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# Dyslexia and Self-Esteem: Stories of Resilience

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## 1. Introduction

This study investigates stories of resilience in people with dyslexia. It provides a brief overview of some of the key literature in this area and draws on earlier research which I conducted (Glazzard, 2010). Data was collected using narrative genre. Four informants volunteered to tell their stories. The study considers ways in which dyslexia has shaped the self-esteem, self-concepts and identities of the informants. The stories provide powerful insights into the lives of people with dyslexia and the reader is invited to draw their own interpretations from the narratives. The study concludes that an early diagnosis of dyslexia is essential for creating a positive self-image and recommends that further narrative research is necessary to explore the significant impact that dyslexia has on people's sense of self.

## 2. Theoretical framework

### 2.1 Summary of key literature

According to Humphrey:

Despite a barrage of anecdotal evidence from teachers and practitioners, there is a paucity of published research in self-concept and self-esteem in children with dyslexia. (Humphrey 2002: 30)

Much of the research into dyslexia has focused on causation and remediation. Consequently this study examines the effects of dyslexia on people's lives in general and on their self-concepts and self-esteem more specifically. Gurney defines 'self-concept' as 'the image or picture that we have of ourselves which we carry around and use to define ourselves as well as to categorise our behaviour' (Gurney, 1988: 4). In contrast, self-esteem is defined as 'the relative degree of worthiness, or acceptability, which people perceive their self-concept to possess' (Gurney, 1988, p.13)

According to Lawrence:

One of the most exciting discoveries in educational psychology in recent times has been the finding that people's levels of achievement are influenced by how they feel about themselves (and vice-versa)'. (Lawrence, 1996, p.x1)

Key research findings indicate that learners with dyslexia experience teasing and bullying and feelings of exclusion (Edwards, 1994; Riddick, 1995; Riddick, 1996; Humphrey, 2001;

Humphrey, 2002; Humphrey, 2003). Unfair treatment by teachers has also been a consistent theme in the literature (Edwards, 1990; Osmond, 1996; Humphrey, 2001; Humphrey and Mullins, 2002; Humphrey, 2003) as well as teacher resistance to the existence of dyslexia (Riddick, 1996).

Osmond (1996) presented case studies with children and adults with dyslexia. According to Osmond 'the worst problem any dyslexic has to face is not reading, writing or even spelling, but a lack of understanding' (1996: 21). Osmond's case study descriptions show evidence of pupils experiencing feelings of anger and frustration with their own difficulties. The reader is provided with vivid descriptions of life experiences using the participants' own words. There is evidence of pupils' efforts being destroyed by teachers and persecution from other pupils (Osmond, 1996, p.21). There is evidence in this research of pupils experiencing anxiety when placed in situations where their difficulties were exposed. Examples of this include forcing pupils to read out in class and being made to leave their regular class for special lessons. Osmond's interviews with the pupils' parents provide evidence of schools and local education authorities adopting dismissive attitudes towards dyslexia. He quotes one parent who said:

I think they regarded us as middle-class pushy parents, probably making too much fuss over a problem that would come right of its own accord...

(Osmond, 1996, p.75)

The case studies which Osmond (1996) describes, provide rich detail of pupils' experiences of living with dyslexia. This detail is essential in order for the reader to develop understanding of what it is truly like to have dyslexia or be a parent of someone with dyslexia.

Edwards (1994) carried out case studies on a sample of eight adolescent boys from a special school for dyslexics where she worked. During her interviews with the students, it became evident that the majority of the participants had suffered extremely bad experiences as a result of having dyslexia. Many of these experiences were related to their education prior to coming to the special school. Indeed, Edwards was deeply shocked by the severity, extent and multiplicity of unpleasant experiences, which the pupils in her study had suffered. She found that five out of the eight boys had been on the receiving end of violence from their teachers, the cause of which they attributed to them having dyslexia. This is alarming. Edwards (1994) also found that seven out of the eight students had been humiliated and 'shown-up' by their teachers and incidents ranged from work being torn up, 'put-downs' and low teacher expectations. Additionally, Edwards (1994) found evidence of teasing and persecution from other students. This was in the form of verbal abuse and tormenting about their dyslexia. Seven of the students registered an extreme lack of confidence and all the students developed behaviour problems at some point.

Edwards' (1994) research provides an insight into the lives of students with dyslexia. Whilst both studies are now dated, they make an important contribution to the knowledge base within this field. Interestingly more recent studies have demonstrated similar findings.

Humphrey's (2002) study into teacher and pupil ratings of self-esteem of pupils with developmental dyslexia also makes an important contribution to the knowledge base on the relationship between dyslexia and self-esteem. Humphrey (2002) gathered data from three

groups of pupils. In this study, the pupils ranged in ages between the ages of eight years to fifteen years. One group of pupils with dyslexia were taught in mainstream settings, a second group attended specialist units for specific learning difficulties and a third group formed a control group of pupils who did not have learning difficulties. Teachers' ratings of their pupils' levels of self-esteem were assessed using an adaptation of Lawrence's (1996) self-esteem checklist. Humphrey (2002) used a Likert scale to assess the behavioural manifestations of self-esteem. The teachers who were involved in the research were asked to assess the frequency of each behaviour trait on a four-point scale: 'Never', 'Sometimes', 'Most of the time' and 'Always'. An example of this is that the teacher was asked '*Does he/she make excuses to avoid situations which may be stressful?*' The teacher responded by circling one of the four words. In addition to the teacher ratings of pupil's self-esteem, Humphrey (2002) measured pupils' ratings of self-esteem using the 'semantic differential' method adopted by Richmond (1984). The pupil participants were required to place themselves on a seven-point scale between two opposite adjectives to represent their perception themselves. This relates to Lawrence's (1987) concept of 'self-image'. Humphrey (2002, p.31) provides an example to illustrate this: The pupils were asked for example, to place themselves on a scale of popularity ranging from popular to unpopular with a score of one representing 'extremely popular' to a score of seven indicating 'extremely unpopular'. The scale consisted of ten items. On completion of the initial scale, the pupils were asked to repeat the task but on the second scale, the pupils were required to indicate where they would like to be on the scale. This relates to Lawrence's (1987) concept of 'ideal self'. Humphrey (2002) then calculated the discrepancy scores between the pupils' self-image and ideal image for each item and mean discrepancy scores were then calculated for each group. The results of Humphrey's (2002) teacher ratings indicated that the pupils with dyslexia in mainstream settings and in units were significantly more likely to ask continually for help and reassurance than the pupils in the control group were (Humphrey, 2002, p.32). His findings also indicated that both dyslexic groups were more likely to display timid behaviour and avoid situations of possible stress compared with the pupils in the control group (Humphrey, 2002, p.32). The results of the pupil ratings of self-esteem also produced interesting findings. According to Humphrey (2002), the dyslexic-mainstream group had significantly lower levels of self-esteem than the other two groups in reading ability and writing ability. Humphrey (2002) also found that there was a significant difference in self-esteem related to spelling, intelligence and popularity between the dyslexic mainstream group and the control group, with the mainstream group having significantly lower levels of self-esteem in these three areas. Interestingly, Humphrey (2002) found no significant differences in pupils' ratings of self-esteem between the control group and the group from the specialist units in the areas of reading, spelling, writing, perceptions of intelligence and popularity. Humphrey argues that his results 'support the notion that dyslexia has an effect on the self-esteem of children' (Humphrey 2002, p.34). He argues that his results show differences in the self-concept and self-esteem levels between pupils with dyslexia who are placed in mainstream settings and pupils without learning difficulties. However, he also argues that his research shows that dyslexic pupils who are placed in separate units 'develop more positive self-concepts and levels of self-esteem than those left in mainstream education' (Humphrey 2002, p.34). This could be due to teachers in units having specialist training, more knowledge about self-esteem and smaller class sizes which enable them to spend more time talking to their pupils than their mainstream colleagues. The validity of the findings depends on whether self-esteem remains stable or changes over time and this has been debated in the literature.

