dyslexic difficulties are often creative and said that he does not understand ‘the whole kind of exclusive club’:

‘Some people say it comes with extra creativity. Okay, I think I've only had the creativity that I have inside myself... I think generally my creativity is the same as or less than other people... I never was like particularly worried about having the ability to look at shapes from different angles in my head...’ (Seb, 14)

Seb’s cynicism may come from not wanting to be grouped with other people just because he has dyslexic difficulties or from a place of having received good support and now feeling relatively unaffected by his experiences. However, the narrative of dyslexia advantage may be unhelpful for other reasons. For example, for Harvey, it simply reminds him that he has not found a talent yet and increases his sense of shame and embarrassment: ‘He always says, why haven’t I got a talent, maybe artistic?’ (Harvey’s mother).

Some young people expressed positive narratives of competence through the object metaphor work they did for me. Although not every participant brought an object to discuss, as a tool, it has helped me to better understand how they make and survive a
dyslexic identity and reminded me that their emotional lives are not always centred on their difficulties. It was immediately obvious that most young people wanted to present a positive impression of themselves at the beginning of the interview, or what Goffman (1959) would describe as the ‘front stage’. For Georgia this was her university art book, which represented something she loves and is good at. I spent at least 10 minutes of the interview flicking through this with her, while she talked enthusiastically about her work. Gina and Arthur both brought their mobile phones. Gina did so because it contains videos of her dance performances, which ‘in essence... make up who I am these days’, reflecting how strongly she identifies with her Performing Arts degree at university.

Rather than bringing an object that represented him or his world, Matthew preferred to show me his free-running talents as soon as I arrived at his home. His parents clearly encourage his interest and his achievements appear to give him a sense of pride. Sid, who was 10 when I met him, showed me the cartoons he draws and excitably talked at length about each of the characters. His mother was very encouraging about his drawings and was keen to tell me how good he is at it; she has even made wrapping paper and a toy figure from his designs (Figure 10), which she enjoyed showing me. As someone who spent several years trying to convince my son of his talents, her efforts resonated with me strongly.

*Figure 10: Sid’s toy figure, cartoons and wrapping paper*
Similarly, Adam brought his pen-knife along to the interview which he uses to do woodwork with his grandad, something that made him feel proud and gave him a sense of achievement. Jack showed me a picture of a parrot that he painted in Year 6, which is on the wall in the living room. The picture seemed important to him because he saw it as proof that he is able to concentrate in the right environment, saying ‘...I can focus a lot – by myself, not around other people’.

7.4.3 Summary of section
This section has described how identification, and a focus on the advantages associated with dyslexia, can restore some young people’s confidence and help them to move away from a narrative of shame towards feelings of pride. By highlighting young people’s positive accounts of competence, it has also served as a reminder that their emotional lives are not always concentrated on their difficulties.

7.5 Managing the stigma associated with dyslexia
As discussed in chapter 3, when young people find that they are perceived by others to have a spoiled identity (Goffman, 1963), they are faced with the tasks of impression management and information control. Goffman characterises this as:

‘...to display or not to display; to tell or not to tell; to let on or not let on; to lie or not to lie; and in each case, to whom, how, when, and where.’ (Goffman, 1963, p. 57).

Literacy difficulties and dyslexia are only visible to other people when a child or young person is required to read or write, which mostly happens in the context of school. This means that in other environments such as the playground, clubs after school and at home, they may not be stigmatised.

In using the work of Goffman (1963), I am aware of critiques. These include the work of Hunt (1966) who argues that the stigma of poor literacy is being theorised from the point of view of so-called ‘normals’ and does not acknowledge that it is a social problem, rather than a result of individual impairment. Tyler goes further and describes Goffman’s (1963) definition of stigma as passive, highlighting the way in which he ‘diverts attention away from those doing the stigmatising’ (2020, p. 100) and from power relations. The following analysis does indeed focus on how young people
manage stigma but this is because it is important to highlight the extent of the emotional work they have to do and is not without an understanding that relations of power are an integral component of social norms.

Goffman’s (1959) approach uses dramaturgy, likening social life to the theatre and performance as though on a stage. In terms of stigma this involves playing a part, demanding different types of concealment and movement between ‘front’ and ‘back stage’ (Goffman, 1959). We may think of school as a front stage where young people must conceal their emotions and home as a back-stage where they can express their unhappiness, frustration or anger. Goffman states that ‘because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent’ (1963, p. 95). He also writes about the price of disclosure or concealment. Indeed, the young people in my research have developed a variety of strategies to help them cope with the situation they find themselves in at school due to their dyslexic difficulties. These range from trying to keep their difficulties a complete secret to deciding not to ‘pass’ and providing complete information. Young people with severe dyslexic difficulties have to make decisions regarding when, where and how, if at all, to disclose their difficulties and/or their label of dyslexia. These decisions will be made according to the reactions of those around them, as well as the environment they are in. It should be remembered that having severe dyslexic difficulties is not easy to conceal in the context of school, while it may be possible to hide the label of dyslexia.

Reflecting Luhmann’s (1979) theory of risk assessment and the findings discussed in section 6.4 about trust, Ella told me that she considered carefully who she should and should not disclose her difficulties to. She described how she is open with her friends but is cautious around people she knows less well. She identified herself as reticent about speaking up in the mainstream class if she needs help and tends to wait until the end of lessons to talk to the teacher, when all of her peers have left the room. She explained this to me as a way of protecting herself from the people she does not know and the potential reaction they could have towards her:
‘Because sometimes, I don’t want people to know... So I don’t really... because I don’t know them that well... Well, I don’t mind them knowing... but it depends, like what they would do if they were bullying me because of it.’ (Ella)

Ella also told me that she sometimes pretends she can do something when she actually cannot. In order to do this, she hides her work from other people.

Embarassment about the impact of dyslexia on his schoolwork led Matthew to mask his difficulties, particularly in front of his peers. He explained that even though they do not say anything disparaging to him, just them knowing that he cannot do something stops him putting his hand up in class and seemed to cause him concern. Although he chose to hide his difficulties and not disclose, he knew that he should be more open:

‘Like sometimes I don’t want to put my hand up because I’m embarrassed but... I shouldn’t be. I shouldn’t be embarrassed of it.’ (Matthew, 13)

Arthur described schools as reinforcing homogeneity, referring to how this makes it easier for them to operate and led to him masking his difficulties for fear of being recognised as different. He clarified that he does not regret his strategy of masking but advised other young people to accept their differences and not be afraid to be themselves.

‘I mean I went through the entire education system... because I was afraid if I speak, if I spoke up and asked for something, I would be different from everyone else.’ (Arthur, 17)

After watching the BDA video, which talks about how some people hide their dyslexia, Jack spontaneously told me that he always tries to hide his own difficulties. He explained that he does not tell his friends about his dyslexia and has an interesting approach to concealing his difficulties which involves telling his peers that he is ‘dumb’, then rushing through a task so that they end up thinking he is clever:

‘And when I say I’m dumb, I quickly rush through it, ‘cos it makes everyone else think ‘he’s dumb, he must be so smart’. (Jack, 11)

In this case, Jack must believe that being ‘dumb’ is somehow more desirable than having literacy difficulties. Goffman (1963) would describe this as passing the indicators of his stigmatised difference (dyslexic difficulties) as signs of another, less
stigmatised, attribute. Arguably, Trevor could also be said to have done this when in secondary school he preferred to behave badly and get detention rather than make his dyslexic difficulties visible.

Very early on in the interview Jack also told me ‘I struggle with reading and writing but everything else I am brilliant at, like maths, art’. Over-compensating for his difficulties by telling people how good he is at other things reminded me of my own son. Unfortunately for Jack, this approach led to his friends calling him a show-off:

‘Some of my friends tell me like I show off a little bit too. And they don’t really like that so...I try not to show off but when, say, if there’s a sport I’m really good at, like long jump, and I get the longest, then they will probably be saying you are a show-off and stuff’. (Jack, 11)

7.6 ‘I sit up, I lie back down, I fall asleep’: counting the emotional toll

There was a theme of high levels of fatigue in several participants’ accounts, reflected in the quote from Jack which forms the title of this section, in which he describes his tiredness at school. Jack twice spoke about falling asleep in class and Ella told me that school makes her ‘just like so tired and I want to go home and sleep’. Todd’s mother told me that her son still finds it difficult to understand why ‘his brain is so tired, even when he has much more sleep than his friends’ and Harvey’s mother worried that his school did not understand the impact of his dyslexic difficulties and thought she was a bad parent for letting him stay up late:

‘But he still comes home absolutely exhausted. Normally he’d be asleep by now. He comes in at 4pm and he’ll sleep until 5pm. I think it totally takes it out of him at school because he does try’. (Harvey’s mother)

Some mothers – Adam and Gina’s – directly attributed their children’s tiredness to having to work so hard at school to counteract their difficulties and engage in ‘tortured learning’ (Goffman, 1963, p. 21):

‘Gina always had a regular bedtime (around 7 – 7:30pm) on a school night. I think that maybe just the amount of extra work she had to do contributed to her being tired’ (Gina’s mother)
Arguably, the fatigue felt by some participants may not simply be an outcome of the additional academic load but could also be accounted for by the extra emotional work they have to do in the environment of school. Hochschild’s (1983) concept of emotional labour, as discussed in chapter 3, provides a framework for understanding the impact of the emotional regulation required at school and the effort that young people have to put in to negotiate and, in many cases, conceal their differences, as well as realise the norms of the institution. Ashforth and Humphrey (1993) describe this as part of engaging in impression management (Goffman, 1961) and suggest that Hochschild's (1983) concept of emotional labour draws significantly on Goffman’s dramaturgical perspective (Goffman, 1959).

Research about emotional labour generally takes place in the workplace among adults, often in caring professions. A study by Wilton (2008) suggests that when workers with disabilities are in a non-accommodating environment, described as when the organisation is set up in terms of ableist norms, they are forced to use additional emotional energy to fit in with the emotional culture and hide their differences. Drawing on the examples in the previous section about how my young participants manage their stigma at school and the findings from this section on fatigue and tortured learning, arguably this scenario can be equally applied to a school setting and young people with severe dyslexic difficulties.

### 7.7 Discussion

The multiple methods employed in my work with young people have allowed me to capture the complicated feelings associated with living with dyslexia and explore how some feel shame and experience stigma and others develop a sense of pride. In considering these concepts it is important to remember that young people’s feelings are not binary and that their actual emotions probably lie somewhere between the two. Indeed, in situations out-of-school, dyslexia may not even form part of their identity.

