The narrative construction of dyslexic identities in adults

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Abstract
Identity and self are complex and fragmented concepts. There are various theories, but narrative is a useful framework for understanding and investigating them. Narrative theory and social constructionism, which have similar ontological foundations but differ somewhat in other ways, are combined in this thesis to investigate how adults with dyslexia construct their identities. A new concept, ‘storyworld’, is presented and used to demonstrate how the narrative construction of lived time shapes identity construction.

The stories adults tell about their lived experience of disability allow a glimpse into the impact of disability on identity and selfhood. Dyslexia, as a specific disability characterised by difficulties with literacy, has the potential to be a moral issue with which sufferers have to contend in everyday life. This study presents findings from narrative life interviews with 14 adults who identify as dyslexic.

First, the adults’ discursive constructions of dyslexia are presented. Decisions about disclosure and concealment are important and have impacts on lived-lives and future plans. They bring up identity issues such as change and difference. Change and difference vis-à-vis a label of dyslexia, perceptions of self, thoughts about people’s perceptions and new ways one can deal with difficulties related to dyslexia, were expressed through the participants’ narratives.

The life narratives of two women are then presented as case studies, with specific reference to disclosure and their journeys from initial suspicions of dyslexia to current difficulties and identity struggles. The concept of ‘storyworld’ is used to shape the analyses, focusing on how the lived life is framed within the told story and how the participants narratively construct their lives. Finally, the narrative structures, plots and timelines of the participants’ stories are analysed. In terms of identity, the temporal complexity of the stories, exposed through a storyworld analysis, indicates the self-significance of the lived-events that are told.
DECLARATION

This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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This thesis is being submitted in partial fulfillment of the requirements for the degree of PhD......(insert MCh, MD, MPhil, PhD etc, as appropriate)

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STATEMENT 2

This thesis is the result of my own independent work/investigation, except where otherwise stated.

Other sources are acknowledged by explicit references. The views expressed are my own.

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STATEMENT 3

I hereby give consent for my thesis, if accepted, to be available online in the University’s Open Access repository and for inter-library loan, and for the title and summary to be made available to outside organisations

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Acknowledgements

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Chapter 1: Introduction

1.1 Introduction

At a primary school somewhere in the English Midlands, Katie, a seven-year-old year 3 pupil, is asked by Mrs Smith, her teacher, to sit next to Tom and help him with his work. Tom has recently been identified as having a specific learning difficulty. The school cannot provide a dedicated classroom assistant to help Tom for more than one day a week. The teacher is confident that Katie will be able to help Tom and continue with her own work unhindered. Katie becomes friends with Tom and his friends. Both Tom and Katie's lives have been influenced by Tom's identification of dyslexia.

This was the experience I had when I was a child, which led to my interest in dyslexia and how it has an impact on lives and identities. I have never had the kinds of difficulties that Tom had and I have never been identified with dyslexia. However, during the final months of studying for this thesis, I experienced an important change in my life. I was having seizures; some partial, some severe. I felt like I had become someone else. I had to take some sick leave, and plans at work and home were postponed or changed because of me. After many trips to casualty, and to see doctors and consultants, I was eventually diagnosed with epilepsy. The seizures and diagnosis had thrown my life into chaos. I have been put on medication which is supposed to control the seizures, but I am often fearful that I will have another seizure. Despite this, I mostly feel like ‘myself’ again and life has returned to relative normality.

Epilepsy is an impairment associated with damage or differences in the brain. It is disabling in the sense that authorities have confiscated my driving license, and I have been advised not to ride a bike or swim. Those who have more severe forms of epilepsy may have many more restrictions placed on them, and may never have their seizures controlled. However, it is not immediately obvious that I have a disability\(^1\). Epilepsy is one of a number of hidden disabilities. Even during those weeks where I had no diagnosis or medication, members of the public were unaware that I was ‘different’. To have had a seizure in public would make my epilepsy visible, but all but one of my

\(^1\) Unless you notice the medical alert bracelet that I wear on my right wrist.
seizures have occurred in my own home, although my first fit occurred when I was out with friends.

Thus, the impact of epilepsy on my identity has been confusing. On the one hand, I know I am different. In those first few weeks, I felt that my life had changed forever. My friends and family knew that there was something wrong with me. My father suddenly became more prominent in my life, with frequent visits to Cardiff. Suddenly, I missed my mother more. My relationship with my partner changed. Yet, I still look the same; I talk the same; I walk the same. My position in the world remains; I am still ‘me’. If I appear to be the ‘same’ person and other people cannot see my difference, how different am I really?

1.2 Identity, narrative and disability
Identity, a sense of self and ‘who we are’: these are salient issues in 21st century western society. In a world where subscribing to certain belief systems, ideologies, living in ways help to define who I am, it seems to me that identity as a subject of study is necessary in a variety of fields. If we are to understand dyslexia as more than the cognitive difficulties it represents, and if we are to understand its impact on individuals’ lives, we must engage with the project of determining how dyslexia has an impact on one’s sense of self. The life, the self, and the identities one constructs, are given meaning by the experiences one has.

Academic debates about identity and self have been theorised in many ways. Sociology, psychology, and related fields consider identity in terms of national identities, race, ethnicity, gender, sexuality and work. According to Bruner (1990), identity and self can be construed as a story told to oneself and an audience. A narrative allows identities to be constructed in interaction (Bamberg, 2011; Georgakopoulou, 2006). A narrative is also a performance of self. The story is of the lived-life (Wengraf, 2001) and the past-self (Ricœur, 1994), but it is interpreted and relayed in the present (Ricœur, 1984). This means that the narrator can construct past, present and possible future-selves, which may or may not be different. A narrative of the life may contain discrete stories of events and experiences. The notion of a narrative identity, therefore, can draw on ideas of multiple selves, represented in different narrative contexts, or storyworlds, and positioning of the self in recalled, recounted experiences. Narratives of the lives of people who have disabilities can give
a particular insight into identity construction. The concepts will be discussed in chapter 2, where I argue that narrative is a useful framework for studying and understanding identity.

Dyslexia can be considered a hidden disability. There are different approaches to theorizing disability (Riddell, 1996). Essentialist and realist perspectives posit that there are biological causes for deficits or characteristics within an individual. Thus, medical and educational provision can be applied to solve the within-person problem or treat the deficit. Marks (1999) writes about a label of mental illness leading to institutionalization from which people struggle to escape. All behaviours can be explained by their label. The many facets of human experience and behaviour have become medicalised in the twentieth century. Many social scientists have critiqued medicalisation in terms of micro-level interactions (Marks, 1999). Such research has tended to render the patient as a victim and the medical profession as harmful (Marks, 1999; Lupton, 1997). Materialist perspectives view the oppression of disabled people as rooted in economic structures and strongly related to capitalism. Disabilities have biological causes, rather than being a result of social constructs. Post-modernist perspectives theorise that no single account can accommodate the complexity and diversity of human experience.

In the present thesis, a social constructionist perspective on disability is taken. Although there may be some agreement on the definition and boundaries of impairment categories, for some labels there are no ‘adequate measuring instruments’ and applying labels relies on value-judgements (Barton and Tomlinson, 1986, p. 72). For example, Woods (1998) stated that lay people are likely to be confused about how the term dyslexia is used. This is particularly important considering the hidden nature of dyslexia.

A diagnosis of disability is a life changing experience. The changes associated with it are told through the medium of narrative whereby evaluations give insight into identity construction.

1.3 Proposal
The particular disorder of dyslexia is used to study the link between disability and narrative identities, particularly the link between hidden disability and identities. The
literature shows that there is a gap in our knowledge and understanding of hidden disabilities and the narrative construction of identities. There is very little academic research regarding narrative identities and hidden disabilities, particularly dyslexia. The research that exists within the field of dyslexia focuses on particular populations, such as teachers (Glazzard and Dale, 2013; Burns and Bell, 2011); mothers (Skinner, 2011); adolescents (Coombs, 2012); students (Pollak, 2005) and criminals (MacDonald, 2012). Thus the focus of the present study is the narrative construction of identities of those who identify as dyslexic.

In chapter 2, I present the philosophical grounding of the study, drawing on narrative theories (Dennett, 1992; Ricœur, 1984; 1994) and social constructionism. I introduce a new concept, storyworld, and argue for narrative as a way to study self and identity. In chapter 3 I discuss how narrative has been used in studies about disability or illness and identities and in chapter 4 I present the particular case of dyslexia as a hidden disability. I describe what it is and present the research questions as they relate to chapters 2 and 3.

Chapter 5 introduces methods that are useful for studying these research questions, such as narrative methods, as well as procedures that were taken in the study and the ethical issues involved and how they were resolved. I also give further explanation of storyworld and how it is used.

The data are presented and analysed in chapters: 6, 7 and 8. Chapter 6 explores how the participants talk about dyslexia, their difficulties and what dyslexia means to them. I argue that the participants’ social and personal understandings of dyslexia are essential to the continued medicalization of dyslexia and that the connotations of dyslexia and its associated difficulties have an impact on decisions about disclosure.

Chapter 7 is a case study comparison of two life narratives. Rose and Ellie both found dyslexia a hindrance at the time of my interviews with them. However, their journeys to this view of dyslexia were very different. I present their narratives of change and difference and argue that the discourses associated with dyslexia have an impact on their life story plots. In chapter 8 I focus on the other participants’ narratives of change. In particular I look at the difference between narratives of self-significant change and narratives of change not significant to the participant’s present self.
Chapter 9 presents a discussion and conclusion to the thesis, focussing on how the participants narrate their experiences of dyslexia, and how this can be explained by the literature on narrative, time and identity. I shall also discuss the implications for policy and practice, as well as the ethical issues raised in the course of this research.

1.4 Conclusion

Four years of reading, writing and fieldwork have brought me to the research reported in this thesis. The gulf between my participants and me was wide. I did not share their difficulties, and this difference was added to other aspects of my identity as a white, well educated, middle class, woman in my mid-twenties. MacDonald (2009) states that many of the participants in his research would not have taken part had he not been diagnosed with dyslexia like them. Unfortunately for this research, I cannot become dyslexic. Thus, my position as a non-dyslexic researcher has been important during my studies.

Despite the discomfort I have experienced during the past few months, I have come to realise that my diagnosis of epilepsy has given me some things in common with my participants. I now have a ‘disability’, which is mostly invisible, unless an event occurs where it is made visible. Both conditions have some form of stigma attached to them. There are, of course, considerable differences between dyslexia and epilepsy, but I think that my experiences have enhanced, if somewhat retrospectively, my understanding of the field and my participants’ stories. As a result, I hope that the participants will accept the conclusions presented herein.
Chapter 2: Narrative, identity and time

2.1 Introduction
The purpose of the present research is to investigate how people who have literacy difficulties make sense of the issues in the context of their lives. The focus of this chapter is the philosophical and theoretical underpinnings of this investigation. I will introduce theories and concepts that are important herein and discuss some their philosophical and theoretical origins. Narrative, as a form of talk, is generally understood to be universal and pervasive (Gergen, 1994). It is a form of talk that we acquire as children and it is the primary way in which we communicate our experiences and what they mean to us (Bruner, 1987; Gee, 1986; Riessman, 1990). The pervasiveness of narrative as a way of obtaining details of humans’ lives and experiences (Bruner, 1987) can be exploited to obtain data relevant to my research aim. Allowing someone the space to spell out what they have done, what those around them have done to, for and with them, and how institutions and structures have influenced their lives, can give researchers the chance to collect interesting and useful data for the study of numerous phenomena. Asking people who have dyslexia and other literacy difficulties to tell me ‘their story’, particularly how they give meaning to their experiences of living with dyslexia, will be a key part of this investigation.

How narrative data are used and analysed varies across the social sciences and humanities, but its prevalence in these diverse fields of study is a testament to its usefulness. Thus, in this piece of research, I have collected life narratives from individuals who have literacy difficulties. They have told me about their lives and what their difficulties mean to them. In analysing these stories, I have developed and used a new analytical concept that I have called ‘storyworld’\(^2\). This concept will be outlined in section 2.4, and is discussed in more methodological detail in section 5.3.2. In section 2.2 I discuss how social constructionism is an important part of narrative psychology in general, and how it is considered alongside narrative theory in this dissertation. In section 2.3, I outline the narrative theories on which this thesis rests, incorporating the concepts that are pertinent here. I will then conclude the chapter in section 2.4.

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\(^2\) The concept of ‘story world’ has been suggested by the narratologist Herman (2002) to replace the concept of ‘story’. Herman’s idea of ‘story world’ is different from the one argued for here. Herman suggests that ‘story worlds’ are mental models created by readers about the who, what, where, and how of the text.
2.2 Social constructionism
This thesis has a generally relativist framework. It assumes that reality is constructed by humans (Burr, 2003), rather than something that is “out there” to find and study objectively. Thus, the participants’ talk is considered in terms of what it does within its context. In leaning toward a ‘light’ social constructionism (Danziger, 1997), I understand that our discourses, that is our ways of talking about the world, influence the structures we live under, through, and within. Social constructionism is the foreground for many other theories of human psychology. One of these is narrative. Narratives, discussed below in section 2.3, are central to human existence (Bruner, 1987). Telling stories is a way of constructing the personal and social world, and of passing down cultural knowledge.

However, critiques of social constructionism focus on what it cannot do. Parker (1991), for example, argues that social construction’s inability to consider reflexivity as an integral part of the human condition is a weakness. In addition, the idea that individuals have any central sense of themselves is denied, giving only context dependent identities, which are continuously in flux, disorder, and incoherence (Crossley, 2000). Social constructionism is removed from the phenomenological realities that individuals face every day. The ‘subject’ is thus lost in the ether of ontological ambiguity. Given the ontological difficulties associated with a discursive self, Crossley (2000) argues for the use of narrative within psychology. She argues that narrative psychology has the methodological and theoretical fortitude to uphold the social constructionist principles of linguistic and discursively constructed selves, whilst also acknowledging the lived, personal, and coherent nature of self-understanding (Crossley, 2000). In this way, narrative can be seen to add depth to social constructionism.

2.3 Narrative
2.3.1 Narrative identity
The ubiquitous nature of narrative means that studying it can give useful answers to concerns of human and social psychology. We live according to narrative structures (Bruner, 1990; Sarbin, 1986). In general, narrative theories (e.g. Bamberg, 2011; Bruner, 1987; 1990; McAdams, 2001; Sarbin, 1986) subscribe to the notion that human life is storied, and that we live our lives in ways akin to narratives. We think, imagine,
interact, perceive, and make moral decisions according to narrative structures (Sarbin, 1986). These narrative structures allow us to impose order, give structure to, and make meaning of our experiences.

However, there is tension between narrative as a way of understanding personal and social life and as a mode of transmitting past events in the form of a story. This tension can be built on as part of the strength of the approach. It can be re-configured as the simultaneous expression of past events and meaning-making of personal and social life. The past events that a narrative brings to the fore are constructions of former worlds lived by the narrator and the characters he or she creates. In analysing these stories, these constructed pasts, I aim to understand how the narrator constructs his or her selves and identities.

The notion of ‘self’ is a ‘quirky idea’ according to Bruner (2002, p. 63). It seems like common sense but evades definition. The variation of thoughts about identity, self, subject and person reveal the difficulties inherent in studying the ways in which human beings are individuals, whilst simultaneously belong to groups and societies. There are important differences between self and identity, although these differences are understood in distinctive ways across the social sciences. The APA dictionary of psychology (Vandenbos, 2006) states that identity is:

an individual’s sense of self defined by (a) a set of physical and psychological characteristics that is not wholly shared with any other person and (b) a range of social and interpersonal affiliations (e.g. ethnicity) and social roles (p. 312)

The dictionary then states that a sense of self reflects one’s feelings of identity, uniqueness, and self-direction, as well as their self-concept, and self-image (Vandenbos, 2006). I take this to mean that identities are features of and within the self, and simultaneously the self is labelled and given meaning through identities.

One of the many ways in which we can talk about identity is through the use of categories, specifically membership of social categories. These may include gender, ethnic group, nationality or class among others, and mark out differences and similarities between individuals. Medical labels represent other kinds of categories, such as ‘disabled’, ‘epileptic’ or ‘terminally ill’. In disability studies, markers of disability are ripe for stigmatization. In the literature on disability, there are three important
aspects when considering identity: stigma, labelling and embodiment. These will be further discussed in Chapter 3.

The assumption that life is storied (Bruner, 1987) has consequences for how research on identity and selfhood can be done. The inherent temporality of narratives allows me to consider a sense of self as the ‘whole’, which has some stability across time, whilst simultaneously changing through experiences. Thus, a self is a changeable entity, with past selves, a present self, and possible future selves (Ricœur, 1984). The self is made by the lived-life and is told through narratives which recount actions, meaningfully organised to accomplish coherence in terms of the life: the narratively constructed self.

Thus, selves are broad in the sense that they encompass a range of identities. Identities, in this thesis, are understood as positionings (Davies and Harré, 1990; Lucius-Hoene and Deppermann, 2000). People can only express and make sense of their experience of the world through discursively available categories (Davies and Harré, 1990). People are ‘positioned’ by discursive practices in which they partake by learning and using particular discursive practices (Davies and Harré, 1990). A person sees the world from the vantage point afforded by the subject position they take up. The images, metaphors, stories and concepts of discursive practices, which vary within discourses, inform the individual’s options in taking up particular subject positions (Davies and Harré, 1990). Identities vary depending on available positions within the discursive practices and stories through which we understand our lives (Davies and Harré, 1990). The stories within discourses allow subject positions to become available. Multiple selves are realised through diverse performances and identities are negotiated in different social situations (Harré, 1998). The process of positioning can be understood to mean that identities are located within conversations through discursive processes and are fleeting constructions made in talk, and as such can be investigated through analysing talk.

According to Davies and Harré (1990), discourses shift and positions change in different storylines, thus we have many possible selves. One’s thoughts about oneself are not necessarily coherent. These contradictions need to be dealt with and resolved in some way. We learn how to do this through our lived narratives and knowledge of
other narratives, social structures and discursive practices. The notion that there is choice within contradictory positions allows agency (Davies and Harré, 1990). Taking Davies and Harré’s (1990) arguments, one way in which researchers can access identity is through the narratives that individuals tell.

Lucius-Hoene and Deppermann (2000) took up Davies and Harré’s (1990) theory and suggested analytic focus on discursive frames of interaction, with early stages of interaction as important as interview interaction. There are a number of interactions taking place in the interview situation, and thus numerous positionings. These include the present-narrator with the past, present, or future narrated-self, the present, past, or future researcher, ‘hidden addressees’ of the past, present or future, and other individuals of the past, present or future. The narrator may also tell of interactions between narrated past, present, and future selves and those around them. These positionings are situated in past, present and future storied events. Lucius-Hoene and Deppermann (2000) suggest that plot organisation is a device to position characters performatively. Drawing on Sacks (1992), they argue that emplotment is advantageous for presenting the self by narrative events that indicate claimed identities through category bound activities (Lucius-Hoene and Deppermann, 2000).

Our lives, our selves, and our identities are brought into being through story telling (Dennett, 1992; Ricœur, 1994). We make meaning of lived events, which without human sentience would be a series of random events, through narrative (Ricœur, 1994). Many scholars argue that narratives can outline peoples’ claims about who they are and how they want to be understood. For example, Gergen and Gergen (1988) state that it is through stories that we are and wish to be understood, and through which we understand ourselves. They argue that particular forms of narrative telling point to different forms of self. If an individual told a ‘stability’ story (one of three forms of story that Gergen and Gergen present, the others being regressive and progressive), directionless and repetitive, he or she would be considered ‘a candidate for psychotherapy’ (Gergen and Gergen, 1988, p. 28). Similarly, Riessman (1993) states that life narratives are often concerned with the breaches between self and society, between ‘real’ self and ideal selves. Tellers’ attempts to convince interlocutors that certain events happened allow them to present evidence of how these events had an
impact on their past selves, present self, and possible future selves (or identity in Riessman’s (1990) terms).

Thus a particular self and particular identities are created in particular conversations for particular reasons, although certain elements of the self are maintained (Riessman, 1990). These ‘particularities’ of stories told in different circumstances mean that difficulties lie in how much a told story can tell us about the narrative self and identities of a person (Lucius-Hoene and Depperman, 2000).

Bamberg (1999) draws on Davies and Harré’s (1990) theory of positioning. He reports on personal accounts which tell stories of similar circumstances in different ways. A speaker may attempt to position herself in many ways: to save face; to present herself as particularly knowledgeable or ignorant about certain topics; to appear kind and moral; or to appear powerful or weak, among many more. These positions are made possible in two ways. The dialogical context of the conversation (Bamberg, 1999) is one way. The context of the telling of narratives is related to the discourses which shape acceptable forms of narrating experience. There are subtle, tacit, rules which are ingrained in discursive practices (Davies and Harré, 1990). Life narratives depend on the discourses of particular cultures and subcultures (Bruner, 1987). Culture allows ‘possible selves’ through its influence on narrative telling (Bruner, 1987). ‘Life is not ‘how it was’, but how it is interpreted and reinterpreted’ (Bruner, 1987, p.31).

The second way is the listeners’ positioned identities. These identities are positioned both through the story told by the teller, and by the listeners’ actions within (and external to) the interaction (Davies and Harré, 1990). Davies and Harré (1990) expand on this in their theory of identity positioning. When someone behaves from a position, they bring their history into conversations. This history encompasses experiences of being in multiple positions and engagement in different discourses (Smith, 1988). However, positioning may not be intentional. It is through conversations we discuss and tell personal stories, and thus these autobiographical parts of conversations help participants to know how their co-conversant envisions their self and other people (Davies and Harré, 1990). They are able to identify the positions they take up in particular stories, and thus how they are positioned (Davies and Harré, 1990). The
process of positioning in conversations, with stories consisting of parts, characters and scenes, is no different from narrative processes of positioning.

Squire (1999) studied narratives of people affected by and infected with HIV. She argues that the narratives told by the participants enabled possible, provisional identities to be articulated. Through using the ‘coming out’ genre, individuals in this research narrated their experiences of stigma negotiation and the possibility of death. These interviews showed that personal storylines are linked to wider historical, cultural and social formations of ‘self’ (Squire, 1999). This analysis supports the idea that identities are taken up in particular interactions through dialogical positioning, as well as discourses and the socio-historical context of both the telling time (when the story is told) and the time being told (the storyworld, as discussed below) (Davies and Harré, 1990).

The philosophical underpinnings of this thesis, that life is storied and that selves and identities are constructed through narratives, come from theorists such as Ricœur (1984; 1988; 1991; 1994), Taylor (1989) and Dennett (1992). These theorists, although working in the same field, have different views on how identity and self are related to narrative. Perhaps the most radical of these is Dennett (1992). Although he is a ‘mild realist’ when it comes to psychological phenomena such as beliefs and selves, believing that empiricist methodologies can allow us insight into any number of phenomena, his ideas about how the brain creates a ‘fictional self’ are useful. He argues that we have the mental (brain function) capacity to narrate our lives (Dennett, 1992). Thus we can organise our lives, our selves, and define the boundaries between ourselves and our peers.

In essence, the self is like a ‘centre of gravity’. It is not real, merely a product of what can be described from life; thus accounts of life, both first- and third-hand, constitute the self. He states:

We try to make all of our material cohere into a single good story. And that story is our autobiography. The chief fictional character at the centre of that autobiography is one’s self (Dennett, 1988, p. 1029)

Dennett (1992) argues that third-person stances are needed to explain human experience and behaviour, as the psychological tradition of mapping psychological
concepts onto areas of the brain is insufficient in understanding the human condition.
His focus on the brain as a central aspect of making the self is problematic for this
thesis, mainly due to my commitment to a more relativist approach. However, the idea
that the brain creates a ‘fictional self’ is useful when considering the narrative
construction of selves and identities.

In contrast to Dennett, Ricœur’s (1994) theory about self includes the notion that self
is not a mental object. Instead, it is constructed through narrative, which solves an
important problem for ideas of self and identity: the problem of change and
continuity. If the self, along with everything else, can only be experienced in the
present, as Ricœur (1984) argues, the use of narrative, represented by a story told in
the present, is necessary for understanding and constructing selves and identities. As
discussed above, self and identity are different, and Ricœur brings together the
change/continuity problem with the temporality of narrative, a ubiquitous form of
communication.

On a slightly different note, Taylor’s (1989) view of self is that it is understood in a
space of ethical questions. He notes that the ‘good’ we implicitly take for granted is
made explicit through our use of narratives, and thus we construct ourselves through
the evaluations we make of the events we have narrated. The evaluations we make of
our lives are a part of being-in-time, which is dependent on localising lived events into
larger temporal wholes. These wholes, and thus the evaluations we make, are situated
within a wider context of our lives. We experience, and therefore narrate, lived events
in terms of their value and morality.

2.3.2 Plot
In narrating our ‘selves’, we constantly reconstruct the past, which includes memories
and dreams, through the lens of the present, in order that we can make sense of
ourselves (Bruner, 1987). Steedman (1986) states that the past can only be interpreted
through our knowledge of the social world and our place within it. Ricœur (1991)
echoes this sentiment when he suggests that the stories we tell are linked to wider
narratives (i.e. the social context in which public narratives are told). This means that
we can frame the stories that people tell (the personal) through the wider social
context in which they are told (the social). This is what identity can be framed as, the
space where the social and the personal meet, and where ethics are considered important (Taylor, 1989).

The present study draws on the notion that the self can be presented through narratives of life. Telling a life narrative allows multiple selves to be presented across time. Time is important in the told-story. It becomes ‘human time’ as it is organised within the narrative. We thus understand our life, and selves, through narrative. Narrative represents human reality (Ricœur, 1984). By interpreting life, we story it. This means that life is interpreted as narrative and leads to self-understanding (Ricœur, 1984). Plot and causality are essential to narrative. Ricœur (1984) stated that narrative is meaningful ‘to the extent that it portrays the features of temporal existence’ (p. 3).

However, plot is only one aspect of narrative. Ricœur (1984) argues that narratives exist on three fronts, the three Mimeses. In Mimesis 1, he references the ‘world of action’, the events of the story that are imitated in the narrative. For this thesis, Mimesis1 is considered the ‘lived life’, to use Wengraf’s (2001) term. There are no beginnings, middles, or endings: the world of action is pre-narrative, but is organised through structure, symbols, and temporality. Mimesis2 represents the process of emplotment transforming actions into a story (Ricœur, 1984). Plot combines various indispensable aspects of narrative, such as agents, interactions, intentions, and temporally distant elements through a unifying theme. Mimesis3 represents the juncture of the text (story = M1 and M2) with the hearer (or reader). I understand this to be where the teller and the listener come together in a co-construction of meaning of the teller’s life, as represented in her story.

In Wengraf’s (2001) two-pronged approach to narrative analysis, where he draws a (somewhat faint) line between the lived-life and the telling-of-the-told-story, it is the narrative themes that are part of the end goals of the analysis, like imposing a ‘sense of an ending’ on a story (Ricœur, 1984, 66 – 67). The events are from Mimesis1, the world of action, or the lived-life, but the play is created by the author through Mimesis2, or Wengraf’s (2001) told-story.

Although temporal aspects of stories were the subject of much early narrative work, more recently temporality has fallen out of vogue and been replaced by work on
‘small’ stories (Bamberg, 2011), narratives-in-interaction (Georgakopoulou, 2006), and genres (Squire, 2003). However, I think that the temporal nature of stories is what makes them interesting to study in the first place. In Bamberg’s (2011) research, ‘small’ stories are analysed as talk-in-interaction using discursive and conversation analysis (CA) techniques – in the same way that other spoken prose is. Using Bamberg’s (2011) ideas, we could be studying any kind of talk or interaction. All that makes such work ‘narrative’ is its unit of analysis – a story. By contrast, the present piece of work returns to earlier conceptions of narrative analysis, with a particular concern for narrative temporality.

Emplotment keeps a story together and should be the main subject of study. The temporal ordering of a story gives the listener or reader a hook on which to place their understanding of the events as they unfold. How the events are ordered leads the narrator to convey his or her understanding of those events in their evaluation (Labov and Waletzky, 1997). The listener, and researcher, are given an insight into the narrator’s frame of mind in the moment of the telling (the told-story) and in the time the events took place (the lived-life) (Wengraf, 2001).

Narrative time and real time mirror one another (Ricœur, 1984). We understand narrative because we understand life and vice-versa (Ricœur, 1984). Narrative, as a form of language use, consists of many elements. Labov and Waletzky (1997) outlined these in their seminal work about narratives of personal experience. However, evaluation is considered the most useful in terms of identity and selfhood, although content is also important in this respect (Labov and Waletzky, 1997; Bruner, 1987). Time is threefold in Ricœur’s view. Past, present and future are held in mind though memory and intention, which gives meaning. Meaning is produced and understood within time, so narrative is the richest form of language use in human meaning and identity (Ricœur, 1984).

2.4 Time, narrative and storyworld
Back and forth time-travelling in narrative is vital to understanding the present (Andrews, 2014; Mead, 1932; Jarvinen, 2004; Brockmeier, 2000; Ricœur, 1983; 1984; 1985). Jarvinen (2004) noted that Ricœur and Mead’s theories of time and narrative have similarities that can be exploited in social scientific studies of narrative. Ricœur
(1983) argued that pasts and futures only exist in the present and Mead (1932) stated that the past can only be understood in the present. Life is only ever understood backwards; the present is always confused and unintelligible until it becomes the past. The pasts we choose to narrate are significant for making sense of our current circumstances.

Earlier experiences are given new meanings after emergent events (Freeman, 2003; Jarvinen, 2004). Meanings constructed in the present reflect the self and are a result of the emplotment of earlier experiences. Although the end of the story is the present day, an autobiographical life-story can never be finished (Jarvinen, 2004; Brockmeier, 2000; Bruner, 2002). The ‘end’ of the story may leave a ‘to-be-continued cliff-hanger’, although the narrator may move forward in time to suggest futures made possible by present day meaning-making. Narrative time-travelling is essential to the narrative construction of identities (Andrews, 2014).

History is a form of knowledge that relates today’s perspective to yesterday’s lived experience (Ricoeur, 1988). Questioning about the past is always from specific perspectives of the present. In the interview situation, the narrator evaluates past experiences from the circumstances in which she finds herself (Jarvinen, 2004). Life must be understood backwards, from the perspective of the present, therefore the narrator’s present circumstances frame the plot of his or her life narrative (Brockmeier, 2000; Jarvinen, 2004). Time is manipulated by the narrator from her present perspective as she attempts to make sense of her past. The self is able to reference ‘beyond the present’, to the past and future (Mead, 1932). We organize people’s attitudes towards us and our attitudes towards them into our biographies. Life history is constructed indirectly from someone else’s perspective. The present is anchored in social interaction, so the audience is important, as Lucius-Hoene and Deppermann (2000) argue.

I build on Lucius-Hoene and Deppermann’s (2000) framework, Mead (1932) and Ricoeur’s (1983) theories, and Wengraf (2001) and Rosenthal’s (2004) approach for a new concept in narrative research: ‘storyworld’. The interactions within the narrator’s story between the narrator and an interlocutor are situated in the interview context, but also within the life-narrative itself. The lived-life can only ever be known in-the-
living or in present day narrative re-constructions. A life narrative comprises some self-contained stories and descriptions of events. As narratives do not tend to stick to a linear model (Brockmeier, 2000), the narrator time-travels in telling his or her life story, narrating self-contained stories and descriptions in a non-linear order (Andrews, 2014). One way of conceptualising self-contained stories is as a ‘storyworld’ – a time-bound event or experience told within a narrative. This helps to break down a life narrative into particular time periods, within which one or more experiences and events took place.

A storyworld can represent as big a time frame as the narrative or analysis calls for. A part of the narrator’s life where he or she was depressed is a storyworld, and the events that are narrated within that year of depression are further storyworlds. Thus a narrative can become a series of storyworld frames, and frames within frames. Positioning occurs within each storyworld, as each one is an account of the narrator’s experience(s). A series of told ‘storyworlds’ represent events that contribute to the teller’s present day evaluations. Evaluations may stretch across time, or be bound within storyworlds, which I call ‘storyworld evaluations’.

This concept is useful in linking the lived-life and the telling-of-the-told-story. A storyworld is an experience in a particular point in a subject’s life. A ‘storyworld’ can be anything from a few words in a full narrative, e.g. when the narrator says “and of course I was being bullied in year 10”, to a ten minute narrative in which the narrator gives a very detailed account of his or her experience. The length and style of the ‘storyworld’ is relevant to the point of the narrative and the theme through which the researcher can analyse the narrator’s identities.

Analysis of the storyworld includes how the subject re-constructs the experience, positions the self, and constructs identities. Studying changes in identities from then to now, and analysing the temporal structure of the narrative and the narrator’s evaluations demonstrates the importance of events. The past is reframed in the present. Events happened in linear sequence until the narrator reached the present and future events will inevitably take place. However, telling all those events one after the other within the context of a story, or an interview, would be pointless. The narrator tells with a point in mind and selects which events and experiences to
reconstruct. Each storyworld is only relevant to the situated narrative and may only make sense at the end of the interview as argued above. The narrator evaluates and gives meaning to the lived-life within the ‘telling-of-the-told-story’.

The use of evaluation, an important part of storytelling that illuminates the narrator’s meaning structures in different parts of the narrative, may show the importance of temporal interaction (Lucius-Hoene and Deppermann, 2000). Drawing on Lucius-Hoene and Deppermann (2000), I suggest that the positionings of the past, present, and future selves can be used to express the relationship between those selves across time, some of whom know different things, have had different experiences, and who have had more or less time and opportunity to give meaning to their experiences.

The narrator’s present self-situation is shaped by their relationship towards the past self they are narrating and evaluating (Lucius-Hoene and Deppermann, 2000). The past, present and future selves acted in particular circumstances at particular times. The temporal aspect considered important by various scholars (Brockmeier, 2000; Lucius-Hoene and Deppermann, 2000), can be used to categorise those selves as more than ‘past’, ‘present’ and ‘future’. The concept of ‘storyworld’ makes it possible to consider temporal interactions between these selves more clearly. For example, a childhood has multiple selves and identities. By analysing the stories told, as well as the interactions between the narrator and narrated self in each storyworld – a bounded childhood event or experience – it is possible to consider multiple identities and the more complex ways in which they interact with present, future and further past identities and to contribute to the self.

Our autobiographies are constructed as continuous interpretations and reinterpretations of experiences. As time moves forward, our identities change through the stories we tell which are re-informed with new experiences, old experiences constructed in new lights, and new possible selves as a result of the more recent past. Our narratives, and thus our identities, are inextricably bound up with the temporal. If we conceive time as constituted of three presents: a past present, a present in the present, and future present discussed above (Ricoeur, 1984), Lucius-Hoene and Deppermann’s (2000) ideas about intra-interview positioning can be developed.
Individuals use their memories and hopes and fears for the future to guide them as they continuously construct and re-construct their selves (Bruner, 2002). The stories that we tell our-selves, far from being made up from scratch each time we tell them, are updated, as we grow older and as our memories fade and change through the stories that we tell (Bruner, 2002). We have no other way of relating ‘lived time’ except in the form of narrative, as it seems that narrative is best able to capture the sense of ‘lived time’ (Bruner, 1987; Ricœur, 1983). ‘Life itself’ does not exist in any real sense, but is firstly an accomplishment of memory recall and secondly an interpretive act (Bruner, 1987).

Identity is constructed through memories shaped in the story (Lucius-Hoene and Deppermann, 2000). The narrator needs to select storyworlds which give the overall life story credence and coherence (Lucius-Hoene and Deppermann, 2000). The plot of the story is constructed through the organisation of storyworlds and the time-travelling narrator who takes the researcher along with him or her (Andrews, 2014).

According to Rosenthal (2004) a life story approach to research interviewing is based on a number of theoretical assumptions. First, in order to understand and explain psychological and social phenomena, researchers need to reconstruct how they were created, reproduced and transformed. Secondly, studying individuals’ subjective perspectives and meanings they give to their actions allows researchers to understand those actions. In order to understand and explain a biographer’s narrative, researchers need to interpret it in the context of their current life and present and future perspectives (Rosenthal, 2004).

The distinction between life history and life story should be considered in narrative research (Rosenthal, 2004). Wengraf (2006) argues that the distinction between the lived-life and the told-story emphasises its situated nature. He suggests that narrative interviews should be analysed through two tracks, the lived-life and the ‘telling-of-the-told-story’. The concern in analysis should be the Real Author’s subjectivity and our reconstruction of it as the author struggles to tell and not tell through their narrative (Wengraf, 2006). Like Lucius-Hoene and Deppermann (2000), Wengraf (2006) advocates the idea that what is spoken is merely one part of what is heard. He states that:
The significance of the ‘telling’ can lie in as much or more in exposition of the ‘asides’, in patterns of apparently trivial idiosyncratic expression, as it can in the formal exposition of the ‘story’ on the ‘theory’ on which the speaker is focussing their self-presentational attention (p. 3)

Thus, analysing the ‘telling-of-the-told-story’ helps to seek the ‘basic theme’ of the person behind the text and his or her subjectivity in historical (biographical) situations. The telling-of-the-told-story is the business of the temporal organisation of storyworlds. These temporal placings reflect a narrator’s meaning making – how they are making sense of their lives in the here-and-now. Temporal and positioned identities show how the narrator’s there-and-then selves became their here-and-now selves. For Wengraf et al (2002) life stories are based in both social history and individual personality. Life stories reach forwards and backwards in time, and analyses of them help us understand links between the personal and the social.

2.5 Conclusion

In the present research, the philosophical grounding lies in narrative psychology. Narrative and social constructionism are two different traditions that have different emphases. However, like Crossley (2000), I take a narrative approach which upholds the social constructionist principles of discursively constructed identities and selves. Taking Ricœur (1984; 1994) as a starting point, I use narrative theory as a framework for identity and self construction. Narrative is an important aspect of human psychology, incorporating the lived-life and told-story (Wengraf, 2001). The told-story organises lived experiences into a plot, constructing past worlds in the light of the present. These constructions can be analysed to investigate narrators’ past-, present- and possible future-selves.

The new concept of storyworld integrates ideas from Dennett (1992), Ricœur (1984; 1994), Lucius-Hoene and Deppermann (2000) and Jarvinen (2004), and will be used in this thesis to analyse the stories of adults who identify as dyslexic. In chapter 3 I review previous research on narrative, identity and disability.
Chapter 3: Disability and identity

3.1: Introduction
In chapter 2 I argued that narrative is a useful framework for identity and introduced a new concept: storyworld. In the present chapter I am going to further explore the idea of ‘narrative identity’ through empirical applications of narratives of disability. I shall argue that identity construction is influenced by disability and that there are differences between visible disabilities and less visible disabilities in identity construction. There are different approaches to theorizing disability (Riddell, 1996). In the present chapter, I discuss narrative studies of disability and identity. In section 3.2, I shall outline different perspectives on disability, but the focus will be on the social construction of disabled identities. In section 3.3 I shall discuss the concepts of diagnosis and labelling in relation to disability, particularly more visible and less visible or hidden disabilities. Section 3.4 focuses on what narrative is and how narrative analysis can be conducted. Section 3.5 focuses on narratives of less visible disabilities and chronic illness. Studies of those who experience conditions like chronic fatigue syndrome (CFS) / myalgic encephalomyelitis (ME), multiple sclerosis (MS), autism and others will be discussed. Finally section 3.6 will conclude the chapter with a summary of some of the aspects of identity and disability.

3.2: Disability
Disability has a variety of aspects to it: visible or invisible physical differences; mental and psychological impacts; social relationships; and cultural understandings. An example may be pertinent here. An individual, who has a facial disfigurement, maybe through an accident, is visibly different from most individuals. The psychological impacts of this accident and its embodiment means that their outlook on life may change; people see them differently and their social relationships may suffer (or improve). Cultural understandings of disability have a huge impact on how they are treated and how those around them understand them and their difficulties. There are barriers to the world, which may prevent their participation in certain experiences and events. They could be admitted to a group of people who face some of the same experiences (Prior and O’Dell, 2009).

If one is disabled, one is ‘different’. Social practices, such as the treatment of people with disabilities, produce and are produced by discourses of what it means to be
‘disabled’. Differences which characterise disability are pathologised and treated within medical discourses of ‘healthy’, ‘strong’ and ‘normal’ or ‘unhealthy’, ‘weak’ and ‘abnormal’. These dichotomies form understandings of what it is to be ‘disabled’ or ‘not disabled’. However, Shakespeare (1996) argues that disability is not a case of stark differences between ‘disabled’ and the able-bodied. Instead, we are all impaired to a certain degree. It is important to deconstruct the ‘normality-which-is-to-be-assumed’ (Shakespeare, 1996, p. 96).

In contrast, an approach which takes as its starting point that all aspects of life are a result of cultural and social processes allows those with impairments to be considered within the social context they inhabit. The disabled people’s movement, and the social model of disability, posit that disability does not reside in the individual, rather it resides in the culture and society in which the individual lives, works and plays. According to the Union of Physically Impaired Against Segregation (UPIAS), a disability is defined as:

> the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of activities (Cited in Riddell and Watson, 2003).

This definition follows from a definition of impairment as ‘lacking all or part of a limb, or having a defective limb, organ or mechanism of the body’ (cited in Riddell and Watson, 2003). Barnes (1994) states that disability is the limitation of opportunities to participate in community activities equally due to physical or social barriers. A ‘social organisation’ and its lack of provision for people with disabilities mean that there are exclusionary barriers for these individuals, which do not exist for those who do not have impairments (Marks, 1999).

This shift in perspective from disability as a within person deficit to disability as a result of social barriers means that these barriers and their impacts can be investigated to inform debates about disability and identity and, on a more practical level, to challenge society’s treatment of people with disabilities. The term ‘disability’ is construed as a negative label of difference that upholds social marginalization. There are a variety of approaches used within disability studies to understand disability as
more than biological deficit and individual defect. An approach related to the social model approach focuses on a disabled minority oppressed by the state (Shakespeare, 1996). The focus is on power and identity politics, and in an attempt to receive better provision for those with impairments. Another approach focuses on how the state deals with people with disabilities; social policy is seen as the body constructing and labelling individuals with impairments as ‘disabled’ (Shakespeare, 1996).

However, the approach most aligned to the social and cultural construction of identity discussed in chapter 2 considers disability in the same way. Shakespeare (1996) argues that such an approach, without ignoring the material, environmental and polity factors of disability advocated by the social model and the other approaches outlined above, ‘offers a richer and more complex picture of disability’ (p. 98). Disability as a social construction and as a product of cultural norms and social practices is nicely juxtaposed with narrative identity construction (Shakespeare, 1996). Shakespeare (1996) argues that disability identity is important, as it is through identity that we can begin to understand the complexity in the relationship between individuals, biology and society.

3.3 Hidden or visible disability
Identity is embodied (Giddens, 1991). The body allows us to cope with external situations and events; it is a practical thing. The relationship between the body and identity is complex. For some disabilities, embodiment is an immediate concern. If one is to be, and be seen as, a competent social actor, one needs to monitor both body and face. People are supposed to be completely in control of their bodies. If they are not seen to do so they must maintain that nothing is ‘wrong’. The identity is maintained through control of the body, whilst also being ‘on display’ (Giddens, 1991). Loss of limb, pain and limited mobility give solid clues to both the individual and society that the body is different. Able bodied, healthy individuals are part of the normative discourse that surrounds the idea of ‘human nature’ and the social hegemony of activity. This is more apparent for those who have the most visible disabilities, which are markers in social contact.

The differences for people with facial disfigurement, for example, are visible. The impact of such visible differences were investigated by Prior and O’Dell (2009). They interviewed mother-child pairs about how they coped with the child’s difference.
‘Living with impairment’ was an important active process needing constant vigilance by both mothers and their children. Mothers compared how well they were coping ‘now’ with previous times. The children’s experiences with bullying seems to show the importance of appearance to adolescents. However, some disabilities do not have this obvious connection with the body.

Labels help to categorise and identify those who are different from ‘normal’ people. They are linguistic devices that ‘other’ people who have disabilities. Labels allow people to identify those who are in need of assistance, but rely on the dependence of disabled people, on the non-disabled. Labelling is a focus of contention within academia and the media. Gallagher (1976) gives a summary of the positive and negative outcomes of having labels. Labels lead to further research and greater understanding of the affliction under study. They may lead to treatment and helpful changes in the environment, whilst also calling attention to a lack of resources which can be rectified through funds and legislation. However, labelling may not be helpful. If it is done for its own sake there may be no treatment or support. It may help to maintain the status quo by keeping minorities at the bottom and focus on within-child problems rather than on changing the environment.

Riddick (2000) identifies seven key areas in the labelling process:

1) the nature of the label and its content;
2) what the label means to social groups;
3) relationships between labels;
4) the context in which the label is applied;
5) who applies the label;
6) why the label is applied;
7) and the history of the development of the label.

Huibers and Wessely (2006) discuss the advantages and disadvantages of labelling chronic fatigue syndrome (CFS). On the positive side, a label gives the individual empowerment; the knowledge gained from a diagnosis brings an end to uncertainty and determines the next steps, including treatment. There seem to be positive feelings related to receiving a label – it is comforting and there is relief to know you are not imagining things and you can maintain or regain credibility and legitimacy in terms of
your symptoms. A label can provide access to patient organisations, which may provide support and information. As a socially accepted reason for what may be a stigmatised behaviour, a label can help an individual preserve his or her self-esteem. A diagnosis may ‘bring meaning to suffering’ (p. 898) and understanding and sympathy from some people.

However, there are of course negatives which may counter these advantages. The belief that one has a serious disease could be harmful to identity and self-esteem (Huibers and Wessely, 2006). A diagnosis may lead to focusing on the symptoms which may be self-reinforcing and lead to worse outcomes and thus the label may be a self-fulfilling prophecy, particularly in the case of CFS (Huibers and Wessely, 2006). The individual may transgress into the sick role and develop an ‘illness identity’ above all different identities (Huibers and Wessely, 2006). They may experience victimisation. Access to support groups tend to over-represent chronic sufferers who hope for a ‘cure’ where this is unlikely (Huibers and Wessely, 2006).

Despite these positives and negatives, it seems a ‘fact’ of life that individuals are labelled and diagnosed, particularly those with impairments. At the most basic level, ‘the disabled’ as a label is used in contrast to those who are not disabled (Shakespeare, 1996). This sets up a binary opposition between normality and abnormality, which infiltrates policy, culture and society. ‘The disabled’ are physically different, defective and less productive in a society which values wealth production. There are various forms of impairment and there are labels for each, no matter how arbitrary. The cultural construction of disability is made up of how we describe individuals and how we then interact with them.

In most physical interactions, individuals are able to see any visible impairments, such as the use of a wheelchair, a guide dog or cane, or the lack of a limb. In terms of identity, Charmaz (1994) comments that when disability is visible, it becomes a ‘master status and a master identity’ (p. 48), it overrides any other aspect of identity. A visible difference may interrupt the social norms of physical interactions and is the focus of social interactions.

These obvious differences, along with other aspects of visual presentation of self (e.g. clothes, hair, stature, skin colour) contribute to linguistic interaction. Riddick (2000)
states that there is a common belief that labelling automatically leads to stigmatization, negative expectations, experiences and outcomes. Labelling also denies the individuality of the person. However, stigma can occur both before the label is applied, or even when the label is not applied at all. In this sense, labels merely support and maintain existing stigma.

Goffman (1963) was an important thinker in self and identity studies. His work on stigma shows how important the ‘right’ or ‘wrong’ attributes can be to identity but he has been critiqued on his theory of stigma, particularly for being too negative (Barnes et al, 1999). However, the distinction he made between visible and hidden disabilities was important. It meant that individuals are disgraced with visible disabilities, yet discreditable with hidden, or less visible, disabilities. If you are discreditable, due to dyslexia or CFS for example, it becomes easier to ‘pass’ as ‘normal’ (Goffman, 1963). However, in different contexts less visible disabilities become more visible to peers and powerful and important people, which may lead to stigmatisation. Thus, a label is not necessary for stigma to occur (Riddick, 2000).

Goffman (1959; 1963) is useful up to a point. His ideas about presentation of self are useful for explaining ‘passing for’ normal, as outlined above, and discredited and discreditable identities. However, in the present thesis, selves and identities are more than performed in interaction. As discussed in chapter 2, they are constructed through narratives and are strongly dependent on the temporality of lived-life. Goffman’s focus is on how the self is presented in the current interaction. In contrast, the study of narrative allows past- and future-selves to be considered as well. Thus, the use of Goffman is confined to incidences of the participants’ references to discredibility or stigma.

Labels may be formal or informal, and private or public (Riddick, 2000). Stigmatisation can be independent of formal labelling and having a label at the private level can be positive. People can reframe their labels as providing explanations of their difference and deflecting negative criticism of their difficulties. However, when a label moves into the public sphere, it may lead to ridicule and inferiority. Low (1996) states that context is very important for people with disabilities. Individuals have to negotiate connected and contradictory non-disabled and disabled identities depending on the environment.
In addition, Quicke and Winter (1994) argue that the advantages and disadvantages of labelling depend on context and the nature of the label.

3.4 Narrative studies
Before embarking on any kind of analysis, narrative or otherwise, it is useful to operationalise the unit of analysis. The term ‘narrative analysis’ suggests that the unit of analysis is ‘a narrative’. However, ‘narrative’ is a slippery concept and one that needs further attention. How it is defined depends very much on the analytic approach used (Riessman, 2008). Narrative analysis has many different approaches. These approaches can often be divided into three kinds: structural analysis, thematic analysis and dialogic / performance analysis (Riessman, 2008). The approaches can also be thought as either micro (Gee, 1991; Labov and Waletzky, 1997) or macro (Riessman, 1993; 2008).

One touchstone for most social researchers who use narrative is the work of Labov and Waletzky (1997) (Riessman, 2008). Labov and Waletzky’s (1997) approach rests on stripping the narratives people tell to their constituent, functional parts of Abstract, Orientation, Complicating Action, Resolution, Evaluation and Coda. According to Labov, these are structural clauses inherent to narratives, which are temporal and referential. The clauses in a narrative need to appear in the order in which they happened; otherwise, it is not a narrative. Labov and Waletzky (1997) found that all the stories told by their participants adhered to this model of narrative. The first of these, the abstract and the orientation, occur before the first narrative clause and orient the listener to the contextual elements of the narrative: behavioural situation, place, time and person. This function may be performed within the narrative proper (Labov and Waletzky, 1997).

The second clause is the main body of the narrative: the complication. This clause is where the story hits an important turn of events. The characters reach some significant experience and the plot is entrenched. The clause may comprise of a series of events, which in the narrative may consist of several complication sections in several simple narrative cycles. The complication section is followed by the resolution, which signals the end of the complication.
The evaluation is considered to be the section which makes a narrative complete (Labov and Waletzky, 1997). The evaluation gives the point of the story and fends off the question ‘so what?’ It gives meaning to the narrative and helps the narrator establish the function of the narrative. Andrews (2010) suggests that the end of the narrative is important and allows an appreciation for concluding the events described. Lives are lived forwards, yet understood backwards. Formally, the evaluation section does not contain temporal clauses and it is often merged with the result of the clause. The degree to which it is merged with the result is an important characteristic. Ricoeur (1984) states that the end of a narrative provides a view point from which the story can be understood. The narrative may end here, or there may be a coda which brings the narrative back to the present time (Labov and Waletzky, 1997).

Labov and Waletzky (1997) state that this overall structure is not prescriptive, but represents a ‘normal form’ for the presentation of personal experience. Although Labov and Waletzky’s (1997) definition of narrative does not provide researchers with ways of analysing the narratives they elicit from their participants, their structural description of narrative may provide a starting point for analysis. Indeed, by determining which clauses of a narrative have the functions that Labov and Waletzky (1997) describe, researchers can analyse how a narrator persuades listeners events really happened, or happened in the manner described, and brings drama to a story (Riessman 2008). Moreover, it can help researchers to interpret the relationship between meaning and action in the early stage of analysis (Riessman, 2008).

Several researchers have formalised ways of defining narratives that do not fit into Labov’s criteria neatly. For example, Kraus (2002) postulates that such narratives may be called ‘deficit’ narratives, while Prince (1989) argues that they may be described as ‘minimal narratives’, and Bamberg (2005) states that narratives which do not meet all of Labov’s criteria can be called ‘small stories’. It can be argued that narratives are much more than the sum of their parts and Labov and Waletzky’s approach does not allow researchers to see how stories that are longer and more complex with flashbacks and asides are put together (Riessman, 2008). According to Gee (1991), his approach is useful for analysing these more complex narratives.
Gee (1991) gives a description of his structural approach, which allows researchers to investigate how listeners interpret narrators’ stories. His conception of narrative is broader than Labov and Waletzky’s (1997) (Riessman, 2008). Gee (1991) maintains that the structure of spoken language is similar to the structure of language used by poets. He says that the ways in which narratives are told, in terms of stress and pitch glides, reflects the narrator’s intentions in telling the story (Gee, 1991). He gives a five level approach to analysis, the first of which involves the researcher parsing the interview text / narrative into idea units, lines, stanzas, strophes and parts of the narrative. This provides a framework for the other analytic levels to work. The second level involves interpreting the syntax and cohesion of the narrative, which give narratives their logic (Gee, 1991).

The next level involves distinguishing material that is on the ‘main line’ of the plot, usually main past tense or historical present clauses, from material that is not part of the ‘main line’ of the plot, but which contributes to the narrative in other important ways by giving context (Gee, 1991). The fourth level is what Gee (1991) calls the ‘psychological subjects’, which are the grammatical subjects of main clauses; the subjects from whose points of view the listener hears the narrative. There may be many in one narrative, but usually only one or two in each stanza or strophe. The final level, which Gee (1991) calls the ‘focusing system’, takes on board all of the interpretation from the previous levels as well as locating the themes of the narrative in order to make sense of it.

Gee’s approach allows researchers to interpret narratives in terms of narrators’ intentions and therefore is useful in investigating individuals’ narrative selves as the narrative is studied as being close to the person. However, this can also be understood as its limitation, as, if individuals’ selves and identities are created in interaction (Davies and Harré, 1990), interpretations of the speakers’ intentions are only as useful as the listeners’ interpretations. In addition, structural approaches to narrative do not focus on the content of narratives. The content of narratives is important, as it gives narratives interest and can relate strongly to speakers’ identities. Indeed, given that one of the main aims of this research is to investigate how dyslexia is constructed, focusing on the structure of narratives alone would not enable me to study dyslexia constructions. However, using grounded theory approaches to analyse the content of
the participants’ stories would provide useful analysis of dyslexia constructions, as discussed in chapter 5.

In addition, approaches to narrative that use thematic analysis focus on the content of what is told, rather than how it is told (Riessman, 2008). Murray (2003) suggests that the researcher needs to consider the narrative account as a whole, paying close attention to the structure. He states that themes may be considered, but only in relation to the narrative framework (Murray, 2003). Riessman (2008) states that as it does not attend to the interactional properties and form of language, thematic analysis of narratives is similar to grounded theory. The narratives presented tend to be ‘cleaned’ up and the interviewer tends to be written out. This means that the interviewer’s role in constructing the narratives, and therefore participants and their selves or identities, are in danger of not being considered in this kind of analysis. However, constructions of ‘dyslexia’ can be considered with this kind of thematic analysis.

An interactional approach to narrative is used by many researchers in the field of narrative analysis. The dialogue between narrator and listener, or two narrators, is analysed. This can be done in a variety of ways, from using an approach such as conversation analysis to approaches which draw on grounded theory (Riessman, 2004). Closely aligned to this approach, Riessman (2008) states that the performative aspects of narration can be useful to analyse. This takes elements of thematic and structural analysis, whilst adding other dimensions such as conversation analysis and symbolic interactionism (Riessman, 2008). It allows researchers to investigate how talk is dialogically produced and performed as narrative (Riessman, 2008). It asks ‘who?’, ‘when?’ and ‘why?’ of the narratives produced (Riessman, 2008). In this kind of analysis, how culture and society enter storytelling is important, so interactional, historical and institutional contexts may be considered.

In the dialogic / performance approach to narrative analysis, narratives are considered a performance of identities. This has important implications for how narratives are studied. In addition, this approach also draws on the work of Bakhtin (2000), who said that meaning emerges between people in a dialogic environment. He also stated that texts come from many voices, such as political and historical discourses, as well as the
voice of the one speaking or writing (Bakhtin, 2000). This means that narratives are also multi-vocal and that they are saturated with meanings from previous usage. Context, therefore, is imperative to the interpretation and analysis of narratives in this approach.

One other way of analysing narratives is to consider the genres that narrators draw on in telling their stories (Murray, 2003; Riessman, 2008). Fyre (1957, cited in Murray, 2003) gives four genres that narrative can take: comedy, romance, tragedy and satire. This was extended by Plummer (1995) who added the following genres: taking a journey, engaging in a contest, ending suffering, pursuing consummation and establishing a home. He stated that genres tend to have common elements: tension, crisis (or turning point / epiphany) or a transformation. In addition, different plots can be present in the same narrative.

In Gergen and Gergen’s (1988) approach, the story’s journey through evaluative emotion can be brought out. This enables researchers to match emotional ups and downs of a narrative, to particular genres which tend to follow the emotional patterns of normative narratives. Narratives can thus be visually represented to aid researchers with links to these ‘grand’ narratives which are important in society as a whole. The ways in which individuals draw on ‘grand’ narratives, whether purposefully or not, can help researchers in their quest to investigate identity presentation and construction from the telling of narratives in either naturally occurring or research specific contexts.

3.5 Disability and illness in narrative studies
Whatever the context, the study of turning points has proved useful for researching illness and disability narratives (Holland and Thompson, 2009; Cuhna, Gonçavles and Valsiner, 2011). Bury (1982) has conceptualised the impact of illness on the self as a biographical disruption. Illness may also cause a ‘loss’ of self, whereby the ‘new’ self is not a valuable replacement for the ‘old’ one (Charmaz, 1983). They struggle to reconstruct their life histories, which need to be repaired to continue to maintain consistency and rebuild the self (Werner et al, 2004; Whitehead, 2006). Individuals need to participate in the sense making opportunities that narrative provides in order to incorporate their diagnosis into their life histories (Whitehead, 2006). The difficulties of incorporating illness or disability into self-narratives include thoughts of
illness related to shame, blame, and stigma, which serve to construct illness as a moral event (Werner et al, 2004; Horton-Salway, 2001a).

The last few decades have seen an increase in studies that focus on illness, disability and identity. For example, Charmaz’s (1994) work on the identity dilemmas of chronically ill men. She states that sudden onset of illness in men poses particular identity dilemmas. These result from the loss of valued parts of their lives, such as physical functions, social roles, leisure activities, valued attributes and understanding of self. The dilemmas are lived out along the lines of risk taking, independence, dominance, a particular public persona versus forced passivity, dependence, subordinance and acknowledgement of private feelings. An individual’s choice between these differing aspects of being brings costs. This means that the maintenance of the previous identity is very difficult.

Charmaz (1994) identifies the course of the lived and told illness narrative: at first it is experienced as an ‘acute interruption’ before it becomes an ‘intrusive illness’ (p. 38); then the individual’s development of narrative of self changes; this is followed by an attempt to recapture the past. Identities are shaken by the threat of death: attempting to maintain one’s former, healthy self risks death or decline; acknowledging a closer death is threatening to identity. Some men may attempt to ‘bracket’ off their illness or disability so that it has no impact on their life or identity. However, Charmaz (1994) states that acknowledging the illness and its attributes can lead to turning points, reflection of the past and self-appraisal, where one comes to value the shift in one’s life and starts to ‘live in the present’, rather than the past that is so different from present and future circumstances.