Humphrey and Mullins (2002) collected rich qualitative data relating to pupils' individual experiences of dyslexia. They interviewed the pupils about their general self-concept and self-esteem, peer relations, teacher-pupil relations and academic self. This allowed the pupils to have a 'voice' and gave them the opportunity to provide richer information relating to their experiences of being dyslexic than quantitative data was able to supply. They found that around half of the pupils with dyslexia in mainstream settings and special units were regularly bullied or teased about their dyslexia. This is in line with the findings of Edwards (1994) and Riddick (1996). They also found that almost half of the dyslexic pupils in mainstream settings and in special units, prior to their placement, had been 'persecuted' (Humphrey and Mullins 2002, p.7) by their teachers. Indeed, they state that '...many of the participants had been called lazy, stupid or thick by teachers' (Humphrey and Mullins 2002, p.7). This is in line with Dewhirst's finding (1995) who quotes an extract from an interview with a teacher:

**Teacher:** Well...I mean, it's one of those things that has been conjured up by 'pushy parents' for their thick or lazy children; quite often both.

(Dewhirst, 1995 in Riddick, 1996 p.94)

Humphrey and Mullins (2002) found that around one third of the dyslexic mainstream group felt they were 'stupid', 'lazy' or 'thick' (p.8). They also found that one quarter of the dyslexic mainstream group and one third of the dyslexic pupils in special units felt that they were less intelligent than their peers. In addition, they found that in both groups, the pupils felt least confident in situations where their dyslexic tendencies were on display, such as reading out in front of the class. Another interesting finding was that around half of the pupils in both groups indicated a desire to swap places with someone else. The data provides evidence that the pupils with dyslexia in the special units have had negative experiences prior to their placement in the units. According to Humphrey and Mullins (2002) this has left them with 'emotional baggage' (p.10), or what Edwards (1994) refers to as the 'scars' of dyslexia.

The research by Humphrey and Mullins (2002) indicates that the experience of dyslexia can have a negative impact on pupils' self-concept and self-esteem. In addition, they found that pupils with dyslexia tended to attribute success to external factors rather than internal factors (Humphrey and Mullins, 2002), thus illustrating the theory of 'learned helplessness' (Peterson, Maier and Seligman, 1993). Research has indicated that learners with dyslexia attribute success to factors such as teacher quality rather than to their own intelligence (Humphrey and Mullins, 2002). Success is therefore blamed on external factors rather than being perceived as something which can be controlled (Humphrey and Mullins, 2002). This suggests that learners with dyslexia have a very poor internal locus of control. They feel that they are not in control of their own success in relation to learning, due to their own perceived inadequacies. Research has pointed to the link between learned helplessness, attributional style and low self-concept (Butkowsky and Willows, 1980; Humphrey, 2001). In contrast learners without dyslexia blame failure on internal factors such as lack of effort or lack of interest in a subject but not lack of ability, thus protecting their self-concept (Humphrey and Mullins, 2002). This suggests that learners without dyslexia have a very strong locus of control.

Burden and Burdett (2005) focused on pupils' attitudes towards learning and their sense of agency in an independent residential school for pupils with dyslexia. The researchers use

their data to challenge the findings by Humphrey and Mullins into the relationship between dyslexia, self-esteem and locus of control. In contrast, Burden and Burdett (2005) found that the pupils with dyslexia had 'highly positive attitudes towards learning' (p.103) and had a strong sense of being in control of their own destinies. The study found that the participants felt in control of their own learning and they felt capable of achieving their ambitions. Thus, the participants had not generally internalised feelings of learned helplessness (Burden and Burdett, 2005).

It is just feasible that similar results might be forthcoming from a comparison group of pupils with dyslexia attending mainstream secondary schools, but we very much doubt it.

(Burden and Burdett, 2005:103)

My own research (Glazzard, 2010) challenges this hypothesis. The mainstream pupils with dyslexia whom I interviewed were all very confident and they attributed this to the diagnosis and ownership of the label. For these pupils the label helped them to explain their difficulties. They realised that they had a specific difficulty and that this was unrelated to intelligence. Prior to the diagnosis their self-esteem was significantly lower than it appeared to be after diagnosis, in part due to negative interactions with peers or teachers. Their self-esteem had been damaged as a result of negative interactions with teachers and peers, although in all cases the parents had worked hard to preserve their self-image (Glazzard, 2010). Research has also indicated that peers are an important source of self-esteem (Kirchner and Vondraek, 1975). My data suggests that the negative influences from both teachers and peers negated the positive support provided by parents (Glazzard, 2010). The diagnosis was a turning point in terms of building up confidence, self-concept and self-esteem and consequently its significance should not be under-estimated. Thus, I concluded that the need for an early diagnosis is therefore crucial in order to stop children from developing learned helplessness.

### 3. Methodology

I have chosen to use narrative as a methodological tool to explore the effects of dyslexia on self-esteem. In adopting a narrative genre I have used the life history specifically to tell the stories of four people who were diagnosed with dyslexia. I had personal and professional connections with the informants and this is a common thread in life history research. Through my connections with the informants it became evident that dyslexia had had a profound impact on their lives. The stories they tell illustrate the powerful effects of dyslexia on self-esteem and personal identity and what emerged throughout all the stories was the theme of resilience. This theme united all the informants and this formed the basis for selecting the sample.

The life history method emerged in the early part of the twentieth century and was further popularized by the emergence of feminism and the growth of sociology as a discipline. I have chosen to dedicate most of this chapter to telling the stories of my informants and in doing so, I make no apologies. My intention is to privilege the stories that people have told me, to let their voices speak and consequently to allow the reader to make their own sense of the stories they have been told. Clough (2003: 448) believes that narratives should 'challenge their readers to create their own meanings from them'. He believes that the narrative should

'lead the reader to a place where they might begin to search for the meanings and issues that lie behind and surround the story' (Clough, 2003: 448). In keeping my analysis relatively brief, my intention is to allow the reader to make their own sense of the stories that they have been told.

Drawing on Goodson and Sikes (2001) I view a life stories as as stories as told. In contrast my analysis essentially transforms the stories into life histories by exploring the wider contextual discourses which have shaped the lives of my informants. I believe that life histories can expose suffering, pain, misfortune, and injustice in order to 'speak to the heart of social consciousness' (Clough, 2002: 8). According to Goodson and Sikes (2001: 42), 'as social beings we are constantly storying our lives'. People enjoy telling and listening to stories and this renders this approach dynamic in that it has the potential to expose pain and suffering and illuminate the wider political, social and cultural discourses which have shaped people's lives. For my informants this approach can be empowering and emancipatory (Goodson and Sikes, 2001). Bowker (1993) has argued that an age of biography is upon us.

It has been argued that:

...in their nature, already removed from life experiences: they are lives interpreted and made textual. They represent a partial, selective commentary on lived experience.

