An exploration of the emotional health and well-being of severely dyslexic children in mainstream primary school and the role of teachers in supporting them

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ABSTRACT

Through Biographical Narrative Interpretive interviews with two parents of severely dyslexic children, this dissertation aims to uncover the factors, other than lack of resources in education, that influence the experiences of severely dyslexic children in mainstream primary school. The use of an interpretive panel comprising specialists and non-specialists has allowed for a deeper interpretation of the parent’s narratives and for the views of teachers to be taken into account, and a reflexive approach has enabled the researcher to introduce her own personal story and motivation for writing the dissertation. This research demonstrates that lack of teacher training in special educational needs significantly effects how severely dyslexic children experience mainstream school in terms of the likelihood of getting an early diagnosis, individualised intervention and understanding of their difficulties. However, the dissertation asserts that there are things that teachers can do, even without resources and training, such as learning how to identify children at risk of reading failure at an early age, adopting an inclusive approach in the classroom, responding to children who develop low self-esteem, valuing and celebrating non-academic competences and strengths, encouraging children to participate in decisions around their learning difficulties and recognising and harnessing the knowledge and energy of parents to work towards what is best for the child.

Glossary

BNIM - Biographical Narrative Interpretive
ITT – Initial Teacher Training
SpLD - specific learning difficulties
SEN – Special Educational Needs
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I must also thank the parents who I interviewed and the five very kind people who participated in my interpretive research panel. I am grateful to you all for giving up so much of your time.

DEDICATION

I would like to dedicate this dissertation to all those children who have not had their strengths and talents recognised at school and perceive themselves as a failure because they cannot read and write.
Why Dyslexic?

A present from the depths of hell
A pain that’s like no other
An essay for some is a piece of cake
All it does to me is make me ache
Pen and paper mock me
My imagination roars but can’t perform

By Marcus Malley, 13, from Moon Hall School, a specialist school for dyslexic children.
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CHAPTER 1: INTRODUCTION

1.1 Rationale

My main motivation for conducting this research project is a personal one. My son is severely dyslexic. His needs were not met at mainstream primary school and this resulted in him developing extremely low self-esteem and becoming anxious and depressed. Through my involvement with online forums and local support groups I have become aware of other severely dyslexic children who have had similar experiences. With one in ten children in the UK affected by dyslexia (Dyslexia Action, 2012) and around 4% experiencing it severely (National Literacy Trust, 2015), I believe that the emotional health and well-being of dyslexic children is also an issue of wider significance. I have also been struck by the lack of research on severe dyslexia in general and in particular the emotional health and well-being of severely dyslexic children.

During the six years that I spent trying to secure appropriate support for my son, I encountered a special educational needs (SEN) system which was defensive and adversarial and was not led by the needs of the child. My MA in Childhood and Youth Studies has provided me with an interdisciplinary framework with which I can engage with the broader issues affecting children and attempt to create meaning out of my son’s experience. I hope that my research will contribute to knowledge and understanding in this area.

My son’s story is shown in the Appendix. Please read it. What happened to him is not representative of all severely dyslexic children, but his story provides a background and context for my dissertation and demonstrates my motivation for wanting to undertake this research.

1.2 Definition of Dyslexia

This dissertation uses a definition of dyslexia which highlights problems with word decoding that impact on spelling performance and the development of reading fluency (Snowling, 2013). The Rose Report emphasises that dyslexia occurs ‘across
the range of intellectual abilities’ (2009, pp.32) and also causes difficulties with verbal memory and verbal processing speed. Rose (2009) also describes dyslexia as a continuum from mild to severe, where severe dyslexics have the most entrenched difficulties.

1.3 Research Questions

Main research question:

- Other than lack of resources, what are the factors that influence the experiences of severely dyslexic children in mainstream primary school?

Subsidiary research questions:

- How helpful is the term ‘dyslexia’?
- What do teachers understand by the term dyslexia and how well do they perceive they can support severely dyslexic children?
- Is it possible to effectively support severely dyslexic children in mainstream school?
- How can teachers facilitate a positive sense of self among severely dyslexic children?

1.4 Overview of the Dissertation

I have conducted a literature review which provides the theoretical framework and policy context for my empirical research and has academically grounded my study. My empirical research will explore the lived-experience of two parents of children with severe dyslexia through the use of a biographical interview.
CHAPTER 2: THEORETICAL FRAMEWORK AND POLICY CONTEXT

In order to conduct a review of the literature relevant to the issues I have identified and accessed electronic resources such as JSTOR, SCOPUS and ASSIA and relevant books through the library at Sussex University. I did this in a systematic, methodical manner.

There would seem to be a gap in research on severe dyslexia in general and in particular on the emotional health and well-being of severely dyslexic children, therefore my literature review is to a large extent based on searches using the term ‘dyslexia’.

2.1 Dyslexia: the historical and policy context

The term dyslexia was coined in 1887 by German ophthalmologist, Rudolph Berlin, who used the term to describe word blindness in adults caused by brain trauma. It was not until 1896 that British physician, W. Pringle Morgan, wrote about developmental word-blindness. The view that dyslexia was caused by deficiencies in visual processing was rejected 30 years later by Samuel Orton and nowadays it is accepted that reading is principally a linguistic skill and that the most significant cause of difficulties in learning to read is ‘in establishing connective bonds between a word’s spoken and written counterparts’ (Vellutino et al 2004, p.30). Today experts across all disciplines agree that dyslexia is likely to be, at least in part, neurological in origin (Eden & Flowers, 2009). Goswami says that dyslexia is ‘genetically carried, but not automatic... It’s more common in males, and we don’t yet understand why’ (Telegraph, 2015).

Dyslexia was first acknowledged by Parliament in the Chronically Sick and Disabled Persons Act 1970 and in 1995 it was acknowledged under the Disability Discrimination Act and was also mentioned in the 2010 Equalities Act. The Rose Report (2009) provides a valuable framework for strengthening both policy and practice, however the extent to which its recommendations have been incorporated into the fabric of mainstream education is debateable, in particular in terms of the need for more teacher-training in dyslexia.
It is notable that recognition for dyslexia in Britain started to occur at a time of post-industrialisation. An increase in service industries led to a greater expectation for the population to be literate and in 1988 the National Curriculum, which places a strong emphasis on reading and writing, was introduced. There has also been an increase in the school leaving age from sixteen in the 1970s to eighteen in 2015. This expectation for children to stay in education longer constructs children as incomplete, ‘novices’ and ‘not ready yet’, rather than people with their own interests and preferences (Stables 2008, p. 5). In Britain, children’s competence is very often measured by their educational achievement and the focus is on their educational outcomes and what they will become rather than on their everyday lives as children (Morrow, 2011).

Elliott makes the link between perceptions of intelligence and reading and says that ‘public perceptions often link reading difficulties with intelligence and, in our culture, an attribution of low intelligence often results in feelings of shame and humiliation’ (2005, paragraph 13). The National Literacy Trust says that prior to dyslexia being recognised as a condition ‘there was a general feeling that dyslexia was a polite term applied to middle-class children who were just not very bright’ (2015).

There is a great deal of information available about dyslexia, however there is still plenty of debate, controversy and myths surrounding the subject, often stimulated by media sensationalism. Some theorists, such as Rice and Brooks (2004), argue that no distinction can be made between people with dyslexia and those with general reading difficulties, while others, for example, Moats and Green (1995, cited in Wadlington and Wadlington, 2005) highlight the importance of differentiating dyslexia from other learning difficulties in order to implement appropriate treatment. Stanovitch (1996, cited in Reid, 1997) casts doubt on the role of intelligence tests to identify dyslexia and perhaps the most vocal of them all - Elliott and Grigorenko (2014) – state that the term dyslexia does not constitute a separate category in terms of cognitive profile, neurobiology or genetics and say that it creates unfair boundaries between those who have a diagnosis and those who do not. Gillies (2005) suggests that a diagnosis of dyslexia is related to middle-class cultural power within education, which leads to inequality for working-class children. I am
interested in the extent to which these kinds of debates around dyslexia affect the perception of teachers and in turn their attitudes towards dyslexic children.

Gardner (1983) was the first to argue that dyslexia might be a different way of learning and therefore a difference rather than a deficit. He took the view that intelligence was expressed in several different ways and that linguistic ability was just one of them. This interpretation is still held by the British Dyslexia Association (2015) which believes that viewing dyslexia as a learning difference focuses policy and practice on inclusion and differentiation and leads teachers to find solutions themselves rather than relying on specialists.

2.2 The role of teachers

The section above has illustrated the ambiguity and confusion surrounding the term dyslexia. I am interested in how much teachers know about dyslexia, to what extent they believe some of the myths around the term and how able they feel to support dyslexic children.

The 2009 Rose Report, which was commissioned by the Government, recommended that the Training Development Agency for Schools and the initial teacher training (ITT) sector strengthen the coverage of SEN and disability (including dyslexia) in courses and through professional development. The Coalition Government declined to make SEN and specific learning difficulties (SpLD), including dyslexia, a compulsory part of ITT on the basis that this should be left up to individual training institutions.

The Driver Youth Trust conducted two recent surveys about teacher training in dyslexia – one among teachers and the other among teacher training providers (2012 and 2013). They found that 7 out of 10 providers (69%) spent less than a day training students how to support children with dyslexia and nearly a third spent less than half a day. Half of teachers (53%) reported that they had received no training on dyslexia and three-quarter (74%) did not feel satisfied that their ITT provided them with the skills they need to identify and teach children with dyslexia.
Jones and Burden, in their study about the attitudes of student teachers (2010) reported positive beliefs and values about dyslexia, however, only a small proportion claimed to know how to support dyslexic children. Wadlington and Wadlington (2005) developed a Dyslexia Belief Index to investigate teachers’ beliefs about dyslexia and found that the majority held misconceptions about what dyslexia is, for example that word reversal is the key measure used to identify dyslexia.

2.3 The Dilemma of Difference

This section examines difference and how the education system approaches it in terms of labelling and inclusion.

2.3.1 Providing for individual difference and labelling

The word ‘normal’ entered the English language in 1830 through statistics and was later adapted to the human body and human traits. Davis (2014) talks about the dangers associated with the word and how Golten, the founder of Eugenics, used the word when trying to improve the genetic quality of humans. So what happens in schools when not everyone fits under the bell curve of normality?

There is a clear tension in SEN between, on the one hand treating all children the same, and on the other hand providing for their individual differences. The former risks not supporting children in a way that is relevant to their individual needs, while the latter risks labelling and stigmatisation. This contradiction was highlighted by Warnock in 2005 and is a key debate in special and inclusive education. It has become known as the dilemma of difference (Terzi, 2005). Within this debate there are opposing arguments relating to whether or not disability and special needs are caused by individual shortcomings (the medical model) or by limitations inherent in society (the social model), or more specifically, in the school system.

Dyslexia in schools in Britain is seen in terms of the medical and educational model of disability (Macdonald 2009). The medical model recognises dyslexia as a neurological dysfunction which leads to restricted educational participation (Morton, 2004) and the educational model refers to underlying cognitive impairments leading to specific processing deficits which can be overcome by educational adjustments.
This model acknowledges barriers to learning but still focuses on individual limitations and does not fully accept the importance of social and cultural discrimination (Barton & Armstrong, 2001, cited in Macdonald, 2009). Terzi (2005) argues that the capability approach, developed by Amartya Sen, provides a framework for re-examining special needs in school. She would like to see arrangements in schools re-evaluated in terms of capability and believes that disability is relational to the environment.

A separate, but related, argument concerns the classification and labelling of special needs. It is argued that being given a label can lead to opportunities, often in terms of extra resources, which would not otherwise have been gained (Gillman, Hayman and Swain, 2000, cited in Lauchlan and Boyle, 2007). However, Ogilvy (1994) states that the label is only of use if it leads to relevant interventions. Others claim that labelling increases awareness and understanding of particular difficulties and may lead to ‘increased adult tolerance . . . that helps teachers and carers understand why the child [has particular difficulties]’ (Gross, 1994, p. 105).

The counter argument to this is that labelling leads to stigmatisation, although Riddick (2000) challenges this and showed in her study of dyslexic adults and children that stigmatisation occurs even before a label is attached to their difficulties.

2.32 Inclusion

Particularly relevant to a discussion about difference is the subject of inclusion. I am interested in why both of the children in my research went to a specialist dyslexia school and how education can move towards inclusion.

The United Nations views inclusion as ‘a dynamic approach of responding positively to pupil diversity and of seeing individual differences not as problems, but as opportunities for enriching learning’ (2005, p.12). Interestingly, the UK government was the only country to place restrictions on Article 24 of the Convention on the Rights of People with Disabilities (2009) and by so doing retains the option for disabled children to be educated outside their local community when more suitable education provision is available elsewhere (Disability Action, 2015).
There has been a small shift in education to developing a more social model approach which recognises that disability is caused by the way society is organised, rather than by a person's impairment or difference, however Rieser (2012) argues that the medical model is still deeply ingrained. Rieser describes the social model of disability as breaking down 'physical barriers, communication barriers, social barriers, attitudinal barriers, educational barriers, institutional barriers….' and emotional barriers’ (2012, p.158). However, making these kind of changes is extremely complicated and requires whole school reform. Instead, schools often graft special education on to the mainstream school in the form of an inclusion class or room. Slee (2011) makes it clear that this is not inclusion. Peer and Reid (2001) write specifically about dyslexia and inclusion and say that an inclusive school has strong leadership which promotes a dyslexia friendly ethos throughout the school from senior management to dinner ladies and ensures that dyslexia has status throughout the school, for example, by including it in the School Development Plan which Ofsted uses to evaluate the management of the school.

2.4 Self-concept and Self-esteem

There is a general consensus that children with special educational needs often have lower self-concept and self-esteem than those without difficulties (Elbaum & Vaughn, 2001). However, studies on severe dyslexia are rare. The research presented below has therefore mostly been conducted among children with dyslexia, rather than severe dyslexia.

Pastorino & Doyle-Portillo describe self-concept as ‘... our perception or image of our abilities and our uniqueness’ which at a young age is ‘very general and changeable...’ (2013, p. 557). It is thought that people can have a good opinion of their competence in some areas (eg. sport) but a low opinion in other areas, eg. school work (Elbaum & Vaughn, 2001).

Self-esteem, on the other hand, is seen as a measure of how a person’s self-image matches up to their ideal self. James’ theories of self-esteem (1890) link how we feel about ourselves (pretensions) and how well we actually do; we can feel better about ourselves by succeeding but also by varying the levels of our hopes and
expectations. Children who are unable to do either of these may suffer from poor self-esteem.

Research has shown that children as young as 7 or 8 start to assess their own competence in relation to their peer group (Ruble et al, 1980, cited in Banerjee 2011). This starts in the form of glances at how peers are doing (Altermatt et al, 2002, cited in Molloy, Gest & Rulison 2010) and peaks in early adolescence when young people are more likely to make comparisons to measure their own competence levels (Dweck, 2002, cited in Molloy, Gest & Rulison 2010) and there is an increased emphasis on testing and grades at school. For those children who are achieving below average grades it becomes increasingly difficult to maintain self-belief in their own competence.

Humphrey’s study (2002) of dyslexic children found that the presence of dyslexia had a significant effect on both their self-concept and self-esteem. He found that dyslexic children often feel isolated at school and as many as half reported having been teased and bullied. In a Norwegian study of 70 severely dyslexic children and 70 non-dyslexic children aged around 12 and a half (Dahle, Knivsberg and Andreassen, 2011), severe dyslexics were reportedly more withdrawn, anxious and depressed than controls. They also had more somatic complaints, social problems and attention problems. In addition, they were rated with more delinquent and aggressive behaviour, but these problems were less severe. 9 out of the 70 severely dyslexic children had suicidal thoughts.

Dyslexic children can also have a tendency to avoid any activity at which they are likely to fail. Covington (1992, cited in Reid & Wearmouth 2002) described this as self-worth concern and others (eg. Seligman, 1975, cited in Reid & Wearmouth 2002) describe it as learned helplessness, when a child who faces failure over and over again begins to feel they are not going to succeed and sees no sense in trying. Humphrey and Mullins (2002) also found that dyslexic children at primary school age believe that when someone is good at reading, they are also happy and intelligent.

Alexander-Passe (2008) highlights possible sources of stress for dyslexic children when they start primary school: their short-term memory may put them at a
disadvantage when taking oral instructions from teachers (Thomson, 1995, cited in Alexander-Passe, 2008); poor phonological awareness makes it difficult to learn to read and harder to process spoken language affecting the child’s ability to participate in classroom discussion (Dockrell, Peacey, & Lunt, 2002, cited in Alexander-Passe, 2008); poor fine motor skills which may open them up to being teased by their peers (Alexander Passe, 2008). Thomson (1995, cited in Alexander-Passe, 2008) describes two ways in which children react to stress at school: the first is an under-reaction where the child withdraws and becomes anxious and the second is an over-reaction where the child hides their failure by saying that they don’t care or acting as the class clown.

So how can schools prevent a sense of failure from setting in at a young age? Research studies show that intensive early intervention over a long period leads to progress for children at risk of reading difficulties (Brooks 2007, cited in Rose 2009) which in turn means they are less likely to develop low self-esteem. Casserly (2012) also says that work on improving dyslexic children’s self-esteem must go hand-in-hand with well-founded, individualised intervention to support literacy. Lawrence (1996, in Humphrey, 2003) suggests that teachers can have a positive effect on a child’s self-esteem by having a warm relationship with them and developing good counselling qualities which Rogers (1951, cited in Humphrey 2003) describes as acceptance, genuineness and empathy. Biggar and Barr (1993, 1996, cited in Reid 1997) add to this that there must be an accurate diagnosis, agreement between parents and teachers and that the child must be consulted and feel understood.

2.5 The Right to Participation

Throughout the years that I was trying to secure my son support, particularly during the lead up to the tribunal, and the tribunal itself, I was struck by how both the school and the local authority did not involve him in any of the decisions that affected him. This section will explore children’s participation in education, specifically relating to children with special needs.
In the majority world childhood is based on a model that highlights children’s progress towards becoming mature human beings in the future (Kjorholt, 2002, cited in Baraldi, 2008). James and James say that education is perceived as the environment to introduce children into society and establish ‘how, as adults, they will find their place within it’ (2004, p.123).

Article 12 of the United Nations Convention on the Rights of the Child (United Nations, 1989) provides children with the right to express their views freely in all matters affecting them, in accordance with age and maturity. It also states that children have the right to be heard in any judicial and administrative proceedings affecting them. Article 3 of the UNCRC requires that the best interests of the child are a primary consideration in everything concerning them and emphasises that in order to do this it is essential to take account of the views of the child.

There is, however, a distinction to be made between simply consulting children and directly involving them in decision making. Wearmouth describes children as often ‘impotent at the hands of powerful others’ (1999, p.19) and Lansdown (2006) writes about the criteria that must be fulfilled for there to be meaningful participation: children must understand what the process is about, what it is for and what their role is; power relations and decision-making structures must be transparent; children must be involved early on in the process; there must be equal respect for all children regardless of their age, ethnic group, abilities etc; ground rules must be established; and there must be voluntary participation.

Lansdown, Jimerson and Shahroozi (2014) believe that when decisions are being made about a child’s education, for example, a change in the school setting, there must be opportunities for children to express their views. They strongly argue for children with special educational needs to become actively involved in their educational planning. Their review of research by Mason, Field, and Sawilowsky (2004) suggests that there are positive outcomes from children being more involved in educational planning, such as improved academic, advocacy and communication skills.
Ensuring that children can participate in decisions affecting them challenges the popular cultural assumption that adults know best. However, within the school environment, and in particular in the case of children with special educational needs, being involved in decisions about their education and their lives is important, not just in terms of exercising their right, but also in terms of creating more positive outcomes.

2.6 The role of parents in the SEN system

Thackray refers to the special educational needs system in Britain as ‘problematic and adversarial’ (2013, p.1) and cites the 2011 Green Paper which describes it as a domain "where parents feel they have to battle for the support they need, where they are passed from pillar to post, and where bureaucracy and frustration face them at every step" (DFE, 2011, cited in Thackray, 2013, p.1). The following section explores this further.

Parents are often the first to suspect that their child may be dyslexic and recognise that extra support is needed (Reid, 2011). In June 2012, Dyslexia Action published a report which concluded that parents nationally are ‘struggling to have their concerns recognised by schools’ (Dyslexia Action, 2012, p. 5). Although some schools can be supportive of parents, others can be unwilling to even acknowledge dyslexia (Lawrence, 2009). The Rose Report (2009) states that it is often a perceived lack of urgency from schools to provide support for the child that can cause parental anxiety.

Reid (2003) says that it is often the case that parents know more about dyslexia and the support required for their child than the school. Thackray suggests that when parents are more knowledgeable than practitioners about their child’s condition, or about the special educational needs system in general, practitioners can feel threatened and wish to ‘restore the status quo in placing them in a position of superiority over a parent, sometimes to the detriment of the child’ (2013, p.5).

Riddick (1996) points out that in many cases it is only when parents are able to carry out their own research and pay for assessments that dyslexia is identified. By the very nature of what is required in terms of completing forms and often dealing
with professionals across a range of disciplines, these parents are often middle class. Macdonald raises the issue of cultural capital in relation to dyslexia and states that middle class parents have ‘the knowledge and financial capital to challenge and control educational discourse’ (2009, p.133).

Riddick notes the importance of the relationship between parents and teachers when considering dyslexia (2010) but argues that parents are often treated as clients and not as partners by schools. A study by Bigger and Barr (1996) among parents, teachers and children about self-esteem, indicates that children can be sensitive to disagreement between their parents and the school. This puts parents in a difficult position if they need to convince the school of their child’s difficulties (Ong-Dean, 2009).

Riddick (1996) talks about how schools may perceive parents of dyslexic children who are in conflict with the school as overambitious, overanxious and unrealistic in their expectations for their child. When this happens collaboration between the school and parents becomes complicated and achieving a diagnosis of dyslexia can be difficult and lengthy, as well as causing anxiety (Lawrence, 2009).

It can be that behaviour differs significantly between home and school and some children with dyslexia may display anger or frustration at home whilst appearing withdrawn and detached within the academic setting (Riddick, 1996). This can cause difficulties in discussions between parents and teachers and parents can feel undervalued if their concerns are not taken seriously (Riddick, 1996).

Negative school experiences for dyslexic children can leave parents feeling helpless, frustrated, and unsure how to help their child (Dyslexia Action, 2012). In addition, dyslexia is believed to be hereditary and parents can experience feelings of guilt, as well as anxiety about their child’s education, which may be reminiscent of their own experiences (Rose, 2009). Earey’s study (2013) showed that parents can also feel guilty if, in the past before they had a diagnosis of dyslexia, they have accused their child of being lazy.
CHAPTER 3: METHODOLOGY AND ETHICS

3.1 Rationale for Research Method

The approach I have taken for my empirical research is psychosocial because it has allowed me to examine my research questions in an interdisciplinary way which resonates strongly with the ethos of my Masters. It recognises that the individual is at the centre of networks of interpersonal relationships, organisations, and cultural/political/economic systems and draws on a range of disciplines including psychology and sociology.

