

Developmental Communication Difficulties in
Adulthood: Life Outcomes, Family Experiences, and
Transitions at Post-16

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Abstract

This thesis presents an exploration of outcomes for pupils and ex-pupils of a residential special school for severe and complex developmental speech and language difficulties (SLD), and the views and experiences of their families and the education staff who work with them.

The thesis is divided into three parts. Part one presents a study that recruited seventeen ex-pupils of the school and three of their nonlanguage impaired siblings to map the stability of their language, literacy and nonverbal abilities over the life span. Only three ex-pupils resolved their language difficulties. In the others there was evidence for a relationship between severity and pervasiveness of SLD. Literacy difficulties were the most persistent type of difficulty in adulthood. Four ex-pupils also experienced a drop in nonverbal ability with age. The siblings outperformed the ex-pupils on psychometric testing.

Part two presents two studies of the psychosocial outcomes and life experiences of the ex-pupil and sibling cohort described in part one. The first study used semi-structured interviews to document their psychosocial outcomes which were wide ranging. Academic and employment outcomes were more strongly related to persisting levels of SLD than friendships and relationships. Independent living proved to be an area of difficulty and issues with financial management were the biggest barrier to this.

The second study documented the life experiences of the parents of 8 ex-pupils of the school and the three siblings. Raising a child with SLD proved to be challenging on three levels: children's care was demanding; families needed to fight for access to support, and limited knowledge of SLD in the public domain. Part two also found a strong preference for special schooling over mainstream education; support outside the school environment often had negative experiences attached to it.

Part three presents a prospective study of post-16 pupils before leaving full time education. It reports the views, experiences and expectations of fifteen pupils attending the school's further education (FE) department, five of these pupils' parents and eight learning support assistants (LSA). Leaving FE was associated with challenges for the future, such as gaining employment. A clear demand for ongoing support for adults with persisting SLD at post-16 and beyond was also found.

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Chapter 1- Terminology and Structure for this Thesis

1.1 The Aims of this Thesis

This thesis explores the outcomes of ex-pupils of a residential special school for developmental speech and language difficulties (SLD) in adulthood, examined the views and experiences of their families and conducted a prospective study of younger post-16 pupils with the same educational needs. This was with the view to seeing what could be learnt about the persisting nature of SLD over the lifespan, the impact these have on the lives of the individuals who experience them and their families, and the role of support services.

The aims of this thesis are:

- To examine the nature of language, literacy and nonverbal difficulties over the lifespan for individuals with severe and complex developmental SLD.
- To identify the psychosocial outcomes for adults with persistent developmental SLD and examine the relationship between psychosocial outcomes and levels of persisting difficulty.
- To examine the experiences of families to adults with life long histories of persisting developmental SLD to see what can be learned.
- To examine experiences and hopes for the future of pupils attending a post-16 provision at a residential special school for individuals with persisting SLD.

The research questions for this thesis are therefore as follows:

- How stable are SLD, literacy difficulties and nonverbal abilities in individuals with severe, complex and persisting developmental SLD over time?
- What challenges to achieving positive psychosocial outcomes are faced by adults with persisting, severe and complex developmental SLD?
- How important is access to specific support for individuals with lifelong speech and language difficulties?
- What are the challenges for families to children with SLD?

Chapter 1 will now introduce the background to this project, define the terminology and outline the structure of this thesis.

1.2 Speech and Language Difficulties in Childhood

1.2.1 What are Speech and Language Difficulties?

The term SLD covers a broad range of difficulties. These can be developmental and interfere with language acquisition in childhood or can be acquired and occur in individuals who previously had no SLD as a result of neurological damage. This project is concerned with the long term effects of severe and persistent developmental SLD. A speech difficulty can be caused by physiological or structural abnormalities (e.g. cleft lip and palate), or neurological impairments (as in cerebral palsy) (Clegg, 2007a). In many cases however, there is no apparent cause for developmental speech difficulties. These children may have difficulty differentiating similar sounding words, storing words clearly and producing words in speech (Stackhouse and Wells, 1997).