As my metaphor work with young people shows, dyslexic difficulties are often perceived as hostile and as an obstacle that is experienced as a deficit and as a challenge. Learning to live with dyslexic difficulties and acknowledging difference may
be an important basis for avoiding associated challenges. I recognise, however, that young people cannot do this alone and need the adults and institutions around them to normalise and value the differences they experience. The accounts shared in this chapter suggest that young people have times when they are defined by their difficulties and that these times are characterised by some profoundly troubling feelings which are theorised through their experiences of stigma. Shame-laden notions of feeling ‘stupid’ and ‘dumb’, words borrowed from the judgements of teachers and peers and conceptualised by parents through the discourse of self-esteem, plus emotions of sadness and anger/frustration, were difficult to hear. I found myself being very concerned for those who were noticeably lacking in hope, particularly Trevor and Harvey, and was struck by the extra emotional work young people find themselves doing at school in terms of emotional regulation, stigma management and realising the norms of the institution. However, the stories of other young people suggest that moments of despair can pass and some participants communicated how they made sense of and even enjoyed their dyslexic identities, with several participants positively associating some of the skills they have with neurodiversity. This narrative of pride and hope occurred when needs were met and young people considered school a safe space to express difference, or when they left school and they felt enabled to experience themselves as once again competent.

This chapter set out to understand young people’s self-image in relation to dyslexia. All of the young people in this study were identified by their parents as having severe dyslexic difficulties and many found this useful in some way, for example allowing them to gain some understanding of experiences previously felt to be chaotic and overwhelming. Yet the label itself was not necessarily empowering unless it gave rise to a change in experience, which in turn might open up identities beyond dyslexia. Of the young people in the research, only Pia and Seb could, with any certainty, be said to have forged identities beyond their dyslexic difficulties. Arguably this is because their primary school provision was so effective that they no longer thought of themselves as dyslexic. Todd, and to a certain extent Adam, are really the only other young people still in mainstream school who have developed a sense of pride about their difficulties. For the others, it is only when they leave school altogether or attend specialist
provision that they begin to experience an identity beyond their dyslexic difficulties.
Chapter 8. Discussion

In the following sections I draw together and make sense of the findings described in the previous chapters. Focusing firstly on the young people at the centre of my research, in keeping with the ecological approach (Bronfenbrenner, 1979) that opens this thesis, I then move outwards to wider structural and social processes. My interpretation of the findings and evaluation of their significance is guided by my three research questions, as detailed in section 4.4.1, and shaped by my dual role as a researcher and mother of a young person with similar difficulties to the young people participating in my research.

8.1 Understanding the young people at the heart of my research

The young people in my research were all engaged in building increasingly complex accounts of self as they lived with the experience of dyslexia and storied themselves through their teenage years. One young man in particular, Trevor, articulated his story with clarity, honesty and emotion in a note he sent me in advance of our meeting. Unsure how to include his words in my thesis, which so neatly encapsulate many of the themes of my research, I have edited them into an ‘I’ poem which is shown below. In it he plots his emotional story, recounting his experience of teachers, in particular during SATs, how he feels different to his peers because of his literacy difficulties and how he misses his friends, as well as talking candidly about his mental health and wanting to stay at home with his mother. Using an ‘I’ poem in this way highlights Trevor’s journey through school and into home-education, emphasising his despair in the first four verses and suggesting in the final verse that his struggles are not over:

I hated school. They just thought
I was lazy
I just gave up trying because they gave up on me
I’m going to fail anyway.

I knew
I wouldn’t do well
I tried my best
I was in a room with 2 adults
I was under so much pressure
I wanted to cry
I loved playtime
I told him
I did but he just shook his head
I wanted to cry.

I’m dyslexic you see
I always felt like the teachers either didn’t believe in dyslexia or didn’t understand it
I don’t think they wanted to
I’m different
I look at my friends
I wish
I could write like that
I feel stupid
I struggle to read to myself.

I just can’t do it
I’m stupid
I get stressed and angry
I suffer anxiety and panic attacks
I started refusing to go to school
I couldn’t get out of bed
I didn’t want to face another day of failing
I just wanted to stay at home with my mum.

I do now
I stay at home with my mum
I’m home schooled
I miss my friends
I’m much happier
I still get anxious when
I leave the house but
I’ve not got the constant worry of failing anymore.
(Trevor, advance note)

My research is situated in an education system where the dominant discourse is the medical model of disability, which locates children’s differences within individual pathology and prioritises treatment of the ‘deficit’, and where young people have to contend with historically rooted discursive formations that frame literacy skills as something to aspire. Only a few of my older participants, who were in further or higher education, had started to consider the possibility that their difficulties may have been
caused by their school’s lack of support and accommodations rather than by their own deficit.

My data was infused with emotion, including a sense of shame arising from difficulties in accessing learning and from the stigma of struggling with literacy. The accounts of parents in section 7.3.1 provide a powerful sense of the emotional toll of literacy difficulties, revealing young people’s shame-laden use of words such as ‘stupid’ and ‘dumb’ and their experiences of sadness, depression, anger and frustration. Sometimes parents articulated these emotions through psychological concepts such as low self-esteem, in a way that was familiar and affective as the mother of a child with similar difficulties. The narratives of those who were in the midst of unhappiness, in particular those who lacked hope, such as Harry and Trevor, were particularly distressing. It is important to note, however, that my findings do not indicate that the label ‘dyslexia’ itself is stigmatised (see also Riddick, 2000), rather it is the experience of literacy difficulties which brings young people into conflict with a social valuing of competence in reading and writing. Indeed, for some young people the ‘dyslexic’ label was part of a process of developing feelings of pride, giving them greater understanding and comfort and allowing them to acknowledge that they may be particularly able in other areas.

My research suggests that, in the context of school, young people experience a tension between being marked out as different (which may include being separated from peers) and the relief of having difficulties acknowledged, often in the form of a label. I argue that the way in which young people conceptualise difference may be consequential for how they build an identity and evaluate themselves. In chapter 7, I use the example of Arthur to suggest that acknowledging difference, or at least being resigned to it, may be necessary in order to work with and around the challenges of dyslexia. I suggest that, to facilitate this, the people and institutions around young people must be accepting of, and value, difference. My findings suggest that a whole-school ethos of inclusivity and neurodiversity, where difference is recognised and appreciated, helps young people to flourish without stigma. However, my research shows that unfortunately most young people attended schools where difference was
not valued and they had to engage in demanding work to cover up their differences, including information control, impression management, passing and disclosure etiquette. In section 7.6, I draw on the concept of ‘emotional labour’ (Hochschild, 1979) to describe this extra work, which takes place on top of the additional academic load they have to endure and have related it to the high levels of fatigue experienced by some young people. Whilst many of the parents in my research were actively involved in encouraging their children to value their differences, many still perceived it in the context of school as something from which they wanted to defend their children. Their strategy for protecting them – seeking a label and intervention – arguably further exposes their children’s difficulties and demarcates them as different at school, which puts them in conflict with their child’s desire to appear the same as their peers.

Throughout my research I have listened attentively to young people’s emotional stories, which range from struggle and suffering to moving on from the experience of chaos to finding pleasure in their differences. Paying attention to the lived experience of these young people has produced greater understanding of how it may be possible to change the narrative of deficit and shame to one of pride. I have done this by looking beyond the young people themselves to the institutions and discourses around them and to the social interaction they have with their parents, peers and teachers.

8.2 Taking a broader perspective to understand young people’s emotional wellbeing

Like many of the parents in my research, when my sons were young, I perceived effective intervention alone to be the key to unlocking positive emotional wellbeing. Writing this at the end of my PhD, I now have a more nuanced understanding that while early, effective provision is a critical foundation for a positive sense of self, other factors are also important. Employing a theoretical approach based on pluralism and drawing on three different bodies of theory (Foucault, Bourdieu and Symbolic Interactionism), scaffolded by Bronfenbrenner’s Ecological Model (1979), has enabled me to think critically about the lived experience of young people with severe dyslexic difficulties and draw attention to the complex intermeshing of the self with
institutional, cultural and interactional regimes. Foucault’s (1970) ideas on the historical and cultural discourses that give rise to classifications, which in turn shape subjectivities, has been an essential part of this research, discouraging me from legitimising the status quo and conducting research that is pre-determined by taken for granted categories or labels. This approach resonates with a growing understanding of how dyslexia has been constructed through a medical model of disability and by an approach to education that venerates and endorses literacy as a social norm (Donald, 1983). By considering the history of the term dyslexia, I have understood that it is not characterised by a universally agreed definition or means of diagnosis, yet have at the same time been mindful of how the term is taken up in creative ways by young people. Understanding dyslexia and disability as social constructs, while also taking seriously how differences in literacy are experienced, is a challenging stance that has not been easy in this research. However, it has been productive in terms of opening a space for witnessing and thinking critically about lived experience. Translating these insights back into a policy and practice field is far from easy, however, in the sections below I outline the key insights that arise from this conceptual position.

8.2.1 The importance of timely and effective intervention

I have spent a good deal of time in this thesis writing about provision for young people with severe dyslexic difficulties, both in terms of distribution and effectiveness and how it might interact with emotional wellbeing. In thinking about this I have reflected on the dissonance between government policy and government discourse on dyslexia (Ross, 2017). On the one hand, government policy endorses a medical model of disability, which favours interventions aimed at remediating individual deficit. This is the type of provision that parents are made to “want”, which some teachers perceive as beyond their remit and is arguably an approach that is more vulnerable to budget cuts than one that addresses the needs of all learners within the classroom. Government discourse, on the other hand, suggests something more akin to the social model (Ross, 2017) and focuses on dyslexic difficulties being addressed through good mainstream teaching. This tension is intensified in schools by a lack of investment, which leads to intervention often becoming a scarce resource, and many teachers not
being equipped with the necessary skills to understand and manage dyslexia within the classroom.

Complementing previous studies (eg. Snowling, 2013), my findings in section 5.2 suggest that access to early (before a child is around seven or eight), evidence-based intervention (including both specialist instructional 1:1s and group learning and teaching assistant support in class) is an imperative because it interrupts feelings of shame that grow from the experience of exclusion and enables a sense of competence and hope about the future. The example of the twins, Pia and Seb, suggests that early intervention makes it possible for young people to move on from a dyslexic identity and progress alongside their peers. Their experience in primary school, described in section 5.2.1, can be held up as a benchmark for provision to which schools and teachers can aspire, demonstrating that investment in early intervention can reduce the need for later provision.

However, as my research suggests, there are many local inconsistencies in provision, something that is a key concern for parents and a source of perceived unfairness. This variation was highlighted in section 5.2, showing some young people to be receiving very effective support and others receiving none at all. Pia and Seb’s stories of early and effective provision were unique in the context of my research and for everyone else provision ranged from ‘good enough?’ to poor or non-existent. The category that I conceive as ‘good enough?’ comprises a group of young people whose difficulties were identified relatively early and whose schools recognised their difficulties and were able to provide some interventions and accommodate them in the classroom. Their provision nowhere near matched that of Pia and Seb’s specialist support but, based on participants’ assessment of provision and parents’ understanding of their emotional well-being, could be deemed adequate. However, the case of Toby raised the possibility that good provision (as identified by his mother and verified by myself through the paperwork she sent me) does not always lead to positive emotional wellbeing. This suggests that the picture is more complex and nuanced and that we need to look beyond educational provision when exploring young people’s self-image and emotional wellbeing.
8.2.2 Evaluating the role of the social actors around the child

My analysis has focused attention on the interrelationship between discourse and social interaction and the impact of both on young people’s lived experience of school. I have found symbolic interactionism to be a vital resource for connecting insights across my analysis and body of evidence, helping me trace how micro-level interactions and activities are connected through social relationships to discursive and cultural practices, and how these in turn are absorbed and internalised by young people.