This methodology also recognises that reflexivity can lead to richer insight and deeper interpretation and has allowed me to introduce my personal story and motivation. Walkerdine, Lucay and Melody state that by paying 'attention to our thoughts and feelings during the research process we can often come to an understanding that might otherwise pass you by' (2001, p.89). I appreciate that in adopting this approach I have had to 'negotiate the swamp of interminable self-analysis' (Finlay, 2002) but hope that I have negotiated a path and developed understanding. With this in mind, I made field notes before, during and after conducting my research.

I have adopted a Biographical Narrative Interpretive Methodology (BNIM), which was developed by Tom Wengraf in the 1990s. This was a new methodological approach for me which would not only allow me to learn about a different research method and develop as a researcher but also provide me with an effective tool for exploring lived-experience through the use of a life story format.

The assumptions of BNIM are broad based; its analytic strategy aims to analyse three interrelated facets of humanity: the person's whole life history (Biography) and how they tell it (Narrative), whilst appreciating that narratives are subject to social interpretation (Interpretive) (Wengraf, 2006). I was attracted to BNIM because the 'interview' gives the respondent 'a space for their free associative thinking and feeling, thus enabling underlying preoccupations and defences to be expressed without interference from the defended subjectivity of the interviewer' (Froggett and
In addition, I find BNIM appealing because it requires a bond of understanding and rapport to be built between the researcher and the interviewee. I believe that my experience of having a child with severe dyslexia allowed me to form that important bond.

The use of interpretive panels in the BNIM methodology prevents what Wengraf calls the biographic inevitability illusion where the researcher has already decided on the interpretation of a story (2006). Instead the involvement of others allows for deepening interpretations and minimises researcher bias (Jones 2003). I believe that this is particularly important given my own possible parallel experiences.

3.2 Participants

I interviewed two parents of children aged 13 who have a diagnosis of severe dyslexia. My recruitment criteria were that the children could have other co-occurring specific learning difficulties, such as dyspraxia or dyscalculia, but not have a diagnosis of behavioural difficulties, such as ADHD. Both children had attended a mainstream primary school.

Through my own experiences as the mother of a severely dyslexic child I have built up an informal network of parents whose children have similar difficulties. This network comprises contacts I have made through word-of-mouth locally, as well as through Parent Champions (a support group for parents with children with dyslexia which was set up by the SpLD Trust). I approached two parents of children who fit the above criteria and both agreed to participate in my research.

3.3 Ethical considerations

Social researchers have many responsibilities when carrying out research, including protecting the interests of participants, protecting themselves and the institution they are associated with and ensuring that their research is conducted in a way that serves the interests of individuals, groups and/or society as a whole.
I had planned to interview three children, however, as the aim of the research involved reactions and emotions from the diagnoses of a disability, there were ethical considerations. Through discussions with my tutor, and in accordance with the British Educational Research Association’s ethical guidelines (2011) on interviewing children in potentially vulnerable circumstances, it was decided I would interview the children’s parents instead.

3.31 Protecting respondents

Key to ethical considerations was maintaining the anonymity of the participants and making sure that they did not experience any adverse effects from my research (Heath et al, 2009).

In order to protect the identity of the respondents in my research I have completely anonymised the transcriptions by changing names, place names, names of schools and local authorities. On the other hand, I realise that it is impossible to completely hide the identity of participants from people who know them well, or have encountered their story (Merrill and West, 2009, cited in Thackray, 2010). The anonymised, transcribed interviews will be seen only by my Tutor at the University of Sussex and by any Examiners for my Master’s Degree. Once the research study is finished I will destroy the recordings. As part of my ethical procedure I gave respondents an Information Sheet (see Appendix).

I was also mindful that research can have longer lasting effects on respondents beyond the actual interview (Joanou, 2009) and was therefore also careful to tell respondents before they gave their consent that sometimes people find that taking part in research studies about issues close to them can be distressing. For this reason we discussed their support networks prior to the interview.

In addition to protecting my participants, there are also ethical issues around telling my son’s story. I made sure from the outset that my son was agreeable to me telling a very concise account of certain aspects of his life. He has also read my version of his story and consented to me using it.
3.32 Protecting myself and Sussex University

The University of Sussex’s Ethical Review Board approved my proposed research as a low risk project. In order to maintain the highest possible standards of research practice throughout my project I have endeavoured to always take account of the consequences of my work and safeguard the interests of my participants. As part of this I established informed consent from both of the parents I interviewed and each of the panel members (see Appendix).

3.33 Ensuring the validity of the research

Qualitative research, and in particular narrative research, raises several unique ethical issues. Shaw said that when we ask someone to tell their story ‘we become characters in those stories, and thus change those stories’, which has ethical consequences (2008, p.408). Mills (2002) makes the point that a researcher can miss what the respondent is telling them if they pay too much attention to their own agenda and describes it as having two voices in the narrative – the respondent’s life story and the researcher’s autobiography. Liz Thackray (2010) discusses this blurring of roles and cites Becker (1967) who states that there is no problem in conducting research from an acknowledged perspective as long as other standpoints are documented and understood. I believe that I have minimised these risks by using a panel of five people to help me interpret the data and by my systematic and methodical analysis. I have also been open about my motivation for conducting the study and even written about my son’s story.

3.4 The interview

It was important that the interview was conducted somewhere quiet and private so that respondents could talk freely. One interview took place in my own home and the other was at the respondent’s home.

As prescribed by the BNIM methodology the interview itself with parents was very open-ended and I started by posing a Single Question aimed at Inducing Narrative (SQUIN) (see Appendix).
Whilst the respondent was telling me their story I made brief notes. I tried to follow Wengraf’s suggestion of just noting down three or four words for each key topic but found this difficult and inevitably wrote more than perhaps I should have. When the respondents insisted that they had finished telling their story we took a five minute break in which I reviewed my notes and selected items which I would probe in the second session. The key objective of this session was to probe for Particular Incident Narratives (PINs) (Wengraf, 2008), in the same order as told by the respondent, by asking open questions which would induce further narrative, such as: ‘Can you tell me what it was like...’; ‘Tell me more about....’ During this further narrative I once again noted down key words and phrases.

Once I had asked all of my follow-up questions I conducted another sub-session which took the form of a more conventional semi-structured interview in which I showed my research questions one-by-one and asked for the interviewee’s response to them. In the case of one of my respondents I also emailed her after the interview to clarify a few biographic details.

Both before and after the interview I wrote field notes in which I recorded my feelings, initial impressions and observations. These have provided me with an evidence base for my decision-making.

3.5 Interpretive Panel

Wengraf (2008) suggests that research panels should be made up of specialists and non-specialists. I therefore recruited three people who are involved in education plus two non-specialists. One of my research aims was to gain greater understanding of teachers’ knowledge of, and attitudes towards, dyslexia and I felt that this would provide a good forum in which to do this.

My participants comprised an experienced SENCo, a primary school teacher and a senior teaching assistant plus two fellow MACYS students. All were known to me previously but only two knew about my experiences with my son. Each participant brought her own social context or ‘lived life’ to the process and contributed to the process in a unique way.
In preparation for the panel I set about writing a chronology of objective life events (Wengraf, 2008) for each of the parents I interviewed. These are events that have occurred in a person’s life that could, if necessary, be independently checked. In advance of the panel I also selected around 10 meaningful extracts from my transcriptions. It was important that my selection was made without bias and therefore the process of selection was long and thorough and involved my supervisor and husband in this process. (Life events and extracts are shown in the panel transcript in the Appendix)

Objective life event and segments of text were presented to the panel in chronological order and they were asked to respond to a series of questions (shown in the Appendix) and discuss each one as a group.

I stressed to my panel members that it was an informal process and it was their opinions I was interested in. With panel members permission I recorded the discussion.

3.6 Analysis

Having read widely and talked to people who have experience of the BNIM method of analysis, I decided that it is too prescriptive and not for me. Instead I developed an analysis framework which seeks to look beyond the face value account. It involves concentrating on the plot of the story at the first listening and reading, before moving on to examining the unconscious by focussing on words and metaphors, contradictions, oversights and tone of voice. Brown and Gilligan refer to these as the ‘harmonics of relationship’ (1992, cited in Walkerdine, Lucey and Melody, 2001, p.96). The final stage of analysis involved referring to my field notes and paying attention to my thoughts and feelings during the interviews and panels, in particular the times when I felt anger or anxiety, sadness or empathy. Walkerdine, Lucey and Melody (2001) describe these as the times that psychoanalysts would say that counter-transference takes place. Given my dual role as researcher but also as someone who has had similar experiences to my two respondents it was important that I listened to these emotions and reported them in my research findings. I
reviewed the panel transcripts in a similar way as described above and tried to weave their interpretation of the narratives with my own.
CHAPTER 4: RESEARCH FINDINGS

4.1 Parent’s Narrative

This section explores the narrative structure of the two life stories which while unique, follow a similar narrative arc. I trace how their structure and content evolves through a focus on the beginning, middle and end.

4.11 The beginning

Suzanne starts her story by telling me about the complications of Sam’s birth. She says ‘that was the beginning really’ indicating that she sees this as a marker for where their problems started and suggesting that she was alert from the beginning to the possibility that he may develop difficulties.

Donna began her story by telling me that she ‘noticed from a very young age that he was different with books’. Reid (2011) says that parents are often the first to suspect that their child may be dyslexic and recognise that extra support is needed. In fact Donna mentioned to a teacher in primary school that she thought James could be dyslexic but the teacher said that she wasn’t qualified to comment:

Bearing in mind that I have never heard of dyslexia, I started thinking when I was reading with him – I wonder if he’s dyslexic? I quickly looked into dyslexia, never really thought that much of it, but I remember mentioning it to his teacher and her response was that she wasn’t qualified to comment on whether or not he was dyslexic.

Suzanne explains that up until Year 2 she was accepting of the teacher’s interventions to help Sam concentrate (he was provided with a wiggle mat, then an armchair and chalkboard), but when teachers, and mothers who helped with reading at school, started to suggest to her that she should read more with Sam, she comes across as feeling humiliated. This marks the point at which Suzanne takes control and she takes Sam to her GP for advice. She explains that her embarrassment was added to when social services were called to investigate how she and her husband had been dealing with Sam’s homework:
He was getting homework and he wasn’t bringing it home. Then the next day at school he was getting told off. At that time, because no one was taking me seriously, we were trying really hard. We were reading with him, doing spellings. So he was having anxiety attacks because of us and that’s when as well, in Year 2, he started having sleepless nights and night terrors. So he said to the teachers please don’t tell my dad, because he gets really angry with me. He said that three times so they had to get social services out. It was us trying to nag him, still not realising that Sam needs special attention.

Looking back, Suzanne explains that she feels guilty about the way she and her husband had become angry with Sam about homework before his difficulties were diagnosed – a point also made in Earey’s study of parents in 2013. She describes how it was maths homework that was the tipping point for deciding to take the local authority to tribunal over their choice of secondary school.

The final straw was when he was doing maths on the computer and sometimes it was against the clock. The anxiety that was coming out of that. I wouldn’t help him because otherwise it’s my work. That’s when the behaviour started coming and he started head-butting and biting himself.

Early on in her story Donna talks about feeling disheartened at parent’s evenings but at this stage she has no reason to disbelieve the school’s claims that they are doing all they can and she puts her faith in the teachers.

The school’s report didn’t really suggest much in-depth intervention. It pretty much said that they were doing all that they could. I kept going to the parents evening and coming away disheartened. James in himself was doing ok.

It is only when James is at secondary school that Donna starts to understand that she has rights as a parent:

I didn’t realise that you could demand what you want, go in and say I want this and I want that and all they had to do was say no and you could appeal....I didn’t know any of that.

Although James is described by the school as having dyslexic tendencies Donna says that he does not make progress and explains that she paid for him to have a few
sessions with a specialist dyslexia teacher. The turning point in Donna’s narrative is
when a teacher describes James as lazy. This acts as a marker for when she stops
believing in what the school is doing:

I remember him being in Year 6 and the teacher saying he was lazy and that
really made me cross. He was a sports teacher and he liked James.

Rose (2009) discusses the significance of parents who are themselves dyslexic and
how they may see their child’s experiences being reminiscent of their own. This is
also the case for Donna who recalls how she begins to realise that she is dyslexic
and sees James’ experiences as mirroring her own:

I wish my parents had been a bit more into my education because I still have
self-worth issues now because I was made to feel dumb. That’s stuck with me
for the rest of my life.

4.12 The middle
The middle section of both narratives is the most impassioned, using vivid language
which resonated strongly with me and reminded me of my son’s story.

Both parents report being happy that their children are awarded a Statement of
Educational Need and there is a sense that this could signify real change. However,
these emotions soon change to overwhelming sadness and disappointment as they
realise that it will make no difference to their children:

Nothing! Nothing changed. The Statement wasn’t very good. I looked at it
and thought ‘brilliant’ but when I went for a meeting at Northease the Deputy
Head there ripped it to shreds....... (Suzanne)

It was good news that he got a Statement, in fact I was over the moon, but it
still wasn’t that solid. You don’t realise until you become a parent with a
dyslexic child that you have to have everything in black and white – as solid
as it can be. If there is room for going off and not following what is on the
document, then they will. (Donna)
In both stories parents report this moment of disillusionment as being followed by a breakdown in the relationship with the school and consequent feelings of frustration, sadness and huge disappointment on their part. They both describe these emotions as giving way to anger and a determination to convince the local authority they should fund a place at a specialist dyslexia school. In narrative terms this marks the ‘complication’ of the story, the moment when the parents prepare to go into ‘battle’. They seek legal advice and pay for their children to be formally assessed by an Educational Psychologist/Specialist Dyslexia Teacher and a Speech and Language Therapist. Donna sums up the sheer determination to improve her son’s situation when she is speaking to a local authority Educational Psychologist:

...the Ed’ Psych brought me in and I think she was sounding out whether or not I was prepared to go the whole way. She said to me, ‘how did you feel about that meeting. It must have been very intimidating’ and I said ‘yes, I’m tired but I won’t stop. He’s my son and I won’t stop’.

4.13 The end

Both parents describe winning their tribunals, with the result that their children go to specialist dyslexia schools. This victory is greeted with feelings of relief.

The end of Suzanne’s story is about relief and happiness that her son is thriving at his new school. She talks about not feeling that she has to worry about him anymore and is clearly excited when she talks about his successes in athletics:

I feel totally relieved. Sam goes to school and I know I’m not going to get a phone call. I suppose I’ve let all my guard down and it’s like phew. Even with his homework I don’t panic if he doesn’t get it done.

Donna talks about feeling empowered from the moment she had the private dyslexia report in her hands and could demonstrate what she had been trying, unsuccessfully, to explain to the school. Although her respite is short-lived because James continues to get into trouble at his new school, she talks with huge pride about her son and tells me that she was nearly moved to tears when she saw his artwork:
... and she said he’s going to be an A’ level student, I nearly cried. When I looked through his work I couldn’t believe it. I said. ‘James, this is fantastic. Why haven’t you told me about this’.

I sensed that there is a very strong connection between Donna and her son, perhaps because she is also dyslexic and can empathise with his experiences. When she talked about James and how dyslexia has affected his self-esteem, it mirrored what she had said earlier about herself:

He’s a lovely boy. …. He has a heart of gold. But I know he has been damaged by this journey. He hasn’t got the confidence. I see it. Looking back I think he finds it hard to keep friendships going…..because of his self-worth. He doesn’t think he is worthy. He thinks he is stupid. He thinks he is thick. Still.

Donna says that her own dyslexia has made it ‘quite a personal and stressful journey for me’. I would hypothesise that her ‘battle’ to get James support felt very personal to her because of her own difficulties and unmet needs and she therefore feels, perhaps more than with her other children, that she understands him and what he has been through. I also think that her own experiences of dyslexia may have made her more steadfast in her decision to take James away from his mainstream secondary school and his friends despite the fact that he did not want to leave.

This section has shown how two parents narrate the story of their child’s dyslexia, including how they are likely to be the first to understand their child’s difficulties and how, a previously trusting relationship with the school can become hostile when their child’s needs are not met. In the next section I will use my data to explore why it may be that schools do not harness the energy and commitment of parents and why parents with children with SEN and teachers can be in dispute.

4.2 The SEN system

Thackray (2013) says that the SEN system is recognised as being adversarial. Both of the parents I interviewed found this to be the case and it was noticeable that they were more emotional when talking about the perceived inertia of schools, the
attitude of teachers and SENCos and the hostile relationship with the local authority than at other times during the interview.

Donna was particularly vocal on the subject. She believed that James’ primary school tried to cover up how he was not making any progress and that his secondary school was directly responsible for him having to go to a specialist school:

I forgot to mention, they faked some of his figures - SATS. How I know they did that...they put in the letter that they couldn’t change his figures but they were incorrect. They were trying to make out that he was getting better and he wasn’t.....

I was told by that specialist dyslexia lady that if he’d got the right support he wouldn’t have needed to go to a specialist school. If he’d got all the provision on the Statement he wouldn’t have needed to go to a specialist school.

The two parents both drew attention to the significance of the timing of interventions and the Rose Report (2009) states that it is often a perceived lack of urgency that causes the greatest parental anxiety. Suzanne was particularly critical that Sam went three years without any speech and language therapy, then a month before the tribunal, a speech and language therapist came to see him. Both children went through most of their primary schooling without a Statement, and without any specialist support. In Donna’s words:

It was a dyslexia friendly school. How can a dyslexia friendly school not have teachers know about dyslexia. He was in there 7 years and it wasn’t until the last 6 months that they went for the Statement. (Donna)

Donna was clearly angry about this, however Suzanne still supports the primary school’s decision not to apply for a Statement until Year 6. As an involved parent, as well as a researcher, I found myself feeling outraged on her behalf during the interview and afterwards wrote in my field notes ‘Why did she express no blame towards the primary school?’

The interpretive panel also talked about how schools sometimes take a wait and see approach to SEN:
Because they do tend to wait, don’t they? Give a child the chance to either grow into something or it disappears. (Higher Level Teaching Assistant)

The SENCo in the panel explained that schools have to prove how far below their peers a child is before they can apply for a Statement and that it is easier to do this in Key Stage 2 when differences become more extreme.

Professionals on the panel acknowledged the frustrations faced by parents when they perceive schools to be intransigent and how disappointing it must be for them when nothing much changes in terms of support after a dyslexia test has been undertaken:

I think that sometimes a parent will push for a dyslexia test and they get a date and the test takes place ..... and they expect lots of things to be put in place for their child in the classroom. But in my experience, it’s a pack of paper that given to the parents, the teacher will look at it and quite often nothing comes of it. (Higher Level Teaching Assistant)

The SENCo on the panel was critical of the standard dyslexia screening test used in schools because it simply gives a ‘at risk’ quotient and others in the group felt that it would make more sense to use a more thorough assessment. The SENCo warned that this was unlikely to happen because schools would not be able to afford to pay for it.

The quality and rigour of the Statement was discussed by both the parents interviewed and the panel reflecting on the interviews. The parents were shocked and felt very let down for two reasons: firstly that the content of the Statement was often vague and unclear, and secondly that there was no monitoring and enforcement:

The Statement suggested Dictaphones, touch typing. None of it had been done. I had presumed they would do it. It was a legal document and they should have done it. (Donna)
The panel discussed the parent’s frustration and feelings of disillusion with the education system and agreed that schools will only meet their statutory requirements if pressed:

It also shows that Statements which are statutory documents and technically you can take a school or local authority to court if they don’t provide it, and actually the schools don’t give a monkeys! That’s the reality of it. (SENCo)

The SENCo on the panel also mentioned that sometimes Statements do not accurately reflect what the child needs because the cost of updating and rewriting it is too high. However, she felt optimistic that the new Educational Health Care Plan will be more fluid and therefore a better reflection of what the child needs. She also raised what she called the ‘curious role’ of the local authority Educational Psychologists who have a conflict of interest when providing evidence about children for tribunals and Statement applications.

Lack of dyslexia training for teachers was raised by both parents but it was only Donna who made the link between this and the defensiveness that she experienced in her interactions with teachers. She talked about a meeting at the secondary school where she thought the school was trying to ‘humiliate’ her by having so many senior management and professionals there, but she conceded that it is difficult for teachers because ‘it’s about them identifying themselves as not being the best they could be’. Thackray (2013) argues that teachers can feel threatened because parents are more knowledgeable than them about their child’s condition or about the special educational needs system in general.

The teachers on the panel were shocked at the reported hostility and the way that the parents felt they were disbelieved. In relation to the meeting described above, the SENCo on the panel said:

She (the SENCo at secondary school) knows they are not meeting their statutory duties and they are very defensive. And that is true of many secondary schools’. (SENCo).
In order to prove that their children were not having their needs met at mainstream secondary school, both parents had to take their local authority to tribunal. They explained that in order to build a case they paid for private assessments and one paid for a legal team to represent her. Only Suzanne had to actually attend the tribunal (Donna won her case without one), however both children were assessed by the local authority and the professionals who the parents had paid for privately – assessments which can often last up to three hours each. As an example of the lengths that parents have to go to in order to build a case, Suzanne was advised by her legal team to keep sending Sam to his secondary school where he was extremely unhappy and to keep a diary as evidence of his suffering.

Sam absolutely hated it. He was very uncomfortable, very nervous about going, didn’t want to go, crying a lot. I was going to keep him at home but the solicitor said ‘no, do you think he will cope at Secondary school’. I said no and she said to send him, just for extra evidence. So then I kept a diary from the middle of September about his anxieties.

Although the panel responded very sympathetically to the accounts of the two parents in the research, they also talked about parental anxiety and Munchhausen by Proxy Syndrome in which a parent or caregiver causes or fabricates symptoms in a child. They explored the difficulties that teachers have in discerning genuine cases of special educational need as opposed to cases where ‘the parents don’t want to admit that it’s partly their parenting and it suits the mother to put it all on to the child rather than’ (SENCo). They concluded that teachers with experience would be able to discriminate:

I think it depends on the school and their level of experience. I think some people may go ‘here we go again, another parents going on and on and there’s nothing wrong with them’ and if you have too many like that, sometimes you can misjudge and I think that’s really unfortunate. The few spoil it for the many. But I think the more teachers communicate between themselves and the professionals, if they’ve got the time and resources to do it, you’d very quickly get to see the genuine cases. (Primary school teacher)
4.3 The Children

There seems to be general agreement that dyslexic children often have lower self-concept and self-esteem than those without difficulties (see earlier section on ‘Self-Concept and Self-Esteem’). However, very few of these studies were specifically undertaken with severely dyslexic children and so I was interested to explore to what extent severe dyslexia impacts children’s emotional health.