(Goodson and Sikes, 2001: 16)

In presenting my stories I accept that I have presented partial and edited lives. In choosing specific storylines, I have effectively rejected others (Goodson and Sikes, 2001). This inevitably raises ethical issues around researcher neutrality. However I reject assertions that any research can be objective, neutral or value free (Greenbank, 2003). I am mindful that some critics question the value of approaches that are value-laden, subjective, non-generalisable (see for example Tooley's critique of educational research, 1998). I am not concerned with such criticisms. In my view stories can serve as powerful research tools by casting lights onto the lived experiences of those whose voices have been silenced and consequently marginalized. I argue that certain criteria used to judge the credibility of a piece of research (for example, objectivity, reliability, validity) are inappropriate indicators for judging the credibility of narrative research. I do not claim that my stories are generalisable but they are stories that others might relate to and consequently for some readers, the stories might ring true to them. In evaluating the quality of this research I hope that my readers choose to evaluate the extent to which the events of the stories engage them, and seem to be true. My intention is for the readers to bring their own interpretations to the stories. Several authors have emphasised that criteria other than objectivity, validity and reliability should be used to judge literary work. For example, Denzin (2003) cites Ellis (2000) who argues that texts should be engaging and have the capacity to evoke thoughts and feelings. Ellis (ibid) argues that texts should include authentic and life-like experiences woven into a good dramatic plot. Two other authors are cited by Denzin (2003), namely, Bochner (2000) and Richardson (2000a and b). Bochner (ibid) wishes to read a story that 'moves me, my heart and belly as well as my head' (cited in Denzin, 2003: 255). Richardson (2000a) is concerned with stories that contribute substantially to our understanding of social life, which are 'a credible account of a cultural, social, individual or communal sense of the "real"' (Richardson, 2000b in Denzin, 2003: 255). Hitchcock and Hughes (2003) refer to the

criteria of 'authenticity' or the extent to which the events in the story ring true to life. I share these positions and hope that my readers can take something away from the stories I have chosen to present.

## 4. The stories

### 4.1 Rich

#### Context:

*The 1944 Education Act in England emphasised the importance of segregated education for children who were deemed to be 'uneducable'. The term 'educationally subnormal' was used to describe children who had learning difficulties. During the 1960s the disability rights movement emphasised the rights of children with disabilities to a mainstream education. The comprehensive system of education was introduced and the 1970 Education Act facilitated the development of special education units within mainstream schools. There was an increasing acceptance during this time that children with learning difficulties had rights to a good education within mainstream provision.*

Rich was born in 1959 to a middle class family in South Yorkshire, England. His father was a relatively successful engineer. His mother, whose background was from a working class family in Barnsley, England, had great ambitions for both of her children. She had achieved little in her own life and was seemingly intent on rectifying the situation by driving her children to success at all costs. Rich was, as a young child, placid and somewhat withdrawn. He lacked confidence when faced with social interactions with his peers and in such situations, whenever possible, would stay by the side of his older sibling for comfort and reassurance. In more familiar situations he appeared comfortable. He generally conformed to the expectations of the household, that he should be seen and not heard and other than an occasional confrontation with his sister was in general a very easy going child. Shortly after his birth his mother suffered from severe post natal depression and for the first 18 months of his life Rich and his sister were brought up by their elderly grandparents.

In 1964, 3 months before his 5<sup>th</sup> birthday, Rich began full time education in a local primary school. From the outset he found this new experience distressing. He spent much of each day choosing to isolate himself from his peers and in tears. His teachers would frequently call upon his older sibling to visit him in his classroom to offer him reassurance. However this only provided temporary consolation, and as soon as she left, the traumas of school life quickly enveloped him again. Rich would stand alone anxiously searching for his older sister during playtimes. His distress was so great that he was unable to develop relationships with his peers. Within only a few months of starting school life it became evident that Rich was struggling with early reading and writing skills. This in turn caused his mother great distress. Her anxieties were evident and these must have been transmitted to her son. However it cannot be doubted that all subsequent events retold in this story were intended to be in his best interests.

Rich seemed unable to grasp the rudiments of the alphabetic code. As children in his class began to make progress and develop a basic knowledge of phoneme/grapheme correspondence, Rich sat in a wilderness, seemingly unable to make sense of it all. His mother set to work cutting graphemes from sticky backed paper and adhering them to his



bedroom wall in an attempt to support him. Relentlessly his mother subjected him to several coaching sessions each day. These had little or no effect and the alphabetic code continued to remain inaccessible to him. The obvious anxiety and desperation exhibited by his mother, without doubt, was absorbed by Rich who became more withdrawn. Unsurprisingly his behaviour also became more challenging. He would become very uncooperative, refusing to comply with even the most trivial expectations. He would begin to undertake tasks but would rarely complete them. The household became a battle ground and Rich became more and more unhappy and challenging, resulting in his mother becoming increasingly anxious. The downward spiral had begun.

Within a year of Rich starting school his mother contacted a local teacher and weekly private tuition was arranged. Rich was offered exactly the same diet as he was being given at school. There was simply more of it. His private tutor found him difficult to motivate and it was equally difficult to keep him focused on a task. He much preferred to engage with her dog or to engage her in discussions which in her view had little relevance to given tasks and were simply a means of distracting her from the role she had been given. She suggested to Rich's mother that private tuition was not supporting Rich and even indicated that they had so little value that the tuition was of no value and should cease. Rich's mother did not appear to hear such comments and the private tuition continued for a further two years while Rich made very little headway. When he was 7 his private tutor withdrew her services. This was apparently due to her retirement although this is questionable and may have been a means of dismissing her challenging pupil and his equally persistent mother.

Rich continued to display challenging behaviour at home. By now he had begun to feel a failure in many aspects of his life. His initial difficulties were in reading and writing as well as some aspects of maths. He was now perceived by his mother as badly behaved, uncooperative and as having an inability to concentrate. Their relationship was deteriorating rapidly.

The school which Rich attended became the next target. The classes were too big and in the eyes of his mother Rich was simply not receiving enough attention. A private education became the next perceived solution to his difficulties. Smaller class sizes would surely result in more attention being given to Rich and he would quickly make progress. A private school in the city was chosen where Rich would continue his education. He was only 8 years old. The school clearly had reservations about Rich joining their role. These were ignored by Rich's mother and a transfer to this fee paying school was swiftly arranged. Rich hated every day of every week that he attended the school. There were frequent communications from the school in regard to Rich relating to his lack of academic ability. He continued to struggle in school and after only a year he returned to the primary school where he had initially begun his education. He was certainly happy to return there despite the fact that he continued to find reading and writing, particularly difficult.

His secondary education did little to improve the situation. Reports from school consistently made reference to his 'poor' work, lack of concentration and inability to organise the daily demands of school life. Another private tutor was employed to support him but this tutor also quickly expressed concerns and declined to support him further.

*The comments made by Rich's teachers poerfully illustrate the medical model of disability that prevailed during this time. Within-child factors were blamed for Rich's problems. There was no onus on the school to reflect on its policies or practices and make adaptations to cater for Rich's needs. Consequently Rich was labelled as a failure by a schooling system that failed to accept that it played a significant part in the problems that Rich was experiencing.*

As a teenager, he was reminded on a daily basis of his 'failings'. Homework, which must have already been a challenge for him, heralded a daily battle ground. He was, by now, extremely de-motivated and frequently failed to complete homework. He often denied that any homework had been set. Communication between home and school all those years ago was sadly lacking and this enabled Rich to dodge the bullets until the annual parent's evening when his lies were usually unearthed. He began to truant from school. Everyday tasks were a challenge for him. His mother no longer blamed schools for Rich's difficulties. On a very personal basis his failure was now totally levelled at him. She perceived him as 'difficult' and uncooperative and their relationship was at an all time low. Rich took exams but his grades were poor and he left school at the age of 16. It is only thanks to his father that he managed to acquire a job in the mining industry as a fitter. Within 5 years he was, unfortunately made redundant and for the next ten years did not work again.