Different views or perceptions of illness or disability seem to impact differently on identity (Charmaz, 1994). These different perceptions are by no means mutually exclusive; they change over time or across different situations and contexts. By making illness meaningful, the men change their definition of it which leads to a change in their sense of self (Charmaz, 1994). In attempting to lead a ‘normal’ life, one must preserve the self by maintaining continuity and coherence. This may involve limiting how much illness interferes with particular aspects of life, controlling one’s definition of the illness, and using strategies to minimise the visibility and knowledge of the
illness or disability (Charmaz, 1994). By using their agency in this way, some of the
men in Charmaz’s (1994) study were able to do impression-management (Goffman,
1959) and ensure continuing interaction, thus maintaining identity.

The dilemmas encountered by the men in Charmaz’s study reflect the crises identified
in McQueen and Henwood’s (2002) analysis of troubled teenage boys’ talk. They
compare and contrast the narratives of two boys. They highlight one boy’s use of
cultural images and ideas of masculinity to position himself in the context of his life
history. The accounts given suggest dilemmas of self-positioning as a young man. The
other boy describes himself as having different ‘sides’ of his personality. The boys’ self-
positioning was related to the inconsistencies and contradictions in their talk. The
identity constructions available to the boys were used through the concept of
traditional masculinity.

Watson (2002) analysed accounts of disabled people, conceptualising these accounts
as situated, contextualised and partial. He reports that some reject any notion of
impairment in the construction of their identity, but acknowledge and negate their
physical difference. Identity is constructed as ‘normality’ for these participants. The
creation of a narrative incorporating impairment in identity normalises the impairment
itself. The separation of body and identity is part of their narratives. Those who are
‘othered’ by their impairment reconstruct ‘normality’, acknowledging their difference
but presenting it as insignificant. They distance themselves from the ‘disabled’ label
and make identities away from conceptions of ‘disabled as inferior and subordinated’.
However, whether they are reinforcing a stigma by denying disability, or attempting to
strip difference of its importance is debatable. In contrast, another set of participants
did incorporate disability into their identity, but as a negative attribute with negative
consequences.

Robinson (1990) analysed the written personal accounts of the lives of people
diagnosed with MS. He used a framework of illness in relation to sickness and disease.
By focusing on the trajectories of the stories (Gergen and Gergen, 1988) and then the
content and form, he presents an understanding of the telling of ‘stories of MS’. He
found that those with MS seem more likely to tell narratives that emphasise positive
perceptions of life than earlier studies indicated. Although not a study of identity,
Robinson advises that the methods he employed and the subsequent analyses could provide greater understanding of ‘the person and their illness’ in a novel way.

A study which does focus on identity in MS is a case study. Riessman (1990) presents the narrative told by a man with MS and the presentation of self and illness in his telling. The narrator has MS and was recently divorced from his wife. In her analysis, Riessman argues that the narrator (Burt) uses narratives of particular experiences and events to present himself as a good husband, willing to forgive, a good father who was limited in the extent to which he could take up that role; and a good employee. All his problems with marriage, fatherhood and employment are the result of his physical impairment. In this way he maintains a positive impression of himself. The narratives he tells help to keep important aspects of his masculinity alive.

Riessman (2002) looked back at the data presented in the 1990 study in a talk at Cardiff University in which Burt’s narrative was contrasted with another man’s narrative (Randy), also diagnosed with MS and divorced. In their narratives both position themselves as agents in a world where their illness was forced upon them. Their outlooks, perceptions of their abilities and constructions of new selves differ substantially. They ‘do’ illness and masculinity differently in their talk. Riessman states that their illness narratives reflect their resources, the historical context, the kind of men they have been in terms of employment and the kind of men they are becoming. For Randy this is a progress to a new self, for Burt this is a static narrative in which he longs for work, but with that possibility looking less likely all the time.

Werner et al (2004) studied the accounts of women who suffer from chronic pain, sometimes as a result of MS. They found that the stories the women told were performed as persuasive counter-narratives to a culture of scepticism and distrust, to convince an audience of their credibility, as there is always the danger of invalidation in a disorder which has no obvious signs of causality. There are social rules, norms, dictating the extent to which one should talk about pain and difficulties (Werner et al, 2004). The participants’ narratives negotiate self-identity as only ill within bio-medical expectations and the accepted performances of self.

There is an attempt be a ‘good’, moral patient. Werner et al (2002) discuss the discourses the women draw on in their accounts of difficulties. The medical narrative
of ‘hysteria’ and their difficulties having no legitimate cause seemed to permeate their stories, but they engaged in counter-narratives to the medical stereotype of laziness, craziness, weakness as a woman and an excuse for all three. Their stories maintain their faultlessness in their disability, but they struggle to legitimise their difficulties (Werner et al, 2002).

Horton-Salway (2001a) also analyses narratives of a less visible disability: myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS). She takes a discursive approach to investigate how someone with CFS and her partner make sense of the condition and its causes. This approach defines psychological phenomena as situated, discursive constructions. Thus, in narratives of events experiences, individuals’ stories can be considered performances of social action, ‘where identity construction is part of a practical activity of defining an illness and explaining its causes’ (Horton-Salway, 2001a, p. 248).

CFS is a contested and controversial condition (Huibers and Wessely, 2006; Horton-Salway, 2001b), blighted by early debates over its nature and how it should be named or labelled. There is a wealth of debates within academia and media about its existence, causes and treatment. Speakers run the risk of their account being dismissed due to perceived stake or interest. There is a danger that the status of CFS will be denied within social interactions (Werner et al, 2004; Horton-Salway, 2001b). How those with CFS discuss it is important to their identity construction. In the narrative Horton-Salway (2001a) analyses, the interviewees work up the idea that the illness is physical rather than psychological. Through their talk on life before CFS, they provide evidence that negates the psychosomatic causes of difficulties.

Huibers and Wessely (2006) ask whether a diagnosis of CFS is disabling by encouraging people to identify with label of ‘illness’, or whether it legitimises people’s suffering so that they can obtain support and care. They investigate the pros and cons of labelling, as outlined in section 3.3. The label itself, the choice between ‘chronic fatigue syndrome’ and ‘myalgic encephalomyelitis’, reflects divisions within the literature and lay persons’ understandings. The term ‘ME’ is a bio-medically rooted term sometimes preferred by patients wanting to give legitimacy to their diagnosis. In contrast, the medical and academic community seem to prefer the ‘CFS’ label, which suggests a lack
of causal attribution, allowing a multi-factorial approach. According to Hamilton et al (2005) the labels given (or taken) have different impacts on identity. In addition, Huibers and Wessely (2006) cite evidence to suggest that negative perceptions of illness, self and symptoms may impact negatively on their physical and psychological difficulties.

The idea that CFS is a cultural phenomenon and a mirror of society is espoused by a number of commentators (Ware, 1999; Zavestoski et al, 2004). Huibers and Wesseley (2006) discuss the depiction of CFS as a meme; it allows symptoms of distress to be organised in a medically accepted diagnosis. Diagnoses of CFS have increased since its identification and increased media exposure (Huibers and Wesseley, 2006). Receiving a diagnosis is influenced by various factors such as access to health care, perception of illness and diagnosis seeking, beliefs and aspirations, and medical professionals’ attitudes. By attributing symptoms to a bio-medical label (diagnosis), an individual and his or her symptoms are given legitimacy, responsibility is negated and it is easier to deflect stigmatisation (Horton-Salway, 2001a). In addition, this label affirmed by a doctor maintains illness beliefs.

The quest for understanding of symptoms of any illness or disability is important in attempting to acquire a diagnosis and ending a period of uncertainty (Huibers and Wessely, 2006). It also gives an individual a chance to reconstruct their lives to fit with their new diagnosis (Whitehead, 2006). Whitehead (2006) found that after developing CFS, it is possible for sufferers to develop new and positive self-identities. She cites the three phases identified by Charmaz (1994): symptoms are experienced as ‘acute interruption’ before becoming an ‘intrusive illness’; development of narrative of self changes; then an attempt to recapture the past. However, these identity-illness stages were not fully linear, with participants often swinging between total disruption in the first phase of illness and either disability as ‘total self’, as part of the whole self, or as a ‘supernormal’ self, and back again. At first, identity related to career, social life and family life were disrupted (Whitehead, 2006). For most people in Whitehead’s study new identities were positive, incorporating both aspects of old self before CFS and the new self, maintaining continuity in the self-narrative. The individual adapts to the change that illness or disability brings.
3.6 Conclusion
In this chapter I have argued that disability has a profound impact on identity. Disability is a product of impairment and disabling social, polity and physical environments. Disabilities are diagnosed and labelled as a result of these environments, which has effects on the identity of individuals with impairments. Illness or disability onset as a disruption of biography is well documented in the literature (Bury, 1982); a lost, past self needs to adapt to illness in the construction of a new self (Charmaz, 1994). The reconstruction of life narrative can maintain coherence (Werner et al, 2004; Huibers and Wessely, 2006; Whitehead, 2006), although there are difficulties inherent in this act (Horton-Salway, 2001a). Narrative can be used as a sense making device after the onset of symptoms and diagnosis.

Disability may be experienced as gendered identity crises through which effective impression management needs to be performed (McQueen and Henwood, 2002; Riessman, 2002; Werner et al, 2004; Charmaz, 1994). The construction of disability and identity may reflect cultural norms, images and the historical context (McQueen and Henwood, 2002; Riessman, 2002; Horton-Salway, 2001a; Huibers and Wessely, 2006). Disability may be constructed as a part of a normal identity, although physical difference is acknowledged and identity narratives tend to express attempts at maintaining agency and control over life (Watson, 2002; Riessman, 1990; 2002). Contested and controversial disorders such as CFS may present opportunities for dismissal and stigma in social interactions (Horton-Salway, 2001a). It is to another contested, less visible disability that we turn to in chapter 4.
Chapter 4: Dyslexia as a disability

4.1 Introduction
As discussed in chapter 3, disability is characterised by both bodily and environmental challenges. In the present chapter, dyslexia is depicted as a particular, and peculiar, disability. This is highlighted by discussions of an environment where literacy is considered normative, through the idea that illiteracy is a morally unacceptable position, as discussed in section 4.2. Literacy encompasses acquired skills, which need to be taught and learned. Teaching and learning are never equitable; some may struggle to teach, some may struggle to learn. In addition, there are external factors which influence how well someone is able to read and write.

One reason for literacy difficulties is that an individual is dyslexic. Dyslexia, as argued below in section 4.3, can be construed as a result of a physical impairment. Added to an environment where literacy skills are highly valued, and illiteracy is considered useless, and even immoral, the inability to interact with written language can be considered a disability. However, dyslexia is a unique disability. Like others, though, dyslexia has its own peculiarities. Similar to other conditions such as CFS and ME, dyslexia is a ‘hidden’ disability (Horton-Salway, 2013). The debates surrounding dyslexia can be compared to the debates surrounding other ‘hidden’ and controversial conditions.

Despite a plethora of research on the self-esteem and self-image of dyslexia, as well as sociological research, very little research has been conducted on the narrative identities of adults with dyslexia. In section 4.4, I present an argument for doing such a project by bringing together the knowledge, and lack of knowledge, about these issues in the literature presented above.

4.2 Literacy in society
Literacy is an important aspect of society in the UK in the 21st century. Governments work hard to attempt to increase the literacy skills of children and adults in their countries. Individuals who are deemed ‘functionally illiterate’ have a twofold disadvantage: economically and emotionally. At the macro-level, the consequence of adult functional illiteracy relates to the country’s economy. Literacy, or illiteracy, does not exist in a vacuum. There are a number of factors associated with the ability to read
and write. The education of children, both by their parents and their schools, is seen as a major influence on literacy levels. Illiteracy is stigmatized (Collinson et al, 2011). Individuals who struggle to read and write may be seen as stupid, lazy or otherwise inferior. But, what if your struggle to read and write is due to neither of those things? What if you have a ‘reason’ for your difficulties?

Literacy refers to the ability to read, understand and write written language. It means that one has the ability to use written language to communicate effectively. Someone without these skills is said to be illiterate (Carey, Low and Hansbro, 1997; Young and Tyre, 1983). Individuals in modern Western cultures need to acquire literacy skills in order to participate fully in society (Carey, Low and Hansbro, 1997; Pumfrey, 1990; Young and Tyre, 1983). Although the ability to communicate verbally may be considered an inherent attribute that children develop through their interactions, reading and writing skills are more complex and need to be taught (Pumfrey, 1990; Snowling, 2000). Many children learn these skills with ease, but many require more teaching, possibly specialised instruction, in order to attain the basic skills required to function in society in the UK (Pumfrey, 1990). There are those who never attain these skills and are deemed ‘functionally illiterate’ (National Literacy Trust, 2010).

The importance placed on literacy skills cannot be overstated. The cost of low or nonexistent basic skills is threefold: personal economic (i.e. the inability to get a job, keep a job or attain a promotion), personal emotional (through social exclusion for example) and public economic (the cost of supporting those who cannot find work due to their difficulties and the cost of training in these skill areas). According to a CBI survey (2009), 40% of employers are worried about their employees’ poor basic literacy and numeracy skills. Many employers take it upon themselves to train employees in these skills, but feel frustrated by this need (CBI, 2009). However, it is generally expected that these basic skills are taught in compulsory education (CBI, 2009). Literacy is perceived as a necessity in modern Western society (Snowling, 2000).

Literacy, then, is considered to be a ‘good’ thing, while illiteracy is considered ‘bad’. This polarisation gives credence to policy making which favours literacy over illiteracy. Policy makers then try to ameliorate society’s literacy level (Welsh Government, 2009). The term ‘functionally illiterate’ refers to people who are not able to read or write beyond the level of an 11 year old (National Literacy Trust, 2010).
2012a, b). Literacy skills are taught in schools, which are mostly state controlled. In addition, families are also expected to take part in teaching children literacy skills (Clark, 2009; Clark and Hawkins, 2010). This means that those children whose parents are less literate may be starting out in life with less favourable circumstances than children whose parents are literate. Moreover, there is a stigma associated with illiteracy, as literacy skills are often associated with intelligence (Young and Tyre, 1983) and illiteracy is considered a moral imperfection (Collinson et al, 2011). This makes identifying those adults who struggle to read difficult, if not impossible. Despite this, the evidence remains that there is a substantial percentage of adults in the UK who struggle with reading and writing.

The reasons for people struggling with these ‘basic’ skills are varied and may depend on their experiences of compulsory education (Dugdale and Clark, 2008; Pumfrey, 1990). This is especially important given the number of policy changes that have come into effect in the past half-century. There is a possibility that a proportion of ‘functionally illiterate’ adults had some form of additional educational need. Given that provision for such pupils has changed dramatically over the past 50 years, different generations of adults would have different experiences of school. It is possible that there are many adults whose needs may not have been recognised at school, for three reasons: first, some individuals may not and may never be considered to have special educational needs, for various reasons; second, teachers may not be able to identify special educational needs; and third, there are adults who went to school before the effects of the Warnock Report (1978) were felt.

Various governments’ definitions, reports and statistics regarding citizens’ abilities to read and write are not the whole picture. Cook-Gumperz (1986) states that schooling ensures the continuance of a stable society and helps the development of important social changes. Literacy has a ‘symbolic significance’ in Western societies as literacy rates provide an indication of ‘how well’ society is doing. Individuals who ‘perform’ literacy are exercising socially approved and approvable talents. Literacy is thus socially constructed and has moral virtue. However, there is a tension between the idea of literacy as a moral virtue and literacy as a functional set of skills. Functional literacy is

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4 The Warnock 1978 report, *Inquiry into the education of handicapped children*, informed the subsequent 1981 Education Act. This Act introduced statements for pupils who have special educational needs, which allowed them to have specialized help in accordance with their particular needs.
based on school taught and classroom-learned literacy and is essential to the social transmission of knowledge. Social class remains an important aspect of literacy acquisition (Cook-Gumpertz, 1986). The morally and socially acceptable ‘functional literacy’ is constructed through school and formal teaching of reading and writing.

There are a substantial number of adults in the UK for whom reading and writing remain a struggle. The stigma associated with their difficulties means that theirs may be a hidden struggle. As mentioned above, responsibility for teaching people these skills tends to rest with the schools we attend in childhood, although there are other arenas in which individuals can develop these skills beyond school. There may be several reasons for people’s reading and writing difficulties. However, the heterogeneity of the problems that are associated with poor basic skills does not seem to have been recognised until recently. Although functional illiteracy and dyslexia are not synonymous, many of those adults who struggle with reading and writing may have dyslexia. Their dyslexia may have been formally identified, or it may not be identified. Although there have been many research studies that investigate the impacts that functional illiteracy has on health and crime, as well as on the cognitive abilities of adults who are illiterate, there seems to be a dearth of research that gives a voice to those who struggle with reading and writing. In section 4.3, I go into a more thorough discussion of ‘dyslexia’, its nature, causes, the debates that surround it and the gaps that have emerged in the literature.

4.3 What is dyslexia?
Like CFS, dyslexia is a condition that has divided academics and practitioners (Hunter-Carsch, 2001; Rice and Brooks, 2004; Tønnessen, 1997). It is characterised by literacy difficulties, but only in certain circumstances. Dyslexia cannot be identified if the individual has another condition which may otherwise explain his or her difficulties or if he or she has not had adequate instruction (Riddick, 1996). Some literacy difficulties may not be identified as dyslexia; if an individual’s intellectual ability explains their poor reading and writing, they may be described as ‘garden variety’ poor readers (Badian, 1994). Since dyslexia has become more widely acknowledged, both in the education sector and in policy, it seems that more and more children have been identified as dyslexic at school. However, this leaves generations of adults who may have never been identified with dyslexia, or who may have been identified in later life.
Dyslexia, described variously as a learning difficulty, learning disability (LD) and special educational need (SEN) (Riddick, 1996), can be compared to and aligned with other aspects of human variation: disabilities and medical disorders. There is a significant amount of research that has been carried out to discover the causes of dyslexia (Burden, 2005). There has been a significant amount of money spent on trying to help individuals with dyslexia. Regardless of the debates surrounding its existence, nature, causes and treatment, dyslexia is a reality for many (Burden, 2005). In addition to literacy difficulties, dyslexia has other aspects to it: organisational problems, sequencing difficulties and confusion between left and right (Riddick, 1996). However, the relationship between literacy and dyslexia is strong, and the idea that literacy is an important skill in the context of 21st century Britain can be related to the hegemony of literacy (Collinson et al, 2011).

Like CFS, or ME, the term ‘dyslexia’ is contested and controversial. According to the Code of Practice for Special Educational Needs (DFES, 2001), pupils are entitled to special educational provision if they have a learning difficulty that cannot be overcome with standard educational provision. Special provision refers to provision that is additional to or different from educational provision that is made for children of their age in LEA maintained schools. A learning difficulty is defined as a significantly greater difficulty in learning than their peers or a disability that prevents pupils from accessing educational facilities that are otherwise accessed by their peers (DFES, 2001). In the UK, the term ‘specific learning difficulties’, or SpLD, is often used interchangeably with ‘dyslexia’. However, this seems to be an umbrella term, which encompasses dyslexia and dyscalculia (Elliott, 1990).

According to Miles et al (2003), the term ‘specific developmental dyslexia’ is used to describe the syndrome. This is shortened to ‘dyslexia’ in the UK. In the USA, the term ‘dyslexia’ is also used, but many research papers refer to the same syndrome as ‘reading disability’ (RD) or ‘learning disability’ (LD) (Hunter-Carsch, 2001; Kavale and Forness, 2000). These differences in terminology may not be important, as they all seem to describe the same difficulties. However, the differences between and within the USA and the UK represent just one way in which the field is ridden with controversies and contestations. Huibers and Wessely (2006) state that the term ‘myalgic encephalomyelgia’ (ME) is often preferred by sufferers as it has connotations
of a bio-medical cause. In contrast, professionals and academics tend to use the term ‘chronic fatigue syndrome’, suggesting a lack of causal attributions. I think that the preference for ‘dyslexia’ or ‘SpLD’ is not so marked, but in the present study, I use the term ‘dyslexia’ throughout, rather than RD, SpLD, LD or specific developmental dyslexia. The reasons for this are threefold. First, the research is being carried out in the UK, where the term ‘dyslexia’ is in common parlance, helped by the various media reports about ‘dyslexia’. Second, most people I have talked to who have this syndrome refer to it as ‘dyslexia’ rather than anything else. Finally, I think that the term ‘dyslexia’ is easier to read than any of the other terms, especially when it is not in inverted commas.

Controversy surrounds the definition of dyslexia (Tønnessen, 1997; Woods, 1998). Although it had been recognised since the later 19th century as ‘congenital word blindness’, ‘developmental alexia’, and ‘dyslexia congenita’ (Campbell, 2013), one of the first official definitions was offered by the World Federation of Neurology who defined dyslexia in 1968 as:

a disorder in children who, despite conventional classroom experience, fail to attain the language skills of reading, writing and spelling, commensurate with their intellectual abilities. (World Federation of Neurology, 1968, cited in Tønnessen, 1997).

Since then there have been various definitions applied across disciplines. The Division of Educational and Child Psychology (DECP) of the British Psychological Society (BPS) gave a working definition of dyslexia as:

evident when accurate and fluent word reading and / or spelling develops very incompletely or with great difficulty. This focuses literacy learning at the ‘word level’ and implies that the problem is severe and persistent despite appropriate educational opportunities (BPS, 1999, p. 8).

More recently, the British Dyslexia Association (BDA) defined dyslexia as:

a specific learning difficulty which mainly affects the development of literacy and language related skills.
It is likely to be present at birth and to be life-long in its effects. It is characterised by difficulties with phonological processing, rapid naming, working memory, processing speed, and the automatic development of skills that may not match up to an individual’s other cognitive abilities.

It tends to be resistant to conventional teaching methods, but its effects can be mitigated by appropriately specific intervention, including the application of information technology and supportive counselling. (BDA, 2010)

In contrast, definitions given in scientific (biological, neuropsychological) papers tend to suit the tone of the article. For example, Grigorenko (2001) defines dyslexia as:

...a complex biologically-rooted behavioural condition resulting from impairment of reading-related processes (phonological skills, automised lexical retrieval and verbal short-term memory, in any combination) and manifested in difficulties related to the mastery of reading up to the level of population norms under the condition of adequate education and a normal developmental environment (p. 94)

The differences between these definitions are related to their purposes. The definition given by the World Federation of Neurology was a first attempt to define a concept that had hardly been reported. The BPS is a society for academics and practitioners and the DECP working party maintains that their definition is a working definition to be used by practitioners, but that it can be changed as more research is completed. The British Dyslexia Association is a charity which exists to lobby for change that benefits people with dyslexia. The BDA considers adults with dyslexia, parents of children with dyslexia and dyslexic children as the main benefactors of their work.

The benefits and disadvantages of these definitions of dyslexia have been discussed and debated at length in the literature (Hunter-Carsch, 2001; Riddick, 1996; Stanovich, 1992). Such variety of definitions (along with other factors) feeds into differing research findings, which explains why so many experts in the field have widely differing views (Tønnessen, 1997). The definitions presented above remain controversial in terms of their commitment to explaining dyslexia as a ‘within-child
deficit’. For over a century, there has been no one over-arching definition that is agreed upon by researchers, academics or policy makers, let alone teachers, parents and dyslexics themselves.

Indeed, Miles (1995) suggested that context-based descriptions are more desirable than definitions. A description, rather than a definition, negates the need for the meaning or explanation of the term dyslexia, and instead provides us with an account of the syndrome. Thus, it can be said that the majority of practitioners and academics in the UK would describe dyslexia as:

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\text{an unexpected difficulty in reading, writing and spelling, given the child’s intelligence, that is not due to lack of educational opportunity.}
\]

In the present study, the description of dyslexia above is considered appropriate. However, what does it mean in practice?

The notion that dyslexia is solely about difficulties in reading, writing and spelling seems an obvious fact that the various definitions and interventions support. However, there are arguments that claim that dyslexia is much more than literacy difficulties. Mortimore (2003), for example, argues that both strengths and difficulties occur in the dyslexic profile. Indeed, many commentators note that dyslexia is characterised by: a difficulty in learning sequences of things, such as the seasons or the months of the year; confusion between left and right; difficulty in spelling; organisational difficulties; as well as difficulties in learning to read and write (Ried & Kirk, 2001; Stein, 2001; MacDonald, 2009). In addition, Ried and Kirk (2001) and Stein (2001) argue that it is experienced differently by different people. Not all dyslexics display the same characteristics, nor will they display them to the same degree (Ried and Kirk, 2001; Miles et al, 2003). However, the traditional dyslexic profile is of someone who is bright, but who has difficulties with reading, writing and spelling (Mortimore, 2003). The ‘bright but frustrated’ stereotype prevails.

Given the heterogeneity of dyslexia, some researchers claim that there may be different ‘subtypes’ of dyslexia (Miles and Miles, 1999). The existence of subtypes of dyslexia provides a neat explanation for why individuals experience their difficulties differently. Research in the 1980s and 1990s focused on the possibility of two subtypes: a phonological deficit subtype and a surface dyslexia subtype (Fletcher et al,
In the 2000s this research has continued and has generated important and exciting insights into the neurological functions and mechanisms implicated in dyslexia (Katzir, 2008). However, we do not seem to be much further in pinning down and describing specific dyslexic subtypes. At least, research in other fields of dyslexia does not seem to distinguish between different subtypes. It seems that one is either dyslexic, or not dyslexic.

Research into the aetiology of dyslexia seems to be fragmentary, contradictory and inconclusive, due to the variety of definitions and screening procedures used in research projects (Rice and Brooks, 2004). There are a variety of theories that attempt to explain dyslexia. Theories of dyslexia have tended to either focus on the biological level or the cognitive level. Either way, these theories have tended to construct dyslexia as a ‘within person’ problem, whose cause can be attributed to measurable cognitive deficits and differences.

Theories about the causes of dyslexia vary between cognitive theories (of phonological deficit (Bradley and Bryant, 1983; Snowling, 2000; Ramus et al, 2003; Pennington and Bishop, 2009); visual system failures (Rice and Brooks, 2004); memory deficits (Stein, 2001)); biological theories (genetic influences (Meng et al, 2011); and cerebellar deficits (Nicolson, Fawcett and Dean, 2001)). Although much progress has been made in trying to establish why some pupils struggle to learn to read and some do not, these are competing theories, and some (such as the cerebellar deficit hypothesis) are controversial.

How should practitioners, parents and individuals identified with dyslexia deal with dyslexia? Interventions to aid pupils who have reading difficulties, dyslexia in particular, are varied (Shaywitz, Morris and Shaywitz, 2008). Various studies have found that interventions which provide focused, explicit instruction in phonemic awareness, phonics, fluency, vocabulary and comprehension result in improvements in reading ability (Shaywitz et al, 2008). Multisensory teaching approaches are often hailed as the best form of reading instruction for individuals with dyslexia (Birsh, 2005). The learning styles approach focuses on the reading, writing and other strengths of the (adult) dyslexic individual (DfES, 2004).
There are also various physiological approaches, such as the Meares-Irlen approach and the Dyslexia, Dyspraxia and Attention disorder Treatment (DDAT). The Meares-Irlen approach works for those who have Meares-Irlen syndrome, a visual disorder that is often comorbid with dyslexia (DfES, 2004). DDAT is a controversial technique which has divided the dyslexia research community. The evidence used to support it (Reynolds, Nicolson and Hambly, 2003) has been criticised at length (Snowling and Hulme, 2003; Rack et al, 2007) for poor design, lack of validity and lack of reliability.

The controversies outlined above demonstrate the contested nature of this field. As a result, there are a number of specific debates that surround dyslexia. These include whether dyslexia actually exists; if there should be a discrepancy between expected reading ability, given IQ scores, and actual reading ability; the wider SEN debate regarding labelling; and whether there are gender differences in terms of prevalence.

The debate surrounding the existence of dyslexia is possibly the most controversial of these. There are several sides to this debate:

- dyslexia exists as is stated in the description above (an unexpected difficulty in reading, writing and spelling, despite educational opportunity);
- dyslexia exists, but there are subtypes which need to be identified in order to identify individuals accurately so they can get the appropriate support
- dyslexia does not exist and instead is a product of middle-class hysteria regarding parents’ assumptions of their children’s intelligence (Gillies, 2005)
- there are probably distinct aetiologies within the population of poor readers, but the term dyslexia mistakenly implies that there is evidence to suggest that these causes are correlated with reading-IQ discrepancy, in which case the term ‘dyslexia’ should not be used (Stanovich, 1994)
- dyslexia exists, but given that interventions designed for dyslexic pupils aid those pupils who are ‘garden variety’ (Share, 1996) poor readers, we should not exhaust our efforts and budgets on those ‘dyslexic’ children
alone, rather we should spread our efforts and money on all children who struggle to learn to read and write (Elliot and Gibbs, 2008).

Labelling is a controversial issue across disability and illness. In terms of dyslexia, some would argue that the label of dyslexia is necessary in order that appropriate support can be given (Reid and Kirk, 2001). In addition, the label of dyslexia is often conceptualised as a useful explanation for the difficulties that people face (Reid and Kirk, 2001; Riddick, 1996). However, labels have their drawbacks. They may stigmatise the individuals to whom the labels apply (Elliot and Gibbs, 2008; MacDonald, 2009). This is not helped by the fact that dyslexia is not visible (Ried & Kirk, 2001). Riddick (2000) found that:

- those ... who thought dyslexia was perceived negatively by others were reluctant to use it in public, whereas those that saw it as having basically positive connotations were willing to use it in public (p. 660).

Thus, the perception of how dyslexia is construed is important and may have an impact on individuals’ identity.

Labels only put a name to a problem that would exist despite a discursive term for it (Riddick, 2000). What is important is the individual’s treatment and their sense of self with and without the label. Riddick (2000) states that before a formal label of dyslexia is applied, informal labels have probably been used, such as lazy, stupid or careless.

Despite this, perhaps the stigma of reading and writing difficulties is greater than the stigma of dyslexia. Research done by Kirk & Reid (1999), where focus groups of dyslexic adults were consulted, found that labelling was a contentious issue. They found that using the label for the sake of it was frowned upon, but for some adults who had failed at school and had low self-esteem, having a label was helpful. However, Reid and Kirk (2001) suggest that individuals’ emotional needs should be accounted for when they are identified as dyslexic. In addition, an explanation of dyslexia may be more helpful than the actual label, as discussed in chapter 3 (Reid and Kirk, 2001).

As academics and professionals struggle to agree on a common definition, let alone a common cause, it is difficult to uphold the view that ‘dyslexia’ as a ‘disorder’ exists. Such arguments are prone to making parents either break out in a cold sweat or
become consumed by anger; the amount of forums on the internet following the Channel 4 Dispatches programme ‘The Dyslexia Myth’ are testament to this (broadcast on 8th September 2005, Channel 4). This, among other reasons, has led to dyslexia being referred to as a middle-class disorder. The other reasons may include the notion that middle class parents have more cultural capital to draw on in explaining away their child’s problems at school. The idea that dyslexic children are ‘intelligent but frustrated’ may hold a certain appeal to parents who may be in denial that their child is ‘slow’ (or stupid, unintelligent, thick, lazy etc).

The notion of the ‘slow’, ‘lazy’, or ‘stupid’ child in opposition to the ‘dyslexic’ child was a key aspect of the establishment of dyslexia at the turn of the 20th century (Campbell, 2013). This differentiation has moral implications. Morality as concerned with deserving and undeserving is an important consideration vis-à-vis dyslexia (Campbell, 2013) and identities. A diagnosis of dyslexia protects a child from being considered ‘stupid’ or ‘lazy’ and thus being treated unfairly or unjustly (Campbell, 2013). Unjust treatment in the early 21st century may differ from 100 years previously, however children with labels of stupidity or laziness are ‘undeserving’ of the kind of support that a label of dyslexia would lead to. The ‘deserving’ children are those whose difficulties are ‘curable’, and if perseverance leads to usefulness for society. Thus, the moral implications of having or not having a formal identification of dyslexia may have an impact on the construction of identities and a sense of self, as argued above and in chapter 2 (Taylor, 1989).

4.4 Is dyslexia a disability?
In chapter 3, I discussed the meaning of ‘disability’. In this section I will argue that dyslexia can be construed as a hidden disability. Extrapolating from section 4.3 above, dyslexia can be thought of as an impairment of one or more areas of the brain, or the visual systems. In addition, if we follow on from section 4.2, 21st century society in the UK can be considered a disabling environment due to the notion that literacy pervades culture and society; those who struggle with literacy are likely to struggle with many aspects of life.

Two terms for dyslexia which tend to dominate the American literature are ‘reading disability’ and ‘learning disability’. The NHS Choices website acts as the ‘online front door’ to the health service, allowing people to access information and make decisions
regarding their health (NHS choices, 2013). This website provides information about dyslexia, its ‘symptoms’, ‘causes’, ‘diagnosis’ and ‘treatment’. Dyslexia is one particular kind of disability that is covered under the Equality Act 2010. These representations of dyslexia within academic literature, patient services and legal policy seem to suggest that dyslexia is considered a ‘disability’, if not a medical condition, in a variety of settings.

In some respects, dyslexia may be seen as a result of a defective ‘mechanism of the body’, as some researchers would say that the reading, spelling, writing, organisational, time and spatial difficulties associated with dyslexia are the result of deficits in certain parts of the brain. Universities structure websites, as well as departments, by separating information for normal, independent students from information for those who need support, extra expense and adapted environments (Collinson et al, 2011). The student service often entitled ‘Disability and Dyslexia Service’ is one example of this. The inclusion of dyslexia within this service seems to suggest that dyslexic students are considered equal to their peers who have other disabilities. However, the fact that the term ‘disability’ is not inclusive of dyslexia may suggest that dyslexia is not considered equal to other disabilities. There seems to be confusion in the representation of dyslexia within student support systems, although dyslexia is recognized as a disability in law.

The support of students with disabilities, including dyslexia, within higher education institutions, however, has been critiqued. Collinson et al (2011) have analysed public representations of dyslexia and disability in the Skills for Life (2003) document and on university websites. They found that disabled students, including dyslexic students, were represented as dependent and burdensome on peers, instructors and institutions. Those in the literate elite, the peers and instructors who are represented as helping the dyslexic students, hold the power in an unequal relationship which upholds the social hegemony of literacy. The disability and dyslexia services at universities, which tend to occupy different web spaces, perpetuate the dependence and neediness of disabled students (Collinson et al, 2011).

As discussed in section 4.2, in 21st century Western society literacy is considered desirable. One needs to be literate in order to engage with a literate society. Literacy is
promoted as the ‘key’ to success and one of the tenets of the knowledge economy and the advancement of capitalism. The concept of social hegemony (Gramsci, 1971) is useful for understanding the literate elite’s position in society. The ‘literate elite’ keep those less literate in a dependent position (Collinson et al, 2011). The literate have more opportunities to succeed in society. Power and literacy seem to go hand in hand.

Lacking literacy means that you have less value to society than those who are literate. Students with dyslexia are not encouraged to use the technological tools that are designed for deaf people and blind people, such as audio files and text readers. Instead, they are expected to undertake remedial instruction in order to engage with the lexic discourse. These practices, and the images and discourses that surround education, reinforce the deficit model and medicalisation of dyslexia (Collinson et al, 2011).

People with dyslexia have been ‘othered’ by the social norms of literacy (McPhail and Freeman, 2005; Collinson et al, 2011). The dominant lexic discourse and paternalistic attitude towards dyslexic adults reinforces the social hegemony of literacy (Collinson and Penketh, 2010). Normative assumptions about literacy and the practices used by ‘experts’ disempowers dyslexics, in the same way that normative assumptions about bodily experiences disempower those who have other disabilities. Disability, like dyslexia, is often represented as a ‘troublesome’ difference. This is associated with bodily and cognitive deficiency and is upheld by the medical discourse which surrounds disability and the social and economic practices associated with support. Non-disabled people do not need assistance, but disabled people are dependent, burdensome and expensive (Collinson et al, 2011). People with dyslexia are required to conform to a dominant construction of ‘normality’ within a literate society (Bertilsdotter Rosqvist et al, 2013). Thus, those with dyslexia can be considered ‘disabled’.

Dyslexia is included in legislation about disability. There are social barriers which mean that people with dyslexia are disabled by things in their environment (MacDonald, 2009). However, there are three other aspects of dyslexia that need to be acknowledged: it is hidden (you cannot tell someone has dyslexia just by looking at them); it depends on the social hegemony of literacy (MacDonald, 2009); and it can only be formally identified by people who are qualified to do so (Pollak, 2005).
Dyslexia, therefore, is a particular and peculiar disability, medicalised in the literature, as well as society and policy.

A label gives a name to an otherwise unidentified aspect. The difficulties associated with dyslexia are given the ‘dyslexia’ label. There are various theories of labelling, outlined in section 3.3. Marks (1999) writes about a label of mental illness leading to institutionalization from which people struggle to escape. All behaviours are explained by their label. The many facets of human experience and behaviour have become medicalised in the twentieth century (Marks, 1999). However, many sociologists have critiqued medicalization in terms of micro-level interactions rather than by studying institutions and policies at the macro-level (Marks, 1999). Such research has tended to render the patient as harmed and the medical profession as harmful (Marks, 1999; Lupton, 1997). However, medical institutions can also be very helpful. In addition, patients can uphold the medical discourse as labels offer treatment and explanations for symptoms.

Debates surrounding the integration / inclusion debate are linked to debates which surround the idea of labelling. Riddick (1996) found that most of the children in her study (95%) were happy to use the label ‘dyslexic’ to understand their difficulties. However, half of the children were not happy to use the label publicly (Riddick, 1996). It seems, from the work Riddick (1996) has done, that the impact of labelling is very much context dependent. The parents in Riddick’s (1996) study were mostly positive about labels that allowed them to understand and provide a reason for their child’s difficulties. The label ‘dyslexia’ was deemed as preferable to being labelled slow, thick or lazy by teachers (Riddick, 1996). Despite this research, there is a sense that labelling children is ‘wrong’ (Riddick, 2000). This is because labels can be seen to define a child completely, rather than recognizing their other attributes and abilities (Riddick, 2000). There is also a notion that people may stereotype individuals with a label (Riddick, 2000). Moreover, the stigma attached to some labels can be hard to shake off. However, the stigma of reading and writing difficulties may be more profound than the stigma of having dyslexia.

MacDonald’s (2009) research set out to develop the dyslexia labelling debate by analysing the lived experiences of people diagnosed with dyslexia. He interviewed
adults with dyslexia from different social backgrounds and concludes that the lived experiences of these dyslexic adults do not support the anti-labelling perspective. It rejects the notion that stigma only happens after a label is attached, which is something supported by Riddick (2000). Indeed, it suggests that a label is conducive to effective support for those with difficulties of a dyslexic nature.

Identities of individuals with dyslexia are likely to be influenced by how they construct their dyslexia. How individuals construct their dyslexia can be investigated by looking at the stories they tell about it. McNulty’s (2003) work gathered life stories from adults who had been diagnosed with dyslexia as children. He used Atkinson’s (1998) life story approach and narrative analysis to analyse and compare 12 accounts of adult dyslexics (McNulty, 2003). McNulty (2003) used the transcripts of the participants’ accounts to create their life stories, as per the life story method described by Atkinson (1998).

McNulty (2003) found that the prologues of many of the participants’ stories consisted of the recognition that something was ‘not right’ when they were children. Sometimes they would recognise this themselves, sometimes someone else would notice. For all the participants, expositions, the set of circumstances that occur at the start of their story (or ‘orientations’ in Labov and Waletzky’s (1997) terms) consisted of difficulties in their early schooling which affected their motivation and sense of intelligence (McNulty, 2003). These difficulties were often interpreted negatively, so that the participants reported feeling as though something was wrong with them (McNulty, 2003). The complicating action is interpreted as the testing for and diagnosis of dyslexia (McNulty, 2003). This is unsurprising given that the participants were all diagnosed as children. It is probable that for individuals who are not diagnosed until adulthood, or, indeed, not diagnosed at all, a different complicating action would be described.

There have been a variety of books published which focus on the stories of those diagnosed with dyslexia. Edwards (1994) is one of the earliest of such works. Her book, entitled ‘The scars of dyslexia’, profiles eight case studies of teenagers diagnosed with dyslexia. Kurnoff’s (2000) book, ‘The human side of dyslexia’, features interviews with 142 people with dyslexia in the US, from young children to college students. However, both of these books, as interesting and useful as they may be to children, their
parents, and adults who have been diagnosed with dyslexia, do not give an academic
discussion of these stories. One book which can be deemed more academic is Rodis et
dyslexia gave autobiographical accounts of their difficulties. The second half of the
book consists of five scholarly essays written by educational professionals and
psychologists. However, its target audience is students learning about dyslexia, and
teachers and parents who need advice on how to cope with individuals who have
dyslexia.

Rawson’s (1995) book is unique in the field of dyslexia in that it is a 55 year
longitudinal study of 56 boys who went to an independent school in the US in the
1930s and 1940s, some of whom were diagnosed with dyslexia between the ages of six
and 12 years, and some who did not have dyslexia. Rawson (1995) analyses the
backgrounds of the boys and their subsequent careers and finds that the vast majority
of the boys who went to this school, which was concerned with helping its pupils reach
their potential and provide additional help to those who needed it, had successful
careers, whether they were dyslexic or not. Rawson’s (1995) is a unique work and such
work is unlikely to be done again.

Pollak’s (2005) study focuses on the educational life histories of university students
with dyslexia. He interviewed 33 university students of different ages from four
institutions. Each institution was of a different type (Northern, older ‘traditional’
university; a ‘new’ university in the Midlands; a Southern, younger ‘traditional’
university; and a ‘new’ university in the South). He analysed the learning life histories
of the participants, their educational psychologist reports which demonstrate their
dyslexia and the various literature the universities published as guidance to students
who have dyslexia. He found that these students drew on four different ‘discourses’ of
dyslexia: a patient discourse, through which the participants talked about dyslexia as
something that is diagnosed, that has symptoms and that is treated; a student
discourse, through which the participants talked about dyslexia as something which
only impacts their academic lives; a hemispherist discourse, through which the
participants talked about dyslexia as a ‘difference’ rather than a ‘deficit’; and a
campaigner discourse, through which participants talked about dyslexia as something
to campaign about. Pollak (2005) describes these discourses as flexible. Some
participants adhered more strongly to one discourse than another, but all were related to the participants’ experiences. For example, Pollak (2005) found similarities between the participants’ use of discourses and the language used in their psychological dyslexia reports.

Despite these interesting findings, Pollak (2005) states his study is a social constructionist piece. He focuses on the language the participants and the psychologists used. However, the book relies on a realist epistemology. Pollak (2005) assumes that the participants’ language is a reflection of their ‘actual’ feelings and experiences, rather than a representation. He pays no regard to the notion that their life histories are products of the interview and research context, nor does he acknowledge the idea that the participants’ stories are a product of the historical, social and political contexts in which they were co-produced. Therefore his study is inconsistent with the philosophy of this one, despite its interest here.

There have been a handful of studies that have studied the impact of dyslexia on adults and young people. These have generally focused on particular populations. Glazzard and Dale (2013) and Burn and Bell (2011) focused on teachers with dyslexia, while Skinner (2001) investigated dyslexia in mothers. MacDonald (2012) used BNIM methods to explore identity within criminals with dyslexia. Struggling adolescent readers, both dyslexic and non-dyslexic were the focus of Coombs’ (2012) study.

Morris and Turnbull (2007) investigated student nurses’ disclosure of dyslexia through in depth interviews and thematic analysis. They found that disclosure decisions were difficult for this population, particularly in terms of stigma and potential reactions of those around them, particularly important people. Disclosure of dyslexia, and other hidden disabilities or medical conditions, has identity implications, particularly in terms of self-presentation. More recently, Evans (2013) used narrative methods to collect data from student nurses with dyslexia. He investigated their identity constructions and found that most of the participants rejected references to medical and disability discourses, and chose not to disclose in professional settings, citing the possibility of not being understood. The students also discussed links between stupidity and dyslexia. Evans (2013) concludes that the discursive construction of dyslexic identities has an impact on disclosure. These studies are very important to the study of dyslexia
and identity. However, Evans’ use of narrative in data collection did not translate to his analysis, which engaged a discursive approach. The contemporary nature of these papers suggests that the study of dyslexia and identity is a topic of interest and relevance.

4.5 Conclusion
To be literate, means to be equipped for living and working. Those who are literate are more employable, they are part of an elite whose more valuable skills uphold the discourse of ‘literacy equals intelligence’ (CBI, 2009; Collinson et al, 2011). Thus, there is a stigma attached to difficulties with reading and writing, which may have an impact on an individual’s identity. However, identity is a difficult concept to pin down. Through psychology and philosophy, there is a plethora of ideas and theories about this elusive concept. It is almost impossible to study all of them, although there are common themes which run throughout.

Literacy is an important aspect of 21st century life. Without it individuals and societies suffer. A lot of money is invested in teaching, improving and researching reading and writing skills. Despite this contribution, many people struggle to acquire literacy skills. Notwithstanding some impressive gains in biological and cognitive psychology, teaching and instruction methods for children who struggle with reading, controversies surrounding this intriguing disorder persist. The conceptualization of dyslexia within the media, the organisations founded to empower those who have it, and the education system all support the idea that dyslexia is a disability which needs to be diagnosed, treated and researched.

It has been shown in the preceding few pages that dyslexia is a contested concept. Different terminology is used between and within countries. Different definitions are given by different groups and individuals depending on their allegiance. This in turn influences research findings. The nature of dyslexia is also discussed in the literature, especially regarding the existence of subtypes, comorbidity and prevalence rates. In addition, the extent to which dyslexia is more than a literacy problem has been the topic of some debate. Moreover, the existence (or not) of dyslexia is controversial and has been debated at length in the literature and the media. Wider SEN debates, such as labelling and gender, are also considered important for dyslexia.
All these contentions are ongoing whilst aetiological and intervention research is carried out. The phonological deficit hypothesis has the most support as an explanatory hypothesis of dyslexia, but there are competing hypotheses. Research into the inheritance of dyslexia has made progress over the last few years, but dyslexia is thought to be a result of genetic and environmental factors. Although multisensory techniques are thought to be the most successful in teaching dyslexic pupils literacy skills, there is a lack of appropriate evidence to support this claim. Whilst there has been a plethora of research on the causes of dyslexia and how to support dyslexic pupils and students, research into the psychosocial factors of being diagnosed with dyslexia has been rather thin on the ground.

The majority of research that has been done on the social and emotional impact of dyslexia has focused on self-esteem and self-concept. Dyslexia has long been associated with low self-esteem. However, more recent research has suggested that the relationship between dyslexia, self-esteem and self-concept is complex and varied. Other research into the social and emotional consequences of dyslexia has focused on the experiences of special education. Nugent’s (2008) work challenges the ‘inclusion is best’ dogma and MacDonald’s (2009) research challenges the anti-labelling argument. Research into how teachers, parents and SENCOs understand dyslexia supports Woods (1998) claim that there is confusion among parents and professionals. McNulty’s (2003) work seems to be the only study that focuses on the life stories of dyslexic adults.

Identity connects the social and the personal to present the individual in a collective context, what we call society (Shakespeare, 1996). The notion of narrative identity offers the potential for a nuanced model of self and identity (Shakespeare, 1996). Narrating the life is an important way of presenting, whilst simultaneously constructing, selves and identities. The above discussion regarding the debates that surround dyslexia reflect the debates that influence many other less visible conditions, such as chronic fatigue syndrome (Horton-Salway, 2007). They also make it easy to conceptualise dyslexia as a medical issue, a disability and condition that individuals need to be diagnosed with and treated for.
4.6 Research focus

Chapter 2 argued that selves and identities can be understood through a framework of narrative. Plot is an important part of narrative, and the temporal nature of it means that present constructions of past, present, and future selves and identities can be analysed from research interviews. I introduced a new concept to the field of narrative: storyworld. The methodological implications of this will be expanded in chapters 5 and 9. In chapter 3 it was noted that disability can be construed as disruption in a life narrative and has an impact on identity. The discussions in the present chapter argue that dyslexia is a disability. However, there are a number of gaps in the literature. Firstly, there is very little social and psychological research about adults who have dyslexia. What there is seems to focus on self-esteem, or self image, as discussed in section 4.4. The participants in these studies tend to be part of specific groups, such as nurses, teachers, and students (Glazzard and Dale, 2013; Burn and Bell, 2011; Skinner, 2001; MacDonald; 2012; Coombs, 2012). The participants in these studies have a formal identification (or diagnosis) of dyslexia which precedes their participation in these projects. An identification of dyslexia as a prerequisite for participation excludes those who went to school at a time when dyslexia was not identified, who do not have a formal identification of dyslexia, but who think they have dyslexia and identify as dyslexic.

Horton-Salway’s work on CFS, a condition that is less visible in a similar way to dyslexia, covers this condition and its impacts on identity in a way that has not been done with dyslexia. Thus, the following research aims were developed:

- To investigate the lives of adults who identify as ‘dyslexic’, whether they have been formally ‘diagnosed’ as dyslexic or not.
- To study the narrative identities of individuals who identify as ‘dyslexic’.
- To explore how experiences of dyslexia are narrated and understood by adults who identify as dyslexic.
- To use a new concept, storyworld, in an applied context.

In the following chapters, I explore how these research aims can be met using social scientific methods (chapter 5), and I attempt to uncover the narrative identities of dyslexic adults (chapters 7 and 8) and their understandings of what dyslexia ‘is’ (chapter 6).
Chapter 5: Methodology

5.1 Introduction
Many different methods are employed in social research. The choice available to social researchers seems so vast, one may wonder to what extent researchers can make informed decisions about methodology. The first decision to make reflects the difference between qualitative and quantitative data and the techniques used to analyse such data. This decision may be informed by the research questions being asked. Considering the research focus in the present study (given in section 4.6), and the theoretical framework of this research, I decided that the present study’s research questions require qualitative methods. Even having made this decision, though, there is still a plethora of different methods from which to choose for collecting and analysing the data needed to answer the research questions. This chapter, therefore, aims to give an overview of the methods used in the present study and how I made the decisions to use them. It will first give the rationale for the data collection techniques (section 5.2), the data collection techniques that I used (section 5.2) and the actual procedure used (section 5.2). Pen profiles of the participants are presented, along with ethical considerations and implications. Then follows a discussion of the data analysis techniques and procedures used to analyse the data (section 5.3). In section 5.4 I discuss reflexivity and the changes I have made to the project as a result of being reflexive. Finally, section 5.5 concludes the chapter.

5.2: Data collection

5.2.1 Rationale
The present study uses two different kinds of data collection techniques. The first is a life history interview, which draws on narrative interview techniques, and the second is a photo-elicitation interview (PEI), which draws on the Thematic Apperception Test technique and visual methods. These techniques both allow narratives to be collected and then analysed using narrative analysis.

5 The arguments demonstrating the advantages and disadvantages of quantitative and qualitative methods could be discussed at length. However, within the paradigms explored in chapters 2, 3 and 4 above, it seems that methods which give in-depth insight to how individuals give meaning to their lives and the social world around them are those which allow individuals to talk more than quantitative methods would allow.
Life history approach

As discussed in Chapter 2, narrative is a pervasive method for telling about human experience (Bruner, 2002). It is argued that the narratives people tell about their experiences are the closest a listener can get to what actually happened to, and was experienced by, the narrator (Rosenthal, 2004). There are a number of ways of eliciting personal narratives. Some, like Wengraf’s (2001) biographical-narrative-interpretive method (BNIM) which uses a single question aimed at inducing narratives (SQUIN), are very thoroughly designed and posit that all rules must be followed. In this approach, the interviewer asks the participant to ‘tell their own story in their own way, beginning wherever they like, for as long as they like’ (Wengraf, 2001: 141). The narrative elicited by this question is then the primary focus of analysis. The narrative is supplemented by further questioning, which takes place only after the participant has finished telling his or her story (Wengraf, 2001).

This approach is similar to that of Rosenthal (2004), who recommends that a narrative eliciting question be supplemented by further questions. However, she points out that questions relating to what the participant has already discussed should be asked before questions about topics that have not been discussed. This is because a researcher should not impose his or her frame of reference onto the participant until the last possible moment so as not to influence the participant’s responses. Henwood et al (2008) also discuss these issues. For them, framing the topic is integral to the research process, but researcher imposed framings are possibly problematic and therefore need to be addressed and acknowledged within the research process.

Another approach described by Murray (2003) is more flexible. According to Murray (2003), the aim of an episodic narrative interview is to obtain detailed accounts of particular personal experiences. In this approach, the interviewer outlines the topics of the research during the interview and then asks the respondent to give narratives relating to those topics. In contrast, a life history interview is broader and asks the respondent to recount their whole life, rather than just narratives of particular topics or events (Murray, 2003). The approach a researcher adopts depends on what the topic of the research is.

on a number of theoretical assumptions. First, in order to understand and explain psychological and social phenomena, researchers need to reconstruct how they were created, reproduced and transformed. Secondly, in order to understand actions, researchers need to study the courses of action as well as subjective perspective and the meaning given to these actions. In order to understand and explain a biographer’s narrative, researchers need to interpret it in the context of their current life and present and future perspectives (Rosenthal, 2004).

These theoretical assumptions, in turn, imply certain requirements of the methods for collecting and analysing data. First, methods should allow for insight into the genesis and the gestalt of the life history. Second, the methods need to allow for insight into the courses of action and experiences of a life. Third, these methods must allow for the reconstruction of a biographer’s present perspectives, whilst allowing for a difference between the present perspectives and past perspectives (Rosenthal, 2004).

According to Rosenthal (2004), one method that meets these criteria is the biographical-narrative interview. It is argued that researchers should not restrict themselves to parts of their participants’ biographies, but rather allow the whole life to be told (Rosenthal, 2004). The interview is split into two parts. The first part involves the interviewer asking a narrative question, followed (hopefully) by a narrative response by the participant. The interviewer listens attentively and takes notes during the participant’s narration.

It is also important to encourage the respondent to tell their story, which means that the interviewer should not interrupt the participant’s narrative but encourage their telling by use of paralinguistic expressions such as ‘mmhmmm’, gestures and eye contact (Rosenthal, 2004). This is reiterated by Murray (2003), who maintains that the interviewer’s role is to encourage the respondent to tell his or her story, by being empathic and giving support. Rosenthal (2004) argues that the first question should be left as wide open as possible. This allows the participants to frame the research interest (dyslexia) in their own ways, without the researchers imposing their frame of reference (Henwood et al, 2008). In addition, Rosenthal (2004) argues that this approach opens up the possibility of new thematic connections that may not otherwise be considered.
It has been argued that in some contexts the initial question should be narrower, for example where the research question does not pertain to the whole biographical history of the participant (such as their time in hospital, or at school) (Rosenthal, 2004). One way of combining these approaches would be to mention the research topic, but encourage participants to talk about their whole life. This allows the participants to give their biography, whilst also ensuring that the research topic is addressed within it. It ensures that what is said by the participant is relevant. This kind of approach was considered for the present study. However, given that there will be a second interview, in which reading and writing difficulties will be discussed, it was decided that an open narrative question would be more suitable.

After the main narration, as Rosenthal (2004) refers to it, the interviewer asks narrative-generating questions, first about what the participant has already discussed and secondly about the research topic and areas of it that the participant has not yet discussed. This means that, once again, the researcher’s frame of reference is not imposed on the participant until very late in the research process.

**Implications of life history approach**

In narrative research, especially research that aims to collect the life stories of participants, one important consideration is the extent to which cultural expectations of ‘life story’ impact on the telling of lives. There are several assumptions of what is and is not worthy of telling. How participants start their stories is subject to cultural expectations (Bruner, 2002). These may include the notion that ‘life’ starts in childhood with a family, for example.

In asking participants for their life stories, it is possible that the research topics of dyslexia and reading and writing difficulties do not emerge in the course of their narrative. This may show either a difficulty with expressing this (Rosenthal, 2004), or that their presumed difficulties are not that meaningful for them. Thus, this leaves these possibilities to be explored in a second interview. A second interview would give me the opportunity to ask the participants follow-up questions to the narrative provided in the first question. If a participant, for example, does not mention their time in education, the second interview gives me a chance to bring that up and say: ‘last time we met you briefly mentioned your time at school, could you tell me more about that please?’
**Visual methods**

Visual methods have a long history in social science research (Reavey and Johnson, 2008; Reavey 2011). However, the linguistic turn in social sciences and the epistemologies to emerge from it have marginalised and limited the prominence of visual data and visual methods (Banks, 2007; Bohnsack, 2008). This is incongruous with the ubiquitous nature of the image in 20th and 21st century Western society (Banks, 2007). Nevertheless, in recent years more researchers have been attempting to bring the use of visual methods to the fore in qualitative social research (Banks, 2001; Bohnsack, 2008).

Reavey and Johnson (2008) point out several reasons why mono-modal, mostly linguistic, discourse is so prominent in academia. One point that they make is that the meaning which qualitative researchers are so often in search of is assumed to be what we can ‘hear’ or ‘read’ (Silverman, 2001). The arguments made for using text as data are that words carry greater clarity and objectivity. This is debatable. Language is seen by many in critical psychology as a non-neutral mode of communication (Burr, 2003). A second argument is that language users understand each other because they share communities of meaning (Reavey and Johnson, 2008). This is a seemingly obvious point, but I would argue that it is the particular use of English in academia that gives researchers a shared community of meaning. A third argument is that the interpretation of text is more systematic and transparent than any interpretation of images would be (Reavey and Johnson, 2008). However, as Bohnsack (2008) has argued, there is no reason why an analysis of images cannot be just as systematic and transparent as an analysis of text.

A fourth argument is that language is given cultural prominence and value (Reavey and Johnson, 2008), despite the abundance of the visual in society through television, the Internet and advertisements (Banks, 2001; Reavey and Johnson, 2008). In academia, though, language is seen as the prime mode of communication, analysis and research. Images have thus been marginalised in academia (Banks, 2001; Bohnsack, 2008; Emmison and Smith, 2000). However, language is not the only way in which people engage with and experience the world (Reavey and Johnson, 2008). Reavey and Johnson (2008) argue that the marginalisation of visual research in psychology has led
to a dearth of research into the relationship between images and peoples’ subjective experiences of them.

It seems, therefore, that the use of visual methods can be heralded as positive in the social sciences, and the value of these methods is argued compellingly by their proponents (Harper, 2002; Henwood et al, 2011). The notion that images are ubiquitous in 21st century Western society is often cited as a reason for using them in social research (Banks, 2007; Bohnsack, 2008). Indeed, with the advancement of modern technologies and the prominence of the Internet, it has been argued that our social reality is represented by and produced by images (Bohnsack, 2008). Therefore, it can be argued that social scientists should use visual methodologies in their research.

It is also argued that visual methods allow researchers to access that which may be inaccessible using more traditional mono-modal methods (Harper, 2002). Reavey and Johnson (2008) argue that visual methods allow researchers to examine how people manage their relationships and identities. How we live feelings and experiences is not always available to verbal description (Henwood et al, 2010; Reavey and Johnson, 2008), which is problematic for mono-modal research. By using images in research, it is hoped that participants are able to engage with these otherwise inaccessible feelings and experiences.

However, some authors advise caution in the use of visual methods in social research (Bohnsack, 2008; Emmison and Smith, 2000). Emmison and Smith (2000) point out that although photographs are primarily a means of capturing information and events (data), it is often assumed that they are something else. They suggest that researchers may confound the reality they are trying to study with the means of capturing that reality (Emmison and Smith, 2000). These are important points, but they seem to relate more to the analysis of images than to the use of photographs as data collection tools, which is what I have done for the present study.

Eliciting narratives by means of photographs

Photo-elicitation is a very simple way of using photographs (or other objects) to elicit comments, memory and discussion in a semi-structured interview (Banks, 2007). Discussions can be both broadened and sharpened depending on the image being shown and the subject being investigated (Banks, 2001). One advantage of using
photo-elicitation is that it can alleviate times of awkwardness in an interview; the photograph can serve as a neutral third party (Banks, 2001). However, photo-elicitation may not always be so straightforward in practice, as issues of photographic multi-vocality and the complex relationship between photographs and social interactions need to be considered (Banks, 2001).