Suzanne says that Sam responded to being at secondary school by turning in on himself and experiencing feelings of self-loathing:

.... he felt awful about himself, he hated himself. He said he wanted to kill himself. He said he couldn’t do what they wanted him to do.

Donna describes James as lacking in confidence and having low self-worth:

But I know he has been damaged by this journey. He hasn’t got the confidence. I see it.

Looking back I think he finds it hard to keep friendships going.... Because of his self-worth. He doesn’t think he is worthy. He thinks he is stupid. He thinks he is thick.

Both parents attribute their child’s low self-esteem to their specific learning difficulties and the way it makes them feel in the school environment. Donna describes James as being relatively happy during most of primary school, while Suzanne reports that Sam experiences stress and self-hatred when doing homework. However, it is in the first year of secondary school, a time of greater emphasis on academic performance and an increase in social comparison that both parents describe their children as experiencing a drop in self-esteem. As a consequence James responds by focusing his negative emotions outwards and being physically aggressive at school, while Sam’s behaviour is internalised and he engages in low level self-harm and becomes very anxious.

The language used by Suzanne to describe Sam’s response when he felt under stress with homework at primary school and when he moved to secondary school is visceral: ‘headbutting’ (the wall), ‘biting himself’; ‘pulling his eye-brows out’, ‘biting
his fingers until they bled’. She said that he also had panic attacks, was nervous and anxious and cried a lot during the term he was at mainstream secondary school:

He was literally lost, going into the wrong classes. Sam absolutely hated it. He was very uncomfortable, very nervous about going, didn’t want to go, crying a lot.

Suzanne told me that it was a relief for Sam to start at the specialist dyslexia school and that he settled in quickly. She describes him nowadays as ‘very confident’ and attributes this to the support he is getting at his school:

Instantly it was like a big relief for him……. It’s going back to basics – he’s not afraid of asking. He’s not frightened of getting things wrong now. His report…his grades jumped up….. Just with that support.

Donna reports that James became confrontational with teachers and started fighting when he went to secondary school. She sees a direct link between this behaviour and his lack of support from the school for his dyslexia and she challenges the school by saying ‘happy children don’t fight’:

James seems to clash with quite a few teachers…. He clashed with an English teacher because he doesn’t like English.

I was having phone call after phone call from the school about him fighting, being put in a secure unit. Even now I dread the phone ringing at home because it used to be the school phoning everyday with problems about James.

The interpretive panel felt that there could be other factors contributing to James’ change in behaviour, as well as his dyslexia. They mentioned the transition to secondary school and the fact that Donna has a baby around the same time which means that James was no longer the youngest in the family:

The fighting is the expression coming through and maybe also a way of getting attention because he doesn’t feel as though he’s getting enough. (Student)
And going to a new school with new people and knowing that you are going to have that label and be treated differently, that must make him feel anxious. It’s an anxious time for all children but having that as well...

(Student)

When he starts at his new school Donna says that he once again gets into trouble for refusing to read, being rude, setting light to a book, kicking a locker and refusing to accept one-to-one support. She also told me that out of school he has been caught for shoplifting and on a separate occasion has received an anti-social behaviour order. The interpretive panel discussed whether his behaviour could be attributed to him protesting about having to go to a specialist school or because he is ‘just a teenager kicking off at school’ (Student). There was some uncertainty about the cause of his behaviour, however the teacher in the group felt that it was because of his low self-esteem:

It sounds like he is just unteachable and he is in a really, really bad place. He thinks he’s useless because all of his school life he’s been told he can’t do it, he’s not good enough. (Primary School Teacher)

My field notes indicate that I felt unsure and slightly irritated by this discussion. Whilst accepting that the arrival of a new baby may have affected James’ behaviour I felt certain that later on his behaviour was a direct result of his learning difficulties. The panel’s differing viewpoints offered me new insights and caused me to reflect on my initial standpoint. I am grateful to the panel for showing me a more balanced viewpoint.

Donna expresses anxiety about the friends that James mixes with at home. She believes that his desire to be ‘normal’ and fit-in is getting him into trouble:

I’m not saying that James is a goody two shoes, no he’s not, but he doesn’t go out of his way to hurt people. It’s just that he’s impressionable and wants to be like everyone else and if everyone else is being naughty then I guess he’ll be naughty.

4.4 Child’s Participation and Agency
The advancement of children’s rights to participation and agency has received a steady increase in awareness. The United Nations Convention on the Rights of the Child (UNCRC) (United Nations, 1989), locates children as entitled to autonomy, and to fully participate in, and influence matters that concern them. Mayall et al in their work in primary schools said that ‘children here are regarded as social actors, who aim to order their own lives in interaction with adults. But they are a minority group who lack power to influence the quality of their lives (1996, p. 207). I am interested in to what extent the children in my research expressed agency and participated in the decisions made about them at school.

There are a few occasions during Sam’s narrative where he asserted his will. On two of these occasions he knew that his mum would approve of what he was doing:

> We’d only talked about it but Sam took it upon himself the next day to take himself into the other class and just sat there. So he did it himself. That was quite hilarious.
>
> They were quite easy sums for somebody that understood them, but it was complicated for someone who found it difficult. So he started colouring it in and then got a pencil and scribbled all over it.

On the third occasion Suzanne reports that he was feeling so angry with the way he was being treated by his mainstream secondary school that he purposely lost an athletics race:

> Sam was winning the cross country but he stopped because he had indigestion. He told us later that he stopped because he didn’t want the secondary school to have a medal. He felt so angry about school that he didn’t want them to win.

Suzanne also describes how Sam was often rude to teachers. One of the panel members felt that by doing this he was expressing his frustration in a way that the teacher could understand:

> Was it that he couldn’t express his own problem so by kicking off and being rude he is creating an exchange. So, if people can’t understand what he is going through, being rude is something that the teacher does understand. (Student)
Donna also cites examples of James taking control of his situation: refusing to work one-to-one; refusing to work with a private dyslexia teacher; threatening to kill himself/run away when his mum wants him to go to a specialist dyslexia school:

He sat in the back of the car on the taster days for the specialist dyslexia school and said he wasn’t going. He said that if I made him go he was going to kill himself or run away.

Donna also says that she gave him permission to tell teachers that he does not have to read out loud:

The teacher threw the book and him and said read the book. James said ‘I don’t have to. My mum’s said that I don’t have to’.

As I listened to Donna’s account of James’ fighting at school I found myself comparing him to my son who internalised his unhappiness at school and expressed his frustration by pretending to need the toilet and crying in there alone. I wrote in my field notes ‘good for him - James is doing something’, by which I meant that he is trying to take control over his situation and express his agency.

Neither Suzanne nor Donna mentioned anything during their narrative about measures the schools took to engage with the children about their difficulties and ask them what they needed. The SENCo picked up on this during the panel:

I wonder how much people have been talking to James about what he needs. If they had started in Key Stage 1 saying ‘what do you want. It is difficult for you’. Because if he doesn’t want it, he can’t see the point in support, then it won’t work. Maybe they could start doing that.

The other panel members agreed and talked about ways this could be done, in particular Pupil Passports which are produced in consultation with the child about what they find difficult, what they need, targets etc.
4.5 Teachers

Both parents were aware of teacher’s lack of training in dyslexia and cited this as one of the main reasons why the early signs of their child’s dyslexia were misunderstood and the focus was put on behaviour, why their needs were not met and also the reason that some teachers called them rude or lazy:

In mainstream they don’t understand dyslexic children because they’ve never had a course on dyslexia. They had one teacher that was dyslexic trained and I think there was 200 dyslexic children at the secondary school. The rest didn’t understand it because they’ve never had any training in it. (Suzanne)

They also recognise that teachers in mainstream schools have large classes and little time to pay attention to the children with SEN. There is therefore a level of understanding about lack of funding and training, however Donna still felt that teachers should be looking to improve themselves and if there is something they do not know about, like dyslexia, they should make it their business to find out:

I couldn’t understand why the SENCo wouldn’t even know what a Wave 3 programme was. I couldn’t comprehend that. And didn’t go away and find out. ……So I do think that teachers have so much to do, but I would say that they still need to be accountable for the profound effect they can have on a child’s life.

The educationalists in the panel agreed about the lack of training and time to learn more about dyslexia:

I haven’t had any training to deal with dyslexic children. I think they mean well and they all try and do their best but I think because we are constantly being loaded with the next thing and the next thing. I think that less experienced teachers would think they are being lazy. ……………but then schools don’t have the money to pay for it, you can do it yourself but then I don’t know how you’d fit that in. (Teacher)

The teaching assistant in the panel pointed out that she has had some training in dyslexia and that she brought lots of ideas back to her school with her which were not implemented consistently across the school:
In my work as an SEN TA we did really practical things, like, all along the corridor we would get boxes and put stuff in them for teachers and then say, you can do this and that in class. So we practically set it up for them..... and it didn’t carry through.

The teacher in the panel also noted that teachers now have even less time to address issues like dyslexia as the government has introduced performance related pay:

If what you’re judged on is your levels, then that becomes....it’s another way of shifting you away from the reason you went into the profession.

Donna was critical of the lack of understanding of teachers about how dyslexia can affect children’s emotional health and well-being and suggests that they should be given training so that they can help children with low self-esteem:

The teachers didn’t have a clue what was going through a dyslexic child’s mind. They didn’t have a clue.

The panel agreed that there should be a greater emphasis on children’s emotional needs in teacher training, with the teacher conceding that ‘teachers don’t know what to do with kids who are unhappy’. The panel discussed programmes that can be implemented, for example Carol Dweck’s ‘Growth Mindset’ which is being trialled in one of the panellists’ school and teaches children that their ability is not fixed but can be developed through dedication and hard work.

Donna seemed particularly angry about teachers who made no connection between dyslexia and bad behaviour in school and regularly sent James to internal exclusion rather than ‘tackling the main issue’:

At the meeting one of the teachers said that he didn’t think James’ behaviour was linked to his dyslexia..... That’s the sort of attitude you are getting from the teachers.
Donna talked about the need to give dyslexic children ‘constant praise for the little tiny things’ and would like to see teachers looking beyond children’s difficulties to the person underneath and what they have to offer:

They never said anything nice about him. They never saw the true him, just the dyslexia, dysfunctional, misbehaving, bad behaviour. They didn’t see the amazingness, the cleverness that I see, the potential.

Suzanne reported that Sam’s new school has been focusing on what he is good at and this has boosted his confidence significantly:

But now at the specialist dyslexia school, they have made him feel brilliant. They focus on his sports – he stands up in assembly and shows his medals off, he’ll talk about them. And also, he’s a really good entertainer. He stands up in front of them all and sings or dance. It’s fantastic.

The teachers in the interpretive panel also called for schools to recognise the skills and talents of children other than those related directly to education:

Other children who are really bright and clever and good at writing, teachers rarely say, look at the other child who is better than you at something other than writing...... that doesn’t happen often enough. (Primary School Teacher)

There was a note of optimism when the teacher told the panel about a new approach that their school is taking which means that teachers have to consider the needs of children with SEN before the higher ability children:

In our school we are trying to introduce a new approach. We have to come at it differently. We start with the dyslexic children or the special needs children and then work outwards to the other children. So that’s in terms of the environment, your planning, everything...... It used to be the SENCo and the SEN TAs that were responsible for the children with SEN but now it’s the teacher who should be mostly working with the children with SEN. It’s happening, it’s just very gradual. So the teacher is much more in tune with what they need. They spend more time with them so they know them better. (Teacher)
The SENCo also felt that the 2014 SEN Code of Practice, which promotes everybody in schools as teachers of children with SEN, may be having more impact than previous Codes of Practice.

4.6 Helpfulness of term ‘dyslexia’

Both parents believe that having a diagnosis of severe dyslexia is important. Donna states that in an educational setting it is important for parents to know what their child’s difficulties are so that they can address them:

I think the label needs to be there in an educational environment because of the lack of support for dyslexic children.

Suzanne, on the other hand, is more skeptical about having a label because she feels that it made no difference to Sam in mainstream school:

When he was in mainstream school it didn’t mean anything. Saying he was severely dyslexic didn’t help in any way – they didn’t treat that as anything different.

However, she concedes that having a label has helped her daughter who was diagnosed when she was 15 years old by the same school that Suzanne was taking to tribunal. She now has access to a quiet room and extra time in exams which she finds helpful.

Opinion is divided about having a label among the two boys in my research. Donna reported that James refuses to even mention the word ‘dyslexia’ and refers to it as ‘it’s just like a different thing in the brain’. Donna reports that he has a strong desire to be what she calls ‘normal’:

He really hates it. He will not say that he is dyslexic. I don’t know why, I really don’t. He’s really impressionable. He has to have all the designer stuff. He wants to be like everyone else. He wants to be classed as normal.
The teacher in the interpretive panel concurs and talked about how dyslexic children in primary school often try and cover up their difficulties:

I know from the classroom that it often children who struggle with reading and can be dyslexic will choose big thick books like the most able readers and just sit with that all term if you let them, because they want to appear just like everyone else.

It was interesting that one of my panel members who is dyslexic but did not identify herself as such to the group was often the one to pick up on how James might be feeling. When we were talking about how Donna was concerned about him in primary school she said:

James doesn’t sound like he’s got a problem with it (being dyslexic), it is mum who wants him to be able to get on. (Student)

She was also concerned about how James might be feeling about going to a specialist school:

Or maybe he feels, now that he’s at a special school, that it’s labelled him even more. (Student)

I think her empathy for James shows insight that perhaps a non-dyslexic, such as myself, is less likely to have. Clearly, she was seeing his story through a different lens which was shaped by her own experiences of being dyslexic.

Suzanne, on the other hand, reports that Sam is comfortable with the labels that he has because he knows that he is in the right place to help him and he embraces that:

I think he knows it’s going to help him. The school specialises in dyslexia, it’s on the board as you go in?
4.7 Is it possible to support severe dyslexics in mainstream school?

Both Donna and Suzanne are unconvinced that, in the present circumstances, schools can adequately support severely dyslexic children. Donna believes that it might be possible if schools treat Statements as the legal documents that they are and do everything that is on them:

If he’d got all the provision on the Statement he wouldn’t have needed to go to a specialist school. I haven’t heard of any severely dyslexic children doing well in a mainstream school ....on websites, like IPSEA.

For Suzanne, on the other hand, the answer is an emphatic ‘no’. She is extremely critical about the way Sam was treated in mainstream secondary school, in particular the nurture group where he was placed with 17 or 18 other children who were ‘all different, all with different needs’:

He started copying behaviours of the other kids in the class, being rude....... They all needed their own different help, but they were all in one class. Sam would often come home with colouring that he’d been doing all day, or saying that he’d been watching a dvd, instead of actually doing work.

One of the students in the panel describes the nurture group as ‘out of sight, out of mind!’ and others could not understand why the school would amalgamate children with such different needs.
CHAPTER 5: CONCLUSIONS

5.1 Discussion

My research for this dissertation has reawakened feelings of anger and frustration and made me realise that, perhaps inevitably, I am still looking through a lens of my own experience. However, I have been open about this and have taken steps to ensure that my views have not influenced my analysis. Conducting this research has also convinced me of the importance of writing this dissertation and it has helped me to understand the reasons why some mainstream schools are not meeting the needs of severely dyslexic children.

It seems clear from my research that lack of teacher training in SEN effects how severely dyslexic children experience mainstream school. Late and inaccurate diagnosis, lack of appropriate individual intervention and misunderstanding about severe dyslexia caused both of the children in my research to experience feelings of failure and low self-esteem which gave rise to Sam self-harming and may have contributed to James’ physical aggression. Following the Carter review of ITT (2015) which found particularly significant gaps in a number of areas, including SEN, the Government has agreed to develop a framework of core content for initial teacher training. However, the Government still falls short of making a more significant amount of SEN training mandatory for course providers and therefore, in my opinion, I doubt that this will lead to any meaningful change.

Parents appreciated having an accurate diagnosis, and therefore a label for their child. They perceived that it increased the likelihood of their child receiving appropriate intervention, even though the reality for both of my respondents was that they had to pay for the diagnosis themselves and it made no difference to the level and type of support. Ultimately, the lack of early diagnosis and intervention resulted in them both needing to go to a specialist school. Having a label ‘severe dyslexia’ should mean that teachers have a greater understanding of, and empathy for, children, such as those in my research, and can use appropriate interventions to support them. However, a label may make no difference if teachers are unable to
appreciate what severe dyslexia means. Making schools truly inclusive by embracing the social model of disability would break down the barriers preventing severely dyslexic children from accessing the curriculum, but this requires Government support and whole school reform. On this basis, in my opinion, this is unlikely to happen in the near future.

It would seem that neither of the children in my research was encouraged to express their views about their learning difficulties and they were not asked to participate in the tribunals about their future education. I agree with Lansdown (2006) when she says that there can be meaningful participation with children with SEN and that they can be actively involved in their educational planning. However, this challenges the popular assumption that adults know best. The teachers in the interpretive panel talked about Pupil Passports which go some way to doing this, however, I believe that it requires a huge cultural shift among politicians and educationalists in order to make this standard practice.

Both of my biographic interviews demonstrate huge commitment and resolve on the part of the parents to try and get their child’s needs met. At the beginning of both of their stories they explain that they trust their child’s school implicitly, are fairly deferential in their interactions with teachers and seem to have little awareness of their own, and their child’s rights, in the context of education. They also both reported that they were the first to understand their child’s difficulties. In the middle of their stories, when their attempts to have their child’s needs met through greater support from the school are thwarted, they both talk about confusion, helplessness, anxiety, disappointment and frustration. Neither of them appear to have the kind of cultural and financial capital described by Macdonald (2009) that enable some parents to effectively challenge schools and local authorities, yet they both make a decision to confront the SEN system. It is at this stage of their story that we can see both parent’s language change to one of struggle and battle. Donna also starts to describe her feelings of empowerment in terms of her interactions with the school and her ability to be able to affect decisions. Both stories resolve in narrative terms with a sense of relief. For Donna this is complicated by the ongoing issues with her son, however for Suzanne the sense of relief is tangible and, for the first time during
the interview, she becomes animated and talks about her son’s achievements at his new specialist dyslexia school.

My research has confirmed to me that the current SEN system is extremely adversarial. The lack of urgency and wait and see approach adopted by schools is frustrating for parents and, as shown, can be damaging for children. Given the energy, commitment and knowledge that parents have about their children’s difficulties and needs, it is disappointing that schools so often become defensive and end up in dispute with parents. Parents often end up knowing more than teachers about their child’s difficulties and there should be a mechanism for harnessing this knowledge and energy for the sake of the child. There was some optimism in the interpretive panel that the new Educational Health Care Plan will be more fluid and allow greater parental choice, however this was tempered by a feeling that the professionals representing the local authority, for example, Educational Psychologists, will remain conflicted by, on the one hand, enforced cuts to the education budget and, on the other hand, the needs of the child.

5.2 Limitations and Strengths

My study is on a small scale and comprises interviews with just two parents which means that the scope for generalisability is limited. However, it is exploring what would seem to be an under-researched area and has raised issues which would justify further, more detailed research in the future. For example, it would be interesting to study in greater depth teachers’ attitudes towards dyslexia and the extent to which they are influenced by the myths and confusion that seems to permeate the media. It would also be interesting to further explore the relationship between parents with children with severe dyslexia and teachers, the effect of parent’s anxiety about educational attainment on their child’s sense of failure and low self-esteem and the extent to which gender influences how children deal with their learning difficulties.
5.3 Future Directions

Lack of resources for SEN and teacher training in SEN are two factors that should be addressed immediately. The impact that these have on severely dyslexic children is huge in terms of the likelihood of getting an early diagnosis, individualised intervention and understanding of their difficulties. However, there are things that teachers can do, even without resources and training. Teachers in the panel said they thought it would be helpful if I were to go into schools and talk about my research. For now I have put together some points for consideration for teachers which I hope will be helpful and make life in mainstream schools better for severely dyslexic children:

- The ‘wait and see’ approach used by schools is unacceptable. The earlier a child’s difficulties are identified, the earlier they can start receiving appropriate intervention. Teachers in Foundation and Key Stage 1 should be able to identify children at risk of reading failure at an early age by being aware of the signs of dyslexia.

- A whole school shift to the social model of disability requires huge institutional change. However, this does not stop teachers adopting a more inclusive approach by always considering SEN children first in terms of the classroom environment and in lesson planning. Teachers should also spend more time with children with SEN and allow teaching assistants to work with the higher ability children.

- Children with severe dyslexia can develop low self-esteem. Teachers must understand their emotional needs and respond to them. Teachers need to develop good counselling qualities – acceptance, genuineness and empathy – and may need to work with severely dyslexic children on resilience building or dyslexia coping programmes.

- All children in school, and in particular those who have learning difficulties, should be recognised, valued and celebrated for their competences and strengths beyond the classroom. This requires teachers to see the whole child and promote the things they are good at to the other children in the class.
• Teachers should be aware of the positive effect of children participating in decisions around their learning difficulties. It is important that teachers talk to children about what they struggle with and what extra support they require.

• It is vital that teachers work in partnership with parents. Sometimes parents will know more than teachers about their child’s difficulties and needs and may become frustrated at what they perceive to be the intransigence of the school. It is important that rather than becoming defensive teachers should use what parents know to secure the best for the child.
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APPENDIX

1) Dexter’s Story

Dexter had a difficult birth in which he was deprived of oxygen, however to our great relief he developed well as an infant, walking at 10 months and riding a bike at 3 years!

When he was two we started to become concerned that he wasn’t talking and when he did speak, we couldn’t understand him. He was given a diagnosis of a moderately severe speech disorder with features of both verbal and oral motor dyspraxia plus an expressive language delay. Although communication was difficult for him and sometimes caused him great frustration, he was generally a happy, spirited and very cheeky little boy. He had a lovely relationship with his older brother who looked after and protected him by acting as translator. Somehow Tom nearly always understood what Dexter said when his dad and I couldn’t!

Dexter began school enthusiastically but by Year 1 he was socially isolated and was bullied as a result of being unable to communicate with his peers. He became a very unhappy boy, his self-esteem was very low and he told us his life wasn’t worth living. By Year 2 his speech had improved a little and he was able to communicate better, however he was failing to learn literacy skills. He was formally assessed (by a private dyslexia specialist) as being severely dyslexic. Although he was on School Action Plus he had no specialist intervention and made little progress. At the end of Year 3, with huge regret we decided to move him to another school.

At the new school he made friends and enjoyed his reputation as a good footballer. He received support but it was neither specialist nor focused on his specific learning difficulties. At age 10, still years behind his peers in terms of reading and writing and unable to play any sport (due to Severs Disease, a painful bone disorder that results from inflammation of the growth plate in the heel), he was seen by the Child and Adolescent Mental Health Service (CAMHS) because he had worrying low self-esteem, he threatened to self-harm and often refused to go to school. He frequently cried in class when presented with something he felt he couldn’t do and was unable to see past his learning difficulties and appreciate the strengths and talents that he had. Dexter often referred to himself as ‘stupid’ and talked about feeling ‘different’ from a very young age.