A language difficulty can have a number of aetiological causes: hearing impairments; general learning difficulties, or specific learning disabilities. A child with a language difficulty can experience difficulties developing vocabulary, syntax, and pragmatics in varying combinations and to different degrees. Language difficulties are also associated with receptive and/or expressive language impairments. Receptive language difficulties are when a child's comprehension of language is impaired while expressive language difficulties impair a child's spoken language. Speech difficulties and language difficulties typically occur together but can also happen in isolation from each other (Clegg, 2007a).

It is difficult to estimate the exact prevalence rates of childhood SLD, however Law, Boyle, Harris, Harkness and Nye, (2000) estimated it could be as high as 24.6 percent of children putting it amongst one of the most common childhood disorders. Beitchman, Nair, Clegg and Patel (1986) also estimated communication disorders to affect 19% of 5 year old children in the Ottawa-Carleton region of Canada; with a proportion of 6.4% experiencing speech disorders and 12.6% experiencing language disorders.

SLD can persist into later childhood. Bishop and Edmundson (1987) followed the progress of 87 children with SLI between ages 4;0 to 5;6. Nineteen of the cohort turned out to have general delay despite the authors' efforts to exclude children with intellectual difficulties. At follow-up 38 of the 68 children with SLD and 17 of the 19 children with general learning difficulties presented with persistent SLD. These children were still falling behind their nonlanguage impaired peers by 5;6. Beitchman and colleagues followed the progress of 124 children with SLD from ages 5 through to 12;5. They reported that 72% of

the children with language difficulties only and 81% of those with both speech and language difficulties still presented with difficulties at the end of the study period. In addition, they reported that individuals with both receptive and expressive language difficulties were more likely to experience persisting difficulties than those with only one type of language difficulty (Beitchman, et al., 1986; Beitchman, Wilson, Brownlie, Walters and Lancee, 1996). More recently Glogowska, Roulstone, Peters and Enderby (2006) followed-up 196 children who had all been referred to speech and language therapy (SLT) due to concerns about their speech and language development before age 3;6 years. They reported that only 27% continued to have SLD at age 7-10 years of age. These levels of persistent SLD were lower than in previous studies and this was likely to have been because this study saw a broader spectrum of SLD and therefore these children were experiencing less severe difficulties overall.

1.2.2 What is Specific Language Impairment?

Specific Language Impairment (SLI) is a specific type of developmental SLD that occurs when a child experiences unexpected difficulties with language development in the absence of any identifiable causes (Leonard, 1998). Traditionally SLI has been identified using exclusion criteria or as a language disorder that occurs without an identified origin, such as general learning difficulties; autism; neuromotor impairment, or hearing loss (Stark and Tallal, 1981).

Alternatively, different methods of identifying SLI according to explicit criteria have also been proposed. One definition of SLI is based on the presence of a discrepancy between verbal and nonverbal ability. Here a child's language ability falls below what would be expected in comparison to their nonverbal abilities, or present with significantly poor language skills in the absence of nonverbal difficulties (Aram, Morris and Hall, 1993). This would be measured using specific standardised language assessments and cases of SLI would present with language skills in the lower ability range of the normal distribution but show no such difficulties on tests of nonverbal ability. However, this method is limited as the cut off criteria that identifies SLI can be drawn at different places; e.g. a verbal score of less than 1 S.D. or less than 1.5 S.D. below the mean. There will inevitably be a group of children who are boarder line and subsequently have SLI according to one set of criteria but are typically developing according to another. This method also has the limitation of not being able to

provide more specific details of the children's difficulty; for example with the child has expressive or receptive language difficulties (Rice 2000).

A third method has aimed to identify SLI according to diagnostic markers; this is also based on performance on language assessments. For example, Conti-Ramsden and Hesketh (2003) outline that children with SLI may perform below their chronological age on language measures and therefore display a profile similar to a younger typically developing child. This motivated the authors to aim to identify specific areas of 'abnormal' development to distinguish children with SLI (or disordered development) from those with delayed language development. They proposed that nonword repetition may be a marker for SLI; however it is unclear whether this was a symptom or a cause of SLI and furthermore nonword repetition difficulties can be present in other clinical groups and are not exclusive to SLI, for example dyslexia.