Yannick Geffroy and Paolo Chiozzi stumbled across photo-elicitation in fieldwork (Banks, 2001). In Geffroy and his colleague’s case, they were interviewing a participant who brought out pictures so that the researchers could ‘see how’ something had happened. They realised that this allowed her to recall events and contexts as well as allowing them to collect more data about the emotions she was reliving (Geffroy, 1990: 374). Chiozzi describes showing a catalogue of photographs from an exhibition that he happened to have on him to a participant who then talked a great deal about things of which the photographs were reminding him (Chiozzi, 1989).

According to Temple and McVittie (2005), there are three types of visual materials. One involves the use of pre-existing visual materials that exist outside of the research arena, for example art or published photos. Another involves the use of time-limited visual data, which are produced within the research process. A third type involves the use of enduring visual products, which are produced within the research process, for example video diaries and photos produced by the participants, which have a continued existence after the project has finished.

Researchers need to decide if visual material is to be used as a trigger for stimulating verbal discussions, or whether participants will be invited to take their own photographs. Alternatively, the focus may be on the participants’ use of visuals in the community. Depending on the status of the visual images, there are implications for understanding and interpretation in psychological research (Temple and McVittie, 2005). I considered allowing participants to take their own photographs. However, apart from the practical implications of this, I believe that it could be very difficult to for the participants to take photographs that relate to dyslexia and associated difficulties. Therefore, the present study uses pre-existing visual materials that are used to trigger verbal discussions about the research topic.
Henwood et al (2011) have used photo-elicitation interview techniques in their men-as-fathers study. Three different variations of PEIs were used with contrasting outcomes. The first method they describe is presenting the respondents with a collage of images, which depicted fathers in a variety of ways, in different settings, times and participating in different activities. According to Henwood et al (2011), presenting this collage at an early stage in the interview was practical, as it helped to stimulate the respondents in engaging with the research topic. The images used in the collage had been selected to show diversity in fathering activities and identities, which the researchers envisaged would elicit nuanced data about how fathers contextualise their experiences compared with other cultural possibilities. They also believed that by presenting the images simultaneously, individual images would gain more importance from being part of an elaborate visual statement (that of the collage).

Henwood et al (2011) comment that although the collage generated useful data, and was useful in starting discussions around what types of fathers the participants wanted to emulate, presenting the pictures together meant that some of the images were overlooked in the discussions about fatherhood. They also comment that by encouraging the participants to engage with the collage (e.g. sorting them into categories, agreeing on their meaning) may have generated responses that are more detailed.

The second method that Henwood et al (2011) used in their study was a temporal visual sequence, in which images were presented in chronological order from Victorian times to the present day, which was designed to address participants’ perceptions of continuity and change. The participants were asked to interpret the images in terms of how they ‘saw’ the images, whether they saw any of their own family in the images. Henwood et al (2011) comment that presenting the images individually led to more detailed data than presenting the images simultaneously. It meant that participants commented on each picture and were able to revise their interpretations of earlier images from the perspective they take while viewing later ones. Henwood et al (2011) comment that the detailed insights that the participants gave in response to images presented individually would not likely be generated using the collage technique. However, they also note that by using a collage it allows the researchers to see what
aspects of fatherhood were important to the participants, an aspect that is lost when showing the images individually.

The third method that Henwood et al (2011) used was to ask the participants to provide their own photographs to be discussed in the interviews. They asked the participants how the photographs made them feel, whether they had any favourites, and any they thought represented good fathering. The reasons for using such a technique are that personal photographs may induce biographical memories and emotions and allow the participants to explore their temporal experiences. They note that drawbacks in using such a technique are that personal photographs are produced for particular purposes and viewing contexts, and could represent an ‘ideal’ of family life (Rose, 2007), although some images were chosen because they did not reflect this ‘ideal’. However, it can also be argued that such images can reveal biographical memories and emotions unavailable through other methods (Kuhn, 2007). The authors comment that how the participants took photos and used them influenced the data collection. Moreover, the researchers noted that they were having difficulty in generating interpretations and reflections in how the photographs and data related to the participants’ lives which also supports my decision to not use researcher generated images in this project.

In psychology, images are used in a variety of ways. Images of faces have been used to look at attractiveness and emotion (Leder and Bruce, 2000). Graphics are used in the reporting of results. However, it is the use of images in psychodynamic and clinical psychology that is most relevant to the present study. Traditionally, images have been used in psychoanalysis for projective techniques (Groth-Marnat, 1997). The Rorschach inkblot test is probably the most famous projective test. It was developed by Hermann Rorschach in the early 20th century as a method of eliciting the projections of psychoanalytic clients. It was believed that the ambiguity of the inkblots allowed the fears, desires and repressed memories of the unconscious to surface (Kline, 2000). The Rorschach test is just one of a number of projective tests used in psychology.

The Thematic Apperception Test is a projective personality test devised by Christina Morgan and Henry Murray in the late 1930s (Groth-Marnat, 1997). It comprises 31 pictures of ambiguous situations, of which a sample is selected for each client,
depending on their gender and age (Martin et al, 2007). For each image, the client is asked to tell the examiner what is happening, what led up to the event, what the result was and what the protagonist(s) were thinking and feeling (Martin et al, 2007). It was originally designed as a personality test to find out what a client’s needs were, and subsequently to assess personality characteristics. The popularity of tests such as the TAT, the children’s apperception test (CAT), Gerontological TAT, and the Senior Apperception Test as personality assessment tools has not diminished (Kline, 2000; Groth-Marnat, 1997).

In the TAT respondents are told that it is a test of imagination and are asked to tell the examiner what is happening in the picture, including what happened before, who the protagonists are, what they are doing, what they are feeling and what the result is. Respondents have five minutes to talk about each image. In the present study, given the different function of the photo-elicitation interview from the traditional TAT, the participants are asked to describe what is happening in each photograph. When all the images have been talked about, the participants are asked if they feel they can relate to any of the images or if they cannot relate to any of the images and why this is the case. This allows the participants to tell me about experiences that they may not have thought of in the first interview and also gives them the opportunity to talk about reading and writing difficulties, which they may not have mentioned in their life stories.

According to Banks (2001), using images that are not produced by either the researcher or the participant, or using images that seem to have no connection to either individual, is rare in this field. He claims that such images would not promote intimacy and may detract from the research aims (Banks, 2001). However, allowing the participants to talk about the images I have chosen should enable me to discern their understandings of reading, writing and the difficulties they find with these tasks.

In light of the work that Henwood et al (2011) have carried out, it seems sensible to present pre-generated photographs to the participants individually. I am interested in how participants respond to images of people reading and writing in contexts with which they may be familiar and which are likely to correspond to their life course (e.g. in the classroom, library, at home).
The focus on temporality, and on the new concept of storyworld, means that it is apposite to present a series of images that portray episodes in a generic life. The major life events that people in Western cultures tend to discuss, include, but are not limited to, education, employment, marriage, moving home and retirement. Most of these involve some engagement with written text and form filling at the very least. A novel way to incorporate visual representations of these important aspects of life would be to present to participants a set of images that represent a variety of reading and writing tasks across the lifespan.

The photographs were selected from Google searches and searches on free stock exchange websites, such as www.sxc.hu. A set of ten images were chosen that show individuals involved in reading and writing tasks that may be experienced by all of us in our lifetime. Some of the images show individuals struggling with the task, some show individuals who are not struggling with the task. The images are intended to be representative of males, females and people of different ethnicities. They were presented to the participants in order of the protagonists’ ages. The images are presented in the appendix, in the order they were shown to the participants.

According to Lynn and Lea (2005), reflexivity needs to be at the forefront of visual research. They argue that the context in which the image is produced needs to be considered, as well as the image itself. In addition, I need to be aware of the possible influence that audiences have on the interpretation process, as well as the influence that I as a White, middle class, educated female have on the collection of data and their interpretation (Murray, 2003; Reavey and Johnson, 2008). It can be argued that reflexivity is an important aspect of all research (Murray, 2003). Indeed, according to Henwood (2008), epistemic reflexivity is an important way of making qualitative research as transparent as possible. She argues that researchers should refrain from colonizing the ‘others’ they are researching (Henwood, 2008). In addition, it is argued that qualitative researchers should consider the question of centering marginality in a reflexive way, in order that they are able to attend to emotive forms of data and to take research in surprising directions (Henwood, 2008).

Jenkins et al (2008) have argued that in photo-elicitation interviews (as well as traditional qualitative interviews), analysis happens in the interview and is a
collaboration between the researcher and the respondent. They give an example (paragraphs 42 to 44) of analytic collaboration in a photo-elicitation interview they did in research on military identity. In this particular example, Jenkins et al (2008) argue that the respondent leads the theoretical analysis rather than the researcher, and that both researcher and respondent are reflexively analysing what the photograph means and represents. This does a lot to suggest that what is written up in research reports is not necessarily what happened in the research. However, one could argue that this is an example of the respondent making sense of the pictures he has presented, rather than him making academic analyses, as Jenkins et al (2008) argue.

This raises some serious questions about the nature of social psychological analysis. We have to be careful in suggesting that the respondents in photo-elicitation interviews are analytically collaborating with the researcher. In this example, it could be the case that the researcher is tentatively testing hypotheses, but as a reflexive reaction to the respondent’s sense making process. We need to define what ‘analysis’ is, and in this way differentiate it from what happens in interviews such as this. In a lot of introductory textbooks, data analysis is separated from data collection. Separate chapters are allocated to each, and students are instructed how to analyse the data they have previously collected. However, Silverman (2000) states that data analysis does not start after data collection. Rather, transcription and reviewing early data in the light of research questions is needed, particularly in terms of grounded theory (Charmaz, 1990; Silverman, 2000). Despite this notion of analysis starting as soon as a researcher has their first data, the idea of analysis starting in an interview between a researcher and participant is not considered in introductory texts and teaching.

5.2.2 Pilot interviews

I decided that pilot interviews would be conducted in order to test out the methods in terms of the specific interview questions and photographs used. It also allowed the testing of the recording equipment. The participant chosen for this first interview is an acquaintance of mine who offered to be a pilot participant. She was also chosen because she met the criteria for participation in the study and due to her status as a fellow researcher who would be able to give feedback on the experience of being a participant. In the first interview the participant was asked to tell me about her life in her own words. When I thought her story had come to an end, which was signalled by
her saying ‘that’s it, is there anything more you want?’, I asked her if there was
anything she would like to add.

The second interview started with me explaining that I was going to show her some
photographs and that I would like her to explain to me what was going on in them. I
had planned to ask after every photograph whether it related to her experience.
However, when it came to the interview, I felt that this was not the right thing to do. I
felt that by asking about her own experiences immediately after her imagined
narrative, this would interrupt the ‘flow’ of her imagination. Therefore, after each
image had been talked about, they were left out on the table, out of immediate sight
of the participant but still in sight if the participant chose to look.

After all the images had been discussed, I motioned to the photographs, which by now
were placed collage-like on the table facing the participant, and asked her whether any
of the pictures and stories she told about them relate to her experience. After she had
talked about which images related to her experience and why, I then told her that
there were a couple more questions I had for her. These were about how she got from
her previous university to the one she is currently studying in and how life has been for
her since she started at her current university. The interview ended with me asking if
she knew anyone who would like to take part in the study.

In the first interview, the following exchange happened (K = me, Kim; M = Madison,
the participant):

K I would just like you to tell me about your life in your own words
M err, ok, well where do you want me to start?
K wherever you feel comfortable
M is this in relation to anything?
K whatever you, whatever you, whatever you think’s important that’s been in
your life, maybe you’d like to start with your childhood? May be a good place
to start
M hm, I really should have thought about this, maybe I could start with my family
This extract shows that Madison expressed hesitation in response to my request. This may be due to a variety of reasons. However, I decided that I should give participants the opportunity to talk about things seemingly unrelated in order that they may be aware that any topic is relevant. This is because though the participants are recruited due to their difficulties with reading and writing or their identification with dyslexia, the research focus is the identities of these participants. As argued above, identity can be closely linked to the stories one tells about one’s life. In addition, I decided that some small talk with the audio recorder on would be a good way to make participants more comfortable.

In the second interview, 12 images were shown to Madison, who had no trouble in describing what was happening in each of them. She also seemed to find it easy to relate to some of them and discuss why this was the case. However, at the end of the interview she said that she thought that there were too many photographs to discuss. I also thought this was the case. Moreover, I thought that there were too many that displayed children and not enough that showed adults. Therefore, I decided to take out three of the photos, all of which were of children. One photograph was added, of an older woman reading, seemingly without any difficulty. This left 10 images for the rest of the research interviews. This pilot procedure and the subsequent discussions informed the final procedure for collecting data.

5.2.3 Procedure

Sample

Two different kinds of participants were recruited to take part in the study: adults (over 16) who have been formally identified with dyslexia; and adults who have not been identified with dyslexia (at the time of the research) but who had reading and writing difficulties or thought they might be dyslexic. The sampling was purposive and therefore non-random. I sent out letters to various institutions whose clients might be
interested in participating, in particular six universities, and three dyslexia associations situated in cities in South Wales, the English South West, and English Midlands\textsuperscript{6}.

In addition, I put up posters strategically in various locations advertising the study, such as colleges, leisure centres and community centres. These posters were made specifically to make it easier for people with dyslexia to access. This meant that the text was large, minimal and presented on a pastel coloured background. I also asked acquaintances, friends, and family members that I know have dyslexia or reading and writing difficulties, if they would like to participate. I asked participants if they knew anyone who would meet the criteria to participate. All these techniques combined to give me access to a variety of people from different backgrounds and of different age groups.

I provided the participants with an information sheet, printed on pastel coloured paper, which explained what participating in the study would entail, and a consent form (copies of which can be found in the Appendix). Once informed consent from the participants was obtained, a date, time and place for the first interview were arranged. The date for the second interview was arranged at the end of the first interview. Interviews were conducted at a location convenient to the participant, most often in their homes, although some were completed at the university.

The participants varied in age, gender, their ‘dyslexic status’ (whether they were or were not dyslexic), and ethnic background. Although I did not ask the participants outright their age or ethnicity, they very often volunteered that information during our pre- and para-interview conversations (para-interview conversations being those that occurred within the interview frame but were unrelated to the data collection), and during the interviews themselves. Table 1 below shows details of the participants, which are more fully presented in pen profiles below, presented in alphabetical order.

\textsuperscript{6} These are the areas I could most easily travel to and cover a variety of different regions.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Dyslexic</th>
<th>Where do they live?</th>
<th>Education</th>
<th>Work history</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andy</td>
<td>Yes</td>
<td>South Wales</td>
<td>Unknown</td>
<td>Creative industry</td>
</tr>
<tr>
<td>Betty</td>
<td>No</td>
<td>South Wales</td>
<td>Unknown</td>
<td>Unknown</td>
</tr>
<tr>
<td>Claire</td>
<td>Yes</td>
<td>South Wales</td>
<td>PGCE</td>
<td>Police force, planning to teach</td>
</tr>
<tr>
<td>Danny</td>
<td>No</td>
<td>South Wales</td>
<td>MPhil</td>
<td>Retail and charity</td>
</tr>
<tr>
<td>Ellie</td>
<td>Yes</td>
<td>East England</td>
<td>Studying for PhD</td>
<td>Civil service</td>
</tr>
<tr>
<td>Fred</td>
<td>No</td>
<td>English Midlands</td>
<td>O levels</td>
<td>Police force</td>
</tr>
<tr>
<td>Hilary</td>
<td>No</td>
<td>English Midlands</td>
<td>Teaching qualification</td>
<td>Teacher, SENCO</td>
</tr>
<tr>
<td>Jacob</td>
<td>Yes</td>
<td>South Wales</td>
<td>Degree, studying for MSc</td>
<td>Government, charity</td>
</tr>
<tr>
<td>Madison</td>
<td>Yes</td>
<td>South Wales</td>
<td>MSc, studying for PhD</td>
<td>Unknown</td>
</tr>
<tr>
<td>Natasha</td>
<td>Yes</td>
<td>South Wales</td>
<td>Unknown</td>
<td>Creative industry</td>
</tr>
<tr>
<td>Peter</td>
<td>No</td>
<td>South Wales</td>
<td>MSc, studying for PhD</td>
<td>Unknown</td>
</tr>
<tr>
<td>Rose</td>
<td>Yes</td>
<td>South Wales</td>
<td>Degree</td>
<td>Politics, education</td>
</tr>
<tr>
<td>Simon</td>
<td>Yes</td>
<td>Wales</td>
<td>Degree</td>
<td>Professional, service</td>
</tr>
<tr>
<td>Xander</td>
<td>Yes</td>
<td>Wales</td>
<td>PhD</td>
<td></td>
</tr>
</tbody>
</table>

Table 1: Demographic details of participants

I interviewed Andy, a man from a minority ethnic background, at his home in a South Wales city, the city where he was born and had been brought up. Andy worked in the creative industries and was not formally identified with dyslexia until a few years before our meeting. He had a grown up son who was in the same industry as him. He heard about my research at a dyslexic institute and volunteered to take part.

I interviewed Betty, a woman in her late 70s who lived on her own on a social housing estate in a South Wales valley. She was told about the research by a mutual acquaintance. She was virtually illiterate and had had a difficult childhood and had lived in that area her entire life.

7 ‘Yes’ means that the participant has a formal identification of dyslexia. ‘No’ means that the participant either thinks they have dyslexia, or they have an informal identification of dyslexia.
8 Highest level.
Claire was a white woman who lived with her husband and two children in a South Wales town. She had a formal identification of dyslexia and contacted me after seeing a poster at the dyslexia institute. She grew up in a small town in the North of England, one of four children whose mother divorced when Claire was about seven years old. She moved to the South of England after completing A levels to join the police force and moved to Wales a few years after that. At the time I spoke to her, she had recently completed a PGCE (Post-Graduate Certificate In Education) and was looking for a teaching post. She discovered the research I was doing through the dyslexia institute and volunteered to take part.

Danny was a white 34-year-old man. He lived in a South Wales city and worked for a charity as an office manager at the time of the interviews. He was born and grew up in London and had no formal identification of dyslexia. He moved to Wales when he started university. He is an acquaintance of mine and enthusiastically volunteered to participate when I told him about my research. I had known him loosely in a professional capacity for five years before I interviewed him. Our relationship was such that I knew very little about him save for the fact that he had been to university and we had mutual acquaintances and friends. We conducted the interview at his home.

Ellie was a white woman who lived in the East of England with her son who was of primary school age. She had a formal identification of dyslexia and was doing a PhD at the time of my research. I met her at a research conference and when she found out about the focus of my research she was very keen to participate and told me her mother (Hilary) might also be interested. She had worked in Cardiff, Brussels, and Birmingham, in the civil service and teaching, before starting her doctoral studies. I interviewed her at her mother’s house.

Fred was a white 53-year-old man who was born and grew up in a village in the West Midlands of England, and lived in a nearby city at the time of our meeting. He had been a police officer who joined the police force after finishing school, but had retired a few years before our meeting. He was a civil servant at the time of the interview and lived with his wife. They had three grown up sons, one of whom I also interviewed (Xander). Xander had informed his father of my research. Fred did not have a formal
identification of dyslexia, but thought that he probably was dyslexic. I interviewed him at his son’s home.

Hilary, Ellie’s mother, was a white 58-year-old woman who was born and brought up in the north of England with an older sister. She trained to be a teacher after leaving school, and was then a teacher and a SENCO (special educational needs co-ordinator) at a primary school in a West Midlands city. She did not have a formal identification of dyslexia, but thought that she was due to her professional training and experience. I interviewed her at her house.

I interviewed Jacob, an African American man, in a room at the university in Cardiff. He was from the United States of America and had moved to the UK five years previously. Jacob was studying for a Masters degree at a university in South Wales. He was formally identified with dyslexia only 4 months prior to the interviews. He heard about my research through a flyer he had seen at university.

Madison was a 25-year-old white woman, who I interviewed in a room at a South Wales university where she was doing a PhD. She was born and brought up in Bristol and moved to Wales for university. She was formally identified with dyslexia when she was doing a Masters degree a few years before our meeting. She heard about my research through her university and acted as a pilot participant.

I interviewed Natasha in a room at the university. She was a white 47-year-old woman who was born in England and had moved around the country in her childhood. She had moved to Wales 20 years before our meeting and worked in the creative industries. She was not formally identified as dyslexic until a couple of years before the interview. She had heard about my research from Andy, as they work in the same industry.

I interviewed Peter, a white 28-year-old man, in a room at the university. He was a PhD student who had not been formally identified with dyslexia, but who had had a screening test which suggested he might be dyslexic, and thus came to find out about my research.

Rose was a woman who lived in South Wales with her husband and two children. She had lived in a British Overseas Territory and moved back to the UK when she was about 14 years old. She had been formally identified with dyslexia at university, and
was unemployed at the time of our meeting. She had found out about my research through a dyslexic institute. I interviewed her at her home.

Simon, a man in his 30s, was interviewed in a room at university. He was a call centre worker and was formally identified with dyslexia while he was at university doing an undergraduate degree. Simon was told about my research by a mutual friend and agreed to participate.

I interviewed Xander, a white man in his late 20s who I knew before the research, in his home in a South Wales city. He had just finished his Doctorate and was due to start a new job the week after the interviews. He was formally identified as dyslexic when he was 11 years old at secondary school.

**Ethics**
The major ethical considerations discussed in contemporary social research are about minimising harm to research participants and maintaining anonymity (BPS, 2009; ESRC, 2010; Reavey and Johnson, 2008). However, in research that involves visual methods, there are other issues to consider, concerning the status of pictures and their ownership. If using pre-existing images, copyright issues need to be considered and permission to use the image may need to be sought. This is especially important when using images obtained from the Internet. This section is divided into two parts. The first is about general ethical issues which need to be considered. The second part focuses on the specific ethical issues that pertain to the present study. Although these are being presented separately, it is important to consider all ethical issues as a whole.

**General ethical issues**
The British Psychological Society (BPS) and the Economic and Social Research Council (ESRC), by whom I am funded, both give guidance for researchers conducting studies using human participants. Both guidelines state that those participating in the research should be fully informed about the purpose, methods and intended uses of the research, as well as what participation in the research entails and what risks, if any, are involved (BPS, 2009; ESRC, 2010). They also state that consent should be obtained and that participants should not be deceived in the course of research (BPS, 2009). For the present research the participants were given an information sheet (see Appendix) which detailed the purpose of the study, the methods used and what was involved for
those participating, the intended uses of the data and that participating in the research was unlikely to entail any known risks.

Also, it is expected that all participants be given ample opportunity to consider participation (BPS, 2009). In the present study, the information sheet encouraged participants to talk to friends or family before agreeing to take part. This is especially important with people who are dyslexic or lack sufficient reading skills, who may not understand the information sheet fully. Both guidelines also state that the anonymity of participants should be assured (BPS, 2009; ESRC, 2010). In the present research, I made clear to the participants in the information sheet and verbally that the data they provided would be kept as anonymous as possible.

Both sets of guidelines also uphold the view that participation in research should be voluntary and that participants have the right to withdraw, without reason, from the study (BPS, 2009; ESRC, 2010). The information sheet given to participants made clear that it was their choice to participate and that they were free to withdraw from the study at any point, including after they have participated. In addition, both guidelines also state that research should not inflict harm, physical or psychological, on those participating (BPS, 2009; ESRC, 2010). It was anticipated that the present study was unlikely to cause harm to those participating. However, by giving participants the opportunity to talk about their lives and issues they may not have considered before may provoke anxiety. Warren (2002) maintains that interviewers are dangerous to participants by their very nature of listening. This is because participants are often forced to confront past versions of themselves in the presence of interviewers. Therefore, it was important for me not to be over intrusive and to pay attention to the well-being and comfort of those participating. All participants were debriefed at the end of their participation and all were given details of their nearest Dyslexia Institute (see Appendix).

**Specific ethical considerations**

There are also ethical issues that pertain specifically to the present research. One of the main ethical issues within this project is that the participants are dyslexic or have reading and writing difficulties and thus they may have difficulties in accessing the participant information sheet and informed consent form. To resolve this I put up first-contact posters which I tried to make as accessible as possible (see Appendix). The
information sheets and informed consent forms were also made as accessible as possible. In addition, the information sheet encouraged participants to discuss the study with friends or family before consenting to take part.

A second ethical issue is that those participants who were not dyslexic, but who think they may be, may ask me for advice about being tested for dyslexia or something similar. This issue was dealt with sensitively. As far as I am concerned I was not trying to conduct an emancipatory study, but it would have been unethical and immoral for me to conduct the research without consideration for the nature of the difficulties encountered by the participants. Therefore, I made all participants aware of places they could seek advice or testing in a debriefing sheet that was given to the participants at the end of their participation (see Appendix).

A third ethical issue relates to the presentation of extracts from the interviews in the thesis. Participants told me a lot about their lives, which made confidentiality difficult. To ensure that extracts were made as anonymous as possible, identifiable place names and people’s names have been changed sufficiently. The full transcripts have also been made as anonymous as is practicable and both recordings and transcripts have been kept password protected. Any printed transcripts have been kept in a locked cupboard on campus. In presenting extracts in the thesis, issues also arise as to the ownership of the extracts (Pidgeon et al., 2008). It has been suggested by various researchers that member-checking, that is participants checking the transcriptions, or parts of transcriptions of their interviews, is a good way to redress the power imbalance inherent in qualitative research, especially at the interpretive stage (Murphy and Dingwall, 2003; Pidgeon et al., 2008). In the present study, member-checking in relation to the representation of participants was considered. However, this would require people with reading difficulties or dyslexia having to read a large amount of transcription, something which I believe would have been unfair and unethical.

One practical implication of using photographs is the issue of copyright. I used photographs obtained from the internet for the photo-elicitation interviews. Half of these were obtained from a free stock exchange website. The authors of these images allow their images to be used free of charge. Some request that you make them aware that they are being used; some allow full use without acknowledgement. The other
half of the images was obtained from various websites. According to copyright law, images can be copied for non-commercial research purposes and educational purposes without obtaining permission from the copyright holder. However, if I were to publish these images in a journal article or book, I would need to obtain permission. Out of courtesy, I have cited the websites from which these six images were taken. I have taken a photograph that is similar to one of the images used in the photo-elicitation interviews. This image is used on the first contact poster in order to publicise the project and recruit participants (see Appendix). Unfortunately permission to use the original image on a poster was declined.

**Interview 1**

The first interview initially involved some participant-centred small talk. For example, most participants mentioned some aspects of their lives when I had first contact with them over the phone, such as the fact that they were on holiday or they were decorating their house. This gave me something to talk to them about that did not necessarily relate to dyslexia, helped to build rapport and hopefully helped to relax the participant in front of the audio recorder. The audio recorder was switched on during the small talk. When the small talk was over, I told the participant that I would like them to tell me about their lives, starting wherever they like. If they questioned this or seem to not know where to start, I suggested that they could start with their childhood. I then listened to them tell their story, interjecting with the occasional ‘ummm’ and nod of my head in order to encourage them. When they seem to have finished, I asked them if there was anything else they would like to add. I again listened to whatever else they had to say until they finished. We then arranged a date, time and place for the second interview.

Once I was away from the participant, I took time to make reflexive notes on the interview. I noted down the feelings I had towards the participant, how I felt the interview went and possible questions to ask in the second interview. I then transcribed the interview at the earliest opportunity, usually within 48 hours of the interview, making notes as I went as to possible questions to ask in the follow-up interview. If there was not time to do a full transcription of the first interview before the second interview, I listened to the interview in order to note down follow up questions.
*Interview 2*

The second interview again involved some small talk in order to keep up the rapport that was hopefully established in the first interview. If the interview was at the participant’s home, I made sure that there was a big enough flat surface on which to place the photographs. I explained to the participant that I was going to show them a series of photographs and that I would like them to tell me what is happening in each photograph. I explained that this may seem a little odd at first, but to bear with it and to try to enjoy it. If they questioned this I advised them to use their imagination and make it up. I then gave the participant the first image and asked them to tell me what was happening in it. When they had finished, I put the image down on the flat surface. This procedure was followed for each of the ten images. Then I asked the participant if they could relate to any of the images, or if they found they could not relate to any of the images, and why this was the case. I listened as the participant talked about the images they selected, making notes as to which number image they were discussing each time.

The second part of the interview then began. I told the participant that I had a few more questions that I would like to ask. These were unique to each interview, but tended to focus on omissions and clarifications. For example, if a participant did not talk about their time in school, which I believe is something pertinent to dyslexia and associated difficulties, I asked them about this time in the second interview. This meant that the second part of the second interview was more like a semi-structured interview. I asked the follow-up questions and listened to the answers. I asked for clarification on certain matters, as I was aware that this was the last chance for me to hear about the participant’s experiences.

I asked the participant if there was anybody that he or she knew who would fit the criteria to participate in the study and who might like to participate. I asked the participant if they could tell them about the research and to pass on my contact details. I gave the participant a thank you letter and debriefing sheet (see Appendix) and thanked them for their participation. Again, once I had left the participant, I made reflexive notes on my experience and transcribed the interview as soon as possible in order that the interview was recorded as accurately as possible and so that a backlog of transcription was not created.
5.3 Data analysis

The research aims are to study how adults who identify as dyslexic construct their difficulties and to investigate how they construct their narrative identities. In addressing these aims, I will consider the processes by which the research participants make sense of and build up meanings of dyslexia, identity constructions, and their sense of self. The research aims are addressed by the analysis of life narratives through the narrative theory. This section of the chapter focuses on the analytic techniques employed to study the data and present findings which answer the above aims.

5.3.1 Rationale and techniques

Grounded theory

In the social sciences much research is done which tests out existing theories and contributes to the advancement of knowledge in either supporting or refuting theories (Henwood and Pidgeon, 1992). According to Charmaz (1990), exploratory studies such as this are complimentary to grounded theory. The nature of this method means that researchers begin with loosely framed research questions (Charmaz, 1990). This study is primarily a narrative study. However, one of the research aims is to investigate how people with dyslexia construction dyslexia and their difficulties. Drawing on social constructionism, I decided to use grounded theory to analyse the data in order to answer that research aim. This was to separate out the idea of dyslexia as a constructed entity from dyslexia as a part of the life course. Due to the narrative focus, the data collection was conducted in specific ways – namely life history interviews, PEI, and an additional semi-structured interview. As such, the data collection techniques used in grounded theory were not used in this study. Instead, the principles of data analysis from grounded theory were applied.

The grounded theory approach to analysing qualitative data involves developing general research aims, rather than specific research questions. These research aims are developed to guide the research, but are subject to change after starting the analytic process. Sampling is strategic and aligned to the initial research aims. Interviews are transcribed and researchers code their data to establish emerging themes. Theoretical and analytical memos are written and sorted, integrated and written up to reflect the grounded analysis and theory that has been developed. Writing research memos whilst reading the data and developing codes and categories
allows researchers to note down their analytical hunches and ideas, an important aspect of grounded theory (Charmaz, 1990).

Grounded theory is a method of constructing social reality (Charmaz, 1990). It involves developing theory from the data, analyses are built up with concepts constructed from close readings of the data. Other approaches to analysing qualitative data may draw on pre-existing theory and literature to influence the analytical reading of data. In contrast, grounded theory allows researchers to look beyond existing theories, whilst affirming, checking and refining their developing ideas. Researchers are not limited by pre-existing ideas about the phenomena they are investigating. The analysis not only involves coding and categorising, but following interests and hunches that emerge from their close readings of the data (Charmaz, 1990). These aspects of grounded theory are important for this study given the lack of research on this topic, the research aims, and the potential that these data could lead to unexpected findings.

Grounded theory strategies can yield rich data and dense analyses (Charmaz, 1990). The aim of grounded theory is to synthesize, explain and interpret data. It encourages rigour by developing a range of conceptual categories, saturating (filling out and repeatedly supporting) the categories and explaining the data (Charmaz, 1990). Maintaining rigour in exploratory studies is important to guard against bias and improve credibility (Charmaz, 1990). Despite this effort to ensure rigour in these methods, many authors have outlined a number of limitations of grounded theory approaches.

The main criticism seems to concern the extent to which researchers can be completely neutral when conducting their research. One of the main tenets of grounded theory is that researchers should leave prior knowledge, previous theories and ideas about the phenomena under study behind when entering the field and when doing the analysis, at least until they start to write up their findings. However, Charmaz (1990) makes it clear that this does not mean that researchers neglect the literature in their field. In addition, Burck (2005) states that researchers cannot be without prior hypotheses whilst collecting and analysing the data, as the ‘researchers’ implicit hypotheses and theoretical interests will always have an influence’ (p. 245). However,
in the process of conducting grounded theory research, an investigator can acknowledge the risks of putting theory first (Pidgeon and Henwood, 2004).

Charmaz (1990) uses a social constructionist approach to grounded theory which is apposite to this research. She states that the categorisation process in this approach is dialectical and active. The researcher’s decisions shape the process and product of the research and his/her perspective is important and needs to be acknowledged during the research. The researcher’s perspective encompasses his/her philosophical stance, his/her school of thought, his/her methodological strategies, experiences, values and priorities. His/her school of thought is perhaps the most crucial part of the researcher’s perspective, as it provides the conceptual roots for the development of analytical categories. The researcher needs knowledge of psychological concepts to inform his/her data collection and analysis.

I applied grounded theory in chapter 6 to study how people construct dyslexia. However, I did not use grounded theory completely. The data collection techniques did not change with further sampling after initial analysis of first few interviews, but as I was listening to further interviews and writing up notes of these interviews, I had the findings of my initial coding in mind. Using aspects of grounded theory was fruitful in allowing me to access the themes and narratives that cut across the interview data, particularly for chapter 6.

The line-by-line coding that grounded theory advocates led me to realise that dyslexia came up a lot in the interviews. I made analytical and conceptual notes about the constructions that the participants made about dyslexia and associated difficulties. In order to do this I read the interviews several times and made notes about issues and words that seemed to come up again and again within interviews and across the data regarding dyslexia and its impact on the participants’ lives. This enabled me to find out what the participants cited as their main concerns regarding dyslexia and how they talked about it. Whenever dyslexia was mentioned in an interview, the surrounding talk was highlighted and all these highlighted parts were compared and contrasted to establish how dyslexia was constructed within the participants’ stories, responses to photographs and follow-up questions. How these constructions of dyslexia, particularly
those which cut across most of the participants’ interviews, interact with each other was of particular interest to me, and are analysed in chapter 6.

**Narrative Analysis**

In chapter I introduced ‘storyworld’ and in chapter 3 I discussed how narrative approaches have been used empirically in the study of identity and self. In this section, I shall elaborate on the use of ‘storyworld’ in general, and how it is used specifically in this thesis. Narrative analysis brings a different aspect to grounded theory. However, grounded theory analysis needs to change when using a narrative approach. Line by line coding does not seem to work when a researcher wants to investigate the narrative that a participant tells about their life or a particular experience. I have found that using grounded theory to identify the particular stories that the participants tell about their experiences of being dyslexic, was fruitful in allowing me to investigate the commonalities and differences between these stories. In addition, the analysis I had done of the content of the narratives informed the focus of the narrative analysis.

As outlined in chapter 2, storyworld is a new concept developed within this thesis. In section 5.2.1 I discussed Wengraf’s (2001) biographic narrative-interpretive method to the study of narratives. In an extension of his approach, using the theories of Ricœur (1984; 1994), Davies and Harré (1990), the analytical and methodological concept of storyworld can be discussed. The theoretical framework of storyworld was introduced in chapter 2. Here I shall expand on the methodological features of story, specifically how it is used in the present study.

A storyworld is a bounded temporal experience told by a narrator; it could be ‘the story of my 21st birthday party’, or ‘the tale of my twenties and romantic relationships’; it could be as short and simple as ‘I fell over when I was 9 and now my knee always hurts’, or as long and complex as a full life-story told in one sitting. When I say an experience is bounded, I mean two things: one, the narrator tells a story which tends to have a beginning, middle and an end; two, the analyst can split a life story into parts to suit her analysis. The researcher may wish to look at one particular aspect of the narrative – a diagnosis story for example – which means that she has to choose which parts of the narrative to use in her analysis. For this thesis, this aspect of storyworld is useful. I am interested in dyslexia, and in between the parts of participants’ interviews that are relevant to this study, there will be parts that are not
particularly relevant or interesting to the thesis I am writing. Thus, I will need to choose which parts to include in the analysis, and which to exclude, hopefully for a later research project.

A researcher will select a relevant part by picking up where the narrator first starts to recount experiencing symptoms – this is the starting point for analysis of the ‘tale of the diagnosis’. The researcher may analyse the prose from that point to the end of the interview (or conversation, or medical consultation) or to the point at which she feels the participant’s talk has become irrelevant to the research. Researchers are selective in their work – we cannot analyse all the data we have to write about in a succinct, relevant and readable thesis. That part of the narrative which has been chosen for analysis is a ‘storyworld’.

However, within that large ‘diagnosis’ storyworld are other stories: the story of ‘when I discovered the lump on my breast’ and the story of ‘when I went to see my GP about it’ are but two examples. These are also storyworlds, and the researcher may want to analyse each of these stories and the events that unfolded in that time separately – this will break down her task, and will help her form the backbone of her book, chapter, or journal article. In addition, one particular storyworld may become the focus of the end product (book, chapter etc), or two or more storyworlds, or the researcher may choose to use their analysis of the wider ‘diagnosis’ storyworld.

The point is that a ‘storyworld’ is a way of packaging parts of narratives in ways that are helpful to the analyst. Of course, this is not new. Analysts have always chosen parts of interviews and narratives to focus on when doing their research. This is uninteresting if you consider what social researchers do in their nuts and bolts methods. However, what I think is new is that storyworlds of different lengths, covering different periods of time, can be treated equally. They represent important parts of the narrator’s past, and can be considered in temporal terms.

As discussed in chapter 2, stories are produced in particular contexts which have their own local interactional rules, both in ‘real world’ settings and more contrived, research based settings, such as the narrative interview. The theories of Harré (1991) and Gergen (1994) have been used as bases for investigating the para-linguistic devices and interlocuter practices through which identities are locally and continuously
constructed during the telling of small stories. The positioning approach to analysing talk enables researchers to focus on relational, locally emergent co-constructions in interactions. As such, it is used to capture the situated, action-oriented, practice based nature of identity constructions (Deppermann, 2013).

By using Davies and Harré’s (1990) theory, researchers can study the discursive production of selves in social interactions and gain insight into how meaning is achieved. Their framework, based on individuals’ use and negotiation of discursively available categories shows how individuals position themselves in relation to those categories and others. Identities are thus conceptualised as positions. People are ‘positioned’ by discursive practices in which they partake by learning and using particular discursive practices (Davies and Harré, 1990).

Within the research interview, as in ordinary conversations, a multitude of possible identity constructions are opened up, which the narrator can realise in their telling (Davies and Harré, 1990). A narrator constructs an identity position in relation to the interviewer. The narrating self tells the story of the past self endowed with features and actions in a social world, revealing categories and qualities which make up their personal perspective. Other characters narrated in their interactions with the narrator are often vividly described in the present tense and brought to life with constructed dialogues (Tannen, 1989).

The use of positioning theory in narrative analysis was given a framework by Lucius-Hoene and Deppermann (2000) who suggested analytic focus on discursive frames of interaction, with early stages of interaction as important as interview interaction. By the time the narrator and the researcher get to the research interview, they have already been in contact with each other, interactions which need to be considered for analysis (Lucius-Hoene and Deppermann, 2000).

Lucius-Hoene and Deppermann’s (2000) framework is shown in Figure 1 below.
Frame 1 represents the narrator’s and researcher’s prior knowledge of one another.

Frame 2: first contact, negotiation of aims and rules

Frame 3: narrative situation

Figure 1: Lucius-Hoene and Deppermann’s (2000) framework for positioning analysis in narrative research

NB: N1, R1: narrator and researcher’s pre-knowledge of each other; N2, R2: narrator and researcher in first contact; N3, R3: narrator and researcher in the interview.

The researcher has a particular type of person in mind to include in her research, while the narrator has certain assumptions and knowledge of social science and scientists (Lucius-Hoene and Deppermann, 2000). Frame 2 represents first contact as the researcher asks the narrator to take part in the project (Lucius-Hoene and Deppermann, 2000). In Frame 3, the roles of the narrator (N3) and researcher (R3) are realised. After some pre-narrative pleasantries in which the researcher may attempt to put the interviewee at ease and negotiate rules for the interview, the narrative begins (Lucius-Hoene and Deppermann, 2000). This frame represents the ‘present’ interview time, within which various positions are made available through storytelling and narrator-researcher interactions (Lucius-Hoene and Deppermann, 2000).

The procedure outlined above led to the identification of discrete narratives which then became the unit of analysis for these chapters. These narratives changed across the course of analysis because, as discussed above, definitions of narrative vary. Where a narrative begins and ends influences the analysis and arguments made. As grounded theory dictates, the data drove the analysis, but analysis also drove what
was to be analysed, for example where a narrative starts and ends. The content of the narratives was analysed as described above using grounded theory until the argument was established. This involved discussions with peers, supervisors and others outside the university. This was very useful as it helped me to develop and expand my argument. This sometimes meant returning to the data, as suggested by grounded theory.

In chapter 7, I employ narrative analysis of two women’s interview stories through a mix of three lenses: the structure of the story; its content and themes; and the interactional nature of the storytelling experience. The focus is therefore on the micro and macro aspects of analysis in order to construct analytically strong arguments. This is a methodologically novel way of doing narrative analysis. Originally, several themes were identified in the women’s stories that could have appeared in the chapter. However, I found their reference to change and difference relevant to the analysis of identity. In addition, these were themes that cropped up across all the participants’ stories. The extract to be analysed for each participant in each theme was chosen on the basis of where the theme started to become prevalent in the interview. The extracts were limited by the nature of the story ‘moving’ on in a direction, which meant that the theme changed.

The ways in which I heard the speaker and responded to her is also brought to the fore in order to present the narrative as an interactional life account that presents the speaker in a particular way in relation to the external social world. Two participants’ narratives and experiences (as told in narrative) were very different, but seemed to say the same thing about dyslexia. The focus on these two participants allowed me to bring out the identity aspects linked to narrative and dyslexia. This helps to set up the final empirical chapter.

The participants all told narratives about being identified with dyslexia or coping with dyslexia. The procedures involved in the construction of chapters 6 and 7 enabled me to identify narratives regarding participants’ narratives of change, especially change related to dyslexia. In chapter 8 these narratives of change are presented in three parts. The first part includes narratives of recent or current change, which are analysed in terms of their content, characters and plots. However, the focus is on the
evaluations of the stories and on their temporal structure. The second part of the chapter presents narratives of past change related to present difficulties and the final part presents narratives of past change with no relation to present difficulties. By focusing on evaluation content and temporal structure of the storyworlds, I discuss the self-significance of these changes and thus the participants’ identities.

5.4 Reflexivity
I do not have dyslexia myself, nor do I think I have dyslexia. I have never struggled with reading, writing or spelling. This means that, as a researcher, I am an outsider investigating the lives of those who have difficulties and abilities of which I have no experience. Pollak (2005) was in a similar position to me and stated that as he was a non-disabled person investigating ‘disabled’ people, his privileged position meant that he had responsibilities. As much as I agree with the sentiment of Pollak’s (2005) concerns, and as much as I acknowledge the sometimes profound differences between me and the participants in this study, I feel that I need to exert caution in drawing on such reductionist views. By drawing on the notion that I was non-disabled, I may illuminate the disabling aspects of dyslexia, which is dangerous given the contested nature of dyslexia and the arguments made for using the social model when talking about dyslexia. Being non-disabled may make me privileged, but it does not preclude my privileged position as a White, middle class woman. All of these ‘privileges’ need to be acknowledged, especially in contexts where a participant is very different from me.

There was very little I could do in terms of leaving my values and expectations at the virtual door of the research. In contrast, my skills and abilities were much easier to change.

The interviews I conducted mostly went to plan. The participants were very generous with their time and their stories. I tried to allow them the space to tell their stories with only encouraging ‘mmms’ and ‘yes’s’. However, in transcribing these interviews I found that, as careful as I thought I was, I made interruptions where none were needed. For example, I sometimes told some of the participants what I thought they meant before they had had a chance to explain it to me. This would clearly have had profound effects on the data I collected. However, the more people I interviewed, the better my interview skills became.
Another aspect of the research I needed to be reflexive about was the fact that I knew some of the participants personally, both as friends and acquaintances. I am very grateful to these participants for their time. However, my familiarity with these individuals needed to be considered against my position as a stranger to the other participants. Although this project was not an ethnography, the ethnographic principles of making the ‘strange familiar and the familiar strange’ was an adage I tried to uphold. In particular, I made sure that I started each interview with small talk, whatever our previous relationship. If there was any reference to shared friends, experiences, and knowledge beyond that of general knowledge, I did not expand up on it. I merely nodded and encouraged the participant to talk further. Thus, I was able to gather data that are consistent and suitable for secondary analysis.

I differed from the participants in the study in different ways, the most obvious of which is that I am not dyslexic. My gender, race, age and education may mean that I am in a position of privilege. This was important to consider during the recruitment of participants and during the process of obtaining informed consent and during the interviews. In addition, some of the participants were known to me personally as friends or acquaintances. This presented immediate confidentiality considerations. Some of these participants did not want people to know of their dyslexia and associated difficulties. Some of the participants have kept in touch with me through email, Facebook and friendship circles.

The participants in the study gave their time freely and their contribution was imperative to the success of this project. As a token of my appreciation I have offered to send them a summary of the findings of the research. This will need to be done in an accessible way given the participants’ difficulties with literacy. It will also need to be sensitive. The reporting of the academic analysis of identity may be upsetting for the participants to read. Therefore, care needs to be taken about what is presented to the participants in the summary. These general ethical considerations do not include the two main ethical issues I encountered during the course of this research.

After having transcribed the interviews and proceeding to analyse the participants’ stories, I came across an issue that I could not ignore. One participant, who I have named Betty, did not seem to fit in with the other participants. She was the only
person I recruited who struggled to read and write enough to be considered illiterate. Her story alluded to an extremely difficult childhood and an unusual relationship with her current partner. It soon became clear that Betty thought I was meeting her to teach her how to read and write. In addition, her story and her mannerisms suggested to me that, although she had signed the informed consent form, she did not give informed consent. She did not understand what my intentions were and she did not seem to have the capacity to understand.

As soon as I realised this, I tried to make it as clear as possible that I could not do this. I emphasised my reasons for talking to her. Despite the appearance that she had given consent to participate, I think that she was not able to have given informed consent. The expectations she had of me, and the stark gap between those expectations and what I could deliver, meant that I made the decision to exclude her data from the study. She has been informed of this and was referred back to the services she was using before.

Second, I had to change or omit details in some of the participants’ data. One participant had signed an agreement not to talk about certain things. In the interview, he did talk about these things, but I have changed specific details in order that his anonymity is protected. Other participants had particularly extraordinary careers and journeys, the divulgence of which may have made them identifiable. Care was therefore taken to ensure that confidentiality was maintained, whilst also giving accurate representations of their stories.

Participants provide researchers with data, give their time, give part of their lives, and may be changed as a result. The impact of research on individuals varies. In analysis, then, we should ensure that the participants’ stories and lives are represented accurately, sensitively and treated with respect. However, the participants’ stories are elicited by the researcher and therefore come to exist in a particular context. In analysis, it is important not only to represent the participants appropriately, but also to ensure that the participants’ quotes are not taken out of the context in which they were given.

As Burck (2005) states, researchers’ implicit knowledge and theoretical interests will inevitably influence their analyses and findings. This is important. As a white, British,
non-dyslexic, middle class, woman in her 20s, with a particular degree and particular experiences, I went into the research field with implicit, preconceived ideas about dyslexia and life stories. I also had preconceived ideas and expectations about the participants I was going to meet, having spoken to them on the phone, met them in person, or having known them for a number of months or years. These unavoidable aspects of social research need to be noted and considered throughout the research process.

One aspect of conducting social, and other types of, research is the danger that reality fails to meet expectations. However, by being reflexive on the research process, a researcher can gain perspective on their task, and learn from mistakes. The data collection method discussed above is designed to elicit narratives. One other way of eliciting narratives from people may be to show them photographs. By showing photographs that relate to dyslexia and associated difficulties to participants in a second interview, it is possible to focus their stories on the research topics, without imposing my frame of reference on the participants before they have told their life stories.

As argued in section 5.2, visual methods have a long history in social and psychological research (Reavey and Johnson, 2008). By using images in the present research study, it was hoped that participants would be able to engage with these otherwise inaccessible feelings and experiences. According to Banks (2001), using images that are not produced by either the researcher or the participant, or using images that seem to have no connection to either individual, is rare in this field. He claims that such images would not promote intimacy and may detract from the research aims (Banks, 2001). The images that were chosen seemed, superficially, to have a connection to the participants, in the sense that the protagonists in the images were completing reading and writing tasks which may be difficult for them, and may bring about some emotional response in the participants. However, in the process of using the photographs in the interviews, I found that some of the participants struggled to relate to the images.

The literature regarding visual methods as a tool for data collection guided me in my thoughts about how to collect data with my research focus in mind. However, the data
produced through the use of images did not help to answer those analytical aims. However, four of the participants seemed to relate to one image in particular, and talked about aspects of having dyslexia which other participants also talked about at other times. This image and the responses to it are presented in chapter 6.

5.5 Conclusion

Narrative has been described as a pervasive method that humans use for relating past experiences (Bruner, 2002). It can be argued that we live by narrative, and selves and identities are constructed through our use of narrative (Bruner, 2002; Gergen, 1994). There are a variety of ways to elicit narratives. In the present study, participants were asked to tell me about their lives in their own words. A second interview then gave me the opportunity to ask relevant follow-up questions.

Despite the ubiquitous nature of images in present day Western society, visual methods in social research have been marginalised (Banks, 2007; Bohnsack, 2008). There are a number of positives associated with using images in social research (Reavey and Johnson, 2008). However, some writers urge caution (Emmison and Smith, 2000). The present study is informed by techniques used by Henwood et al (2011) and I have adapted the TAT (Ritzler et al, 1980) for use as a photo-elicitation interview technique. Part of the data collection included using photographs to elicit narratives from participants. However, this method did not produce the data expected, and analysis of it did not contribute sufficiently to the thesis presented here. In section 5.4 I wrote about the need to be reflexive in conducting social research, explaining my reasons for not using most of the data I collected.

The sample consists of two groups of adults, some who have been identified with dyslexia and others who have not, but who have reading and writing difficulties, or think they may be dyslexic. Opportunity, snowball and theoretical sampling was used to recruit participants of differing backgrounds and ages. The ethical guidelines published by the BPS (2009) and the ESRC (2010) were adhered to. However, there are specific ethical issues that relate to the present study, such as the difficulties that the participants may have in accessing written forms. In addition, I have tried to be as reflexive as possible during data collection and data analysis, in order that the research is as robust as possible.
I conducted pilot interviews with one participant, which informed the procedure used in the study. The interview schedule was open-ended in the first interview, where participants were asked to tell me about their lives. The second interview was more structured. Ten images were presented individually to the participant, who was asked to talk about what is happening in the image. The images were then presented together, and the participant was asked to pick out images to which they relate, or to which they do not relate, and explain why. The images were chosen to show tasks that an individual may come across during the course of their life. They were presented to participants in order of the protagonists’ ages. The participant was then asked follow-up questions relating to his or her life story, particularly in terms of dyslexia, difficulties and interesting parts of the story told in the first interview which I felt should be followed up. I made reflexive notes after each interview and the interviews were transcribed at the earliest opportunity.

The theoretical framework is narrative as a method of constructing selves and identities. I will use the storyworld concept to analyse narratives of adults who identify as dyslexic in terms of plot, time, their identities and selves. The methods used in this thesis are a combination of grounded theory and narrative analysis. I have built up theory from common themes in the participants’ storytelling of their lives in relation to dyslexia. In this way, it is hoped that the research aims of how the participants construct both their lives and their dyslexia can be addressed, including how these answers can relate to the current policy and practice context, which is discussed in chapter 9.
Chapter 6: ‘I’m still adjusting to the word, the disability, the dyslexia’: constructions of dyslexia

6.1 Introduction to the analysis

In the interviews the participants talked about dyslexia in various ways. In the present analysis chapter, I will draw out how and why the participants constructed dyslexia, especially in terms of the medical discourse that surrounds dyslexia. I focus on the ways in which the participants constructed their identities, illuminating how the participants negotiated the stigma attached to dyslexia, and how they position themselves in relation to dyslexia. I shall present the participants’ musings on their dyslexia and how they constructed their difficulties.

The idea that dyslexia has an impact on identity construction is pertinent to this study. Two of the women in the study, Ellie and Rose, had very different experiences of dyslexia and told very different stories, although they had both been formally identified with dyslexia. However, Ellie’s formal identification was made during her childhood, whilst Rose’s happened when she was in her 20s. Rose and Ellie are both facing difficulties because of their dyslexia. However, their experiences have been very different. Rose has had difficulties her whole life, whereas Ellie’s difficulties were only now beginning to surface at the time of the interviews. This means that comparisons between their stories and how they construct dyslexia will enable a discussion about their identities, which is presented in chapter 7: Rose and Ellie: dyslexia and the life narrative.

In chapter 8, Narrative identity in changing lives, I focus on the ways in which the participants narratively construct their experiences of dyslexia. I will bring out how the participants negotiated the stigma attached to dyslexia and how the participants position themselves in relation to dyslexia. I will also continue to look at how the participants construct their identities and thus negotiate their present-selves in contrast to their past-selves. This will entail discussing the narrative structure, plotlines and present self-significance of the stories they tell, to draw out how narrative telling illuminated their identity constructions.
6.2 Introduction
Section 6.3 will be about the participants’ particular difficulties and how they ‘cope’ with these difficulties. In section 6.4 I shall outline how responding to these difficulties is constructed as a battle. I shall describe how the participants constructed their difficulties and dyslexia as a medical issue in section 6.5, before section 6.6 discusses the benefits and limitations of being formally identified. In section 6.7, I shall move on to describe how dyslexia is dealt with in schools, with a particular emphasis on the stigmatising nature of special educational needs (SEN). In sections 6.8 and 6.9, the participants’ constructions of dyslexia as a reason or an excuse are presented and analysed. Finally, in section 6.10, I shall outline the tension between hiding and disclosing dyslexia. Throughout the chapter, I shall make reference to and argue that the participants’ environments have an important role to play in how the participants see themselves and imagine others to see them.

I argue that dyslexia is constructed in particular ways for particular reasons, the most important of which is the medicalisation of dyslexia. People with dyslexia have to subscribe to and engage with a medical discourse in order to get the support they need. However, this is bound up with morality and stigma, so that individuals who identify as dyslexic do so in the knowledge that it is a contested concept. This has real implications for decisions regarding disclosure and censorship of dyslexic identities.

6.3 Difficulties
Dyslexia was constructed in various ways by the participants in this study. These constructions are described and analysed in the following pages. In the present study, all of the participants talked about having difficulties in one or more areas of their learning or their employment. Many of these difficulties relate to problems that the participants had at school. For example, Madison talked about the change she experienced between primary and secondary schools.

Madison, Interview 1:

Yeah I’d say in primary school everything was alright but in secondary school I think I began to realise how much I struggled in school
Madison presented her comfort at primary school as an illusion, because at secondary school she ‘realised’ that she had difficulties at school. This change in self-perception is important. In making this statement, Madison was aware that we had met to talk about dyslexia, which suggests that, with hindsight, she knew that this was part of having dyslexia, although she was unaware of it at the time. Similarly, Natasha struggled in school. However, her struggles led to her exclusion from school.

Natasha, Interview 1:

then they moved me to a convent [school] for a year, yeah, but they would only take me for a year because I wasn’t academically good enough, erm, and then in between that and going to a- then when I was eleven I went to a secondary school- a Church of England secondary school but I can remember having extra lessons. I had to, you know, come home from school and then this teacher would come with bad breath (laughs) and try and teach me but it’s all a bit of a blur, erm until probably I must have been 12 or 13 when I- and I picked up Black Beauty and read it and everybody fell over. Then, you know, as school, as school goes on erm I was not in maths I was in arithmetic and I can remember sort of I could do, I could do the maths where if you had the whole class doing that formula that was fine, but arithmetic was, if you had a lorry and it went so many miles how much petrol, you know, rather than, and I could never remember what formula went with what question, so it was alright if you did it all day long, but then the minute you had to find the right one and do that and, yeah at school it was always a feeling that I was never going to achieve very much

Natasha constructed her school identity as good enough ‘academically’. This suggests that there were certain things she was not good at. This was important for Natasha, as the prospect of not being ‘good enough’ was not good for her sense of self. Her lack of academic ability was emphasised by her report of private tutoring. The detail of the tutor’s bad breath gave the story credence. Indeed, her difficulties were given further weight by everyone’s surprise at Natasha reading Black Beauty. Her problems in maths continue to support the idea that Natasha is not very good ‘academically’. At the end of the above extract, she said ‘it was always a feeling that I was never going to achieve very much’, suggesting that there was more than one person who thought this. This was a general expectation which did not need proof or challenge. Like Natasha, Andy also struggled in school.
Andy, Interview 1:

I well erm, I mean, I suppose looking back as a child erm always never ever felt, well I never understood why erm, you know, learning letters and stuff was er so difficult when other children around me always seemed like they like ‘how did they know and I didn’t?’ When I went to school, ok I was sickly as a child erm, I had meningitis and stuff so, but erm I never understood why I couldn’t, when it came down to letters and sounds and things like that they never ever, never stuck in my mind, so I was in, so consequently in school I find that, I found that very difficult, so you kind of rebel a little bit, so books and all that, so all I ever concentrated on at school was sport and art cos I do, I do drawing so when it came down to other things er, where maths and English was concerned I had no interest of the fact that, you know, I just didn’t know what was going on I just, didn’t understand really, so then, like I say really, I just ended up going in high school, it led me to a special school which I found a lot easier, but still at the same time, and that’s where I first heard the term ‘dyslexic’ the teacher there, she er, she kind of told me ‘you’re dyslexic’, so that was like oh well, oh right, but there was no follow on from that

Andy, unlike Natasha, described his difficulties in relation to his peers who did not have difficulties. His rebellion against reading and writing took the form of choosing to concentrate on sport and art. His difficulties were emphasised by his time at a special school, although the recognition that he was dyslexic did nothing to change his experience or his identity as a sporty and arty child who was poor at reading and writing.

In the disability studies literature, a deficit model of disability states that individuals can become defined by the difficulties they have. The non-disabled world’s reaction can dominate one’s self-image (Shakespeare, 1996). Struggling in school, finding school difficult and not being ‘good enough’ for school were common themes in the interviews. When the participants talked about not being ‘good enough’ and struggling in school, they seemed to be presenting themselves in opposition to another alternative of being good enough and finding school easy. They were different from those who did not struggle in school. The participants’ position as different from their ‘normal’ peers was salient in their constructions of dyslexia.
An academically able identity is important in a lexic society. However, those who struggle at school seem to reject being academically able as the only legitimate identity. They are either told this is the case, like Natasha was, or they figure it out for themselves by making comparisons with their peers. Thus, they choose other areas of proficiency instead, such as the ability to succeed socially, in sports and the arts.

Lessons at school were not the only place where the participants felt poor at literacy.

Claire, Interview 1:

I used to have to try and write my own notes, a lot of the notes would be fairly simple, instead of ‘she had a bad stomach’, it would be ‘she was ill’, because it was easier to spell and easier to write so erm, most of the time if one of the children couldn’t go in I would always have to write, cos I was the oldest I had to write the note for school which I was a bit embarrassed about, but it’s just the way it was

Claire talked about the recurrent event of writing sick notes for herself and her siblings. However, this was difficult for her due to her problems with spelling and writing. Later in the interview, Claire talked about her mother’s literacy problems. The extract above has the underlying aspect of the reasons for her note-writing chore. Her embarrassment was thus twofold. First, she was embarrassed about her inability to spell certain words and use only simple language. Second, she was embarrassed about taking on the role that should have been her mother’s. Her mother’s inability to write sick notes for her children contradicts the expected familial roles and has moral connotations.