Redundancy resulted in Rich living at home with his parents. They were thrust together for 24 hours each day. The relationship between Rich and his mother was one of total conflict. His father was now retired and disabled and such conflicts caused him great stress. The stress placed upon him now resulted in a rapid decline in the relationship between Rich and his father. There were tranquil moments but these would be short lived. The inevitable conflict between Rich and his mother resulted in a snowball effect and would quickly lead to conflict between Rich and his father, who simply wanted peace and quiet.

Over the next 10 years Rich was perceived as the centre and cause of all conflicts within the household. He applied for several new jobs which would inevitably lead to renewed conflicts as he struggled to complete applications forms. His father would write them for him but he found it difficult to copy what had been written. Time and again a new form had to be sent for before yet another error was made as he tried to copy onto the form. Arguments and verbal abuse would follow.

Life continued in the vain for several years. How the family existed on a day to day basis under the same roof is nothing short of miraculous. In 1991 Rich's father suffered his final illness. It was a surprise to his family that although his father's death was imminent Rich made no attempts to visit him in the hospital. This was in fact to be the turning point in Rich's life. He was informed of his father's death. He chose not to be present at the funeral. Rich made one last visit to his home several weeks after his father's funeral. There was another dispute with his mother who ordered Rich out of the house. Twenty years later Rich has never been seen by any members of his family since that day. No-one has any idea of his whereabouts. He has simply vanished without trace. His mother is left distraught by the absence of her son, seemingly confused by his ability to cut himself off from his family. Rich, however, is happy and well. In 1959 there was seemingly little support or understanding of children with dyslexia. For Rich there was additionally little support or comfort offered by his parents. He simply made his escape to begin a new life. There is a plethora of support

which he can now access to overcome his difficulties. Rich was never diagnosed as having dyslexia. This could well have remained the case today. He did, however, encounter severe difficulties in both reading and writing. He faced an uphill struggle, but, having left his old life behind him, he has successfully made a transition to a life in which he has managed to overcome his difficulties in peace and without judgement.

*At the time when Rich went to school in the 1960s and 1970s there was no assumption that a child's learning difficulties could be the product of a schooling system that has failed to meet the needs of a child. The medical discourse located the problems firmly within the child. Had Rich attended school in the late 1990s rather than in the 1960s his story could have had a very different ending. Rich was ultimately failed by a system of education that assumed he was responsible for his own problems. The inclusion agenda, in contrast, places an onus on schools to be proactive in meeting children's individual learning needs.*

## 4.2 James

### Context:

*The Warnock Report (Warnock, 1978) examined the education of handicapped pupils and recommended the concept of 'handicap' be replaced by the term 'special educational needs'. The report recommended the integration of pupils with special educational needs into mainstream schools and classes and it emphasised the importance of parent partnership and an expansion in the role of local authority support services to support the needs of children with specific needs. The 1981 Education Act established the concept of integration and the statementing process. This process (which still exists today in the UK) involves local education authorities in conducting an assessment of the child to identify their specific needs. If the needs are severe, local authorities issue statements of special educational needs which set out the statutory educational entitlements that the school and Local Authority must provide to ensure that a child's needs are met. The 1988 Education Act saw the introduction of a National Curriculum which became an entitlement for all children, irrespective of the type of school that a child attended. In 1989 the United Nations Rights of the Child emphasised the social and educational inclusion of children with special educational needs and disabilities. The 1994 UNESCO Salamanca Statement emphasised the rights of all children to an education and the important role that mainstreaming can play in combating discriminatory attitudes. The 1993 Education Act resulted in the first Code of Practice. This led to the introduction of a named person within schools who was responsible for the education of children with special educational needs, the special educational needs coordinator (SENCO).*

James is 28 years old. He is the eldest child from a marriage between 2 teachers. James views his life today as happy and secure and he eagerly looks towards the future with great optimism. He is no different in many respects to thousands of people of the same age. Life is good and the future looks bright. So what makes James and his enthusiasm for life different? In reality James has travelled a very long and often turbulent journey. It is that journey that has made James the young man he is today. His journey has paved the way to what he now believes to be a future abounding with renewed optimism.

James was born in Sheffield, England in 1983. He was the first child of a middle class couple and his arrival in the world was welcomed and celebrated by both his parents and their extended families.

James was not the easiest baby. He was born at 36 weeks and spent the first month of his life in intensive care. He rapidly made progress and was discharged from the hospital to return home with his parents. In terms of sleeping he was a challenge for his young parents and from the early weeks of his life would sleep for only three hours before waking. This continued until James began full time education shortly prior to his 5<sup>th</sup> birthday. The school he attended was placed in a very middle class catchment area and systems in the school can only be described as traditional. James had always been an extremely active child. His energy levels seemingly had no bounds. He was inquisitive, the world was exciting and every waking moment was a journey of exploration and intrigue. Life was full of questions. He had a genuine love of books and the times he frequently shared these with his parents were undoubtedly the only occasions on which he ever sat still. School life was not the easiest of transitions for James. Suddenly there was an expectation that he would sit still and listen for extended periods of time. He asked copious questions and within weeks he was already labeled as difficult to motivate. The questions he asked were viewed a challenge to authority. On one occasion he had spent an entire Friday afternoon immersed in developing a model. As the school day drew to a close he was asked to disassemble his creation. He enquired as to whether or not he could leave his construction and complete it the following week. This was viewed as challenging behaviour and communications with his mother quickly followed. His teacher was clearly none too impressed. James was happy when engaged in practical tasks. Such opportunities rarely presented themselves and he quickly developed a reputation for being a disruptive influence on his peers. His parents endeavored to offer James additional support at home. They would concede to this day that James much preferred situations in which learning was active and as teachers made every effort to capitalize on this need to engage him in his learning. James enjoyed a degree of success although he was clearly falling behind his peers in terms of his attainment in school. Life was for living, life was fun and quickly James became the class clown. He was by no means a naughty child. He could best be described as a rogue and both at home and at school he would often test the boundaries and needed to know exactly where those boundaries were. His antics gained him huge popularity with his male peers and he loved the attention. In retrospect it was clear that James was a square peg in a round hole. The educational establishment chosen for him did not effectively meet either his needs or his preferred learning style. He spent many play times completing unfinished work. James clearly found acquiring both early reading and writing skills challenging. He worked slowly and was made to complete one task set by his teachers before beginning and completing the next. To enable him to do so he often missed the elements of the curriculum that he so enjoyed such as physical education, and technology. Consequently he spent the most part of each day tied to a desk, trudging through endless reading and writing tasks that he clearly hated and found very challenging. There were few opportunities for him to express himself or to engage in physical activities which he clearly needed. James gravitated towards children with similar personalities. They often came from backgrounds which were very dissimilar to his own and such children did not enjoy the support of parents like those of James. He found a common ground with these children and was thrilled by their antics and freedoms in life. His parents continued to work with James and also to work alongside the school to support him. James at the very least raised a few eyebrows amongst his teachers. By the age of 8 he encountered one very severe teacher who was prepared to make absolutely no adjustments to her 30 years of practice to accommodate the likes of James. Her systems and approaches were extraordinarily rigid and there was absolutely no room for manoeuvre. His