Through my findings I have been able to show the interplay of parents, peers and teachers in shaping how young people imagine and respond to their dyslexic difficulties. In exploring the emotional narratives of young people, I have seen how they become caught up with the stories of parents. In section 6.1, we saw how parents, particularly mothers, play a powerful role both in their struggle to gain access to resources and in seeking to protect and nurture their child’s sense of self. We also saw that involving the wider family in nurturing young people’s self-worth can be effective, as well as finding out-of-school activities that young people enjoy and are good at and, as Adam’s mother said, shouting ‘it from the roof-tops’. As shown in section 6.1.1, this strategy seemed to be effective for young people like Todd, Adam, Ella and Matthew because their confidence in other areas outside of school seems to have offset negative feelings about their dyslexic difficulties.

In considering my research through the lens of Reay’s work on emotional capital (2000), I found a couple of mothers who may have transferred their own anxiety to their children by overly focusing on their education. However, my findings suggest that in most cases, even when parents associated educational success with future happiness, they were very focused on their children’s happiness in the moment and improving their emotional health. Their strategy for doing this involved seeking effective provision and, in section 6.1.2, I started to think about how this could be interpreted by some children as prioritising educational achievement. If this happens, there is a risk of parents’ anxiety and distress being passed on and getting in the way
of young people’s emotional wellbeing. This was a finding that particularly resonated with my own experiences and in reflecting on it caused me some anguish.

My research suggests that teachers absorb and interpret institutional discourses that privilege literacy and position dyslexia as a deficit. They enact these assumptions through micro interactions with learners – both young people with severe dyslexic difficulties and their peers. On this basis, teachers have a very significant role to play in young people’s stories of identity and emotional wellbeing, prompting peers to make insulting and hurtful comments and young people to form negative perceptions of themselves. While it could be argued that teachers are in a position to challenge these institutional discourses and encourage an ethos of neurodiversity as well as an understanding of the specificity of dyslexic difficulties, questions have to be asked about the extent of teachers’ autonomy and freedom to make change.

I have used Goffman’s work on stigma as a way of understanding how a discreditable attribute, which becomes discredited in the context of school, can impact identity construction. Moving attention from Houston’s (2010) focus on social workers to a focus on teachers, I have suggested that recognition by teachers in the form of interaction, care, respect and validation can make a meaningful difference to young people. In section 6.3.1, I illustrate how important it can be for young people to feel they can trust their teachers and enjoy caring relationships with them. I show that essential elements of the teacher-learner relationship are teacher empathy and sensitivity, as well as teachers encouraging young people to value themselves and show self-compassion. As the examples in section 6.3.1 show, having just one trusted adult at school who shows care can be enough, with young people finding it particularly helpful to be matched with a teacher or teaching assistant who also has dyslexic difficulties. The example of Pia, in section 5.2.1, also suggests that informally linking young people with similar difficulties can provide relief in being around ‘fellow-sufferers’ (Goffman, 1963, p138). However, a sad but important finding from this research is that young people often felt patronised, undermined, criticised, humiliated and blamed by teachers, usually unintentionally; this is shown in section 6.3.2 where I recount the negative stories of young people’s interactions. Many also felt silenced
and were rarely consulted, either formally or informally, about decisions affecting them at school. With a notable feeling among young people of powerlessness to express their opinions, much improvement could be made to create an environment that empowers young people and nurtures their agency.

In chapter 6, I argue that teachers may be more likely to form a respectful and caring relationship with young people if they have an understanding of dyslexia, which we know from chapter 5 is very variable. Based on parents’ concerns in section 5.1.1, that teachers do not have enough training on dyslexia, I make suggestions for what I believe from my research are particularly salient areas for training. These include teachers learning to identify difficulties early and provide timely and effective support in the classroom, as well as communicating the importance of involving young people in decisions that are made about them and allowing them to express their views openly and without judgement. There should also be discussions about neuro diversity and the shame that some young people feel about their literacy difficulties, the emotional impact this can have and what teachers can do to challenge norms and stigma.

8.2.3 How do we move towards greater equality?

In thinking about inequality, I am drawn to consider my position within the on-going dyslexia debate, which I see as based around an argument for disability rights over rights for all children with literacy difficulties. As long ago as 1976 Yule observed that:

‘The era of applying the label ‘dyslexic’ is rapidly drawing to a close. The label has served its function in drawing attention to children who have great difficulty in mastering the arts of reading, writing and spelling but its continued use invokes emotions which often prevent rational discussion and scientific investigation’ (Yule, 1976, p. 166).

Forty-five years later the term ‘dyslexia’ is still in dispute and emotions are possibly even higher than when Yule wrote about it in 1976. My view on this debate derives from a belief that every child should have access to effective provision, regardless of their parents’ circumstances.
Based on the findings in chapter 5, I found schools to often be reactive rather than proactive when it comes to supporting young people with severe dyslexic difficulties and parents to be the driving force for making change for their children. Although I found inequality in terms of parents’ capacity to identify dyslexia and access support, I also highlight how privilege does not always lead to better provision when schools/local authorities are simply unwilling to respond to children’s SEND needs. For example, Arthur’s mother used both her economic and cultural capital to secure an EHCP for her son and a secondary school that she thought would support him. Nevertheless, she still felt, and from what I know, I agree, that the school had let her son down badly.

Questions of privilege are a central preoccupation for this thesis, and I draw on Bourdieu’s (1986) conceptual framework of capitals for a vocabulary to understand them. In section 5.3.2 I suggest that economic capital is important in terms of accessing an assessment for dyslexia, citing several parents who paid for one themselves. However, it is social and cultural capital, in terms of awareness and understanding of both dyslexia and the SEND system, that allow parents to confront the power differentials that exist between them and their child’s school. For example, I discuss how Adam’s mother, a teacher, used her knowledge to access provision for her son. However, if schools are not amenable to the demands of parents there is very little they can do other than move their child to another school or take the school/local authority to tribunal, which requires either extensive parental knowledge of the SEND system (or know someone who does) or economic resources to pay for a professional to negotiate for them at the court hearing. Although my research highlights the cases of Sid and Arthur’s mothers who had access to capitals but still did not succeed in influencing how their sons’ schools supported them, I argue that in the current education system in England there is inequality in how provision is acquired and a sense among parents that the SEND system is adversarial and unfair.

In my contact with participants, I tried to mirror the words they used to talk about their difficulties, however, in my writing I have referred to young people as having severe dyslexic difficulties. A key reason for doing this was to distance myself from the
categorical term ‘dyslexia’ and the need for assessment, both of which I could see privileged those with the greatest resources. With my research providing me with evidence that families are not equally positioned to secure provision, I stand by this decision and find myself favouring the approach of RTI for all young people with literacy difficulties (whilst retaining the word ‘dyslexia’ and using it interchangeably), rather than intervention for just those assigned the label ‘dyslexia’. Dyslexia organisations, in particular those promoting the narrative that the term covers more than just literacy difficulties, would undoubtedly argue that this may lead to hard fought rights for people with a dyslexia diagnosis being lost. This is a good argument, however, perhaps now is the time to put the needs of all those with literacy difficulties above the few that have received the label and resolve the arguments around dyslexia once and for all. I appreciate that this view is not a popular one, even amongst my own family who have suffered in an imperfect system and have emerged from it as part of a dyslexia community. In particular, my views are at odds with my husband who not only has dyslexic difficulties himself, but now works as a dyslexia specialist teacher and is invested in maintaining the status quo and the strength that the term brings.

My position within the dyslexia debate places me out of step with the majority of academics involved with work among people with dyslexic difficulties. In disseminating my research findings, I will have to find a balance between pursuing this standpoint and ensuring that the rest of my work on identity and emotional wellbeing is not rejected because of it. This seems a difficult path to follow, but is one that I am certain I must pursue.

8.3 Summing up

This chapter has drawn together the various strands of my research into a discussion looking for meaning and greater understanding. It has described what is debatably a flawed SEND system, in which provision is not equally distributed and where the discourse of dyslexia is based on individual deficit rather than accommodating and valuing neurodiversity, which contributes to young people’s feelings of shame. What has evolved is an unfair structure in which provision differs by location and school and where parental access to resources often determines the timing and effectiveness of
the support that young people receive. In order to address this social inequality, as described above, I propose that dyslexia requires a reframe as just one aspect of literacy difficulties that are all treated in the same way at school, allowing a move away from the need for diagnosis.

In examining the way in which dyslexia and literacy difficulties have been produced as a problem, I make a call for literacy norms and notions of deficit to be challenged in schools. However, this raises questions about the extent of teachers’ freedom to contest existing discourse and I have, therefore, started to consider how assistive technology could create space for this change to take place, enabling greater participation in literacy related aspects of education and leading to less reliance on intervention and support at school. Ultimately this could lead to norms around literacy, as well as its assumed empowering properties, becoming less significant within schools, and discourses of deficit being questioned.

Throughout this thesis I have discussed a range of factors that may impact young people’s emotional wellbeing – a whole school ethos of neurodiversity, family reassurance and reinforcement, as well as teachers who young people can trust, who respect and validate them, as well as show care. However, while these are all important in moving young people from a position of shame to one of pride, without the foundation of early identification and intervention their impact is undermined.

Following on from this discussion, the next chapter brings my thesis to a close by focusing on my contribution to knowledge and looking at recommendations for policy and practice.
Chapter 9. Conclusions

9.1 Introduction

Working with both parents and young people I have sought to understand the complex interaction of factors that influence the lives of young people with severe dyslexic difficulties at school. At the centre of my approach has been a conceptualisation of an interactive self that becomes the interface between personal experience, diverse social relationships and discursive formations of knowledge and expertise.

I start this chapter by reflecting on my learning journey. I will then outline how I have addressed my research questions and explain the distinctiveness of my research and what I claim to be my key substantive contributions. This is followed by a discussion of policy and practice recommendations, the limitations of my study and areas for future work.

9.2 My learning journey

Over the course of this PhD, and as detailed in chapter 1, I have moved from being an advocate to being an academic. My choice to undertake research that is so closely related to my own experience has made my research “journey” particularly poignant. It has not only brought back some painful memories, but more significantly, has raised questions about how I supported my son and what I could have done differently. In being reflexive throughout this thesis I have had to find the right balance between allowing the emotions raised by my research into my writing, whilst ensuring that they do not overwhelm my findings and the words of my participants. Knowing how and when to include myself in the research has been resolved through time and experience of writing and finding my voice. Harder to shift was my mode of address that had become ingrained over a 30-year career as a social researcher in large research organisations and persisted in slowing down my writing progress. After much reading around the subject, attending writing workshops and undertaking my own free writing, I hope to have developed a style that is not only reader-friendly, but also analogous to the philosophical traditions with which I align myself. Although I always wanted my thesis to be accessible to people with reading difficulties and would have liked for my husband and sons to be able to read it, I now realise that this will not be possible at
doctoral level. However, I will ensure that, at some point in the near future, I write a summary at an accessible functional reading level so that it is available for them to read.