Danny, Interview 1:

I’m not very good at exams, I panic, I get panic attacks before exams, if I did any, everything orally I’d have straight As, but I’m not very good at exams, huh cue ‘why didn’t someone notice this earlier?’ sort of thing

Danny, who struggled with exams, presented a clever identity but only in certain circumstances. The literate, lexic, world in which he resides is not geared up to measure his abilities appropriately. Danny recognised this and challenged the idea that he is not capable of achieving straight As. Difficulties with writing and exams were also apparent for Simon too.
Simon, Interview 1:

[it] was just the sheer volume of time it took to write stuff, cos I, I can write a paragraph and that could take me about a day because I would just get really confused, and spent too much structure in sorting that out, otherwise I would probably do what I’m doing now, which is go off subject and then go back off subject and go back off it, so it was, it was, I always spent an awful long time writing stuff, and my output was tremendously slow, which was never helpful

For Simon, his output was slow and he struggled to structure his work. These difficulties were not conducive to partaking in a schooling system which expects work to be done quickly and accurately. Fred also had problems at school.

Fred, Interview 1:

I can’t, I can’t remember too much about my early school days erm, I think I cried a lot (laughs) erm, and I remember mum always seemed to know I’d been crying when I got home, I don’t know how she managed to do that (laughs) erm, yeah so progressed through school ok, not many real memorable incidents in primary school

I remember we used to have a maypole and we used to dance round it on May day, and I always used to get the, I always used to get it m- it was always me who used to get it er messed up (smiles). I’d go in instead of out, or out instead of in or whatever erm, I think I’d always had problems with my handwriting

Fred found school upsetting but ‘progressed’. He had coordination problems, unlike his peers. This emphasised his difficulties and differences at school, which also included handwriting problems. Indeed, dyslexia is not just about difficulties, it also means that you are different. These difficulties and differences can be explained by the diagnostic category ‘dyslexia’, but sometimes this is not an option. Difficulties and differences therefore need to be explained in other ways. Jacob’s experience at school gives an example of this.

Jacob, Interview 1:

I think I realised I had some challenges with, not as much numbers as much as reading. When I was in maybe 3rd or 4th grade I had transferred private, going to this private school to erm Montessori school, to this private school, and the learning habits were
very different and that confused me for a little while, and it took me a while to get up to speed erm, because you pronounce things, you do things differently from Montessori school than you do for a, but I didn’t know that I had any other challenges and I just thought, ‘oh well, it’s a different way of learning things and all’

erm I knew early on that I had strange things about reversing letters and things but I didn’t think it was strange, I just thought that other people did it too so I didn’t do anything about it and it wasn’t really a problem until I got into, I don’t know what you’d call the years here, 7th grade so when I was like 14, 13-14 when reading became a lot more intensive, there were a lot more papers that needed to erm be written and erm, instead of saying anything about it I realised that there was something going on, I kept it to myself, but I just burned the midnight oil, and would just stay later and check my stuff and check my stuff because I had a erm, felt like there was a stigma against me because of my colour, so I certainly wasn’t going to have one because of other issues, or if this was an issue and everything else so

and I just remember all the things my parents had been through in their education to get it, so I thought ‘who am I to complain or say anything about this’, plus I knew that, you know, if they did think of that I had a learning disability or you know, they would have thought I was dumb or, not dumb but remedial, and I would have been put in different classes and I was in top form classes throughout, just killing myself to stay there erm, but I was doing it and I did well in most well, math calculus and things was very very difficult for me because I think it was too abstract in the way it wasn’t described enough with boards and whatever, a lot of things would be talked out by the per- by the teacher rather than, I’m a very literal visual person and that was difficult for me erm, but again I took that as that I was not very good at math

Like other participants, Jacob struggled with reading and maths. However, changing schools and pedagogical styles offered an explanation for his difficulties. When his problems got worse, Jacob actively hid them due to both the stigma attached to his skin colour and the stigma attached to learning disabilities. He identified as an intelligent, ‘type A’ student who invested a lot to remain in top sets.

In describing difficulties, the participants compared their identity positions with their peers who did not have difficulties with these tasks. This may mean that they were attempting to present themselves as having always been different from their peers.
The participants were thus doing identity work in describing their difficulties and therefore in positioning their selves away from the norm of finding these tasks easy.

The difficulties the participants professed to have are mentioned in the literature (MacDonald, 2009; Reid and Kirk, 2001). Indeed, some definitions of dyslexia focus on the difficulties with which it is associated (British Dyslexia Association, 2011). All participants talked about these difficulties regardless of whether they formally identified or not. Again, this is hardly surprising given that most of those who self-identify as dyslexic have strong evidence to back up their claims (Hilary came out as dyslexic in the tests, Peter had an ‘unofficial’ diagnosis and Fred’s dyslexic sons’ difficulties were similar to his own). Moreover, all the participants talked about ‘coping’ with their difficulties regardless of whether they had been formally identified or not. For example, Hilary talked about being able to cope despite her difficulties at school.

Hilary, Interview 1:

I do know that I erm, tried to opt out of things sometimes and I do, I mean remember one instance where I sat in a puddle because I thought I would get sent home when I was about 6, and I don’t know why, but I assume it was do with not having to do, I thought it would be easier to be at home than having to write, so writing was always a bit of a problem, not a major problem erm, reading I coped with fine, maths, I coped with fine unless it was do with tables erm, concepts were no problem erm, so I was always particularly good with concepts at school and ideas erm, but not necessarily about the writing, that was, I would shy away from writing from as early as I can remember really, erm it was never looked at as a problem, that was a, that just appeared to be who I was and I was accepted for that within family and at school erm, and although maybe I wasn’t as successful with those skills as I could have been, I was certainly more successful than the majority in the primary school erm, again at secondary school erm, continued liking the social aspect, maybe the after schools clubs the sports erm all the extra that go round school really, really disliked languages erm only did French, but hated French, couldn’t do French, couldn’t remember, couldn’t hear it actually, and I still can’t, hearing languages I find very difficult erm, managed to get O levels and A levels, probably got my A levels partly on the back of my sister’s work, just reading what she’d written, doing that, but I’d never had a, my problems are
minor compared to a lot of people I suppose, but also I think I worked out ways of coping

Hilary found writing, times tables and languages problematic. Despite these difficulties she was accepted by her school and family. This is a counter argument to a presumption that having such difficulties may lead to non-acceptance among relatives and school. Although she found mathematical concepts relatively easy, she said that she was not as successful as she ‘could’ have been at maths. However, she was better at that than her peers. As she shied away from the subjects she found difficult, she embraced the social side of school and sports clubs, constructing alternative identities. She coped at school and presented her problems as ‘minor’ compared to ‘a lot of people’. She thus distances herself from her difficulties and downplays the extent of her difficulties in relation to those who have bigger problems.

‘Coping’ is a psychological term that means that an individual changes their environment or internal emotions and thoughts in order to protect the self from stress. It requires adaptation to a change in one’s environment or knowledge (Livneh and Martz, 2007). Coping can either be successful or unsuccessful, and can be positive (adaptive) or negative (maladaptive) (Livneh and Martz, 2007). There is also a social element to coping, which is often about comparing oneself to one’s peers and the norm (Singer, 2007), a common aspect for these participants. In addition, support is strongly related to coping strategies (Singer, 2007).

There is a plethora of literature about coping, but the participants who mention coping in their interviews seem to be talking in a general way about dealing with their difficulties. The interesting thing to note is that dyslexia and its associated difficulties are things that the participants in this research need to cope with, either with or without support. In the extract above, Hilary says that she ‘worked out ways of coping’. Fred says something similar after I asked him whether he would consider being tested for dyslexia.

Fred, Interview 2:
K would you ever think of getting a diagnosis, getting tested?
F I don’t see any point to be honest, it would, it would be interesting to say whether, whether I was or not. I have managed to cope my way through you know, alright I, I
erm English is, English has never been a strong point whether the, whether that’s dyslexia or not I don’t know erm, spelling has always been er difficult, I quite often have to ask how to spell a word, obviously these days with word processing sort of thing it’s a lot easier. I can remember going back erm many years erm, when I was doing a job called the collator where we had to, it’s like sort of type up on cards I could always, I was always spelling ‘Michael’ wrong, then one of my colleagues said ‘the way, the best way you remember that is to do with the ‘a’ and the ‘e’, is that the ‘a’ is right over on the left hand side of the keyboard’, and that’s something that I’ve, that’s stuck, and the er my wife would tell you the problems I have at work, one of my sergeants once told me that I’d spelt the word ‘problem’ four different ways in one report

Both Hilary and Fred seemed to say that they coped with their difficulties without suffering many negative consequences. They had not been formally identified with dyslexia; therefore they did not have the support that their dyslexic children have since had. It may be that Fred and Hilary were saying that despite the lack of identification of dyslexia and support that is now a consequence of formal identification, they constructed their past- and present- selves as adaptive and successful – both in terms of their careers and other aspects of their lives.

Similarly, those participants who have been formally identified with dyslexia talked about how they dealt with dyslexia and its associated difficulties. However, they were slightly more specific. In particular, they talked about doing things differently from their peers and methods of making it easier. Thus, coping with dyslexia and its associated difficulties can mean having to identify as ‘abnormal’, unlike one’s peers. You have to find different ways of doing things in order to overcome challenges in your everyday life, challenges that your peers do not seem to have. This coping could be seen to be a way of ‘passing’ as ‘normal’ and avoiding the stigma that comes with having reading, writing and many other tasks that one’s peers take for granted.

The participants’ talk of managing their difficulties and coping with their dyslexia can be thought of as managing oneself and attempting to ‘pass’ as normal (Goffman, 1959). They constructed their past-selves in contrast to normality, ‘othering’ themselves, yet presenting ‘normal’ identities. It is similar to the kind of talk that sufferers of illness and impairment undertake (Reynolds, 1997; Persson and Rydén,
In managing difficulties, the participants also talked about hiding their difficulties from their peers.

6.4 Battle
Four of the participants constructed dyslexia as a battleground. For example, Andy talked about learning that dyslexia can be coped with.

Andy, Interview 1:

And then going there (the Dyslexia Institute) was like er, a breath of fresh air really, you know, erm I, it kind of let me realise, ooh, you know that there are reasons for what, for why I am the way you know, why I couldn’t do what the others could, why there are reasons for that and that there’s ways to combat those things and there’s ways to, to learn and stuff

Accepting support from the Dyslexia Institute not only gave Andy a reason for his difficulties and differences, it also showed him that he could ‘combat’ those things.

Claire also presents coping as a battle.

Claire, Interview 1:

I’m absolutely convinced that she probably is dyslexic erm, but I’m determ- you know, I was determined not to be in her position, and you know, cos my mother was the main care giver for us erm and I was determined I wouldn’t be in her position erm, and that I would, you know, work hard in school, even though my first teacher, you know, had it in, had it in for me in the sense that, ‘no you’re not going to be’ which made it even worse for, cos actually I just said, ‘I’m going to show you that I can do it’, and you know, I- I’ve had to battle all the way along

Claire compared herself to her mother, who she suspected was dyslexic due to her difficulties with reading and writing. She made an active decision to not be like her, but that meant hard work and battling ‘all the way along’. Similarly, Madison struggled to succeed.

Madison, Interview 1:

we took nine GCSEs and I think you had to get five A to Cs in order to get into sixth form, that had to include an A to C in English, Maths and Science and I actually didn’t, I failed, well got a D in Maths, so they made me re-sit it three times, so once I was in the
sixth form in order to keep my place there I still failed it, and (laughs) after the three
they kind of gave up, it was like, ‘yeah, you’ve already been here for a year, you can
you can stay now’, so I never did actually manage to get that yeah, I mean it was
always definitely a battle, definitely, it was one of my least favourite times

The rules regarding progression from compulsory schooling to further education and
beyond rest on exams and grades. Despite Madison not getting the grade required for
Mathematics, she managed to stay at college. However, this period in her life was
presented as very difficult. Higher education can also be very tough.

Peter, Interview 1:

when I did the, my Masters was one of the- like I almost dropped out because I didn’t
think that I would be able to finish it in time, just because it was so many modules and
the way that I do things like, it wasn’t kind of, it wasn’t designed around somebody
who has difficulties when it comes to that, and nobody knew about them, so it just
looked like I was struggling when I- well I was struggling, but it wasn’t through lack of
effort it was just through like, my process didn’t fit to the the- the way that it was set
up, but I fought through, did it erm, and I think that like summarises it, it’s always a
battle rather than something that comes easily, which is kind of good like, I like the
end product, but the- I don’t like the process that leads to it

Peter’s recent experience of completing a Master’s degree was hard work, as signified
by how he ‘fought’ the difficulties in the course which was ‘always a battle’.

The difficulties described by the participants in section 6.3, as well as being ‘managed’
and ‘coped with’, are battled against by the participants. In the popular media, dyslexia
as a ‘battle’ has been used to signify the difficulties associated with it. The BBC Three
documentary ‘Kara Tointon: Don’t Call Me Stupid’ (2010) has been cited as Kara’s
battle with dyslexia (Magrath, 2010). There may be two reasons for dyslexia to be seen
as a ‘battle’: the media, advocacy groups and professionals’ constructions of dyslexia
and the individual’s perception of it being a battle. These participants may draw on the
metaphor of battling because of the way dyslexia has been portrayed or because they
feel that they are fighting their dyslexia. The battle related imagery used in the
participants’ talk may serve one of two purposes. First, it may serve to emphasise how
difficult they find dyslexia. To battle something implies there is hard work involved.
Second, it can be inferred that you would have to be strong in order to do this. They
construct themselves as ‘strong against the odds’, both in the past and present. However, support is needed. Dyslexia and its related difficulties are not things that can, or should, be battled alone.

6.5 SEN
Discussed in chapter 4, the relationship between school and dyslexia is referenced here. In school practice, dyslexia is considered a Special Educational Need (SEN). Historically, pupils who have such difficulties have been labelled and treated differently from their peers (Cole, 2005). The general idea is that individuals whose difficulties with learning are much more severe than their peers’ difficulties need extra support and help. This idea was the cornerstone of the Education Act (1981), a hugely significant bill which laid the foundation for the education of pupils who have additional learning needs. Some of the participants in the present study linked their own difficulties with the idea that dyslexia is a learning difficulty (or SEN). Some participants picked up on this. Jacob, who was educated in the USA where dyslexia comes under Learning Disabilities, said: ‘part of me realised that there was probably some level of a learning disability’.

Peter, who had not been formally identified as dyslexic, said, ‘I had some learning difficulties while I was going through school from quite an early age’. This emphasises the general common sense notion of learning taking place solely through school, which highlights dyslexia as a cultural phenomenon which is salient due to the high value placed on written language, as discussed in chapter 4.

Claire comments on how many people may perceive dyslexia as a ‘major learning difficulty’. This serves to show that perceptions of dyslexia and related difficulties are important. Indeed, Peter, Claire and Jacob all related their dyslexia, or presumed dyslexia, to special educational needs. However, as discussed in chapter 4, and in section 6.3, dyslexia does not just encompass difficulties with reading, writing and spelling. Despite this, in school and other educational settings, dyslexia may be seen solely as an SEN. SEN does not just relate to dyslexia and its associated difficulties, it can also relate to intellectual disabilities, Down’s syndrome, Autism, physical impairments, ADHD and many others. Like these conditions, dyslexia can also be construed as a medical condition: an important, if subtle, shift for these individuals.
6.6 Medical or disability issue

All the participants in the present study talked about dyslexia as the result of a test or a diagnosis and therefore as a label given to them by a professional.

Andy, Interview 2:

I erm took the test the test and they confirmed that I had dyslexia

In the extract above, Andy was referring to his experience of being identified with dyslexia at the Dyslexia Institute. In taking a ‘test’, he referred to the method used to identify individuals who have dyslexia. Claire also talked about being identified with dyslexia.

Claire, Interview 1:

when I had my er, erm, test for dyslexia ,when I had it, not in school, I only had a dyslexia test because of finding the information, I find I can’t read and take it in, it doesn’t make a lot of sense

Claire referred to the popular notion that dyslexia is generally identified in school, but lets the audience know that this was not the case for her. By saying that she ‘only’ had the test due to her reading difficulties, she seemed to suggest that this was not something she was particularly keen on doing. Like Andy, being identified with dyslexia involved a ‘test’, which was something that Danny acknowledges in his second interview, when he said: ‘yes, I want to be tested’. Like Danny, Hilary did not have a formal identification of dyslexia, in her first interview she said: ‘in all the tests and things [I] came out as severely dyslexic’. Which was similar to Peter’s experience.

Peter, Interview 1:

so I went for a erm a test at the university learning centre... so it’s kind of like an unofficial diagnosis

A label like dyslexia, with its medical connotations, can only be given by a professional. This is why Peter’s statement above is so interesting. He had an ‘unofficial’ diagnosis, which meant that he could not obtain any ‘treatment’ for his difficulties. Being ‘tested’
for dyslexia and obtaining a ‘diagnosis’ appear to be the norm for people who identify as dyslexic, even those who do not have an official identification of it.

However, those who self-identify as dyslexic imagined this label (or diagnosis) as having little or no value. In the second interviews with the participants who did not have a formal identification of dyslexia, I asked them whether they would consider getting a formal identification. In response, Danny asked, ‘what benefit can it do me now?’; Fred stated, ‘I don’t see any point to be honest’; whilst Hilary stated, ‘I don’t see it as being of any value, having a label as such’.

Danny, Fred and Hilary’s imaginings of the lack of value of a diagnosis and label may have served to protect their choice of being self-identified and not getting a formal identification.

Claire, Interview 2:

I just think that the label dyslexia is very erm limiting

Being identified with dyslexia means that you have a label and a particular identity to uphold or suppress, for practical or other reasons. For Claire this label is ‘limiting’. There is a stigma attached to the label of dyslexia. However, a label can also be positive.

Xander, Interview 2:

If you’ve got it formally identified then there’s lots of benefits you can get. To me it would seem that there ar-, there’s, there’s more avenues for you to get help

Xander saw the label as related to the support one can obtain, which is a positive outcome. The participants in this study constructed dyslexia as the result of a diagnostic test and a label. Those who had the label may have seen it as limiting or helpful. However, three of those who did not have the label imagined it as being worthless. They may have been attempting to uphold their decision about remaining unofficially identified as dyslexic without searching for a formal identification. Given that dyslexia can be construed as a diagnostic label, it is hardly surprising that these participants saw dyslexia as a medical diagnosis, a medical condition and a disability.
This is in contrast to Evans’ (2013) study, in which student nurses rejected the idea of medical and disability discourses in their talk.

Claire, in her first interview, told me that she ‘wasn’t diagnosed as a child’. In the second interview with Danny, he said, ‘I don’t know how serious it is, but I’ve been told it sounds like you’re dyslexic’. Both Claire and Danny engaged in this medical discourse. Danny’s use of the word ‘serious’ can be compared to its use in describing medical conditions and diseases. Jacob also talks about dyslexia as a disability:

Jacob, Interview 1:

Part of me realised that there was probably some level of a learning disability whatever, but also knew that coming from the States which has a huge stigma attached to it...I’m still adjusting to the word, the disability, the dyslexia

However, this is partly due to the different terminology used in the US where dyslexia is often cited under the umbrella term of learning disabilities (Hunter-Carsch, 2001). His identity as an American, having lived in an environment that constructs dyslexia as a learning disability, means that he constructs dyslexia differently, referring to it almost exclusively as a learning disability. The extract above supports the notion of dyslexia as a disability, and along with this comes stigma. The ways in which he constructed his experiences since being diagnosed in the UK are very positive.

Jacob, Interview 1:

they (admin staff at his university) were very understanding. It was very supportive and I have to say that so far with DSA (Disabled Students’ Allowance) and all [it] has been pretty efficient

Jacob mentioned that a diagnosis of dyslexia was a way of getting financial and academic support, something which will be discussed in section 6.7. Despite the terminological differences between the US and the UK, dyslexia remains under the Disabled Students’ Allowances (DSA), an institutional support fund for those students who have disabilities and need extra support. The inclusion of dyslexia within this funding policy serves to perpetuate the notion that dyslexia is a disability. This was picked up on by Rose.
Rose, Interview 1:

when it came through that I have dyslexia, I have dyscalculia, they want to check me for Irlen syndrome as well erm, it was like, ‘no! No! Now all of a sudden I’m disabled!’

When you, when you apply for a job and they say, ‘do you have any disability’, so long as I got, ‘well, I might be dyslexic’, I didn’t have to tick yes. Now I have to actually tick yes

Rose drew heavily on the notion that dyslexia is a disability, specifically in relation to information gathered on job application forms (a requirement of the Equality Act 2010 and the previous acts that it replaced, e.g. the Disability Discrimination Act 1995).

Rose’s abhorrence to the idea that she ‘has to tick yes’ to the question of whether she was disabled helps her to construct a non-disabled identity. This is tightly linked to the idea that dyslexia is something that can be disclosed or withheld (which will be discussed in section 6.9) and that these decisions are part of positioning an identity within a potentially hostile environment.

These participants’ constructions of dyslexia as a diagnosis, a medical condition or disability can be seen as part of a general medical discourse surrounding dyslexia. There was a need for individuals to engage with this socially constructed medical discourse in order to get support. This was problematic for those who did not have an official ‘diagnosis’ of dyslexia. In order to be dyslexic, one needs proof. This is something that Natasha commented on.

Natasha, Interview 1:

I’m not dizzy Natasha anymore, I have a condition

The above extract is from a part of Natasha’s interview where she told me that she wanted her colleagues to know about her identification of dyslexia. The word ‘condition’ suggests that she is upholding the medical construction of dyslexia.

Natasha self-identified as dyslexic many years ago, having heard about it through the popular ‘media’. However, it was not until she needed support for an adult education course that she was told that she could not say she was dyslexic without some sort of proof, i.e. a formal diagnosis.
I sort of obviously gleaned from the media or whatever what it meant and just thought ‘well, I can’t spell, I can’t do maths, I think I’m quite intelligent, so I must be dyslexic’. So I- I’d been telling everybody I was [dyslexic] ... so when I went in, I said, ‘I’m a dyslexic’, and they said, ‘well, you can’t just say that, you don’t have proof’

Having a diagnosis, and therefore proof, of dyslexia allows individuals to access the support they need at work and in education. This formal identification also means that individuals with dyslexia also fall under the Equality Act 2010, which means that it is considered a disability in legislation and they can be ‘disabled’. However, the diagnosis of ‘dyslexia’ itself is not a prerequisite for being ‘dyslexic’. One can have dyslexia without a diagnosis, like one can have a cold without being told by a doctor. However, unlike a cold, but similar to the conditions of chronic fatigue syndrome (CFS) and chronic pain, self-identification is not externally recognised until there is a diagnosis (and sometimes not at all). This suggests that there is a culture of suspicion that individuals may invent their dyslexia or difficulties. This culture of suspicion may also exist for sufferers of other conditions (e.g. CFS or chronic pain (Clarke and James, 2003)). There is a threat to self.

Some participants encountered scepticism about the authenticity and credibility of their difficulties and diagnoses. In addition, some people may assume incompetence; may question them about whether they are lazy; may perceive them as less intelligent; and in some cases pupils may be placed in segregated classrooms (Beilke and Yssel, 1999; McDonald et al, 2007). However, dyslexia, along with other less visible disabilities and illnesses, may be less likely to be identified (McDonald et al, 2007). They may be able to ‘pass’ as non-disabled in certain circumstances. It seems that cultural discourses that surround disability in general do not readily apply to dyslexia and other less visible disabilities / impairments.

In chapter 4, it was argued that dyslexia is a particular and peculiar disability. It can be construed as a particular disability because it is included in legislation about disability and there are social barriers which mean that people with dyslexia are disabled by things in their environment (MacDonald, 2009). It is a peculiar disability for three reasons: it is hidden (you cannot tell someone has dyslexia just by looking at them); if literacy skills were not so highly valued by society, then people with dyslexia would not
be disabled anyway (MacDonald, 2009); and it can only be formally identified by people who are qualified to do so (Pollak, 2005). Dyslexia, therefore, is medicalised in the literature, and yet is different from other medical conditions and impairments.

There is a plethora of literature on chronic fatigue syndrome and stigma, as discussed in chapter 4 (Dickson et al, 2007). It is common for patients formally diagnosed with chronic fatigue syndrome to report that its credibility as a ‘real’ illness is questioned, with the implication that these patients are putting it on and are lazy (Werner et al, 2004). Like dyslexia, chronic fatigue syndrome is debated in terms of its existence, nature, aetiology and treatment, which leads to confusion among patients and the general public (Huibers and Wessely, 2006). In addition, chronic fatigue syndrome is also called myalgic encephalomyelitis (ME), a more medicalised term for the same set of symptoms (Huibers and Wessely, 2006). Like dyslexia, chronic fatigue syndrome can also be seen as a cultural condition (Huibers and Wessely, 2006).

Huibers and Wessely (2006) also say the following about chronic fatigue syndrome: that many may not have a formal diagnosis; that the probability of getting a diagnosis is related to an individual’s access to health care, her view of illness, her readiness to engage with the medical model and diagnosis seeking behaviour; that the symptoms can be blamed on the physical illness; and that the search for a diagnosis reflects the need for relief, belief (that they are really ill, not faking), understanding and legitimacy. All of these aspects can be applied to dyslexia. Huibers and Wessely (2006) discuss the advantages and disadvantages of labelling (diagnosing) individuals with chronic fatigue syndrome, stating that despite the possibility that a label (diagnosis) of chronic fatigue syndrome can be empowering and bring legitimacy to an individual’s symptoms, there is a danger that the label could become a self-fulfilling prophecy. However, for the participants in this study who had an official identification of dyslexia, a label was important for the credibility of their difficulties and thus their identity positioning. Therefore, it is possible that people with dyslexia engage with the medical language and the medical discourse in order to obtain access to support.

6.7 Support
Madison, in her first interview, said that she went to the ‘Disability and Dyslexia service’. For university students, like Madison, Disability and Dyslexia Services provide
access to support. However, those who are not students do not have a ‘disability service’ to attend. Instead, charities such as Dyslexia Action provide similar services. Moreover, these organisations provide participants with points of reference in order to explain and give meaning to their diagnoses. This meaning is built on the notion that dyslexia is a kind of medical diagnosis and / or impairment. The diagnosis, or proof, of dyslexia is a practical end point.

The cost of being assessed is high enough to put some people off being formally assessed. This is certainly the case for some of the participants in this study. Madison was fortunate to have her test funded.

Madison, Interview 1:

I think that you had to prove that you had no money in order to get it funded by the uni, that was it... it was certainly something I couldn’t have afforded

Madison was advised to prove she could not afford it in order to obtain financial support from the university to be formally tested for dyslexia. Peter talked about having an informal test to see if there was the possibility that he had dyslexia.

Peter, Interview 1:

The signs were that I was either dyslexic or dyspraxic and- but you’d have to pay £200 to have a test which I couldn’t afford at the time

The cost of the test was given as one of a number of reasons for not taking the ‘test’ for dyslexia and getting a ‘diagnosis’. By quoting the extract figure, Peter seems to emphasise the cost of the dyslexia test. Jacob does the same, but unlike Peter, Jacob spent the money.

Jacob, Interview 1:

Doing a full assessment, which cost me £250 I might add, at a horrible time. I had to think about it cos I- one the money, I’m skint

Jacob had to consider the cost of doing the dyslexia test, but it was not enough to stop him from paying to be formally identified. Andy explained his reasons for paying for the test.
Andy, Interview 2:

It’s not a voluntary thing, it’s something you have to pay for... but then I just weighed that up with well erm, you know, at the end of the day, you know, it’s going to bring me far more erm benefits, do you know what I mean?

For Andy, the costs of doing the test and paying for support were considered as sacrifices for the benefits that this support would provide. Natasha and her husband also had to consider the cost of doing the dyslexia test and being formally identified.

Natasha, Interview 2:

My husband said, ‘look, just do it [the assessment], you know, it’s a lot of money, but do it, you know, it’s a big chunk of money’

These negotiations between individual participants and their families and finances add to the stereotype that dyslexia is a middle class condition (MacDonald, 2009). The expense of getting tested is a barrier that does not exist with many other medical conditions in the UK (unless one pays for private care).

I tried to reflect on my position as a white, female, middle class researcher, which helped when I interviewed and analysed data from, Jacob and Andy, both black men.

Jacob, Interview 1:

there was always a lot of discrimination there because I was one of maybe ... six black males in the whole school ...? so there was an attitude that you didn’t have to achieve, you should just be happy to be here because you were fortunate to be here, erm I didn’t take on that attitude I always took on over achiever type A attitude erm, but also took on the attitude that I always had to be 5 to 10 steps ahead of all of the other majority white kids to get anything anyway

Jacob identified as an ‘over-achiever’ who worked hard, but this was juxtaposed with views that he should be grateful for having the opportunity to study at this particular school. His attitude towards schooling and success were closely bound up with race and competition. He believed that he needed to work harder than his white peers to ‘get anything’.
Andy, Interview 1:

I feel a little bit er annoyed or er angry that in school, er but then I think well you know back then maybe people didn’t know or the system didn’t cater for that or ... I think people did know back then about these situations but er coming from where I come from ... and with the ethnic side of it, it was oh well (gestures pushing away) I’m angry about that in some ways but I think that well, you make your own life in this world.

Andy discussed his anger at the lack of support he received at school, relating that to his ethnicity and the deprived neighbourhood, which had a large migrant population, in which he lived. So, although Andy presented education, special educational needs and race as closely bound, he rejected ideas about his background, and people’s reactions to him, holding him back when he said, ‘you make your own life in this world’. He constructs a survivor identity, in a similar way to how he, Claire, Madison, and Peter construct themselves as fighters in section 6.4.

Diagnosis, identification or assessment of dyslexia (Pollak, 2005) can only be given by an educational psychologist (EP) or an occupational psychologist (OP) (Pollak, 2005). In Brownlow and O’Dell’s (2006) study, individuals with autism in an online community recognised the power of an ‘official’ diagnosis and thus its importance. Given the financial and practical support that results from identification of dyslexia (proof), Educational Psychologists (EP) and Occupational Psychologists (OP) are powerful in their roles as experts who have the ability to deny or allow an individual the proof they need to get support. The construction of a convincing dyslexic-identity rests on access to these experts. Identities can be positioned through talk, but they may need to be supported by evidence.

Given the connection between racism, education and SEN, as evidenced by the high proportion of individuals with SEN who are excluded or who are inmates in prisons (Macdonald, 2009), it is perhaps surprising that ethnicity is not a feature of much educational research. Ethnicity and race tend to be silent in such research, although data is often collected regarding the ethnicity of pupils (Diniz, 1999; McDonald et al, 2007; Hoyles and Hoyles, 2010). There are accusations that education and SEN are institutionally racist (Diniz, 1999). Research has shown that teachers may have lower
expectations of black and minority ethnic (BME) pupils (Hoyle and Hoyle, 2010). Pupils with English as an additional language (EAL) do not have SEN as such, but this may mean that pupils with both SpLD and EAL may only be identified as EAL and thus not be referred for SEN support (Diniz, 1999). In addition, pupils with dyslexia who speak a different language or dialect at home from school may encounter more difficulties in their learning (Cline and Reason, 1993). This may also be relevant to those pupils who have accents, which impinge on perceptions of their social class (Hoyle and Hoyle, 2010).

McDonald et al (2007) found that minority ethnic people with learning disabilities use various methods to resist cultural oppression. The ‘narratives’ (McDonald et al, 2007) are that dyslexia is illegitimate and that those with dyslexia have low intelligence, that they can ‘pass’ easily as not disabled, that dyslexia exacerbates negative gender stereotypes and that gender and race / ethnicity discourses are relevant for dyslexia. The methods that are used include removing oneself from the oppressive environment, reframing negative discourses, and replacing negative discourses with positive ones related to the self. In terms of race, McDonald et al (2007) state:

> by concealing their disability, individuals with learning disabilities may build connections with their racial / ethnic group, but the choice may entail negative consequences (p. 157)

Jacob and Andy’s positioned identities as both black and dyslexic suggests the importance of these identities to their past-selves.

As well as race / ethnicity, a few participants talked about gender. Apart from studies which suggest that the gender difference in prevalence rates for dyslexia is part of its aetiology (Miles et al, 1998), there does not seem to be much research on how gender intersects with dyslexia. Indeed, in this project, gender is not salient for the participants. One exception to this is two female participants’ thoughts regarding dyslexia as a vehicle for understanding how their children experience dyslexia. Ellie and Natasha were both mothers of boys who have dyslexia.
Ellie, Interview 1:

my son, he’s now been in school and he’s now doing letters and sounds like the government letters and sounds strategy, and so I’ve had to learn for him to be able to do it, and he already gets spellings that I can’t spell and he’s not 6 yet (laughs)

For Ellie, her son did not have the same difficulties that she has. She attempted to improve her skills in order to support her son. She presented her identity as a good mother, which was difficult to uphold as there are things that she could not do which her son could. The laughter the end of the extract above suggested that this was difficult, and could suggest self-deprecation in order to cope with this loss of the maternal role. In contrast, Natasha constructed an identity position as a mother who is able to help her son.

Natasha, Interview 2:

of course, I have a dyslexic son, it’s allowed me to help him and explain to him why he thinks the way he does

Her recent formal identification of dyslexia meant that she was able to explain to him why he had difficulties at school. She could therefore present an identity as a good mother, although she did not talk about the work for which she may not be able to give help to him. Such talk would have downplayed the positive aspects of dyslexia in motherhood.

Social psychological thoughts regarding gender and disability have tended to focus on the detraction of traditional gender roles by an individual’s impairment. For example, disabled men may be seen as less ‘masculine’ and disabled women may be excluded from traditional and non-traditional female roles and may not be seen as sexual bodies. However, these academic constructions are problematic when we start thinking about how these issues interact with dyslexia and other hidden disabilities or illnesses. In terms of dyslexia, the obvious gender issue is that the prevalence of dyslexia among boys is greater than among girls (Pennington and Bishop, 2009), which may suggest that this is an essential aspect of dyslexia, or it may suggest a cultural issue. Girls may wish to hide their difficulties, or may be better at hiding their difficulties, than boys.
As discussed above, obtaining formal identification of dyslexia is the primary way of obtaining support for most people with dyslexia. Indeed, most of the participants in the present study made reference to the support that they obtained. Most of those participants talked about support as being positive and in terms of DSA, funding from other sources, people (proof reading), technology, and from disability services at HEIs and Dyslexia Action.

Andy, Interview 2:

they have erm a fund within the company and er, the first term that I did, they funded me through ... Shaw Trust then er took it over and they’ve been funding me ... so financially it hasn’t been as er traumatic as I initially thought it was gonna be, so that’s been a great help

Andy was entitled to receive financial support from a charity in order to pay for literacy support at the Dyslexia Association. So, he did not have to reduce his standard of living. This financial help was constructed as very important to Andy. In contrast, Claire had been given extra time on her university course.

Claire, Interview 1:

They were really supportive mind, extremely supportive in the university and ...the course co-ordinator, erm did allow me some extra time because of the dyslexia ... which enabled me to complete the course cos otherwise I wouldn’t have ever, ever finished it

The extra time given to Claire was imperative to her ability to complete her course. Having support, with extra time and technology, to complete university courses can be construed as an acceptable method of breaking down the social hegemony attached to literacy (Collinson et al, 2011).

The photographs used in the second interviews with the participants allowed me to ask them about particular reading and writing events. As discussed in chapter 5, there were various methodological issues with using the data collected through presenting the images to the participants. However, the responses to one image, below, did elicit responses which are pertinent to the issues being discussed in the present chapter.
To begin the second interview the participants were asked to tell me what was happening in the pictures. After all of the pictures had been presented, I then asked the participants which images they felt they related to and why. Jacob, Rose and Danny’s comments below are responses to the latter question, while Peter’s comment is a response to the former.

Jacob, Interview 2:

This is me standard right now, typing away rather than writing because less errors that way and word processing helps to make it easier

In Jacob’s response to this image he strongly identified with the protagonist of the photograph who was typing. Jacob presented an identity as a ‘good’ student and computer user, who used a word processor to help with his university work.

Danny, Interview 2:

Hm, I would say I relate to that because I’m much more comfortable typing than I am writing, mainly because of the glory of spellchecker, and I can’t touch type because of broken fingers so (laughs) even the typing isn’t exactly easy, but I would prefer to type than write
Rose, Interview 2:

This one believe it or not, even though it’s just someone typing, it turned my life around being able to touch type and not having to write things by hand, so that has meaning for me

Peter, Interview 2:

Erm, so even using a computer reminds me that, I think like it just makes me think like it’s the best invention ever cos it helps you

Danny, Rose and Peter found that their access to computers was positive. If you are at university and have a formal identification of dyslexia, your local authority (LA) may provide you with a computer and software. Although some individuals are able to receive financial and other forms of support, there are many for whom support needs to be purchased. The rules and resources governing who gets what from where, and how this is interpreted, impacts lives and identities differently.

Despite the need for ‘proof’ of dyslexia to obtain support, not all of the participants in this study had a formal identification of dyslexia. I asked those who did not have a formal identification of dyslexia whether they would consider being tested for it. Peter and Danny were not convinced of the benefits of this.

Peter, Interview 2:

you don’t have any extra compensation when it comes to the PhD

Peter acknowledged that being identified with dyslexia would not allow him much compensation in doing his doctorate. Although he was attending university, there were no exams to obtain extra time for, nor were there any essays for which he could get a proof reader. He could possibly use a proof reader for his thesis, but most doctoral students would employ a proof reader regardless, so having proof of dyslexia would not afford Peter any additional support.

Danny, Interview 2:

I have a calculator in my drawer and I have a spell checker on the computer. Practically what advantage can it make to me knowing?
Danny referred to items that most people would have access to that support him with writing and numeracy, so being formally identified would not give him anything that his colleagues did not already possess. Although Danny and Peter have both constructed identity positions as ‘different’ and their difficulties as part of their difference, both acknowledged that their circumstances would not change with formal knowledge of their possible dyslexia. However, in supporting their decision to not get a formal identification of dyslexia, both Danny and Peter seemed to protect themselves from the possibility that they were not dyslexic, that they did not have a legitimate reason for their difficulties.

Without access to free support and without the official knowledge that they were dyslexic, those who self-identified, as well as those with formal identifications, talked about the ways they coped with their difficulties and the self-support methods they used. Peter told me that he checked ‘everything’. Other participants drew on peers, family, friends and professionals to help them, were thankful for the advancement of technology and developed their own ways of coping.

Hilary, Interview 2:

when I’ve been doing further studies I have had some support from erm other people, but I haven’t used in-house support from universities erm as a dyslexic because I haven’t needed to do it, erm I’ve found other people who would sort of proof read

Fred, Interview 2:

I suppose in many ways I’ve been extremely lucky that as I’ve worked the technology has erm progressed and sort of handwriting isn’t as important these days

Danny, Interview 2:

I had a really good junior school teacher who basically said, ‘just write and then go back and correct your mistakes afterwards’ ... and I always found that was a much easier way for me to write than to correct my mistakes as I was going along

Simon, Interview 1:

One thing I’ve got really good at recently is sort of like saying- do you know when you watch sort of like police stuff and they sort of like say letters associated to sort of like the alphabet? I’ve started to do some stuff like that not because I like doing that, I
actually hated using it, but because it’s the only way I can get around the phonetic stuff ... I was trying to do stuff in my own way cos it made more sense to me and I could understand it my way

In the absence of funded support due to a lack of formal identification, the inability to pay for such support, or the ignorance that such support exists, the participants in the present study found their own ways to deal with the difficulties they faced. This included using people, technology, advice and doing things in ways that made sense to them. This kind of self-support seemed to be used regardless of whether there is a formal identification. This meant that although a formal identification is necessary for access to formal, free support, and is surrounded by medicalised language, the participants in this study did not always choose, or did not always have the option, to use the support that is offered to them and nor did they always subscribe to the medical discourse of dyslexia.

Those participants who were formally identified as dyslexic needed to engage with the medical discourse in order to get appropriate support at school, university, college and the workplace. This kind of support, such as someone to proof read essays, may come from disability services at HEIs and charities such as Dyslexia Action. Financial support for students comes in the form of Disabled Students’ Allowance (DSA). Therefore, there are obvious associations with disability when individuals with a formal identification of dyslexia access support. This means that participants must subscribe to medical and disability discourses surrounding dyslexia in order to access the support they need. The above extracts and analyses also show the intricate and subtle ways in which the participants’ interpretations of how dyslexia is perceived and dealt with in their environment permeate their identities. The complexity of their difficulties and the support they used is also played out in the tensions of how a diagnosis of dyslexia can be constructed as a reason for their difficulties.

6.8 Reason
A positive aspect of being identified with dyslexia is the notion that having a formal diagnosis provides a reason for past, present and future difficulties and being different from one’s peers.
Claire, Interview 2:

It was important for me to be diagnosed so that I knew for myself that there were reasons, you know, why I found reading difficult or whatever and erm and then processing information

Claire stressed the importance of being identified with dyslexia. There was a reason for her difficulties with reading and processing information. Andy felt a similar experience.

Andy, Interview 1:

going there [Dyslexia Action] was like er a breath of fresh air really you know, erm I it kind of let me realise ooh you know, that there are reasons for what for why I am the way, you know, why I couldn’t do what the others could, why there are reasons for that... I suppose the biggest thing was there was a reason cos that’s one thing that always used to really bug me, cos I’m not stupid

Being formally identified with dyslexia gave Andy a reason for his differences. It meant that he was not stupid. This idea that having a formal identification of dyslexia explained stupidity seems common.

Ellie, Interview 2:

I didn’t think I was stupid, I knew I had difficulties with writing and reading for a specific reason

Ellie’s difficulties with reading and writing had a reason. To be merely ‘stupid’ is not a good enough reason for such difficulties. The self as a person of value is at stake. If you do not have a legitimate reason for your literacy difficulties, you risk being seen ‘at fault’, an identity position which is a threat to the self.

Simon, Interview 1:

well actually, the reason why I’m not going to be able to do this is because of x y and z and it’s, it’s not something that is entirely my fault, if you get what I mean
Simon was able to explain his difficulties using a legitimate reason. These positive outcomes for identity have been previously reported in the literature (Riddick, 1996). In contrast, the dyslexia reason also allowed Andy to claim a ‘not stupid’ identity, a construction on which Simon also drew, constructing his difficulties as ‘not his fault’. The dyslexia reason allows a change in how participants see themselves and the outside world. There may be a change in identity, from possibly stupid or lazy to definitely not stupid or lazy. If you have reasons for your difficulties and proof that you are not stupid or lazy, then disclosure of your difficulties becomes easier. You may also need some people to know that you are neither stupid nor lazy; they need to be aware of your change of identity, not only to provide you with appropriate support, but to protect yourself and your self-esteem. It means that disclosing dyslexia is active identity work.

For some of the participants who talked about a formal identification of dyslexia as being a reason for their difficulties, disclosure is something that was easy.

Natasha, Interview 2:

I must be dyslexic, so I’d been telling everybody I was... my boss is into it all being confidential, I said, ‘no, I don’t want it to be, I want people to understand that I’m not dizzy Natasha anymore I have a condition’... I’m really, I’m very open about all sorts of things like that, the thing is why hide it?

Ellie, Interview 1:

it’s something I happily disclose

For Natasha and Ellie, they were happy to disclose to anyone and everyone their diagnosis, or suspicion, of dyslexia. This was a very straightforward matter for them. Natasha even disclosed her dyslexia without having ‘proof’. This only became problematic for her when she needed support on an adult education course and those in charge needed to be convinced that she deserved the help she was requesting. After she had been formally identified Natasha latched on to the idea that having a diagnosis of dyslexia meant that she was ‘not dizzy’ anymore. The control Natasha and Ellie had over their disclosure may have been paramount to their decision. Indeed, dyslexia
being a reason did not seem to be enough to disclose. This may be partly because dyslexia can also be seen as an excuse and therefore is a moral event.

### 6.9 Excuse

Hilary, Interview 2:

> Other people who get the label of dyslexia often just think it can be used as an excuse, so I think it has to be very carefully dealt with

If a formal identification of dyslexia is used as a reason, then it can also be used as an excuse. A subtle change in emphasis speaks volumes about the assumptions behind the use of either word. An excuse for behaviour suggests a deliberate attempt to deceive, or a behaviour that could be avoided by changes the agent can make. In contrast, a reason suggests that the individual was unable to change her behaviour due to something out of her control. Therefore, using dyslexia as an ‘excuse’ is unethical or immoral compared to using it as a reason. The participants in this study actively sought to avoid using dyslexia as an excuse. ‘Excuse’ has connotations of not trying hard enough, being a bad student, whereas having a ‘reason’ suggests a legitimacy for failure.

Rose told a story about a teacher who referred to dyslexia as an ‘excuse’ for Rose’s perceived laziness.

Rose, Interview 1:

> When I was about 14 I’d told one of my teachers that I thought I, maybe I had dyslexia, because I’d heard that there was a condition that erm meant that children struggle with reading and writing, and you know, but they’re not stupid, and I don’t think I’m stupid so- ‘No darling, you’re not stupid, you’re lazy. You’re lazy, you don’t apply yourself and I don’t want to hear excuses like dyslexia coming out of your mouth’. That was the last time I mentioned dyslexia

In this story Rose enabled dyslexia to be identified by her teacher as a reason; she is not stupid. However, the teacher positioned Rose very differently: as lazy because dyslexia is an excuse. The idea that dyslexia can be used as an excuse has echoes of research that has been done on chronic fatigue syndrome and chronic pain (Werner et
al, 2004; Dickson et al, 2007). Werner et al (2004) found that women with chronic pain frequently found themselves being questioned about their supposed condition.

Diagnostic labels pathologise people and uphold the medicalisation of conditions such as dyslexia, chronic fatigue syndrome and chronic pain. The excuse / reason dichotomy depends on being formally identified and depends on there being doubt about the condition’s veracity (e.g. chronic fatigue syndrome and chronic pain as well as dyslexia).

The identification of physical causes of many illnesses, disabilities, and learning difficulties due to recent technological developments may mean that the prospect of a physical aetiology leads to more status for the illnesses and disabilities in question. However, this may serve to downgrade those conditions whose causes are more elusive (such as chronic fatigue syndrome, chronic pain and dyslexia). Therefore there is a hierarchy of conditions (Nettleton et al, 2004). This hierarchy may serve to discredit less visible disorders such as dyslexia. If dyslexia is low down in the medical hierarchy of disorders, and therefore discreditable (Goffman, 1963), then using it as a reason may be harmful to one’s sense of self. There is a danger, therefore, of dyslexia being seen as an excuse for undesirable, taboo behaviours and attributes.

Dyslexia is in danger of being denied or invalidated, which means that individuals who identify as dyslexic are also in danger of being invalidated. Dyslexia can thus be considered a moral event, concerning shame and stigmatisation. Illiteracy can be thought of as a taboo and those who struggle with reading and writing are at risk of being marginalised in society. The participants in this study show that they are aware of the alternative ways in which their difficulties can be interpreted and provide examples of this happening. Therefore, dyslexia as an excuse can also be related to the debates which surround the existence of dyslexia. If there is uncertainty about whether dyslexia is real or not, then it can be used as an excuse for poor reading and writing, stupidity and laziness among other things. There is doubt about the legitimacy of dyslexia as a reason for difficulties.
Madison, Interview 1:

I also think that dyslexia is one of those terms that now can almost be used as almost an excuse for people sometimes but I’ve heard lots of parents that I know say oh I think my kid’s dyslexic because he’s not doing very well at school and I’m like well there’s lots of reasons that he might not be doing very well at school he might not be trying very hard or he might have you know crap teachers and things have changed so much since I was at school it’s such a buzzword I think in that everybody knows about it

Madison, was making a moral statement about parents (ab)using the term dyslexia as an ‘excuse’ for their child’s perceived academic failure. Some participants in this study referred to their diagnosis as a morally acceptable reason for their difficulties. They are legitimately using dyslexia to explain their difficulties. They did not wish, however, to be seen as the people using the term dyslexia as a morally unacceptable excuse. Dyslexia may be used as an excuse by those who do not have it, which is morally wrong, but these participants risk being seen as doing the same thing. This is a risk which is pertinent to one’s self and may mean that participants chose to hide their dyslexic identity and difficulties rather than disclose them.

6.10 Disclosure / concealment tension
I have already presented examples of people who had little trouble in disclosing their dyslexia, relating this to the ‘reason’ of dyslexia. However, I mentioned that this may not be enough to encourage disclosure. When disclosure is compulsory this can cause problems.

Madison, Interview 1:

I’d just arrived in the city and I had to tell all these people I didn’t know that I was dyslexic, so I’ve already got a complex about being stupid and that was really, that really upset me

Madison constructed an identity position as someone who already had a ‘complex’ about being stupid. She constructed dyslexia as something that could be perceived as linked to ‘being stupid’. Claire constructed dyslexia similarly.
Claire, Interview 1:

I wasn’t going to disclose it because obviously people’s perceptions would have been changed

Claire also imagined ‘people’s perceptions’ of dyslexia, and more importantly of herself as dyslexic, as negative. Unlike Madison’s, Claire talked about disclosure of dyslexia extensively. Claire, at the time of the interviews, was looking for a job as a newly qualified teacher. She described her excitement about starting a new job, but constructed her diagnosis of dyslexia as a barrier to getting a job. Claire positioned imagined employers’ ideas of extra qualities against a disclosure of dyslexia. She constructed dyslexia as something that she imagined people to have ‘preconceived ideas’ about. In this way she attempted to distance herself from dyslexia. However, this was bound up with possible regrets.

Claire, Interview 1:

the fact that you’ve got someone who is committed and studious, who’s got distinctions, who is very good with the children, who can see, identify problems… they’re not going to see that, they’re just going to see the word dyslexia, they’re just going to see the label

Claire constructed her diagnosis of dyslexia in various ways: as a label; as access to support; as a barrier to accessing future employment. She also claimed different identity positions: a good student; a good teacher; a mother; a job applicant; a former non-dyslexic. Claire’s constructions of dyslexia and identity positions are bound up in complex ways. Jacob talked about disclosure with similar difficulties. In Jacob’s case, he was doing a master’s course and he talked about disclosure to peers.

Jacob, Interview 1:

[I] asked for an extension. I was terrified about doing it …I don’t know if I want people to know, cos I’ve had people on the course when I said I’d got an extension and I didn’t say well er, why they were like, ‘well, oh well, I could have done that, then I could have got a distinction in everything if I’d just had more time’ blah blah blah ‘I didn’t know they were this easy to come by’, but I haven’t explained to them the reason for it or
Getting an extension for coursework is something which Jacob constructs as morally unacceptable, in terms of superiors’ and peers’ negative attitude towards extensions. However, what is particularly interesting is Jacob’s construction of dyslexia as something not to be ashamed of, but this construction of dyslexia makes his position of discomfort about disclosure untenable. His peers’ judgements of his extension, as morally unacceptable, are liable to be constructed as morally unacceptable themselves, given that the reason for the extension negates the moral unacceptability. However, the ignorance of his peers saves them from being constructed as morally unacceptable. In this way, Jacob constructed dyslexia as an acceptable reason for academic extensions on his course and as something not to be ashamed of, whilst constructing himself as a good student and a forgiving peer.

So, the participants in this study who talked about their desire to hide their dyslexia and their difficulties, Madison, Claire and Jacob, found themselves in a quandary, because in order to get support they needed to disclose their difficulties. Therefore, there is tension here between disclosure and hiding related to the benefits associated with having an official diagnosis. This also has implications for identity, which are two-fold: the first implication is that of subscribing to the medical discourse surrounding dyslexia and the second is of hiding ones difficulties due to shame and possible stigma.

Claire, Interview 1:

There’s no doubt that you probably will be looked at fairly unfavourably than other people … there’s still a lot of stigma out there

Like many hidden or partially visible disabilities and medical conditions, people who have dyslexia often need to make decisions about whether to tell people that they are dyslexic. Morris and Turnbull (2007) found that student nurses struggled over the decision to disclose or conceal their dyslexia due to people’s attitudes, patient safety concerns, confidentiality and discrimination concerns. According to the Equality Act 2010, if individuals want support from their employers or teachers, they should disclose. However, the stigma that is attached to dyslexia and difficulties with reading...
and writing may make disclosure particularly difficult. Conversely, the support that is available to people who disclose their dyslexia can be seen as a motivation to reveal their problems. However, without proof that one does indeed have dyslexia, support and sympathy may be hard to come by.

Individuals, such as Claire, who acknowledged potential unfavourable reactions, may take steps to avoid making people aware of an attribute which is stigmatised (Goffman, 1963). By hiding one’s difficulties and by using the strategies presented earlier in this chapter, some of the participants in this study, such as Claire, Jacob and Simon, seemed to be attempting to pass as normal in society, to avoid being discredited (Goffman, 1963). In short, they were partaking in identity management.

6.11 Conclusion
There is debate over the term ‘dyslexia’; over its definition, over its nature, over how it should be identified and what interventions are best. Woods (1998) suggests that such confusion within the academic and practitioner community is likely to lead to confusion in how teachers, parents, SENCOs and individuals with dyslexia understand it. Paradice’s (2001) work supports this view in relation to parents, teachers and SENCOs. However, very little research has focused on how adults with dyslexia construct it (Paradice, 2001; Woods, 1998).

Although dyslexia is a useful word used to describe a particular set of difficulties and abilities (Snowling, 2000; Stein, 2001), the ways in which it is legislated for and how people need to engage with it has big implications for people’s identity constructions. The socio-cultural framings of dyslexia within participants’ talk reflected the moral business entrenched within systems that aim to deal with dyslexia and people who identify as dyslexic. Grounded theory has been used to identify themes that cut across the participants’ interviews. These themes are important to the present study as they demonstrate the ways in which dyslexia was constructed and presented by the participants. This has informed the following two chapters, 7 and 8, in which I present particular narratives from the interviews to further explore the participants’ identity constructions.

This chapter has shown that the difficulties inherent to these participants’ experiences of being dyslexic make them different from their peers. In O’Dell et al’s (2010) work,
young carers were different to their non-carer peers due to their responsibilities in a social milieu where their peers did not need to do the same tasks. There was no sense of community for them. The issues surrounding medicalization and individualisation within disability research is pertinent here. Carers are not visibly different from their peers, in a similar way to those who have dyslexia. This may make it difficult to form communities of ‘people with dyslexia’ or ‘young carers’. Their differences are stark yet hidden.

The participants’ differences are medicalised by the label ‘dyslexia’. This label is necessary to receive the support they need. This support is yet another aspect of the medicalization of dyslexia, as well as a way of reinforcing the social hegemony attached to literacy in 21st century Western society (Collinson et al, 2011). This social hegemony, where the literate elite have the knowledge and power necessary to succeed in a lexic world, requires literacy skills. In addition, the stigma attached to dyslexia, and illiteracy, is such that being labelled ‘dyslexic’ may have an impact on how those ‘diagnosed’ with dyslexia position their identities and construct their selves. Although researchers consider the social and cultural meanings of labels, it is also important to address how a label is powerful in its effects on lived lives (Brownlow and O’Dell, 2006). The decision to disclose or hide this label, with the various consequences this can bring, is difficult.

Dyslexia is a word for a set of difficulties that people have at school and in the workplace. These difficulties are enduring and need to be ‘combated’, which may or may not happen in school. In school, dyslexia comes under the remit of SEN. Like many SEN, dyslexia can be construed as a diagnostic label, which may or may not be helpful. However, one of the benefits of having an official, formal identification of dyslexia, is that one is entitled to and can obtain appropriate support, which takes many guises. However, such support does not always come for free, and neither does a formal identification. This means that the notion of dyslexia being a middle class condition is strengthened. Ethnic and gender identities intersect with dyslexia and other partially visible disabilities in different ways. In addition, in order to obtain support for the difficulties that these individuals have, one needs to have a formal identification, which is often likened to a diagnosis.
A medical discourse is thus built around dyslexia, to which individuals who have a formal identification of dyslexia need to subscribe in order to obtain the support they need. However, without the financial means to obtain such support, or knowledge of such support, most of the participants talked about the ways in which they faced their difficulties. Another benefit of having a formal identification of dyslexia is that it gives a reason for one's difficulties. It explains why they differ from their peers and helps them to understand how to deal with it more effectively. It allows them to dismiss identities of stupid or lazy. However, the participants in this study were aware that some people may construe dyslexia as an excuse for laziness and stupidity. Hacking (1986) states that identities and behaviours come into being ‘hand in hand’ with the categories that label them. This highlights various forms of the social construction of disability, and, ultimately, dyslexia.

The dichotomy between reason and excuse is closely linked to the decision to disclose or hide one's difficulties and dyslexia. By disclosing their difficulties or dyslexia, the participants risk being seen using dyslexia as an excuse for laziness or stupidity. The constructions of dyslexia as a medical condition, a disability, a reason or an excuse have significant impacts on how the participants construct and maintain their own identities in the face of change and the knowledge that they are different from their peers. The participants’ constructions of dyslexia presented in this chapter begin to show the importance of dyslexia for identity development and construction. The relationship between the participants’ constructions of dyslexia, how dyslexia is perceived by the external world, and how they position their identities is complex, as show in this chapter. These relationships will be further explored in chapters 7 and 8.
Chapter 7: Rose and Ellie: dyslexia and the life narrative

7.1 Introduction
As the previous chapter showed, the concept of dyslexia is replete with discourses about struggle, stigma and disability. In this chapter I wish to focus on just two of the participants, Rose and Ellie, and how their struggles with dyslexia and its influence their life story plots. Jarvinen (2004) provides a framework for studying life narratives which draws on the thoughts of both Mead (1932) and Ricœur. Mead’s theory of the past as only existing in the present can be combined with Ricœur’s theory of time and narrative. As discussed in chapter 2, Ricœur (1988) suggests that plots organize past experiences, but they are always organized by an author from the present. Therefore, the present-self of the author, as well as their current circumstances, informs the emplotment of past events.

Rose was a 41-year-old woman who lived with her husband and two children in South Wales. She was formally identified with dyslexia in her mid-20s when she was at university. At the time of the interview, Rose was living on incapacity benefit. Although she constructed an identity position as an intelligent woman, she struggled to maintain a full-time job that was both challenging and rewarding, whilst also being a wife and a mother. She was highly educated and was given the opportunity to study for a doctorate. However, her family circumstances meant that she was unable to take up that opportunity. She desired an answer to her problems, which she believed were related to her dyslexia and society’s value of literacy. However, she also believed that dyslexia itself was not her main problem, as the associated difficulties (for example co-ordination difficulties) made daily tasks a struggle. Simultaneously, she presented herself as a capable, competent, articulate individual who should be able to work and raise a family.

Conversely, at the time of the interview, Ellie was undertaking a doctorate. Ellie was a 31-year-old woman who lived with her son in the south of England. She was identified with dyslexia when she was seven years old, because her mother, a teacher, recognised her ‘symptoms’. She was also highly intelligent, and believed herself to be capable and competent. Unlike Rose, Ellie had support for her difficulties since childhood. However, in the week before I interviewed her, she had been told that the support she had asked for would not be available. Thus, Rose and Ellie found
themselves in similar circumstances vis-à-vis their dyslexia: it was a hindrance at the time of the interview. However, how they got to this evaluation differed. The emplotment of the events of their life stories gave the audience an impression of their lives and their selves.

Simply, the plots of their stories can be represented as follows:

![Plot of Rose’s story](image1)

![Plot of Ellie’s story](image2)

The linear representations above do little to represent the whole of Rose and Ellie’s narratives. However, they do make it easy to see some of the differences in their narratives. Rose and Ellie’s situated, present-selves were constructed and understood through their tellings of past experiences in the narratives of their lives. Ricœur’s theory of time and narrative suggests that the plot of a personal narrative exists only in the perspective of the present (Jarvinen, 2004). Similarly, Mead’s theory of the past suggests that our present problems determine the ways in which we (re)structure the past. Thus, it can be argued that Rose and Ellie’s present circumstances, outlined above, framed the plot of their life narratives.