A fourth methodology has attempted to identify SLI according to distinct SLI-subgroups defined by specific patterns of difficulty. Rapin and Allen (1987) measured the phonological, syntactic, semantic and pragmatic skills in spontaneous language during play in preschool children with SLI. From this they were able to identify six distinct subgroups of SLI: verbal auditory agnosia; verbal dyspraxia; phonological programming deficit syndrome; phonological-syntactic deficit syndrome; lexical-syntactic deficit syndrome, and semantic-pragmatic deficit syndrome. In an attempt to replicate this, Conti-Ramsden, Crutchley and Botting, (1997) assessed 242 children with SLI at age 7 years on a range of psychometric assessments that measured receptive language, expressive language, syntax, vocabulary, phonology, syntax, reading, numerical ability and nonverbal ability. They identified 6 discrete subgroups of SLI similar but not identical to those identified by Rapin and Allen (1987). These studies showed it was possible to divide cases of SLI into distinct subgroups. This methodology has the advantage, over the discrepancy or exclusion criteria methods as it also provides specific details of each case.

As with other types of SLD, SLI is also likely to persist into later childhood (Conti-Ramsden, Botting, Simkin and Knox, 2001). Tomblin, Buckwalter, Zhang, Smith and O'Brien (2003) followed-up 180 children with SLI from kindergarten until age 9 years. They reported that 60% of these children continued to show language impairments at follow-up and concluded that early childhood difficulties were likely to persist throughout the primary school years.

The prevalence rates of SLI are lower than for SLD. Law et al. (2000) estimated SLI affected 3-7% of children in the general population. Tomblin, Records, Buckwalter, Zhang, Smith and O'Brian, (1997) carried out a large population based study in America and estimated a slightly higher prevalence level of 7.4% of children. The disagreement on how to measure SLI means the prevalence rates are difficult to measure as they will inevitably be influenced by the different criteria by which SLI can be defined.

In this thesis the terms SLD and SLI will both refer to developmental SLD and may be used interchangeably in the literature view chapters. This will be dependent on the terminologies used in the literature cited.

1.2.3 Issues Surrounding Co-morbidity and the Changing Nature of Speech and Language Difficulties with Age

Co-morbid difficulties and the changing nature of SLD longitudinally both further complicate the formal identification of cases of SLD. Firstly, different types of SLD do not necessarily occur as distinct disorders. For example, a single individual could have a combination of articulation, expressive, receptive or nonverbal difficulties. In these cases it is difficult to identify an individual's difficulties according to one specific label. Secondly, SLD can change in the way they manifest themselves as the individual ages. Longitudinal studies have presented cases where SLD manifest themselves differently at different points during an individual's life.

Bartak, Rutter and Cox (1977) presented evidence for co-morbidity when they reported on a small group of 5 boys (aged 4;6 to 9;11 years) who displayed the symptoms of both autism and developmental language disorders (DLD) but could not be unequivocally classified as fitting all the criteria for either specifically. Further evidence for this subgroup of children originates from studies by Conti-Ramsden et al. (1997) and Rapin and Allen (1987) (previously described in 1.2.2). Both studies reported a subgroup of children that presented with mild receptive language difficulties and unusual social behaviours; such as interpreting things in a very literal sense. These children experienced difficulties with the social use of language and are often not recognised as having language impairments as they tend to perform well on most language assessments with the exception of narrative.

A second set of studies have highlighted how SLD can change in how they affect the lives of those who have them as time progresses. Conti-Ramsden et al. (2001) revisited a

cohort originally identified as having SLI at 7 years (Conti-Ramsden and Botting, 1997), when they were 11 years to see if they still met the criteria for SLI. However, they identified a new small group of children who had the symptoms of mild to severe autism and pragmatic language impairments that had not been identified in the original study. Moreover their new profiles no longer fitted the exclusion criteria employed by the original study and therefore these cases would not have been recruited. Similar findings were reported by Cantwell, Baker, Rutter and Mawhood (1989) who followed up the cohort identified by Bartak, Rutter, and Cox (1975) aged between 6;6 and 11;6. They reported that 9 boys originally diagnosed with DLD were now showing more features of autism.