In Year 6 we applied for a Statement of Educational Need and it was immediately granted. However the local authority refused to fund a place for him at a local specialist dyslexia school which meant that we had to take them to tribunal. We won our case and the local authority conceded that his needs could not be met at the mainstream secondary school they had named.
Dexter is now 14 years old and back in mainstream education after 18 months at a specialist dyslexia school where he had lots of counselling and slowly began to get his confidence and self-esteem back. The support he receives in mainstream school still does not meet his needs and his reading and spelling age is significantly below that of his peers. He is very disengaged from school - it is a constant struggle for him - and he sees little purpose in it, however, he is now happy and confident again and more able to cope with the challenges that he faces. He is still a good sportsman and hopes to make that his career. His experiences have made him resilient, tolerant and very driven and I am very proud of him.
2) Research Consent Form

Thank you for your interest in the research study which I am undertaking as part of my dissertation for a Master’s Degree in Childhood and Youth Studies.

Please sign below to formally confirm that you are willing to be interviewed as part of the study. Please only sign once you feel able to tick each of the following boxes indicating that you have received enough information from me and fully understand what your involvement will be:

- [ ] I have read the information sheet
- [ ] I understand the purpose of the study and my involvement in it
- [ ] I give my permission for anonymised information in my interview to be used in the dissertation named below
- [ ] I understand that my taking part in this study is completely voluntary and I can withdraw at any point without giving a reason or explanation.

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Many thanks for your help with this study. I look forward to meeting you soon.
3) Information Sheet for Parents

An exploration of severely dyslexic children’s emotional health and well-being in mainstream primary school and the role of teachers in supporting them

What is the research study about?

This research study aims to explore the experience of severely dyslexic children in mainstream primary school, in particular their emotional health and well-being. In a separate part of the research it will also examine the impact that teachers’ understanding of, and attitudes to, dyslexia has on the support they provide.

I would like to interview two parents of children aged between 12 and 14 who have a diagnosis of severe dyslexia. The children may have other co-occurring specific learning difficulty, such as dyspraxia or dyscalculia, or speech and language difficulties, but not have a diagnosis of behavioural difficulties, such as ADHD. They will both have attended a mainstream primary school.

As the parent of a child with severe dyslexia I am aware that it can be difficult for parents to get their own, and their child’s, voice heard. This study aims to redress this balance.

How you might help

I would like to interview you at a time and place convenient to you. It is important that we meet somewhere that is quiet and private so that you can talk freely.

The interview itself will be very open-ended and I will start by asking you to tell me, in your own time, and starting wherever you want, about your child’s story. It is really important that you tell the story in your own way and therefore I will listen and not interrupt. You will be able to talk for as long as you want, up to a couple of hours, but please don’t feel under any pressure to fill this time. When you have finished talking we will take a break of about 15 minutes which we will spend apart. When we come back together we will talk about the objectives of the study to make sure that we have covered everything. With your permission I will record the interviews so that I can make a transcript of them later.

I may need to ask your permission to contact you again if anything is unclear but this would be done by phone.
**What will happen to my interview?**

As mentioned above I will make a transcript of the interview, which I will send to you to ensure that you agree with what I have written and that it reflects what you told me.

From the transcript I will select several sections which represent the key themes of your interview. These will be anonymised and presented to a panel comprising five people - three teachers and two non-teachers. One of my research aims is to explore teachers’ knowledge of and attitudes towards dyslexia and I believe that this will provide a good forum in which to do this. Both the teachers and non-teachers will also allow for deeper and more objective interpretation and will minimise any researcher bias. I believe that this is particularly important given that my experiences with my severely dyslexic child may be similar to your own.

After these panels I will fully analyse and write-up my findings. The findings will be completely anonymised and I can assure you that it will not be possible to identify you or your child. I will also change place names, names of schools etc. to ensure complete confidentiality.

The anonymised, transcribed interviews will be seen by my Tutor at the University of Sussex and by any Examiners for my Master’s Degree. I should stress, however, that all of these people are bound by strict ethical codes of conduct which means that they have to keep all information confidential.

**Can I change my mind?**

You can pull out of the study at any stage without having to give a reason.

**Are there any risks to me taking part?**

I hope you will find the interview a positive and rewarding experience and a chance to have your, and your child’s, voice heard. You may find it helpful to recall your child’s story, particularly as you know it is being used to benefit other children in similar positions and develop better teaching practice.

Sometimes people find that taking part in research studies about issues close to them can be distressing. I hope this will not be the case for you but we will discuss your support networks prior to the interview so that I do not have to leave you at the end of the interview without someone to talk to further.
How can I get further information?

If you are still interested after you have read this Information Sheet I think it would be useful for us to talk on the phone to ensure that you understand what the study is about and what taking part will involve. If at this point you are sure that you would like to participate then I will ask you to sign a Consent Form.

Many thanks

Claire Durrant
4) Information Sheet for Panel

An exploration of severely dyslexic children’s emotional health and well-being in mainstream primary school and the role of teachers in supporting them

Background and Objectives

This research study aims to explore the experience of severely dyslexic children in mainstream primary school, in particular their emotional health and well-being. It will comprise research with two parents of severely dyslexic children, an interpretive panel and an evaluation of relevant literature.

My research objectives are:

1. To synthesise material from the literature review and my own research to:
   - gain further understanding of the experiences of severely dyslexic children in mainstream primary school and what affects their emotional health and well-being.
   - explore teachers' knowledge of, and implicit attitudes to, dyslexia and what they see as their role in teaching children with severe dyslexia.

2. To reflect on these findings and consider the implications for teaching practice.

Methodology

I will be using a Biographical Narrative Interpretive Methodology (BNIM) to interview parents. The assumptions of BNIM are broad based; it aims to analyse three interrelated facets of humanity: the person's life history (Biography) (in this case the parents story of their child) and how they tell it (Narrative), whilst appreciating that narratives are subject to social interpretation (Interpretive).

BNIM highlights the socio historical complexities which influence all of our lives and recognises that the individual (in this case the child) is at the centre of networks of interpersonal relationships, organisations, and cultural/political/economic systems. It is relevant to the subject of my research because the way that severely dyslexic children experience mainstream school is impacted by government policies and school procedures, as well as individual teachers.

The BNIM interview with parents will explore their child’s lived-experience through the use of an uninterrupted life story format. The interview itself will be very open-
ended and I will start by asking them, with a single question, to tell me about their child’s story. Interviews will be recorded and then transcribed.

**BNIM Panels**

From the transcriptions I will select several sections which represent the key themes of the two interviews and these will be presented to a panel, of which you will be a part. They will comprise four or five people and will include those working in education (teachers/teaching assistants) and non-teachers. These specialists and non-specialists will allow for a deeper and more objective interpretation and will minimise any researcher bias, which is inevitable on any research project. I believe that this is particularly important in this study given that my own child has experienced being severely dyslexic in mainstream primary school and I may have my own prejudices. I am also interested in gaining greater understanding of teachers’ knowledge of, and attitudes towards, dyslexia and I believe that this will provide a good forum for exploring this with the teachers in the group.

**What will I have to do at the Panel?**

As mentioned above, I will ask you and the other people on the Panel to respond to sections of the interviews with parents. This will involve you discussing as a group and giving your own opinions on each section. For each section I will also ask you to tell me what you think happened next.

I should stress that it is an informal process and it is your opinions I am interested in. There are no right or wrong answers. With your permission I would like to record the discussion so that I can refer to it later when I am writing up the findings. Once the research study has finished I will destroy the recordings.

Throughout the session I will document the discussion on a flip chart and I will pin up summary sheets around the room so that we can follow each interview section by section.

Most panels take around 2 or 3 hours. I appreciate that this is a long time and thank you in advance for helping me with this invaluable process. I will provide food and drink and we will stop for regular breaks.

**Are there any risks to me taking part?**

I hope you will find the Panel an interesting and positive experience. I believe that it will enhance the quality of my research greatly and hopefully improve the experience of mainstream primary school for severely dyslexic children.
After the Panels I will fully analyse and write-up my findings. The findings will be completely anonymised and I can assure you that it will not be possible to identify you in the report. I will also change place names, names of schools etc to ensure complete confidentiality.

**How can I get further information?**

If you would like any more information after you have read this Information Sheet please let me know and we can talk on the phone to ensure that you understand what the study is about and what taking part will involve. When you are sure that you would like to participate then I will ask you to sign a Consent Form.

Many thanks

Claire Durrant
5) Narrative Interview Script including Single Question aimed at Inducing Narrative (SQUIN)

(1)
As you know I’m interested in the emotional health and well-being of severely dyslexic children in mainstream primary school and the role of teachers in supporting them.
I’m going to ask you to tell me Will’s life story, in particular his time at primary school. All the experiences and events which were important for him, up to now.

Start wherever you like.

Please take the time you need.

I’ll listen while you tell your story and I won’t interrupt.

I’ll just take some notes in case I have further questions for after you’ve finished telling me about it all.

When you’ve finished telling me Will’s story we will take a short break and then come back and I’ll ask you a few questions, mostly for clarification but also about some of the themes of my dissertation.

OK, so can you now please tell me Will’s story. All the experiences and events which were important for him, up to now.

Brief notes using their words; don’t interrupt, no clarification, pro narrative nudges if goes off course (eg. ‘Is there anything else you remember happening at school’), attentive listening, moderate amount of eye contact, want to elicit story, not self-theorising.

If upset, ‘That’s still hard for you’, ‘It’s still painful for you to remember that’, ‘That makes you sad when you think about it’, ‘You still feel angry about it’.

Don’t paraphrase (if have to – ‘I think I haven’t quite grasped what you are saying: it is X, or Y, or something rather different’)

Leave silence at end to reflect on whether there is anything else they would like to say.

Is there anything else you would like to tell me about Will’s story. Is there anything else you remember happening. Let’s now have a short break. I need to look through my notes for a few minutes and see what I need to ask you about next.

Break – tea, toilet, think about cue words, no chat.
(2) Ask in order, narrative only questions/topics raised, use only their words, don’t interpret.

“You said that......’

‘Can you tell me what it was like...’

‘Do you remember anything or anyone from ....’

‘Are there any thoughts or images that come to mind’

‘Tell me more about....’

‘You said that you ......, can you tell me .....’

‘Can you recall’,

‘How did that happen?’

‘Can you remember?’

‘Reflecting back’.

‘Can you give me ANY example of an occasion when?’

‘Can you give me any MORE examples of similar events/incidents at that time’

‘Was there some particular CRUCIAL incident or situation or time that you can recall?

Again, write cue words.
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<th>Themes</th>
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That’s all my questions about Will’s story. Is there anything else you would like to tell me before we move on to some questions about the themes of my dissertation?

(3)

Here are my research questions for my dissertation. Do you think we have answered......

1) How helpful is the label ‘severely dyslexic’?

2) Is it possible to effectively support severely dyslexic children in mainstream school?

3) How can teachers facilitate a positive sense of self among severely dyslexic children?

4) What do teachers understand by the term dyslexia and how well do they perceive they can support severely dyslexic children?

I thought you might have talked a bit about ....... What do you think about.......?
How helpful is the label ‘severely dyslexic’?

Is it possible to effectively support severely dyslexic children in mainstream school and how should this be done?

How can teachers facilitate a positive sense of self among severely dyslexic children?

What do teachers understand by the term dyslexia and how well do they perceive they can support severely dyslexic children?
6) Donna’s Story - Transcript

D = respondent C = researcher

Sub-session 1 (D only)

What I'd really like to point out is that with James, one of my 4 children, I noticed from a very young age that he was different with books. He absolutely loved books but he never seemed to recognise the words. I just remember he used to like the same book but he never seemed to pick out the words or attempt to pick out the words.

Then he went to a local nursery school, there was never any signs of him being any different. He was a typical boy, into everything. One of the staff was particularly excited one day about a picture he drew of a potato man. She was saying how clever he was, intelligent and never any concerns at that point.

But the moment he joined primary school .... it was probably quite apparent within the first year that things weren't as they should be. I don't remember big events but I'll tell you what I do remember. I always remember going to parents evening and them telling me that he doesn't try hard enough. It was almost like they were talking a different language. I knew he had trouble reading and writing but he wasn't getting into trouble and he had loads of friends. I kept going to parents evening and coming away thinking that they aren’t getting what I am getting. Things are not right there. I’m guessing that this was when he was about 6 or 7. It was really apparent then.

Bearing in mind that I have never heard of dyslexia, I started thinking when I was reading with him – I wonder if he's dyslexic? I quickly looked into dyslexia, never really thought that much of it, but I remember mentioning it to his teacher and her response was that she wasn’t qualified to comment on whether or not he was dyslexic. I think this was a lot later on. It’s hard to remember because it has all been such a roller coaster ride. And I was quite surprised - she was a really nice teacher and James really gelled with her. But by that time I was definitely getting concerns. He was on School Action Plus but of course it was all new to me and I didn’t know what my rights were as a parent. I didn’t know what I should be doing but I knew that what was happening wasn’t helping. I might have spoken to Parent Partnership and they threw it back at me and said that if I had concerns I needed to speak to the school. Parents evenings were still saying he should try harder and they were telling us all about the things they were doing with him and the extra help. I do think it was helping to a degree but there was still no assessments done at that time. They did one assessment but it was a specialist teacher assessment. At the time I didn’t know the difference and I presumed it was an Educational Psychologist assessment. But it wasn’t. They were saying that it was the same sort of thing. I
don’t know whether it was or not but it did pick up that there was dyslexic tendencies. They still wouldn’t address the fact that he was dyslexic.

The specialist teacher’s report didn’t really suggest much in-depth intervention. It pretty much said that they were doing all that they could. I kept going to the parents evening and coming away disheartened. James in himself was doing ok. He had a good lot of friends, he liked playing. Primary school wasn’t like secondary school. He liked playing and he liked doing his football. He seemed to be managing fine. It was just me being disheartened every time at parents evening and things just didn’t seem to be progressing as I thought they should be. I remember him being in Year 6 and the teacher saying he was lazy and that really made me cross. He was a sports teacher and he liked James. I couldn’t believe that he’d said that to me and I remember emailing the SENCo and saying that I wasn’t happy. They somehow got round what he’d said.

After this I started doing some research and speaking to IPSEA and I thought, look at his levels, they are not improving. They made out he was improving at the school but actually they were fictitious results. I know that because I asked simple questions – can I have his targets, can I have his IEP, I needed to see his levels. As soon as I asked those questions, I don’t know what happened, but it inspired them to go for an assessment. And they said that they would try and get a Statement of Educational Need. I was really surprised. To me the whole of the primary school period I was struggling to get him some help. There was help there but it didn’t seem to be making any difference. But in himself he seemed to be fine.

So we had to go to the hospital where he was weighed and they made sure there was nothing physically wrong with him. And I think maybe mentally as well. That all came out fine. Then I met briefly with the Educational Psychologist. Just told her my concerns. And that was pretty much it.

It was a bit awkward because the Statement came after he left primary school. It was good news that he got a Statement, in fact I was over the moon, but it still wasn’t that solid. You don’t realise until you become a parent with a dyslexic child that you have to have everything in black and white – as solid as it can be. If there is room for going off and not following what is on the document, then they will. I remember passing the Statement to a lady locally who was dyslexic and saying have a look at this. IPSEA didn’t offer a service to look at statements to see if they are any good. I didn’t know what I was supposed to be looking for or whether what was on there was any good. She gave me some advice which actually wasn’t very helpful, but I didn’t realise that at the time. She said just grab it. It’s very unusual to get a Statement for someone with dyslexia. I just thought, ok. So I just accepted it. There is room for amendments but at the time I wasn’t really aware that things could go wrong later down the line.
I felt that once he left primary school he wouldn’t get the support he had and that things would spiral and it wouldn’t be good for him. I could see him going off the rails. I didn’t specifically choose a secondary school which was specialist dyslexia because there weren’t any in place. We didn’t choose the local secondary because it was in special measures and I didn’t want him to be the school clown. I wanted him to be as focussed as he could be.

Everything seemed to be fine at his secondary school. In the first year they were going over the top trying to make adjustments for him. I met the SENCo and she seemed very nice. But things started going downhill. He was starting to fight quite a lot. I got in contact with IPSEA and they were saying that his Statement wasn’t as it should be. One of the things I learnt was that Parent Partnership weren’t impartial. They are the opposite. I remember phoning them and telling them about my concerns and literally the same day I had a call from the SENCo. It was very apparent that they had had a conversation with the school. The secondary school were very much about fluffing things over.

IPSEA said that we needed to push for an early Annual Review or ask for further help. By that time I was becoming quite empowered. I’d done quite a lot of research. I say empowered but also really disheartened because I had this legal document in place but still my son was struggling and now fighting. I was having phone call after phone call from the school about him fighting, being put in a secure unit. Even now I dread the phone ringing at home because it used to be the school phoning everyday with problems about James.

I remember going to an Annual Review and saying I want a specialist …..I didn’t realise that you could demand what you want, go in and say I want this and I want that and all they had to do was say no and you could appeal….i didn’t know any of that. I said that I wanted to know why he was fighting. I said happy children don’t fight. I asked for a play therapist – I know my son and I thought he has always liked playing.

I’ve just remembered something, I took him to a private lady for tuition at primary school. She was recommended by the school. He went a couple of times but he was really uncomfortable. She said to me that he will only ever learn through play. He wasn’t confident about me leaving him, I had to sit there while she was teaching him. He didn’t like her – she was an older lady and that didn’t suit him. He wasn’t enjoying it, he wasn’t learning, so we stopped that. He only had 3 or 4 sessions.

At the Review I asked for him to be reassessed, have a play therapist or some sort of counselling to find out what is going on. And I also said that I wanted more one-to-one support. On the Statement it said 22 hours of support a week but it wasn’t that good because it said it could be in-group or some one-to-one. There was no solid route of what it should be. By this time I was taking my husband in with me
because I thought I needed him there for support. It was also good for him to listen because people hear things differently. A couple of these meetings happened and we weren’t really getting anywhere and I remember him coming out and saying, they didn’t really listen.

In between all this going on the SENCo promised that she would get him reassessed but it would be after Christmas. For me that was like dragging it out and dragging it out. They set up a play therapist and that seemed to be going ok and he was enjoying it. And then I was in a play review meeting and the SENCo was there and all of a sudden she said that he wasn’t going to be reassessed. I got up and I was so angry and I said ‘What, you just happened to mention that in a play review meeting. I can’t believe you have done that’. If I’d known before that I could have appealed and done something about it. They were just dilly dallying around. There were so many things they could have done. So I decided to get really tough and I spoke to IPSEA and we decided to take the County Council to tribunal for failing to meet the needs of my son at this school. So then I did the tribunal and they had to assess him.

I was fortunate enough to get a mentor through IPSEA. If it wasn’t for her we probably wouldn’t have got where we did. Out of all of this I have learnt that I was probably severely dyslexic at school as well. I can speak but I’m not very good at putting things down in writing. The school would send letters out and I’d get upset and she would say, no no that’s fine, that’s what they normally do, or helped me draft solicitors letters. I felt so empowered having her. She did so much and it was all free. When I had to say goodbye to her it was quite sad.

We went ahead with the tribunal. Meanwhile the school weren’t doing anything different. He was in the secure unit most days, he had no one to talk to, he would have to get on and do his work. Things weren’t getting any better even though we were taking them to court. And then I came across this school called the specialist dyslexia school (independent dyslexia specialist school). I spoke to someone there because we needed an Educational Psychologist assessment for the tribunal. Anyway, they gave us the details of a dyslexia specialist teacher and she assessed James. I sat next to him for 3 hours during this assessment. I came away really sad because I could see how severe he was and how he gave up very quickly and how he got frustrated. It really made me feel crap. Here was a boy that I had been trying to get help for for god knows how long – 6 odd years – and he was still not improving. Then we got the report and I just got very angry then. He still couldn’t read and write and he’d been in secondary school for a year and a half.

We had to go into school for another meeting. This time they were trying to humiliate me. In this meeting was the Headteacher, the Deputy Headteacher, the Educational Psychologist, the SENCo, the LSA and another two people. I was really
ready then because I had this report and I brought my husband in. Basically, this was one of the most empowering moments of my life because I had this report and it said that he couldn’t read and write. I threw it at the SENCo and I did attack her quite personally – my husband picked me up on that. But I was frustrated and at the end of the day we are talking about my son. She didn’t even know what a Wave 3 programme was and so I ripped into her for that because she was meant to be there helping my son. She had done nothing on the Statement and it became obvious during that meeting that they weren’t going to win the tribunal because they had failed to meet my son’s needs. The Statement suggested Dictaphones, touch typing. None of it had been done. I had presumed they would do it. It was a legal document and they should have done it. At the meeting one of the teachers said that he didn’t think James’s behaviour was linked to his dyslexia. That was so out of order. It wasn’t until later on that I thought he shouldn’t have said that. That’s the sort of attitude you are getting from the teachers. They never said anything nice about him. They never saw the true him, just the dyslexia, dysfunctional, misbehaving, bad behaviour. They didn’t see the amazingness, the cleverness that I see, the potential.

It got resolved without going to tribunal and I think that it was based on the specialist teacher’s report and how I was. After this meeting had happened the Ed’ Psych brought me in and I think she was sounding out whether or not I was prepared to go the whole way. She said to me, ‘how did you feel about that meeting. It must have been very intimidating’ and I said ‘yes, I’m tired but I won’t stop. He’s my son and I won’t stop’. She did some assessments and agreed with everything the specialist teacher had said.

It was all agreed before the tribunal date and then we had to go looking for private schools. And that was hard. By this time my son didn’t want to move – better the devil you know than the devil you don’t. He was still being excluded within the school. We took him to 2 schools – Northease Manor: something happened while we were there. James is quite sensitive and this boy looked like he had been crying and had pen marks all over his hands. It was always going to be hard because he didn’t want to go anywhere, whatever school we went to look at. He made up his mind and didn’t want to go to Northease Manor. We went to look at the specialist dyslexia school and loved it – on National Trust land, like a farm, animals, greenhouses – absolutely amazing. Lots of things James likes. It had energy. Northease Manor felt flat. We met the head teacher and he was brilliant and got James involved in acrobats and we really liked him. James liked it but he still said he didn’t want to move.

He went for a couple of trials and they seemed ok. One of the trial days he had a bit of a blip and this was when I realised that his mental state was going. All the time he was at secondary school and fighting, he wasn’t being nasty at home. He was still the James I knew. He was still helping out. A lot of things were happening as well.
In 2012 which was when he was in Year 7 I’d had a baby so there was lots of change for him – he was no longer the youngest.