In the present chapter, I will argue that the change and difference prevalent in the lived experience of dyslexia has an impact on the self, which is demonstrated through the plot lines of Rose and Ellie’s stories. In order to argue this, I shall present these three main claims:
1. Dyslexia, and its associated discourses, is experienced as a change in life and self, whilst simultaneously is a socially recognized label of difference.

2. The ways in which this change and difference are incorporated into the life story plot are varied and can give insights into identity positions and thus self.

3. Plot is imperative to narrative as it enables present day circumstances and identities to be explained and considered in the light of past experiences, through the use of storyworld.

Dyslexia was experienced as both change and difference, evidenced by the arguments made in the previous chapter. I will expand on this by discussing Rose and Ellie’s perceptions of their difference and change in sections 7.2 and 7.3 and how they were incorporated in to their life stories. These claims will be evidenced by presenting Ellie and Rose’s stories of change and difference. These will be analysed and discussed with reference to arguments and theories constructed by Mead, Ricœur, Järvinen and Brockmeier. These authors will then help me to explain how plot is imperative to narrative identities in 7.4. In section 7.5 I will conclude the chapter.

7.2 Emplotment of difference

7.2.1 Difference
As shown in chapter 6, all participants in this study presented identity positions of ‘difference’. Their differences were from peers, friends, and ‘normal’ expectations and were based on their constructions of dyslexia, normality, stigma and their difficulties, as discussed in chapter 6. One way in which both Rose and Ellie showed that they were different was by reflecting on their experiences of school and childhood. In this section, I present Rose and Ellie’s stories of their childhoods, followed by analysis. The analysis will compare and contrast how their experiences of difference and change are emplotted through their narratives.

7.2.2 Rose: Childhood and difference
Rose’s telling of her childhood marked the beginning of her life story. This first part of her narrative was characterized by her transition from school to the world of work.

    erm, I- my life. I’ll start off with when I was tiny. I- by the time I was 10 I already had confidence issues. I noticed that I was different to other kids in that I couldn’t catch a ball to save my life
First, she gave a short, evaluative, narrative of a past storyworld, constructing a childhood self as unconfident. Her differences from her peers were clear to Rose and made obvious to the audience. It was the first thing she commented on in her narrative and was characterized by her lack of hand-eye coordination (catching a ball) compared to her peers. This is a skill which children should learn easily, therefore Rose’s lack of mastering it is proof that she was ‘different’.

This was followed up by a short particular incident narrative in which Rose described an encounter with her teacher in the first week of school:

at school the teacher on, I think it was like the first week that the teacher had said ‘now if anyone has any problems spelling any word at all just ask me’ and I thought, ‘great’, and I said to her ‘how do you spell ‘I’?’ and she went, ‘what do you mean ‘eye’? as in ‘eye’ (Rose points to eye)?’ and I said ‘no, ‘I’ as in ‘me’” because to me it sounded like a y l e maybe? Ayie? Erm and she told me not to be so silly, to only ask proper questions, and I never asked another question after that

In this storyworld, Rose positions her teacher as a villain, with Rose as an innocent victim who was labelled ‘silly’. The moral positionings in this narrative are interesting. The ‘villain’ teacher allowed her pupils to ask ‘any question’, but she soon limited this to ‘proper’ questions, which should not be asked by ‘silly’ pupils. With her question and identity dismissed as ‘silly’, Rose narrated her withdrawal from participating in class academically. The teacher was presented as both a liar and a villain. Although not all participants presented all teachers as villains, most participants mentioned a teacher or two whom they considered to be unfair. Of course, this is not necessarily only true for people who have dyslexia. However, the difficulties that individuals with dyslexia have may be exacerbated in educational situations with uncompromising teachers. Constructions of teachers as villains serves to position the participants as victims, innocent of using dyslexia as an excuse, and thus supporting a present identity of dyslexic, not lazy or stupid.

It was unclear whether this teacher was an exception to the other teachers Rose had encountered or an example of other teachers. What is clear, however, is the emotional affect this incident had on her. Narrating can be construed as a persuasive exercise (Riessman, 1993). This small incident narrative, in which Rose reported the speech of
the characters involved (the teacher and her childhood self), not only helped to explain Rose’s confidence issues and her difference, but also gave me an insight into her difficulties and the way she responded to people, such as her teacher. The teacher was presented as blame-worthy of Rose’s subsequent disengagement from interactions with school. Her vivid, detailed, emotional retelling of this experience suggested that this was a significant event in her childhood.

It was an example of Rose’s experience of the classroom; a classroom in which she was different from her peers, different from her teachers’ expectations and lacked academic, but not social, confidence. This was evidenced by various experiences that Rose recounted in this part of her story. She said that although she was sociable, she ‘did not have much confidence to be putting my hand up’, which was presumably the villain teacher’s fault. In addition, she described an experience with her brother.

I used to get picked on by my brother, cos he’d say ‘how do you spell so-and-so?’, and I’d get it wrong and he’d laugh at me

This general incident narrative of her brother picking on her was not given in much detail, but the wording used suggests that this was a recurrent experience. She told a similar story about her father teaching her times tables.

I used to get in trouble as well, cos my dad would sit down with me to teach me the times tables, I, I remember that, I don’t know how old I was, I must have been tiny, erm but he’d be teaching me the times tables and we’d be there for hours, he wouldn’t go until I’d got it, and then the next day when I failed the, the test at school, he’d just be like, ‘oh my God’, you know, ‘what were you thinking? You knew them, you knew them last night’

erm so I had issues of, you know, there’s something wrong with me, there’s something not quite right

over the years, by the time I was 14, I’d had enough, because I thought initially I was quite smart like the other kids. I didn’t feel any less capable…but obviously I couldn’t do certain things that they could do erm, so by the time I was 14 I’d just had enough of schooling
This story of learning, or not learning, times tables, was also recurrent. She failed despite her father’s input, which was surprising for her father as it went against his taken – for – granted expectations of teaching and learning. All these differences and negative experiences led to the thought that something is ‘not quite right’. Rose presented her past-self as capable, but she rejected schooling.

This evaluation was given further meaning by the next storyworld in which she recounted a move to another school where, after an oral assessment of some kind, she was placed in the top stream.

I’d lived in [another country] for a while, and when I moved back I was 13 going on 14. They interviewed me at school with all the- just to check what kind of level I was at, and from that they put me in the top stream where I was meant to be doing 7 O levels, 3 of them a few months early and erm (sighs), because I couldn’t do my homework properly, I mean I had teachers holding my work up saying that this is an example of someone who couldn’t be bothered to make the effort, obviously did it on the bus on the way in, and I’d be sitting there thinking, ‘that was 2 hours work, I had to throw away so many pieces of paper, I gave you the one that you could read.’ It was torn out of a book, it was, you know, I get why the teacher would say, ah but for me it was a big thing and erm

so after about a month and a half they moved me from the top stream down to the 8th, the bottom stream and told me that I wouldn’t be able to do any O levels, I’d have to do the CSEs instead, which if you get a grade one is equivalent to a C, but erm, they weren’t even prepared to enter me for them, because they said that my English and my grammar was so bad, that there’s no way I’d be able to get one, erm they told me at school that my best options for life were to maybe not aim too high, erm to just, you know, make sure that, I, I- waitressing or hairdressing may be a good option for me

Her introduction to the ‘top stream’ and the possibility of taking O levels early led to important people around her positioning her as capable and intelligent. However, she did not live up to expectations. Another teacher was positioned as a villain, as she fell from the top stream to the bottom stream, from O levels to CSEs, from aiming high to not aiming ‘too high’. This all serves to demonstrate her fall from expectations to none,
and helps her construct her past self as different from those around her and their expectations.

An interview at the school meant that Rose was placed in the top stream in her new school. The practice of streaming and setting pupils by ability in schools is a form of labelling and a form of separating children of different abilities, ostensibly for their own benefit, but also to aid teachers (Hallem and Ireson, 2007; Meighan et al, 2003). Children who are setted and streamed are aware of their abilities compared to their peers (Hallam et al, 2004). Many studies have shown that pupils in lower sets tend to become stigmatised, disaffected and alienated from school (Hallam and Ireson, 2007). Similarly, some participants in this study (such as Madison) talked about their experiences of being streamed, and call the sets they were placed in ‘the stupid group’ or the ‘bottom set’. Those, like Jacob, who were not put into lower sets talked about having to work ‘extra hard’ to stay in higher sets. This is another way in which participants presented their childhood selves as different from their peers, who were positioned as ‘finding it easy’. By presenting their own experiences of school as difficult, these participants were juxtaposed against their peers and those who ‘found it easy’. In so doing, they positioned their own identities as ‘hard workers’, despite the obstacles they faced, which in turn would cement their ‘hard worker’ identities.

Rose’s performance in the top stream was demonstrated in the storyworld about homework. The teachers, who were positioned as villains, used to humiliate her due to her poorly presented homework. This led to her being moved to the bottom set. This important physical, literal movement at school is out of her control and meant that Rose was entered for CSEs, rather than the more prestigious, more academic, O levels. O levels, up until the introduction of GCSEs in 1988, were part of the academic progression to A levels and were the first step in access to university. Rose’s drop from top stream to bottom stream was presented as out of her control. She reported that teachers told her that she should limit her opportunities and aim ‘not too high’.

However, when Rose left school with her CSEs, she takes back some control.

so when I finished school, to prove them wrong, I went and did drama at college, I did a drama O/A level, an English literature O level, because apparently that’s where I’d failed completely in my my CSEs, and erm art I think it was, or film studies, or
something, a few just lame, you know, interesting subjects that I thought, you know, that I stand a chance of finishing, as it happened I didn’t finish all of them, I did finish the English literature and the drama, and I got Cs for both and I thought, ‘Ha! That shows you I can pass an O level’

In her narration of the college storyworld, Rose evaluated her success as proving that she could pass an O level, unlike the expectations of her teachers. Some of the participants also talked about proving that they are capable and can exceed the expectations that teachers may of their abilities. This notion of taking control of their lives to ‘prove’ that they are better than the expectations of their teachers seems to be an important aspect of the lives of people with dyslexia. This may also be the case for those who have other specific learning difficulties. Madriaga (2007) found that many students with disabilities enter HE to ‘prove their self-worth’, usually as a result of having received discouragement. This seems to be an attempt to improve how people perceive them and to steer away from labels and categories imposed on them at school.

However, it is not that simple.

and erm after I left school, after I left college, I pretty much did exactly what they said, I started waitressing, I was going from one dead end job to another, I tried to work in a casino erm and I, I got into it, but I couldn’t get through the training because they were doing all the, you have to be able to multiply a lot on roulette, you need to know your 37 times table, and I just I could do the tables, I could learn them but I couldn’t add them together, it was like the two step process was too much for me, so in the end they sacked me, and they said it was cos I, I lacked erm the ability to work as a team as well, apparently that’s an issue I’ve always had, I’m very, I’m a real perfectionist and when other people do things with me I want them to do it my way (laughs), so therefore I’m not really a team person, but erm I got sacked from so many different jobs, and then there were other jobs that I’d do for 6 months and leave because I thought, ‘oh my God they’re going to realise I put the numbers in wrong for the payment, they’re not going to get the £2000 pay’, or whatever and I’d tell them and I’d give in my notice at the same time, ‘sorry’ erm so I, I worked in sales, I worked in erm commission only kind of jobs

Despite her exercise of control, Rose did not follow the academic path to which O levels could lead. Instead she got ‘dead-end’ jobs in which she made mistakes and was
either fired or resigned. She evaluated these events as proof that her villain teachers were right. This was disappointing for Rose.

There is a discrepancy in her story. On the one hand, Rose constructs a capable identity in the top stream at a new school. On the other, ‘villain’ teachers positioned her as not good enough for the top set and subsequently placed in the bottom stream and advised ‘not to aim too high’. This was important in the plot of her story, as it set up two important events: her passing an O level at college, over which she had some control, and her subsequent failure in the world of work, where she had little control. The small piece of success at college supported Rose’s identity as bright and capable, like her peers. However, this self-belief was juxtaposed with stories of failure and negative difference both at school and at the workplace. To be constantly failing when she had a glimmer of self-belief was narrated as the cause of Rose’s nervous breakdown at the age of 25.

Rose told me a particular incident narrative about how this breakdown manifested itself.

and when I got to 25, I had what, what I think was a bit of a nervous breakdown, I couldn’t take it anymore, I had a flat which was being repossessed from me, I’d forgotten to make payments, and then I didn’t have the money in the account to make it up, and erm, so I had the flat being repossessed, I’d got other debts because I just, I went by impulse and you know, a bit of independence, I’ve got my own place you know, I’ll get furniture, I’ll do this, and before I knew it I’d spent way beyond my means, erm so I was struggling financially, I couldn’t get a job, I was applying, sending spec letters off, I used to go through the yellow pages and apply to every single company in the area where I lived, just to say, you know, ‘I can do anything, I can do anything, I need some cash’, and I’d just hit the bottom of the barrel

so I went to sign on and the woman at the centre told me that I wasn’t trying hard enough, that there was plenty of work out there if I looked for it, and I thought ‘I’m not- I don’t have a car or any means of transport and yet I’ve applied for jobs up to 15 miles away from here’, so you know, and I took in the file cos I kept the spec letters everything I- I- I- I- I wrote I photocopied and kept a copy of just in case they got back to me, I’d need to remember what I’d said to them, erm so I took the file in and I said, you know, ‘this is what I’ve been doing and you’re telling me this isn’t enough!’, and I
had a complete sense of humour failure, and erm they said that I, you know, if I didn’t calm down they’d ask me to leave, so I went to the doctors I, I went home, I broke a few things, I was livid, absolutely livid and erm, I went to the doctors and they put me on anti-depressants, they said, ‘it sounds like you’ve got depression erm chemical imbalance maybe’, you know and they put me on anti—depressants and they got me a counsellor.

The employment of this storyworld enabled Rose to present herself as both capable and incapable. Her ‘breakdown’ was understood by Rose to be the culmination of a series of events which were determinants of her failure in early adulthood. This part of her narrative was told with drama, evidenced by the change in tense as she reported the events in the job centre and the performance she gave in the interview. She acted this event out, shouting out her lines and repeating ‘I’, which signalled her discomfort and anger.

The first part of Rose’s story charted her childhood and early adulthood in terms of her differences. She presented herself as different from her peers, from her brother, from her father’s expectations and from her teacher’s expectations. Her failures were punctuated by some success, by passing two O levels for example, a result of her ‘taking control’. This enabled Rose to uphold a capable identity position. However, her inability to keep a job and her financial difficulties led to a nervous breakdown at the age of 25. There is therefore a dissonance in her story, where she is both capable and incapable simultaneously.

This tension was evidenced throughout her story. Rose told positive evaluations about experiences over which she has had more control. When she had less control, when people positioned her as incapable, her evaluations tended to emphasise the negative aspect of the conflict. The conflict between her capability and her incapability and disability were narrated in reference to Rose’s ability to exercise agency in the face of external factors. Stories of survival, which Plummer (1995) describes as stories of strength and resistance, seem to be a part of Rose’s telling.

Despite unfortunate and difficult circumstances, Rose was able to ‘take control’. These difficult circumstances were exacerbated by the people who stigmatised Rose’s behaviour and difficulties. Rose’s narrative of this part of her life was replete with
examples of overcoming difficulties. These difficulties were presented as not being entirely her fault. Her differences were thus made salient in her ‘survivor’ story, and meant that she constructed distinct positioned her identities in distinct ways. Her peers and her brother were ‘normal’ where Rose was not. Her father’s expectations and her teacher’s expectations reflected Rose’s capability, but she was also incapable and so did not live up to those expectations. Rose thus presented her childhood (past) self, through storyworlds of this part of her life, as different and lacking in academic, rather than social, confidence.

She did this, not only with the content of her talk, but with the way she structured her narrative. Experiences that displayed her difference and the inevitability of her situation at the age of 25 were narrated vividly, with direct reported speech and drama. The audience is thus drawn into the storyworlds that Rose created. In so doing, Rose made her story persuasive and thus ensured that the audience was convinced of her ‘difference’ during her childhood and early adulthood, due to her own constructions of self and the constructions of her and her difficulties by those around her.

7.2.2 Rose: Different now
Near the end of Rose’s interview, she talked about how she would like ‘expert’ help and a ‘diagnosis’ for the difficulties she faced when she worked in a role that she found fulfilling and challenging. The tension throughout her story between capability and incapability, between being intelligent yet struggling to do daily tasks, manifested itself in a final part of her story where her identity was explicitly realised.

people who just keep saying ‘oh yes, it’s tough’, (laughs) I can read, I can, I’m slow and I have to read a lot of times sometimes before something makes sense, but I can read, I can comprehend, so I find the way they talk to me when they’ve had their one day’s training on dyslexia patronising

‘oh yes it must have been very hard for you, oh well done’ (sighs)

yeah, I know it was well done, I don’t need you patting me on the back, what I need is an answer to the question I’m asking, which is how do I go about getting someone who knows about all these conditions to actually help me find out what- what- what- what-what-what it is that my brain does differently
The above extract shows an example of the responses she got from experts to her difficulties and their assumptions about her. These experts were presented as villains who lacked the appropriate knowledge to help her. She reported this experience in the present tense, emphasizing that her problems were happening currently. She constructs a present-self who is at loggerheads with ‘non-expert’ experts.

Rose drew on the medical model of dyslexia and her other difficulties to present her brain as ‘different’. This reinforced the medical discourse that surrounds unexplained and hidden difficulties. Her troubles have not been resolved. This is important, as unresolved troubles are difficult to narrate (Bruner, 1987). Rose’s story has come to its end in the present day, as all narratives do (Jarvinen, 2004). However, the end point is unstable and slippery, due to the unresolved issue of ‘what is wrong with me?’ The following discussion will outline how Rose deals with this and how she structures her telling of this part of her life to create new understandings of her present circumstances and her past experiences and how she reconciles past-self with present self.

Lucius-Hoene and Deppermann (2000) discuss the extent to which, in an autobiographical interview, the narrator does not only address the interviewer, but also addresses an unseen audience. Rose positioned this unseen audience, the ‘experts’, as barriers to the knowledge she wanted about herself. Her happiness that she has dyslexia can persuade this audience that she was not trying to make trouble, which would be morally risky. This is ‘counter narrative’, in which Rose is arguing against the idea that dyslexia is a negative (Andrews, 2002). Rose did not need to expand on the narrative she was arguing against, as it goes without saying that people may not be happy they have dyslexia, due to the negative discourses that surround dyslexia, as discussed in the previous chapter.

I’m happy I’m dyslexic, I love that I’m dyslexic, I can do things that my husband can’t dream of, and he’s really intelligent, but I can mix colours together in my mind, in closed my eyes or open, I can mix them together and see what colour they make, you know, I said to my husband once, ‘can’t you do that?’; ‘hm, no!’ (laughs), cos to me, well I suppose not many people can, I learnt to play the guitar by myself by watching someone else, just sat there watching what their fingers were doing, and then when they left I copied, you know most people can’t do that
I get material, I throw it on the floor, I know where to cut it to make something, so I love, if that’s dyslexia then I love that I’ve got it.

Rose constructs a happy dyslexic identity by talking about the things that she can do that some people, particularly her husband, who was positioned as intelligent within the storyworld frame, cannot (Lucius-Hoene and Deppermann, 2000). Rose learnt to play the guitar by watching someone else, which made her different, and her method of making clothes differed from ‘standard’ methods. Thus, she ‘loves’ dyslexia.

Bertilsdotter et al (2013) state that people with autism who use online spaces to talk about their autism discuss the idea that their autistic state was better than a neurotypical (NT)° state. People with autism may consider themselves ‘equal to and in some cases better than NTs’ (Brownlow and O’Dell, 2006, p. 319). This focus on positive differences from peers represents a stark distinction from her childhood self as being different for more negative reasons. However, Rose continued to self-evaluate with negative connotations.

but I don’t like that the other issues, I still have the the self-doubt the, you know, maybe it’s just cos I’m a klutz, maybe it’s just cos, negative words to describe all the problems I have that take the focus away totally from what I can do, so to this day I’m still on incapacity benefit, I still haven’t found a way to do something that can use what I’m capable of and not leave me in a complete state of permanent anxiety and fear

Without the medical reason for her difficulties, Rose risked being seen as ‘merely’ clumsy. This has moral connotations and would be catastrophic for Rose as she relied on the legitimacy of her problems to present herself as justifiably different and ‘struggling’ rather than somehow at ‘fault’ for her difficulties.

Rose remained different, particularly as she remained on incapacity benefit and regretted not being able to return to work. Rose’s ‘differences’ were presented in various ways. In her childhood, she was both different and unconfident academically, which she emphasised through vivid and detailed narratives. She was different from her peers (the pupils in her class), her brother and from the expectations of her father.

° Neurotypical people are those who do not have autism or any other kind of neurological difficulty or disease. In contrast, neuro-diverse people do. In private correspondence, Rose has talked extensively about experiences of neuro-diversity and is actively involved in movements to inform and change the status-quo.
and teachers. As an adult, Rose was different partly due to her dyslexia, but also due to the other difficulties she had with depressive tendencies, social phobia, aggression and perfectionism. In addition, she was different because she could do things like learn to play the guitar by watching someone else, mixing colours in her head and being able to make clothes patterns, which she evaluated as being related to dyslexia (and the other related ‘difficulties’) and that she was happy with. However, Rose was not happy being on incapacity benefit, and her construction of her childhood and adult selves as ‘different’ was complex.

7.2.3 Ellie: Childhood and difference
Like Rose, Ellie also starts her story with tales from and evaluations of her school and childhood.

my school didn’t recognise dyslexia at that time, so my parents had to pay for me to come out of school and go to, one morning a week I used to go to [place 1], to the dyslexic institute... and that was when I started to learn to be able to do some reading and writing, and did that all the way through my junior school, so from when I was seven to when I was eleven when I went to secondary school, then it, I had a really supportive English teacher, so my parents didn’t carry on with the dyslexia institute, that was the one in [place 1], just before I was doing my GCSEs I did intense evening sessions with the dyslexic association in [place 2], the people I saw in [place 1] were really helpful and they definitely taught me some skills. I can remember what I used to do in the lessons. We used to go in and the first thing I would have to do was finish the thing I had done the week before, and I’d have had to have read a text onto a dictaphone which would have been a tape recorded dictaphone, and then I’d go in the next week and I would have to write it all out, and then she’d get me to write sentences about something, and I can remember a rule was that a sentence was only a sentence if it had more than 7 words in it, cos my sentences were never 7 words, when I was seven I thought that was far too many words

when I was in junior school my mum and dad had to fight quite hard for me to stay in my class, cos my parents would say, ‘she needs extra help with this that or the other’, and within our school there was special unit and the head teacher was like, ‘well, if she needs all this extra help then she needs to go into the unit’, and my mum was quite against me going into the unit, she was like, ‘she doesn’t need to go into the unit’, erm so I didn’t go into the unit, which was quite good
The storyworld Ellie was narrating above allowed her to position several characters in
different ways – her mother as good and persistent; her school’s head teacher as
irrational and unhelpful; a secondary school teacher as supportive; the dyslexic
association and institute as helpful; and identities of her as a good student. Her
positioning of her parents as ‘fighters’ for their daughter was done in such a way that
they were constructed as integral to the plot, particularly in terms of the construction
of the ‘unit’ as negative. Unlike Rose, Ellie constructs school and teachers as both good
and bad. For Rose, they are bad, and like Ellie, they are narrated as important causes
for later events.

so by the time I went to secondary school I didn’t know my alphabet, so I couldn’t do
my alphabet. I’m still not really, I know my alphabet but if you asked me where ‘q’
comes, what comes, which kind of 5 letters come before and 5 letters after I have no
idea, I have to start at ‘a’ and go all the way to when I get to ‘q’ (laughs), some at the
beginning and some at the end I’m ok with, but the middle ones I’ve got not the
foggiest (laughs) where they are, so when it comes to now, when I’m in a library and
it’s with a system that’s got an alphabetised system, I will go through and I will go
abcdefhijklmnpqR R I’ve found R, then I’ll have to do it for the next digit and the
next digit (laughs)

and I have to say it out loud cos I can’t do it in my head (laughs), so I’m forever in
libraries going abcdefhijklm erm, I’m noticed I was doing it, I do it at work now, so
yesterday I was having, I was filing all my journal articles I had out and I was trying to
get them into alphabetical order before I put them in my filing cabinet, cos that’s how
I’ve organised the filing cabinet, which seems a bit daft as I don’t know my alphabet
but it’s an alphabetised (laughs) filing cabinet out of my own choice, but that did seem
like the easiest way to sort my journal articles, cos doing it by what areas they’re in a
stuff would just be a complete nightmare, because a lot of them cross over, so the
alphabet is still the easiest way for me to do things, and I do use it out of choice erm,
but yeah, I realised I was in my room yesterday going through the alphabet and saying
it all out loud which some people must think ‘what? Why is she saying the alphabet
out loud all the time?’ for about 10 minutes (laughs), so there are still things I have
difficulty with, although I can obviously write really well, so they tell me when I hand
work in
Ignorance of the alphabet was significant for Ellie, as she was different from an assumed ‘average’ pupil who does know the alphabet by this age. Ellie continued to use coping mechanisms for the alphabet, described in the general incident narratives above. She then evaluated her identities as facing difficulties, as well as a good writer. Despite her difficulties with the alphabet, then, Ellie presented herself as ‘doing really well’.

so when I went to secondary school, I obviously didn’t have my alphabet, I wasn’t a confident reader erm, I’m still, I would say I’m a good reader and I read a lot, but when I have ed psych reports done, so when I had the last one done I was about 25, no I must have been a bit older 26 or 27, (child) was born, and I know it was brought up that my decoding ability is minimal, from I would have thought I was quite a good reader I’m obviously not as good as I think, it takes me a long time to read things

In the extract above, the tense changed to the past, as she alluded to her reports from educational psychologists, which said that her ‘decoding ability is minimal’. Her use of this professional idiom may suggest that Ellie is knowledgeable about dyslexia and possibly saw me, the audience, as knowledgeable about dyslexia too. The narration of storyworld events is only one frame through which a narrator operates. She also must operate through the frame of the interview, and can position the interviewer / audience differently within the same conversation (Lucius-Hoene and Deppermann, 2000: 214).

Ellie’s use of ‘expert’ language helped to explain her reading difficulty. She had been told that there was a ‘scientific’ reason for her difficulties: her decoding ability was poor. In the previous chapter, I argued that individuals with dyslexia who desire support for their difficulties need to subscribe to the medicalization of dyslexia. This emphasizes the difference between those who have dyslexia and those who do not. Ellie had dyslexia and subscribed to its medical discourse, thus ensuring that she had access to support that results from the normative, socially acceptable form of negotiation between dyslexia and society.

Ellie constructed an identity as a ‘good reader’ and evaluated it with the caveat ‘obviously not as good as I think, it takes me a long time to read things’. This was then reinforced by a comparison between me and Ellie.
so if you were given an article and I was given an article I would get exactly the same out of it at the end, if not a bit more because I’m quite good at reading articles, but it would take me a bloody long time to read it

everything like that I just realise is an extra bit of hard work erm, and it just takes a little bit longer, but it makes it all worthwhile I think when you haven’t been able to do something you really value it, so I can remember watching my friends read, read a book like Charlotte’s Web or something like that when I was in junior school, I still haven’t read that I’m, I may get to read it one day, but I do, I could have just looked at the book and know, I just knew without even looking at the words inside it that that would just never be something that I-I could never sit down and read a book for pleasure

now I can and it is what I do, I really love reading books, it’s just amazing what words, what as a, what a whole different world you can go into with words, and when you’re young and you know that you’re excluded from that, that’s really quite hard erm, and you kind of self-exclude yourself from lots of things, so I remember that I always thought that I’d have to be a hairdresser. I hate hair, I’m useless with hair, it’s really not my forte in life, but when I realised that actually I could get on top of this, and I would be able to deal with words, and I would be able to read I was just so excited I wouldn’t have to be a hairdresser, so I’m not a hairdresser, my best friend is and she loves being a hairdresser, nothing against hairdressers, erm but so my reading wasn’t that great, but my writing was a lot worse, so when it came to my GCSEs erm, I couldn’t read and write very much at all, I think I was getting level 2s and 3s, I don’t, I think that’s like what you’re expected to get in year 2 and 3 of school, so when you’re 6 and 7 and 8 erm, I couldn’t do sentences still or paragraphs

Ellie positioned herself in opposition to me, a ‘normal’, non-dyslexic audience, which allowed her to emphasize her differences. By evaluating her childhood self as being unable to ‘sit down and read a book for pleasure’ and juxtaposing this with her present ability to read a book, ‘which is amazing’, she suggested that her adult, present self is no longer different from her peers and is in fact ‘normal’. This, in turn, reemphasised the difference between her present self, her childhood self, and her childhood peers.

O’Dell et al (2010) studied young people’s perceptions of young carers. Young carers have responsibilities that their peers do not share. They are different and cannot participate in ‘normal’ teenage activities. Similarly, Ellie excluded herself from ‘lots of
things’ as a result of her difficulties. She gave an example of this as her childhood self’s imagined future that she would ‘have to be a hairdresser’. As a child, thoughts about what one wants to be when one is ‘grown up’ are common (King and Hicks, 2007). However, these change with life events and new understandings of the world and one’s place in it (King and Hicks, 2007). The imagined career of hairdressing was unacceptable for Ellie, who gave a self-assessment of her abilities with hair as ‘useless’. This represents a discord between her desired self and her imagined self, which was resolved by finding out that hairdressing was not necessarily her future. The discomfort this potential career caused was contrasted with the excitement Ellie felt when she ‘realised that actually I could get on top of this’. This realization changed her perspective on her imagined self and represented a change in her self.

Ellie then returned to a secondary school storyworld, when her ‘reading wasn’t that great, but my writing was a lot worse’. This meant that she was not attaining the expected levels in key stage 4. This evaluation further emphasised the difference between Ellie’s childhood self and her peers at school.

but I can remember I had to have 5 pieces of coursework for English, everybody else over the course of the 2 years did about 20 pieces of work, my English teacher I had from year 7 to year 11 and he told me, ‘you’re never going to get 20 pieces of work done’, in say English language I got A*s in all the stuff that was verbally assessed, erm but my written work was all Ds, which somehow it measured out so I got Cs in both my English GCSEs, so that was what I had to have, I just did 5 pieces of coursework

erm so the discrepancy between my grades I was getting at GCSE was quite dramatic and luckily my teacher just made me do 5 pieces of coursework, and I can remember sitting at home erm, one was that I had to make a book along the lines of the Jolly Postman, so it was to do with rhyming patterns and a story that was for infant school aged children

Ellie reported that her teacher, who was presented as a hero character, allowed her to do five pieces of coursework for her English GCSE, instead of the 20 pieces that her peers were expected to do. Again, she presented herself as different from her peers. However, this was framed in a positive way as, for the first time, it meant that she had a chance of passing and the potential for success. She gave a general incident narrative about her mother ensuring that she completed her coursework:
I can remember when I was doing my homework at home, how I used to have to sit with my mum. We were on a semi-circular table and, she never did my work for me, but she used to make sure I stayed there and I kept concentrating and I kept going.

Again, her mother was presented as a heroine character in the narrative, who persuaded the ‘villain’ head teacher not to place Ellie in the ‘special unit’ at primary school and who ensured Ellie works hard for her GCSEs. Another interpretation of Ellie’s mother is that she was doing what a ‘good’ mother should, standing up for her daughter, using her teaching knowledge and helping her daughter with her GCSEs. In contrast, the hero teachers went out of their way to help Ellie. Regardless, this all upholds notion that Ellie had support that Rose did not have. Ellie talked about making a conscious decision with her mother to not do work for the French and DT (design and technology) GCSE courses.

Ellie evaluated the decision to focus on passing her English literature GCSE at the expense of studying for design and technology (DT) and French.

so that meant that I didn’t do any work for DT or any work for French, which is obviously disappointing as I have no French or DT skills (laughs)

This is uttered with sarcasm and irony in her tone. Irony is a device that shows listeners that the speaker believes the opposite of what they are saying (Parkhill et al, 2009). This is powerful because it shows that Ellie has some understanding of the social hierarchy of academic subjects. She presents her past-self as both hard-working (for English) and practical (for French and DT).

Passing her GCSEs in English was an important achievement for Ellie. She was able to continue with her education. She was ‘shocked’ and ‘excited’; her best friend’s mother cried. This further adds weight to the notion that Ellie was somehow different from her peers, who may not be shocked that they had passed the English GCSE. Ellie combined stories of difficulties in her childhood with stories of difficulties in adulthood, which emphasised her present self as in flux. She was different at school, in both positive and negative ways; she was different ‘now’ and, despite her difficulties, she was confident about her abilities. However, she was aware of people’s perceptions and positioned her audience accordingly.
Being a highly educated British woman in the early 21st century did not sit well with Rose’s circumstances. Rose was ‘different’ by her own admission and she positioned her differences in relation to an unhelpful historical and political context. At the end of the interview she talked about how useful her skills would be if she lived in a society at a time when reading and writing skills were not so highly valued. In contrast, Ellie positioned her differences in relation to her childhood narrative, giving present day evaluations with mini stories supporting these evaluations. Ellie presented herself as different from me, from her peers and friends at school and different from her previous imagined future as a hairdresser.

Rose and Ellie both presented their childhood selves as ‘different’ from their peers at school and from important people and their expectations. However, Rose also presented her current self as ‘different’, with both positive and negative identity positions. ‘Difference’ is one of the many ways in which we make sense of our identities. However, feeling affinity with people is important (Woodward, 2002). The notion that children with dyslexia, and other difficulties, disabilities, disorders, or labels that mark them out as different somehow, may feel different at school is not new. Riddick’s (1996) research made it clear that children with dyslexia often feel different at school. The present study shows that these differences may be long remembered and are incorporated into narratives about present life events.

7.3 Change in storied lives
Narrative is a pervasive way of talking about change (Bruner, 2002). Labov and Waletzky (1997) posit that a complicating action is the key part of a narrative. A change in one’s life and outlook is one type of complicating action (Labov and Waletzky, 1997). Indeed, it is change in one’s life that can have some of the most drastic impacts on one’s identity and sense of self. The following section of this chapter presents Rose and Ellie’s stories of change in their lives, demonstrating how these stories are incorporated into the overall plot of their life narratives.

7.3.1 Rose: Change and dyslexia
All of the participants talked about change in their lives from one aspect or another. When Rose left school, she entered and left a range of ‘dead-end’ jobs. She was often fired from them for not fitting in as a ‘team player’ or for making mistakes. Sometimes she would realize her mistake, admit to it and hand in her notice at the same time. At
the age of 25, after seven years of dead-end jobs, Rose was struggling financially, was on the brink of losing her flat and could not find a job. She had a nervous breakdown and had counselling. This led to studying for an A level and going to university. Madriaga (2007) found that one of the reasons for attending higher education was to get out of ‘dead-end’ jobs and increase earning potential. However, there may be other reasons, and for Rose, A levels changed her life, but originally they were a part of her therapy. Going to university was narrated as a fortunate outcome of that, rather than a specific plan.

At university, Rose was scraping through her first year ‘grade wise’ and became pregnant in her second year. She was struggling with the reading and the workload. These circumstances led to her thinking of quitting university, but she was worried about the financial impact of this decision. To minimise the risk of things going wrong, she spoke to someone at student services who made her an appointment with a financial person. Rose took control of her circumstances by trying to manage the risk of being unable to complete the course and the potential financial difficulties that may occur after quitting a degree halfway through and through which she obtains grants and loans. Although she was thinking of quitting, she carried on with the course in the meantime and gave a particular incident narrative as an example of her reading difficulties.

I mean the, the moment that did it for me was, I had a newspaper and it had an article, it was really relevant to one of the subjects we’d just covered and I was trying to erm, understand the, the, the concept and I couldn’t even understand the sentences. I was stuck on this one word, three letter word and I was getting angrier and angrier by the second ‘wh- wh- wh-‘ I couldn’t work it out and I threw the newspaper across the room. I mean I must have read three letter words a million times, so why couldn’t I understand it?

In this vivid account of her difficulties Rose presented an identity as someone who was quitting university for a good reason. Her difficulties were legitimate. The finance person at the university, who agreed to help, wanted to know more about Rose’s decision to quit.

when I went to see the finance person at the uni they said, you know, ‘why are you quitting? we’ll help you out and understand what’s going on, but I’d like to know why’
and I said, ‘because I can’t do the reading. I can’t do the reading, it was a mistake them taking me. I blagged my way in. I was just lucky the amount of work I had to do to get that A level, I don’t deserve to be here, I’m not up to it and I’m wasting everyone’s money and time being here’ and she said, ‘what do you mean you’re not keeping up with the reading?’ I said, ‘I can’t bloody read ok? I’m getting notes in class and I’m pretending to read them, I’m asking questions just, I’m not reading, I’m scanning for words that I can say, ‘oh, I don’t quite understand this’, because hopefully then they’ll describe the whole bloody thing, I’m blagging all the time. I’m just blagging my way through making it up’ and she said ‘well ok (laughs), you must be very good at blagging then’ (laughs)

and she erm asked me if I could go and see a specialist at the university who helps students with these kind of problems, and I went to see him and he did a few erm things, he asked me to point at his left ear and I sat there like an idiot doing ‘sorry ok I’ve got mine (laughs) I didn’t realise that I couldn’t do that’ and he was asking me a few different questions about from when I was young, and I said to him ‘what on earth has this got to do with me leaving uni, am I going to owe more money or something if I (laughs) I don’t get it’ and they said, ‘no, no, didn’t they tell you that I check, I’m doing dyslexia screening’ and I said, ‘oh ok’

Rose provided a particular incident narrative about her interaction with a finance person and a ‘specialist’. In reporting direct speech, shouting and swearing whilst telling this part of her story, she juxtaposed her agitated past self against the reasonable, calm, and collected finance person. Her present self, acting out her past self-character as she did, provided some comic relief from the disquiet and drama of this interaction. In this way Rose brings our attention to a rational identity position, and thus the rational nature of her present self whilst not taking away the legitimate nature of her past self’s outburst described above.

This interaction led to Rose meeting ‘a specialist’. Rose told a particular incident narrative about her interaction with this person, who turned out to be assessing her for dyslexia. As she was telling the story, I anticipated that she would continue with what happened next in this encounter, following the now established chronology of her story. Instead, Rose suspended the action by referring to a previous episode: her style of telling changed.
now, just to put you in my mind-set, when I was about 14 I’d told one of my teachers that I thought maybe I had dyslexia, because I’d heard that there was a condition that meant that children struggle with reading and writing, and you know, but they’re not stupid and I don’t think I’m stupid so, ‘no darling, you’re not stupid, you’re lazy, you’re lazy, you don’t apply yourself and I don’t want to hear excuses like dyslexia coming out of your mouth’, that was the last time I mentioned dyslexia, so then I mentioned it to other people and they’d come out with things like erm ‘oh yeah, I hear that they’re really gifted, you, you can’t possibly be’ (laughs) so the, no one was connecting the pieces and I’d got it in my head that obviously I am just stupid then, you know?

In her story, this was Rose’s first mention of dyslexia in the interview. She referred back to previous encounters with a teacher and people who told her that she could not be dyslexic because she was ‘lazy’ and not ‘really gifted’. She described these individuals as kinds of ‘experts’ (or at least people who claimed to know what they are talking about): a teacher and people ‘who knew about it’. Rose, therefore, was positioned as a non-expert in these interactions. This then allowed her to believe the people who told her that she ‘can’t be dyslexic’ and therefore allowed her to construct a ‘stupid’ identity.

Rose negotiated her past selves in terms of stupidity and dyslexia. The story that she told about the teacher who rejected the possibility that she was dyslexic allowed Rose to bring three identity positions into play: dyslexic, stupid and lazy. Rose’s suspicions that she was dyslexic are framed against the idea that she was not stupid. This was the idea that she put to her teacher. However, the teacher rejected both of these identities and positioned Rose as lazy. Rose did not accept the notion that she was lazy; in fact, she never mentioned the idea of being lazy again during our meetings. Rose then told me about people who she had asked about the possibility of being dyslexic, who brought in another identity position, gifted, which was then comprehensively rejected, along with the notion that Rose was dyslexic. The only identity Rose had left to draw on was stupidity.

Despite this, it had never been proven that Rose was not dyslexic. Being and feeling stupid is a difficult identity position to hold, especially in a society that rewards intelligence and intellect. It is a threat to well-being and self-esteem, especially when
you suspect that you are not stupid. The suggestion that someone can formally show that Rose is or is not dyslexic is a threat to Rose’s ‘little ray of hope’ that she is dyslexic. It was a threat to her self and the ‘possible dyslexic’ identity that she had built as a reaction to responses about dyslexia. In the rest of Rose’s story, she brought up how dyslexia, and her other difficulties, had meant that she could not hold down a job for long.

She moved back to a past storyworld, from when she was 14, which she had not mentioned previously in the interview. Although a previous turning point in her life was studying hard for her A level, which she stated ‘changed my life’, this part of her telling brought the audience much closer to the action that she was narrating than the A level story. This sudden change in Rose’s narrative is interesting. The change in chronology in interview time suggests that this part of Rose’s life was particularly emotionally significant. Her use of the word ‘now’ was important. She used this word as a device throughout her story, which signalled to me that what she was about to say was important. The rest of that utterance: ‘just to put you in my mind-set’ served to inform the audience that the following was relevant to the encounter with the specialist and it was something she was thinking about at the time.

The extract above can be called a retrospective narrative and highlights the emotional significance of this part of Rose’s life. The fact that Rose remembered the interaction with her teacher when she was 14 highlights the importance of this interaction, but what is more interesting for identity studies is the framing of this event within the narration of Rose’s interaction with the specialist (Lucius-Hoene and Deppermann, 2000). In her telling, Rose moved from past tense to present tense frequently, with the effect that she, and the audience, moved closer to the action of the storyworld she was narrating. It was the most vivid, most detailed part of her story.

This retrospective narrative explained Rose’s reaction to the suggestion that she may have dyslexia and should have a test to confirm it. If she did not provide the audience with a reason for saying ‘no’ to this suggestion, she risked looking irrational. This has moral connotations, as the emotional nature of saying ‘no’ must be supported by justified reasons (Parkhill et al, 2009). The audience of this story seemed to be multiple: me, who she must persuade of the importance of these events; the ‘villain’
teacher whom she must contradict; and the dyslexia specialist, to whom she must explain her reticence.

The plot of a life narrative can also be thought about in terms of its chronological structure. The idea that a story starts at one point in history, moves through linear time chronologically before finishing at a later date is common sense, particularly in terms of causality. However, life must be understood backwards, from the perspective of the present (Brockmeier, 2000; Jarvinen, 2004). Before the extract above, Rose gave a particular incident narrative about her interaction with the specialist, which continued after this extract. In essence, then, this part of Rose’s interview has a circular structure (Brockmeier, 2000), represented in Figure 4:

Figure 4: Structure of this part of Rose’s narrative

The retrospective account of what happened when she was 14 was important and emotionally significant in Rose’s narrative. Rose displayed this significance this in her change in tense, in the tense confusion and with the use of the word ‘now’. In addition, it served to contextualize her reaction to the possibility of being tested for dyslexia and her reluctance to the test. Most significant, though, is that until this point
in Rose’s story, she had not mentioned this episode with her teacher, which is a big omission given her narrative’s structure up until this point. It was the positioning of it during this part of her story that made it so powerful.

However, it must be acknowledged that earlier experiences are given new meanings after emergent events (Freeman, 2003; Jarvinen, 2004). The sequence of narrative segments forms a larger narrative structure. The meaning of any narrative is only understood in relation to narrative context (Kleres, 2011). According to Brockmeier (2000), autobiographical remembering involves the back and forth movement between past and present. This is evident in the above extract from Rose’s story, where the past is used to give light to the more recent past.

This story was told in the interview time. Being identified with dyslexia is a big change in Rose’s life. It was still relevant in the interview as it meant that she was dyslexic, rather than stupid or lazy. As discussed in chapters 4 and 6, dyslexia is a particular and peculiar disability. However, being identified with dyslexia, and identifying oneself as dyslexic, has a complex impact on identity. Watson (2002), among many other disability researchers such as Shakespeare (1996), compares disability with homosexuality. Like gay and bisexual people, individuals with disabilities, particularly hidden disabilities, can ‘come out’ as disabled. This is problematic, though, as the (more recently) positive social status afforded to those who come out as gay is not afforded to those who come out as disabled:

In the hierarchy of social values prevalent within British society, which accords little or no status to disabled people, describing oneself as disabled cannot be seen as a positive step. There is no social status to be gained for ‘coming out’ as disabled. Indeed, the very term ‘coming out’ may be inappropriate when used in conjunction with disabled people (Watson, 2002, p. 525)

Nevertheless, social attitudes towards disabled people appear to be changing. The 2012 Paralympic games and the so-called ‘legacy’ for disabled people would suggest more acceptance of disability within society. However, it is important not to forget the
peculiar nature of dyslexia as a disability. The hidden nature of it, the contested nature of it, and the discourses that surround it, make living with dyslexia a complex process.

7.3.2 Ellie: Recent change – *dyslexia is a problem*

Until about halfway into her interview, Ellie told her story, chronologically covering her time at school, university, her graduate job and time abroad, her pregnancy and further study. This was similar to the start of Rose’s story. This kind of telling was linear and, as discussed in section 7.3.1, it is rare (Brockmeier, 2000). This was evident in Ellie’s story, as she interweaved the chronological events with talk of her difficulties with reading and writing. This took up about half of the interview. However, at this point she changed her style of telling. She brought the action to the present day, which is also where she was evaluating and making sense of it all (Brockmeier, 2000).

Ellie started to tell me about her experiences in the week before the interview. She said that her ‘issues to do with dyslexia... have come to the fore in this last week’. She stated that her educational psychology report named certain adjustments that institutions should undertake in order that they do not discriminate against her. This orients the audience to the narrative that comes next.

and I’ve realised doing a PhD my dyslexia’s kicking in a lot more than I thought it would, so I’ve decided that it would really help me if I could go part time, and not take on any extra work, and it would just give me that extra time where I could do the reading and I could do the writing, and I kind of broached this to my head of research and he was like, ‘studentships are normally only given on a full time basis. If you choose to go part time then we won’t be giving it to you, so you’ll lose your studentship’, and I sat there and I said, ‘erm I’m sure in view of my reasonable adjustments and the disability discrimination act that normally such (laughs) is the section of the policy that you should adapt to do with dyslexics’, and he was like ‘well, our argument will be that you can use student support and a proof reader’. I was like, ‘well, that’s a different part of my reasonable adjustments’. So at the moment being dyslexic is really hitting home, in that it does take me longer to do things and it does make things a bit bloody harder

Researchers have found that people with disabilities want to lead a ‘normal’ life as much as possible, by ‘just getting on with it’ despite impairment (Watson, 2002). The extract above shows that ‘normality’ is something that is presented to Ellie as her only
option. However, she rejected it. Her dyslexia (impairment) means that Ellie wanted to be treated differently, to be accommodated by the institution. She was told that this was not an option, which was a shift for Ellie as she had previously encountered no problems in obtaining extra support for her difficulties. This extract represented a shift in Ellie’s telling of her life, and it may also represent a shift in her understanding of her life. The story of the encounter was finished, but how this will be resolved is unknown and therefore the overall story of ‘getting extra time in PhD studies’ is unfinished.

An autobiographical life story can never be finished (Brockmeier, 2000; Bruner, 2002). The end is the present day, the time from which it is told and evaluated (Jarvinen, 2004). In this case, Ellie’s story and life was on the brink of change, particularly, as Ellie told it, her view of dyslexia. In autobiographical telling, the storyworld-time is evaluated in the present telling-time or possible future (Brockmeier, 2000). However as the storyworld-time was so close to the telling time and the story was unfinished, Ellie had to make sense of this uncertainty and change in her attitude, thoughts and life. In so doing, the pattern of her telling changed quite drastically. The first part of her story had a mainly linear structure, but from the point where her current problems were narrated, the structure became more complicated and cyclical (Brockmeier, 2000). After reporting what happened in the confrontation with the head of research, Ellie brought the focus back to ‘today’, as being dyslexic is ‘hitting home’, which she then related to depression. She then moved back in time to talk about depression a few months earlier, and then at her previous job a few years earlier.

I think in turn that’s linked into me getting depression at times, which I haven’t always put together, but I had, I had a depression in December last year, that was just as I was starting to do my APG report, which was my end of first year report, and it was just all too much (laughs), ‘blimey, how am I going to do this?’ and I sud- and I realised that another point when I had depression was when I was doing a similar sort of thing, and I was doing writing a report, so it was another big tight deadline written, took by yourself, ‘write the bloody thing Ellie, get on with it’, and that those are my crisis points and that I need to learn how to manage them better generally I’ve done really, I’ve been able to go through school, I’ve had supportive people, this is the first time that anyone, when I’ve asked for any help to do with dyslexia, apart from my junior school head teacher, which it was the 80s and they
were only just coming round to being understanding of dyslexia, but work, other educational places, everyone always said, ‘yep, fully understand, yep we’ll put that in place for you no problem, we’ll do stuff through access to work, or through student finance’, and there’s been no problem at all and this is the first time to do with dyslexia where I’ve felt, ‘no I’m going to have to fight this and I’m going to have find out what my rights are and I’m going to have to be a pain in the arse’, erm that’s annoying

In the above extract, Ellie compared her recent bout of depression, whilst completing a report for her PhD with the depression she suffered at her previous job whilst trying to meet a deadline. She described these events as crises, but with supportive people she had been able to cope. She moved back and forth between her present dilemma and these past events. This continued for the rest of her story, until this final part of her narrative.

and that’s what I can remember in school, I could tell you anything, I could talk to you about it til the cows come home, give me a piece of paper and I could write like the kids in the first year of infant school, and I’d just sit there watching my friends write, and I’d be like, ‘that’s what I want to be able to do’, and it’s taken me a long time to be able to do it

and those people when they read my writing say, ‘ooh, I wouldn’t know you’re dyslexic’, or they say, ‘you’re not, you, well if you’re dyslexic maybe’, I- I know I give people doubts that dyslexia is actually something, because I’m quite competent and I’m quite capable and I can write fine, and they’re like ‘oh, you can’t be dyslexic if you can do this (laughs)’ and it’s like, ‘no, I can do so much more if I wasn’t dyslexic but this is quite good enough (laughs)’, so I think that’s how I’ve got where I am now, so dyslexia was a big issue in my life I’d say until I was say 13 and I started getting some writing and reading skills, and then it hasn’t really been a big issue again until this last week, which is a bit disappointing really that in 2011 it has to become an issue, but I suppose it’s been an issue for a lot of other people for that whole time, so I’ve just done very well and had supportive people around me, so yes that’s my life story kind of centred around where dyslexia’s played a role or not played a role

This pattern of present day evaluation followed by a tale of what happened at various points in her life that back up her current decision making and help her to make sense of the changes that may be imminent, repeated itself throughout the rest of the
interview. In this way, she also compared herself to those who were different from herself, represented by friends and peers from the past, presented in past storyworlds, in order to back up her present day evaluations of herself, her difficulties and the imminent changes in her life. She finally gave a present day evaluation about the disappointment she felt that this change in her life has occurred, particularly in the historical context of 2011 in the UK. Her belief in the tolerance of society, where laws protect and support people like Ellie, and which she took for granted for so long, has been shaken. In the latter part of her life narrative Ellie starts to renegotiate her self through the emplotment of events that are re-presented in the light of her changing environment.

Ellie presented herself as someone who has done very well, has worked hard and who is aware that many dyslexic people have not had the support that she has. She said that people did not perceive her to be dyslexic, which may show how much their opinions and influence or power are important. Interestingly, their positioning of her as too competent to be dyslexic reflects Rose’s experience of people telling her she was not competent enough to be dyslexic. However, this was countered by the situation she found herself in at the time of the interview, to which Ellie came back time and again, evaluating past experiences through the lens of the current difficulties and changes she was experiencing, in order to make sense of her unfinished story. Suddenly, Ellie found herself being unsupported in a world which had always supported her. Like Rose, she was left with the feeling that dyslexia is a disadvantage.

7.4 Plot and identity
Plot is imperative to narrative as it enables present day circumstances and identity to be explained and considered in the light of past experiences. Ellie and Rose’s present day circumstances are different, but they both view dyslexia as a disadvantage. For Ellie, dyslexia was not a problem in her early life. Rose, however, was unaware she had it, although she had her suspicions and encountered difficulties at school. However, both have experienced difference and change in their lives as a result of dyslexia, their understanding of it, and how it is understood in society at large.

These changes and differences were emplotted in their life stories in particular ways. Ellie was different in childhood in some negative ways, although this did not appear to be the case in adulthood. Yet, recent changes have meant that the relationship
between her dyslexia and social structures was becoming more complex. Ellie represented past experiences to renegotiate her changing dyslexic identity. Rose was also different in childhood, but she was different in adulthood in both positive and negative ways. A change in the middle of her life (identified as dyslexic) meant that she reflected on her difference in adolescence. Although she had a reason for her struggles, she straddled the border between capability and incapability.

Mead, often known for his theory of the self, also developed a theory of the past. For Mead, there is only the present, which is where pasts (and futures) are constructed (Jarvinen, 2004). The past we choose to narrate is significant to our current circumstances. He argues that truth is the ability to state the past so it fits with current problems. The self refers to one’s ability to reference ‘beyond the present’, to the past and future. Mead emphasises the emergent, novel elements, which are interpreted through past experience and a new perspective allows the emergent to be comprehensible. The present gives structure to time because the past can be understood as causal conditions for the novel event and the future can be predicted.

This has similarities to Ricœur’s theory of time and narrative (Jarvinen, 2004). Ricœur (1988) states that history is a form of knowledge that relates today’s perspective to yesterday’s lived experience. The present is always unintelligible and confused until it becomes the past. Questioning about the past is always from specific perspectives of the present. Events are organized by ‘emplotment’ into stories, which are meaningful because of the present circumstances. This means that Rose and Ellie had to tell me their story and make it relevant to their current circumstances, whilst also informing me of their present circumstances and problems. The plot makes the story of previously unrelated events coherent. Events become meaningful through plot development. Having a plot means that there is an endpoint from which the story can be seen as a whole.

However, when a narrative is blocked the narrator, listener, or both, look for other explanations (Ricoeur, 1988). Ellie was in a particular circumstance that blocked her story, which had been plotted as ‘going well’ up to ‘this’ point. Dyslexia came to be a salient feature of Ellie’s self and life due to changes which put her past experiences in a new light.
According to Mead, narrating involves acting towards oneself. We organize others’ attitudes towards us and our attitudes towards others into our biographies. Life history is constructed indirectly from a generic other’s perspective. The present is anchored in social interaction, so the audience is important, as Lucius-Hoene and Deppermann (2000) argue. Narrating is part of belonging to community. In distancing themselves from their peers, Rose and Ellie distanced themselves from a community of learners who they construct as having no such difficulties. This is difficult to uphold, so concessions were made: Rose maintained that she was socially involved in class, was an active part of her community and has the potential to do a higher degree; Ellie maintained that she could read and write as well as, if not better than, her peers. Therefore, Rose and Ellie maintained their positions in a community through their narratives as they were socially integrated and harmonized with the generic person’s perspective. In addition, they acknowledged their difficulties and disability identity as important aspects of their selves and their current circumstances. Mead states that a new past is a condition for a new self. Ellie and Rose were in the process of acknowledging changes to their lives and selves and were constructing their pasts in the light of these emergent events.

7.5 Conclusion
As demonstrated in chapter 6, dyslexia represents differences in life and identity for those who are identified with it. Even for those who have not been formally identified with dyslexia, there is still a sense that they are different from their peers due to their difficulties. The participants in this study sometimes distanced themselves from the ‘norm’ of finding certain tasks easy. Their difficulties needed to be ‘coped’ with and overcome, something that their peers did not seem to have to do. They thus have to identify as different from their peers, whilst also attempting to be the same. Individuals with dyslexia were aware of its stigma. In schools, dyslexia is a SEN and pupils who are formally identified with dyslexia may be labelled and treated differently from their peers. Dyslexia is a particular and peculiar disability. It is different from other medical issues, not easily visible, so an individual or a family would need to invest a lot (of time and money) to be taken seriously, identified and supported. Therefore, individuals with dyslexia need to subscribe to the medical model and subsequently invest in their differences from their peers.
Rose and Ellie both presented themselves as ‘different’ as a result of their dyslexia and its associated difficulties. As a child, Rose was different from her peers, from her teacher’s expectations, from her brother and from her father’s expectations. She found it difficult to engage with the curriculum and struggled with spelling and times tables. In adulthood, Rose continued to be different from her peers and people’s expectations. She struggled to maintain a job that was satisfying and challenging. In this way her differences were negative, many people are ‘better’ than her at spelling, times tables, and paid employment. However, she was also different due to some positive aspects of her dyslexia. She claims that she learnt to play the guitar by watching someone else; that she can cut out material to make clothes more easily than many people; and that she can mix colours in her head, all of which serve to construct her as different. Here she constructs identities for herself that give a positive ‘spin’ to her dyslexia, all the more so because of the negative aspects of it that she has talked about throughout her interview.

Ellie’s difficulties also meant that she was different from her peers at school. She was not as good at reading as her friends; her writing was poor; and she was not very good at remembering the alphabet. These are all skills and abilities that her peers, particularly her friends, found easy. As an adult, Ellie was better at reading and writing, and presented herself as being as good, if not better, than me. The difference, however, is that Ellie would take longer to do these things. She was still poor at remembering the alphabet, however, and recognised that her son was able to read things that she could not as a child.

Being identified, either formally or informally, as dyslexic represents a change in life and identity. For example, Natasha stated that she is not ‘dizzy’ anymore as she has a condition, as discussed more in the chapter 8. This is an important change in identity and how she is perceived. Since being formally identified with dyslexia, some participants have been able to receive support for their difficulties with reading and writing. Some have received DSA during their time at university, as well as technological support. Some participants saw a formal identification as an unwelcome change to their identity and their future interactions.
Rose was formally identified with dyslexia and dyscalculia in her late 20s whilst studying for a bachelor’s degree. Although her ‘diagnosis’ of dyslexia follows years of suspicion, Rose responds negatively to the label of dyslexia. She cited the stigma that dyslexia carries, as it means you ‘can’t read, you can’t write, you can’t add up’. She was unhappy at being labelled ‘disabled’ and recognised the social impact of such a powerful label, particularly on her chances of finding employment. However, she also learnt about her abilities and difficulties after researching dyslexia on her disabled students’ allowance (DSA) computer. This meant that she changed as a student and was able to apply her support to her studies.

Ellie, in contrast, was identified with dyslexia when she was seven years old. She thus did not talk about her identification with dyslexia in the same way that Rose and some of the other participants did. Throughout her life, Ellie received support for her difficulties very easily. Dyslexia and change intersected Ellie’s life very recently whilst she was studying for a PhD. Her difficulties became more pronounced and she asked for more support from the university. However, this was declined. At the time of the interview, Ellie was experiencing a change in her life as a result of social and institutional barriers.

Rose and Ellie both experienced dyslexia as a socially recognized label of difference that has both advantages and disadvantages due to both social structures and the choices they made. They have both experienced change in their lives as a direct result of this label and the discourses that surround it, such as stigma and medicalization. Rose and Ellie told me about these differences and changes in the course of the interviews in which I asked them to tell me about their lives. The concomitant existence of positive and negative change and difference unfolded through Rose and Ellie’s narratives of their lives.