I have also found it challenging, and at times lonely, to make the shift from working as part of a team, to being alone with my thoughts and ideas and writing for myself and the requirements of academia rather than to fulfill the needs of my clients. Setting up an online peer support group with three other doctoral researchers has helped enormously to feel part of a research community. ‘Meeting’ online once a month for the last four years has provided me with a way of regularly keeping in touch with people who are going through the same experience as me and has proved invaluable at addressing feelings of isolation and ‘imposter syndrome’. Working with the doctoral school, I have promoted the idea throughout the University and it has been gratifying to see online peer support groups being set up in other departments and even in a couple of other universities, including one in Denmark.

9.3 Addressing my research questions

In this thesis I have sought to answer three key questions about the identity, emotions and provision of young people with severe dyslexic difficulties in mainstream, state education in England.

Chapters 6 and 7 address my first and second research questions about young people’s identity construction and emotional response. Whilst acknowledging the importance of early identification and intervention, as well as whole school recognition of dyslexic difficulties and an ethos of inclusivity, I emphasise the significance of social relationships, highlighting how discursive and cultural practices are absorbed and internalised by young people through their social interactions. These chapters also explore the emotions expressed by young people, which can be theorised through their experiences of shame and stigma. Although the emotions of some young people in relation to their dyslexic difficulties are very troubling, others communicated how they made sense of and even felt pride about them. Using these positive examples I explore how parents, peers and teachers can help young people to move from a
narrative of chaos and anxiety to one where they associate their difficulties with neurodiversity rather than deficit.

Chapter 5 addressed my third research question about equality of provision and the resources required by parents to access support. It suggests that the distribution and quality of provision is not only extremely inconsistent but that accessing it is often dependent on parents’ economic resources and cultural and social capital. On this basis, I argue that access to provision for young people with severe dyslexic difficulties is a matter of equality.

9.4 The distinctiveness of the research

This study is relatively unusual in that it brings sociological theory to discussions of dyslexia and emotions. A distinctive contribution of my approach is the inclusion of institutional and relational dynamics in an understanding of emotional wellbeing, which involves highlighting how the interactions and activities of key social actors reinforce discourse and cultural practices, and how these in turn contribute to the lived experience of young people.

By engaging with three sociological theories in an approach based on theoretical pluralism and framed by Bronfenbrenner’s Ecological Model (1979), I have developed a broader understanding of the lived experience of young people with severe dyslexic difficulties in a way that would not have been possible with a single theory. A ‘top-down’ (Hacking, 2004, p. 277) Foucauldian approach focusing on discourse and taking account of social and political context, as well as issues of power, broadens the conversation about young people’s experiences at school to consider the wider influences that shape their lives and identities. Although not unusual in SEND research, this is a less common approach in research about young people with dyslexic difficulties. In also drawing on symbolic interactionism, my research contributes to a growing body of research illustrating how the judgments and responses of other people impact on young people’s sense of self. In particular, my research focuses on how social actors reinforce discursive and cultural practices and in doing so influence young people’s emotional wellbeing. These theoretical frameworks are underpinned by Bourdieu’s (1986) notion of capitals, which has allowed me to understand structural
limitations and the extent of unequal access in the way provision is accessed. Bourdieu’s (1986) capitals have been used in previous studies examining social inequality and SEND (eg. Holt, Bowlby and Lea, 2018) and a few studies about people with dyslexic difficulties (eg. Macdonald, 2009a).

An iterative research design has allowed me to take the time to reflect on emergent findings, process new ideas and feed my learning into the next stage of my research. It has also made me more responsive to the needs of my participants, for example, parents’ narratives gave me advance insight into their children’s stories, which helped me to react appropriately when I met them. This design also meant that I could compare what parents told me about their children with young people’s own narratives. As I have pointed out in previous chapters this has sometimes been a case of young people mirroring their parents’ words and on other occasions, I have felt a tension between what parents and young people have said. Either way, this has brought greater understanding and depth of meaning to the findings.

Finally, I am not aware of any other sociological studies about emotions and dyslexia that have been written by the mother of a young person with dyslexic difficulties, in particular where she has used reflexivity to critically reflect on her role in the research. Whilst it has been a challenging path to follow, I believe that my research is more relevant as a consequence of my personal experience.

9.5 Substantive contribution to knowledge

As I show in chapter 3, a key substantive contribution of this study is to create knowledge with, and about, the lived experience of those whose dyslexic difficulties are most severe. By generating nuanced knowledge that facilitates recognition, representation and understanding of this group of young people, I am contributing to an area where very little research exists.

I have sought to understand the dynamic relationship between need, provision and young people’s emotions. In doing so I have drawn attention to variation in the distribution and quality of provision and highlighted what I consider to be the benchmark of support – early identification and intervention, as well as whole school
recognition of dyslexic difficulties and an ethos of inclusivity and neurodiversity. I suggest that without this foundation of early effective provision, it is very difficult for teachers and parents to positively impact young people’s emotional wellbeing.

I also draw attention to the way in which parents are subject to disciplinary power and are made to “want” a model of provision that prioritises a label and individual intervention over one that values neurodiversity. In pursuing this at all costs, there is an argument that parents are unintentionally reinforcing the very framework that renders their child, through a deficit model, as ‘behind’ in the first place and inadvertently increasing their child’s sense of otherness. By also focusing on the unevenness of parents’ ability to negotiate access to support and linking this to an unequal distribution of economic, cultural and social capital, I am contributing to existing research on social class, capitals and dyslexia provision. Furthermore, based on my findings, I suggest that even parents who have capitals may be unable to access provision for their children when schools/local authorities are not willing to listen and respond to their needs.

A Foucauldian framework has enabled me to explore processes of subjectification, through which young people’s self-image in the context of school is incited by discursive formations around literacy and development. The conceptual resources of Symbolic Interactionism have enabled me to reveal social interaction as the connective tissue between discursive and cultural practices and the inner worlds of young people. In making these connections I have highlighted how certain interactions cause some young people to feel shame and experience emotional distress. This aspect of my research is a key contribution to knowledge and opens up ways for people around the child to not only check their language and behaviour, but also challenge and disrupt discourses of deficit and cultural norms of literacy. It also creates space for policy makers and educators to consider the potential of assistive technology to break down cultural norms about literacy and support young people like my participants in school.

My approach is also unusual within the field in that I approach emotions sociologically, highlighting the emotional labour involved in managing shame (Hochschild, 1983) and
revealing the kinds of emotional regulation and information control required at school. By focusing on the positive stories of interaction and learning from the negative, I have been able to suggest ways in which teachers can support young people to develop a positive self-image and move away from feelings of anxiety and unhappiness. In particular I have focused on the importance of teachers showing recognition and care towards young people, as well as promoting their agency and participation. As well as the need to challenge the discourse of deficit and the social and cultural norms inherent within SEND, as mentioned above, another contribution to knowledge is the emphasis that my findings have placed on understanding and valuing difference, and creating a whole school ethos that reflects this.

Finally, my research endorses previous studies highlighting the importance of parents advocating for their child, as well as providing reassurance and reinforcement in terms of reframing dyslexia towards ideas of difference and away from notions of deficit or fault. I suggest that an effective strategy for counterbalancing young people’s poor self-image is for parents to encourage their children’s involvement in out-of-school activities that they enjoy and are good at, including those with wider family. Inspired by the work of Diane Reay’s (2000) work on emotional capital, my analysis also attends to classed cultures of parenting, which can give rise to particular kinds of anxiety that complicate our understanding of parental support.

9.6 **Recommendations for policy**

I now turn to the role of policy-makers, whose responsibility it is to shape the conditions in state, mainstream schools under which young people with severe dyslexic difficulties can thrive.

My thesis highlights inequality in terms of how parents secure effective provision and links this to the on-going debate about dyslexia. My research has given me a better understanding of why it is such a difficult debate to resolve and has helped me to begin to see a way through. I argue for greater equality of opportunity by giving literacy difficulties parity with dyslexia, so that all young people receive the same support regardless of economic resources and cultural and social capital. However, in order not to alienate those who align themselves with the term and find comfort in it,
this may mean holding on to the term ‘dyslexia’, as in the local education authority of Cambridgeshire, but focusing on individual difference rather than diagnostic categories. With a recognition that certain difficulties co-occur (Rose, 2009) and overlap (Bishop, 2014), this approach would take account of co-occurring differences and build up a picture of the needs of the whole child. Government investment in evidence-based RTI approaches would be necessary for this method to work, but over time this could be offset by the savings made through not having to formally assess children and there being fewer disputes with parents. In addition, this reform would reduce the amount of contradiction and confusion surrounding the term ‘dyslexia’ and may in turn decrease any antipathy among practitioners towards it.

There is no doubt in my mind that evidence-based intervention in early primary school, where there is an ethos of inclusivity and neurodiversity, can disrupt feelings of shame and stigma. However, my research suggests significant inconsistencies in the distribution of provision and a lack of schools that understand and value difference. On this basis, I call for there to be a minimum requirement of identification and intervention to start in early primary school and by the end of Year 3 at the latest, before children become aware of the discourses and norms relating to literacy that are prevalent in most schools and can impact emotional wellbeing. My research has also highlighted the importance of teacher training to ensure that teachers are adequately prepared to effectively support young people with dyslexic/literacy difficulties and all SEND. An essential part of this is ITT, where there should be greater opportunity for learning about individual learning differences, such as literacy difficulties, and where there should be a required number of hours spent on SEND. This would include increasing awareness of the emotional impact associated with severe dyslexic difficulties and what teachers can do to alleviate these feelings. It is also important to give student teachers an opportunity to reflect on what it means to include all learners and value diversity and challenge teachers’ assumptions about deficit. Reducing barriers for young people in the classroom, in order to allow for greater inclusion and a move away from provision being associated with intervention, could also be addressed.
It is also important to pay attention to the ‘discursive construction of learning differences and disabilities in context’ (Cameron and Billington, 2017, p. 1359). My research suggests that young people internalise the discourse of deficit and the privileging of academic achievement and literacy, a situation that is endorsed by government regulation of schools in the form of testing and league tables and the favouring of academic results over vocational qualifications. As mentioned above, change would involve challenging attitudes to difference and deficit in ITT and continuing professional development, alongside training programmes that systematically focus on the discursive construction of terms like dyslexia. This kind of training would allow teachers time for reflection on the importance of language and how we speak about learning differences. As suggested in the previous chapter, government investment in assistive technology for schools could also go a long way to challenging cultural norms of literacy.

Finally, my research has shown the importance of young people feeling validated and valued by their teachers and has highlighted the significance of caring relationships and the positive impact this can have. I would therefore concur with Rogers and argue for a ‘care ethics model of disability’ to be mapped on to the current education system, ‘where relational, ethical caring practices are charted’ (2016, p. 58) and there is a move towards a ‘re-humanising’ of education (p. 58). Although Rogers’ work is mostly about intellectual disability and schooling, I concur with her sentiment when she states that ‘inclusion alone, without the care-full and caring work necessary across all spheres will not work’ (ibid, p. 60).