He sat in the back of the car on the taster days for the specialist dyslexia school and said he wasn’t going. He said that if I made him go he was going to kill himself or run away. I told the school and they said that if there was any chance of him running away they didn’t want him there. I felt quite sad about that. It had taken me so long to get him there, it needs to be positive. I understood their concerns but I asked them to please not send him away, not in front of him, I try not to talk in front of him. I said I’d make an appointment at the doctors and told them that I didn’t really think he was suicidal. I thought he was just lashing out. He stayed for the taster day. One of the days he didn’t go because it was his birthday. Doctor agreed that it was just a really, really stressful time. The doctors husband had been to the specialist dyslexia school and she said that it had turned his life around. It was quite surreal, how things happened.

While all this was going on James was externally excluded for one day for refusing one-to-one support. I decided to appeal against it. I didn’t go to the appeal because my focus was on the tribunal case. I think if I’d have gone to the appeal, with legal assistance, it would have been disallowed. They said that James can follow an instruction and therefore they felt that what they did was just.

Everything seemed to be going well – County said they would tweak his Statement and that he could go to a private dyslexia school and they would fund everything, even transport. Then we found out that the head teacher was leaving and that they couldn’t take him until September. This meant that James had to stay at secondary school. And that was one of the worst nightmares out. He had to go back to the school which had failed him for nearly 2 years. They made no allowances. We’d just held them accountable and they still weren’t going out of their way to do anything. Then my mentor said to email the head of Education and the next thing is that they are getting a specialist dyslexia teacher in to support him with the Wave 3 Intervention. And they were paying for it all. That helped things but it was all too late and I just wanted to get the hell out of that school. I do feel that the school got into a lot of trouble and that lady was there to teach the school how to do things. I was at a meeting and the specialist teacher was telling the SENCo what papers to get out because she didn’t know what she was doing.

In the end James got into this pattern where he wouldn’t work with people. Now that’s partly to do with me and partly to do with his conditioning in primary school and the early years of secondary school. Something happened at secondary school – a teacher belittled him in front of the whole class but the school really covered it up really well. The teacher said James you need to read this book and James said ... I’ve always said and it was put on the Statement that he must not be asked to read
out loud in front of the class. Because he can’t read and he can’t write so why would you want to do that. The teacher threw the book and him and said read the book. James said ‘I don’t have to. My mum’s said that I don’t have to’. The teacher said ‘look at the book. It’s just pictures’ (this is James’s view of the event). I know that this was out of order because when I heard about it the Deputy Head called him in and got him to sign a statement. James can’t read. When I heard about it I asked for a meeting. They showed me the statement and I asked for him to move teachers. And they did. If they weren’t guilty they wouldn’t have changed teachers.

James seems to clash with quite a few teachers. When he gets on with someone he excels but when he doesn’t, it doesn’t work. He clashed with an English teacher because he doesn’t like English. So I asked another woman to help out and we were working together. He seemed to be getting on well but just about when he was about to leave they changed him back. I said to them ‘don’t you think he’s gone through enough. They didn’t seem to comprehend what was going on for him as a child – change left right and centre’.

I begged County to let him go back to the specialist dyslexia school as soon as possible but the specialist dyslexia school said they couldn’t take him – it would knock the dynamics out of the classroom. I think at the taster days they saw a bit of him that made them think they weren’t prepared for him. I think James is a little bit hyperactive.

He started in September. James still wasn’t engaged in going to the specialist dyslexia school. We went to get some uniform and he sat cross armed. We got him to the specialist dyslexia school. I took him for 2 weeks – 50 miles a day – because I didn’t want him going in a taxi – I wanted him to settle in.

Within a week and a half there were problems. The new Head teacher called me in and said that James was refusing to follow instructions and he wanted me to take him home. I went in and I said ‘please don’t send him home. If you are going to send him home it’s going to be like the other school and he won’t actually want to come back’. This school was supposed to be making the difference for him. The Head said that this school wasn’t a behaviour school and that they don’t have the resources to give him the one-to-one support he needs. He went on to mention ODD. Anyway he did listen to me and he stayed at school but I asked to talk to the SENCo because she really knew about the boys and their weaknesses. The Head didn’t really know – he was like a project manager and hadn’t worked with special educational needs children. The SENCo had been emailing me and telling me how well he’d been doing – reading this and reading that. She said she didn’t know what had happened. She said, let’s see if he’ll read now – he had refused to read. Anyway he did read and he got to stay at school. I asked about ODD and whether or not they are treated any differently if he has that and she said no we don’t. The Head
shouldn’t have said this because he wasn’t qualified to diagnose whether he had it or not.

It snow-balled saying he’d been doing this and that – he’d kicked a locker. I think he had 3 exclusions (1 day only) for things like kicking a locker, being rude and refusing to work with someone. Nothing major. Within 4 weeks I had the Deputy Head Teacher phoning me up saying he really liked James but we are going to exclude James for a day to calm down. He was saying he was a nice lad and the next thing is I had the Head Teacher saying he couldn’t tolerate James’s bad behaviour – he had a list of things James had done. He said he didn’t know what to do with him. He was permanently excluded for a combination of reasons that we didn’t really know.

IPSEA helped me with the case – the Director drafted me a letter. I tried to do it myself but I kept getting into a state. That day 3 boys got excluded. I said the only way this was going to get overturned was if we got IPSEA involved or used a lawyer because it was a private school. I knew we wouldn’t get it overturned just by saying my son deserves to be here because he has a Statement. Then I met someone else locally who is a solicitor and she said she wanted to help too. I am so grateful for all the help I got. One of the worst things was going to the hearing. I was so nervous. Headmaster, 3 on the panel, my husband, me and an observer from the County Council. I always remember my husband saying don’t be aggressive, be assertive. He did a lot of the talking – he’s not James’s father by the way, I’ve been with him since James was 2. He was very unemotional and he knew what he wanted to put across. We looked professional, we weren’t aggressive. But the Headteacher came across like such a bloody idiot. He changed his reasoning at the hearing. It was so embarrassing. We overturned the decision and my son went back to the specialist dyslexia school – it must be an awful thing for him to live with. They said that James was permanently excluded for bullying. The school did lots of things wrong and we heard within a couple of days. It said they were disgusted with James’s behaviour and if it happened again they would have to exclude him. We got them on disability discrimination because he’d only been there 4 weeks. The other child didn’t come back because the mum went through Parent Partnership and didn’t get legal advice. Parent Partnership really dropped her in it. We needed to know the law.

IPSEA said that I should go into the school and ask what they were going to do to support him. I went in and it looked all great – Headteacher shook our hand and said clean slate. But he has been excluded for one day since then because he set a book alight in a playing field with 2 other boys. I’m still not entirely sure how long James will be at the specialist dyslexia school. Out of all this, the SENCo didn’t know about his troubles. The teachers weren’t talking to her. Teachers were complaining about James because he wasn’t doing as he was told. I’ve had feedback from people who have said if he is still doing all this then things obviously aren’t right still. I live on tenterhooks. I still don’t answer the phone. The school did so many things wrong.
I kept asking for it in writing and they spent 3 or 4 days putting it in writing saying he was permanently excluded. He’s still being pulled out of English lessons because he clashes with the teacher. They asked if I mind and I said no because he’s getting one-to-one. That’s what he wants. They said he will be reintegrated in. He’s chosen his options. He doesn’t talk about school like he used to. He talks about working with the animals – all the things he loves. IPSEA don’t think they will permanently exclude him again.

In all of this there has been trouble with the police. He shoplifted in TK Maxx in Brighton. James panicked and gave his dad’s address because he didn’t want to upset me. I got a phone call from the security people and phoned them back with our address. I thought he’d get a fine but he didn’t. It was his first offence. He nicked a pair of headphones and when we asked him he said he did it because he was showing off in front of his friends. He’s had a couple of anti-social behaviours locally – throwing eggs at a house and people and trying to set a bush alight. I phoned them up and asked them what I should do about it. I said that I was willing to help my son via them – you are telling me he has been anti-social – what shall we do about it? They said that we didn’t fit the criteria for help. In the meantime I got some help from a youth worker and he said that James needs to be a mentor in a youth group. Then I went to the doctors – 3-6 months ago - and said I was concerned how this was all affecting him, can he see CAHMS. CAHMS said that he wasn’t showing that bad stuff. I understand that there are people who are worse than him. So far we haven’t heard anything. He does go out. I think he mixes with the wrong people. But we’ve not heard anything more since the last anti-social letter.

I think that’s it. I’m waiting for my Annual Review. I’ve made a point of trying to belong to the school so I joined the PTA. the specialist dyslexia school is miles away from where I live. I don’t know any of the mums. It’s not like a local school where mums chat. I’ve been to social events because I want to be seen to be involved.

BREAK

Sub-session 2

C Can you tell me some more about how James was at primary school?

D I didn’t hear a thing at primary school. It was just the struggles with him reading and writing. They never said he refused to read. It was never like that, it was almost like primary school was the fairy tale bit. It wasn’t until you go to secondary school, I think it’s the same with everyone, you have to learn. But primary school you sort of play and it was very much....I was never called in for any fighting or bullying. He was always playing football. I never had any calls saying he was doing this and doing that. It was just every parents evening it would be that he
wasn’t getting anywhere and was thinking why isn’t he getting anywhere? It was disheartening. In the end I stopped taking him because I didn’t want him to sit and listen to them saying that stuff about him. I still went because I didn’t want to be seen to be not interested. In himself he was fine. He was popular. The only thing that stuck out was that it was a struggle with homework. My husband used to spend ages doing it with him but it was quite a struggle to get him to do it. And he was tired a lot, being at school he was tired. Sometimes he would get really good grades for his homework and my husband would laugh and joke and say that’s not bad I got an A for doing your homework.

C Can you tell me about the teachers?

D Crap! It was a dyslexia friendly school. How can a dyslexia friendly school not have teachers know about dyslexia. He was in there 7 years and it wasn’t until the last 6 months that they went for the Statement.

C When did he go on to School Action Plus?

D That was Year 2, about the time when they tried to fob me off with the specialist teacher report.

C When he got to Year 5 and 6, when it starts getting serious with SATs was he still ok?

D It didn’t seem to bother him. I think he is slightly immature for his age. But his levels were all low, level 1s and 2s. But it never used to bother him. I think they did it in a way that didn’t seem to bother him. I forgot to mention, they faked some of his figures - SATS. How I know they did that...they put in the letter that they couldn’t change his figures but they were incorrect. They were trying to make out that he was getting better and he wasn’t. That letter was given in as evidence for his Statement. They didn’t say why, just that they were incorrect. I don’t know why they did it, unless they assessed him wrong. He didn’t improve. I’ve got all the evidence that he wasn’t improving. Towards the end I said ‘can I have his levels and something about his IEP’. The SENCo was very good at fluffing over – all SENCOs seem to be good at fluffing over, making you feel better but not really addressing the issues.

C Did your other son go to the mainstream secondary school?

D Yes, my other son went there and he was classed as gifted and talented.

C So James is the only dyslexic in the family apart from yourself. What do you think happened to make him change?

D Less support. No support.
C Can you tell me more about the support he got at primary school and secondary school?

D In primary school they were inclined to do group work. There wasn’t as much attention put on him. You’ll know as well, they changed how they did the phonics. He’s a 2001 baby. Someone said that they changed how they taught the alphabet and that had a knock on effect on all these children in that particular year. They were all struggling with reading and writing, not just James. It was described as a challenging class because they were all struggling with it. It was all group work and I don’t think he was really aware that he had an issue. And he hates it. He doesn’t call himself dyslexic. He really hates it. He will not say that he is dyslexic. I don’t know why, I really don’t. He’s really impressionable. He has to have all the designer stuff. He wants to be like everyone else. He wants to be classed as normal. There are other people on the dyslexia sites, girls who have it and they go and promote it. But he’s not like that. Even being in a dyslexia school he still doesn’t like saying that he is dyslexic. I mentioned about dyslexia yesterday because I said that I was coming to see you and he said ‘I’m not dyslexic. It’s just like a different thing in the brain’. I wasn’t going to go there. But he does say that he wants to be a millionaire. He’s the only one out of all of the kids. I say, ‘why do you want to be a millionaire’ and he says ‘I want to be able to do the things I want and not have to worry about money.’ He’s a lovely boy. He has a heart of gold. But I know he has been damaged by this journey. He hasn’t got the confidence. I see it. Looking back I think he finds it hard to keep friendships going.

C Why do you think that is?

D Because of his self-worth. He doesn’t think he is worthy. He thinks he is stupid. He thinks he is thick. Still. the specialist dyslexia school hasn’t really done much for his confidence. They said they would work with SEAL. He doesn’t come home any different. To me he doesn’t talk about school as much and he is plodding along. They haven’t tapped into who he is because he is amazing. I’m not just saying that because he’s my son. He has got so much potential. He can do so much. He mows the lawn, he knows how to do the washing machine. He does so many hands on things. He has ideas. He has his own tools. He’s really, really intelligent and clever. It’s just this stupid reading and writing. I’ve watched him recently with S, my nearly 3 year old, I’ve asked him to read things and he feels very uncomfortable. The specialist dyslexia teacher that did the assessment for the tribunal gave the impression that he’ll probably never properly read and write. It was very much geared up about voice recognition software, dictaphones, touch typing. But I got the impression that he probably wasn’t going to ever read and write. One of the things she said and I do think that some dyslexics can teach themselves to read and write when they are ready. I’ve got a dyslexic friend, she hated school, but when she matured she was able to read books and teach herself. The specialist dyslexia
teacher said that James was so severe he would never get to that stage and teach himself.

The SENCo at the specialist dyslexia school said that he’s doing really well and will read out loud now. There was problems at the specialist dyslexia school as well – they got him to read out loud. It’s just been a mash from the word go. Even when you get to a specialist dyslexia school and you think you’ve got it sorted, then you’ve teachers still getting him to read out loud. It’s just been a mess really.

C Can you tell me some more about his friends?

He’s still got his same crowd. His local crowd. Sometimes he is like really into home and does stuff round home and goes to his dad’s. It’s naughty boys, what I would class as naughty boys. They are new friends who went to the local primary school that was in special measures. James’s school was, believe it or not, the best school in the area. Then the local secondary school was literally one of the worst schools in the country. That’s why I made him go to the other secondary school. I didn’t want him to be the school clown. So he hangs around with naughty boys and some of his old friends. But he doesn’t seem to stick to …you never know who’s going to come round. It’s really hard when the naughty ones come round for me to be neutral because whenever he’s with them he gets into trouble. I’m not saying that James is a goody two shoes, no he’s not, but he doesn’t go out of his way to hurt people. It’s just that he’s impressionable and wants to be like everyone else and if everyone else is being naughty then I guess he’ll be naughty.

C What about his new friends?

D He has one friend and he has just been excluded for 5 days. He lives in Glasgow and flies down. They come from all over the place at the school. That puts me on tenterhook – if they are still excluding kids, what’s going on. What they are doing is clearly not working.

There are all sorts of kids at the specialist dyslexia school – ADHD, mild autism, dyslexica, dyspraxia, there might be Aspergers. There’s only 100 at the school. I went to a parents evening recently and I nearly cried. There were a couple of teachers saying how wonderful he was and how creative he is. The artwork he had done….he made a picture with a dog….and I just thought, that’s the James I know. That was the first positive parents evening I have had since September 2014 when he went to the specialist dyslexia school. Some said some weird things that could get them into trouble. One of them said ‘I don’t have a problem with James, I think he’s fine. When I hear teachers talking about him I look at them and think that they’re not talking about the same boy’. That was the maths teacher. I don’t think she realised what she was saying. That’s why when I went to the art teacher and she said he’s going to be an A’ level student, I nearly cried. When I looked through
his work I couldn’t believe it. I said. ‘James, this is fantastic. Why haven’t you told me about this’. He said that he didn’t think it was that good. I think his self-esteem is not great.

C    Has he ever had counselling?

D    No, I’ve asked for counselling but he won’t do it. I think it’s going to be later on when he’s ready for it. He won’t do it now. I am about to learn Emotional Freedom Technique – I’m training this week – and I’m hoping it’s going to be good for all of my kids. I’m trained in complementary therapy and I used to do Reflexology and he used to love it.

C    Does he go to school easily now?

D    Yes. Even when they were excluding him, he still got up …he leaves the house at 7.10 every morning and gets back at 4.45pm. He has not said he doesn’t want to go or anything. At secondary school we had one day where he didn’t want to go. I remember dragging him out of bed saying ‘you will go’. I think it might have been a day when he was going to be assessed for something. I got really upset and he phoned the police. I was so embarrassed. But that’s what he’s like. He doesn’t realise what he can do... what his actions can do. He wanted to phone ChildLine but he phoned the police and they literally came round really quickly. I don’t think he ended up going to school.

C    So when he was going to secondary school, how happy was he?

D    Yes, he was happy, even when he was fighting…it was like the norm to him. I think he might have the ODD - defiance disorder. He doesn’t like taking commands and the patterns is that he always seems to be misunderstood. I always hear him saying that wasn’t how it was. To me there seems a lot of injustice done to him. Like I say it’s been an awful journey for him so I’m not surprised he’s all over the place.

C    When you say it’s been an awful journey for him, what do you mean?

D    It’s like he doesn’t belong and he’s been pushed from pillar to post. Primary to secondary, then secondary to the specialist dyslexia school. And in the days he was excluded from secondary school he had to go to a PRU, a Pupil Referral Unit for one day. I went in there and was all ready to sound off but they said it was the law that he had to be in education. I asked them what support they were going to offer him and they were really nice in the end and I understand why it might have worked for him to some degree. They know a lot about behaviour but they wouldn’t be able to follow hardly anything on his Statement. I said that’s no big deal as long as he did his reading, writing and maths. At that point we were desperate. We just wanted him to get some sort of education and stay out of trouble. He was there for one day and then we won the tribunal.
Would he have stayed there otherwise?

I think it frightened him. He didn’t like it. There were a lot of noisy boys there and he doesn’t like noise and there was a lot of people shouting. It was a bit of an eye opener.

Going back to his journey. To me it’s just not been smooth. Me fighting. Him not being treated as an individual, because he has individual needs. Me having to fight for the extra because he doesn’t fit in like everybody else. My son is studying for A’ Levels at Worthing College and he’s getting A*s and is going on to University, and then there’s my daughter and she’s getting into A*s and then we’ve got James who still can’t read and write and is fighting and being naughty outside the home as well, whereas the other two are focused....they’ve got their issues but they are not like James. James seems to be in no man’s land.

Do you think that could have been different?

Absolutely. When he was at nursery school it was all about praise. There was no difference there. No pressure about learning to read and write. They were just observing them and praising them for all the little things. As soon as you get to primary school it’s very much focussing on whether you are reading and writing and how quickly you are doing everything. I remember mums saying that they were going to teach their children the alphabet before they get to school, I hadn’t even thought about that. PAUSE Socially.....he can mix, he can talk to people, whereas my oldest who’s really clever and brainy has no common sense, seriously he hasn’t. James would know how to look at things and do things and ask.

Sub-session 3

Let’s look at the research questions for my dissertation. I have four research questions. The first one is:

How helpful is the label ‘severely dyslexic’?

I actually think it is really helpful but I can tell you another view as well. I think if you know what the issue is then as a parent you can go out of your way and address it. If you don’t know what the issue is you can’t help. I don’t know if it’s my therapist’s head, but for me personally. But I know another mum who didn’t want her son labelled, knew that he was severely dyslexic, did similar things to James and did go off the rails but has now pulled himself back on track. I think it needs to be a label. From James’s point of view, he didn’t want to know. But it needs to be there in order to get the right kind of help and support. At school I thought I was thick and now when I look back at it I realise that I was severely dyslexic. At the same time I thought I was clever as well and I thought how can I be clever if I can’t read and write very well. My mum and dad didn’t have a bloody clue. So this is why it’s
been quite a personal and stressful journey for me. I remember crying and not being able to get maths right, not wanting to go to school. It really did affect me. I could have done so much better but it just wasn’t recognised in those days – I was born in 1969. But I coped. I compensated. I did that later learning. I remember ever only reading one book but now I read books left, right and centre. I was not ready....I didn’t have the right support at school. With James, he’s very immature for his age, I think some children are not ready to learn and they just want to play. Some are ready and some aren’t. He still wants to play at 14 years old. He plays manhunt, he’s got guns. To me he’s very immature and doesn’t want to face up to growing up. When they are in that stage they won’t want to learn. I also think James lives in the here and now. He struggled trying to choose his options and my husband said that it’s because he had to plan and he doesn’t plan, he lives in the here and now. Dyslexics have a terrible time at school but when they mature and they are ready and know about themselves, then they will go and learn. The school is like in and out and if you don’t fit in then you get left behind. They don't allow for all the different ways of learning because they don’t have the time and resources. That’s just the way it is.

I think the label needs to be there in an educational environment because of the lack of support for dyslexic children.

I think the label severely dyslexic is really helpful....... I didn’t realise how they work out how severely dyslexic someone is – how long it takes them to read and write with all the intervention put in place. And James had had all this School Action Plus but he still couldn’t read and write. I always knew he was severe .....................in secondary school he had to learn some lines and he came home and he was so upset about it – they were really hard words. I phoned up and said that he wasn’t going to do it. I probably didn’t help because I’ve since then seen an article on a severely dyslexic drama teacher and there are other ways to learn it. Apparently if you record it and then listen back he would have been able to learn it as opposed to seeing the words.

C Now the next research questions....

Is it possible to effectively support severely dyslexic children in mainstream school and how should this be done?

D No. I think it depends on the journey. I couldn’t wait to get him out of secondary school school. James didn’t want to go to the specialist dyslexia school but I couldn’t wait. I felt angry at that school. How dare they let my son down. I was told by that specialist dyslexia lady that if he’d got the right support he wouldn’t have needed to go to a specialist school. If he’d got all the provision on the Statement he wouldn’t have needed to go to a specialist school. I haven’t heard of
any severely dyslexic children doing well in a mainstream school ...on websites, like IPSEA.

C What do you think needs to change?

D Become specialist schools. When I say specialist schools I mean, if I had a magic wand and money was no issue, they’d be more focussed on playing, like the Steiner Schools. But not as hippy as that. More individual. When you go to college they seem to do more – they assess you, they get a mentor to help you, they put exams on yellow paper, they seem to be more obliging. But at primary and secondary school they just don’t seem to have the time. At college they want to be learning, they want to be doing their subjects, which is why I think they are willing to support you. In primary and secondary school it’s all about getting you educated as much as you can and then out.

How should it be done? Well, they did support him for a short period of time but it didn’t address all the behaviour problems. To me the teachers need to be educated. The teachers didn’t have a clue what was going through a dyslexic child’s mind. They didn’t have a clue. When someone’s angry or kicking, they didn’t know how to deflate the anger. They didn’t seem to have to expertise. The emotional side of it, whereas the Pupil Referral Unit, they were experts at behaviour.

Also, the question is, why are teacher teaching if they don’t want to make a difference? I want to make a difference as a complementary therapist, I go out and learn and learn and I still don’t feel I know enough. I wouldn’t dare say I wasn’t qualified, I’d go out and learn so I could make a difference.