In this chapter I have argued that dyslexia is experienced as a change in life and identity, whilst also recognized as a label of difference. These changes and differences are narrated within emplotted life events, which give light to the present circumstances in which individuals find themselves. Thus, the change and difference associated with dyslexia have an impact on the plot of life narratives, as shown by Rose and Ellie’s stories.
Rather than being understood as simply a ‘disability’ or a SEN, dyslexia needs to be understood as more complex identity position. The previous chapter emphasized the medical discourses that surround dyslexia and their impact on individuals’ decisions to disclose or conceal their difficulties. Rose and Ellie negotiated the self-constructions in similar ways. They construct their childhood selves as different, and the hero and villain characters served to emphasise their ‘otherness’. Both their plots were complex, particularly when it came to important storyworlds.

The analysis of a life narrative is a useful way of studying identity. Rose and Ellie view dyslexia as a disadvantage. However, Ellie’s childhood identification of dyslexia and her (very) recent inability to access support meant that her dyslexic identity and present self were in flux. She re-negotiated earlier events, comparing them to her present circumstances in a narrative structure that is not linear. In contrast, the themes of capability and incapability that simultaneously intersected Rose’s narrative meant that her dyslexic identity was presented as stable.
Chapter 8: Narrative identity in changing lives

8.1 Introduction
In this chapter, I aim to combine a thematic and narrative approach using storyworld to study moments of change in people’s storied lives. Change is a part of life and moments of change are inevitably narrated in autobiographical telling. This seems to be ‘common sense’ and is supported by authors such as Ochs and Capps (1996) and Labov and Waltetzky (1967). Change in one’s life is a consequence of change in the outside world, and change in one’s own sense of identity. The personal and the social combine in our identities and in the changes in our lives (Woodward, 2002). The interactional circumstances of the narrative interview are part of the framework in which interviewer and interviewee construct the narrative, and thus the narrative identity (Lucius-Hoene and Depperman, 2000).

Personal narratives are therefore replete with talk of change. According to Labov and Waletzky (1997) and others, a characteristic of a narrative is that it has some kind of complicating action, a trouble that has to be overcome, or a change in circumstance to which one needs to adapt (Ochs and Capps, 1996). When someone narrates their life past, present and possible future changes are talked about. Being identified with dyslexia is one example of many changes that have happened to the participants in this study.

Dyslexia may represent a big and important change in one’s life, or it may represent a smaller and less significant change. The medical and disability discourses that surround dyslexia, as discussed in chapter 6, are discourses that people with dyslexia draw on in order to make sense of the circumstances they find themselves in. These discourses are upheld by the individuals who need to subscribe to them for support and understanding. This means that those who uphold these discourses, for example professional experts who identify people with dyslexia, or employers who should abide by the Equality Act 2010, have power over people with dyslexia. Of course, these discourses can also be challenged.

Most of the participants in this study talked about their dyslexia to a certain extent, but they did not necessarily narrate their ‘story of identification’ without being prompted in the second interview. These participants were asked to tell me about how
and when they were formally identified with dyslexia. As this chapter shows, getting a
formal identification of dyslexia was narrated as a change in the participants’ lives. However, the extent to which it was positive, negative or ambivalent varied.

In addition, the variation of the times at which the participants were identified also meant that the current importance of this change to their identity varied between the participants. Some of the participants, such as Xander and Ellie, were identified when they were at school. Some, such as Madison and Jacob, were identified more recently when they were in higher education. Others, such as Andy and Natasha, were identified in later life. Four of the participants had no formal identification at all. This means that being formally identified with dyslexia is not necessarily a change in one’s life, and if it is, it may have paled into insignificance in the light of other, more recent, changes.

Selfhood is related to both sameness and difference (Ricœur, 1994). As discussed in chapter 2, we have multiple selves narrated across times and multiple identity positions. As shown in chapters 6 and 7, the participants in the present study all talked about being or feeling different from their peers, mostly due to their difficulties with dyslexia. These differences were narrated within their talk about change.

In the above paragraphs, and in chapter 7, the notion of time has become important. Time is a big influence on narrative telling (Ricoeur, 1984). Indeed, it is only through human time that we can perceive ourselves as individuals with a past, present and future (Ricœur, 1988). Another characteristic of narrative is that it is a representation of events that are temporally linked (Labov and Waletzky, 1997; Ochs and Capps, 1996). Thus, changing lives and changing identities are interlinked in time and in the telling of personal narratives (Bruner, 2002). In the present chapter, I shall focus on how changes (or ‘critical’ moments, Holland and Thompson, 2009) that occur at different times in peoples’ lives influence the ways in which they present themselves and construct their identities.

Narrative is one of the main methods we use to perceive, experience and judge our actions, as well as the course and value of our lives (Hydén, 1997). Indeed, we use multiple moral and political discourses whilst attempting to understand, judge and link understandings to our everyday experiences (Taylor, 1989). There are moral and
political discourses linked to dyslexia and the stigma associated with literacy difficulties. According to Ochberg (1988), the form, presentation and organisation of a narrative convey something of the narrator’s identity. Although there has been a significant amount of research on a wide variety of illness and disability narratives and identities in the social sciences, there is a dearth of research into the narrative construction and presentation of dyslexic identity.

Narratives are told from the perspective of the present. Past events, or imagined future events, are presented as coherent, chronological and causal explanations of the present circumstances (Brockmeier, 2000). In some cases the narrator may not be able to present a coherent story, but by attempting coherence they attempt to make sense of past experiences. The notion of narratives and stories as linear, as espoused by Labov and Waleztky (1997), are not easy to tell (Brockmeier, 2000). Narrators tend to migrate back and forth between past events and present evaluations, and even between past events from different parts of the life.

The present chapter focuses on the narratives of individuals who identify as dyslexic, at least privately. As dyslexia is a less visible disability, an individual may acknowledge their dyslexia with their peers, employers, friends, teachers, or family, or they may keep it to themselves. I will present extracts of their stories of change which were extracted through research interviews. I then present the analysis of these stories, focusing on the present day (interview day) evaluations they make in relation to the events and experiences they are narrating. These are mostly past events, but there are a number of examples of imagined future events and prospective acquaintances. The evaluations convey the narrator’s sense of identity and the identity changes related to narrated events, or not.

Throughout this chapter, I will present diagrams that show the temporal structure of the narratives of change, based on the storyworld concept introduced in chapter 2 and expanded in chapter 5. The charts show the storyworlds described within the told-story. This means that there may be some charts that miss out parts of the speaker’s ‘lived-life’, but that is because they are not covered in the speaker’s story. The diagrams of recent or current change in section 8.2 of this chapter show that the temporal narrative structures of these stories have some similarities. Throughout
these narratives, the participants often referred to the present day whilst they are narrating what was happening in a past storyworld. It is through the present that we bring meaning to the past, making sense of it in the light of our current problems and circumstances (Brockmeier, 2000; Bruner, 1990).

These diagrams show the extent to which the narrator makes present day evaluations about the events and experiences he or she talks about. Self-significance refers to the extent to which something (an event, experience, person, place or object) is important or meaningful to one’s sense of identity. The temporal structure of these narratives (at which points in the story-told the narrator was presenting events or specific times in the past or present day evaluations) shows the extent to which the narrator makes links between past events and present day evaluations. The content of these evaluations, as well as the amount of present day evaluations, indicates the self-significance of the past events and experiences the narrators presented.

The chapter is split into three sections. Section 8.2 concerns narratives of current or recent, and currently self – significant, change. These are events and experiences that have happened within the two years prior to the interviews. Section 8.3 concerns narratives of past, but also currently self – significant, change. The third section, 8.4, focuses on narratives of past changes that no longer seem self – significant for the teller. The events narrated in sections 8.3 and 8.4 happened to the participants, or which the participants presented as happening, more than two years before the research interviews. These sections will be accompanied by extracts of the participants’ narratives of change and diagrams, which represent the temporal structures of the narratives told. The two aims of the chapter are to show how storyworld can be used in practice and the differences in temporal structures of these narratives as they relate to the self – significance of the change that is narrated. This, in turn, will show that differences in identities in relation to dyslexia depend on the self – significance of dyslexia at the time of the interview.

The participants in this study talked about some recent changes in their lives that relate in some way to their identification with dyslexia. For example, Simon talked about being released from his previous job due to his dyslexia. Natasha narrated being identified with dyslexia whilst she was doing a short course to enable her to teach
adult learners. Claire talked about her struggle to find a job after completing her PGCE, which she related to forced disclosure of dyslexia. Madison told me about her recent identification with dyslexia whilst she was doing a master’s degree and starting her PhD. The participants also talked about changes that happened in the more distant past. For example, Peter talked about the changes in his life between studying at school and studying at university. Claire talked about her identification with dyslexia. Hilary talked about her journey from school into her current job. Fred and Xander talked about their lives from primary school into secondary school.

Narrative techniques were employed to analyse the participants’ stories of being identified with dyslexia. These are accompanied by storyworld diagrams, which show the temporal structure of the narrations. According to Labov and Waleztky (1997), narratives are comprised of several elements, but the most relevant part for my purposes is the evaluation, where the narrator gives meaning and interpretation to the story told. The narrator’s story is told from the present (Freeman, 2010; Ricœur, 1984). Stories are interspersed with evaluations and arguments which are made in the present with the benefit of hindsight (Freeman, 2010; Ricœur, 1984).

The narratives can also be analysed as present day performances made in particular contexts to offer up particular identities (Atkinson, 1998; Davies and Harré, 1990). The narrator is telling the story to an audience, including the researcher (Reissman, 2008). The narration is an enactment of past events and experiences. The characters and plot of the narrative also demonstrate the author’s interpretation of the events and experiences. The temporal structure of the narratives shows the extent to which the events portrayed are significant to the narrator’s identity in the context of the telling. The content of the evaluations and arguments made during the narration show the nuances of how these events and experiences are still relevant to the narrator.

The present chapter, therefore, aims to investigate the structural differences in the narratives about self-significant changes compared to non-self-significant changes. The differences in identities in relation to dyslexia depend on the self-significance of the change at the time of the narration in the interview. The content and frequency of evaluations give clues to the self-significance of the changes being narrated.
8.2 Recent or current change

Simon was a mixed race man in his early 30s. He trained at university to become a professional\textsuperscript{10}. At the time of the first interview, he had recently got a new job. The extracts on the following pages are from the first interview and detail his path from his earlier career to his new appointment. The first extract, below, is where Simon talked about some of the difficulties he had in his first profession.

Extract 1: Simon

I knew you had to work quick to do this, but the most frustrating thing was I knew exactly what I needed to do, so I remembered what the cases were, I knew exactly what I needed to do on each one of them, like there was no problems with the strategy and rubber stamping, it was just implementing it which was just a problem

I mean you kind of had the fatigue factor, because you probably know what it’s like to do really late nights and sort of like work for long periods of time, but eleven months working 12 hour days practically is just not healthy

In the above extract, Simon presented his past self as an employee who understood what his job involved. He positioned his identity as capable; he knew what was expected of him and how to do it. The intellectual tasks he needed to perform were manageable. However, he could not ‘implement’ them in the correct time frame. The time constraints of the job meant that it was unmanageable for him. So he worked very long days, which is ‘not healthy’. Simon was drawing on a popular discourse of ‘work-life’ balance, where too much time spent at work is not conducive to mental and physical health. He related his experience to his imagined experience of me, a doctoral student, who also worked long days, thus trying to normalize the issue, but at the same time challenging this discourse. The scene was thus set for a story in which Simon’s troubles were not going to disappear like Rose and Ellie’s. He was both capable and not capable at the same time.

In the next part of this change narrative, Simon talked about a work-place psychological assessment in which he learnt that although he scored highly in some aspects, such as visual manipulation, the reason for his difficulties at work are his low

\textsuperscript{10} Not disclosed for ethical reasons. He had made it clear that he had to sign a contract disallowing him to talk about the circumstances surrounding his dismissal. Thus I have not named his profession here and some details have been removed or changed appropriately.
scores on processing speed and working memory. In the following extract, Simon talked about what happened after this work place assessment.

Extract 2: Simon

so if you read the report it just makes me out as though, it just makes you look really, really stupid, which you’re not, but it’s just like some of the stuff they put is quite stark and then they did the work place assessment, and we, we looked at it, and it’s just like well, you can buy lots of these courses from them but, which may help you to get techniques, but besides from that, their actual suggestion that was their only practical suggestion, to actually help me out at the workplace, and the woman who did it kind of like explained it in the report, cos she was just like ‘normally we can give suggestions to people’, but she turned around and went ‘I actually think you’re in the wrong job’, I was just like ‘right’, she was just like ‘basically you need to do x y and z and you just, you physically, you just, you’ve done amazingly well to get this far and kind of do it, but the reason why you work late and you can’t do it is because you’ve got these problems and they’re kind of extreme and to be honest you can pay for our courses’ but she was like ‘because you’re so bad at them’ she weren’t really 100% sure that they would impact make a difference, cos she said, and you probably know more about this than the person I spoke to so I don’t know if these statistics are true, but she was just like ‘normally if you, if you’re going to, people will improve but like 10 to 15% in that bit, but because you’re like bottom 5 or 10% you’ll probably improve by about 10% which is still well under the speed which would be required to kind of do that the way they want to do it’ I was like ‘right’, as I said the report had no practical, the assessment basically, it basically said ‘well, you should give him a bit more time to do this or a bit more time to do that’, but there was nothing much they could properly implement, which given what they probably hoped, which is we’ve got an employee we kind of like and he’s got lots of good skills and he knows what to do, but how to get him to be more profitable quicker

and that’s the point where we had the discussion, ‘well actually the only things which we could do would be to change our fee structure just for you and accommodate you only, otherwise we actually, we don’t want you to work for us anymore
In extract 2, Simon presented a complex turn of events. His work place assessment report positioned him as stupid, but his use of the third person in the above extract helped to distance himself from that idea. However, the report did not necessarily say that he was stupid, it was the language used in it which was ‘stark’, which challenged Simon’s sense of identity as intelligent. The assessor did not think that he and his employer would benefit from any extra training as his test results were so low. However, the assessor remarks that Simon had ‘done amazingly well to get this far’. There was surprise at his capacity to do well in this profession, despite these ‘obvious’ disadvantages. The environment of that profession in that particular company was presented by Simon as disabling (Shakespeare, 1996). The overriding message here was that he should be proud of his accomplishments, with condescension of the ‘elite’ literates who do not have impairments (Collinson et al, 2011), even though he has to leave his job and change his identity to a certain extent.

Simon was different. The normal recommendations were not given in his case. In fact, the only recommendation was to get a different job, and to invest in a different career to adopt a new identity. Therefore, he was not normal. The recommendation reiterated his differences from his peers in his inability to do the job for which he was trained and in which he had invested a lot of time. This was a turning point in the story and was told with dramatic effect, as Simon reported direct speech and sped up his talk. However, Simon presented the company’s attitude as disappointed that they could not keep this good, skilled, talented employee, but this is countered by the fact that they sacked him anyway.

There was a complex relationship between Simon, his employer and the assessor. Simon narrated these events as though they were reasonable. He presented himself as good at some things, but bad at other things. The things he was not good at were presented as ‘not his fault’ due to his impairment (Shakespeare, 1996). In disability studies, the idea that disability is socially constructed means that an individual with an impairment can only be disabled by the environment. The environment in which Simon was employed was presented by Simon, and the assessor, as disabling. However, impairment is at the heart of this.
The ‘dyslexia’ label and therefore a dyslexic identity provides a reason, or excuse, as discussed in chapter 6. The disability discourse which surrounds dyslexia was upheld by the assessor who said that Simon has done ‘amazingly well’ to get ‘so far’. Simon seemed to accept this and the discourses of pride associated with ‘success against the odds’ which the assessor provides for him. He seemed to accept this change, and the changes in his life to come, as a result of the inevitability that dyslexia is a disability. Simon presented the company’s position as understandable given the circumstances. Simon presented them as grateful for his input and his abilities, but not too grateful as they dismissed him anyway.

After working for that company, Simon went on ‘some very big holidays’. However, holidays had to come to an end and Simon needed to find a job. In the next extract, Simon talked about applying for jobs and getting a new job at a call centre.

Extract 3: Simon

and I kind of found it really difficult to actually get a job, cos you’ll kind of put on your CV that oh you’ve done this and then you’ll apply for something really basic and they’re just like ‘why are you applying here? Surely you’re a bit too over qualified’, so I had to then dumb down my CV, not tell people various stuff or not tell people that I was qualified and just kind of go in on that basis, cos people get a little bit less intimidated, and to be honest I didn’t tell like ,when we started our induction at (work) it was just, I didn’t tell people I used to work for [employer], I never told anyone I was qualified for a good 3, 4 months, and the only reason I told them was because they asked, I was just like if they asked the right question, I’ll tell them, but otherwise I wouldn’t bother. I don’t volunteer information like, I don’t tell people I got a first or anything like that unless they actually ask

By using the second person singular, Simon seemed to distance himself from the idea of being truthful and inclusive of all work when writing CVs and applying for jobs. He constructed his actions as ‘dumbing down’ in order to be ‘less intimidating’, which showed that he was aware of how the hierarchy of jobs and applications works. An individual needs to ‘fit’ the job for which he or she is applying. Both under- and over-qualification may lead to disqualification from the process.

By not informing colleagues about where he used to work and his professional
qualifications, he was deliberately hiding his past self. This was a deliberate method of changing his identity in order to ‘fit-in’ with his colleagues. Simon’s identity change meant that he was no longer a professional, regardless of his qualifications and previous experience, and this was apparent by his methods of applying for jobs, his new role as a call centre worker, and by the conversations he had with his colleagues.

The narrative Simon told, and the present day evaluations he made can be represented visually in the temporal narrative diagram below.

Figure 5: Temporal structure of Simon’s narrative

Figure 5 shows the temporal structure of Simon’s narrative of change, from the storyworld of his professional job, represented by the box that says ‘previous career’ in the top left of the diagram, to ‘today’, in the box on the top right. He narrated his
difficulties in the first job, followed by dismissal, travels and applying for new jobs. Interspersed with these events in particular times and places were present day evaluations in which he compared himself to his colleagues and me, and in which he talked about the need for this story to be kept anonymous.

Simon spent many years training for his previous career. His difficulty in doing that job, as a result of his dyslexia, meant that he was no longer a part of that profession. His life and identities had changed. His real difficulties, but apparent capability, meant that he was different from both his old colleagues, who were trained like him but do not have dyslexia, and from his new colleagues who were not trained in his previous profession and may be ‘intimidated’ by his history. His new job was different from his old job as he had no responsibilities, he needed very little training, and the environment was not ‘disabling’ in the way that his previous job was. The present day evaluations and statements gave insights into his identity constructions.

The recent changes in Simon’s life, leaving his previous job and getting a new job as a call-centre worker, meant that his identity constructions were represented as changed. He was no longer a professional. He was different from his former colleagues and his new colleagues. The high number of present day evaluations allows his story to allude to his sense of self. Something similar happens in Natasha's narrative.

Natasha was a white woman in her late 40s. She worked as a costume designer for a theatre company and had recently been identified with dyslexia. The part of her story presented here is taken from the second interview, when I asked her about being identified with dyslexia. In the extract below, Natasha talked about her first suspicions of dyslexia.

Extract 1: Natasha

but I was always considered a low achiever, I know that, and one not able to you know, but then I started to- I know that dyslexia was around at the time because my neighbour’s son, [his mother] who was a headmistress, she diagnosed you know, got a diagnosis of dyslexia for him

but nobody I went through all of my college life and one person mentioned that to me and people round me were being diagnosed, but anyway I sort of obviously gleaned from the media or whatever what it meant and just thought ‘well, I can’t spell, I can’t
do maths, I think I’m quite intelligent, so I must be dyslexic’ so I’d been telling everybody I was to sort of cover up the point where I probably didn’t have difficulties

Natasha said that she was considered her as a ‘low achiever’. This is important as it can be related to the notion that one’s identities are not purely personal, but is built on social and cultural aspects, as discussed in chapter 2 (Davis and Harré, 1990). Natasha self-identified as dyslexic, by drawing on her identity position as intelligent with limited literacy and numeracy skills. She presented herself to ‘everybody’ as dyslexic. The following extract continues Natasha’s story of being formally identified with dyslexia.

Extract 2: Natasha

so I decided to try the 10 week course and I sort of did it, one to prove to myself that I was better than at school, you know another 20 years’ experience, and erm hopefully to see it as a stepping stone to do the course, to be able to do the teaching so when I went in I said ‘I’m a dyslexic’, and they said ‘well, you can’t just say that, you don’t have proof’ so erm the tutor was quite good she used to give me she used to write a lot on erm not a white board but the pads the big pads there and she used to give me those every night and everything was re- all the lectures were written down anyway so you did have a handout with each one and the course was great I really enjoyed it but I found it really tricky doing getting my head around writing an essay cos obviously I’d only been up to A level standard so I’ve never gone past that in 30 years (laughs)

erm but they were saying ‘we can’t give you any concessions for being dyslexic until you get tested’ so there was this long palaver going through disability services who finally said ‘well, because it’s only 10 weeks we can’t pay for it’, completely understandable ‘but you can have it for half price’ but it actually took ‘til the day after I had to hand my essay in (laughs) to get me the assessment and I slightly ummed and aahed about it, but my husband said ‘look, just do it you know it’s a lot of money but do it you know’ it’s a big chunk of money and it was great I really enjoyed it I really enjoyed having an hour and a half talking about myself (laughs) and he explained so much more about how I think so it’s really opened up an awareness and of course I have a dyslexic son it’s allowed me to help him more and explain to him why he thinks the way he does and the little triggers the things that could help so so that was only 18 months ago and now I wish I did it sooner

Starting a course for teaching has two aspects for Natasha. The first was proof that she was better than her childhood self, ‘a low achiever’. At this point, she recognised an
identity position as ‘dyslexic’ and showed she knew that disclosing this could provide support by telling the people running the course. However, without proof there was very little they could do. As discussed in chapter 6, no proof of dyslexia may as well mean that you do not have dyslexia, which means that you cannot receive support. The teacher, however, provided unofficial support. Thus, Natasha positioned the teacher as understanding, and an identity of her as a good student.

This part of Natasha’s story gave a relatively detailed account of her negotiating the dyslexia test and the support for her course. She reported conversations using direct speech which gives a certain amount of action and credibility to the events she was narrating. After having these tests, she was ‘officially dyslexic’. She constructed an identity as a different kind of mother to her son who was also dyslexic. In the next extract, Natasha talked about the aftermath of these events at work.

Extract 3: Natasha

my boss is into to it all being confidential, I said ‘no, I don’t want it to be, I want people to understand that I’m not dizzy Natasha anymore I have a condition’, and she went and told me off because I’ve been trying to order this live scribe pen and stuff and I left the report by the phone cos I was in fittings and I said ‘if anyone rings back on the post-it note on the top of the report could you write down the quote for me’ and she gave me a hard time you know for leaving what she considers confidential information by the phone in a work room and I said ‘I was leaving it there because’ and she said ‘no, you’ve got to keep it’ you know you would literally have to take it away and sit down and read it properly it wasn’t like you could glance at it and pick up information and I’m really, I’m very open about all sorts of things like that. The thing is, why hide it?

The formality of a dyslexic identity changed Natasha’s self. She was not ‘dizzy’ anymore. She officially had a condition to explain her difficulties and behaviour. The validity of a ‘diagnosis’ possibly led to support and understanding from her colleagues. She did not hide this change. However, the detailed report of the events surrounding her boss scalding her regarding ‘confidential’ information served to support the notion that Natasha was different from her boss, as well as different from her colleagues as ‘dizzy Natasha’.
The narrative Natasha told of her experiences of being identified with dyslexia can be represented in the following diagram.

![Diagram showing the temporal structure of Natasha's narrative](image)

**Figure 6: Temporal structure of Natasha's narrative**

Figure 6 demonstrates the similarities between Simon and Natasha's narratives – they both made lots of present day evaluations whilst narrating recent changes in their lives. Natasha’s boss, who was ‘into it all being confidential’, was presented as different from Natasha. The ‘it all’ here is a reference to her newly identified dyslexia. She gave an example of this difference in reporting a conversation she had with her boss, demonstrating her boss’ wish to keep things confidential and Natasha’s wish that her colleagues were aware of her ‘condition’ that meant she was ‘not dizzy Natasha anymore’. This was a major and important change of identity. Not only did Natasha

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11 ‘Cheese’ refers to an episode when Natasha was away with work. She bought cheese and bread to eat for dinner. To keep the cheese cold, she ran a bath and placed the cheese in it. This story was told to demonstrate further differences between Natasha and her boss, who thought that this was very funny. In contrast, Natasha thought that this was the logical thing to do.
refer to herself as having this condition as a reason for being ‘dizzy’, she referred to those whom she wanted to know about this change, so they could change their opinion of her.

Like Simon, the recent changes in Natasha’s life mean that her present-self was in flux. By making reference to present day evaluations, Natasha was able to reflect on that change and present her current-self as different from her past-self. Claire also had to negotiate dyslexia and its consequences.

Claire’s narrative of change was about her quest to find a job. She was a white woman in her 30s, who was married and lived with her husband and two children in South Wales. She was identified with dyslexia during her Higher National Diploma (HND) and was entitled to support during her Post-graduate Certificate of Education (PGCE). At the time of the interview, Claire had recently completed her PGCE and was looking for a job. The extract below is from the first interview I conducted with Claire and comes from near the end of that interview. In it, she talked about the tensions between anxiety and confidence in job hunting.

Extract 1: Claire

well I haven’t got a job yet, but once I get a job, but now I’m in a position where I’ve got to on supply

and you become even more anxious because you’re in different schools and everyone is going to be watching you and you, you don’t know what you’re going to be given

whereas when you were on teaching practice, I’d have time to read up on the stuff the night bef- well you’d have, you’d plan all your lessons for 8 weeks and you knew what you were doing, you’d research it, you’d read it, you’d make sure you could do the calculations, or you could do, you know, you knew, or if you were doing report writing, your structures and exactly what you were covering, you were in control, I was in control, I could do it, I was confident, I could go in there

but now having to go on supply, I haven’t got that confidence because you could just go in a classroom and they say, ‘right you’ve got to do equations’ (gasps) I yeah ok you know, erm I’d have my books there, but I won’t be confident, although I’m sure that it would work out ok
This part of Claire’s narrative detailed the current life changes she was experiencing and her attempts to find a job. Claire evaluated this prospect as inducing anxiety. She uses the second person singular here, which may suggest that she is distancing herself from this prospect and does not identify with this evaluation. When she talked about being ‘in control’, she started to use the first person singular; she positioned her past training identity as ‘in control’. This was in contrast to supply teaching and her lack of confidence. She presented an imagined scenario of arriving at a school as a supply teacher and being confronted with a task she would find difficult. She said that she ‘won’t be confident’ in this scenario, which, as she did not have a full-time position, was likely to happen. In this part of her story, there was a conflict between Claire’s confidence in teaching, and her anxiety over supply teaching.

The narrative continued in much the same vein until Claire started to talk about looking forward to getting a job. However, she described a stark difference between her ‘dyslexic’ identity as perceived by others and her ‘actual’ self, that sense of her self as more than a dyslexic identity.

Extract 2: Claire

but erm I am looking forward to being in a job and starting and, and doing that, but been for one interview, but there’s 150 people going for one job and you don’t stand a chance, you know if you’re up against that, then they say ‘well, what extra qualities have you got to give to the school?’, and also the fact that you have to disclose your dyslexia on application forms. They say doesn’t have a bearing on it, but I think because of the competition are they really going to choose somebody who has written dyslexia? Because you know on your application forms? You know if I was in the same position, would you think twice? Because people obviously have their preconceived ideas of what actually dyslexia means, the fact that you’ve got someone who is committed and studious, who’s got distinctions, who is very good with the children, who can see identify problems, they’re not going to see that they’re just going to see the word dyslexia, they’re just going to see the label and,

and, and in a way I’m thinking, ‘should I have really have been tested?’, cos had I not known, I wouldn’t have to disclose it, and now I’m thinking maybe cos, I didn’t know until I was an adult

The above part of her narrative is about her recent and future experiences of trying to
get a full-time position. Although she was ‘looking forward’ to this prospect, there was a lot of competition. Claire made a distinction between people’s perceptions of her based on her application, where dyslexia is disclosed, and her own self-perceptions. She presented potential employers’ perceptions of dyslexia as negative and blocking her way to a fair chance of getting a job. These perceptions were in contrast to what Claire constructed as her ‘committed and studious’ identity, an individual with relevant talents and qualifications. These distinctions were related to the forced disclosure of dyslexia on job application forms.

Claire presented her diagnosis of dyslexia as a dilemma. She regretted getting tested for dyslexia, due to people’s perceptions of her difficulties. Claire presented an identity of the innocent party, whilst also sympathising with those imagined villains who would not employ her: ‘if I was in the same position, would you think twice?’ Claire recognised the stigma attached to dyslexia. However, at the same time, she positioned her identity as different from the stereotypical and stigmatised perceptions of dyslexia, which she believed prospective employers may hold. If Claire got a job as a full-time teacher, she would be able to plan and prepare, and thus have ‘control’ and ‘confidence’.

Her identification with dyslexia, as well as being detrimental to finding a job, had not given her much in the way of other benefits. In this next extract, Claire outlined the discrepancy between the support she was offered as a dyslexic student and her commitments to her course and family life.

Extract 3: Claire

but then again, I had support when I was in university with extra time because I was given, you are given like a specialist tutor that you can go and get help with assignments or whatever, but I couldn’t use it because I was so busy, couldn’t, the hours that I was given to help me couldn’t use them because I didn’t have the time, and because of the distance between the university and here to juggle family life and being aware of your teaching, and teaching practice, and to juggle erm the assignments, I didn’t have time to go to somebody and say, “can I have help?”, I needed help, I- I certainly needed help at times erm, which could have been resolved in a short space of time but, but I just didn’t have the time or the opportunity to do it
so basically, in a way it’s a good, you know, you’ve achieved it on your own without support

but erm erm you didn’t, you weren’t able to take the support because of the how intense the actual course was

Support for dyslexia exists; in Claire’s experience the system works. However, she was unable to take up that support, due to the multiple identities who was upholding, as a ‘good student’: completing work and attending placements; and a good wife and mother: she was involved with her family at this point in time. However, her achievement without this support is to be lauded: she said that ‘it’s a good thing, you know, you’ve achieved it on your own without support’. Claire then talked more about disclosure, people’s perceptions and the possibility of rejection, versus what she seems to consider her ‘real’ self, as competent and able.

Self can be described as a social, as well as a personal, phenomenon, where people’s perceptions of the individual are as important as his or her personal sense of self. The change in Claire’s told story reflected the change in her lived life, which was happening around the time of the research interview. The actual identities she presented were confounded by several things: first, her inability to get a full time job; second, her perceptions of people’s (primarily potential employers’) thoughts of her abilities and her dyslexia, as related to the negative, deficit discourses which surround dyslexia; and third, her perception of forced disclosure of dyslexia was related to the notions of the Equality Act 2010 and the structures that uphold the ideas of support for those with difficulties like dyslexia.

Through her narrative of recent change, Claire presented her ‘actual’ self as very different from people’s perceptions of her. There was a discursive difference between her identities as confident and competent or incompetent and anxious. Thus the narratives she told and the evaluations she constructed seemed to reflect the significance of the events she described for her past, present and future selves. Claire’s story and the present day evaluations she made can be represented visually in figure 7 below.
Figure 7: Temporal structure of Claire’s narrative of change

Figure 7, above, shows the narrative movement in Claire’s story between past events, which happen to be very recent, and the present day evaluations she made about those events and experiences. The content of these evaluations have been presented and analysed over the past few pages. The number of present day evaluations here adds weight to the idea that these events were self-significant at the time of the interview.

Claire’s change in her life was happening during the present time (of the interview). Having completed her PGCE she was looking for a teaching job full time. This ‘ideal’ identity was hindered by compulsory disclosure and her perceptions of important people’s thoughts. Claire became a qualified teacher, which was an important change in her identity, but it was her fears of people’s perceptions of her that were having an impact on how she thought about dyslexia. She said that she was very confident, competent, if a little anxious about the possibility of doing supply teaching, which was caused by her dyslexic difficulties.

However, she said that that anxiety would disappear if she were to get a full time teaching job, in which she would be able to prepare and plan. However, this would be
difficult and Claire recognised that the economic circumstances that were not helping. She claimed an identity position as one of many competent teachers, but one of a few who would disclose dyslexia on their application, which she believed meant that she was ‘paper sifted’ out of the process. Her difference from those with similar aims was a barrier to a steady teacher identity.

This difficult quandary means that Claire was in an uncertain time in her life. Although to me it seems that she constructed a very confident present self, and had a very positive view of herself, it was her fears of a) people’s thoughts of her and b) being seen as incompetent as a supply teacher (due to the lack of planning) that meant that her identity as a teacher is under threat due to her identity as a dyslexic teacher. She jumped back and forth between present day evaluations of herself as anxious and unconfident about possible future situations, which she talked about with examples of tasks that made her anxious. Madison also recounted bouts of anxiety.

Madison was studying for a doctorate and living with friends in a university city. In this part of the first interview, Madison told me about being identified with dyslexia during her Master’s course at her previous university. The following extracts come from the first interview with Madison where she narrated being identified with dyslexia and the consequences of that. In extract 1, she talked about being tested for dyslexia and her fears surrounding this event.

Extract 1: Madison

so that, that freaked me out a little bit cos it automatically felt like you were a bit mental and that you were having this special guy come in to test you and everything, it’s all a bit like, ooh bloody hell, and by then I was a member of staff and I was kind of trying to find my way in the world, and it was all a bit scary, I think as an undergrad it would have been less scary, but that fear of being stupid stayed with me I think, so not massively keen on having the test done, but my, my coping was saying ‘I think if anything, I’m a little bit dyslexic’ [my emphasis]

compound

In extract 1, Madison’s use of phrases about mental health suggest a fear of the ‘otherness’ associated with it, as ‘like you were a bit mental’, ‘a little bit freaked out’, feelings which were compounded by the ‘special guy’ who was going to test her. The
use of the second person singular here was significant, as it served to distance herself from the negative connotations associated with these events. These events, however, were made more complex by her position as a new member of staff ‘trying to find my way in the world’. The context in which she was tested for dyslexia was presented as a reason to downplay the prospect of being dyslexic.

In the next extract, set after the tests she was set, Madison talked about obtaining the results of her test for dyslexia.

Extract 2: Madison

he was like ‘describe to me how, if you are, if you think you are dyslexic, describe to me how like how much you think you are’, ‘well, I think I’ve only got a few issues and that it only you know affects me a little’, ‘incorrect’ you know (laughs) he was like ‘you’re in fact 12 markers over being dyslexic’ and I was like ‘oh, oh well that’s quite a lot then’, again I don’t really know how it worked, but that was quite significantly into the dyslexic scale so I was just like ‘oh that’s interesting’

that changed my view on it a little bit on education, I hadn’t failed, I’d just got a first in my degree and by that point was well on my way to getting a first in my masters which I did get eventually, which is very cool, but it was always like, and it’s still with me now, is that I just, I feel not as good as everybody else and yeah, and it’s the same with like, that’s why I was so surprised when I was picked to do this PhD thing, it’s just mad, but that kind of, yeah I still feel not as everyone else doing it, I don’t know whether that’s something I created for myself or what really, but it always feels that it’s really hard really, and it’s really difficult

Madison expressly downplayed prospect of dyslexia to the psychologist despite difficulties in carrying out some of the tasks. She was identified as ‘very’ dyslexic, to which her response was ‘interesting’. The previous evaluations of these events and her tone suggested that this revelation was more complex than ‘interesting’. Her unhappiness about this was presented as the result of her feelings of inferiority compared to her peers and the contradictions against her success in her higher education and academic career.

The result of these events was Madison’s new entitlement to support.
Extract 3: Madison

what upset me was that in order to get support from the uni, if you are (research council) funded you had to get a supporting letter from both your two supervisors and your head of school, so I’d just arrived in (place) and I had to tell all these people I didn’t know that I was dyslexic, so I’ve already got a complex about being stupid and that was really, that really upset me cos in (uni 1) everything’s really confidential and you don’t need to tell anybody, you don’t need your supervisors to know, it’s something, like, that the disability and dyslexia service can send them a letter saying ‘they need support’ if you want them to, but it didn’t have to have any details like, where as I felt it was really bad, you know, you come to a new uni, I’d never even met the head of school and he had to do, yeah you had to get a letter from him

Madison detailed the procedure for obtaining support for her dyslexia at her university. The disclosure was not only to support services, which was her expectation. She also had to disclose her newly identified dyslexia to many people. The forced disclosure to these individuals and her fears about being positioned as stupid were very upsetting. This discomfort could suggest that Madison was concerned about being identified to new (important) people as solely dyslexic, and possibly ‘stupid’. Thus, the university was presented as not very understanding about the issues which surround dyslexia.

The diagram below shows Madison’s narrative expressed in terms of its temporal structure.
Madison gave present day evaluations of being tested for dyslexia by a psychologist as ‘odd’ and ‘mad’, which may serve to support the presentation of herself as confused by the tests. She also gave a present day evaluation of her difficulties at the time of the interview, which she was able to understand as a result of the test. She evaluated her present self, saying that she feared being seen as stupid and of being tricked into being stupid. The content of these evaluations and frequency with which they permeated her narrative suggested they were currently significant to her sense of self.

Madison was narrating a time in her recent life when her sense of self changed. Not only was she formally identified with dyslexia, this happened when she was a new member of staff rather than a student and not very sure of herself. Like Claire, she downplayed the idea that dyslexia was a part of her self. The theme of ‘feeling stupid’ ran through Madison’s story. However, Madison never expressly constructed an identity position of ‘stupid’. The events and experiences she narrated, such as her achievements at university, contradicted the notion that she could be stupid.
The plethora of present day evaluations of these participants’ past, present and future selves suggests that the events they narrate were significant in the context of the time they were interviewed. The content of these present day evaluations supports this idea. Identities and selves are constructed in the present (Davies and Harré, 1990). It may be argued that recent events and experiences are bound to be self-significant due to their perhaps stronger relationship with the present than more distant events and experiences. However, experiences and events which are in the past may also be very significant to the self.

The particular way in which the narratives were told, with past storyworlds being interrupted by present day evaluations, can be related to Brockmeier’s (2000) narrative models of autobiographical time. These four temporal narrative structures seem to be similar to the cyclical and spiral models that Brockmeier (2000) describes. Brockmeier (2000) relates these models to psychoanalytic theory and therapy, but I think that they are equally as useful for understanding the emplotment of narratives and the significance of the narrated events to the present self and are pertinent to narrative theories of time.

These kinds of telling (spiral/cyclical) are related to the self-significance of the events that are being narrated. Recent or current changes (or life changing events), which are told from the perspective of the present (Ochs and Capps, 1996), are significant to the identity that is being presented, constructed and changed. This means that any present day evaluation of self can be thought of as an attempt to position identities and construct the self in these changing circumstances. However, what happens when these ‘fateful’ moments have already occurred, further into the past than the events and experiences narrated in the extracts above? How are they narrated?

8.3 Past change and present difficulties
In contrast to recent or current changes, the events presented in the narratives in this section happened two or more years ago. However, like the narratives above, these events seemed to be significant to the self at present. I present two examples of this kind of narrative. Peter talked about changes in his life related to his family and his attitude towards studying between doing his GCSEs and his first year of university. Claire talked about being identified with dyslexia. The structures of these kinds of narratives were similar to those presented in the first section about present or recent
life changes.

Peter was a white man, in his late 20s, studying for a doctorate. He had not been formally identified with dyslexia, but had been given an ‘unofficial diagnosis’ and identified with dyslexia privately. He told me that he hid his difficulties and did not inform people that he may have dyslexia. I interviewed him in a room at the university, which was his choice. The extracts presented here come from the first, open-ended, interview. The narrative follows his life from GCSEs to studying at university and the changes in this part of his life. The extract presented below focuses on the changes in his life from studying for his GCSEs to studying for his A levels.

Extract 1: Peter

so up until I was, I did my GCSEs and I did ok, but I wasn’t really like, I passed them all fine but I didn’t do amazingly well in them

and then in fact there was a big family event and my family was all split up and like I was, went my own way

and then decided to go to a different school of my choosing to do my A levels and chose my subjects that I wanted to do erm, and did things like economics and business rather than traditional like English literature and thing which I was pushed to do before hand, and that’s where I did really well

and so I think it like, that people have different brains for different things don’t they, and I think I found what I liked doing in that way

and then that’s when I started to have an interest in learning rather than it being like a chore

In extract 1, Peter positioned his school boy identity as ‘average’. The events around that time, the family split about which he did not give very much detail, were presented as the cause of his decision to change school and choose his A level subjects. One event causing another is key to the uniqueness of narrative as a chronological keeper of events (Labov and Waletzky, 1997). The causality expressed in narrative provides coherence, which Peter used to present this event as a precursor to his ‘real’ identity, coming out to choose the subjects he wished to study. He was able to express his newfound freedom and his ‘real’ self. The ‘big event’ led to him
becoming a good and interested student at university. He described his interest in learning, therefore, as a result of the family split and the choices he made following that event. These experiences were presented as leading him into higher education.

Extract 2: Peter

and I went to university to do economics and then, but I did economics with law as a minor, and then at the end of the first term I decided I wanted to do law as a full subject, and they were like, ‘no you’re a term in’ and I said to them, ‘well let me sit the exams for the first term and if I fail then fair enough I won’t do it’ and then that’s when I- that was the point when I started to get a passion and I worked really hard to pass them and I passed them all really, like, amazingly well and so they let me change my degree like after a term

and so then that’s when I did law erm, which I found quite hard in terms of I think my learning thing, like, it didn’t come easily like, cos there’s so many case names and dates that I had to remember and I found it really hard for my brain to get around that and, although I really, I loved it

I love sitting in the library and reading about the different ways the law is interpreted

In extract 2, Peter provided direct speech, documenting the conversation between himself and the university administration. This gave drama and credibility to the events he narrated, which presented him as a good student and capable at university. His dedication to his studies meant that he could change his course to Law. During this process he developed a ‘passion’ for learning and thus pursued an academic identity more and more.

The difficulties he had studying Law were constructed as a result of his ‘brain’ finding it hard. This was juxtaposed with how much he loved the course. The present day evaluation reinforced his pleasure in studying this subject. There was a contrast here between the difficulties he had, or his brain had, with the subject and the pleasure he got from his studies. This was further complicated by the other aspects of assessment.

Extract 3: Peter

but when it came to examination like I found it really har- like, the way that my brain works I found it hard to perform as well I shou- like I never, like my, my, th- my kind of
thing in life is that I always, in an everyday thing you know, in report cards and kind of general feedback from teachers and lecturers is really good, like got the potential to go really far, but when it comes to the exam like, I don’t do rubbish in the them but I don’t do as well, and I just think that’s the nature again of, maybe that’s where my, like I find it hard to process like in the conventional way rather than (inaudible), does that make sense?’

In the above extract, there is a contrast between Peter’s potential and passion for learning, and his exam results and his ‘brain’. As he changed from an average pupil at school to a good student at school, his difference from his peers, and from his past-self at school, became more prominent.

The changes in this part of Peter’s story (extracts 1, 2 and 3) were about the subjects he studied and his increasing passion for learning. However, running through these changes was the notion that Peter still struggled with certain things. He presented those difficulties as an aspect of his brain, which remained unchanged. Figure 9 represents the temporal structure of this part of Peter’s narrative.
Figure 9: Temporal structure of Peter’s narrative of past change

Figure 9 shows that there was a linear structure to the first part of his narrative, but that changed when he started talking about his difficulties, referring to his past and present struggles. The present day evaluations were told in the context of the events that happened in the second term of university, when he was struggling with the work he had to do. The content and frequency of these present day evaluations of the past events in the told story are similar to those in the visual representation of the narratives in section 8.2.

Claire’s identification with dyslexia took place at least two years before she took part in this research project. In the following extract, she narrated this time in her life.

Extract 1: Claire

when I went to do an HND in early childhood, er I, I thought, ‘well is- is it just the fact that I’m dumb or a bit thick, or that this is just my level or is it something else, could I be dyslexic or a bad reader, why I find it difficult?’ So I went to the dyslexia association ... and I was tested, and it was really just to confirm what I thought, and they said I was dyslexic and I probably had dyscalculia or dyscalculia, I don’t know which how to pronounce it, so erm so you know, and you know that sometimes the two are linked,
cos at first now, even though I’ve done a teaching qualification erm I, I still find it hard to do times tables because of the sequence of it, and certain things, if I need to I can do them, but I need to go over them redo them erm, and refresh things regularly so erm, that’s where I am now, I’ve just finished the PGCE in the summer and at the moment I’m looking for work

In the extract above, Claire talked about being identified as dyslexic. This was a confirmation of her suspicions. However, there was still the possibility that she was ‘dumb’, ‘thick’, ‘a bad reader’ due to her difficulties. The uncertainty of her identities before her identification of dyslexia was put to rest. However, as a newly qualified teacher, her difficulties were significant. These difficulties were incongruous to her new identity, as ‘even though’ she had completed teaching course, she still struggled with times tables. The temporal structure of Claire’s narrative is presented in the following diagram.

![Temporal structure of Claire’s narrative](image)

Figure 10: Temporal structure of this part of Claire’s narrative

The structure of this part of her story is mostly linear. Although her identification of dyslexia happened a number of years ago, through the present day evaluations she made she was able to relate this event to her current difficulties, which were incompatible to her identity as a teacher. Being identified with dyslexia is thus presented as an event which was significant to Claire’s self at the time of the interview.

Despite the obvious differences between the narratives in previous part of this chapter and Peter’s narrative of change (the content and time distance between the present
day told-story and the lived-life experiences and events), the temporal structures were very similar. They both told stories which followed the time frame of the lived-life. One event is told before another, possibly implying chronology and causality (Brockmeier, 2000). These chronological events were peppered with present tense and present day evaluations.

The two narratives presented here include present day evaluations of differences and current difficulties, as well as aspects of their identities that were directly related to the past changes and events that they talked about. In section 8.2, the present day evaluations made by the participants were to do with making sense of a recently changed or currently changing self. In contrast, the evaluations in this section concerned difficulties and differences which were directly related to the past changes which were still significant to their current self.

However, autobiographical narratives are not just about current and past changes that are currently significant for the self. There are inevitably changes that occurred in individuals’ pasts that are no longer significant for the present-self. There also may be times in an individual’s past where they have felt different, or been treated differently, but those differences may not be so important now.

8.4 Past change and non-self-significance in present

The participants also told me about changes that had happened in their lives a while ago and differences that they felt. Here I present three examples of narratives of change and difference that happened a long time ago. These narratives are about feeling different and being treated differently. They have different narrative structures from those presented in the previous two sections.

Hilary, a white woman in her 50s, teacher, had never been identified with dyslexia.

This interview was very short, lasting only 15 minutes. Here is an extract in which Hilary talked about her experiences in childhood.

Extract 1: Hilary

[I] went to the local primary school erm, thoroughly enjoyed school, but always enjoyed the social aspect of school more than the academic, was reasonably successful academically but nowhere near so much as my sister who was a linguist, well, she was just academic erm from a very early age, and as she went through education was
always top of her year in everything, until she got to university and then realised there were other people who were equally like-minded, but until then she’d never had a challenge erm

it was still grammar school erm set up when I went to school, and I actually did pass for grammar school but fortunately it was non-exam based, it was the first year that they did it through teacher assessment erm, which I think allowed me to actually get a place at grammar school then, I don’t think I would have done necessarily, I don’t know

my parents always expected my sister to go to grammar school without any qualms at all, prepared me very much that I might not erm, and that I might go to erm secondary school, which they would have been quite happy about, and I would have been happy about, it wouldn’t have been a problem, but it wasn’t necessarily an expectation that I would do as well to get to grammar school

Hilary presented her past-self as a social child and thus different from her sister, who was academic. Hilary was not expected to go to grammar school and only passed the examination due to changes in assessment practices. The family’s assurances that not getting into grammar school was ‘alright’ is in contrast to a more widely held opinion that not passing the test for grammar school is a sign of failure. Although Hilary passed the 11+, she downplayed it by stipulating that this was only due to the ‘teacher assessment’ rather than a test. Thus, her difference from her sister was presented as a fundamental identity position. Her sister also had a part to play in the part of the narrative presented below.

Extract 2: Hilary

erm managed to get O levels and A levels, probably got my A levels partly on the back of my sister’s work, just reading what she’d written, doing that, but I’d never had a- my problems are minor compared to a lot of people I suppose, but also I think, I worked out ways of coping, and it wasn’t until I went to college to do teaching, and I was particularly interested in helping and always right from the very beginning of wanting to teach wanted to help children who didn’t find learning easy erm, and it wasn’t until, so that was early 70s I was in college, and we started to look at dyslexia, and we started looking at sort of simple tests and simple sort of tricks of the trade then,
almost, of how you could erm decide if a person was dyslexic but I, in all the tests and things, came out as severely [dyslexic]

In extract 2, Hilary downplayed her ‘problems’ and any aspect of a struggle and the negativity which may accompany them. However, her utterance that she ‘coped’ with these difficulties conflicts with the idea that her problems were ‘minor’. Indeed, she recognised herself as dyslexic through the training she did to become a teacher. She did not have an official identification of dyslexia, but in the extract below she explained the impact dyslexia has had.

Extract 3: Hilary

I suppose dyslexia has almost moulded my work, my life actually in a sense, which I wouldn’t have expected to be, cos I never even knew it was there til early 20s erm it affects me in my work, I would say organisation is a problem, spelling is poor but not horrendous erm, and I think it’s been positive in that I’ve had to learn to look for things, look at things in different ways, so I’ve never seen it as a negative, I do wonder if I might have chosen other channels, but then I suppose everybody could have looked at other channels, I mean you make choices don’t you?

and they form where you go, so I’ve never done a lot, well I have recently, a couple of years ago did some post graduate study, and I would actually quite like to pursue that erm and do more, nearly did the dyslexia qualification actually, you know, the dyslexia modules, dyslexia action recently erm, and it is something I would consider doing erm, so I am sort of a dyslexic, I’m, I’m more of a dyslexic in thinking and attitudes, I don’t know that it’s affected my practise erm or achievement to that extent

Hilary constructed dyslexia as a big part of her life and work despite not being aware of it until early adulthood. She had difficulties at work, but these were not all bad and she presented herself as being adaptable through finding different ways to deal with them. She mentioned the possibility of following a different path, but aligned herself to people who could also have chosen different paths. She was therefore ‘normal’ in this sense. Her construction of being dyslexic only in ‘thinking and attitudes’ supports the notion that dyslexic identity is more than a learning difficulty.
As Figure 11, shows, Hilary’s narrative had a mostly linear structure, but with some reference to the present with a present day evaluation of her sister as more academic than her. She positioned herself as different from her sister and her peers, but this is not in a negative light. Hilary presented a counter-narrative (Andrews, 2002) that she may have been hurt or upset by the notion that her sister was more academic than her or that her parents did not expect her to get into a grammar school. She said that it was ‘fine’. She also gave a present day evaluation of her problems at the end of the story as ‘minor’. This meant that she could distance herself from people with major problems, and align herself more with those who did not have problems. Her only other deviance from a linear structure served to give historical context to her story by informing me of the year she was born, and therefore what year she went to school. Hilary’s narrative enabled her to position herself as close to ‘normal’ and ‘fine’ as she could, without negating her difficulties. Fred also presented himself and his childhood as ‘normal’.

Fred had never been officially identified with dyslexia. This part of narrative detailed his life from birth to the start of secondary school.

Extract 1: Fred

I would say we had quite a normal family, dad worked for the GPO, mom, can’t remember, mom might have been working at the garage as a cleaner? And mom, I
can’t, I don’t remember that, erm my sister (sister) was born when I was 7, so mom wouldn’t have been working then, and I think it was the same year I caught chicken pox off a friend at school whose name I can’t remember now, and I think I passed that on to granddad, but of course in an adult it’s shingles, and from then on granddad wasn’t very well, and I think he probably died within 12 months of that, (sister) certainly wasn’t very old erm so then there was the the 4 of us

but I think we had a fairly normal family life, went on holidays, we used to quite, quite often go down to my uncle, my mom’s brother, uncle (name) aunty (name) at Weston, cos they ran a erm boarding house, so that’s my memories of early holidays

In the extract above, Fred constructed himself as the child of a normal family whose parents were employed in normal, gendered, roles. His sister was born, but illness and death occurred, as they do in most families. Fred, his parents and sister took holidays as a ‘normal’ family would.

Extract 2: Fred

I think it was about that sort of time, I was coming towards the end of junior school the, mom and dad were very involved with the, well dad was involved with the parish council, mom was as she always, was involved with the WI and they both were involved in the village hall committee, building the village hall, we had a pig roast in the village, and I can remember helping setting those up erm, in the January before I moved to senior school the old school closed and moved into new buildings, and then I remember around that time I took the 11+ and passed and managed to get into grammar school erm, there were three of us from the village out of a class of about, dunno, 15, 20? If I remember rightly managed to get to grammar school (boy1), (boy2) and myself

His parents had prominent roles in the village, but this was not presented as unusual. The family helped provide a new hall for the village and Fred got into grammar school. Fred’s childhood was not uneventful, but the events are not presented as remarkable. Normality is the key to this narrative, which is presented visually below.
Figure 12: Temporal structure of Fred’s narrative.

Like Hilary, Fred’s narrative has a mainly linear structure. However, Fred made no references to the present day. There are no evaluations in this narrative, only a chronicle of the events that occurred in Fred’s childhood. He presented himself, his early life and family as ‘normal’. There were changes (moving house, sister being born, grandfather’s death, moving to secondary school), but these were not given any particular attention. The overall impression is that Fred’s early life and family were ‘ordinary’

Xander had recently completed a doctorate at the time of the interview and was starting a job very soon after the interview. This first extract is about the start of secondary school.

Extract 1: Xander

so yeah, got into the, got into the grammar school, was good, there were a couple of others went from my school erm, and that was that really kind of, primary school finished, did SATs, is that the one? yeah did SATs, did ok in them erm, and then went to, went to prim- went to secondary school and started there, and in in the first couple weeks of that they did erm, they did lots of well, not lots of tests, they did some tests to find out who were, who was struggling with different things like maths and English and er, they flagged me up as having trouble with English and er, they said, ‘we think this person’s dyslexic’, which was interesting because my brother’s dyslexic and he was
diagnosed when he was at primary school, and my parents knew that and they thought I was similar, but I don’t think they ever thought I was actually dyslexic, but they sent me off to get tests and turned out apparently I was dyslexic, not really badly, but was, so this was all interesting

In the above extract, Xander outlined his path from primary school to grammar school. The tests which led to him being identified with dyslexia were for all pupils. This part of the narrative was very descriptive, and the one evaluative aspect (‘my brother’s dyslexic…’) gave context to the story and some detail about the family context of dyslexia. The change for Xander here was twofold: his move from primary to secondary school and his identification of dyslexia. In the following extract, Xander talked about what happened next.

Extract 2: Xander

[I] was told that, that they offered extra support, so this was something I could go to, which meant coming out of lessons, normal lessons, and going for half an hour seeing someone that they brought in, what was her name? Mrs [name], that was the one erm, and we’d go and do exercises which I can barely remember now, but they were probably useful in some form or another

Xander outlined the consequences of being formally identified with dyslexia at school. A support teacher was ‘brought in’ to help Xander and others with their difficulties. In these two extracts Xander told a story with a relatively simple plot, where chronological events reflect causality in the told-story. The one evaluative aspect did not refer to emotions or Xander’s sense of self. The diagram below shows the temporal structure of Xander’s narrative.
There was a basic linear structure to this part of Xander’s narrative, but a present day evaluation, of his brother as dyslexic, gave some context to the storyworlds he was narrating. This was very different from the present day evaluations given in the narratives presented in the sections 8.2 and 8.3 of this chapter. Xander’s talk in this part of his story was based in the storyworlds of primary and secondary school, and the difference that he talked about meant that his past self is presented within those worlds as well, with no reference to the present. The move to the present was about his brother, and gave context to the story he is telling. This story, although relevant to his present self as someone with dyslexia, was not presented as currently self-significant.

8.5 Conclusion
When identities are changing at the time of the telling, the narrated life, or told story, becomes more complex. The narratives presented above are about change and difference in the told-stories of Claire, Simon, Natasha, Madison, Peter, Hilary, Fred and Xander. Although the events which are narrated in the section 8.2 (Claire, Simon, Natasha, Madison) were more recent that those narrated by participants in section 8.3 (Peter, Claire), the temporal structures of their narratives of change were similar due to the frequency of the present day evaluations they made about the experiences they told. The content of these evaluations were laden with emotional language and reference to the narrator’s identity. In contrast, the narratives in section 8.4 (Hilary, Fred, Xander) had very few evaluations and did not refer to emotion or identity. In addition, the structures of these final narratives were far simpler than those in the
sections 8.2 and 8.3. These differences in evaluative content and temporal structure suggest that the events and experiences narrated in section 8.4 were less self-significant than those which were narrated by participants in sections 8.2 and 8.3.

Common notions of historical time refer to it as a linear, continuous sequence of events (Freeman, 1998). King and Hicks (2007) refer to Piaget’s concepts of assimilation and accommodation in relation to how individuals react to and cope with change in their lives. In the narratives presented here, the changes narrated in the section 8.4 can be construed as having been accommodated into the self already. In contrast, those narratives of change and current self-significance can be construed as currently being assimilated.

The structure of the past narratives that were no longer self-significant, where the changes and differences were already accommodated, were more simple than those narratives which alluded to currently self-significant changes and differences that were being assimilated at the time of the interview. There was a general linear structure to the former narratives (Brockmeier, 2000). However, this kind of linear structure is not easily tellable (Brockmeier, 2000) and there are some inevitable temporal shifts, particularly in relation to the foregrounding or giving context to events and changes. However, these present day, or previous, evaluations are not self-significant, and therefore are easier to tell. Also, these are narratives of long ago events/changes, and as such, may have been narrated many times before, and so may become part of a repertoire of personal stories.

Stories which reflect experiences of dyslexia can be presented in a variety of ways. The extracts presented above show that impact of dyslexia on narrated identity can depend significantly on the events which are told. Individuals with dyslexia are employed in different jobs, have differing commitments and see their ‘diagnosis’ in different ways. The participants acknowledged that they were different and have told stories about change in relation to their dyslexia, or other areas of life. However, the self-significance of the events they narrated does not just reflect the temporal distance between the present day and the event.

It may be expected that talk about such distant events would be characterized by a linear temporal structure, as the speaker is chronicling their early life (Brockmeier,
2000). According to Freeman (1998), the traditional notion of reality as temporally ordered is thought of as a succession of continuous events, mirroring the idea that historical time is linear and irreversible. However, giving meaning to one’s life by telling it in a linear way does not seem to happen (Brockmeier, 2000). There are always features in autobiographical telling which do not suit this kind of telling (Brockmeier, 2000). This is seen in the diagrams above, where the linear chronicle is broken up with visits to earlier times and the present time. The two diagrams that are linear only represent small parts of the participants’ stories. However, the rest of their stories are not as simple.
Chapter 9: Discussion

9.1 Introduction
This thesis has investigated narrative constructions of the identities of 13 adults with dyslexia, whether they have been formally identified as ‘dyslexic’ or not. In order to collect data to study dyslexia and narrative identity, I conducted life story interviews with nine people who had a formal identification of dyslexia and four who did not, but who identified as dyslexic. Through studying how the participants constructed dyslexia, and analysing their narratives of change and difference, I have argued that dyslexia is constructed in a variety of ways, particularly as a reason and excuse, and that the change and difference associated with identifying as dyslexic has an impact on narrative identities. These life story interviews were supplemented by second interviews, comprised of a photo-elicitation interview and a semi-structured follow-up interview.

In my view, Ricœur’s (1984; 1994) theory of narrative is useful for analysis. In this study, it has allowed me to think through how dyslexia is understood by those who identify as dyslexic, how they make sense of their difficulties in the context of their lives and thus how they construct their selves and identities. To this end, Ricœur’s conceptualisation of time and narrative, and Davies and Harré’s (1990) positioning theory was generative for grasping how individuals who identify as dyslexic construct their identities, and past, present and possible-future selves.