Michelotti, Charman, Slonims and Baird (2002) examined both of these issues further in a study that aimed to identify how co-morbid profiles change longitudinally. They identified 18 children (mean age 4;4) who displayed features of autism and SLI but did not meet the criteria for either uniquely. It was predicted that with time the children would show a shift in their profiles and begin to display the difficulties of only one disorder. The children were then followed-up aged 8;7 years. Some had started to show more of the features of SLI more predominantly and others were showing the features of autism more predominantly. However, difficulties associated with the less prominent disorder still remained and these children still did not fit the criteria of one disorder exclusively. In a similar study, Miniscalco, Nygren, Hagberg, Kadesjö and Gillberg (2006) reported high rates of ASD and attention deficit hyperactivity disorder (ADHD) in children originally diagnosed with SLI by age 7.

It is now formally recognised that there is a small subgroup of children who display some symptoms of both language disorder and autistic spectrum disorder (ASD) but cannot unequivocally be classified as having either (Clegg 2007a). Bishop (2000) proposed that this subgroup of children present with a different type of language disorder that is an intermediate case between ASD and SLI. This disorder is known as pragmatic language impairment (Bishop, 2000) or semantic pragmatic disorder (Conti-Ramsden et al., 1997).

These studies demonstrate the complexity of the classification of developmental disorders and different developmental disorders are not as discrete as once believed. Some individuals may fit multiple diagnostic labels at any given time, while others may not quite meet the criteria for any diagnostic labels. In addition, some individuals may show a shift their diagnostic label as they age.

1.2.4 Literacy Difficulties in Children with Speech and Language Difficulties

Children with SLD are also highly likely to experience difficulties with literacy acquisition (Bishop and Adams, 1990; Glogowska et al., 2006; Silva et al., 1987). Catts (1993) documented the progress of 56 children with a variety of SLD from kindergarten until the 2nd grade (4-8 years of age). He reported a relationship between SLD and reading disabilities and that about 50% of the children with SLD fell behind their chronological age for reading. Further analysis revealed that expressive and receptive language ability was related to reading development but that articulation was not. Conversely, Bird, Bishop and Freeman (1995) reported children with severe expressive phonological impairments were at risk of literacy difficulties when they start school. They argued this difference was likely to have been caused by the children in their study having more severe articulation difficulties than those seen by Catt (1993). They also noted that children with articulation difficulties experienced less severe literacy difficulties than those with more complex SLD; Nathan, Stackhouse, Goulondris and Snowling, (2004a) found similar findings in their study of children aged between 4 and 7 years. Bird et al., (1995) concluded that expressive phonological difficulties are likely to impair a child's ability to learn how letters match to sounds. Catts, Fey, Tomblin and Zhang (2002) also showed that children with early language impairments are at risk of reading difficulties later on in childhood and children with additional nonverbal difficulties experienced even greater difficulties learning to read.

Further evidence was reported by Leitão, Hogben and Fletcher (1997) who examined literacy outcomes for children with specific speech difficulties in early childhood. They recruited four groups of children aged 6: a language impaired group (n = 18), a speech impaired group (n = 19), a speech and language impaired group (n = 17) and a typically developing group (n = 20). The children were assessed on literacy and phonological processing tasks. The children with mixed difficulties performed the poorest, followed by the language group, then the speech group, and with the typically developing children displaying the best performance overall. Further analysis revealed that children with atypical speech development demonstrated poorer phonological awareness skills associated with poor literacy outcomes. Children with delayed speech experienced fewer difficulties. Stackhouse and Wells (1997) proposed that children with speech difficulties are at risk of experiencing difficulties learning to spell when they begin literacy instruction. Stackhouse (2006) argued that literacy difficulties, especially in spelling, are likely to occur when an individual has a history of speech difficulties as both are the likely result of speech processing difficulties.

Hence, when a child has difficulty articulating a word they may also have difficulty spelling it correctly.

Bishop and Adams (1990) put forward the 'critical age hypothesis'. This argued that children who still have evident SLD by age 5;6 are at risk of developing literacy difficulties when they begin literacy instruction at school. This was based on findings from a follow-up study they carried out on a cohort of children with SLD originally seen by Bishop and Edmundson (1987). The original study identified 3 groups of children:

- the resolved SLI group who presented with SLI at age 4;0 but appeared to resolve their difficulties by 5;6
- the persistent-SLI group who also presented with SLI at age 4;0 but these difficulties remained at 5;6
- the general delay group who were characterised by a nonverbal IQ of 70 or below.