mother later recalled the ways in which she had attempted to work in collaboration with this same teacher. She accepted, as a teacher herself, that James may not be the easiest or most willing child to educate. To some degree this teacher did enjoy a modicum of success with James. He was indeed terrified of her and would make every effort to complete written tasks. She required a written product at the end of every lesson and was perhaps the first teacher to ever successfully extract this from James. James spent much of his days in school seated alone. By now he was clearly operating at a level below that of the majority of his peers. He was however increasingly sharing, what he perceived to be, his current new found success with his mother. At the end of the academic year there was an annual parents' evening and with a new found optimism James' mother attended a meeting with the teacher. James' mother, although dubious about the teaching styles of the class teacher, did acknowledge the change in her son who by his accounts was seemingly more focused in his work and making progress. The meeting began. A torrent of negative attitudes in relation to James was all that his mother was offered. Yes he was completing writing tasks but, but, but...his writing was untidy, he could not spell words correctly even though they had been learned by him a month before. His reading was not fluent; he was only really focused when he was making things or 'playing' on a computer. The result of this conversation was an unexpected and unrehearsed outburst from James' mother. She had listened to a torrent of negative comments about her son from the very beginning of the conversation; she had not heard one positive comment. As if from no where James' mother halted the conversation and enquired as to whether the teacher had any positive comment whatsoever to make in relation to James. Stunned the teacher confirmed that James was both a polite and kind child. He was able to share and always carefully considered the needs of others. 'Thank you' his mother replied before explaining that she felt that James indeed needed to be aware of the ways in which he could make improvements to his work but that he must also be made aware of his strengths. She wished to communicate both to him on her return home. She then terminated the meeting thanking the teacher for advising her of the areas in which James needed to focus but most importantly for identifying some positive aspects of his nature.

For the next 2 years James slowly built on his progress in reading and writing. His reading was slow and he often read 'new' words using an over reliance on a phonological approach. Indeed when writing phonics was the prime approach he used to aid spelling. His mother continued to engage James in exciting first hand experiences at home in a continuing effort to both support and motivate him. She was now convinced that James, although very distractible, was also facing a genuine difficulty in acquiring skills in both reading and writing.

*James' experiences at primary school illustrate the dominant discourse of integration that was prevalent in the 1980s following the publication of the Warnock Report and the 1981 Education Act. Integration placed an onus on James to assimilate into a system of education that did not address his specific needs. The result was that James became demotivated and began to disengage with education. Within the discourse of integration there was no onus on the teacher or school to make any adaptation to practices and the medical model dominated traditional thinking around special educational needs*

As James began his final year in primary school he was to meet a teacher who he recalls with total admiration to this day. For the first time in his relatively young life James was

made acutely aware of his strengths. As with other teachers she identified his interests and strengths. Unlike previous teachers she capitalized on his strengths and interests. This same teacher embraced his enthusiasm for computers. James was no longer expected to record all of his work through pen and paper. He was encouraged to record much of it through word processing. This was of course well received by James. Writing was no longer a chore and became more enjoyable. This new approach however clearly began to identify that James did indeed experience genuine difficulties in spelling and writing. He was now happy to engage in the process and it became easier to identify his difficulties. James had without doubt mastered the basics of the alphabetic code, however as he was now approaching his 11<sup>th</sup> birthday his work clearly identified his over reliance on phonics as the prime approach to spelling new words. The teacher was fascinated by what she had discovered and in discussions with James' mother expressed her concerns that James was showing all the signs of having surface dyslexia. This year in school was, for James, the happiest to date. He worked with enthusiasm as his teacher celebrated his achievements but he was now also able to acknowledge his difficulties and worked tirelessly to overcome these by sharing them with a supportive mentor. As the time to move to secondary education quickly approached this information was shared with the receiving school. James' future suddenly took on a whole new and positive meaning.

The final year in primary school quickly became a distant memory of a successful and motivating time in James' life. The days of despair returned on his transfer to secondary school. His difficulties with both reading and writing were rapidly identified again. This of course was a positive beginning to his life in a new school. Surely James would continue to receive the support he needed. The reality was to the contrary. He was once again perceived to be failing and there were few support systems in place. Within only a few weeks James was again in the role of the class clown. He lacked focus in most lessons and failed to complete tasks that involved written work. Homework was rarely completed and again he gravitated towards other disruptive influences. During one parents' evening he was described by one teacher as the most stupid child she had ever met. His efforts now focused on having fun, taking risks and he came under the spell of peer pressure. James was excluded from school for taking alcohol onto the premises to drink with friends during the dinner time break. A watch with an alarm was deliberately set by him to coincide with the middle of a mathematics lesson. He was cautioned but repeated the prank the following week. At home, despite the best efforts of his parents, he refused to complete homework. He had given up on school and was now relishing the excitement of testing and breaking rules and boundaries. A significant act of defiance is often recalled by his parents. They had negotiated a contract with him as vital examinations approached. He was to focus on revision during the day and could then enjoy time with friends in the evening. One night James prepared to leave the house to meet friends. He had not revised for his exams during the day. He was now 15 years old. His departure was stalled by his father. James had broken their contract and would not be allowed to meet his friends that night. In an act of total defiance James left the house. He never returned that night and it was only on the afternoon of the following day that he came home. His parents felt that this one incident was a turning point. James had realized that he was ultimately in control of his own life. He coped with the confrontations that followed his challenges to authority and when they were over he challenged it again. When he was just 14 his mother noticed a dramatic change in his behaviour and his personality. Intuitively she knew that such changes could well be the

result of James experimenting with drugs. His father was far from receptive to this suggestion. James quickly identified and capitalized on such opposing opinions and skillfully used them to his advantage. He portrayed his mother as a crazed individual which compounded his father's view that indeed she was paranoid. The marriage did not survive this ordeal and James' parents separated. James and his sister stayed with their mother whilst their father moved on to pastures new. Indeed only two months after the separation James was 'outed' as a drug addict. Family life became very turbulent and strained. His younger sister also suffered as a result of his habit which now revolved around heroine. She was arrested when police forced entry into the house. She lived the nightmare of police knocking on the door in the middle of the night. He fraudulently took several thousand pounds from his mother's account. Eventually his mother was faced with the dilemma of meeting the needs of both of her children. Her decision was difficult but unavoidable and James moved out to live with his father.

*James' experiences at secondary school in the early 1990s illustrate the dominant discourse of integration. James was perceived by his teachers to be a failure. There was no onus on the school to be proactive by making adaptations to meet James' educational needs. Consequently James was stigmatised and marginalised by an education system that was based on a medical model of disability. This had disastrous consequences for James and his parents, as illustrated in the events below.*

The years that followed were turbulent years in so many different respects for the different members of James' family. James divorced himself from his mother for much of the next 7 years. There were meetings and telephone conversations. James was admitted to hospitals on several occasions with life threatening conditions and his mother was always present and James was glad to see her. His parents recalled the stresses felt by both themselves and James during his admittance to hospital. In the main the system was supportive. James would be prescribed methadone. It was rarely administered 'on time' and James would quickly begin to suffer from withdrawal symptoms, threatening to discharge himself from the hospital. Frequently hospital staff refused to communicate with James' parents in relation to his drug addiction. In attempts to ensure that James remained in hospital to receive treatment for life threatening conditions they found themselves in the unthinkable position of collecting heroine for him. Once discharged from hospital he went back to his chosen lifestyle which was financially supported by his father in an attempt to prevent James from thieving to finance his habit. To a certain extent such financial support did minimize the number of occasions on which James became involved with the police although there were several occasions on which he was arrested and he was, on one occasion charged with shop lifting.

During this time James entered into a relationship and within 18 months his son was born. On the day his son was born James was himself in hospital awaiting major surgery and was unable to be present at his son's birth. The relationship floundered. James gave little emotional and no financial support to the mother of his child and the couple separated. James made a few attempts to see his son but has now lost contact with him. Another relationship began and a second child, a daughter, was born two years later. This relationship was with a woman who also had a police record and seemed to prefer to live

life on the wrong side of the law. It was an extremely volatile relationship and disagreements between the couple often resulted in James making his escape to return to his father only to be beaten up by gangs. His ribs were broken on several occasions and during one such incident James was stabbed.