C Next research question:

How can teachers facilitate a positive sense of self among severely dyslexic children?

D I don’t know about this. the specialist dyslexia school said they are doing SEAL, but I don’t know I haven’t seen it in action.

C What do you think James needs to feel better about himself?

D PAUSE Praise. Constant praise for the little tiny things. I always remember the tutor said you have to look at dyslexic children’s achievements like measuring grains of sand. It takes them a long time to do something and you have to really praise and over-praise. Self-esteem courses. Sometimes at the specialist dyslexia school he comes home and says that he feels quite clever because I knows how to do something. But it’s not very often. Positive rewards. the specialist dyslexia school do positive rewards, rather than be on report. But that is only as good as what the teachers are prepared to fill-in. To me it was lack of input from the teachers and James excelled with praise. That should have been happening at primary school. To
me that’s where it all went wrong. I know for a fact that James learnt from secondary school that he would get excluded into the Unit and he wouldn't have to do the work. That was picked up on the reports from the County Council and the private assessment.

C When you say it all went wrong at primary school, what do you mean?

D Because he spent all that time there and they didn't even definitely say that it was dyslexia. They said dyslexia tendencies. And whatever they were doing wasn’t working. He wasn’t improving. I don’t know if he’d got the right intervention whether he would have improved. It’s really hard to say. We’ll never know. Certainly what was happening wasn’t helping. And it was shown on the reports – they even tried to make his SATS look better. You could see he wasn’t getting better. He still came away with levels 1s and 2s when he left primary school. James used to worry about his levels. Schools talk about them all the time – that’s where he must have got it from, because I never talked about them.

C My last research questions:

What do teachers understand by the term dyslexia and how well do they perceive they can support severely dyslexic children?

D At primary school I think they saw it as a child being lazy. Some teachers saw it as every child can learn, they just need to focus. I do think that there are some dyslexic children out there with driven parents and the right teaching, who could overcome it. My husband is dyslexic, not severely, he was given private education and he has A'Levels. So there’s the difference. I think if you have parents who are driven, I wasn’t a driven parent, I’ve been more about letting them do what they want – it’s your life. I have done a lot but I don’t think James knows it. It’s like he’s in a bubble. Maybe it’s there because it’s his safe ground. My husband doesn't comprehend my drive. He said he would have given up long ago. But I know what it’s like. I wish my parents had been a bit more into my education because I still have self-worth issues now because I was made to feel dumb. That’s stuck with me for the rest of my life.

C Do you think teachers understand severe dyslexia?

D No, I think they know of dyslexia but they don’t know there are different severities of it, just like autism and Aspergers. No I really don’t. I used to feel like I was on a different planet to the teacher when they were talking at parents evenings. They talk like they don’t have a clue.

C Have you come across any resistance to dyslexia?
D Yes, at primary school they were a dyslexia friendly school but only the SENCo knew about it. None of the teachers went out of their way to learn more about it.

C Why do you think that is?

D I think it’s all about funding and they have so much to do. They have big classes. He was in a class of 30. One teacher and an LSA. It’s just not having the time. As I said before, why be a teacher if you can’t make a difference. They probably think they are making a lot of difference to the ones that are able to learn and pick up quickly but it’s the other ones that get left behind that it really affects. I bumped into the Headteacher of his primary school about 2 weeks ago and she asked me about my kids because they have all been there. I told her about my troubles with James and told her he was severely dyslexic and she looked at me like I’d just said a really bad swear word. She was the one who actioned the Statement but it was like even she didn’t realise how severe he was. That’s a prime example. She was like surprised that he was at a specialist dyslexia school. She looked like I’d just said ‘poo’ or ‘crap’ to her. And she didn’t really want to talk about him. She wanted to talk about my two other children who are doing well.

C What do you think that is about?

D It’s about them identifying themselves as not being the best they could be. But if someone said something to me that I had done wrong, I’ll give you an example: at Tumble Tots you are supposed to hold the back of your child’s t-shirt when they are on the equipment. I was supporting her on this piece of equipment by holding her hand because she didn’t like me holding her t-shirt. The lady said something to me that made me feel like crying. She said to try and hold on to the back of her t-shirt and I said that she didn’t like it. She picked me up on this because I said it in front of my daughter. I was really taken aback and I felt really crap as a mum. I came away and I almost cried. But I wasn’t too proud to say, actually yeah, I did say that. But we are all only human. We are a work in progress. I try to do the best I can but even now I’m still learning as a parent. But I wasn’t proud enough to not think about it. But at the end of the day there’s only so much you can do. Perhaps that’s what teachers think. They do the best they can and when we throw all these things at them they take it personally in some way. But I would always want to improve. And I actually put that on some of my feedback at the Annual review. I said I am always learning, I would never think that I know everything. I couldn’t understand why the SENCo wouldn’t even know what a Wave 3 programme was. I couldn’t comprehend that. And didn’t go away and find out. How could she be in a secondary school environment and not know about Wave 3? So I do think that teachers have so much to do, but I would say that they still need to be accountable for the profound effect they can have on a child’s life. Even in this
day and age teachers have affected my son. How many years ago was I affected by a teacher belittling me in a class. It’s still happening. We are still so behind in some ways. It’s shocking.

C Have you ever found any resistance from teachers in terms of dyslexia being a middle class thing?

D No, certainly no. The primary school teacher described him as lazy. At secondary school they thought I was a busy body mother. James got friendly with the young LSAs and one of them said that your mum is being a busy-body mum, throwing her weight around. One of the things that really upset me was that they got him a leaving card saying ‘Sorry you’re leaving’. That upset me because they weren’t sorry, they made him leave. It made me look bad as a mother and made the transition worse. It was insensitive. It’s like they are immune to the emotions of both parents and children. Teachers don’t give a damn about the emotional consequences of their actions. He really liked the card. It was hard enough doing what I had to do.

C Do you think now he is ok with being at the specialist dyslexia school?

D He still wants to go to secondary school. One of the teachers recently spoke to him on Facebook and asked how he was. I think

Summing up: With the benefit of hindsight I wish I’d paid for a private Educational Psychologist report in Year 2. But they kept saying that they wouldn’t necessarily follow what was on there. I think they were trying to scare me.
Suzanne’s Story – Transcript

S = respondent  C = researcher

Sub-session 1 (S only)

He was on time. There was a complication with the birth and he got stuck and he had to be resuscitated. That was the beginning really.

Then he was fine. He was only in emergency care for 24 hours and then they discharged him. He seemed to be ok. Milestones, doing all that. He wasn't having any trouble speaking, no trouble with his speech or anything. He did go to preschool. He enjoyed it there but they did say that he didn't understand colours, numbers. He couldn't do his colours and numbers. He couldn't share. He was always climbing. They said he was a streetwise boy. There were no real concerns there. He was an August baby as well, which hasn't helped.

He started primary school a week after his 4th birthday. That was quite harsh. His teacher....she taught Hayley so she knew the family. He was a struggle at school. He wouldn’t concentrate. He couldn’t sit still. They gave him a wiggle mat so he could fidget but that didn't really help. Then they gave him the armchair and he was always climbing on the armchair rather than sitting on it. Then they gave him his own chalkboard and chalk so when the kids were listening to stories he was just scribbling on his board. So the whole time he was quite disruptive, he couldn’t sit still and listen to the teachers talking. That more or less carried on for that whole year. The teacher wasn’t worried at that time.

In Year 1 his teacher really got on well with Sam. She was a dance teacher and she would always show him off by getting him to do things. So they got on really well and she never said anything negative about Sam. She just put up with him.

In Year 2 within the first month of him being there I got called in several times. There were notes in Sam’s reading book saying Sam needs to do more reading at home, he’s not concentrating. I was called in and they asked me if I’d looked at what he was eating. That’s when I decided to get help. So I went to the GP and got referred to the paediatrician. I thought maybe he has autism or what have you. He just couldn’t sit there and concentrate and he came across as being rude. The teachers would say that he is very rude, he doesn’t listen to them. I had the parents who were coming in to school to do the reading saying why don’t you read with Sam at home. So I said that I do read with Sam at home. So I went in and complained. I thought I don’t want mums telling me. The teacher is one thing. But the mums is another. So Year 2 is quite tough and he got really down.

By Year 3 it wasn’t much better. He started getting homework and he couldn’t cope with it. He really couldn’t cope with it. He ended up saying at school please don’t tell...
my mum and dad or they will shout at me again. We ended up having social services round at that time. But it actually backfired on the school because social services helped us. I was waiting for my referral to the paediatrician and with social services it seemed to speed it up a bit. I went to see the consultant to get things going. In the meantime privately I got an Educational Psychologist. I paid for him to do one because the consultant thought he was dyspraxic. He wasn’t. The Ed’ Psych didn’t really give me a lot of confidence. I didn’t know what I was doing or what the outcome was for Sam.

The paediatrician referred him to New Common Centre and he did a day assessment there. He hasn’t got autism, it was purely speech and language difficulties. So they diagnosed him with having dyslexia and complex needs and maybe auditory processing problems.

But as the years went on, when he got to Year 4 he had a teacher who was deaf and had a speech impairment and Sam couldn’t understand her at all. I had to go in to school and explain so they said ok we’ll get Sam into the other class. We’d only talked about it but Sam took it upon himself the next day to take himself into the other class and just sat there. So he did it himself. That was quite hilarious. By Year 4, his writing was terrible, his spelling was non-existent. He was ok with art – he quite liked doing art and of course his sports. He is great at sports.

Year 5, that’s when the SENCo started helping. Sam’s first teacher ended up being the SENCo which was great because she knew Sam. She allowed Sam to have brain breaks - if it got too much he could come out of class and go and sit with her. For more or less two years at primary he wasn’t doing anything. The final straw was when he was doing maths on the computer and sometimes it was against the clock. The anxiety that was coming out of that because I wouldn’t help him because otherwise it’s my work. That’s when the behaviour started coming and he started head-butting and biting himself.

In Year 6 I knew of somebody who was having trouble with their son and went to Northease. So I approached her and asked how she got her son to go to special school. So she explained what to do. What did I do then? No, in Year 6 they had done a Statement for me. The SENCo did it. And I got that straight away, more or less which was good because I didn’t think I’d get it. So I had the Statement. He wasn’t getting any help, only that he was allowed to come out of class and sit with the SENCo. And then in Year 6 I started fighting for him not to go to the secondary school. I got a speech and language therapist, paid for a speech and language therapist, and got an Educational Psychologist. They all done a fantastic report. Sam did a trial at Northease for a day, got accepted there. I was still fighting for the case. It didn’t go through quickly enough so Sam had to go to local mainstream Secondary School. He was just lost. Totally lost there. They did move him into a
tutor of my choice, with his friends, but that was no good really because it’s just tutor. None of his friends were the same level as him so he ended up being in a class with travellers and other kids with special needs – all different. The first week Sam did his CAT tests and came home and told me he had tests. I asked how he did and he said that he just marked ‘c’ the whole way down. But he was totally lost. He used to hang around with his sister for help. She’d end up taking him to his classes. He was also doing attention seeking – silly behaviour. Just acting the clown because that was how he got through things. He was there until Christmas. He would get panic attacks and tell the teachers that he wanted to go home. He was pulling his eye-brows out, biting his fingers until they bled. At that time I had to take time off work. They’d ignore him. His hand would be up continuously. I managed to get an appointment with Guys Hospital for him to be tested for auditory processing. They agreed that he has auditory processing problems, not disorder. He can’t take in information and hold it in. He explained that it’s like listening to a teacher that speaks a different language – she could be talking but none of it is registering.

The tribunal was in November. He went for a day at the specialist dyslexia school and instantly liked it. Two day trial and they accepted him there. We went to tribunal. The SENCo at the secondary school didn’t do any favours for the school. So it went our way. They awarded him a place and a taxi.

In January he started at the specialist dyslexia school. Sam was extremely happy with that. Instantly it was like a big relief for him. They made him feel really welcome. He’s in a class with about 5 or 6, that’s the maximum. They are all very much like Sam.

Since then he’s just been really settled – they’ve never had anyone like Sam before because of his sports. They’ve made him excel in that. He’s a bit of a celebrity there. It’s athletics he’s good at. He does all sports there. It’s going back to basics – he’s not afraid of asking. He’s not frightened of getting things wrong now. His report...his grades jumped up. He was really low and they jumped up to above average. Just with that support. If he doesn’t like something he will have behavioural problems. Like, he’s not interested in music, because he doesn’t understand it his behaviour becomes bad. But they know that and hopefully that is going to counteract that next year because of their options. The specialist dyslexia school is just brilliant. It keeps itself to its self. It’s just all that time of me having to worry, it’s just I don’t need to worry about him. His reports are great. He’s got great friends. He’s very popular. Everyone know everyone else there. He goes off in the holidays with them. He’s very helpful with the teachers – they think he’s amazing. Half of them there are paid for by their parents, but there’s no difference. He’s managed to get gold in the independent schools so he’s going to Birmingham to run in the regionals. It’s a big thing and the school make it a big thing. He does excel. The PE teacher makes Sam
feel so good because it’s one thing he does excel in. Sam helps out as well with the younger ones.

When I start talking about it, it’s just one big relief. He’s only just started coming home with homework because they have recently got a new head. But it’s not a major amount of homework, not compared to his secondary school.

Sub-session 2

C Can we go through the primary school stuff a bit more. What were they saying to you by giving him the wiggle mat in Reception?

S He didn’t seem to want to sit down. The first year they were really sweet about it and didn’t make an issue of it. They weren’t telling me off and saying that I needed to make my son concentrate. He was never told off.

C Can you tell me more about what happened in Years 1 and 2?

S Year 1 it wasn’t an issue. By Year 2 though it was an issue. He couldn’t read, he couldn’t concentrate to read, he couldn’t count, couldn’t do his colours. He was so disorganised when it came to things on paper.

C And they started saying to you about eating.

S Yes, they asked if he had a food intolerance because he wasn’t concentrating. I was fuming and that’s when I contacted the GP.

C Can you clarify what the New Common Centre is?

S It’s at Guy’s hospital. That’s when they did the whole days assessment. They said that he would need a special school – he cannot sit in a classroom of people and concentrate. It was in Year 3 by the time I got there.

C What did the school do with this feedback?

S They did nothing. The SENCo was saying to me that I would have more chance of getting a Statement if I left it until the end of Year 5, for transition to secondary school. I’d have more of a chance to win the case then than in Year 3. They didn’t think I’d have a chance by starting when he was so young.

C With the benefit of hindsight do you think she was right?

S I think so. He was ok at primary, especially in Year 5 and 6 when the SENCo took over looking after him.

C So when they said special school what did they mean?
I don’t really know whether they meant for secondary school or earlier. I didn’t really know what they meant. Then I didn’t want him to go to a special school. I didn’t know about Northease and the specialist dyslexia school. I only knew about Lindfield and schools like that and I didn’t want Sam going there. It was a bit naïve on my part. We tried really hard to do things with Sam at home. The speech and language therapist gave him loads of idioms to do. We tried to do our own speech and language, like drawing ‘S’ on the beach. Doing all that. When my kitchen gets condensation, writing words on the door. To make it fun for him.

C So was speech and language therapy NHS?
S They only came once! LAUGHS.
C So what was his speech difficulty?
S Just retaining information, word-finding problems. He can talk but if you want him to ....it took him two weeks to find the word yorkshire puddings. No way could be find the word. In the end it was his bestfriend (S) who told me. S, he’s got aspergers, helps Sam and Sam helps S.
C What exactly was the diagnosis from the New Common Centre?
S Complex needs. They mentioned dyslexia, with complex needs and auditory processing. They didn’t know what else was stopping him. They didn’t write it down officially that he had dyslexia, just told me. All that was written down was that he has complex need and auditory processing problems. It wasn’t until I did the Educational Psychologist in Year 6 that I paid for that it was dyslexia, dyscalculia. I had to wait 18 months for the appointment with the paediatrician – that was why I paid for the Educational Psychologist (Year 3).
C Can you tell me a little bit more about the time Sam said at school ‘please don’t tell my mum’?
S Because he was getting homework, he wasn’t bringing it home. Then the next day at school he was getting told off. Because at that time, because no one was taking me seriously, we were trying really hard. We were reading with him, doing spellings. So he was having anxiety attacks because of us and that’s when as well, in Year 2, he started having sleepless nights and night terrors. So he said to the teachers please don’t tell my dad, because it was him actually, because he gets really angry with me. He said that three times so they had to get social services out. It was us trying to nag him, still not realising that Sam needs special attention. It was really quite good though because it was really more like a counselling session for everybody realising that we can’t get after Sam – we can’t do this, he needs more than just us. That’s when the ball started rolling. It speeded up the Guys
appointment and it went back to the school that they were happy with us but not the school.

C How did the school react?

S They just apologised and said that they had to tell social services. They gave him star of the week that week. Well done! Thanks very much! Years 2 and 3 were the worst for Sam at primary. The teachers didn’t have any patience with him. They thought he was rude and ignoring them. They didn’t want to help.

C Were you at that stage having contact with the SENCo?

S No, I didn’t know what to do at that stage. It was only in Year 5....

C Can you tell me some more about when you said he was at his worst in Year 2 and 3? How did it manifest itself?

S Because they didn’t have any patience. They used to call him naughty because he wasn’t concentrating. It was the worst time because of his behaviour. Going into time-out, ignoring the teachers, not understanding what they wanted him to do.

C So what did the Ed Psych report say in Year 3?

S It wasn’t a very good Ed Psych. Waste of money. He said that he was dyspraxic. I’d done my research first and I was thinking I don’t think he is dyspraxic. He talked about mental dyspraxia, disorganisation in the brain. He failed all the tests: what would you do if there was a fire? He was failing everything. He failed all the WRAT tests too. I gave the report to school but it was useless. It wasn’t a proper report. He was an Ed Psych but it wasn’t a report that could have been used to fight tribunal. I was getting all these bits and pieces from everybody and yet Sam was still not doing anything at school – still not reading, still not writing, still getting mixed up with his colours. Still wouldn’t know what to call a baby horse. It was so frustrating. It wasn’t until Year 5 and 6 when I got......I got the OT first but there’s nothing wrong with his OT – he’s solid when it comes to that. Manual dexterity and small motor skills are ok. He had trouble with his shoe laces. That was the only thing he had trouble with. Everything else he was quite strong with his movements. And he is very stable when it comes to sports and very balanced. We paid for the OT report.

C What else can you remember about Year 5 when he gets a nice SENCo?

S He still has the same troubles but then he’d ask to go and see the SENCo and that was allowed if she was around. He could just sit with her for a little while, talk to her, play with stress balls and what have you. It made Year 5 manageable. Year 5 was more or less that the whole way through.
C What about levels of support?

S He didn’t get any. None. Only going to see the SENCo.

C Was he on School Action Plus?

S Yes, he went on that in Year 2. They never did anything. He never went into a small group or…. he didn’t have anything like that. Some of the kids with severe behaviour went off somewhere in groups. They did something – his friend did. At that stage it wasn’t as if Sam had behavioural problems, it was just that he didn’t want to concentrate. They didn’t class him as needy. They didn’t think he was that bad – it was just rudeness. He’d sit there, they would say get on with your work and he’d say ‘what do I do?’ He didn’t understand what they had said so they had to explain it all over again and still it was no good – the information hadn’t gone in. Information needs to be broken down, like, Sam write your name here, date here….small stages like that.

C Did the school suggest a Statement?

S Yes. It was discussed that we’d do it and I started the ball rolling. I had learnt a little bit about it by now and could see that there could be an outcome. I phoned up Parent Link saying how do I go about sending my son to a private school and they laughed at me and said ‘you can’t just do that’. I was asking them for help and they were laughing at me. So I never phoned them again, ever. I thought, if I’m asking the question wrong them I’m sorry but I don’t know where to start. It wasn’t until the lady down the road whose son went to Northease….so I thought I’d ask her. We got the Statement around Christmas time I think.

C Can you tell me what happened after you got the Statement?

S Nothing! Nothing changed. The Statement wasn’t very good. I looked at it and thought ‘brilliant’ but when I went for a meeting at Northease the Deputy Head there ripped it to shreds……. I remember my friend saying get someone to look through the Statement, don’t just take it for granted. So then the Statement had to go back to get changed. I think by then it was becoming more of a transition Statement and it was still saying that he would go to the local mainstream secondary school and that they could cater for Sam. So I couldn’t accept the Statement until it had my choice of school on it. It came back in July and then it’s the holidays and everyone shuts up shop. They were still saying that he couldn’t go to Northease and I had to get a solicitor involved.

C You said that Sam was ‘lost’ at the secondary school. Can you tell me more about this?
He was literally lost – not knowing where he was going and time-wise, because they had to get to classes. My daughter followed him around too get him into class. He was literally lost, going into the wrong classes. Sam absolutely hated it. He was very uncomfortable, very nervous about going, didn’t want to go, crying a lot. I was going to keep him at home but the solicitor said ‘no, do you think he will cope at Secondary school’. I said no and she said to send him, just for extra evidence. So then I kept a diary from the middle of September about his anxieties. That helped big time (in the tribunal). He never ran home from school. I thought he would but he didn’t. I know he’d get lost.

C Can you tell me more about the class that he was in?

S It was supposed to be a nurturing group. There was about 17 or 18 in the class with one teacher and occasionally one TA. That class would have stopped in the middle of Year 8. I didn’t know that. Then they get put into...... He started copying behaviours of the other kids in the class, being rude. He was really good friends with a boy with epilepsy. They were all different, all different needs. They all needed their own different help, but they were all in one class. Sam would often come home with colouring that he’d been doing all day, or saying that he’d been watching a dvd, instead of actually doing work. I think the final straw was that he came home with a Halloween card and he screwed it up when he came home because he had to make a Halloween card and put it in the bin. I took it out and took it to court with me and said this is the sort of thing that he is doing. They couldn’t get everyone to do proper work....they were together all the time. Another piece was...he was given a piece of colouring and had hundreds of sums on it. It was like a bird but each bird you had to colour it in to make it look like a bird, but you had to do the sum first. At that time Sam had been diagnosed with dyscalculia and dyslexia and Secondary school knew that, yet they still made him do that. He comes home...I said you have to try and do that Sam, just so I could prove that he can’t do it. They were quite easy sums for somebody that understood them, but it was complicated for someone who found it difficult. So he started colouring it in and then got a pencil and scribbled all over it. I took it to school and said please don’t give my son something like that again. They said he has to do it. I said no he doesn’t.

C Did he have other friends at the school?

S Yes, he saw them at playtime. Not in class. That’s why he wasn’t worried about leaving the school?

C How were the school addressing the Statement?