9.7 Recommendations for practice: changes teachers can make

While policy change takes time, on the basis of my research, I believe there are changes that both schools and teachers can make to help young people with severe dyslexic difficulties avoid feelings of shame and encourage pride. The following changes acknowledge the pressure that practitioners are already working under and, based on evidence from the research, involve a change of emphasis and a different approach to working with young people, rather than specific measures.
My research has suggested that the responsibility for stigma lies with society and that it is perpetuated through interaction between young people and their teachers and peers. School leaders can, however, address this by building a culture of inclusivity and neuro-diversity within their schools, where difference is normalised and accepted and stigma is challenged. I also believe that if teachers were made aware of how young people with additional needs can internalise the discourse of deficit in schools, they may want to challenge it and create an atmosphere within their classrooms in which young people feel valued for who they are rather than what they can achieve academically. This may require teachers to find out about young people’s interests and the areas in which they have confidence and then look for ways in which to promote their strengths among their peers and within the school. Within the ableist environment of the school, where the medical model of disability is most prominent, teachers may also choose to talk directly to young people about shifting their thinking away from the deficit model towards an appreciation of the social barriers they experience. This could run alongside a programme whereby young people are taught self-compassion and are encouraged not to compare themselves with others:

‘Treating oneself with kindness, recognizing one’s shared humanity, and being mindful when considering negative aspects of oneself’. (Neff, 2011, p. 1)

Conceptualising teachers’ role through Houston’s (2010) four interrelated elements of recognition – interaction, care, respect and validation – would go some way to supporting young people to value themselves in spite of their severe dyslexic difficulties. In particular, as my research suggests, having a trusted adult within school to go to with problems and concerns was particularly beneficial for young people – even better if that person also has dyslexic difficulties. Drawing on Goffman’s (1963) concept of in-group alignment 1963), it may also be useful for teachers to put young people with similar difficulties in touch with each other so that they can offer mutual support and comfort. It may also be helpful to pair different age-groups, giving older children the opportunity to act as role models. Finally, my research indicates that young people are rarely consulted directly about their provision, either informally or formally, and any discussions about it tend to take place with their parents. Greater recognition and care will ensure that these conversations are more likely to take place
and agency is nurtured, however it is also important for schools to create a formal system whereby young people are consulted.

9.8 Limitations of the study

In chapter 3, I discuss the challenges of my dual role as a parent and researcher, noting that my insider researcher status will inevitably shape the study and influence my interpretations, thus framing the findings. Overall, I believe that my research is richer because I have an insider perspective, in particular in terms of gaining access to participants and the language they use, as well as my familiarity with the subject area. My own experiences have also given me understanding and insight into the emotions spoken of by parents and young people. On the other hand, there have been times when my own experiences may have coloured my reaction to participants’ comments, in particular those of parents, however, reflexivity has helped me to be open about these emotions.

I also accept that the sample of my online survey was a volunteer group of parents already self-identifying (and self-organising) around dyslexia. This means that the people in my sample were all aware of dyslexia and may have some understanding of it and therefore cannot be assumed to represent the wider population. In particular, the sample is likely to under-represent young people who have low levels of literacy but have not been assessed as having dyslexic difficulties, as well as those parents who are less well-informed about the possible reasons for their child’s educational struggles. In addition, I expect that the sample is less diverse in terms of ethnicity than the general population and over-represents the middle classes. Recognising this does not discount the findings but it does demand that I am circumspect about how I interpret them and the claims I make from them.

There are also limitations in the narrative case studies, firstly in terms of recruitment. In the online survey, I only asked about the severity of children’s dyslexic difficulties if parents said they had been assessed in the previous question. This will have restricted my opportunity to recruit young people whose difficulties were severe but had not been assessed. Secondly, parents were purposively given a very open question to answer for their narrative, but this meant that I had less control over the content than
if I had spoken to them directly. However, where there was information missing that I thought was important, I talked to them after the interview with their child, asking them to explain any points of interest to me. In addition, the way in which the interviews were set up with young people meant that I did not have much time to build a relationship with them and gain their trust. However, as described in chapter 4, I tried to do as much of this in advance of the interview through the communication I had with them and worked hard when I met them to reduce any power differential between us. Finally, I believe that with more experience I could have made better use of creative materials in the interviews.

9.9 Future research

Future research would seek the attitudes of teachers to the findings of this study and generate ideas on how to take them forward into the classroom. If further research were to be undertaken among young people, I believe that it should take place in schools and aim to be more representative in terms of social class and ethnic origin. This would mean including young people in the sample who have not necessarily been identified as having severe dyslexic difficulties but have a similar level of literacy. The research would observe the interactions between young people, teachers and their peers in the classroom and develop the findings generated by this study. It may also be useful to talk to adults about their school experience and how their severe dyslexic difficulties have affected their lives.

9.10 Concluding remarks

My doctoral study has brought a subject that is very personal to me and taken it into the realms of academia. In coming to the end of my PhD and writing the final words about such a large piece of work, I will draw it to an end by seeking to encapsulate the main points. Firstly, this is a unique research endeavour because it focuses on young people with the most severe dyslexic difficulties and highlights the social and discursive construction of their emotional wellbeing at school. By employing Bronfenbrenner’s Ecological Model (1979) to scaffold my thinking about the different layers of influence at play within micro, meso, exo and macro contexts and to bring together different theoretical resources strategically, I have been able to engage with the wider influences that contribute to young people’s identity and emotional
wellbeing and suggest ways that these can be addressed. I have revealed profound inequalities in access to provision and called for this to be addressed through greater teacher training and by resolving the wide-reaching debate about dyslexia, particularly in terms of definition and diagnosis. By viewing emotions as evolving from social relations and socio-cultural processes, I have highlighted the significance of the emotional labour that young people engage in at school to conceal and manage their differences, and looked for ways that schools and teachers can mitigate the toll this takes. However, perhaps the most important message to come out of my research is that, in an education system that prioritises literacy and academic achievement, policy makers, schools and teachers require greater understanding of both the shame and stigma experienced by those with severe dyslexic difficulties and of their role in mediating institutional discourse. I am hopeful that greater understanding can lead to dyslexic/literacy difficulties being constructed differently within schools and that this change will enable young people to thrive.
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Appendices

Appendix i. The search criteria for my review of the literature

My initial literature review was based around electronic searches of the University of Sussex Library database, as well as resources such as JSTOR, Scopus and Web of Science. My search strategy involved using the words ‘dyslexia’, ‘dyslexic’, ‘severe dyslexia’ and ‘severely dyslexic’, combined with ‘school’, ‘class’, ‘classroom’, ‘education’, ‘child/ren’, ‘young people’, ‘identity’, ‘emotional well-being’ and ‘well-being’. I did not limit my search to just the UK and I had no exclusion criteria. This was followed up by ‘snowballing’, whereby I tracked reference lists and followed-up articles and books that I judged to be particularly pertinent to my area of research. Greenhalgh and Peacock (2005) suggest that when subjects are complex, they require something more than a systematic review, which is particularly suited to subjects like medical testing or policymaking issues. In cases like my own research therefore, the more informal and unsystematic method of snowballing, or following up references of references and tracking citations, can be utilised.

I also set up alerts with Web of Science, Scopus and Jisc Zetoc and followed relevant people on ResearchGate and Academia, as well as using personal knowledge and accessing the websites of organisations such as the BDA and the Driver Trust.

During the course of analysis and writing up my research I undertook further searches as necessary which were more focused on particular areas of interest. These searches included each of the words mentioned above, as well as, for example, ‘discourse’, ‘social class’, ‘parents’, ‘peers’ and ‘teachers’. My search terms reflected those mentioned above but I also extended them to include ‘SEN’ and ‘SEND’, ‘autistic’, autism’, ‘ADHD’ and ‘ADD’.
Appendix ii. Online Survey of Parent/Carers questionnaire

Online Survey of Parents/Carers

Dear parent/carer

Thank you so much for completing this short questionnaire. Please leave blank any questions that you would prefer not to answer.

By taking part in this online survey you are consenting to me using anonymised information for the purposes of research only.

Q1 Which of the following dyslexia assessments has you child undertaken? Please tick all that apply

☐ Screening test at school (1)
☐ We paid for a full diagnostic assessment (2)
☐ School/local authority undertook a full diagnostic assessment (3)
☐ Other (please write in) (4) ________________________________
☐ Not been assessed yet (5)
☐ S/he is not dyslexic (6)
☐ Don’t know (7)

Skip to Q3: If 'Not been assessed yet'
Q2 Did any of these assessments indicate the severity of your child's dyslexic difficulties?

- Severe (1)
- Moderate (2)
- Mild (3)
- Other (please write in) (4) ____________________________
- No, we have not been told (5)
- Don't know (6)

Q3 Using up to 5 words, how would you describe the positive effects, if any, of dyslexia on your child?

- Please write your answer in below: (1)

______________________________

- No positive effects (2)
- Don't know (3)

Q4 Using up to 5 words, how would you describe the negative effects, if any, of dyslexia on your child?

- Please write your answer in below (1)

______________________________

- No negative effects (2)
- Don't know (3)
Q5 Overall, how would you describe the impact of dyslexia on your child’s everyday life, attainment at school and emotional well-being?

<table>
<thead>
<tr>
<th></th>
<th>Severe (1)</th>
<th>Moderate (2)</th>
<th>Mild (3)</th>
<th>Don’t know (4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Everyday life (1)</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Attainment at school (how well s/he does academically) (2)</td>
<td></td>
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<tr>
<td>Emotional well-being (3)</td>
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Q6 Please could you tell me some more about this impact and the form it takes?

- Please write your answer in below: (1)
- Don't know (2)
Q7 Does your child have any of the following co-occurring difficulties? Please tick all that apply

☐ Dyspraxia (1)
☐ Dyscalculia (2)
☐ Dysgraphia (3)
☐ ADHD (4)
☐ Autism/ Aspergers (5)
☐ Other (please write in) (6) __________________________
☐ None of these (7)
☐ Don't know (8)

Q8 Which of the following type of support, if any, does your child have at school? Please tick all that apply

☐ Special Educational Needs (SEN) support (previously called School Action/Plus)
☐ Educational, Health and Care Plan (EHCP) (previously called a Statement of Educational Need) (2)
☐ Other (please write in) (3) __________________________
☐ No support (4)
☐ Don't know (5)
Q9 What type of school does your child currently attend?

- Local authority/maintained (mainstream) (1)
- Academy (mainstream) (2)
- Free School (mainstream) (3)
- Independent (mainstream) (4)
- Specialist Dyslexia School (5)
- Other Special School (6)
- Home-schooled (7)
- Other (please write in) (8) ____________________________
- Don’t know (9)

Q10 Overall, how well would you say that your child’s dyslexia has been supported at primary school?