Finally, James admitted to wanting to escape from the horrific lifestyle he had chosen. With the continued support of his family he finally sought help. An initial appointment with the family doctor was made by James. He attended with his father. There was to be no lifeline. Many medical practices had a policy that drug addicts were not treated. Eventually James was accepted by a medical practice several miles away and began a methadone program. The distance between his home and the fact that he no longer resided with his father, meant that James rarely attended appointments with his doctor or missed appointments at the chemists where he was given methadone. Time and again the doctors began a methadone program for James ensuring that he also had access to human resources to support him. Time and again the program failed.

In 2009 James' mother and his father financed a program in a rehabilitation centre. James was admitted for a week and placed under heavy sedations. On discharge from the centre he convalesced with his mother. He was weak, emaciated and 'on his own.' During the ensuing two years James continued to meet his needs for heroine from time to time. He never fully returned to the days of being an addict. Today James is finally 'clean'. He ensures that he attends all follow up appointments and is reunited with his family. James is 'high' on life. He finds casual work whenever and wherever he can, and looks forward to the day when he can find full time employment. His relationship with the mother of his daughter ended and currently he is engaged in a legal battle to ensure that he is able to be involved in his daughter's life. James and his family are indeed positive about the future. James frequently suffers periods of remorse and he still has a need to discuss those lost years. It is all part of the healing process for both James and his family. Without the support of a loving family James may well still be wandering the streets in search of his next heroine fix. In reality he is now well on the road to recovery and a 'new' life. James is eternally grateful for the support given by his family and the medical profession. His family is eternally grateful for his determination to battle through the hell of withdrawing from heroine. James and his family have lost over 10 years of his life to heroine. It is an experience that they will never forget. James' parents never stopped loving their son. Today, they watch proudly, as James boldly takes steps towards the future.

### 4.3 Alex

#### Context:

*Alex is slightly older than James. He was born in 1979 just after the publication of the Warnock report and during his early schooling in the 1980s the dominant discourse was one of integration. The medical model of disability prevailed at this time and 'within-child' factors were blamed for the cause of children's difficulties.*

Alex began primary school in 1984. He attended a large school with approximately 400 pupils on roll in a two form entry system. Alex had good memories relating to school in general until he reached the age of 9. The year was 1989 and his clear memory was of being summoned, with no prior warning, to the Head Teacher's office. His initial reaction was one



of concern and he made the immediate assumption that this was a result of a misdemeanor on his part even though he was unable to identify what this could have been. On entering the office Alex was greeted by the Head Teacher (Mrs. P), his parents and his class teacher (Mrs. E).

It was at this meeting that, for the first in his life, Alex was made aware that he was considered to be a 'slow learner.' This was a totally new revelation to Alex who until this point in time was completely unaware that either his teacher, his, parents or the school held any concerns relating to his progress. Mrs. E explained that Alex had found it challenging to complete given tasks, in reading and writing, within a given time constraint. Mrs. P's solution to this problem was to suggest that Alex would benefit from a transfer to a special school. It was evident that Alex had absolutely no control or influence in the matter. The decision regarding his future education had already clearly been made. From the outset Alex had reservations about leaving a school where he was, happy settled, and had formed strong friendships with his peers. The term 'special school' did not bode well with Alex either. Despite his anxieties Alex did not express his feelings. His mother insisted that Alex would indeed transfer to the 'special school.' Within three weeks of this meeting taking place Alex was attending his new school on a part time basis. Within half a term his placement was on a full time basis.

*Under the dominant discourse of integration the school had not been proactive in making changes to its practices to meet Alex's needs. Alex had been integrated into a school that was designed to educate the masses and no specialist provision had been made available to enable him to make progress. He had been labelled as a 'slow learner' and no attempt had been made to differentiate the learning to cater for his needs. He was ultimately blamed for his difficulties, illustrating a dominant medical model of disability which prevailed in the post-Warnock period.*

There swiftly followed a series of assessments, resulting in a diagnosis, for Alex, of moderate learning difficulties. Alex had been placed in a special school which supported pupils facing a multitude of differing special educational needs. He was educated in a class of approximately six other children. He witnessed events that are emblazoned on his memory to this day. Events that, until this point in his life, he had never witnessed before. Many of his peers frequently displayed aggression. Chairs were flung across the classroom, rulers were used as weapons, children were frequently restrained and teachers were verbally abused and assaulted. School reports for Alex changed significantly. They frequently made reference to his immature, irresponsible and unacceptable behaviour. His friendships were with those who had been placed in the school to support them in overcoming challenging behaviour. This disruptive behaviour was however, quickly halted following a severe verbal reprimand from an educational psychologist, witnessed by his parents. Thereafter his behaviour improved and he was frequently rewarded for meeting behavioural expectations.

At the age of 12 Alex was offered the option of returning to mainstream secondary education. He embraced this opportunity but quickly struggled to be educated alongside his main stream peers in larger classes. His entry to secondary school had already been delayed by one year. The transition was difficult for him and he faced it with neither peer support nor carefully considered transition planning in place. Consequently Alex made a decision to

move to the 'secondary special needs school' and was reunited with his peers and the challenging behaviours they displayed.

Alex has a clear recollection of facing National Curriculum test papers in mathematics and writing. The outcomes of these tests were never communicated to him. He does however recall, again, struggling to complete the writing of a story within the time constraints. Spelling also remained a challenge for him. There was never an opportunity for Alex to work towards GCSE examinations. He did, however, have the opportunity to undertake focused work placements.

As Alex completed year 11 in secondary school he had gained no qualifications. To the amazement of his parents, however, Alex made the decision to pursue his education at the local further education college. He had not enjoyed school life in more recent years but was able to identify the reasons for this. The challenging behaviour and constant disruptions effected by his peers had been central to his unhappiness. Alex however had never lost sight of the importance and value of education.

At college Alex enrolled on a Health and Social Care course. He still did not perceive that he had encountered any difficulties in learning despite attending two special schools. On being asked if he had any learning difficulties Alex responded in the negative. Alex had a desire to reinvent himself and this seemed to be an appropriate time to do so. He wished to eradicate any associations with the special schools and wished to remove the label of 'the boy with special needs.' During his first year at college his tutor suggested that he should be assessed to determine whether he had dyslexia. Alex agreed to this and subsequently he was given a diagnosis of dyslexia. Following his diagnosis Alex encountered many other students, some of whom were mature, who also shared diagnoses of dyslexia. He listened to their personal recounts of school life which often mirrored his own experiences. Additionally students recalled incidents when they had been the recipients of verbal and physical abuse from teachers. Many had been excluded from lessons. For Alex this was a defining moment in his life. From these frank and open discussions he acquired a true sense of belonging and his sense of isolation was quickly dispersed. Alex was now being educated with like minded people who had similar aspirations for their future but who had all shared similar experiences in their formative years in education.

A diagnosis of dyslexia for Alex opened the doors to additional focused support. He was able to access additional tutor support; computer aided dictionaries and electronic spell checkers as well as being able to readily access laptops during lessons. Through such support Alex achieved a distinction in his Health and Social Care course and further progressed onto vocational qualifications which led into a career in the health sector. Currently Alex is studying towards a science degree.

The impact of Alex's experiences continues, to some degree, to affect his life today. Attending courses to further enhance his own professional development are daunting experiences for him. He worries that on such occasions there may be an expectation for him to read or write in front of others. Alex continues to struggle with spelling, reading and writing and displays a strong preference for using a computer rather than writing by hand. In many aspects of his work he is required to hand write commentaries and notes, such situations are unavoidable and remain a source of stress to Alex.