S They knew all about it but then again they said they were doing the right thing by him being in the nurturing group. But there was no one-to-one. He was
supposed to be having speech and language as well by then but that didn’t happen until about a month before the tribunal. She came and, I sat in, ...they then decided that he could have speech and language so he had one session every week. She couldn’t believe that it had been 3 years since Sam had had the first assessment. And this was NHS. She was totally gobsmacked that all that time had gone by and he hadn’t had any help. She was embarrassed. She was great, really nice. She really got on well with Sam but obviously the damage had been done by then. She came to the tribunal as well. Not for me. For them. She was embarrassed but so pleased that it went the right way. She had a statement that said he’d had 3 years without speech and language. Actually the secondary school didn’t even stand up and say they could cope with him. They should have. The SENCo didn’t really stick up for the school. He really messed up in a lot of ways. My solicitor came out during the break and said ‘what is that guy on?’ . He wasn’t doing the school any favours, which was great for us. I said that there was a time that Sam had his hand up and the IT teacher shouted at him to put his hand down and the SENCo turned round and said ‘he’s elderly and he’s due to be retiring soon’. Of course the tribunal said ‘you are allowing him to teach children in the nurturing group.’ And the SENCo said that he was going soon anyway. I was like ‘carry on…thanks’. You could see it was going our way. They were questioning him more than us.

C   How has he changed as a person since he’s been at the specialist dyslexia school?

S   Very confident. Very, very confident. It’s just he goes in, he know what he’s got to do, he does his homework without me hassling him. He’s not scared about asking. He’s not scared about getting things wrong. He still gets in trouble – he’s a 13 year old boy but ......... He’s got friends – they don’t live very far away. I put him on the train – one goes direct – and the friend’s mum meets him there. And vice versa. It’s a straight route there. The other one doesn’t live too far away either. He has got his friend here as well. He sees him a lot. They have been great friends since they were 4. He does clubs as well – army cadets, athletics and sometimes he does free-style gym too, not so much for a while. He has people.....

Sub-session 3

C   Now the research questions....

How helpful is the label ‘severely dyslexic’?

S   When he was in mainstream school it didn’t mean anything. Saying he was severely dyslexic didn’t help in any way – they didn’t treat that as anything different. I suppose now...my daughter is severely dyslexic as well....it has helped, having that
label. It has helped her for college and having extra time in exams. I think, by having that it gives them that bit extra help. She didn’t find out until I was fighting for Sam. She said to me, you’re fighting for Sam but actually I’ve got some of these problems. I told the secondary school to do an assessment and she came back as severely dyslexic. They have helped her. I think after I did what I did with Sam, they more than accommodated her in any way they could. She’s 17, so found out when she was 15, just in time for GCSEs.

C Why do you think the label made no difference for Sam?

S He only really had the label of severe dyslexia just before the tribunal. The private Ed Psych who told me he is severely dyslexic and severely dyscalculic. She also confirmed about the auditory processing. So he didn’t really have that label until the beginning of Year 7, when I had the proper report.

C How do you think Sam feels about having the label/labels?

S I think he knows it’s going to help him. The school specialises in dyslexia, it’s on the board as you go in?

C Now the next research questions....

Is it possible to effectively support severely dyslexic children in mainstream school and how should this be done?

S From my experience, no. Mainstream school haven’t done anything for Sam. But then they have for my daughter, in that last year. But then that was me having to take them to court. I’ve proved a point that they’re not adequate for one of my children. And was I going to do the same for the second child. From the day they found out...they hurried up the test because her GCSEs were coming up. The day she got the results in she was literally taken from one part of the exam to a smaller room. And she had extra time. And she’s had access to the link room – the quiet room. If it gets too much in class and she can’t concentrate, she’s allowed to come out of that class and go in to have support with the SENCo. Again, it’s the guy who came into tribunal....in the end I bought him a lovely present because he did so well for my daughter. So, unless you really shout, you aren’t going to get it. Does that make sense?

C Yes. Do you think that the level of support that your daughter has had is enough?

S I think that there could have been a lot more beforehand but I missed it as well – too busy on Sam. She’s so quiet. She never moans about anything. She is as severely dyslexic as Sam, but it’s the complex needs that Sam has got. He can’t cope with the auditory processing problems. My daughter doesn’t have that.
Next research question:

How can teachers facilitate a positive sense of self among severely dyslexic children?

At the specialist dyslexia school they do anyway. It’s not an issue at the specialist dyslexia school. It was, especially at the secondary school – he felt awful about himself, he hated himself. He said he wanted to kill himself. He said, he couldn’t do what they wanted him to do. Not one teacher would take Sam’s side. Where he was safe at primary because he had the SENCo the last two years. At the secondary school he had nobody apart from his sister. But now at the specialist dyslexia school, they have made him feel brilliant. They focus on his sports – he stands up in assembly and shows his medals off, he’ll talk about them. And also, he’s a really good entertainer. He stands up in front of them all and sings or dance. It’s fantastic. I had no idea he could sing and he ended up singing a Blur song. It was like, oh my god, and it was in front of everybody. A few months before that, just after he’d started the specialist dyslexia school, he did a mime, again in front of everyone. It was so good that I put him in for Britain’s got talent. Everyone cheered, was standing up. Just going to the audition gave him enough confidence. He wouldn’t have done that at the other school. He feels good about himself at the moment. He’s probably about the most popular boy there – that how he feels. He gets gold medals and ....

Do you think that is something that the secondary school could have done in different circumstances’

Yes. When I was at tribunal Sam was on a cross country at the secondary school. I got a phone call from my daughter saying that Sam was winning the cross country but he stopped because he had indigestion. He told us later that he stopped because he didn’t want the secondary school to have a medal. He felt so angry about school that he didn’t want them to win. Now he runs for the specialist dyslexia school and he wants to beat them. He beat Sally Gunnal’s son. We wanted to get through to the Nationals.

Was there any point at which he didn’t want to leave mainstream?

No, he wanted to leave. A little while ago he said that he missed all of his friends at the secondary school. But he didn’t really have many friends there. Sam is still not really developed. He’s still a 13 year old boy. Some of his friends are mini-men now. A lot of the friends at the specialist dyslexia school are also quite immature. They are quite an immature group, but they do get on well. It’s no trouble getting his friends from the specialist dyslexia school over here. Sam often goes to them as well. He has lots of friends. And he mixes with a lot of the secondary school boys down at the army cadets. They are around if he wants to.
My last research question:

What do teachers understand by the term dyslexia and how well do they perceive they can support severely dyslexic children?

In mainstream they don’t understand dyslexic children because they’ve never had a course on dyslexia. They had one teacher that was dyslexic trained and I think there was 200 dyslexic children at the secondary school. The rest didn’t understand it because they’ve never had any training in it. The one who had the training never spent any time with Sam – she never got round to it. She never did with my daughter either. She was the one that did my daughter’s assessment but after that….they never had time, with all the children there. At the specialist dyslexia school it’s different – they have visuals there and things in place, so if they don’t understand one thing they try another thing. They’ve got different coloured sheets. It’s all there. And his reading and writing has improved. It’s very small but it’s readable. His spelling is still quite bad. Reading is ok. He can read, slowly. He reads what he has to read. Again, they can have it spoken to them if they need to and he’ll have a scribe in exams. He has been awarded all that. They have reviews every year.

What has this whole experience taught you? What advice would you give to other people?

Fight for your kids. I know some kids are different. Even my daughter begged me to go to Sam’s school for the last year – I couldn’t afford it – but actually for my daughter the secondary school was ok. But I had to take the school to court to make them realise I wasn’t messing about. But parents do just get fobbed off. There are loads of kids out there who need a lot more help than they are being given.

How do you feel about it all now?

I feel totally relieved. Sam goes to school and I know I’m not going to get a phone call. I suppose I’ve let all my guard down and it’s like phew. Even with his homework I don’t panic if he doesn’t get it done. I still have to remind him about homework but he gets it done. He’s quite down on his maths but I think he’ll go into smaller groups to have the extra help. I think his English, he’s moving up a level – he was on a low level. Science isn’t too bad. The other things he’s going to be doing... he’s good at drama so he’ll get a good grade for that, he’ll do well in art because he’s good at that and of course he’ll excel at his PE.

Are either yourself or your ex-husband dyslexic?

No, neither. I think Sam, because of his complex needs, it was due to his birth. He was only without oxygen for seconds – I didn’t know what was going on.
think that caused his complex bits and pieces, maybe not the dyslexia because my daughter is dyslexic too.
8) **Panel Transcript**

A  She has been in teaching for 20 years and has been a SENCo for 15 years

B  Part-time primary school teacher. One-form entry school. She teaches Year 4 and says that she has dyslexics in her classroom

C  Full-time student studying MA in Childhood and Youth Studies. Background is playworker, working in after-school clubs, most recently with carers

D  Full-time student studying MA in Childhood and Youth Studies. Background in event management. She is dyslexic.

E  She is a Higher Level Teaching Assistant in a two-form entry primary school. Has previously been a class TA for 4 years and a SEN TA for about 4 years as well. She has been on SEN courses.

Questions asked for each extract

1) How do you think this series of events/period of child’s life was experienced by the parent?

2) How do you think this series of events/period of child’s life was experienced by the child?

3) How does it make you feel?

4) What do you think happened next?

**Donna’s Story**

**Biographical Extract 1 (Read to the Panel)**

- By Year 1 mum was being told at parent’s evening that James doesn’t try hard enough
- An assessment at school says that he has dyslexic tendencies and that the school is doing all they can
- In Year 2 James is put on School Action Plus
- James has 3 or 4 sessions with a private dyslexia teacher but stops as he doesn’t like the teacher
- James’ levels don’t improve
• Mum researches dyslexia, asks lots of questions of the school about targets and levels. She realises she is dyslexic

• In Year 6 school applies for a Statement of Educational Need which he gets after leaving primary school.

E I think for the mum….when you are told that there might be a problem...and then it’s put on to behaviour as well. When you go to parent’s evenings and you don’t know what’s coming and you have ideas. Sometimes you get defensive and then you worry.

A Irritating when she gets the assessment and it says ‘dyslexic tendencies’ but she’s already been told he’s not trying hard enough. You would question if the school is really doing all they can.

B And what happens between Year 2 and Year 6 because that’s a long time for nothing to happen. Well, I know why... because it has to be bad enough, because you can’t get a Statement unless it’s bad enough which is a crazy situation, but that’s the way it worked.

E You have to trust in the school because if you don’t know what is happening behind the scenes. You do always trust in the school that they are doing their best but it’s not always the case....... they can sometimes do a dyslexic test in the Infants but they don’t tend to do them until they get into the Juniors.

A The earliest you can do it is from 6 and a half but you quite often get false positives or false negatives as well.

E But it’s not conclusive is it?

A It’s never conclusive. It just shows risk. You never get an absolute diagnosis...

D I think it’s quite interesting that the mother gets a diagnosis, obviously at quite a late stage. There must have been a lot going through her mind, about if her dyslexia is going to affect her son, and she might be limited in helping him.

E It’s quite scary to be an adult and find out...

D That’s happened to me this year. I remember my French teacher saying are you dyslexic or just stupid. I kind of went with stupid because it was easier. It’s not major at all, but there were things that bothered me and when we were at Uni I got a test. At the age of 41 at least I know.

A The fact that he sees a private dyslexia teacher means that she doesn’t feel the school is doing enough. She’s probably quite anxious.
B And she says that he is anxious too because he doesn’t like the teacher. Someone who is there to help him overcome....

C But he may feel that he’s got a label and he doesn’t want that.

B I know from the classroom that it often children who struggle with reading and can be dyslexic will choose big thick books like the most able readers and just sit with that all term if you let them, because they want to appear just like everyone else.

E And inside they just feel worse and worse all the time. How you feel about it, how your parents react, how your teachers react. If they weren’t supporting him, then James was being made to feel like he wasn’t doing his best or misbehaving. And that’s just horrible.

B I suspect, 90% of the time, what they do in the class, they can’t access. They do much more of other stuff early on in school – PE, DT – but as you go through that just gets pushed to the side. So he probably starts to feel worse and worse about himself and as secondary school approaches ....that’s a big one.

Researcher: What do you think happens next?

E Is it what we want to happen?

D I’d hope he’d get more help at secondary school?

B I get the feeling that they (dyslexics) are side-lined a bit at secondary school.

D So ostracised even more...

B Yes, everyone knows they are the kids going off to the Special Unit or not necessarily integrated that much. I don’t know for sure. I’ve just got a feeling about that.

E I’ve got a friend whose some...... most of his classes are with lower ability, how will that affect him. It’s hard to cope with and the other children do look at them as different – you’re not very clever.

A There’s a lot of lip service to meeting the needs of children with dyslexia.

C And going to a new school with new people and knowing that you are going to have that label and be treated differently, that must make him feel anxious. It’s an anxious time for all children but having that as well...

Extract 1
‘The school’s report didn’t really suggest much in-depth intervention. It pretty much said that they were doing all that they could. I kept going to the parents evening and coming away disheartened. James in himself was doing ok. He had a good lot of friends, he liked playing and he liked doing his football. He seemed to be managing fine. It was just me being disheartened every time at parents evening and things just didn’t seem to be progressing as I thought they should be. I remember him being in Year 6 and the teacher saying he was lazy and that really made me cross. He was a sports teacher and he liked James.’

B  I think it shows the lack of training in teachers. I haven’t had any training to deal with dyslexic children. I think they mean well and they all try and do their best but I think because we are constantly being loaded with the next thing and the next thing. I think that less experienced teachers would think they are being lazy. There isn’t any proper training at all. You can pay for it but then schools don’t have the money to pay for it, you can do it yourself but then I don’t know how you’d fit that in.

E  We’ve had training and you think great this is wonderful, lots of good ideas...you might get a teacher that does that and has all the resources there, but it’s not consistent.

B  In our school we are trying to introduce a new approach. We have to come at it differently. We start with the dyslexic children or the special needs children and then work outwards to the other children. So that’s in terms of the environment, your planning, everything. That means teachers who have been doing it completely the other way are having to be trained to do it differently.

E  Are the teachers resistant to it?

B  I know myself that I started doing it and then all of a sudden you’ve got reports to write, Ofsted coming in, and you go back to your default position and then you think, I’d better print that on buff paper. I feel really bad because I don’t always do the best for the dyslexic children in my class. But they are often the quietest, they’ve maybe learned..

C  ...to hide it. James doesn’t sound like he’s got a problem with it, it is mum who wants him to be able to get on.

B  He probably doesn’t want to be upsetting his mum either.

E  In my work as an SEN TA we did really practical things, like, all along the corridor we would get boxes and put stuff in them for teachers and then say, you
can do this and that in class. So we practically set it up for them, and TAs, and it didn’t carry through.

B This is where it has changed in our school. It used to be the SENCo and the SEN TAs that were responsible for the children with SEN but now it’s the teacher who should be mostly working with the children with SEN. It’s happening, it’s just very gradual. So the teacher is much more in tune with what they need. They spend more time with them so they know them better. The government are trying to get rid of TAs aren’t they? I think children with TAs can sometimes think, if I wait long enough, she’ll tell me. So we are changing how we use the TAs. I couldn’t not have a TA. TAs are working with the higher ability kids and the teacher works more with the lower ability ones. And that is a regular thing.

A The 2002 Code of Practice said ‘we are all teachers of children with SEN’ but nothing much seemed to happen. I think it’s made more impact in this Code of Practice (2014) than it did last time.

B It might be because we are under threat of losing something...(TAs)

Biographic Extract 2

• Secondary school says that adjustments are being made
• In Year 7 James starts to fight at school
• IPSEA (Independent Parental Special Education Advice) say that the content of the Statement isn’t as it should be (doesn’t meet him needs)
• Mum has a new baby when James is in Year 7
• By Year 8 James is in the ‘secure unit’ at school most days
• SENCo refuses to reassess James so mum decides to take County Council to tribunal for failing to meet his needs
• School arranges for him to see a play therapist

A It sounds like there are some pretty big bits missing. It would be bizarre to go straight to tribunal because the school wouldn’t reassess him. It sounds like the school have been quite confrontational. Why wouldn’t they assess him. It sounds like the secondary school aren’t making the right adjustments, just like the primary school. So she must be pretty fed up by now.
D I think the new baby must have been quite an unsettling thing. If he was the youngest and used to more attention.

B On top of ...as it moves up the school it all becomes test focussed.

C It’s probably making him more anxious as he thinks he can’t do it.

D The fighting is the expression coming through and maybe also a way of getting attention because he doesn’t feel as though he’s getting enough.

E It’s often a cry for help, isn’t it?

B If he’s in the secure unit every day, it’s sort of suggesting that the school aren’t dealing with it. They are just letting it happen because it’s easier to send him there. But then he may be one of 50 dyslexic kids in a big secondary school and they’ve got one person to deal with it because of cuts. It’s not an excuse but it does happen.

D It’s so complex, does the teacher give up the needs of the other pupils for the needs of one. So they just put him in the secure unit and hope someone else picks up on him.

E You do get a bit like that, even in primary school, if you are taking a class and one child continuously...no matter how sorry you feel for that child, you want to help him, but you’ve got all these other children and he just isn’t doing as he should be. So you have to deal with him which in our case is sending him to the Head. And you hope he comes back and he wants to do it but sometimes he’s there all day. And it is sad and you do want them to join in, but what do you do? What can you do? It’s hard. And it’s easier to deal with them at primary school. They’ve got all the normal teenage stuff plus all that.

B It doesn’t make me feel very optimistic.

E But you did mention that he was going to get some play therapy?

A It’s a bit late isn’t it. Isn’t that for younger children?

B One session a week for an hour. And again taking him out the classroom.

C They are happy to send him to a play therapist but won’t reassess him. They aren’t tackling the main issue.

E Mum might have thought that she was being fobbed off.

A I suppose now you have Educational Healthcare Plans that that sort of situation shouldn’t happen anymore. It’s supposed to be more about the needs of the family as a unit, leading the process. It should make a difference but my own
experience tells me that it probably doesn’t because people just stay... the professionals involved just stay sitting on the fence. They play a curious role don’t they, people like Educational Psychologists, they are kind of working for County and school are obviously part of that, they have lots of different interested parties that they have to try and keep happy.

B And it comes down to money a lot. If money was no object the professionals would be saying, let’s try this and that. This doesn’t work, let’s try that. It’s funding.

Extract 2

‘The Statement suggested Dictaphones, touch typing. None of it had been done. I had presumed they would do it. It was a legal document and they should have done it. At the meeting one of the teachers said that he didn’t think James’ behaviour was linked to his dyslexia. That was so out of order. It wasn’t until later on that I thought he shouldn’t have said that. That’s the sort of attitude you are getting from the teachers. They never said anything nice about him. They never saw the true him, just the dyslexia, dysfunctional, misbehaving, bad behaviour. They didn’t see the amazingness, the cleverness that I see, the potential.’

LOTS OF SIGHS AND AAHS

A Mum must be feeling pretty pissed off.

B Disillusioned with the educational system.

A It also shows that Statements which are statutory documents and technically you can take a school or local authority to court if they don’t provide it, and actually the school don’t give a monkeys! That’s the reality of it.

E I think that sometimes a parent will push for a dyslexia test and they get a date and the test takes place ..... and they expect lots of things to be put in place for their child in the classroom. But in my experience, it’s a pack of paper that given to the parents, the teacher will look at it and quite often nothing comes of it. In our small groups we have things like Dictaphones, we explore those things and make suggestions to the teachers, this works and this works, but .......

B That’s why it’s good if it starts with the teacher and they have to resource it ...so there is Dictaphones and touch-typing, or that they are given training to do it out of class, but then someone has got to do the training. There’s no point allowing a child to use an ipad if they don’t know how to do it. I think on the whole primary schools are better as trying their best to do something, I think secondary school
don’t. I had a similar situation with my son who is seriously behind target in maths. So I went in and I was questioning their teaching and professionalism, so there was three of them there. Anyway, when I asked what intervention they would be doing, they said they don’t do anything until Year 10 – my son is in Year 7. If that’s the sort of thing that happens with a non-dyslexic child, then you wonder what they are doing for the others.

A The answer is probably nothing. I was talking to someone in the SEN team at a secondary school about the training the teachers have for dyslexia. I asked what they do about monitoring and she said ‘nothing, it’s up to the TAs in the class, no one else monitors what happens at all’. And this has ‘dyslexia friendly’ status. I think that’s part of the culture in secondary schools, you can’t question the professionalism of the teachers and Head.

B I could only do it because I worked in a school and knew how to do it. I thought long and hard about it and didn’t want to antagonise them or want them to come defensive. But not many people have that knowledge.

E You do find, in primary school anyway, that it’s the parent that shouts the loudest that the action will be taken. The SENCo in our school acts like that. If you keep on asking, but if you say ‘when you are ready, possibly you will go to the bottom of the list because she knows she can.

B I think that happens a lot. The other side of it is parents who won’t acknowledge that there child has problems and will not do anything. And he’s dyslexic and she won’t do anything with him at home. She doesn’t want him to succeed. She wants to keep him always with her. He never gets to join in anything. In that case you say, well there are four other people screaming their heads off, we’ll go with them. The loudest shouters are not necessarily the most needy.

D I suppose every child is the number one priority for the mother.

B What was it his mum said, about him being creative, I think that’s one of the biggest problems in mainstream schools, they are so limited in letting children shine in different ways. Other children who are really bright and clever and good at writing, teachers rarely say, look at the other child who is better than you at something other than writing…… that doesn’t happen often enough.

C That’s the education system and all the tests ….. everything is structured to exams and they aren’t given the chance.

Extract 3
'Something happened at secondary school – a teacher belittled him in front of the whole class but the school really covered it up really well. The teacher said ‘James you need to read this book’. I’ve always said, and it was put on the Statement, that he must not be asked to read out loud in front of the class. Because he can’t read and he can’t write so why would you want to do that? The teacher threw the book at him and said read the book. James said ‘I don’t have to. My mum’s said that I don’t have to’

E     That’s horrible.

A     The information just isn’t passed to the staff. Whoever has a copy of his Statement hasn’t made sure that teachers know.

E     And you do get promised that don’t you, that the information will get passed on and it doesn’t.

B     They don’t know who half of them are. They are seeing so many people come through. They have photos at parents evening and still don’t seem to know them all.

A     You’d think with a child with SEN, teachers would at least know them – a handful that you’d be quite certain about.

D     You say that you’ve got 24 in your class with issues. That’s a hell of a lot.

B     It is and there is going to be more and more because they come in at Reception and can’t speak - they sit and watch TV all day. And teachers, with technology now could have an ipad in front of them at parent’s evening, linked to registration, that identifies the children.

C     I was going to say that.

E     Why doesn’t the teacher care enough to know all the children. Why doesn’t that happen.

Researcher: What do you think about what James said and what his mum told him to say?

A     She probably didn’t say, tell them your mum said you can’t read aloud, but she maybe said to him that he doesn’t have to because of the Statement.

B     Yes, she’s explained what his rights are.

E     That’s probably all he could get out. He was probably frustrated. Why should he have to explain?