These data were analysed in two ways. First, I used grounded theory to identify themes that cut across the participants’ stories and identify how they constructed dyslexia. Second, I used narrative analysis to investigate how the participants told their stories of dyslexia and negotiated their identities. I started from the question ‘what is this thing called dyslexia?’ to the end point ‘this is how dyslexia may influence narrative identities’. There are various themes which cut across this journey: change, for example, from not-dyslexic to dyslexic; difference and otherness, such as differences from peers; support, whether that be formal or informal; and the socio-historical context in which dyslexia was diagnosed and in which the interviews took place.
In this chapter I will discuss what I found in relation to previous research on dyslexia and disability in sections 9.2 and 9.3, focusing more on disability and dyslexia in the life story in section 9.3. In section 9.4 I discuss ‘storyworld’ and how it has been useful in this study. I conclude the chapter and thesis in section 9.5, as well as commenting on potential future research.

9.2 Dyslexia

In this study I focus on adults from a range of backgrounds, nine of whom have an official identification of dyslexia and four who self-identified as dyslexic. In chapter 6 I argued that dyslexia is a multi-faceted part of life for these participants. They construct it as representing medical discourses, problems, reasons and excuses. In contrast, most research about the experiences of adults with dyslexia have focused on specific groups of people: Glazzard and Dale’s (2013) study on trainee teachers, Morris and Turnbull’s (2007) study on student nurses, Skinner’s (2001) work on mothers, and MacDonald’s (2009) work on prisoners are some of them.

9.2.1 Dyslexia as a medical concept

In the literature, dyslexia is both medicalised (Campbell, 2013) and considered a disability (Collinson, 2014). The participants in this study drew on these discourses of dyslexia in their talk. Chapter 4 developed the argument that dyslexia can be considered a disability and that it has similarities to disabilities and illnesses, e.g. myalgic encephalomyelitis (ME) and chronic pain. These similarities include the nomenclature of the conditions, as dyslexia is also known as a Specific Learning Difficulty (SpLD) which has a less ‘medical’ connotation, whilst ME is also known as chronic fatigue syndrome (CFS), a term which also sounds less ‘medical’ than the former. The bio-medical aspects of a ‘diagnosis’ of dyslexia were welcomed by some participants, but caution was evident, and disclosure was a carefully considered process.

In this study, the participants ‘othered’ themselves from the mainstream due to their perceived differences, by drawing on their differences from those around them and their perceptions of ‘normality’, and through constructing ‘different’ identities, in both positive and negative ways. Literature tells us that people with dyslexia are ‘othered’ by the social norms of literacy (McPhail and Freeman, 2005; Collinson et al, 2011). The participants in this study were different for many reasons: the multi-faceted nature of
dyslexia as they constructed it meant that their differences varied, but the overall difficulties they encountered were medicalised by the label ‘dyslexia’.

9.2.2 Labelling and disability
In the present study, dyslexia was sometimes constructed in terms of empowerment, ending uncertainty, and as leading to helpful next steps and treatment, and regaining credibility and legitimacy, as shown in chapter 6. A formal identification of dyslexia helped preserve self-esteem, protected the individual from stigma and led to understanding and sympathy. Huibers and Wesseley (2006), in their study of CFS, noted similar findings. However, given the controversy over dyslexia, there are other outcomes, and some of these participants constructed their present and future selves as at risk from a dyslexic identity, from those around them perceiving it as an excuse, and thus as a barrier to work or study.

Riddick (2000) gives a list of seven aspects of labelling, as outlined in chapter 4, one of which is the context in which the label is given. The storyworlds in the participants’ narratives were constructions of lived-life events, some of which detailed their labelling/diagnosis experience which occurred in difficult contexts, such as school (Xander, Ellie); university (Madison, Rose, Simon, Claire, Peter, Hilary, Jacob); work (Andy); courses (Natasha). However, there were also storyworlds in which dyslexia was constructed as a key part of the story’s context. These were identity construction moments. For example, Ellie’s storyworlds in which she presents identities of a good student, a good reader, not a confident reader, self-deprecating, a bad decoder, a hard worker, a possible hairdresser, a fighter. The protagonist – the self doing the telling the narrative – exists in different storyworlds which construct different versions of ‘dyslexic’ Ellie.

9.2.3 Constructions of dyslexia and identity
In Charmaz’s (1994) study, the men’s identity dilemmas result from the loss of various aspects they considered valuable in their lives, such as social roles, physical functions, leisure activities and understanding of self. In contrast, I found the participants in this study did not have the same kinds of experiences. This is unsurprising given the differences between dyslexia and chronic illness and serves to accentuate the contextual nature of identity construction in individuals with illness and disabilities. Although the identity dilemmas of the chronically ill men in Charmaz’s (1994) study are
particular to them, the idea that different views, perceptions and meanings of illness impact differently on identities is pertinent for the findings of this study. In the present study, some of the participants considered their ‘dyslexic’ identities in terms of how they would be perceived. Dyslexia was constructed as a difficulty, as a medical condition or disability, as something to be battled, as a SEN, as something that can be supported; and as a reason and excuse for literacy problems.

In my view, the discursive construction of dyslexic identities has an impact on identity constructions, which are mediated by disclosure decisions, in turn influenced by how the individual constructs dyslexia. The circular connection between what dyslexia means to these individuals, what they decide to do with that knowledge and their diagnosis, and how they constructed their identities and narrated their selves, is a key part of the findings of this research. In Morris and Turnbull’s (2007) work on student nurses with dyslexia, they found that decisions about disclosure were difficult due to stigma and perceived reactions of work colleagues and managers. Similarly, Evans (2013) found that most student nurses in his study rejected medical discourses of dyslexia and did not disclose due to possible misunderstandings. In this study, those participants who discussed disclosing their dyslexia did so in relation to the implications for identities, such as being ‘dyslexic’ before ‘a good teacher’, or being ‘stupid’ before ‘legitimately dyslexic’.

The participants’ possible future selves were constructed in terms of the outcomes of those kinds of decisions. Indeed, for some, their present selves were negotiated in relation to past decisions, for example Claire’s failed attempts to get a teaching job, and thus not having a ‘teacher’ identity, were explained through her decisions to be formally identified with dyslexia and to disclose this new dyslexic identity on application forms.

9.2.4 Morality
The analysis of the data has shown that whilst these participants did not explicitly construct themselves as ‘disabled’; they did draw on medical discourses of dyslexia which were not only used to accentuate their difficulties but to support their claim for support/help. Their claims for support rested on the idea of dyslexia as a legitimate condition, which is a contentious postulation. In chapter 4 and the sections above
discussed constructions of dyslexia as a disability. One prevailing aspect of dyslexia is the notion of dyslexic as separate from ‘lazy’ or ‘stupid’ (Campbell, 2013). This thesis has conceptualised dyslexia, and the various aspects attached to it, as a moral event, and decisions regarding disclosure as morally significant. In Campbell’s (2013) work, the idea that dyslexia negates laziness and stupidity has moral implications. Rather than the concepts of ‘good’ and ‘evil’, morality in this sense concerns the extent to which an individual deserves understanding, support, and a label like dyslexia. In my view, this has been an important part of the findings of this research, particularly in terms of Taylor’s (1989) view of the self as narrated within questions of ethics and morality.

One key aspect of a diagnosis of dyslexia is that it protects the self from any accusations that an individual is lazy or stupid (Campbell, 2013), something which the participants in this study noted. However, as discussed in chapter 4, dyslexia is a contested condition, which has proponents and opponents. Chapter 6 found that some of the participants in this study considered the complexities of being identified with such a disputed condition, through the dimensions of reason and excuse. When dyslexia is a reason, a medical discourse legitimises their difficulties, in contrast, when dyslexia is an excuse, there is no legitimate explanation for difficulties which are the result of laziness or stupidity. This distinction and the slipperiness of the boundaries makes disclosure - risky in terms of being perceived as ‘undeserving’ of the diagnosis, label, or support. In this sense, morality is important for a dyslexic identity position and constructions of the self.

Important identity positions, such as worker, were mediated through the moral position of dyslexia. The participants distanced themselves from the negative identities associated with the undeserving, whilst acknowledging the potential that those around them may position them as such. The construction of dyslexia in a dichotomy of excuse and reason puts the self in a dilemma – to disclose or not? Thus, disclosure is a complex decision, negotiated with reference to potential identities, drawing on past, present and future selves.

I thought that the participants’ decisions to disclose in the workplace would be the key part of their narratives, but there were other disclosure decisions that were of
concern: to university staff, to friends, to peers, as well as to potential employers. Disclosure was considered an important, yet contextual, decision. Collinson (2014) uses two thought experiments about dyslexics going back to the 17th century in a time machine to argue that the relationship between the norms of literacy and their dyslexic (different) bodies that effects the extent to which they face difficulties. The context in which one ‘is’ dyslexic influences the extent to which dyslexia is considered an excuse or a reason, is disclosed or concealed, and therefore identity positions and self constructions. In the literature, illness and disability has been constructed as a moral event, with shame, blame and stigma attached to them (Werner et al, 2004; Horton-Salway, 2001a). The findings of the present study have shown that morality is also invested in dyslexia and thus the identities of those who are identify as dyslexic.

9.3 Dyslexia in the life story
The participants’ constructions of dyslexia were made within wider narratives of their lives. The methods used meant that the narratives presented within this thesis were often about more than dyslexia and their difficulties. Most of the participants talked about school and work and how dyslexia was important or not in those contexts, and some talked about other aspects of their lives, such as their romantic relationships, family life, and hobbies. Robinson (1990) reported that sufferers of MS emphasised the positive aspects of their lives. The participants in this research did not always do that, but by talking about other aspects of their lives they may have been drawing attention away from any negativity associated with dyslexia and a dyslexic identity. Alternatively, they may have been adhering to my request of telling me about their lives. Either way, the life narratives allow study of more than a ‘dyslexic identity’.

As discussed above in section 9.2, the participants in the present study imbued their constructions of dyslexia with legitimacy and eschewed the conceptualisation of dyslexia as an excuse for their problems. Riessman (1990) found that her case study participant Burt emphasised the non-ill aspects of his self (as a father, husband); and any problems in his life were a direct result of his impairment. In this study, Claire, Rose, Ellie, and others emphasised ‘good’, ‘positive’ identity positions, negating the risks associated with dyslexia.
9.3.1 Narrative of dyslexia, disability, illness

Illness is a biographical disruption (Bury, 1982) and turning points are useful in the study of illness narratives (Holland and Thomson, 2009; Cuhna, 2011). The orientation (Labov and Waletzky, 1997) of narratives in McNulty’s (2003) work were early school experiences (like the context/place/time of the storyworld) where something was ‘wrong’. The complicating action, or turning point in Holland and Thompson (2009) and Cunha et al’s (2011) terms, for them was the testing and diagnosis of dyslexia. For some of the participants in this study this was similar, like Rose, Natasha and Madison, but not all. Some did not want the testing/diagnosis, like Fred and Danny. For some, the complicating action was a recent event, like Ellie’s talk with the head of research at her university about having extra time to complete her doctoral studies.

A prevalent concept in the study of identity and self and disability is ‘loss of self’ (Charmaz, 1983; Horton-Salway, 2001a; Thomas, 2008). The maintenance of previous identities is very difficult, which for many illness or disability diagnoses is problematic (Charmaz, 1983; 1984). Narratives provide sense-making opportunities, incorporating diagnosis and change into life histories. It is important to maintain narrative consistency to rebuild the self after a disruption like a diagnosis (Werner et al, 2004; Whitehead, 2006). In the present study a diagnosis of dyslexia was often a positive thing, and the new identities that it brought were helpful in negating any deleterious reactions to their past undiagnosed difficulties. This is connected to the arguments I made in section 9.2. For example, Natasha was not ‘dizzy’ anymore because she now has a ‘condition’. Thus, the stories that Natasha and some of the other participants told constructed their past-selves as moving on to new identities and constructing present and future-selves with these new identities in tow.

Many of the diagnosis turning points were in past storyworlds, but there were various changes in the participants’ storyworlds that were not diagnosis stories, some of which were related to their dyslexia, and some which were not. For some of the participants, the storyworlds with these kinds of turning points were in the present. Ellie’s recent storyworld of change was one where narrative disruption was evident, and where she constructed her present-self as different from a past-self. In the present storyworld of the interview she negotiated her dyslexic identity vis-à-vis her new circumstances which were the result of recent interactions.
According to Watson (2002), narrative telling involving impairment in identity normalises the impairment. Dyslexia was a problem for both Ellie and Rose in the present and they narratively constructed their past and present selves as ‘other’. However, they also constructed ‘normal’ identities within some of their storyworlds. Whitehead (2006) found that by reconstructing lives to fit with a new diagnosis of CFS, it is possible to develop new, positive self-identities.

9.4 Storyworld
The storyworld concept has been fruitful in showing the temporal structures of participants’ narratives. Their present, past, and future identity positions were analysed within storyworlds, which described the turning points they experienced in their lived-lives. The evaluations of these turning points were analysed to see how the narrators constructed their past, present, and future-selves, particularly in relation to change. In this thesis, the concept of storyworld has been introduced on two fronts, methodologically and theoretically, and will be evaluated in the following paragraphs.

In constructing diagrams to represent the storyworlds of the participants’ narratives, I was able to literally ‘see’ the plots of the stories, and both the lived-life and the told-story. Taking the theoretical grounding of this thesis, a storyworld diagram should allow one to visualise a narrator’s life, and thus their self. This is, of course, too simplistic and does not do justice to the complexity of notions of ‘self’ and ‘identity’. However, the diagrams in chapter 8 were useful for showing an overview of the narrator’s life, or that part of the life that was the subject of the analysis.

Storyworld allowed me to consider situated identities in terms of changing life circumstances and temporally changing selves, which were represented in each storyworld. The evaluations of the lived-life (bounded storyworld) were present-day constructions of past identity positions and past-selves. Analysing them enabled me to see how the changes were significant to past, present, and future-selves. The past, present and future can all be represented in a storyworld diagram. This is important with regard to notion that narrative telling constructs multiple selves across time. Storyworld allows ‘time’ to be considered in the analysis. The lived-life can be visualised in relation to the told-story in a new way.
In particular, the storyworld diagrams were useful for showing when the narrator engaged in evaluating aspects of the events they were describing in relation to the rest of their evaluations and the lived-events across the rest of their story. The analysis of the participants’ evaluations was an important part of this study and combining analyses of their evaluations with analyses of the emplotment of their stories was beneficial. I think in future studies that use this concept the presentation of any storyworld diagrams needs to be carefully considered, particularly in terms of the ordering of the analysis. In chapter 8, the extracts and analyses of the extracts were presented before the storyworld diagram. This made sense in the context of that chapter, however, further developments may warrant the presentation of data and storyworlds to be different.

Storyworld cannot be used as an end unto itself and needs to be considered within a theoretical framework. As argued in chapters 2 and 5, this way of displaying parts of narratives could be useful for a multitude of theories in the social sciences. However, this may be too complex and may make any development of storyworld difficult because the separation of method and theory could detract from its potential for theoretical novelty. That is to say, any use of storyworld to merely represent data without the use of theories of narrative and time, would hinder the theoretical development of the concept.

I have two more concerns about using storyworld diagrams. First, the occasional difficulty to name a particular storyworld in 1 – 3 words, for example on page 194 of the present thesis, Natasha’s ‘cheese’ story needed to be explained in a footnote. Second, the fact that a storyworld does not represent time accurately means could be detrimental to its relationship with theories of narrative and time. More importantly, however, the storyworld concept needs further theoretical grounding. As discussed in chapter 2, I believe what the field of narrative inquiry has gained from recent studies of small stories and genres has resulted in a loss of the key aspect of narrative: that is its temporality. Storyworld, as used in this study, aims to re-establish the temporal aspect of narrative into analysis, and so doing, to create a theoretically informed method to analyse selves and identities.
9.5 Conclusion
In this thesis I aimed to study how adults who identify as dyslexic construct dyslexia, and how they construct their dyslexic identities. In section 9.2 I discussed the analysis for the first aim in relation to previous research on how dyslexia is constructed and identity constructions. There is not a generic dyslexic identity, but an individual’s dyslexic identity is complex and negotiated through constructions of dyslexia mediated by excuse/reason dichotomy, morality, and disclosure. The interactions between dyslexic identity, disclosure decisions, and constructions of dyslexia are complex and central to understanding dyslexia as a moral event.

In terms of identities, in their storyworlds the participants distanced their past, present, and future selves from negative identity positions, but sometimes kept their ‘otherness’ in their identity positions. There are those who distance themselves from dyslexia; it is an aspect, but their tales of it are not self-significant. Some participants spoke very little of dyslexia until I asked explicitly. All of them talked about more than their dyslexia, and some of their storyworlds were analysed in chapter 8. Different kinds of turning points and life changes were analysed and I found that some were significant to the present-self of the interview storyworld and some were not, and that did not depend on when the lived-event took place as much as it depended on the evaluations of the lived-events and the structure of the storyworlds within the narrative. Wengraf may call this the telling-of-the-told-story.

Due to the constructions of dyslexia as a potential excuse, yet a positive reason, and as a moral event, it has many identity aspects. Some participants in this study positioned their identities in terms of difference, ‘otherness’, capability, and incapability. They were students, workers, teachers, and unemployed. They were mothers, daughters, sons and brothers. They were sometimes dyslexic, and sometimes not. However, being identified with dyslexia was a change in self to a certain extent, as past-selves, before dyslexia, were different from present- and future-selves. In addition, those who were not formally identified with dyslexia constructed potential future-selves identified with dyslexia as different from their present-selves. These self-constructions were shaped by disclosure decisions and the reason/excuse dichotomy.
The questions asked in the interviews elicited stories about the participants’ lives, very often commencing in childhood, particularly at school. The majority of those who had been diagnosed with dyslexia talked about their diagnosis in their life story in interview one. Those who did not were asked to talk about it in the second interview. Dyslexia is a peculiar disability as discussed in chapter 4, and its peculiarities have been brought out in the findings of this research. The impact of formal identification of dyslexia on these participants was complex, where issues of morality, disclosure, and risk interface with identity positioning and self-construction.

9.5.1 Policy and practice implications
There are several features of this thesis that I think are pertinent to policy and practice. The first two are related. The fact that an assessment for dyslexia costs money was highlighted as a problem by some of the participants. Andy, Natasha, Jacob and Madison had to think carefully about the monetary costs and possible benefits of being formally assessed. Although support came as a result of a formal identification of dyslexia, for some this was superfluous. They were already using computers and calculators to manage at work and in education. Peter made a decision not to get a formal assessment, which was linked to his fear of disclosing his difficulties. The participants’ talk about disclosure is the second matter that needs to be considered within policy and practice.

After an assessor has confirmed dyslexia, the individual needs to make a decision about who to tell. It seems that the label of dyslexia is no better than not having a label at all, a finding corroborated by Riddick (1996). Some participants stated that people perceive literacy difficulties and dyslexia negatively. Being identified with dyslexia does not mean an end to stigma. Individuals with dyslexia need to make decisions about disclosing their dyslexia and thus their difficulties. If an individual fears people’s reactions, they may hide it and may not get formal support.

Third, the stories that these individuals tell may be important. Their evaluations of particular events may give practitioners an idea of what changes are important. Practitioners should understand that changes that are significant at the moment might not be the most recent things that have happened to them. Experiences of dyslexia are more than difficulties with reading and writing. The experience of coping with
expectations and reactions to their dyslexia and its associated difficulties formed significant parts of the participants’ stories.

9.5.2 Future research
There is more to be done on the use of narrative methods within psychological and social research. I think that the novel concept of storyworld is the continuation of debates within the field. As noted in section 9.4, it will need development as a methodological tool and analytical concept. In addition, the theoretical impact needs work and thorough testing in different research areas. I strongly believe in the use of temporal/structural analysis of narrative in psychological research. Further research could expand these methodological questions, whilst possibly providing fruitful findings in relation to the construction of identities, particularly in the field of disability studies. For those more interested in disability and dyslexia studies, further research needs to be carried out on the importance of disclosure decisions to present and future selves, particularly in terms of risk and what it means to identify as dyslexic in particular contexts.
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Appendices

Participant Information Form

You are being invited to take part in a research study. Before you agree to take part it is important that you understand why the research is being done and what taking part will involve. Please read the following information about the study carefully. Feel free to talk to others about the study. If you have any questions about the study please feel free to contact me on 02920 874 436 or at HortonKL@cardiff.ac.uk.

What is the research about and why is it being done?

Most research about dyslexia looks at children, but there are very few studies that take the views of adults with dyslexia into consideration. Also, I am aware that there are many adults who have reading and writing difficulties that are very similar to the symptoms of dyslexia, but who have not been diagnosed with dyslexia. I am interested in the views of adults who have dyslexia, as well as those who think they may have dyslexia but have not been diagnosed.

Who can take part?

Any one over the age of sixteen who has been diagnosed with dyslexia, who thinks they may be dyslexic or who has experienced difficulties with reading and writing.

What is involved?

Your participation will involve two face to face conversations. I will ask you to tell me about your experiences with dyslexia or the difficulties that you have with reading and writing in both meetings. This will involve you telling me your story, with very few questions from me. In the second meeting I will give you some pictures to look at and ask you about them. I will also ask you to discuss some of the things you talked about in the first interview.

Where and when is the research happening?

The interviews will happen at a time and place convenient to you. This can be organised as soon as you have given your consent to take part.

How is the information recorded? What happens to it?

Our conversations will be recorded on a digital voice recorder and a transcription (a written copy) will be made of them. The audio recordings and hard copies will be kept securely and will only be seen by the researcher and her two supervisors. You are quite welcome to listen to the recording and look at the transcript. Any part of it that you do not wish to be included in the findings will be removed at your request.

The information that you provide will be used for three things: I will analyse the information and use it in my PhD thesis; I will publish the information in academic research articles and conference presentations, and I will write a summary report to be circulated to all interested participants or other interested parties.
Confidentiality and anonymity

Only you, my supervisors and I will have access to the information you provide. All recordings and transcripts will be anonymised. This means that your name will not appear anywhere on the transcripts or recordings and pseudonyms (false names) will be used throughout my research and any publications that arise from it.

Can I withdraw?

If at any time you decide that you do not wish to take part in the study, you are welcome to withdraw with no questions asked. Just send me an email, write to me at the address below or call me to let me know that you do not wish to take part. I will then remove all recordings and transcripts of the interviews you participated in from the research.

Who is the researcher? Who is funding the research?

The researcher is Kim Horton, a PhD student at Cardiff University School of Social Sciences. The research is funded by the Economic and Social Research Council. You can contact me in the following ways:

Email: HortonKL@cardiff.ac.uk

Phone: 02920 874 436

Post:

Cardiff University School of Social Sciences
1 - 3 Museum Place
Cardiff
CF10 3BD

If you would like to take part in this study, please complete the consent form on the next page and return it to me.
Please read the following statements and initial the box next to them to confirm you agree with them.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Please initial</th>
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<tbody>
<tr>
<td>I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.</td>
<td></td>
</tr>
<tr>
<td>I understand that I will be offered a copy of my interview transcript and provided with the opportunity to take out or amend any part of it that I do not wish to be reported in the findings.</td>
<td></td>
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<tr>
<td>I understand that the data from this research will be used in the following ways:</td>
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<td>• A PhD thesis</td>
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<td>• Academic research papers and presentations</td>
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<tr>
<td>• A summary report to be circulated to all interested participants or other interested parties.</td>
<td></td>
</tr>
<tr>
<td>I understand that my participation in this study is voluntary and that I may withdraw from the study at any time.</td>
<td></td>
</tr>
<tr>
<td>I agree to take part in the study.</td>
<td></td>
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</table>

_______________________  ___________  ____________________  
Name of participant  Date  Signature
Cardiff University School of Social Sciences
1-3 Museum Place
Cardiff
CF10 3BD

22nd November 2010

Dear Sir/Madam,

I am a doctoral research student at the School of Social Sciences at Cardiff University. My research interests are reading and writing difficulties, dyslexia and identity. I am about to embark on research to investigate reading and writing difficulties and how they relate to identity.

I am contacting your institution because I believe that you would be interested in such work. In addition, I would like to interview some of your clients who have difficulties with reading and writing.

Please find enclosed an information sheet about the study. If you believe that any of your clients would like to take part in this study, please support them to read the enclosed information sheets and get them to contact me.

I would also be grateful to receive your thoughts on this study and I would be willing to provide your institution with information about the findings in due course.

Thank you for your time and I look forward to hearing from you.

Yours faithfully,

Kimberley Horton

HortonKL@cardiff.ac.uk

02920874436
Thank you for your participation.

I would like to take the opportunity to thank you for your time and commitment to this project. Your participation is appreciated.

I will use your stories and responses to help me write my doctoral thesis. They may also be published in journal articles and spoken about in presentations. If you have any further questions about this, please feel free to contact me on the telephone number or email address below.

You are invited to receive a report of the study’s findings. If you would like to receive the report, please give your address or email address to me and I will ensure that you receive a copy.

If you feel you would like to withdraw from the study please let me know and I will remove your responses from my research.

Below I have provided contact details for organizations that may be of interest to you.

Once again, thanks for your time.

Kim Horton
PhD student
School of Social Sciences
Cardiff University
1-3 Museum Place
Cardiff
CF10 3DB

029020874436

HortonKL@cf.ac.uk

The British Dyslexia Association
www.bdadyslexia.org.uk
0845 251 9002
Do you struggle to read and write?

My name is Kim Horton and I am a researcher at Cardiff University.

I am interested in adult dyslexics’ views of dyslexia. I am also interested in the views of adults who struggle to read and write.

If you would like to take part in this study, please contact me and I will provide you with further information.

Contact details:
Cardiff University
School of Social Sciences
1-3 Museum Place
Cardiff
CF10 3BD

HortonKL@cardiff.ac.uk
02920 874 436
Interview guide

I will explain to the participant that I will not interrupt what they are saying; I will let them tell their story, as they want to.

Interview 1

Ask generic question about what they are doing at the moment.

*Can you tell me about your life in your own words?*

*Just start where you feel comfortable.*

Interview 2

*I am going to show you some pictures now. I would just like you to talk about them.* (I will show the pictures one at a time.)

*What do you think is happening in this picture?* (for each picture)

*How does that relate to your experience?*

The previous time we met you said that….can you tell me more about that? (for a number of themes)
Appendix

Images used in Interview 2

Image 1
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Image 2
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Image 3
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Image 4

© Kimberley Horton 2011

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Image 9
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Image 10
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Ellie

K  erm and I would just like you to tell me about your life in as much as detail as you want say as much as you want say as little as you want start wherever you feel comfortable if you really struggle I’ll give you some prompts erm just talk as much as you would like to

E  ok erm well I was born in London moved to Bristol when I was 4 or 5 so I did all of my schooling until I was 18 in Bristol at 18 I went to university and I did that in Birmingham so I did three years in Birmingham I got on to the civil service graduate fast stream and moved to Cardiff was based in Cardiff for 7 years but for 3 years of that I was in Brussels working with the FCO and then I had my son during that time so when I came back from Brussels I was pregnant I had a son continued working for the assembly for about a year and a half two years took redundancy from there then moved to Birmingham to retrain as a teacher so I did a PGCE in secondary citizenship decided that wasn’t really going to work for me and my son so I’ve currently got a studentship and doing a PhD in Lincoln to do with Gypsy Roma traveller education so that’s kind of where I’ve been so quite a lot of that has involved education although I have also worked erm so that’s kind of a basic overview but London I don’t really remember much about when I was in Bristol went (name) infant and (name) junior school in (place) and (place) comprehensive school and that’s where I did my sixth form as well and we did what did we do what did I do? Then oh the names changed to (place) enterprise college erm to do with dyslexia I was diagnosed with dyslexia when I was 7 which is quite young but my mum is a trained teacher and while she was at university she did some modules on dyslexia so she picked up on my symptoms quite quickly

K  mm

E  erm as well as going my school didn’t recognise dyslexia at that time so my parents had to pay for me to come out of school and go to one morning a week I used to go to Bath to the dyslexic institute I think it’s the one that used to be in the circus in Bath and that was when I started to learn to be able to do some reading and writing and did that all the way through my junior school so from when I was seven to when I was eleven when I went to secondary school then it I had a really supportive English teacher so my parents didn’t carry on with the dyslexia institute that was the one in Bath just before I was doing my GCSEs I did a intense evening sessions with the dyslexia association in Bristol the people I saw in bath were really helpful and they definitely taught me some skills I can remember what I used to do in the lessons we used to go in and the first thing I would have to do was finish the thing I had done the week before and I’d have had to have read a text onto a Dictaphone which would have been a tape recorded Dictaphone and then I’d go in the next week and I would have to write it all out and then she’d get me to write sentences about something and I can remember a rule was that a sentence was only a sentence if it had more than 7 words in it cos my sentences were never 7 words when I was seven I thought that was far too many words

K  mm
when I was in junior school my mum and dad had to fight quite hard for me to stay in my class cos my parents would say she needs extra help with this that or the other and within our school there was special unit and the head teacher was like well if she needs all this extra help then she needs to go into the unit and my mum was quite against me going into the unit she was like she doesn't need to go into the unit erm so I didn’t go into the unit which was quite good erm so by the time I went to secondary school I didn’t know my alphabet so I couldn’t do my alphabet I’m still not really I know my alphabet but if you asked me where ‘q’ comes what comes which kind of 5 letters come before and 5 letters after I have no idea I have to start at ‘a’ and go all the way to when I get to ‘q’ (laughs) some at the beginning and some at the end I’m ok with but the middle ones I’ve got not the foggiest (laughs) where they are so when it comes to now when I’m in a library and it’s with a system that’s got an alphabetised system I will go through and I will go abcdefghijklmnopqR R I’ve found R then I’ll have to do it for the next digit and the next digit (laughs)

and I have to say it out loud cos I can’t do it in my head (laughs) so I’m forever in libraries going abcdefghijklm erm I’m noticed I was doing it I do at work now so yesterday I was having I was filing all my journal articles I had out and I was trying to get them into alphabetical order before I put them in my filing cabinet cos that’s how I’ve organised the filing cabinet which seems a bit daft as I don’t know my alphabet but it’s an alphabetised (laughs) filing cabinet out of my own choice but that did seem like the easiest way to sort my journal articles cos doing it by what areas they’re in a stuff would just be a complete nightmare because a lot of them cross over so the alphabet is still the easiest way for me to do things and I do use it out of choice erm but yeah I realised I was in my room yesterday going through the alphabet and saying it all out loud which some people must thing what? Why is she saying the alphabet out loud all the time? For about 10 minutes (laughs)

so there are still things I have difficulty with although I can obviously write really well so they tell when I hand work in erm so that so when I went to secondary school I obviously didn’t have my alphabet I wasn’t a confident reader erm I’m still I would say I’m a good reader and I read a lot but when I have ed psych reports done so when I had the last one done I was about 25 no I must have been a bit older 26 or 27 (child) was born and I know it was brought up that my decoding ability is minimal from I would have thought I was quite a good reader I’m obviously not as good as I think it takes me a long time to read things

so if you were given an article and I was given an article I would get exactly the same out of it at the end if not a bit more because I’m quite good at reading articles but it would take me a bloody long time to read it
so everything like that I just realise is an extra bit of hard work erm and it just takes a little bit longer but it makes it all worthwhile I think when you haven't been able to do something you really value it so I can remember watching my friends read a book like Charlotte's Web or something like that when I was in junior school I still haven't read that I'm I may get to read it one day but I do I could have just looked at the book and know I just knew without even looking at the words inside it that that would just never be something that I I could never sit down and read a book for pleasure

now I can and it is what I do I really love reading books it's just amazing what words what as a what a whole different world you can go into with words and when you're young and you know that you're excluded from that that's really quite hard erm and you kind of self exclude yourself from lots of things so I remember that I always thought that I'd have to be a hairdresser I hate hair I'm useless with hair it's really not my forte in life but when I realised that actually I could get on top of this and I would be able to deal with words and I would be able to read I was just so excited I wouldn't have to be a hairdresser so I'm not a hairdresser my best friend is and she loves being a hairdresser nothing against hairdressers erm but so my reading wasn't that great but my writing was a lot worse so when it came to my GCSEs erm I couldn't read and write very much at all I think I was getting level 2s and 3s I don't I think that's like what you're expected to get in year 2 and 3 of school so when you're 6 and 7 and 8 erm I couldn't do sentences still or paragraphs but I can remember I had to have 5 pieces of coursework for English everybody else over the course of the 2 years did about 20 pieces of work my English teacher I had from year 7 to year 11 and he told me you're never going to get 20 pieces of work done in say English language I got A*s in all the stuff that was verbally assessed erm but my written work was all Ds which somehow it measured out so I got Cs in both my English GCSEs so that was what I had to have I just did 5 pieces of coursework

[Interuption by son]

erm so the discrepancy between my grades I was getting at GCSE was quite dramatic and luckily my teacher just made me do 5 pieces of coursework and I can remember sitting at home erm one was that I had to make a book along the lines of the Jolly Postman so it was to do with rhyming patterns and a story that was for infant school aged children and I can remember when I was doing my homework at home how I used to have to sit with my mum we were on a semi-circular table and she never did my work for me but she used to make sure I stayed there and I kept concentrating and I kept going and one of the other things that we did at with we decided that my French GCSE I was doing and my DT GCSE I was doing weren't so important I needed my English GCSEs to go on to do A levels so that meant that I didn't do any work for DT or any work for French which is obviously disappointing as I have no French or DT skills (laughs) but I do have my English GCSE which has allowed me to keep going (laughs) in education so that was very important so I got my GCSEs I was very shocked oh I was so excited when I got my English GCSEs I
remember my best friend’s mum cried cos she was so excited that I’d got my English GCSE (laughs) my mum didn’t cry she’s not a softie like that (laughs) but my best friend’s mum did cry and if my head of English if that English teacher had been staying on he was the head of English at the school the whole time I was there Mr(man) if he’d stayed on then I would have done English lit for A level definitely because he just knew how to teach me and he made English so interesting even though the books he chose were regularly so boring Sherlock Holmes really I wasn’t interested in Sherlock Holmes in the slightest but that’s what he chose for me but Hamlet is still one of my favourite Shakespeare plays and the Catcher in the Rye is still one of my favourite books and they are books that he introduced me to

and when I’m reading it cos I re-read Catcher in the Rye I remember exactly what he used to say in lessons and so much of it now makes sense which really didn’t when I was 14 15 sat in his English lessons (laughs) erm so I owe a lot to Mr(Man) he was an absolutely fantastic teacher I got in touch with him last year actually told him what I was doing and thanking him and saying that without him there was no way I would have had the life chances that I’ve had because without an English GCSE really there is not that many options open to you and being dyslexic getting an English GCSE is bloody hard work erm I did sociology and psychology A level and at that point Mr(Man) had prepped the head of sixth form that I’d need support and I used to see the head of sixth form everyday and he used to ask me what lessons I had and what times they were you’re obviously tied into a you have free time that you have to start using appropriately and organisation has always been one of my crap things so in my bedroom always a disaster it has been all my life erm my desk is always a disaster I do now always know where everything is but organisation was always one of the bits to do with dyslexia that I’ve always had problems with as well erm so he used to be my organiser he used to say you’ve got this to do today he also taught me for both my A levels so he did know what I was meant to be doing and when and erm so he used to tell me you’ve got a free period then that free period you can mess about with your friends in that free period you’re going to sit down and you’re going to be doing this work and he used to my whole timetable so that it was he used to do it for the evenings and the nights this is when you’re going out (laughs) this is when you’re at work (laughs) this block here this is where you’re doing some work on sixth form stuff (laughs) so he did and again like Mr(Man) Mr(Man2) got me through my A levels and made sure that I left with grades that meant I could to university erm and that was fine didn’t really have any problems erm I’d developed enough skills to be able to work out what I was doing erm and then I got a place on a MA at Warwick that was going fine but got appendicitis and was off from the October all the way through to December which obviously when you’re doing an MA in a year is a bit of a nightmare (laughs)
erm so at that point I had arranged to go part time on my MA in the January I got on to the Civil service fast stream and decided that actually having employment and a good job my MA had to come a distance 2nd to that so I moved Cardiff and started working and again no enjoyed my job so the first job I had was working in HR did stuff to do with equality so it was about changing the team I was working with so that they were in line with European regulations so sexual equality gender equality race religion disability and there's a sixth one I've forgotten what it is right now erm sorting out the team for that again no problems with dyslexia erm when I was out in Brussels there was a dyslexic organisation in Brussels and the FCO sent me along to try out some of the their new software that they'd developed and I realised that software had come on an awful lot from when I'd tried it out when I first started at uni cos when I first started at uni it just seemed like more hassle than it was worth erm so when I came back for Brussels I got some access to work funds got read write help erm inspiration a Dictaphone and those sorts of stuff and that did make a difference at work that's the same time as I started at erm Masters in Public Administration an MPA rather than an MBA at Cardiff so I started that when my son was 5 months old (laughs) that was really stupid so I managed to do that for about five months and then realised no this is really stupid I couldn't work full time be a single parent and do an MPA all at the same time erm but I had an Ed psych report done then and that really flagged up some of the difficulties I encounter without realising they are difficulties

K mm

E so my spelling was in the bottom 1%ile and my decoding ability was in the bottom 4%ile erm my reading was although in the age appropriate linked to me being my spatial awareness being in 99%ile that my reading was all in about the 50s and 60s it did it just showed me that actually these difficulties do still make a difference even though I may not notice them

K mm

E and that I've been getting along fine erm and when I was so I kept doing that job it was really good I loved working for the assembly but again I had a child and he needed some of my time so I went to do a PGCE that was great it was really interesting I worked in special school in Birmingham for one of my placements in Selly Oak erm and did every they do is every morning after registry they have a targeted half hour on one of their main weakness areas and I was with a group that were doing decoding so they were just learning the basic decoding stuff that really helped me I thought blimey this is really useful and they used to laugh at me they were like miss you don't know you're sounds do you? Are you meaning this sound or that sound how's it written in the book? Cos I'd just have to read out a sound to them and they'd be like miss you don't get this do you? I was like no this is really hard for me I'm really not a good decoder (laughs)

K (laughs)
so they taught me lots of skills in decoding and then with my son he’s now been in school and he’s now doing letters and sounds like the government letters and sounds strategy and so I’ve had to learn for him to be able to do it and he already gets spellings that I can’t spell and he’s not 6 yet (laughs) and he gets some words on his reading sheet like “were” and “where” and those ones are really tricky for me I’m not very good at those basic words but luckily I don’t come across them too often and in a sentence I can I know which one it is but if you just gave me a flashcard I’ve got not the foggiest (laughs) which one it is

so that’s quite funny it does make me realise that my reading ability isn’t always that of a six year olds (laughs) erm so my issues to do with dyslexia I’d say have come to the fore in this last week surprisingly enough (laughs) because I’m dyslexic I’ve got an ed psych report which gives me certain it says on the front page unless Ellie has these adjustments you will be unfairly discriminated against in her education and then it gives five things so I should get student support I should get photocopying rights and I should get 25% extra time for examinations and for written coursework I should have extended deadlines and I’ve realised doing a PhD my dyslexia’s kicking in a lot more than I thought it would so I’ve decided that it would really help me if I could go part time and not take on any extra work and it would just give me that extra time where I could do the reading and I could do the writing and I kind of broached this to my head of research and he was like studentships are normally only given on a full time basis if you choose to go part time then we won’t be giving it to you so you’ll lose your studentship and I sat there and I said erm I’m sure in view of my reasonable adjustments and the disability discrimination act that normally such (laughs) is the section of the policy that you should adapt to do with dyslexics and he was like well our argument will be that you can use student support and a proof reader I was like well that’s a different part of my reasonable adjustments so at the moment being dyslexic is really hitting home in that it does take me longer to do things and it does make things a bit bloody harder

erm and I think in turn that’s linked into me getting depression at times which I haven’t always put together but I had a depression in December last year that was just as I was starting to do my APG report which was my end of first year report and it was just all too much (laughs) blimey how am I going to do this and I sud- and I realised that another point when I had depression was when I was doing a similar sort of thing and I was doing writing the strategy for drugs and alcohol in the assembly so it was another big tight deadline written took by yourself write the bloody thing Ellie get on with it and that those are my crisis points and that I need to learn how to manage them better generally I’ve done really I’ve been able to go through school I’ve had supportive people this is the first time that anyone when I’ve asked for any help to do with dyslexia apart from my junior school head teacher which it was the 80s and they were only just coming round to being understanding of dyslexia but work other educational places everyone always said
yep fully understand yep we'll put that in place for you no problem we'll do stuff through access to work or through student finance and there's been no problem at all and this is the first time to do with dyslexia where I've felt no I'm going to have to fight this and I'm going to have find out what my rights are and I'm going to have to be a pain in the arse erm that's annoying

K mm

E but compared to people who were say in my tutor group like there was a kid called (boy) who was blatantly dyslexic don't know how any of my teachers didn't pick up on it but I could have told you he was dyslexic at the age of 13 by the age of 15 he was a heroin addict then he was put in youth detention by the time he was 16 erm I saw him when he was 18 he was buying silver foil when I worked in (laughs) Kwiksave so he was obviously still on heroin and then I think he's been back into prison and when you look at the figures of people with dyslexia that end up with mental health problems with erm prison related things being trapped in jobs they don't really want to do well I've always been able to do what I want to do so this week is a first time (laughs) that anything's happened to me so to do with my identity as an adult and a dyslexic I would say that it hasn't really shaped me cos as an adult I haven't really had any problems to do with it I've known I'm dyslexic and because I've known since I was 7 it's never been a negative my parents never made out it's a negative they were like well you just have a different brain you learn in a different way erm it'll mean you're good a different- I've always been fantastic at maths so most of my friends were crap at maths and just didn't have the concept of maths whereas I would just sit there and go blh that's the answer so I couldn't do maths a level because I knew the answer but not the workings out and they mark you on your working out as well erm but I've always I've always had other strengths that my mum and dad have always been able to say well that's your strength area and that's their strength area and different people are different and you'll be able to do different things erm when I was in junior school I can remember my mum got a book by Susan Hampshire Every Letter Counts and it had people in it who were dyslexic and what they'd managed to do and that just gave me the feeling that I could manage to do things and that it would be alright in the end I might hate going to school on a Friday and dong my spelling tests and getting 2 out of 10 and then having to write them out for the whole of the rest of the week and not being able to any art or any PE or any playtime my mum didn't know this used to happen at my school because I obviously didn't tell her that if I didn't get my spellings right that was all I did for the next week was copy the words out (laughs) obviously really improved my education copying words out cos that was going to be how I was going to learn to spell words

K mm

E just repeatedly copying them out again but I'm always very open I tell people I'm dyslexic erm it's something I happily disclose because I think it's an important part of me and it's made me who I am erm I think it makes me empathetic towards other people who are different for whatever reason because we're not all the same and we are all different and we need to respect each other and it makes I think it
makes me determined so when I was younger people tried to get me do a PhD and I didn’t do one then because I knew the only reason I’d be doing it was to show somebody else my headteacher from junior school that I am academic and see this shows you I don’t need to go to a school for thick people

as he would have told me and but I knew I didn’t need to do that so I stopped then (laughs) but now I’m doing a PhD cos I want to it fits well with my life and it’s something that works for me at the moment so long as they don’t tell me I can’t do it part time and then I’ll kick their arses erm I might get the equality and human rights commission to kick their arses too cos I’ve been in contact with them and they’re quite happy to do a bit of arse kicking with the new equality act and they’ve got to get a few test cases through (laughs) so yeah erm I’ve never seen it as a disadvantage really until this last week where it’s becoming a disadvantage so that’s maybe changing my outlook on what I’m doing erm it’s interesting having a child cos I just presumed my son would be dyslexic because my brother was dyslexic and my mum’s dyslexic my dad’s got borderline dyslexic tendencies sorts of things so I just assumed if I had a child they’d be dyslexic but my child seems to be if he is dyslexic a lot less so than I was so he reads to me he likes picking up books and trying to read them I can never remember so last night he picked up the Giant Jam Sandwich which was one of my favourite books when I was a child and I know there was there would have been absolutely no way I could have even tried reading words in that book when I wasn’t 6

I’ll be surprised if I could have read it by the time I was 10 or 11 because he could decode he was decoding words he was using his knowledge of sounds to try reading the words didn’t have any of that I had no I would just look at a word and I’d be like there’s loads of random letters in there that are trying to tell me something and I haven’t the foggiest what they’re trying to tell me I just look at words and they’d mean absolutely nothing to me so that’s been a really interesting thing I’ve talked to his teachers and I know that actually his ability to write down what he knows they’re saying is lot lower than his verbal and his knowledge intake but he’s only 6 and he’s a July birthday and he’s a boy and they’re not quick up at picking these things up but I know in his class he’s already I’ve already spoken to his teacher and they said knowing that I’m dyslexic and we’ve got a family of dyslexics that actually that might be something that although he can do writing and he’s a lot better than I was so he’s already got about 150 words he can read his reading his writing especially is lower than his knowledge he says (son) is the one who will remember everything I’ve said and can put complex ideas together and understands them but when it comes to writing them down he can’t write them down and that’s what I can remember in school I could tell you anything I could talk to you about it til the cows come home give me a piece of paper and I could write like the kids in the first year of infant school and I’d just sit there watching my friends write and I’d be like that’s what I want to be able to do and it’s taken me a long time to be able to do it
and those people when they read my writing say ooh I wouldn’t know you’re dyslexic or they say you’re not you well if you’re dyslexic maybe I know I give people doubts that dyslexia is actually something because I’m quite competent and I’m quite capable and I can write fine and they’re like oh you can’t be dyslexic if you can do this (laughs) and it’s like no I can do so much more if I wasn’t dyslexic but this is quite good enough (laughs)

so I think that’s how I’ve got where I am now so dyslexia was a big issue in my life I’d say until I was say 13 and I started getting some writing and reading skills and then it hasn’t really been a big issue again until this last week which is a bit disappointing really

that in 2011 it has to become an issue but I suppose it’s been an issue for a lot of other people for that whole time so I’ve just done very well

and had supportive people around me

so yes that’s my life story kind of centred around where dyslexia’s played a role or not played a role

great thank you very much

that’s ok

ok I would just like you to tell me about your life starting wherever you feel comfortable erm ending whenever you feel comfortable tell me as much as you want tell me as little as you want

ok

and if at the end of it there’s certain things that you don’t want included in the study we can take them out and that’s fine

and I think that’s the option I’d go for

ok

I’ll tell you as much as I can and you know we can look at it later

ok
erm I my life I’ll start off with when I was tiny I by the time I was 10 I already had confidence issues I noticed that I was different to other kids in in that I couldn’t catch a ball to save my life erm at school the teacher on I think it was like the first week that the teacher had said now if anyone has any problems spelling any word at all just ask me and I though great and I said to her how do you spell ‘I’? and she went what do you mean ‘eye’ as in ‘eye’ (points to eye)? and I said no ‘I’ as in ‘me’ because to me it sounded like a y I e maybe? Ayie? Erm and she told me not to be so silly to only ask proper questions and I never asked another question after that so by the time I was 10 I was a little bit I still participated in class cos I was very sociable but I didn’t really have much confidence to be putting my hand up and coming out with things erm like I say I couldn’t catch a ball erm I used to get picked on by my brother cos he’d say how do you spell so and so and I’d get it wrong and he’d laugh at me and I used to get in trouble as well cos my dad would sit down with me to teach me the timestables I remember that I don’t know how old I was I must have been tiny erm but he’d be teaching me the timestables and we’d be there for hours he wouldn’t go until I’d got it and then the next day when I failed the the test at school he’d just be like oh my God you know what were you thinking you knew them you knew them last night erm so I had issues of you know there’s something wrong with me ther years by the time I was 14 I’d had enough because I thought initially I was quite smart like the other kids I didn’t feel any less erm capable with of talking with them and stuff but I obviously couldn’t do certain things that they could do erm so by the time I was 14 I’d just had enough of schooling that they’d I’d lived in (abroad) for a while and when I moved back I was 13 going on 14 they interviewed me at school with all the just to check what kind of level I was at and from that they put me in the top stream where I was meant to be doing 7 O levels 3 of them a few months early and erm (sighs) because I couldn’t do my homework properly I mean I had teachers holding my work up saying that this is an example of someone who couldn’t be bothered to make the effort obviously did it on the bus on the way in and I’d be sitting there thinking that was 2 hours work I had to throw away so many pieces of paper I gave you the one that you could read it was torn out of a book it was you know I get why the teacher would say ah but for me it was a big thing and erm so after about a month and a half they moved me from the top stream down to the 8th the bottom stream and told me that I wouldn’t be able to do any O levels I’d have to do the CSEs instead which if you get a grade one is equivalent to a C but erm they weren’t even prepared to enter me for them because they said that my English and my grammar was so bad that there’s no way I’d be able to get one they told me at school that my best options for life were to maybe not aim too high erm to just you know make sure that I I waitressing or hairdressing may be a good option for me because when I was little maybe five years old that I’d had to have speech therapy and erm certain letters I couldn’t pronounce and at school they gave me extra 1 to 1 erm tuition to teach me to spell words and after about 2 months of that they’d given up because they said look she knows them she’s just too lazy to apply herself because when we test her a week later she’s got them all wrong or she’s got these big words right and she misspells ‘the’ so they said my language was just so poor that I wouldn’t pass any O levels so
when I finished school to prove them wrong I went and did drama at college I did a drama O/A level an English literature O level because apparently that’s where I’d failed completely in my my CSEs and erm art I think it was or film studies or something a few just lame you know interesting subjects that I thought you know that I stand a chance of finishing as it happened I didn’t finish all of them I did finish the English literature and the drama and I got Cs for both and I thought ha! That shows you I can pass an O level and erm after I left school after I left college I pretty much did exactly what they said I started waitressing I was going from one dead end job to another I tried to work in a casino erm and I I got into it but I couldn’t get through the training because they were doing all the you have to be able to multiply a lot on roulette you need to know your 37 timetable and I just I could do the tables I could learn them but I couldn’t add them together it was like the two step process was too much for me so in the end they sacked me and they said it was cos I lacked erm the ability to work as a team as well apparently that’s an issue I’ve always had I’m very I’m a real perfectionist and when other people do things with me I want them to do it my way (laughs) so therefore I’m not really a team person but erm I got sacked from so many different jobs and then there were other jobs that I’d do for 6 months and leave because I thought oh my God they’re going to realise I put the numbers in wrong for the payment they’re not going to get the £2000 pay or whatever and I’d tell them and I’d give in my notice at the same time sorry erm so I worked in sales I worked in erm commission only kind of jobs and when I got to 25 I had what what I think was a bit of a nervous breakdown I couldn’t take it any more I had a flat which was being reposessed from me I’d forgotten make payments and then I didn’t have the money in the account to make it up and erm so I had the flat being reposessed I’d got other debts because I just I went by impulse and you know a bit of independence I’ve got my own place you know I’ll get furniture I’ll do this and before I knew it I’d spent way beyond my means erm so I was struggling financially I couldn’t get a job I was applying sending spec letters off I used to go through the yellow pages and apply to every single company in the area where I lived just to say you know I can do anything I can do anything I need some cash and I’d just hit the bottom of the barrel so I went to sign on and the woman at the centre told me that I wasn’t trying hard enough that there was plenty of work out there if I looked for it and I thought I’m not- I don’t have a car or any means of transport and yet I’ve applied for jobs up to 15 miles away from here so you know and I took in the file cos I kept the spec letters everything I I I wrote I photocopied and kept a copy of just in case they got back to me I’d need to remember what I’d said to them erm so I took the file in and I said you know this is what I’ve been doing and you’re telling me this isn’t enough and I had a complete sense of humour failure and erm they said that I you know if I didn’t calm down they’d ask me to leave so I went to the doctors I I went home I broke a few things I was livid absolutely livid and erm I went to the doctors and they put me on anti-depressants they said it sounds like you’ve got depression erm chemical imbalance maybe you know and they put me on anti—depressants and they got me a counsellor I was telling the counsellor about myself cos obviously you know they like to hear you say your own thoughts and erm you
know solve your own problems and stuff they don't really contribute much so they
just you know you're sad now tell me why you think you're sad (laughs)

K yeah

R so erm but he was fantastic he was actually fantastic because he was listening to
what I was telling him and you know he pointed out that what I was saying didn't
match what he was seeing this person that was so incapable of doing anything and
couldn't write and couldn't read had the the most eloquent vocabulary he'd come
across in all the years that he'd been doing this and it didn't make sense that I was
there say well I've got 2 O levels and I've got this and you know but I'm I'm not
qualified to anything I've got no actual skills and I don't have the confidence to do
this and I'm scared of doing that and he said you know he he advised that the
doctor sign me off so that I wouldn't need to keep going down to the job centre just
in case they were going to kick me out erm and I got put on incapacity benefit back
then that was '95 erm they he also I mean it took me weeks before I stopped
applying for jobs cos I thought right I don't have to go to the job centre and deal
with those you know people but I still have to find work I can't stay on this pitiful
money forever I need more money I'm I'm losing my house it took me weeks
before he got through to me that I was to stop applying for jobs because that's
what was making me stressed the pressure that I as putting myself under was
having a knock on effect and he he kind of made me realise that it wasn't
depression I was sleep deprived I was sleep deprived I was angry and I had kind
of obsessive compulsive tendencies which I get stressed if I don't do things certain
ways and erm so he told me that what I should do cos I obviously needed
something to apply myself to cos I was just going I couldn't afford heating it was
cold I had nothing so you know he said get out the the flat and actually do
something go down the college you're on low income so you can get the
courses for free and just pick a course pick anything that you're interested in and
do it don't wonder whether you'll be able to get the grade because you don't even
have to enter them what I want you to do is just go there and meet people and talk
to people and get of your house and and have more activity so I went down the
college and I did I enrolled on psychology and sociology cos I thought now that
interests me the blurb interested me so I did that and the the sociology teacher
was fantastic absolutely fantastic and
she kept telling that you know you've got the
worst grammar and spelling I think I've come across in my life but you're first
person that I've taught a lesson to and actually gets it actually gets the the concepts
that I'm trying to teach every time so you know what are you going to do with your
life and I was like pardon? Well eventually someone's going to hire and if I don't
blow it and I don't lose my j- she said what are you going to do with your life I said
well I don't really have much planned and she said well do me one favour apply for
university you're a mature student you're on a low income so you can get grants
and stuff and you know you've got to do it you're wasted if you don't do it you've
got to give it a go and I laughed but I thought why not why (laughs) what have I got
to lose it's not like I'm going to get these A levels anyway I mean the psychology
class oh the guy was dreadful he was really dreadful he was I mean apparently
he'd been teaching lecturing for years but he used to stand erm at the end of the
class and he'd just talk nonstop in just monotone the whole time and I couldn't keep up with the notes and because I didn't understand the concepts I hadn't grasped enough basic knowledge to be doing an A level in the subject from school he'd say things like you know you've got to go and when you when you're looking at statistics you've got to find the median and the mode I'd go home and my notes would say find “mean meanie mo”

K  mm

R  and because I didn't even know of the the things you know so I was taking down most of the time just the the little words and then this happened in 1992 and there was so and so and I actually wrote so and so? I don't know the names you know so I was taking most of the time just the the little words and then this happened in 1992 and there was so and so did and I'd think so and so? I don't know the important things so I gave up that class I packed it in I couldn't do it even though the subject was really interesting to me I couldn't read the books I couldn't I was wasted whereas sociology with the teacher's encouragement and her style of teaching which was very very different erm I I was just doing really well so I did apply to the universities she did put in a good cover note as well and I got offers if you get 2 Cs if you get 2 Bs and I had to ring the universities afterwards and say I'm not doing 2 any more I'm only doing 1 is that going to be a problem and the the college the university I wanted to get into was (uni) I was living up in in (country side near it) erm but I wanted to go (uni) cos it did communication studies and I thought it just it interested me I didn't think what am I going to do with it or any of that just you know it's interesting so I stand a chance of getting through it and erm I rang them up and I said that basically I wasn't going to have the 2 A level results I was only going to have one and it was because I was erm poor (laughs) and I basically went on a bit of a rant at the lecturer about how I felt it was discriminating against me cos I didn't have the money and if they'd like to pay the £30 pounds that I actually needed to pay to take the exam then you know I'd do and then maybe I stand a chance of getting them but without that I I can't enter 2 and they called me in for an interview anyway and then they they reoffered the course on just one A level provided I got a B now little miss couldn't get an O level very easily decided that you know it (sighs) I thought there was no way I was going to pass it

K  mm

R  no way at all now I had nothing else that I was doing in my life at the time erm so I every day that we only had 1 lecture a we-2 lectures a week and they were just half days it was an A level in one year and erm after every lecture I'd go home and I'd spend 8 hours writing down what she'd told us in the class then I'd spend the next 2 days writing questions about what she'd told us and then after that I'd write essays on each question and every time I wrote an essay I timed it to 1 and a half hours so sometimes I had to take paragraphs out or or or shrink it or whatever but I was tried to do it so that I could definitely do it in 1 and a half hours then once we had all the subjects once we'd covered them all as we were approaching as I was approaching the exams I did erm and I can't believe I worked so hard for one thing but it changed my life so I did basically question s that I thought they would ask on every subject so there were gender differentials I made up a question that basically
said what are gender differentials and erm religion what is secularism and stuff like that and I had those essays I practised writing them I took one word from each paragraph made an anagram of the letters so that I'd have every essay had 10 paragraphs erm I think it was 10 or it was 7 7 then when I was at uni it was 10 erm and I would start off on the notes I'd just have the 7 letters but by the time I mean I put it on tape as well so I was listening to it when I was doing my dishes or I didn't have a telly or anything so the tape was on constantly just saying the the essays and when I went in to the exam three of them I think it was 4 essays we had to do and 3 of them I knew word for word I sat down and I didn't even need to do the anagram I could see it there erm I'd learnt it so many different ways and I swear blind it was word for word but when it came to the last 2 options I hadn't erm seen those ones coming I hadn't second guessed those questions so I didn't have essays prepared and I basically just concocted something from statistics that I'd put in other essays kind of borrowed over and and just blagged the rest I just just wrote what I thought maybe and erm I told the teacher that as well and she said you'll probably still get a B because if you've done what you say I've seen the things that you you've worked on and you know I'm confident you'll get the B when the grades came I opened the envelope and (crying) I must have shown 20 people because I didn't believe what it said and everyone kept telling my Rose it says this and I was looking at the back thinking I can't possibly have got an A in an A level no way and the teacher said to me how did you do it? And I said I had I had and she said no no I'm talking about you told me you only knew three answers you have to get an A in every section you can't completely mess up one

K mm

R section and still come out with an A you know it must have been a very high B but you'd generally you need to get high marks in all of them

K mm

R so I told her what I'd put in and she was like unbelievable we didn't even cover that we didn't cover that in class I can't believe you know had you read up on it no I just I guessed (laughs)

K (laughs)

R she was laughing (laughs)

K (laughs)

R saying you know I don't bother teaching that because people don't get it people don't get the the connections so I thought hey and it it gave me such a confidence boost