*Alex's later educational experiences at Further Education College powerfully illustrate a shift in thinking from a medical to a social model of disability. Adjustments were made to enable Alex to achieve his full educational potential and resources were provided which helped to break down barriers to learning and participation. Alex's experiences at college demonstrate the shift from a dominant discourse of integration to the discourse of inclusion, post Salamanca. Alex was no longer blamed for his difficulties and the proactive response demonstrated by the college is synonymous with inclusion which was advanced as a policy agenda under the Labour government post 1997.*

#### 4.4 Sophie

##### Context:

*The 1994 UNESCO Salamanca Statement emphasised the rights of all children to an education and the important role that mainstreaming can play in combating discriminatory attitudes. The 1993 Education Act resulted in the Code of Practice for special educational needs. This led to the introduction of a named person within schools who was responsible for the education of children with special educational needs, the special educational needs coordinator (SENCO). Differentiated educational provision became more common during the 1990s and teachers became skilled in planning learning activities to meet the diverse needs of a range of learners as the social model of disability began to dominate thinking around disability. . The Labour government advanced the inclusion agenda post 1997 and this placed an onus on all educational institutions to be proactive in meeting children's individual needs by making adaptations to policies and practices. Disability Discrimination legislation in the 1990s placed a duty on teachers to make 'reasonable adjustments' to cater for the needs of children with special educational needs.*

Sophie was almost 5 years old when she went to school in a small village in England. Before this time in her life Sophie had enjoyed the continual love and support of her family. She had spent her young life enjoying the love and affection of her parents and grandparents and was never far away from either of them. Sophie found the transition from the securities of home life to the new experiences of school life traumatic. She struggled to cope when her mother left her at school each morning. Each experience was a new experience for Sophie and she yearned to be with her mother for support and comfort. Two weeks later, Sophie continued to find the transition difficult. Her teacher instigated a meeting with Sophie's mother in an attempt to work collaboratively to ease Sophie's distress. This was the prime purpose of the meeting and it was assumed by Sophie's teacher that the reasons would be totally transparent.

On the day of the meeting Sophie's mother arrived, already clearly distressed. She was in fact convinced that Sophie's teacher was poised to reveal her greatest fear. That Sophie was dyslexic. Sophie's mother explained in minute detail her reasoning. She had obviously held this fear for a long time. Well before Sophie had begun her full time education. Schools in England are usually unable to secure such a diagnosis until a child reaches the age of 7 and at this moment in time Sophie's teacher had no evidence to suggest that Sophie was dyslexic. She did not however dismiss the concerns of Sophie's mother. In two weeks she had no evidence to suggest that Sophie was encountering such difficulties. The main areas of concern were Sophie's social and emotional needs.

As the weeks went by the events of this meeting remained fresh in the teacher's mind. Why had Sophie's mother seemed so certain that Sophie was dyslexic? She had spent almost 5

years with Sophie and although the evidence she presented could have related to most children of a similar age she was convinced of her findings. Indeed throughout the following year Sophie did begin to find it immensely difficult to acquire early reading and writing skills. She would appear to master a new skill but quickly lost the skill only needing to be supported again to address it. This vicious circle continued and Sophie's overall attainment, in these areas of her learning, became a cause for concern. She became very distressed when she anticipated the need to complete a reading or writing activity. Frequently her fears were unfounded but if she predicted that she would be asked to read or write she would become inconsolable. Her teachers were supportive and compassionate and Sophie consistently enjoyed praise for her achievements. This was to no avail. Sophie had already developed an innate fear of applying these skills. When engaged in other activities Sophie was confident and during discussions she was extremely articulate.

During the ensuing 2 years the school worked in collaboration with Sophie's mother, never denying that there was now a possibility that Sophie was dyslexic. There was access to little support for the school to support Sophie. Any enquiries were quickly and abruptly dismissed. There was an age barrier to accessing further support for Sophie. Her mother and now her teachers were convinced that Sophie needed additional support to overcome her difficulties. Sophie finally reached that mile stone 7th birthday and the process of screening for dyslexia could finally begin.

In reality the process was slow. External agencies were involved and there was doubt that Sophie was dyslexic. Her mother and the school remained convinced. The specific diagnosis was not a concern. Their shared mission was to receive additional advice relating to supporting Sophie. It was in fact almost 3 years later before Sophie was officially diagnosed as having dyslexia. Until that time the school had worked tirelessly to support Sophie. Sophie in turn had begun to use her difficulties as a crutch. She approached all aspects of reading and writing with a dyslexic barrier firmly placed between herself and the teacher. She was difficult to motivate and had a plethora of excuses. She was able to support her negative attitudes with a multitude of reasons as to why she could not attempt them. The staff in school found her attitudes challenging and on occasions she was confronted by their frustrations. They made every effort to remain clam but the barrage of information relating to 'my dyslexia' aimed at them by Sophie became a huge challenge. Sophie's views were acknowledged and much was done in an attempt to meet her needs. One practitioner recalled the day when Sophie was using a computer to word process her work. She was particularly difficult to engage on this occasion and finally explained that she found it difficult to work when the screen background was white. The screen was in fact yellow and had already been changed to meet her needs as Sophie had previously requested.

During the final year of Sophie's primary school education she finally received the diagnosis she and her mother had sought. Additional support was now readily available for Sophie, her mother and the school. Much of what was offered had already been provided by the school in the years before her diagnosis. However the difference in Sophie's attitudes towards her learning was swift and positive. No one had ever doubted her difficulties with reading and writing, she had been supported by every teacher and yet it was her diagnosis that was the key to opening the door to engaging Sophie in working towards overcoming the challenges she faced. It was as if, in Sophie's mind, everyone now believed her.

*Sophie's experiences illustrate that the process of formally recognising a child's specific needs in England can be a long drawn-out process. The statementing process that was introduced following the 1981 Education Act is complex and in reality children may not receive a diagnosis until the end of their primary education.*

Sophie enjoyed her final year in primary school. She and her mother were now more relaxed and at ease. She was frequently visited by specialist and her diagnosis indeed did much to develop her confidence and self esteem.

Sophie's battle was briefly revisited when she began her secondary school education. It is thanks to her mother, who worked tirelessly for 6 months to ensure that Sophie received the support she was entitled to, that Sophie again began to make progress. Sophie enjoyed her success and left the secondary school with 6 GCSE s before continuing her education and also gaining 3 'A' levels. This was followed by a course in which she successfully qualified to become a nursery nurse.

*Sophie eventually managed to receive the support she needed at secondary school to enable her to make good progress. This demonstrates the shift from integration to inclusion during the 1990s. The discourse of inclusion reflected a social model of disability which placed an onus on all educational institutions to make changes to their policies and practices to enable learners to make progress. Consequently Sophie was able to thrive during the final years of her school career due to the support that she received.*

Sophie secured a position as a nursery nurse where she enjoyed every moment of the next 4 years. Her work was consistently praised and acknowledged. Sophie worked with a range of children with widely differing needs. She effectively supported them all. Over time, working under the direction of someone else became a frustration for Sophie. She had ideas and strategies of her own, which she wished to implement, but was unable to do so in the position she held. Her ideas of a new and different future began to form. In September 2008 Sophie applied to begin a teacher training course and was accepted.