C     If they’d done that to an adult?
A It says something between the children and the adults at the school, in general. Dyslexic or not, a child who doesn’t want to read has a book thrown at him.

B If you take it right back to teacher training…..they need like a bedside manner with a doctor….how to treat children. You need at least a year on child behaviour and the consequences of it, before you start to go into all the other bits.

A Students always say that the SEN component of their courses is very poor. Especially PGCE students….

B Because that’s only 9 months…..

E So still in secondary school it might come down to the teacher and what sort of person they are, and what they give. In primary school, on the whole the teachers are lovely but you know there is going to be that one year coming up that isn’t going to be enjoyable. Sometimes parents call it the ‘right’off’ year.

Biographic Extract 3

• Mum pays for a specialist dyslexia teacher assessment and James is diagnosed as severely dyslexic
• Mum wins the case without going to tribunal and the County Council agrees to fund his place at an independent specialist dyslexia school
• James doesn’t want to leave his secondary school
• In the time between winning the case and leaving to go to specialist dyslexia school James is supported by a specialist dyslexia teacher funded by the County Council
• James starts his new school at the beginning of Year 9

B He’ll soon forget about his old school and friends if he is achieving and made to feel good about himself. Hopefully it works.

E You’ve got to be a strong parent though haven’t you? If you’ve got your child saying ‘I want to stay’. You are right, they will forgive you but …...

B It’s just about their friends at that age….

E Exactly.

C They’ve got Skype and Facebook. It’s a lot easier to keep in touch now.
I don’t understand, they must have assessed him before he got the Statement. If the issue that was driving the Statement was dyslexic tendencies, then you would have thought.......  

The test at primary school is very simple.  

Don’t they have to have one with an Educational Psychologist?  

You would assess again before Year 8, especially if you are going for a Statement.  

What do you think of the test?  

I think the tests (Screener) are a bit peculiar actually. It’s an NFER test. That’s all the Language and Learning Support Unit do.  

The other kind of tests (full dyslexia tests) have to be done privately.  

You would think though that if there is a suspicion of dyslexia or dyslexic tendencies, it would save money in the long run to do that (full dyslexia test).  

Or redo the dyslexia screening test. It only takes 40 minutes. Why wouldn’t you do that at least?  

It should be part of the protocol. If they come up with dyslexic tendencies, why wait another couple of years, or to Year 6, get that expensive one done and then it is all there.  

You probably wouldn’t get that done because, if it was the primary school doing it, it would be really expensive and not viable. It comes up with an at risk quotient. It’s a likelihood of being at risk. What does that mean? A lot of children are on the cusp and you can quite easily get false positives. You do them again a year later and you realise that the issue was something different.  

Researcher: What do you think might have happened next after this?  

That he likes his new school.  

That he’s surrounded by people who are exactly the same as him and he’s not the odd one out anymore. That would be lovely.  

That would be in an ideal world. But the world isn’t like that.
'This time they were trying to humiliate me. In this meeting was the Headteacher, the Deputy Headteacher, the Educational Psychologist, the SENCo, the LSA and another two people. I was really ready then because I had this report and I brought my husband in. Basically, this was one of the most empowering moments of my life because I had this report and it said that he couldn’t read and write. I threw it at the SENCo and I did attack her quite personally – my husband picked me up on that. But I was frustrated and at the end of the day we are talking about my son.’

LAUGHTER

B It’s just an outpowering, isn’t it? All those years of frustration was probably targeted at that one SENCo.

MORE LAUGHTER

A But she’s the SENCo that’s said that adjustments are being made. I’d be cross about that.

B But she’s got something concrete....

C See, I’m right!

E And then he got that bit of support before he left, so they obviously took it on board for that very short space of time. But it was horrible that she had to face them all. She must be a very strong lady.

B That’s a defence. They know they haven’t done what they should have done.

A She knows they are not meeting their statutory duties and they are very defensive. And that is true of many secondary schools. The other thing is that sometimes Statements don’t accurately reflect what the child needs. You have an Annual Review of the Statement and you look at it and decide if all the things it says are still appropriate. But the actual Statements aren’t updated because it costs a lot of money. Someone once told me that it takes £4,000 to rewrite a Statement because to rewrite it you have to have all the professionals involved again and it’s all their time. The Educational Health Care Plan is better because they are more fluid. Statements tend to be put in place and stay there – there is a rigidity about them.

B Presumably people don’t want to change it too much because they might lose the funding.

A I think the official line is that if something is working you don’t take it away. But they’ve sort of done that anyway because now you only get a top-up funding if you child is at the level of a Band B Statement. So now the need has got to be that
much more severe. And even then it’s only £1400 a year, so it’s not that much money. So you have to really meet the needs of the SEN kids through your basic SEN funding which really doesn’t go very far (£6,000).

Extract 5

‘I sat next to him for 3 hours during this assessment. I came away really sad because I could see how severe he was and how he gave up very quickly and how he got frustrated. It really made me feel crap. Here was a boy that I had been trying to get help for, for god knows how long, 6 odd years, and he was still not improving. Then we got the report and I just got very angry then. He still couldn’t read and write and he’d been in secondary school for a year and a half.’

D But just because he can’t read and write, does that mean that he’s still not learning stuff.

E But they’d be quite a lot that he can’t access because of his reading and writing. He would still be learning but not nearly as much.

B And he can’t show what he can do either.

Biographic extract 4

• Within a week and a half at his new school James refuses to read and the school wants to send him home.

• James has 3 one day exclusions for being rude, kicking a locker, refusing to work with someone

• James is permanently excluded but it is overturned at an appeal

• James receives a one-day exclusion for setting a book alight

• James is in trouble with the Police for shoplifting and Anti-Social Behaviour

• James will be going into Year 10 in September.

D Oh James!

E He’s just still so angry, he can’t let go of that.
Play therapy didn’t work then! Mum must have been really pulling for hair out by now. She must be thinking what else? So, going to a dyslexia school wasn’t the answer, she must be wondering if she did the right thing.

Is some of it though just a teenager kicking off at school and not the fact that he’s dyslexic and at a dyslexic school.

A It sounds quite bad though.

But is it related to him not getting on at the school?

It sounds like he is just unteachable and he is in a really really bad place. He thinks he’s useless because all of his school life he’s been told he can’t do it, he’s not good enough.

I wonder if there’s other children there who are behaving equally badly?

Mum must have felt so much relief when she got the Statement and that it was going to be the end of all her worries but it isn’t. It’s just a bit of paper.

Or maybe he feels, now that he’s at a special school, that it’s labelled him even more.

And he didn’t want to go.

Perhaps there’s a lot of protesting going on. ‘You took me away from my friends, so this is not going to work.’

It must have had a huge effect on her and her other children. It’s horrible. Do any of them have any troubles at school?

Researcher: No, they are both of average ability and not dyslexic.

Extract 6

‘He’s a lovely boy. He has a heart of gold. But I know he has been damaged by this journey. He hasn’t got the confidence. I see it. Looking back I think he finds it hard to keep friendships going.....because of his self-worth. He doesn’t think he is worthy. He thinks he is stupid. He thinks he is thick. Still.’

Because that’s what he’s been told. It’s really bad.

If he’s been told in the new school that he’s doing well, sometimes that praise, you don’t believe it if you are in that kind of mindset.
E That’s really true. My son thinks that – if people tell him he’s done something well, he thinks they are just saying it.

C It doesn’t mean anything.

B When you said mindset, I’ve been to a conference on Growth Mindset, Carol Dweck.

E They are doing that at our school too. That’s the key word at our school.

B James has a closed or fixed mindset because he’s not been helped to see how he can get better at something, because of the education system and the way it works. We’ve been trialling it across the school and we are doing it on ourselves as teachers too. No matter now bad it gets, we can do this. What do we need to do to make this better? But it works and it’s saying, well, you can’t do this yet, so what do we need to do in order for you to be able to do it. And very gradually it influences our teaching and the children. We did it very successfully with last year’s class and they are flying. There’s just no stopping any of them.

E So it changes their attitude?

B It changes their attitude to their learning. It works with children with SEN too. It works with everybody.

A It makes them more can-do.

B I can’t do it – that’s a defence. It’s giving them small steps to try and work towards that. I would say it’s slower to have an effect on the children with SEN. You would hope that the dyslexic schools would be embracing that a bit.

A I wonder how much people have been talking to James about what he needs. If they had started in Key Stage 1 saying ‘what do you want. It is difficult for you’. Because if he doesn’t want it, he can’t see the point in support, then it won’t work. Maybe they could start doing that.

E At our school we are doing that with our outside area. We’ve got sheep and chickens and do forest skills. That really helps those kind of children. Something away from the classroom. At the specialist school can’t they just take them away and out of the classroom.

B He doesn’t know how to get himself out of where he is.

D It’s deep-set.

B He needs help and skills. Growth Mindset are skills for life as well. We have a Pupil Passport where they have Smart Targets and we talk to the kids about it and we say this is what you need to do and this is how you can achieve it. They are
involved in it and that is from behaviour, right across. The parents share it too. But until James is helped to change the way he looks at things, it sounds like he isn’t going to progress any further.

C Does he understand what dyslexia is and how it affects him.

Researcher: He is in denial actually. He won’t even use the word dyslexia. He says that his brain works in a different way.

D He’s creating his own label really.

Extract 7

‘Perhaps that’s what teachers think. They do the best they can and when we throw all these things at them they take it personally in some way. But I would always want to improve. And I actually put that on some of my feedback at the Annual review. I said I am always learning, I would never think that I know everything. I couldn’t understand why the SENCo wouldn’t even know what a Wave 3 programme was. I couldn’t comprehend that. And didn’t go away and find out. How could she be in a secondary school environment and not know about Wave 3? So I do think that teachers have so much to do, but I would say that they still need to be accountable for the profound effect they can have on a child’s life. Even in this day and age teachers have affected my son. How many years ago was I affected by a teacher belittling me in a class. It’s still happening. We are still so behind in some ways. It’s shocking.’

B I agree with it but we are in a profession where things are forced upon us and I think that makes it very difficult to lose sight of what you are there for. Now we are performance related pay, technically if the children in our class don’t make the progress they should, it could be questioned as to whether we get our full pay. And it’s worse in Academies because there is very little protection there.

A The advice from government that no more than 50% of staff can move up the pay scale per year. Can you imagine!

B If what you’re judged on is your levels, then that becomes....it’s another way of shifting you away from the reason you went into the profession.

C You went in to teach children.

B I can’t do any of the great fun things that I used to do. It can be very demoralising and disheartening. But then you get moments that keep you going for a long time.
A And now Reception children have to do a half hour assessment within 6 weeks of starting school. So that you can measure failure of the teachers really.

B And there are schools in Lewes that say to parents, we can’t accommodate your child’s needs, why don’t you go to one of the other schools that can. Every school is supposed to be able to provide for the needs of every child. The education system is failing some of the children with SEN.

D It’s shocking, it’s like schools are running a business now.

B That’s what they are trying to make them. Unfortunately. James needs to get to college and do something practical, with his hands.

Suzanne’s Story

Biographical Extract 1 (Read to the Panel)

- Sam has a difficult birth and has to be resuscitated
- In Reception he struggles to sit still and concentrate
- In Year 2 mum is asked by teachers to read with Sam more. He is put on School Action Plus
- Teachers describe him as rude and say he doesn’t listen
- In Year 3 Sam struggles to cope with homework
- A privately funded Educational Psychologist says that he is dyspraxic.

B So mum is obviously worried enough to go outside of the school straight away rather than wait.

A Something must have happened between Reception and Year 2, he must have seen someone to get onto School Action Plus. An OT maybe. So maybe they were doing something about meeting his needs.

C It takes such a long time. Those are really informative years.

B If she went privately it might mean that she asked the school and they said they don’t need to do that, or we don’t think it’s necessary.

E Because they do tend to wait, don’t they. Give a child the chance to either grow into something or disappear.
Extract 1

‘He was getting homework and he wasn’t bringing it home. Then the next day at school he was getting told off. At that time, because no one was taking me seriously, we were trying really hard. We were reading with him, doing spellings. So he was having anxiety attacks because of us and that’s when as well, in Year 2, he started having sleepless nights and night terrors. So he said to the teachers please don’t tell my dad, because he gets really angry with me. He said that three times so they had to get social services out. It was us trying to nag him, still not realising that Sam needs special attention.’

B How much homework were they getting in Year 2? It should just be reading and a bit of spelling. Maybe if that’s what they were called in for the parents got more anxious and it all spiralled into this big battle.

Extract 2

‘Yes, he went on that (School Action Plus) in Year 2. They never did anything. He never went into a small group .... he didn’t have anything like that. Some of the kids with severe behaviour went off somewhere in groups. They did something – his friend did. At that stage it wasn’t as if Sam had behavioural problems, it was just that he didn’t want to concentrate. They didn’t class him as needy. They didn’t think he was that bad – it was just rudeness.’

E How was the rudeness coming out. Was it rude words or ignoring instructions?

Researcher: it was ignoring instructions, that kind of thing.

C Is that again a lack of training of teachers to be able to pick up on....?

B It sounds as though on School Action Plus he should have been working in small groups but she said he was never chosen to do so.

E So was he not chosen because they didn’t think he should go or because of his difficult behaviour.

Researcher: do you think that sometimes children with behavioural problems get more attention than other kids?

E Yes, definitely.
A  He was probably being rude to get out of doing things, not put himself on the line and show that he can’t do it.

E  And for them, they couldn’t see the reason.

D  Was it that he couldn’t express his own problem so by kicking off and being rude he is creating an exchange. So, if people can’t understand what he is going through, being rude is something that the teacher does understand.

B  The school doesn’t have to take what the private assessment says. They don’t have to accept it. On a bit of a tangent, it would be interesting to see what happens in Sweden where they don’t do any formal reading or writing until they are 7. There must be dyslexic children in Sweden and Norway.

Biographic extract 2

•  In Year 3 Sam is assessed at Guy’s Hospital and described as having complex needs, including auditory processing. They mention dyslexia but don’t put it in report
•  Sam is given one session with a NHS speech and language therapist
•  In Years 5 and 6 Sam is allowed to go to SENCo for brain breaks
•  Sam becomes increasingly anxious about homework and starts head-butting and biting himself
•  In December of Year 6 Sam gets a Statement of Educational Need
•  Level of support at school remains the same

A  It makes me think that people aren’t talking to one another. It’s odd that when he’s got complex needs, they mention dyslexia but don’t put it in the report. And then he has one session with a speech and language therapist. What’s that got to do with auditory processing or the dyslexia?

B  He could have done brain breaks within the class.

A  But why is homework the big issue still? Didn’t somebody say to him, don’t do homework?

E  Is it the pressure of home, with the parents trying to get him to do his homework?
But if the school and parents had been talking then maybe they could have said there isn’t any point in doing homework at home.

If homework is making him ill...

Perhaps the parents didn’t feel like they could approach the school.

Researcher: I think she trusted the school.

Sometimes you have to prove how far below their peers you are and that tends to accelerate away in Key Stage 2. To get a Statement you have to wait until the child is on the 2nd or 3rd centile below their peers. Waiting until Year 6 for a Statement was probably about that.

Do you think they could have done it any earlier?

Well yes, but it didn’t make any difference even when they had it.

He must have just been making enough progress for them to not go for a Statement earlier. But then the gap gets really big and it’s very obvious and then you have lots of evidence for a Statement.

Complex needs should have been enough to trigger something.....

How frustrated must she have been. Getting an appointment at Guy’s is a big thing and then it made no difference. I can relate to that, my son was given a diagnosis of sensory modulation disorder but it actually doesn’t mean anything, he doesn’t get any help or anything. He’s doing good though. He got lots of support in primary school because I was working there and so I could keep an eye on things, but it could have been a very different story if I hadn’t been working there. They are good teachers and most of them would have done their best for him, but he could have slipped under the radar. They call it helicopter parenting – that’s what I used to do. I was always asking questions.

Biographic extract 3

- Parents prepare to take County Council to tribunal to contest the named secondary school
- Sam attends trials at two independent specialist dyslexia schools
- Parents pay for Educational Psychologist and Speech and Language assessments. Sam gets a diagnosis of severe dyslexia, dyscalculia and auditory processing
• Sam starts at mainstream secondary school named by County Council and is put in a nurture group of 17/18 children with different needs.

E What is the point in that (putting him in nurture group)?
D Out of sight, out of mind!
E Yes.
D The frustration of auditory processing, where you don’t remember what you did the day before!
A It’s important for kids like that to have strategies.
B You don’t have to do it that way, you can do it this way. There’s no one way of doing it.
B So they didn’t screen him in primary school? Something must have shown up.
A It does sound odd that with both of these scenarios/parents, the relationship between the parents and the schools....the parents shouldn’t have to be forcing the issue or being disbelieved and fighting the school. It does sound like both of them are right from the beginning.
C Yes
B It’s like they’ve got to prove to the professionals and it’s the wrong way round.
C Both of them have done things privately.
B And there are families that haven’t got the where with all to do that.
C And money.
A It’s very difficult if you are in disagreement with a family. With private Educational Psychologists you get what you pay for. You can get an anxious parent who goes to an Educational Psychologist and it’s never a surprise when the report comes back. And you are kind of thinking, really!! It’s really cynical of me, but sometimes there is a reason why we don’t want to assess a child and you know that if the parent pays for a private Ed’ Psych’, they are going to get it anyway, so you might as well give up. As soon as they go to the private EP, they are going to come back with a piece of paper.......the bottom line is that sometimes they are saying what the parent wants them to say. And they are only giving one side of the story and sometimes what parents want is a certain type of provision and you may not have wanted to give that sort of provision for a certain reason.
I would say there is something in that because I’ve had EPs come in and observe children for one lesson and you think, one lesson isn’t enough. And they say, you should try this and this and why don’t you do this and you think, in the real world, you are just thinking of that one child. There are 30 children in this class. It’s not possible to do what they are suggesting. They need to see it over a period of time, not just a little snippet. It’s a difficult relationship. I’ve also experience Munchenhausen’s by proxy. I’ve seen a awful lot of that. It can be so overwhelming and constant and the parent may be completely and utterly justified and absolutely right.

One of the children in one of my schools, the mother desperately wants her to be dyslexic. It all started in Reception and there were some family issues. This child had some play therapy support and then she said that she wanted a dyslexic screening test. So I did it and she was picking up on tiny bits of the test because her daughter wasn’t dyslexic and it all snowballed from there. The parent took the child to the Institute for Brain Injured Children for a weekend’s screening. Then she followed an autistic pathway, then OT and sensory processing. It got bigger and bigger and this week we’ve had 2 paediatricians down from London to observe her, just because her parents insisted she must be on the SEN register. She’s a quirky child but she’s making good academic progress. No one ever dares to say ‘enough’. The parents don’t want to admit that it’s partly their parenting and it suits the mother to put it all on to the child. We’ve also has a request for Disability Living Allowance. But none of the professionals will say anything.

It’s the mother’s need. We had one where the child no longer needed what he had from birth. They said he’s fine and the mother completely disagreed and she kept it in for two years and it affected every part of his life. How do you say……we felt it was quite abusive.

Researcher: do you think these kinds of parents affect how parents like the two in the stories are treated?

No, I think teachers are discerning.

I think it depends on the school and their level of experience. I think some people may go ‘here we go again, another parents going on and on and there’s nothing wrong with them’ and if you have too many like that, sometimes you can misjudge and I think that’s really unfortunate. The few spoil it for the many. But I think the more teachers communicate between themselves and the professionals, if they’ve got the time and resources to do it, you’d very quickly get to see the genuine cases.
I think that teachers don’t know what to do with kids who are unhappy. What do you do with children who say that there life isn’t worth living? How are we going to change this and make it better.

Biographic Extract 4

- Sam frequently gets lost at secondary school, has panic attacks, bites his fingers until they bleed and pulls his eye-brows out
- Sam starts speech and language therapy once a week at school
- Parents win their tribunal and the County Council agrees to fund a place at an independent specialist dyslexia school
- Sam starts at his new school in January of Year 7
- Sam’s parents split up at the beginning of Year 9
- Sam excels at sport and is happy and confident at his new school
- Sam will be going into Year 10 in September

The panel do not react to Biographic Extract 4

Extract 3

‘Since then he’s just been really settled – they’ve never had anyone like Sam before because of his sports. They’ve made him excel in that. He’s a bit of a celebrity there. It’s athletics he’s good at. He does all sports there.

It’s going back to basics – he’s not afraid of asking. He’s not frightened of getting things wrong now. His report...his grades jumped up. He was really low and they jumped up to above average. Just with that support.’

A happy ending! Hurrah!

He found something he was good at and James never found anything he was good at, or was never helped to find anything he was good at.

It’s acceptance. He became a character at the school.

And he could see that he was actually good at something.

If you win, you win.
B The growth mindset is all about the number of hours you put into something. It’s not about being naturally good at something or just being clever, it’s the hours you put in. Whether it’s timetables practice or sport. I think especially boys....I still think we are making these children sit in a classroom for 6 hours. Adults couldn’t do what we are asking children to do now. Boys need to move, all children. Their legs are going...you tire them out physically, then their brains are more likely to relax and tune in.

Researcher: have you noticed any differences between girls and boys and how they cope with special needs/being different?

E There do seem to be more boys. But is that because girls have different coping mechanisms?

C Did you see ‘Born Naughty’. They were saying that autistic girls covered it up much more. They didn’t display the autistic traits as much.

E Or is it different in girls?

C They just said that it comes out differently in their eye contact and language. She was mimicking everything that was said to her to try and show that she could talk, but it was just mimicking and didn’t make any sense.

E Is that because their brains work in a different way?

D The stereotypical view of boys is that.....

E The pressure put on them from an early age, is that still having an effect on them and how they deal with it when things go a bit wrong.

B It starts so early, just in the ways that boys and girls are as toddlers.

E It’s a natural difference. Perhaps we shouldn’t be teaching them the same way at all.

A There’s some evidence that girls are more keen to please than boys and can be more dependent on the whole ‘good girl’ thing.

E Is it easier for a girl........if girls want to be like their mum and boys like their dad, if mum is at home all the time then maybe some girls are thinking that they can get to be like their mum quicker. Whereas if a boy doesn’t see his dad, or his dad gets home late at night, that takes so much longer.

B There are certainly not as many girls diagnosed with dyslexia.

E And other things as well.
C Is that because boys’ behaviour is less acceptable in a female dominated workforce.

A Or is it to do with, in this country, asking boys to develop reading and speech and language skills so early. It would be interesting to see what the Swedish diagnosis rate is. Boys are less verbal than girls as toddlers and we start making them learn literacy skills at an early age.

B We are the only country in the world that is going to be testing children at 4. Sweden and Norway aren’t way behind in the league tables. They are doing well.

A They say it’s for the children but actually it’s to whip teachers with.

B I was just thinking about this lack of communication thing and I think, people like these women who have gone through this, need to come and tell the teachers. On an INSET day, because I’ve learned a lot tonight.