- Very well (1)
- Fairly well (2)
- Not very well (3)
- Not at all well (4)
- Don’t know (5)
Q11 Is there anything else you would like to tell me about how your child's dyslexia has been supported at primary school?

☐ Yes, please write in below: (1)

________________________________________________________

☐ No (2)

Q12 Overall, how well would you say that your child's dyslexia has been supported at secondary school? (Tick 'Not applicable' if your child is still in primary school)

☐ Very well (1)

☐ Fairly well (2)

☐ Not very well (3)

☐ Not at all well (4)

☐ Don't know (5)

☐ Not applicable (6)

Q13 Is there anything else you would like to tell me about how your child's dyslexia has been supported at secondary school?

☐ Yes, please write in below: (1)

________________________________________________________

☐ No (2)
Q14 Which of the following apply to your child? Please tick all that apply

- [ ] My child uses the term 'dyslexia/dyslexic' (1)
- [ ] My child describes his/her difficulties as........... (please write in) (2)
- [ ] My child does not talk about her/his difficulties (4)
- [ ] Don't know (3)

Q15 Does your child's school use the term 'dyslexia/dyslexic' when they are talking about your child's difficulties?

- [ ] Yes (1)
- [ ] No (2)
- [ ] Don't know (3)

Q16 Does your child's school ever refer to the severity of your child's difficulties?

- [ ] Yes (1)
- [ ] No (2)
- [ ] Don't know (3)

Q17 Is there anything else you would like to tell me about your child's experience of being dyslexic that you think may be helpful?

- [ ] Yes, please write your answer below: (1)
- [ ] No (2)
Q18 Based on your experience, what would be your advice to the parents/carers of a dyslexic child?

- Please write your answer below: (1) ________________________________
- Don't know (2)

Q19 Finally, a few questions about your child and your family background and education so that I can check how representative the sample of people answering my survey is of the overall population.

How old is your child?

- Please write in the age of the child about whom you have answered this questionnaire:

_______________________________________________

Q20 Does your child identify as ..........

- Male (1)
- Female (2)
- Transgender (3)
- Other (please write in) (4) ________________________________
Q21 What is your child's ethnic origin?

○ White British (1)

○ White Other (6)

○ Asian British (3)

○ Asian Other (7)

○ Black British (8)

○ Black Other (2)

○ Mixed/multiple ethnic groups (4)

○ Other ethnic group (please write in) (5) ____________________________________________

---------------------------------------------------------------
Q22 Please can you tell me the **highest** level of studies, exams or qualification that you or your partner has completed? *If the UK or foreign qualification is not listed, please tick the box that contains its nearest equivalent*

- No qualifications (1)
- 1-4 O levels/ CSEs/ GCSEs (any grades), Entry Level Foundation Diploma (2)
- NVQ level 1, Foundation GNVQ, Basic Skills (3)
- 5+ O levels (passes) /CSEs (grade 1) / GCSEs (grades A*-C), School Certificate, 1 A level /2-3 AS levels /VCEs, Higher Diploma (4)
- NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First /General Diploma, RSA Diploma (13)
- Apprenticeship (6)
- 2+ A levels/ VCEs, 4+ AS levels, Higher School Certificate, Progression/Advanced Diploma (7)
- NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma (9)
- Degree (eg. BA, BSc), Higher degree (eg. MA, PhD, PGCE) (10)
- NVQ Level 4-5, HNC, HND, RSA Higher Diploma, BTEC Higher Level (11)
- Professional qualifications (eg. teaching, nursing, accountancy) (14)
- Other (please write in) (8) ________________________________
Q23 Please can you tell me where you live?

- England (1)
- Scotland (2)
- Wales (3)
- Northern Ireland (4)
- Republic of Ireland (5)
- Other (please write in) (6) ________________________________________________

Q24 Finally I would like to invite you and your child to take part in a further stage of research which will take place later in the year and will give you both a chance to have your views and experiences heard in more depth. I hope this is something that you might both be interested in - I think it is really important to include the voice of young people in my research, as well as parents. If you are interested in being involved, then please leave your contact details below and I will contact you nearer the time with more information.

- Yes, we are interested in taking part in further research and are happy for you to contact us again with more information (1)
- No, we are not interested in taking part in future research (2)
Q25 Please could you write in your details below so that I am able to contact you about the next stage of research and plan where I do my interviews. Your details will be kept separately from your survey answers:

☐ Your name: (1) ________________________________

☐ Your email address: (2) ________________________________

☐ Your telephone number: (3) ________________________________

☐ Your full postcode or the name of your city/town/village: (4) ________________________________

☐ Your child’s name (5) ________________________________
To the parents/carers of children who are dyslexic

Please can you spare 5 minutes to fill-in an online questionnaire about your child’s experience of being dyslexic. I am a PhD student at the University of Sussex and this questionnaire forms the first part of my research.

You can fill it in on a computer or on your Smartphone and your responses will be completely anonymous.

If you have any queries or problems please leave a comment below and I’ll get back to you asap. Please follow the link ....

UNIVERSITYOFSUSSX.EU.QUALTRICS.COM

Survey of Parents and Carers
Appendix iv. Reminder invitation posted on social media

Claire Durrant shared a link.
27 June 2018

Thank you so much to the 240 people who have already filled-in my short questionnaire. It would be brilliant if some more of you could complete it - the more I get, the more robust my findings will be. Thank you so much.

To the parents/carers of children who are dyslexic

Please can you spare 5 minutes to fill-in an online questionnaire about your child’s experience of being dyslexic. I am a PhD student at the University of Sussex and this questionnaire forms the first part of my research.

You can fill it in on a computer or on your Smartphone and your responses will be completely anonymous.

If you have any queries or problems please leave a comment below and I’ll get back to you asap. Please follow the link . . . .

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Survey of Parents and Carers
Appendix v. Online survey sample limitations and comparisons

In this appendix I assess the limitations of the findings of the online survey by ethnic origin, education and other factors.

**Ethnic Origin**

The ethnic origin question that I used was a shortened version of the one from the Census 2011 for England (see Appendix ii). For example, I subsumed the category ‘Asian/Asian British: Indian, Pakistani, Bangladeshi, Chinese and any other Asian background,’ into ‘Asian British’ and ‘Asian Other’. For the purposes of making comparisons with the MCS and census, these categories have been further combined as shown in the table below.

**Table 1: Ethnic Origin**

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>My Survey (Base: all answering 2018)</th>
<th>MCS Wave 6 (Base: all sweeps in UK (14 years old), 2014)</th>
<th>Census (Base: all usual residents aged 16 and over in UK, 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(352)</td>
<td>No dyslexia (11,335)</td>
<td>Dyslexia (432)</td>
</tr>
<tr>
<td>White</td>
<td>93.8</td>
<td>85.2</td>
<td>89.4</td>
</tr>
<tr>
<td>Mixed/multiple ethnic groups</td>
<td>3.1</td>
<td>4.7</td>
<td>6.5</td>
</tr>
<tr>
<td>Asian</td>
<td>0.6</td>
<td>5.9</td>
<td>0.5</td>
</tr>
<tr>
<td>Black</td>
<td>0.3</td>
<td>2.3</td>
<td>2.5</td>
</tr>
<tr>
<td>Other ethnic group</td>
<td>2.3</td>
<td>1.8</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Looking at the data for the MCS, the proportion of 14-year olds who do and do not have dyslexic difficulties is similar across all ethnic groups except ‘Asian’, where the percentage with dyslexic difficulties is considerably lower. It is also lower than the census, although this is based on UK residents aged 16 and over. The percentage of
Asian families participating in my survey is similarly low at 0.6%. Lindsay et al (2006) conducted a review of the literature published mainly between 1990 and 2005 and primarily in the US and UK, on behalf of the DfES. They reported that UK Asian and Chinese learners are less likely than White British learners to be identified as having Specific Learning Difficulties, Moderate Learning Difficulties and Autistic Spectrum Disorder (Lindsay et al., 2006). They suggest ‘that this could be because of difficulties in disentangling learning difficulties from issues associated with English as an Additional Language (EAL)’ (ibid, p. 4) or because Asian groups are less likely to engage with services (or engage later), meaning that there is a delay in diagnosis (ibid). They suggest that this could be due to language difficulties and lower levels of awareness and knowledge.

At 0.3%, the percentage of Black families participating in my survey is significantly lower than in both the MCS and the census. Lindsay et al (2006) identify Black African learners as less likely to have SEN in relation to SpLD (as well as Mild Learning Difficulties, Behavioural, Emotional and Social Difficulties (BESD) and physical disability), however they found no such evidence for Black Caribbean and Mixed White & Black Caribbean learners. On the other hand, they report that Black Caribbean and Mixed White & Black Caribbean learners in the UK are around 1.5 times more likely to be assessed as having BESD than White British learners. Robinson calls this the ‘deficit thinking’ of teachers who may be too quick to label Black learners as disruptive and in need of behavioural remediation and describing the experiences of dyslexic Black males as experiencing the ‘triple burden’ of ‘prejudice, discrimination, and inadequate resources’ (2013, p.163), as well as being ‘confronted with racial stigmas such as being labelled ‘at-risk’ and dysfunctional’ (p.163).

Other reasons for Asian and Black families being under-represented in my survey may relate to their lack of involvement in support groups relating to dyslexia on Facebook, however, I have been unable to find any literature which discusses the possible reasons for this. It may also be that they follow the Facebook groups with which I engaged for my survey but chose not to participate in the survey.
Education

I anticipated that my achieved sample may be skewed towards those with higher qualifications and therefore I have compared my findings with both the MCS and 2011 Census.

Respondents were asked to select their highest level of study, exams or qualifications from a list of 12 options taken from the 2011 Census for England. These were then combined so that I could analyse the findings of my online survey by highest level of education: those with a degree or higher (Level 4 and 5 qualification; 229 respondents) and those who do not have a degree (121 respondents);

Table 2: Equivalent of highest academic level

<table>
<thead>
<tr>
<th>Highest level of studies, exams or qualification</th>
<th>My Survey (Base: all UK parents/carers responding to online survey, 2018)</th>
<th>MCS Wave 6 (Base: all sweeps in UK, 2014)</th>
<th>Census (Base: all usual residents aged 16 and over in UK, 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(350)</td>
<td>Child is not dyslexic (11,683)</td>
<td>Child is dyslexic (454)</td>
</tr>
<tr>
<td>No qualifications</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Level 1 qualifications</td>
<td>3.3</td>
<td>6.9</td>
<td>8.1</td>
</tr>
<tr>
<td>Level 2 qualifications</td>
<td>6.0</td>
<td>5.7</td>
<td>6.2</td>
</tr>
<tr>
<td>Apprenticeship</td>
<td>0.6</td>
<td>Included in Level 2 qualifications</td>
<td>Included in Level 2 qualifications</td>
</tr>
<tr>
<td>Level 3 qualifications</td>
<td>14.3</td>
<td>13.1</td>
<td>12.8</td>
</tr>
<tr>
<td>Level 4/5 qualifications</td>
<td>64.6</td>
<td>48.2</td>
<td>54.2</td>
</tr>
<tr>
<td>Other (includes {some} overseas qualifications)</td>
<td>4.8</td>
<td>2.3</td>
<td>1.8</td>
</tr>
</tbody>
</table>
Compared to census data 2011 my sample significantly over-represents those with higher qualifications, however, there is less difference when comparing it to a subset of those with a dyslexic child in the MCS. Almost two in three of my sample (64.6%) had a Level 4 or 5 qualification which pertains to a degree or higher/professional qualification/NVQ5. This compares with 54.2% of the MCS subset of those with a dyslexic child and just 27% of the overall population in the census.