Sophie was thrilled to have secured the opportunity to train as a teacher. Her difficulties with reading and writing had by no means disappeared and throughout her teacher training course she accessed a great deal of readily available additional support to aid her with the many assignments she was required to complete. She learned how to overcome her difficulties and spent far more time completing assignments than her contemporaries. Her grades began to improve. By now Sophie was married and the dedication to succeed she demonstrated was met with anger and aggression from her husband. He understood neither her drive nor her determination. The short marriage ended and Sophie was left devastated but still held onto a belief that she could succeed. In the practical aspects of her course Sophie excelled. She was truly committed to her chosen career path. She was creative and would spend hours carefully considering the ways in which she could engage her pupils whilst meeting their many individual needs. Committing her plans to paper was time consuming for Sophie but was deemed time well spent as she was highly motivated to ensure that her pupils enjoyed success. Sophie had been well supported throughout her life to overcome her difficulties. Her mother knew that from an early age Sophie was dyslexic. Could this possibly be because she recognized a mirror image of her own difficulties?

Whatever the reasons she worked tirelessly to ensure that Sophie could access the support she required. Throughout her life in school Sophie's difficulties, even before she gained an official diagnosis of dyslexia, were acknowledged and she eventually gained the specialist support that she needed. The greatest contribution to Sophie's success must be Sophie herself. She has shown great determination and ambition which culminated in Sophie now being poised to begin her first year in teaching as a newly qualified teacher. The future looks bright for Sophie and her dreams have finally become a reality

## 5. Discussion

The stories illustrate the powerful discourses which have influenced children with learning difficulties at various times. Rich's story illustrates schooling in England in the 1960s which failed to recognise individual needs and emphasised perceived deficits: *'There were frequent communications from the school in regard to Rich relating to his lack of academic ability' .... 'Reports from school consistently made reference to his 'poor' work, lack of concentration and inability to organise the daily demands of school life'*. A powerful normalising discourse pervaded at the time. Children were expected to keep up with the rest of the class and deviations from the norm were treated as failures.

Interestingly, the stories of James and Alex illustrate that two decades later, in the 1980s, little had changed despite policy rhetoric which emphasised the necessity for schools to meet children's individual needs. The influential Warnock Report (DES, 1978) had introduced the language of special educational needs and emphasised the capacity of mainstream schools to meet a diverse range of needs. However, under this discourse of integration, James' story powerfully illustrates that no attempts were made to meet his specific needs. Throughout his primary education teachers focused on his deficits and rather than the deficits in their own teaching, which may have contributed to James' disengagement. Within this normalising discourse, James was simply expected to assimilate into a largely unchanged system. Alex's story also illustrates a normalising discourse. The school failed to meet his diverse needs and consequently he was marginalized and excluded. He was viewed in terms of his deficits and punished by not being allowed to attend his mainstream primary school. This story powerfully illustrates the extent to which integration placed the onus on the child to adapt to the schooling system and how not adapting led to punishment. Both Alex and James' story illustrate how integration could be perceived as a normalising discourse which emphasised children's deficits. No attempts were made by Alex's and James' teachers to identify deficit aspects of their practices which could have contributed to their disengagement.

The connecting theme for Rich, James, Sophie and Alex is a theme of discrimination. The consequences of this discrimination were severe in James' case and his subsequent decision to engage in a life of crime could have been the consequence of his low self-concept. For Alex and Sophie discrimination was evident through a late diagnosis of dyslexia and, for Alex, his exclusion from mainstream education.

Sophie's story illustrates powerfully the impact of dyslexia on her self-concept. She approached tasks anxiously and with fear and often used made excuses to avoid certain tasks. Both Sophie's story and Alex's story illustrate the benefits of the diagnosis. In both cases the diagnosis was delayed but following the diagnosis both enjoyed additional support. It is pertinent to note that in both cases, the diagnosis came in the 1990s when

England was moving towards an agenda for inclusion. This discourse placed more of an onus on the schools to proactively meet the needs of the child rather than adopting a deficit perspective.

In all the stories there is an emerging theme of parental support but in some stories it is evident that parents had to fight to get support and worked tirelessly to achieve help for their child. Sophie's mother, for example, worked tirelessly to obtain a diagnosis of dyslexia. In Rich's story it is evident that parental support can be a negative factor: *'On a very personal basis his failure was now totally levelled at him. She perceived him as 'difficult' and uncooperative and their relationship was at an all time low'*. In Alex's case his parents were supportive but were clearly influenced by the views of more powerful professionals when the decision was made by the school for Alex to attend a special school. It was interesting that, at this time, the views of both Alex and his parents were seemingly irrelevant. This was a time before the dominant discourse which exists currently which emphasises the rights of parents and children to be involved in all decision making. This is now clearly articulated in the Code of Practice for Special Educational Needs (DFEE, 2000).

A connecting theme for all stories relates to the impact that dyslexia has had on the informants as adults. Sophie continually has to address her literacy difficulties every day whilst working as a teacher and he has to find strategies to overcome these. Form filling and note taking is problematic for Alex in his current job. Rich struggled to fill in job applications and needed support from his father. James continues to struggle with day-to-day writing tasks. However, despite this, a theme of resilience also connects all four stories. Alex is now successfully re-engaging in education. Sophie has achieved her life time ambition to be a teacher. James has broken away from his life of crime. For these three informants dyslexia has affected them but not paralysed them. For Rich resilience is manifest in a different way. He rejected his family to pursue a new life where he could enjoy being himself. The perpetual deficit view that he had been given was finally shaken off as he sought to re-invent a new identity for himself.

Alex's rejection of the term *'special needs'* powerfully illustrates the extent to which the terminology of special needs can pathologise individuals. The term emphasises a person's deficits, which reflects a medicalized view of disability. According to Thomas and Loxley (2007) 'there is an unspoken acceptance of need as a means of securing removal of the child' (p.54). Within this discourse the child is deemed in need of professional help from 'expert' professionals who focus their attention on locating the source of the difficulty within the child. Within a medical discourse the child is re-conceptualised as a *sufferer* and a *victim* and this reinforces a sense of powerlessness (Thomas and Loxley, 2007). Thus 'need' comes to represent deficit and disadvantage (Thomas and Loxley, 2007). There is a need to move away from such a pathologising discourse and focus on children's *rights* rather than *needs*. Such a paradigm shift has more positive connotations and emphasises the deficits in the school rather than the deficits in the child.

## 6. Conclusion

The narratives presented in this study evidence a united sense of resilience that emerges in all four stories. However, the resilience is demonstrated in different ways in each of the stories. There is evidence in these stories of low teacher expectations, for example in Rich's story, and there is evidence of marginalisation of children with dyslexia. Alex's story represents a powerful example of this. James's story illustrates that the costs of literacy

failure can have devastating consequences and although it is not possible to make a direct link between criminal activity and literacy failure, it could be argued that James' low self-concept, could have been a significant factor in his criminal activities in later life. Parental support ranged from being supportive to over-bearing. For example, the support from Sophie's mum inevitably impacted on developing a secure sense of self which was clearly evident following her diagnosis. However, Rich's mother had overly optimistic ambitions for him which resulted in his determination to rebel and dis-own his family. What emerges from these stories is a sense of success. Through determination and resilience, both Sophie and Alex have achieved their academic ambitions. James has overcome his drug addiction and is now considering re-engaging with education. Rich has made a new life for himself away from the pressures of his mother who, although over-bearing, only had what she considered to be his best interests at heart. The stories expose pain and suffering but, above all, they illuminate the discrimination experienced by all the informants in their education. Rich never had a diagnosis of dyslexia. If he had, the outcomes could have been more positive and Rich might still be in contact with his family today. Alex was denied access to a mainstream primary education. All informants believe that they have dyslexia. Some received official diagnoses, but these often came too late. Others, received no diagnosis, which left them vulnerable and unable to understand why they found reading and writing so difficult. Given the range of issues identified through these stories it is important that further narrative research is conducted and published to illustrate the effects of dyslexia on people's lives.

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## 8. References

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