K mm

R and I thought sod it I've got into university my house is being repossessed anyway so I may as well you know give it a go and I went down there to (uni) and I panicked so much at first I couldn't find my way around I was getting late to
lectures I was I mean the lectures were fantastic they were really interesting but the reading the reading we were getting I couldn’t I think it was my second year before I learnt what an index was for and the time that saved me because they’d recommend books and I’d go home and I didn’t realise the you know ways to identify subjects that were talked about in the chapter like if you read the introduction the conclusion you know it generally gives you a good hint what’s in there so I was reading introductions and just carrying on and trying to cover entire books and I mean I’m a slow slow reader anyway and I couldn’t keep up so I was grade wise I was scraping through for the first year and then I became pregnant in the second year and I guess my stress levels went up a bit because although I was very happy that I was pregnant I was over the moon I was a bit conscious that my grades were not exactly fantastic and a baby coming you know it’s not exactly conducive so I went to see student services and I said look I’m thinking of quitting and I’d like to speak to someone to help me understand what’s going to happen with the the finance because I’ve got a student loan that I’ve had to take and I’m not in a good way financially if I quit I’ve just spent this term’s grant you know do I have to pay it back? I didn’t know how it worked and they made me an appointment with a finance person and then I went back home I was carrying on with the course and I mean the the moment that did it for me was I had a newspaper and it had an article it was really relevant to one of the subjects we’d just covered and I was trying to erm understand the the concept and I couldn’t even understand the sentences I was stuck on this one word three letter word and I was getting angrier and angrier by the second wh- wh- wh- I couldn’t work it out and I threw the newspaper across the room I mean I must have read three letter words a million times so why couldn’t I understand it and erm when I went to see the finance person at the uni they said you know why are you quitting we’ll help you out and understand what’s going on but I’d like to know why and I said because I can’t do the reading I can’t do the reading it was a mistake them taking me I blagged my way in I was just lucky the amount of work I had to do to get that A level I don’t deserve to be here I’m not up to it and I’m wasting everyone’s money and time being here and she said what do you mean you’re not keeping up with the reading I said I can’t bloody read ok? I’m getting notes in class and I’m pretending to read them I’m asking questions just I’m not reading I’m scanning for words that I can say oh I don’t quite understand this because hopefully then they’ll describe the whole bloody thing I’m blagging all the time I’m just blagging my way through making it up and she said well ok (laughs) you must be very good at blagging then (laughs)

K (laughs)

R and she erm asked me if I could go and see a specialist at the university who helps students with these kind of problems and I went to see him and he did a few erm things he asked me to point at his left ear and I sat there like an idiot doing sorry ok I’ve got mine (laughs) I didn’t realise that I couldn’t do that and he was asking me a few different questions about from when I was young and I said to him what on earth has this got to do with me leaving uni am I going to owe more money or something if I (laughs)
K (laughs)

R I don't get it and they said no no didn't they tell you that I check I’m doing dyslexia screening and I said oh ok now just to put you in my mindset when I was about 14 I’d told one of my teachers that I thought maybe I had dyslexia because I’d heard that there was a condition that erm meant that children struggle with reading and writing and you kwen buy they’re not stupid and I don’t think I’m stupid so no darling you’re not stupid you’re lazy you’re lazy you don’t apply yourself and I don’t want to hear excuses like dyslexia coming out of your mouth that was the last time I mentioned dyslexia so then I mentioned it to other people and they’d come out with things like erm I mean the ones who knew about it would say things like oh yeah I hear that they’re really gifted you you can’t possibly be (laughs) so the no one was connecting the pieces and I’d got it in my head that obviously I am just stupid then you know and when this guy said he was screening for dyslexia he said look I strongly suspect you have dyslexia and I want to get an educational psychologist to come in and actually test you erm I said no and he said pardon I said look so long as no one tests me so long as a I don’t have to go through the humiliation of showing someone how challenged I am I don’t even play trivial pursuit (laughs) I don’t want people to see the things I can’t do erm and to have to do that and risk the chance that he will send you a report that says no signs of dyslexia she’s just dim below average intelligence I I that will shatter me so long as no one tells me I still have a little ray of hope that I can tell myself well maybe I am dyslexic

K mm

R erm so I was really scared (laughs) erm he laughed at me and calmed me down about it and said you know you may as well because if if you are there’s things you can do to overcome a lot of the problems you know you should have been diagnosed at school you should have been taught these techniques but people your age they weren’t they weren’t so many slipped through the net and erm so sorry I was just thinking about his office cos he used to have these weird coloured things as well erm so after I saw the educational psychologist I was panicking and telling myself just doesn’t matter what it says doesn’t matter what it says and when it came through that I have dyslexia I have dyscalcula they want to check me for Irlen syndrome as well erm it was like no no now all of a sudden I’m disabled when you when you apply for a job and they say do you have any disability so long as I got well I might be dyslexic I didn't have to tick yes now I have to actually tick yes and they’re not going to want to hire me dyslexic dyscalcula what the hell does that mean? You can’t read you can’t write and you can’t add up what job don’t need those three skills you know so I was on a real downer and I thought I’ll go back to the doctor now and see if I can't get some more antidepressants again because when I’d got pregnant I’d stopped taking them I’d been fine I’d been exactly the same as I was with them I still had panic attacks I still had stress issues but I wasn’t depressed when I was off but I felt like I couldn’t handle the thought that now I was just going to be labelled disabled

K mm
cos deep down I thought there’s nothing wrong with me I am bright I am capable of doing so much erm but I went to the doctor and the doctor referred me to a psychiatrist and this psychiatrist was I wouldn’t say a very good one because he obviously had his standardised questions that you go through but he just added more and more labels to me I all of a sudden I had obsessive compulsive disorder I had social phobia because I don’t like to be around people and I don’t like it when people get close it’s perfectly ok if I invite someone do you know what I mean I’m perfectly happy to have my husband or my daughter but even if my daughter comes in and leaps at me I don’t like that especially I don’t like strangers brushing against or something so I avoid social settings social phobia and obsessive compulsive social phobia depression erm the list was endless of all these problems with me and I came away from that even worse and then my daughter was born 2 weeks before the coursework deadline but because I’d had the disabled student allowance come through my computer arrived the day before she was born and I’ve never found it so easy so easy to do work she was there in the little papoose (laughs) strapped to my my belly and I was stretched over her typing away on the computer I taught myself to touch type when I was bored one day and I didn’t realise by hand it takes me ages my wrist hurts my fingers freeze up I get lumps on my fingers on the computer I can I can write as fast as I can spell so all of a sudden my work was being fmh knocked out and erm so it was just I got my coursework all done on time and all the lecturers were like we expected mitigating circumstances we expected you know you’ve just found out you’ve got dyslexia and you’ve just had a kid so anyway that was the coursework deadline I think it was around May time and I had til October before we started back up so I spent from June to October researching dyslexia finding every site I could on the internet and I loved the computer I really did I got calendars I got diaries I got task sheets every every morning the first thing I do is boot the computer and see what I’m meant to do that day so it it helped me so much getting that and the the months I spent erm looking into dyslexia taught me a lot about what I can and shouldn’t expect to be able to do and it made me realise that a lot of the the I wouldn’t say depression I argue that I’ve never had depression I’ve had bouts of erm depressive tendencies from I get so down when things go wrong because I’ve got them wrong or something but it’s not depression I don’t have highs and lows as such I just you know sometimes it gets to me erm I can’t remember what I was saying now

you were researching dyslexia

yes yes (laughs) and I found out that it’s not just writing and reading it’s problems with short term memory it’s the reason why when I used to get sent to someone’s office and I go and forget what I went for

mm

do you know what I mean the reason why I stand in the room so many times going what on earth am I in here for you know I mean everyone does it I do all the time so you know it realising that dyslexia actually affected those things as well erm so I kind of took on board the issues that I told myself right forget the if I keep trying because my dad my school everyone had always put this philosophy into me of
rote learning you keep trying you keep trying you keep trying same way over and over until you get it and I finally realised that ain't ever going to work with me for some things it does for some things erm like the essay I can't believe I got it right word for word I got my memory to work just fine for that but for other things I can't erm things just go so I have to accept that I'm never going to be able to do that full stop find a new way so I spent those months working out what things I can't do easily what things I can do that cause me a lot of stress and what things I have to find alternative ways for and during the second year my grades had been C to B? at a push low Bs low Cs but I'd been managing to keep up with the reading a lot more because the guy at the the uni had told me you know how to use an index he'd given me a few skills that I really should have had before I went to uni and by devoting every hour that I wasn't with the baby or rather before I had her it was the whole time I was pregnant I did everything keeping erm reading and stuff like that cos I thought when she comes I'm not going to have the time but once she came she was such a quiet good kid

K mm

and I got her booked into the crèche at the university to start in the October so I didn't even defer for a year she was five months old she went to the crèche I carried on with the course with my mates and you know I didn't have to miss out on anything and my grades went put it this way when I finished I rang up my my supervisor of the dissertation and I was crying I said you let me down you let me down because if I'd have got 2 percent more I'd have got a first and if you'd told me it was crap I'd have redone it and he was laughing at me saying in all the years I've lectured I've never had a student unhappy with a high 2:1 well you've come across the first one I wanted a first (laughs) so but I was happy I was happy with the grades you know I'd done it and it felt good and during the third year because I'd taught myself so many ways when I'd gone back during the first term a lot of my friends who were erm having to hold down 2 part time jobs to fund their way through and you know none of them had money they weren't you kwn they they were struggling through they had so little time because they were having to go and do these that they were falling behind and they could see that I'd gone from you know really not very great grades to having As and Bs and so they were coming to me to say what are you doing different and I was teaching them ways of erm time management things of if you want to focus on this this is how you have to do it and so that finished the next year I got a call from one of the girls who had been helping the foreign the En- the TEFL erm lecturer with something or other and they were setting up a drop in centre in the library where they wanted people to to help the mainstream students who were struggling with with sort of study skills and (friend) said you've got to get her in she is fantastic you know the girl's dyslexic and yet she's done this these are her you know and she's helped all of us as well and erm so they got me in and I didn't realise it was a for a position as an English specialist and they gave me a few tests which were like erm a paragraph of something which was timed and I had to go through it correcting the grammar and spotting spelling mistakes and things like that and then they did the they got me to dictate something that they were going to ask I had to write my questions down
and then they’d give half an hour to answer them while they went for a coffee but I
didn’t write the questions down properly I made a complete mess of the interview
completely and I didn’t hear back from them for two weeks I mean I cried about it
cos I thought I am good at helping people you know and I enjoy so it’s something I
can do and I I made such a mess of that they’re never going to take me on but two
weeks later I got a call back and the lady said look I’m ever so sorry I was off sick I
meant to call you much sooner because you were so devastatingly bad at the
interview that I went to see the dyslexia expert at the university and he asked me
how we’d done the tests and then he told us off (laughs)

K  (laughs)

R because apparently we broke just about every single piece of advice he would give
us we put you under pressure we we got you to do things that and that’s not what
we’re actually looking for if you have the ability to guide people into producing
better essays then we don’t care if you don’t spot every spelling mistake on a piece
of paper so we’d like to bring you back in for a second interview and I was like
wow great (laughs) like I really thought that was it no more and I went back in and
it was fantastic what they did was basically the lady who was really friendly really
nice not at all you know scary she sat in the corner writing on her desk like she wa-
she was doing something else and not liste-
ning which I’m sure you know she was
and erm in fact she was probably writing notes and then they brought in a another
lecturer who pretended to be a student with typical issues on on completing an
essay and erm I had to sit down with him identify what the problem areas were in
his work and get him to leave happy that I’d helped him do that and they they were
totally amazed because you know I I read little snippets I did my usual scan
through to see I checked the the question and in my head during the second and
third year I’d worked out that the way I did my essay for sociology was the way
you should do every essay for university cos they don’t care about your opinion
anyway all they want is a set format so first of all you do your introduction then
you do your your arguments for your arguments against the contradictions and
your conclusion is usually that you need to do more research anyway so (laughs)
you know erm so there’s your format then you just need to fill in the blocks so who
are the people for who argues against a few dates and stud and bingo you you
have a format that’s more likely to work and a lot of the students that were coming
in had obviously missed the you know how to write an essay lessons at school like
I’d missed the you know how to find words in a book index lesson at school and
erm they didn’t know how to write essays that’s what the problem was that’s why
they’re procrastinating that’s why they couldn’t actually do it and erm so they took
me on just 4 hours a week and meanwhile the the people I’d done my dissertation
three other subjects were on a related three other modules were on a related area
all independent studies and the lecturers that had marked those said they would
consider them for you know masters to look to go to an er M MPhil to progress to
PhD because it was an original concept I’d come up with and you know the you
need that it’s rare to see it so you know and they’d given me the four hours at uni
and once you’re on the lecturing staff for 4 hours they pay for the PhD so for me it
was like you know it it's it could get me somewhere I don’t think I’m up to a PhD
but then I didn’t think I was up to a O level an A level or a degree and you know apparently I was so I was really keen to do it but for some reason my stress levels started going up again I was having problems at home I was not happy I was having other issues so when I started that I saw the doctor again and said don’t g- don’t give me antidepressants I’m not depressed I want to see someone I want to see someone because I’ve got problems that are causing my dyslexia to get worse I’ve got the prospect of a really good job I’ve been on incapacity benefit for years I want to try this job and I want to come of incapacity and I want to get my life sorted and be something and I’m messing everything up you know I was meant to start work I accidentally used the baby oil on my hair instead of the shampoo I don’t know if you’ve ever made that mistake but trust me it takes hours of repeated washing to get that level of oil out (laughs) it’s horrific I misread the label you’d think the colour would obvious but it looked like the the clear shampoo well excuses aside I messed up things like that were happening all the time at home I was getting ready to go to work I’d leave the house and then I’d stand there thinking my feet are wet I’ve got the baby ready I haven’t even got shoes on I’ve gone outside with no shoes and the anger I was getting that I was messing those things up you know? I was going to blow this job because I couldn’t manage the rest of my bloody life everything was falling down around me and I had a baby to bring up as well and you know

K

I wanted to do something good and every time I try to do something good it’s like everything else just falls apart so I said please let me see someone they again referred me to a psychiatrist and alright I’ve seen so many psychiatrists over the years the first one was the social phobias and the obsessive compulsive this one put me straight onto antidepressants again and spent a while explaining to me that it’s a chemical imbalance and you need to be able to fix that chemical imbalance you know whether it’s caused by clinical depression or you know just what you’re describing is reactive depression it’s still classed as depression it will help now I have a memory problem my family I don’t take tablets unless my husband is there because I can take them and forget I’ve taken them so if I’ve got a headache I’ll take painkillers well I used to take pain killers and then I’d go back and take some more to me that’s really bloody dangerous and all these antidepressants and stuff say you know don’t take them too close toge- you know I didn’t want more tablets it puts so much stress in my life I have charts when I mean I’ve over the years I’ve found way to make it easier so I’ve gotta take a whole load of tablets now erm and I have to tick on my chart when I take them so I can look at it and not mess that up but I didn’t want tablets and stuff and I wanted to fix everything up and he identified that I had a problem with my my erm what was it this time antisocial antisocial behaviour erm aggressive erm I had aggression problems even though I wasn’t being aggressive with people I was aggressive at myself and I shout and I I don’t think I’m shouting I think I’m a bit passionate about what I’m saying but everyone over over the years has repeatedly told me that I talk louder or too quietly or whatever I have those kind of problems so again he just added a whole ream of more issues onto what was wrong with me and over the year I mean I
Appendix

Narratives from Chapter 7

loved the work I did it at the end the year they offered me 8 hours on the lecturing staff which definitely would have given me the phd but the my partner at the time was relocated so we had to move down to (place 2) so I turned it down anyway it took almost a year to actually move so with hindsight I may be should have taken it but I didn’t want them to be left in the lurch with me leaving when I knew that was going to happen so when I moved to (place 2) I wasn’t very happy at all I was having major problems erm all kinds of issues and I’m the kind of person that if someone (laughs) if I go in a shop and I don’t get the level of service I expect I tell them I tell them and if they don’t like what they hear I say get the manager because I believe that everyone did that people would give better service you know it doesn’t hurt for people to do a good service erm I mean for some people it obviously would be too much (laughs) but so I end up getting angry everywhere I go because people don’t actually want to hear it and they don’t want to be told you know your display’s crap and (laughs) so I guess I cause trouble everywhere I go and erm I was in (place 2) and I was causing trouble there I didn’t like the way the council were doing something or other and I called one of the councillors in and I gave him a mouthful and I told him that you know I gave him all the the statistics and the statistics for that and he said well let’s deal with that later what are your political views I said oh my God here we go bloody politician you invite one in the house and you’re going to try and sell me into your party he said I haven’t mentioned who I’m with you obviously haven’t looked at who I’m with (laughs) so let’s leave politics aside I’m asking you what you’re political views are you interested in politics and I said well if shouting at the TV every day counts as interested in politics then yeah whenever they’re on I shout at them erm I’ve obviously got in touch with you because I care about goes on in the community and you’re obviously letting people down in this area and he said right party? And I said that’s none of your Goddamn business really is it? And he said I’m just saying would it be an issue joining any specific party I said well between you and me I wouldn’t really want to go conservative cos there’s just too many you know no way would I ever agree with 90% of the the ideology behind conservative views so absolutely not and I’d have to think twice about either of the others as well cos I don’t like politicians what was happening was they were redoing all the boundaries in that area and it was going from a council with erm I don’t know 28 councillors to 32 so all the parties wanted to find extra people to put in their wards I’d only lived there 9 months my mum had lived there many years but I’d only been there 9 months and erm the thing I I checked was that you know basically if I stand will you as a party ever tell me how to vote? And they said no no the other two parties do have whips that they don’t always use you know it’s pretty you know if you’ve really got a moral objection tnf it’s only one vote but we don’t ever whip so I said ok then I’ll stand and I stood for election and I did a bit of leaflet dropping I had to go with groups of people because I didn’t know my way around the ward at all and I mean it was like maze it was like a complete maze and erm so I stood I got elected and that was just it was interesting it was rewarding it was frustrating it was irritating the work I’d got to do while I was a borough councillor was fantastic cos I worked with a lot of the the community groups I sat on a lot of external boards so things like erm the the regenerations budgets and
stuff I’d go to all the groups that had access to funding help them get more funding and so that was all really worthwhile it was all good but then sitting I didn’t like having to work with politicians erm not because as a breed I didn’t like them it’s just the the I like to argue with statistics with facts with actual things and most of them were very much I feel my residents don’t like it well tough give me some reason why this wouldn’t make sense or why it would make sense and so I got into loads of arguments with them because when it came to certain issues like erm drugs I was perfectly happy to talk with the police and the the groups and stuff and you know I wasn’t the the typical oh bad bad for the community jail them all up which you know suits politics a lot more I think I was just you know take me as you get me really and you know if something sounds like it could work well I’m going to listen I’m not going to you know say oh no no no we couldn’t possibly have that people wouldn’t like it well if it works make them like it you know you’re saying let’s solve this problem you know so that was great but then at the same as that happened again I started having problems the rest of my life was falling apart erm I couldn’t do that I couldn’t cook a meal I couldn’t read a book to my children’s book I couldn’t read them to my my my daughter erm so again went to see another psychiatrist and this guy was brilliant he was brilliant erm he explained to me that you know along with the dyslexia there’s all the things I was describing as having problems with I have balance and coordination issues I’ve fallen down full flights of stairs so I’ve got a bit of a phobia about going up and down stairs erm I’ve really hurt myself falling over I’ve cut myself things like I don’t know what I mean my family still laugh at me cos every now and again I’ll just bash something off the table you know what that cup ever do to you? (laughs) you know those kind of things the the the I don’t know what it’s called my coordination sucks erm the the short term memory problems are so severe I get lost in familiar places not in strange places I mean I can’t find my way anywhere anywhere at all I’m dreaming of the day I get a sat a satnav because suddenly it will be like having my husband in the car if he’s sat with me telling me which way to go I drive really really well but if he isn’t I can only do routes that I know really really well because I refuse to go somewhere I don’t know and panic so you know I was basically confining myself to the house the more and more time went on with the more and more stress building up I wouldn’t leave the house unless I absolutely had to so the only times I would go out would be doctor’s appointments or meetings and I was starting to send in apologies because I just I couldn’t face having to find that place and no one could give me a lift or and this psychiatrist said that you know basically the problems I have with my I think he called it topographic memory ability to find my way round erm the problems I have with my balance and coordination and my short term memory and the other issues erm could all be related to the same part of the brain that you know does the dyslexia and you should accept that you can’t do these things just as much as you accept that you can’t do those and you know but I mean to this day I’ve gone back so many times to say well you know what’s wrong with me? Cos I’ve looked at everything to do with dyslexia and it doesn’t cover all those things it doesn’t so there must be something wrong with me and over the years it’s like I was saying to my husband the other day one day I’ll be able to get a job and do a job long term
that's fulfilling that I actually get to use my skills at that I won't be worried about being sacked after a few months because even though I know in my heart there's a lot I can do my head still screams things I can't so whenever I'm looking at jobs on paper I'm saying yep qualified I've got experience of running committees I've got experience of doing this I've got exp- I've got a degree I've got do you know what I mean? I fit all the things the pay is high the pressure would be you know but inside it's just screaming you can't do it one year and you'd screw your whole life up because you wouldn't be able to cook you wouldn't be able to shop you wouldn't be able to go out and to this day I mean I'm still trying to get my doctor to get me a referral to see if I can erm get the other aspects checked by people who know something about it because in my endless search of dyslexia and what that covers there's a lot of research lately that says erm it it it it's comorbid it has other conditions that go with it well looking at dyspraxia I'm thinking prmp you know I've been diagnosed with balance and coordination problems and and you know things like that is it possible that it's dyspraxia and I know sod all about dyspraxia because I don't know whether or not I have it and I'm not a hypochondriac who's going to sit there going through every single condition saying ooh well maybe last Tuesday I had a bit of that you know in fact I don't want to be looking at everything and and trying to diagnose myself because then I'm going to have to find remedies for things I don't even have but a lot of the things I've been diagnosed with are classic traits for the other related conditions and I cannot get an assessment I can't do it at the moment the doctor and this is the first one that hasn't tried the last one sent me to a local clinical psychologist who I explained you know that that these related conditions and you know there's like you know who knew that a form of autism Aspergers I'd never heard of it but that's allegedly related and she looked at me and said well darling I can tell just by looking at you you've not got autism and I was thinking you know the first thing I read about Asperger's is that it's hidden that you can't tell straight away just by looking at someone unless you're trained to look for do you know what I mean? So so straight away I was angry thinking well you obviously don't know anything do you and she was going mm yes mm yes when I was saying about the dyslexia and the anger and depression she's obviously had a day's training on dyslexia erm but you know I was saying the connection between Asperger's dyspraxia I just want to know what it is that I'm tackling cos if I know look what I knew about the dyslexia I got a degree I became an English specialist and I've worked as a borough councillor dyslexia isn't' holding me back it's the other things the falling over the the the anger the the problems I have with people you know? They have issues with me I'm too honest I'm too aggressive I don't think I am think I'm a happy sociable (laughs) it's like they're describing someone else you know well maybe maybe it's possible that I have one of these related things and if I did and I knew it for definite then I could actually research it and find out how to overcome the problems with that and then I'd be perfectly able to hold down a job and have a life at the same time but without that diagnosis without any expert help and people who just keep saying oh yes it's tough when you can't read (laughs) I can read I can I'm slow and I have to read a lot of times sometimes before something makes sense but I can read I can
comprehend so I find the way they talk to me when they've had their one day's training on dyslexia patronising

K   mm

R   oh yes it must have been very hard for you oh well done (sighs) yeah I know it was well done (laughs) I don't need you patting me on the back what I need is an answer to the question I'm asking which is how do I go about getting someone who knows about all these conditions to actually help me find out what what what it is that my brain does differently cos whatever it is I'll be happy I've got it I'm happy I'm dyslexic I love that I'm dyslexic I can do things that my husband can't dream of and he's really intelligent but I can mix colours together in my mind in closed my eyes or open I can mix them together and see what colour they make you know I said to my husband once can't you do that hm no! (laughs) cos to me well I suppose not many people can I learnt to play the guitar by myself by watching someone else just sat there watching what their fingers were doing and then when they left I copied you know most people can't do that I get material I throw it on the floor I know where to cut it to make something so I love if that's dyslexia then I love that I've got it but I don't like that the other issues I still have the self doubt the you know maybe it's just cos I'm a klutz maybe it's just cos negative words to describe all the problems I have that take the focus away totally from what I can do so to this day I'm still on incapacity benefit I still haven't found a way to do something that can use what I'm capable off and not leave me in a complete state of permanent anxiety and fear because whenever I've taken a job the same thing has happened straight away within one month I need to see a psychiatrist I'm not coping I don't want to give up the work I want to I want a way out of the benefits I want to do and every time the rest of my life my my relationships with people my ability to cook the kids' meals on time or cook at all suddenly would become I mean we're all over weight now because when I get stressed I can't cook I can't remember any recipes even ones I've been doing for like 20 years and I can't read a recipe book without getting stressed getting it wrong buying the wrong ingredients from the shop all of that so all of that falls apart every time I take on something that gives me that satisfaction of finally I'm doing something good

K   mm

R   so there you go

K   ok

R   that's me

I thought this was the end of the interview, but I left the recorder on. Here is what Rose talked about after some unrelated conversation.
I mean my god at the council they used to tell me don’t tell the others you’ve got this problem because they’ll use it against you and I sat on a whole load of boards and the council used to send me the minutes for every single meeting and I used to sit there like an idiot reading minutes from every single meeting trying to work out whether or not it was relevant to me and in the end I told one of them that I was dyslexic and she said well would you like us to colour code so that if they come on yellow or green they’re yours and the others you can just put in the bin my god yes please so much easier instantly the politicians said don’t do that that’s costing the tax payer more money it is costing the tax payer more money and tax payers don’t want to pay for you to have expenses which when you think what the MPs (laughs)

were up to it really does put pale into insignificance that it was costing 50p extra for me but what understanding could they possibly have if they were telling me to hide it

I went to the press and I was bold as you know I’m dyslexic I have problems with this but look what I’m doing cos I think people need to see that they need to see that dyslexia isn’t a problem it’s just difficult because society values writing

so much if I lived in a different age where I had to kill my own animals to feed and build my own house everyone would be wanting people like me but we don’t we live in a society where you have to be able to read and write to achieve an education without an education (wipes her hands) you’re not needed
Simon

so I had that problem where you kind of had a time problem cos it was just a question I knew you had to work quick to do this but the most frustrating thing was I knew exactly what I needed to do so I remembered what the cases were I knew exactly what I needed to do on each one of them like there was no problems with the strategy and rubber stamping it was just implementing it which was just a problem I mean you kind of had the fatigue factor because you probably know what it’s like to do really late nights and sort of like work for long periods of time but eleven months working 12 hour days practically is just not healthy so er so they because round about after the third time I resigned I was just like you said you’d try and help me you kindly did and for one stage they did get a person to check with me and see what I could do with the time recording bit and how things were going and put procedures in place but it just all but it just always went wrong afterwards they left me on my own

and it was just always difficult for me working in that procedure and you’ve kind of got my dyslexia report in for the second time and they did a work place assessment as well and basically the work the dyslexia report they kind of divided you results into four sections so this time they were testing what was it? It was your processing speed your memory your working memory and then there were 2 others so it’s your ability to rationalise stuff formally and something else and they kind of split my report my results into 4 sections and what they said was they kind of had this percentile chart on it and I think for the top 2 things I scored like 95% out of 100 they said I was exceptionally good at those things it was like your verbal rationalisation skills are really good whatever whatever the other bit they tested was really really good and it might be my my ability to interpret visual data I think it was er or to think visually and to communicate in that way ere r stuff I did exceptionally bad on and we’re talking bottom one was bottom 5 the other was bottom 10% was working memory and processing speed which is kind of why I’ve always got a problem if I can’t work quickly it’s not because I don’t know it it’s not for that I can’t do it the way that they rationalised the processing speed to me was that it’s your ability to manipulate and use information so it’s not your ability to understand it it’s just that and that’s where I had the problem of where I knew what I wanted to do with it but physically getting that down on paper and achieving it was actually difficult so and then I’m pretty much that if you got everyone in any law firm to do that test very very few people would ever score that badly in that type of test cos they’re all highly educated

I’m pretty sure they wouldn’t score in the bottom five percent for that type of thing bottom 10% so they also did the work place assessment for me so they kind of went there they viewed what we needed to do and made a report and er the the lady I remember she she came in and explained it to my bosses who were like fine er she explained to me and sat down and worked me through asked me to tell her what those charts meant said I’d had exceptionally bad like my my use of spellings was fragile my my phonetic ability was fragile as well so if you read the report it just makes me out as though it just makes you look really really stupid which you’re not but it’s just like some of the stuff they put is quite stark and then they did the work place assessment and we we looked at it and it’s just like well you can buy lots of these courses from them but which may help you to get techniques but besides from that their actual suggestion that was their only practical
suggestion to actually help me out at the workplace and the woman who did it kind of like explained it in the report cos she was just like normally we can give suggestions to people but she turned around and went I actually think you’re in the wrong job

I was just like right she was just like basically you need to do x y and z and you just you physically you just you’ve done amazingly well to get this far and kind of do it but the reason why you work late and you can’t do it is because you’ve got these problems and they’re kind of extreme and just like and to be honest you can pay for our courses but she was like because you’re so bad at them she weren’t really 100% sure that they would impact make a difference cos she said and you probably know more about this than the person I spoke to so I don’t know if these statistics are true but she was just like normally if you’re going to people will improve but like 10 to 15% in that bit but because you’re like bottom 5 or 10% you’ll probably improve by about 10% which is still well under the speed which would be required to kind of do that they way they want to do it I was like right as I said the report had no practical the assessment basically it basically said well you should give him a bit more time to do this or a bit more time to do that but there was nothing much they could properly implement which given what they probably hoped which is we’ve got an employee we kind of like and he’s got lots of good skills and he knows what to do but how to get him to be more profitable quicker and that’s the point where we had the discussion well actually the only things which we could do would be to change our fee structure just for you and accommodate you only otherwise we actually we don’t want you to work for us anymore

which so the the obvious answer was the second was the second warning and it was just like and a firm that size they’re never just going to let me have an individual billing structure just for me it just wouldn’t work so it was the right decision to make and to be honest I wasn’t enjoying it anymore and it was kind of nice that you could kind of do something and you realised well actually the reason why I’m not going to be able to do this is because of x y and z and it’s it’s not something that is entirely my fault if you get what I mean

it’s just like well I’ve actually over exceeded for ages so actually I should be really really chuffed that I’d done that do you know what I mean so hence why I can’t talk about some of this stuff because cos understandably there’s a few disability discrimination issues with that suggestion which basically meant that we came to an agreement on what to do and they er and they made me sign a confidentiality clause which meant that the terms of that settlement are fine the other option was to not sign it and then kind of just say big city firm sort of like discriminates against people but you just kind of like well what’s the point in doing that it’s not really going to benefit anyone and I was quite relieved to to sort of like stop doing that anyway for those reasons er so that then left me with the problem of what shall I do next so I I think I solved that in a typical way by going on some very big holidays (laughs)

it’s just like why come up with a solution when you can disappear for a bit so er so I did that for most of last year and then I kind of came back and I thought what do I do and I kind of thought I kind of like law jobs but I don’t really want to do that because it was so stressful with that year turns out I just thought I don’t want to physically do that and I was offered my old job back a couple of times which is something I could easily do I just figured that I
didn't actually want to do it because I wasn't overly enjoying it in the first place so why would you want to go back to a lifetime of something you're not you go to work and not there are bits of the job I really do enjoy but it's the whole it's like constant writing it's a constant output which I just don't like I think that's it and er and sometimes I just got knackered of messing up in ways that no one else can mess up

it's cos I think I didn't realise til the other day cos we got chatting but do you know when you read stuff like what I I can remember one of my boss' sons has got dyslexia and they're very good at sort of like blurring the page things don't move about when I do it like you often get that on it I can sort of like get double vision where I can split it up completely which is meant to be a dyslexia trait otherwise it can go blurry completely I didn't realise that I II just thought that was bad eyesight that I needed to get my glasses changed so er I had no idea that that was a pure dyslexia thing so that's so sometimes when I was doing stuff I could read things my own way because like my brain would just like blur out huge sections and I just wouldn't notice it I just kind of read what I wanted to read from that particular thing so

so whenever I messed up or if I wrote something I was like this is this and then I'll come back and look and be like not the same how did I do that? And so like word processing is what I find quite difficult cos it just always goes blurry whenever I read and it's just really odd it's I always thought that was bad eyesight then some one of my friends told me her son does it as well they kind of did this test with glasses where they monitored their eye movements and then it was just going everywhere even though they were just looking at a piece of paper er so moving back to what I was talking about it was literally what do you do after that so I just applied for all just get a job and see where you are which is why I ended up working at (call centre place) er I think in a way it was really good because after 11 months of pure hell and that's probably a nice way of describing what (place 3) was like

I kind of thought right I'd kind of like a job where I've got no responsibilities so you kind of went there and I kind of found it really difficult to actually get a job cos you'll kind of put on your CV that oh you've done this and then you'll apply for something really basic and they're just like why are you applying here surely you're a bit too over qualified so I had to then dumb down my CV not tell people various stuff or not tell people that I was qualified and just kind of go in on that basis cos people get a little bit less intimidated and to be honest I didn't tell like when we started our induction at (work) it was just I didn't tell people I used to work for a legal firm I never told anyone I was qualified for a good 3 4 months and the only reason I told them was because they asked I was just like if they asked the right question I'll tell them but otherwise I wouldn't bother I don't volunteer information like I don't tell people I got a first or anything like that unless they actually ask

Natasha

only thing I can remember my mum saying from school was that she couldn't understand what we'd written

which was a product of the 60s teaching but nothing was ever picked up I've tried to find out more information but I just can't there was for some reason I got taken out of school with about 3 or 4 other children and taken on days out and I can remember going to
Hastings Castle and the sea front and I’ve got no reason went with teachers I’d never met before and I don’t know why I still can’t remember why that was obviously there was some sort of educational they took us out of classes unless they had some sort of estyn report but obviously they didn’t have estyn then and they wanted us out I’ve just thought of that then

but I was always considered a low achiever I know that and one not able to you know er but then I started to I know that dyslexia was around at the time because my neighbour’s son who was a headmistress she diagnosed you know got a diagnosis of dyslexia for him but nobody I went through all of my college life and one person mentioned that to me and people round me were being diagnosed but anyway I sort of obviously gleaned from the media or whatever what it meant and just thought well I can’t spell I can’t do maths I think I’m quite intelligent so I must be dyslexic so I I’d been telling everybody I was to sort of cover up the point where I probably didn’t have difficulties

and um but er because of the skills I’ve got I’d really like to get into teaching on er degree courses which is obviously getting harder and harder these days (laughs) and one of the stepping stones of that now is or not degree courses even erm er what is it you know evening classes and stuff like that and doing workshops and I have been doing them and I have done foundation courses and degree courses at (uni) in the past and now everybody’s got to have a PGCE and a lot of friends have gone through that process so I decided to try the 10 week course and I sort of did it one to prove to myself that I was better than at school

you know another 20 years experience and erm hopefully to see it as a stepping stone to do the course to be able to do the teaching so when I went in I said I’m a dyslexic and they said well you can’t just say that you don’t have proof so erm the tutor was quite good she used to give me she used to write a lot on erm not a white board but the pads the big pads there and she used to give me those every night and everything was re- all the lectures were written down anyway so you did have a handout with each one and the course was great I really enjoyed it but I found it really tricky doing getting my head around writing an essay cos obviously I’d only been up to A level standard so I’ve never gone past that in 30 years (laughs) erm but they were saying we can’t give you any concessions for being dyslexic until you get tested so there was this long palaver going through disability services who finally said well because it’s only 10 weeks we can’t pay for it completely understandable

but you can have it for half price but it actually took ‘til the day after I had to hand my essay in (laughs) to get me the assessment and I I slightly ummed and aahed about it but my husband said look just do it you know it’s a lot of money but do it you know it’s a big chunk of money and it was great I really enjoyed it I really enjoyed having an hour and a half talking about myself (laughs) and he explained so much more about how I think so it’s really opened up an awareness and of course I have a dyslexic son it’s allowed me to help him more and explain to him why he thinks the way he does and the little triggers the things that could help so so that was only 18 months ago
and now I wish I did it sooner but obviously it’s you wouldn’t walk in off the street and say I want a test without being prompted so but it would have saved me a lot of sleepless nights and hassle at work if I had

my boss is into it all being confidential I said no I don’t want it to be I want people to understand that I’m not dizzy Natasha anymore I have a condition and she went and told me off because I’ve been trying to order this live scribe pen and stuff and I left the report by the phone cos I was in fittings and I said if anyone rings back on the post-it note on the top of the report could you write down the quote for me and she gave me a hard time you know for leaving what she considers confidential information by the phone in a work room and I said I was leaving it there because and she said no you’ve got to keep it you know you would literally have to take it away and sit down and read it properly it wasn’t like you could glance at it and pick up information and I’m really I’m very open about all sorts of things like that the thing is why hide it?

I just I just find that I think very differently to her in the twenty years things that I think are common sense and quite normal she’ll make entertainment out of for a good few weeks you it’s bizarre isn’t it how differently we all are she keeps talking about I’ve got an example erm we had to go away for a fitting and I was just in the process of buying my first house on my own which is you know incredibly scary in the days when they weren’t actually bad costs (laughs) and we’d had to go away for a fitting and they give you a certain amount of money to buy food with but it’s never enough you always have to subsidise it and I said well I can’t afford to go out for dinner because they’ve only given us like £5 and I know that going out for dinner will be ten so I went to ASDA and I bought loads of French bread and cheeses and things like that but you’re in a hotel room and they’re boiling absolutely boiling and erm you’ve got no fridge and I knew I had this perishable stuff so I ran a cold bath and floated the things in the bath which is what my mum would have done and she’s not stopped joking about that that I had all my cheeses floating in the bath of cold water (laughs)

it was only for the sake of two hours so I could sit in front of the telly and have French breadcrumbs everywhere and have a nice time but it was just that there was a window where I had to buy the stuff and keep it cool but er yeah she er she still I remember when you had all your cheeses floating in a cold bath (laughs) but you know that’s the way it goes isn’t it

**Claire 1**

well I haven’t got a job yet but once I get a job but now I’m in a position where I’ve got to on supply

and you become even more anxious because you’re in different schools and everyone is going to be watching you and you you don’t know what you’re going to be given

whereas when you were on teaching practice I’d have time to read up on the stuff the night bef- well you’d have you’d plan all your lessons for 8 weeks and you knew what you were doing you’d research it you’d read it you’d make sure you could do the calculations or you
could do you know you knew or if you were doing report writing your structures and exactly what you were covering you were in control I was in control I could do it I was confident I could go in there

but now having to go on supply I haven't got that confidence

because you could just go in a classroom and they say right you've got to do equations (gasps) I yeah ok you know erm I'd have my books there but I won't be confident although I'm sure that it would work out ok but my my anxiety levels now of having to go and do supply teaching when I haven't done if I if I was teaching full time and had a permanent job it's quite quite different the anxiety levels of doing that of having to go out and not knowing what to expect and just being given something I don't know it could be on anything in primary school work it could be anything it could be English or erm something that I haven't maybe just revisited because usually I

I don't know whether it's to do with the dyslexia or not but stuff you know the short term memory side of things doesn't I do forget things so I but once I've read and gone over it again I think oh yes I know I know I'm fine I'm ok I I I know what I'm doing

but to be just given the work to say oh the year sixes are doing this at the moment I want you to get on with it I'd be like ok there's a lot more it it makes me a lot more anxious I'm sure once I've done a few I'll probably be ok but it's the unknown isn't it it's not knowing what to expect it's not knowing what people are expecting you to do and you don't want to be seen to be incompetent cos you know you are competent but it's just being thrown being given things that you haven't had any preparation for or been able to work out what you've got to do

so I think that's what I'm going to find difficult in the future is the fact that you know not knowing what I'm going to be teaching at least when you're doing the teaching you know that (inaudible) mostly at least you know or you've known the week before and you know what you're expected to do you could quite easily teach it and be confident teaching it but going in to schools 7 or 8 o'clock in the morning don't know which class you're going to be in and they're like there you are you've got to teach er this is what the work has been set today and they're asking you lots of questions at something you haven't erm looked at for a little while then you know er II

it just makes me a little bit anxious about doing that

but erm I am looking forward to being in a job and starting and and doing that but been for one interview but there's 150 people going for one job and you don't stand a chance you know if you're up against that then they say well what extra qualities have you got to give to the school and also the fact that you have to disclose your dyslexia on application forms they say doesn't have a bearing on it but a think because of the competition are the really going to choose somebody who has written dyslexia because you know on your application forms you know if I was in the same position would you think twice? Because people obviously have their preconceived ideas of what actually dyslexia means the fact that you've got someone who is committed and studious who's got distinctions who is very
good with the children who can see identify problems they're not going to see that they're just going to see the word dyslexia they're just going to see the label and

and and in a way I’m thinking should I have really have been tested cos had I not known I wouldn’t have to disclose it and now I’m thinking maybe cos I didn’t know until I was an adult

but then again I had support when I was in university with extra time because I was given you are given like a specialist tutor that you can go and get help with assignments or whatever but I couldn’t use it because I was so busy couldn’t the hours that I was given to help me couldn’t use them because I didn’t have the time and because of the distance between the university and here to juggle family life and being aware of your teaching and teaching practice and to juggle erm the assignments I didn’t have time to go to somebody and say can I have help I needed help I certainly needed help at times erm which could have been resolved in a short space of time but but I just didn’t have the time or the opportunity to do it

so basically in a way it’s a good you know you’ve achieved in on your own without support

but erm erm you didn’t you weren’t able to take the support because of the how intense the actual course was

**Madison**

it was kind of towards the end of that end of my second well no no no no it wasn’t the end it was Christmas time Christmas time in my last MSc year at (uni 1) kept handing in all my essays and again the As still kept the firsts still kept rolling I was still on a roll they still kept coming back nothing lower than a 2:1 but they were continually getting the same comments which were you need to proof read you need to proof read you need to proof read all the time and I was like I’m getting really annoyed now cos I proof read these like ten times now I don’t understand what’s going on between me proof reading them and handing them in and obviously a lot it was between because it was on the computer but I was like I don't I don't know why

and I was talking to (name) about it who was my boss now and she said have you ever thought about having erm the dyslexia test and I was like oh no no I haven’t thought about that and she was like I think you should and I was oh well I manage alright you know I don’t think I’ve got any problems and erm anyway she convinced me in the end so I went to the erm Disability and Dyslexia service and said that I think it was quite a long process of waiting and I think you had to prove that you had no money in order to get it funded by the uni that was it that was a problem in itself cos I think the test cost a couple of hundred pounds I can’t remember exactly how much for some reason I’ve got like £259 in my head but I could have made that up don’t quote me on that it was definitely a couple it was certainly something that I couldn’t have afforded and (laughs) I remember the woman there was like look have you got two bank accounts? I was like yeah empty one of them apart from about £20 and hand me the statement for that and I was like ok I can do that and she was like then you’ll have no problems getting it funded (laughs) so she was really cool because it was obviously not something that students can afford it’s
mad so yeah it takes a little while for all that to go through so then I I was booked on that
and on a dyscalculic test thing

and yeah I remember I don’t remember much about the dyslexia test I remember there
being a few tests not just oh no I remember it’s coming back to me now I remember a few
things like speed of writing you have to copy something out

I think it's an odd thing that it's biopsych- psychologist is it? I've still got all my notes my
yeah so that that freaked me out a little bit cos it automatically felt like you were a bit
mental and that you were having this special guy come in to test you and everything it’s all
a bit like ooh bloody hell and by then I was a member of staff and I was kind of trying to
find my way in the world and it was all a bit scary I think as an undergrad it would have
been less scary but that fear of being stupid stayed with me I think so not massively keen
on having the test done

but my my coping was saying I think if anything I’m a little bit dyslexic and that so I don’t
remember I great deal about the test but I remember the speed of writing I remember that
was the only thing I was good at he was like you've got really good speed of writing I was
like you try being a degree student that comes hand in hand you’ve gotta write a lecture it
was like pfuu (mimes writing quickly) but I think what he then tested was what I’d
remembered from what I'd written which was like nothing erm so I I now know I don't
have very good I can write really fast but I can’t take in what I'm writing if that makes
sense

erm and there was these picture cards I think I told you about those before where there
was somebody like somebody was getting up and you had to dress them and leave the
house and you had to put them in the right order I remember that being really hard it was
odd I remember getting really confused about all this and there was a couple of those
whereas I can’t remember any of the other tests but I do yeah I kind of because this whole
idea of being stupid has stuck with me I feel like they’re trying to trick me in catch me out
so I it’s really hard to for me to let my guard down enough for me to do a test like that if
that makes sense but I feel like people are trying to trick me into being stupid but

erm yeah it was relatively ok ok with that and then like the dyscalculia one which I didn’t
even know what that was that was booked for a couple of weeks later and I did that one
and that was an epic disaster it was really traumatic that one it was horrible and I didn’t
expect it to be I think there was like a it was a workbook like three or four pages of sums
and mathematical stuff that you had to do and you had it was in a particular time limit and
it was like an hour or something but oh man that was I had a complete lack of
understanding about how the symbols worked I just didn't know I hadn’t really seen them
before I didn’t understand what it was asking me to do with them so got like three
quarters down the first page and I couldn't do any more and I literally didn't know what it
meant didn’t know what to do and after a little while I was just getting really emotional
and I was like this is and he was like don’t worry I think we’ll stop now I think we’ll we’ll
leave it there because you’re in distress and it’s obvious that you you’re not going to
progress much further than that anyway
then he came back and we had a talk about all like all of the test together what they all meant what we’d done and stuff and he was a really nice guy actually and he he talked to me about I can’t remember the actual question he asked me but it was something like describe to me how you work stuff out no what was it? I was trying like cos I was saying to him it felt like I in terms of like grammar spelling all of that kind of stuff it felt like I missed that week in school like I felt like I was ill that week or something that was always how it like I’ve got no understanding of it in my head I don’t know when I’m supposed to put a comma I just throw ‘em in (laughs) and just hope they’re in the right place and I tend to do it when I need to take a breath and that’s obviously not right the majority of the time

well that’s my golden rule if you you know when you read if you breathe you just chuck a comma in there and he he I remember him saying to me that’s something that’s really common that it doesn’t mean you’re stupid that doesn’t mean that you missed time off school unless you did I was like no no I didn’t have any time off school when I was in primary school like just people with dyslexia work at different speeds their minds work in different ways he was like so in terms of primary school teacher writes something up you write it down they wipe off and then do something else he was like that’s not that’s not the right speed for somebody with dyslexia and yeah he was like talking about a scale of like a point scale of how far you are over

and sorry it’s couple of years ago now I find it difficult to remember specifics but he was like describe to me how if you are if you think you are dyslexic describe to me how how much you think you are well I think I’ve only got a few issues and that it only you know affects me a little incorrect you know (laughs) he was like you’re in fact 12 markers over being dyslexic and I was like oh oh well that’s quite a lot then again I don’t really know how it worked but that was quite significantly into the dyslexic scale so I was just like oh that’s interesting that changed my view on it a little bit on sorry on education

I hadn’t failed I’d just got a first in my degree and by that point was well on my way to getting a first in my masters which I did get eventually which is very cool but it was always like and it’s still with me now is that I just I feel not as good as everybody else and yeah and it’s the same with like that’s why I was so surprised when I was picked to do this PhD thing it’s just mad but that kind of yeah I still feel not as everyone else doing it I don’t know whether that’s something I created for myself or what really but it always feels that it’s really hard really and it’s really difficult and I feel especially with supervisors I feel it’s a weakness they find irritating and they’re not very sensitive to it either like I told them about it and they were really cool when I told them which really not them being cool with it

what pissed me off was that sorry I should stop swearing what upset me was that in order to get support from the uni if you are (name) funded you had to get a supporting letter from both your two supervisors and your head of school so I’d just arrived in (place) and I had to tell all these people I didn’t know that I was dyslexic so I’ve already got a complex about being stupid and that was really that really upset me cos in (uni 1) everything’s really confidential and you don’t need to tell anybody you don’t need your supervisors to know it’s something like that the disability and dyslexia service can send them a letter saying they need support if you want them to but it didn’t have to have any details like
where as I felt it was really bad you know you come to a new uni I’d never even met the head of school and he had to do yeah you had to get a letter from him

Peter

so up until I was I did my GCSEs and I did ok but I wasn’t really like I passed them all fine but I didn’t do amazingly well in them and then in fact there was a big family event and my family was all split up and like I was went my own way and then decided to go to a different school of my choosing to do my A levels and chosen my subjects that I wanted to do erm and did things like economics and business rather than traditional like English literature and thing which I was pushed to do before hand and that’s where I did really well and so I think it like that people have different brains for different things don’t they and I think I found what I liked doing in that way and then that’s when I started to have an interest in learning rather than it being like a chore and I went to university to do economics and then but I did economics with law as a minor and then at the end of the first term I decided I wanted to do law as a full subject and they were like no you’re a term in and I said to them well let me sit the exams for the first term and if I fail then fair enough I won’t do it and then that’s when I that was the point when I started to get a passion

and I worked really hard to pass them and I passed them all really like amazingly well and so they let me change my degree like after a term and so then that’s when I did law erm which I found quite hard in terms of I think my learning thing like it didn’t come easily like cos there’s so many case names and dates that I had to remember and I found it really hard for my brain to get around that and although I really I loved it I love sitting in the library and reading about the different ways the law is interpreted but when it to examination like I found it really hard- like the way that my brain works I found it hard to perform as well I shou- like I never like my my kind of thing in life is that I always in an everyday thing you know in report cards and kind of general feedback from teachers and lecturers is really good like got the potential to go really far but when it comes to the exam like I don’t do rubbish in the them but I don’t do as thing and I just think that’s the nature again of maybe that’s where my like I find it hard to process like in the conventional way rather than a yep does that make sense?

Claire 2

when I went to do an HND in early childhood er I I thought well is- is it just the fact that I’m dumb or a bit thick or that this is just my level or is it something else could I be dyslexic or a bad reader why I find it difficult so I went to the dyslexia association in Cardiff and I was tested and it was really just to confirm what I thought and they said I was dyslexic and I probably had dyscalcula or dyscalculia I don’t know which how to pronounce it so erm so you know and you know that sometimes the two are linked

cos at first now even though I’ve done a teaching qualification erm I I still find it hard to do timestables because of the sequence of it and certain things if I need to I can do them but I need to go over them redo them erm and refresh things regularly
so erm that’s where I am now I’ve just finished the PGCE in the summer and at the moment I’m looking for work and there’s not a lot of work out there at the moment for teachers so erm I’m looking for work this year

**Hilary**

went to the local primary school erm thoroughly enjoyed school but always enjoyed the social aspect of school more than the academic was reasonably successful academically but nowhere near so much as my sister who was a linguist well she was just academic erm from a very early age and as she went through education was always top of her year in everything until she got to university and then realised there were other people who were equally like minded but until then she’d never had a challenge erm it was still grammar school set up when I went to school and I actually did pass for grammar school but fortunately it was non exam based it was the first year that they did it through teacher assessment erm which I think allowed me to actually get a place a grammar school then I don’t think I would have done necessarily

I don’t know my parents always expected my sister to go to grammar school without any qualms at all prepared me very much that I might not erm and that I might go to erm secondary school which they would have been quite happy about and I would have been happy about it wouldn't have been a problem but it wasn't necessarily an expectation that I would do as well to get to grammar school erm never had any diagnosis never any thought of from dyslexia I started school I presume it would have been 1958 cos I was born in 53 erm remembering experiences way back to infant school few and far between I do know that I erm tried to opt out of things sometimes and I do I mean remember one instance where I sat in a puddle because I thought I would get sent home when I was about 6 and I don’t know why but I assume it was do with not having to do I thought it would be easier to be at home than having to write

so writing was always a bit of a problem not a major problem erm reading I coped with fine maths I coped with fine unless it was do with tables erm concepts were no problem so I was always particularly good with concepts at school and ideas erm but not necessarily about the writing that was I would shy away from writing from as early as I can remember really it was never looked at as a problem that was a that just appeared to be who I was and I was accepted for that within family and at school erm and although maybe I wasn’t as successful with those skills as I could have been I was certainly more successful than the majority in the primary school erm again at secondary school erm continued liking the social aspect maybe the after schools clubs the sports erm all the extra that go round school really really disliked languages erm only did French but hated French couldn't do French couldn't remember couldn't hear it actually and I still can’t hearing languages I find very difficult

erm managed to get O levels and A levels probably got my A levels partly on the back of my sisters work just reading what she’d written doing that but I’d never had a my problems are minor compared to a lot of people I suppose but also I think I worked out ways of coping and it wasn’t until I went to college to do teaching and I was particularly interested in helping and always right from the very beginning of wanting to teach wanted to help children who didn’t find learning easy erm and it wasn’t until so that was early 70s I was
Appendix

Narratives from Chapter 7

8

in college and we started to look at dyslexia and we started looking at sort of simple tests
and simple sort of tricks of the trade then almost of how you could erm decide if a person
was dyslexic but I in all the tests and things came out as severely
dyslexic although it really has only affected in academic roots sort of spelling the
organisation of essays and things like that erm it never held me back I don’t think although
maybe I wouldn’t have chosen to teach? Maybe I would have done other roots I don’t know
erm and I think then because of having a family two children who were both ended up
being dyslexic erm my husband says he’s dyslexic but he only comes out very very
marginally but having this sort of whole family of dyslexics special needs has always been
sort the way I’ve ended up going through teaching erm was a bit of a struggle having
children through school being dyslexic I had two one who found it much more difficult to
cope with and battled it erm so that there were more times and instances that I felt I
needed to go into school and be supportive and see if there were ways that the school
were going to be supporting which didn’t happen very much that was sort of early 80s
erm my son who was so much more laid back it didn’t really bother him what he was
doing and again because I had a son who was very able to articulate his ideas and was
doing ok school said he was doing ok all the time that we never actually pursued the
dyslexia with him until he was post 16 whereas our daughter we pursued it from when
she would be started pursuing it about 8 or 9 erm so there was always fam- a bit of family
tension around that

erm and then my own career has followed I’ve done special needs led SENCO through
primary schools and special provision schools for 30 odd years now and dyslexia is a
major part of my job at the moment erm I’m in a middle class well it would be perceived as
a middle class school (posh place) erm sort of leefy green erm it is a mixed school of
different types of people erm a lot of the pressure of my job now are people parents saying
that they feel that their children have dyslexia erm and what are we going to do about and
as (city) have not yet they might have soon but yet really still don’t recognise it

erm their main way of finding out is by paying out to an organisation to have full testing
done can't be done by the authority which is a major drawback erm cos it is expensive for
parents erm and I’m continuing look at looking at the IDP (individual development plan)
and how schools teachers will actually change their practices and it’s a very slow slow
process I don’t think it has actually improved an awful lot school would say they have and
are dyslexia friendly schools still individual staff find it very difficult to look at person’s
work and see further than that they look at the work and see a messy piece of work and
think that the child’s ability is shown through that piece of work they don’t look at the
child first and work the other way and unfortunately I think that is a big battle a big area
to break down so I now teach I live in a home with I have two homes I live with my
daughter weekends and holidays and I live with friends during the working week and
I suppose dyslexia has almost moulded my work my life actually in a sense which I
wouldn’t have expected to be cos I never even knew it was there

til early 20s erm it affects me in my work I would say organisation is a problem spelling is
poor but not horrendous erm and I think it’s been positive in that I’ve had to learn to look
for things look at things in different ways so I’ve never seen it as a negative I do wonder if I
might have chosen other channels but then I suppose everybody could have looked at other channels I mean you make choices don’t you

and they form where you go so I’ve never done a lot well I have recently a couple of years ago did some post graduate study and I would actually quite like to pursue that erm and do more nearly did the dyslexia qualification actually you know the dyslexia dd modules dyslexia action recently erm and it is something I would consider doing erm so I am sort of a dyslexic I’m I’m more of a dyslexic in thinking and attitudes I don’t know that it’s affected my practise erm of achievement to that extent

Fred

right ok I was born in (place1) hospital on the 22<sup>nd</sup> of April 1957 er my mom my dad lived with my granddad at (address) in (place2) I’ve got very few memories of living there we moved when I was just before I was 3 born 1957

so we moved in December 1960 yeah just before I was 3 (sic) about the only memory I’ve got of that is the the dog having a fight with next door’s dog (laughs) erm yeah so in December 1960 we moved to (place 3) (address) and that’s where I grew up I can remember going to the house in (place3) before it was built before the work was completed I can’t remember who it was that was with us but they hadn’t put the stairs in and dad whoever this other man was had to climb up some boarding to go upstairs so as I say moved in with granddad December 1960 erm we settled into village life fairly quickly there wasn’t anything like erm preschool or nursery or anything then so I started primary school as I think arising 5 if I remember rightly and the school was then in the old school building on the (road) er I can’t I can’t remember too much about my early school days erm I think I cried a lot (laughs) erm and I remember mum always seemed to know I’d been crying when I got home I don’t know how she managed to do that (laughs) erm yeah so progressed through school ok not many real memorable incidents in primary school I remember used to have a maypole and we used to dance round it on May day and I always used to get the I always used to get it m- it was always me who used to get it er messed up (smiles) I’d go in instead of out or out instead of in or whatever erm I think I’d always had problems with my handwriting but I can’t remember it being but I don’t I can’t remember there being school reports at junior school there probably was but I can’t remember seeing them erm I would say we had quite a normal family dad worked for the GPO mom can’t remember mom might have been working at the garage as a cleaner? And mom I can’t I don’t remember that

erm my sister (sister) was born when I was 7 so mom wouldn’t have been working then

and I think it was the same year I caught chicken pox off a friend at school whose name I can’t remember now and I think I passed that on to granddad but of course in an adult it’s shingles and from then on granddad wasn’t very well and I think he probably died within 12 months of that (sister) certainly wasn’t very old erm so then there was the the 4 of us but I think we had a fairly normal family life went on holidays we used to quite often go down to my uncle my mom’s brother uncle (name) aunty (name) at Weston cos they ran a erm boarding house so that’s my memories of early holidays
I know the one holiday mom couldn’t come with us so that presumably the year granddad was ill and dad just left me on the beach digging all day and I got horribly sunburnt so the next day we didn’t go to the beach we went to the caves at Wookey hole or cheddar or one or the other I remember that (smiles)

Erm yep erm I don’t when it was about that time or later we had quite a dispute with our next door neighbours which was quite er er nasty I suppose we never talked to them for years after that that was the (family) who lived on the left hand side erm

and about that I think it was about that sort of time I was coming towards the end of junior school the mom and dad were very involved with the well dad was involved with the parish council mom was as she always was involved with the WI and they both were involved in the village hall committee building the village hall we had a pig roast in the village and I can remember helping setting those up erm in the January before I moved to senior school the old school closed and moved into new buildings in (lane)

and then I remember around that time I took the 11+ and passed and managed to get into grammar school erm there were three of us from the village out of a class of about dunno 15 20? If I remember rightly managed to get to grammar school (boy1), (boy2) and my self

Xander

so yeah got into the got into the grammar school was good there were a couple of others went from my school and that was that really kind of primary school finished did SATs is that the one? yeah did SATs did ok in them erm and then went went to prim- went to secondary school and started there and in in the first couple weeks of that they did erm they did lots of well not lots of tests they did some tests to find out who were who was struggling with different things like maths and English and er they flagged me up as having trouble with English and er they said we think this person’s dyslexic which was interesting because my brother’s dyslexic and he was diagnosed when he was at primary school and my parents knew that and they thought I was similar but I don’t think they ever thought I was actually dyslexic but they sent me off to get tests and turned out apparently I was dyslexic not really badly but was so this was all interesting so

erm had to er had to well yeah was was told that that they offered extra support so this was something I could go to which they brought in what was her name? Mrs Helper that was the one erm and we’d go and do exercises which I can barely remember now but they were probably useful in some form or another erm so yeah Mrs Helper taught us went through with us exercises to do with erm to do with coping with the dyslexia I guess I imagine different things erm I remember that we did study skill classes as well at school and they were erm they were quite useful actually erm but that wasn’t just for people with dyslexia or other issues erm that was that was for everyone so but we did lots of stuff then I think that’s because they wanted us to well so good techniques for revising and what have you and stuff like that and a lot of them were quite useful actually so so that was that