Research on the first four waves of the MCS (Parsons and Platt, 2013), focusing on children up to the age of 7 only, show that the socio-economic status of families with SEN differs according to the type of difficulty experienced. While children recognised as having learning, behaviour or speech difficulties are likely to experience the most socio-economic disadvantage, children who are reported to be dyslexic have a socio-economic profile similar to those who are not SEN (they are also more likely to be White and only speak English at home). Parsons and Platt (2013) link this to teachers’ expectations, saying that they often perceive learning difficulties among children from socio-disadvantaged families as related to behaviour rather than something else, for example, dyslexia. This leads to under-identification ‘if children are thought to be working at or near expected levels’ (ibid, p.21).

**Other factors**

The online survey is noticeably skewed towards parents with primary age children: 58.6% have a child aged 5-11 years, 32.8% aged 12-16 years, 4.3% 17-18 years and 4.3% 19+ years. I do not find this surprising given that the sample is made up of people who follow Facebook pages offering information and support about dyslexia, which is more likely to be needed when their children are young and at the beginning of school.

In terms of gender, it was traditionally assumed that dyslexia is more common among males than females (eg. Finucci and Childs, 1981). However, in more recent years, this assumption has had doubt cast upon it (eg. Shaywitz et al., 1990). My survey, however, found that parents/carers were more likely to complete the questionnaire about boys (60.7%) than girls (38.7%). One parent identified their child as transgender and one as female and male.
Bibliography for Appendix v.


Appendix vi. Email sent to parents selected from the online survey asking them to participate in the narrative case studies

Dear X

Thank you for taking part in the online survey and for agreeing that I can contact you again. I am now asking a small number of people who said that they have a child with severe dyslexic difficulties to help me with the next stage of my research involving parents/carers and young people:

**Research with Parents/Carers**

This is happening in October 2018 and would involve you telling me Y's story, in particular all the experiences and events which have been important for him up to now. It will involve you writing as much or as little as you like, either on the computer or using pen and paper. Please read the attached Information Sheet containing important details about taking part.

**Research with Young People**

The second stage will take place in November and December 2018 and will involve me coming to your home to talk to Y for about an hour. The interview will be very relaxed and hopefully it will be fun and interesting. I will bring some activities with me to facilitate our discussion, or if he prefers, we can just talk, or I can ask questions. The types of things that we will be talking about will include school, life outside of school, dyslexia and plans for the future. I have created a website which includes a video and an Information Sheet (also attached to this email), in which I describe what it will involve if he chooses to take part: [https://cdurrant2.wixsite.com/website](https://cdurrant2.wixsite.com/website). Please can you encourage him to look at it.

As the parent of two children with dyslexia, I know how difficult it is to get your, and your child’s, voice heard. This study aims to redress that balance and I plan to use the information I collect to help schools improve the ways in which they support the emotional needs of young people.

Please email, phone or text (07983 347649) me if you would like to ask any questions about the research, or if you are not sure about taking part.
When you and Y are both agreed that you would like to participate, please let me know as soon as possible. Please can you also send me your address so that I can send Consent Forms in the post for you both to sign.

Many thanks in anticipation

Claire Durrant

(PhD Student at University of Sussex)
Appendix vii. Information sheet for parents

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**Information About My Research**

**What is the research study about?**

I have two children with dyslexia and I know it can be difficult for parents to get their own, and their child’s, voice heard. I plan to use the information I collect from my research to help schools improve the ways in which they support the emotional needs of young people.

**What will it involve for you?**

I understand that you have a child with severe dyslexic difficulties. If you agree to participate I will ask you to fill in a short questionnaire and then tell me her/his story, including all the experiences and events which have been important, up to now. You could either do this on the computer and email it to me as an attachment or you could use pen and paper and send it to me (I will send you a stamped addressed envelope).

I am also interested in capturing the voices of young people themselves and would therefore be really grateful if you could encourage your child to also take part in my research. I have created a website for them to look at: [https://cdurrant2.wixsite.com/website](https://cdurrant2.wixsite.com/website) which includes a video for them to watch, and an Information Sheet, in which I describe what it will involve if they take part. I have a DBS Enhanced Certificate.

If both yourself and your child agree to take part, I will be back in touch with further details.

**Who else am I talking to?**

I will also be talking separately to young people, teachers/teaching assistants/SENCOs, dyslexia advocates and young people at a specialist dyslexia school.

**What will happen to my story?**
All of your stories will be completely anonymised and I will change place names, names of schools etc. in order to minimalise the risk of you being identified. Using the anonymised stories and the interviews with young people, I will select several extracts and present them to a panel of people involved in education. The purpose of this will be to see how educators respond to what parents/carers and young people have said and then ask them to reflect on what schools should be doing to better support young people’s emotional needs.

To support my analysis, the anonymised transcripts will be seen by my Supervisors at the University of Sussex. The data will be used by me to write about my findings in my thesis and in journal articles and may also form part of an anonymised dataset for deposit at the UK Data Service.

**Can I change my mind?**

If you change your mind, you can pull out without having to give a reason. You can ask for your child’s story to be removed and destroyed up until one month after you sent it to me.

**Are there any risks to me taking part?**

I hope you will find writing your child’s story a positive and rewarding experience and a chance to have your voice heard, knowing that what you say may benefit young people like your child and help schools to support dyslexic young people better.

Sometimes people find that taking part in research studies about issues close to them can be distressing. I hope this will not be the case for you but I will get in touch with you a week or so after you send me your story to check that you are ok and to give you the opportunity to talk if you feel it would be beneficial.

**How can I get further information?**

Please email, phone or text me if you would like to ask me any questions about the research, or you are not sure about taking part. My contact details are c.durrant@sussex.ac.uk or 07983 347649.

Once you are sure that you would like to participate, I will ask you and your child to sign a Consent Form.
The research has been reviewed through the School of Education and Social Work Ethical Review Process, BUT if you have any concerns about the way in which the study has been advertised and conducted you can contact my Supervisor Tish Marrable at l.f.marrable@sussex.ac.uk

Many thanks

Claire Durrant
Hello, my name is Claire Durrant and I am a student at the University of Sussex. Your parent/carer said you might like to take part in some research.

Thank you for taking the time to read this information sheet or listen to the video recording at: https://cdurrant2.wixsite.com/website

What is it about?

I am doing research to find out about your experience of school.

I really hope that you will take part because it is important that I talk to young people themselves, so that the research is useful.

I will write a report about my research findings and this will be used to advise schools about the best ways to support young people like you:

Who else am I talking to?

As well as interviewing young people like yourself, I will also be talking separately to parents/carers, teachers/teaching assistants and young people at a specialist dyslexia school.
What will I have to do?

We will meet at your home, in a quiet café or somewhere else of your choice.

The interview will be very relaxed and hopefully you will find it fun and interesting. There are no right or wrong answers - I am interested in your views and experiences.

I will bring some activities with me (eg. pens, paper, plasticine, magazines etc.), or if you prefer, we can just talk, or I can ask you questions. The types of things that we will be talking about will include school, life outside of school, dyslexia and your plans for the future.

The interview will take around an hour. I will send you an outline of the questions in advance.

Important information

- When I write my report, I will not use your, or your school’s, real name; if you want, you can pick a name for me to use instead. This means that no one should know that it was you who took part.

- If you change your mind, you can pull out without having to give a reason. You can ask for any data you have provided to be removed and destroyed up to one month after your interview took place.

- Everything you tell me will be completely confidential, however, if you tell me something about you, or someone else, being in danger, then there are rules which say that I have to tell your parent/carer/trusted adult.

- I hope to record what we talk about so that I don’t forget what you have said, but you can refuse if you would prefer me not to.
I will present some of the (anonymous) findings from my research with young people to a small group of teachers (not connected to your school), asking them to tell me how they think schools should support young people like you.

**How can I get involved?**

Before agreeing to take part please ask as many questions as you need and discuss what you want to do with family or friends. If you want to contact me please do so at c.durrant@sussex.ac.uk or 07983 347649.

Thank you. Looking forward to meeting you soon.

*Claire Durrant*
Research Consent Form

University Researcher: Claire Durrant; c.durrant@sussex.ac.uk; 07983 347649

University Project Supervisor: Tish Marrable; l.f.marrable@sussex.ac.uk

This research study aims to explore the experiences of young people with dyslexic difficulties.

Hopefully you have had the chance to read the Information Sheet about my research. If you have any queries at all please let me know and we can talk on the phone.

Please tick the box below if you are willing to take part in my research:

☐ I am willing to take part in this research

Now please tick the boxes below which apply to you:

☐ I have read the information provided

☐ I understand the purpose of the study and why I am involved in it

☐ I understand Claire’s role as a researcher

☐ I give my permission for information from our discussion to be anonymised and used for the research purposes outlined in the information provided, including in further research with teachers

☐ I understand that taking part in this study is my choice and I can stop at any point up to a month after I send my child’s story to you, without giving a reason or explanation
I give permission for my child to participate in Claire’s research as described in the Information Sheet for Young People.

Now please sign below to formally confirm that you are willing to be interviewed.

By signing in the box below I consent to the processing of my personal information for the purposes of this research study. I understand that my information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

Name of study: A research study of the experiences of young people at school

Name of Researcher: Claire Durrant

Your name: ...........................................

Please sign to indicate your consent to take part: ...........................................

Date: .................................
Research Consent Form

University Researcher: Claire Durrant; c.durrant@sussex.ac.uk; 07983 347649
University Project Supervisor: Tish Marrable; l.f.marrable@sussex.ac.uk

This research study aims to explore the experiences of young people at school.

Hopefully you have had the chance to read the Information Sheet about my research, or listen to the video recording. We will also go through this form when we meet, and discuss exactly what to expect from the research.

Please tick the box below if you are willing to take part in my research:

☐ I am willing to take part in this research

Now please tick the boxes below which apply to you:

☐ I have read/listened to the information provided
☐ I understand the purpose of the study and why I am involved in it
☐ I understand Claire’s role as a researcher
☐ I give my permission for Claire to record the discussion
☐ I give my permission for information from our discussion to be anonymised and used for the research purposes outlined in the information provided, including in further research with teachers
I understand that taking part in this study is my choice and I can stop at any point up to a month after the interview takes place, without giving a reason or explanation.

Now please sign below to formally confirm that you are willing to be interviewed.

By signing in the box below I consent to the processing of my personal information for the purposes of this research study. I understand that my information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

Name of study: A research study of the experiences of young people at school

Name of Researcher: Claire Durrant

Your name: .................................

Please sign to indicate your consent to take part: .................................

Date: .................................

Many thanks for your help with this study.
Appendix xi. Screenshot of study website

https://cdurrant2.wixsite.com/website
Appendix xii. Instructions for parents to write their child’s story

Your Child’s Story

Please write in your name:

Please write in your child’s name:

Date:

What to do: Please tell me Alex’s story, in particular all the experiences and events which have been important for him up to now. Start wherever you like and write as much or as little as you want to. When you have finished please email it to me. Thank you again for your support.
Session Plan for Interviews with Young People

I am Claire. Let me tell you a little bit about myself. I am a mum to two boys, both of whom are dyslexic. I live down on the south coast, near Brighton, and I am currently a student at the University of Sussex. Part of my studies involves doing a piece of research – so asking people about their experiences and views on various things (it’s a bit like being a detective – trying to find things out). The subject of my research is young people’s experience of school.

As well as interviewing young people like yourself, I will also be talking separately to parents/carers, teachers/teaching assistants and young people at a specialist dyslexia school.

At the end of all of this I will write a report about my research findings and this will be used to advise schools about the best ways to support young people like you.

Q Before we move on, is there anything else you would like to know about me or my research?

So, as I said, I will be asking you about your experiences and your views on things. I must stress that it is not a test. There are no right or wrong answers. I am interested in what you think about things and about your experiences. I am very flexible about how we do this. I’ve brought along some pens, paper, magazines, playdoh etc so that we can talk while doing some activities – if that is what you want. Or we can just talk without doing anything else or, if you prefer, I can ask you some questions. Or we can do a mix of all three and see how we get on.

Q What do you think? (How does this sound?)

I also wanted to just remind you that you can stop the interview at any time and you don’t need to give me a reason.
Q Would you feel comfortable to do this? (If not) Just say that you’ve had enough and I will stop the interview. I won’t be offended. Obviously, I hope that this doesn’t happen but I promise you, I will stop if you ask me to.

As I mentioned in the video/information sheet, when I write my report, I will not use your’s, or your school’s real name; if you want, you can pick a name for me to use instead? (and name of school)

Q Would you like to pick a name?

This means that no one should know that it was you who took part. You may also remember that I said that everything you tell me will be completely confidential, however, if you tell me something about you, or someone else, being in danger, then there are rules which say that I have to tell your parent/carer/trusted adult. But we would talk about this before I did anything. Does that sound ok?

Q Are you happy for me to record what we talk about so that I don’t forget what you have said? Ok, so can I put you in charge of the machine? Is that ok? (Show how to use it) (I’ll also write a few things down too)

Interview

The young person will have been asked to bring along photographs/objects/images that represent them and their world/things or places that are important to them.

Q How about we start by talking about what you have brought along with you today?

Tell me about them.

What made you pick these particular things/photos?

Why are they important?
Their story:

Timeline: Before we do anything else can you tell me a bit about any important events and memories in your life.

I’ve got a blank timeline that we could fill in together, or you can do it on your own if you prefer and then we can talk about it. (A timeline is just a way of organising your thoughts) Or you could tell me what you want to say and I’ll fill it out for you and you can check it’s correct. So, we could write on the dates here and then important events that have happened in your life here and here. The important events might be positive or negative.

Relational Map: I’m also interested in knowing about your relationships with family, friends (inside and outside school), peers (people in your class), teachers, sports coaches, music teachers etc. This will help me to understand who you are and who is important to you. We (or you) could draw what is called a Relational Map. So, you put yourself in the middle and show me how you connect to the people and the world around you. Or just tell me about them.

Identity

Ok, so we’ve talked about important events/the people around you, so now let’s talk a bit about you.

Describing yourself

How about I start by asking you to describe yourself, as you would to someone who doesn’t know you very well?

(Sometimes I find it easier to say what I think in a drawing or a collage, lego, playdoh. Would you rather you one of these to describe yourself?)

And/or.. how do you think your mum/dad would describe you?

How about your teacher? How about your best friend?

Positives and Negatives

If I were to say ‘the good things about me are…..’ How would you finish that sentence?
If I were to say ‘the not so good things about me are….’ How would you finish that sentence?

(I've got a pack of cards with some strengths and descriptions on them – shall we look at them? 2 piles – ones that describe you and ones that don't describe you)

Happy/sad?

What makes you happy? (In and outside school?)

What makes you miserable? (In and outside school?)

Or finish the sentence ‘I feel happy when….’ ‘I feel miserable when…’

(You could use this rainbow and sun to show me what makes you happy and the cloud and raindrops to show me what makes you sad?)

Attitudes to school

Let’s now talk a bit about school. Is that ok?

What do you like about school? What do you not like about school? (eg. Playtime, school dinners, peers)

Which teachers do you like? Why?

Do you get on with most of the other kids at school? Who? Why?

Differences between primary and secondary school?

Understanding/perceptions of dyslexia

So now we are going to move on to talk a bit about dyslexia. Is that ok?

What do you know about/understand by the term dyslexia? Remember there is no right answer to this. Just tell me what you understand it to be.

If you were to imagine dyslexia as some kind of ‘thing’ or picture in your mind, how would you describe it? (How about drawing it, making it out of playdoh/lego?) Or...If dyslexia was an animal, what would it look like? If dyslexia was a colour what would it be? (You could draw it or make it out of playdoh or lego?)

(If unable to do the above) How would you describe dyslexia to friends/teacher etc? Or 5 words to describe dyslexia?
What would you like your teachers to know about dyslexia?

Attitudes to dyslexia

What do you think about dyslexia?

What does it feel like to be dyslexic? (You could draw this or create a mood board from magazine cuttings of how dyslexia makes you feel)

Positives and Negatives

What are the positives and the negatives?

(Again, you could use some of these to help you:

- pack of cards with positives and negatives and you could sort them into 2 piles of positive and negative; plus are there any others
- or you could use these rainbow/suns to show the positives and clouds/raindrops to show the negatives
- For older participants: let’s look at these Word Clouds)

Show part of BDA video about seeing dyslexia differently and introducing emotional well-being: https://www.youtube.com/watch?v=11r7CFJK2sc (3.10 mins long but only show up to 2.33 mins).

What do you think about this video?

How does it make you feel?

Three elements to the video: 1) everybody’s brain is different and dyslexia affects how the brain handles information it sees and hears (spelling, reading, left from right, instructions, more thinking time to remember right word, writing, organising) 2) dyslexia affects how people feel about themselves – frustrated, angry, sad, hide difficulties 3) the good things about dyslexia (see cards).

Attitudes to support/participation

Support/help for dyslexia

Who supports you with your dyslexia? What does that involve? Probe for parents, friends, teachers, TAs, SENCo
What do you know about the support that you get at school for your dyslexia? What do you think about this support? (who helps you with reading and writing)

For older participants: Social Model of Disability

Introduce the idea of the social model of disability: Some people say that schools disable people with dyslexia because they teach in a way that suits the needs of the majority and not those of people who are dyslexic. Read quote: ‘If someone can’t understand dyslexia it’s their problem. In the same way, if someone oppresses me because of my race I don’t sit down and think, “How can I become white?” It’s not my problem, it’s theirs and they are the ones who have to come to terms with it’ (Benjamin Zephaniah, The Guardian, 2 October, 2015) What do you think of this? How does it make you feel?

Alternative World

Imagine for a moment an alternative world where school was set up for dyslexics, not just those without learning difficulties. What would it look like? (Could use pens, paper, magazines/vision board, lego).

Advice

What would be your advice to younger children who are dyslexic? Or to your younger self?

Participation

How often does someone at school speak to you about the support you get for your dyslexia and how it is going?

Does anyone ever ask you what you want/ what type of support you want?

Read out vignette: ‘Isabel is 14 and lives in Scotland. She is dyslexic. A teaching assistant supports her in class. She sits next to Isabel and takes notes for her. Isabel hates this as she says that it embarrasses her in front of her friends’.

Or it could equally be that the teachers makes Isabel read out loud in class or separates her out in class because of her dyslexia....
What do you think Isabel should do? Should she do anything/speak to someone about it?

What advice would you give to Isabel to make the situation better for her?

**The future, hopes/ambitions**

What do you want to do in the future?

What are your goals/ambitions for the future?

What do you need to do in order to achieve these goals?

How hopeful are you that you can achieve these aims?

Let’s have another look at the timeline/relational map and add what you want to do in the future.

**Video**

Show video about famous dyslexics: https://www.youtube.com/watch?v=Fr0vflgiDZc

What do you think of this video?

What are they saying?

How does it make you feel?

**Questions for educators**

Finally, I am going to also be talking to teachers/SENCos/teaching assistants?

What would you like me to tell/ask them about how they can help children with dyslexia?

Thank you so much. It has been really useful and a pleasure to meet you. Remember, that if you change your mind you can withdraw from the research up to a month after today.

How have you found the interview? Do you have someone that you can talk to about anything in the interview, particularly if you found something a bit distressing? I will
anyway leave you with the Childline number (0800 1111), just in case, and I’ll telephone you in week to see if there is anything you want to talk about further.
Appendix xiv.      Additional email sent to young person prior to the interview

Hi .......

Looking forward to seeing you at    on November 2018. Could I ask you to do one thing before we meet – bring along to the interview a photograph, an object or an image that he thinks represents him or his world or the places that are important to him. This will give him something familiar to talk about at the beginning of the interview, kind of like a warm-up. I hope this is ok?

Many thanks again for all your support.

Best wishes
Appendix xv. Interview resources: Timeline

**Significant events in your life**

Write in dates in chronological order on the chevrons. Write about each event in the space provided and connect to the dates with arrows.
Appendix xvi. Interview resources: Relational map
Appendix xvii. Interview resources: Vignette about a young girl with dyslexic difficulties

‘Isabel is 14 and lives in Scotland. She is dyslexic. A teaching assistant supports her in class. She sits next to Isabel and takes notes for her. Isabel hates this as she says that it embarrasses her in front of her friends’.

Or it could equally be that the teachers makes Isabel read out loud in class or separates her out in class because of her dyslexia....

What do you think Isabel should do? Should she do anything/speak to someone about it?

What advice would you give to Isabel to make the situation better for her?
Appendix xiii.  Interview resources: Poem by Benjamin Zephaniah

‘If someone can't understand dyslexia it's their problem. In the same way, if someone oppresses me because of my race I don't sit down and think, "How can I become white?" It's not my problem, it's theirs and they are the ones who have to come to terms with it’

(Benjamin Zephaniah, The Guardian, 2 October, 2015)
Appendix xix. Thank you card to young people

Dear [Name],

Thank you so much for taking part in my research. It was really nice to meet you and to learn about your views of school. It will be very useful when I write my report.

I was really impressed with your insight and positive attitude. Keep trying hard and be determined and you will do really well.

If you found any of the issues we discussed up setting, please let me know and I can put you in touch with organisations that will try and help (clairedurrant@btinternet.com)

Wishing you and your family a happy 2019.

Best wishes, Claire