They found that the children with persistent difficulties at age 5;6 were more likely to show difficulties with literacy acquisition at age 8;5 (Bishop and Adams, 1990). Similar findings were reported by Nathan et al. (2004a) and Nathan, Stackhouse, Goulandris and Snowling (2004b). They assessed 2 groups of children, one with speech difficulties only and one with SLD, 3 times between ages 4;6 and 6;9 and measured their literacy progress. They also found that later literacy difficulties occurred in children whose SLD persisted beyond age 5;6, however even children who appeared to have resolved their difficulties by age 5;6 were still at risk of literacy difficulties, particularly with spelling.

1.2.5 Behavioural and Social Difficulties in Children with Speech and Language Difficulties

a. Behavioural Difficulties in Children with Speech and Language Difficulties

Children with SLD are more likely to develop behavioural problems. Silva et al., (1987) reported that children with early language delay are at high risk of developing behavioural problems into later childhood and early adolescence. Huaqing Qi and Kiaser (2004) compared the behaviour of 3-4 year old children with and without language delays. They reported that children with language delays displayed more problem behaviours, engaged in more physical aggression and exhibited poorer social skills than their typically developing peers. Similar findings were also reported by Lindsey and Dockrell (2000).

These behaviours can persist. Glogowska et al, (2006) reported that 7 and 10 year old children with SLD also struggled with social relationships and Conti-Ramsden and Botting (2004) found that 11 year old children with persistent SLI were also experiencing social difficulties; some being at risk of social exclusion and victimisation from their typically developing peers. Furthermore, Redmond and Rice (1998) suggested that young children with SLI develop socially maladaptive behaviour as a result of deviant social experience occurring as a result of their language and communication difficulties.

b. Social Difficulties in Children with Speech and Language Difficulties

Children with SLD or SLI are more likely to experience social difficulties than typically-developing children. Van Agt et al. (2005) carried out a population based study in the Netherlands that measured the QoL of 3 year old children according parental reports. The prevalence of language delay in this cohort was 4%. Children with language delays were more likely to experience poorer social interactions than typically-developing children and were therefore at risk of ongoing difficulties with social-emotional development, behavioural difficulties, and learning difficulties at school. Fujiki, Brinton, Issacson and Summer (2001) found that children with language impairments spent significantly less time interacting with peers than typically developing children. Snowling, Bishop, Stothard, Chipchase, and Kaplan, (2006) examined the social outcomes for the Bishop and Edmondson (1987) cohort at 15 years of age. They reported that those with persistent SLI were at a higher risk of social difficulties than those who resolved their difficulties, furthermore social difficulties were worse among those with nonverbal IQ difficulties or comprehension difficulties.

1.2.6 The Relationship between Speech and Language Difficulties and Socio-Economic Status

Although it is not a direct area of focus for this thesis, it is important to highlight the relationship between socio-economic status (SES) and language development. SES can be defined in a number of ways: level of parental education, parental occupation, family income, poverty, or income to needs ratio (Ginsborg, 2006). There is a wealth of evidence suggesting children from low-SES backgrounds are at risk of delayed language development and of underachieving academically. For example, Arriaga, Fenson, Cronan and Pethick (1998) reported that children under the age of 3 from low income families displayed significantly

poorer performance on vocabulary production, combining words and in sentence complexity than children from middle income families of the same age. Walker, Greenwood, Hart and Carta (1994) found that children raised in lower SES environments may encounter relatively fewer early language experiences than children raised in higher SES environments. They argued this can inhibit the growth of early language development, intelligence and later acquisition of reading and spelling. The potential consequence is that children from lower SES backgrounds are at risk of greater SLD than those from higher SES.

1.3 Educating Children with Severe Communication Needs

1.3.1 Inclusive Education and Special Schooling

The goal of inclusive education is that children with special needs will be catered for in mainstream schools or specialist units attached to mainstream schools. Inclusive education is typically characterised by the provision of support to teachers and parents and providing additional classroom assistants or speech and language therapy (SLT) for the children (Dockrell, Lindsay, Letchford and Mackie, 2006). The alternative to inclusive education is special schooling. Special schools cater specifically and exclusively for children with specific special educational needs.

SLT can be provided in school through direct or indirect intervention; direct intervention is when children receive support from the SLT in person while indirect intervention involves teachers and parents acting on the advice or instruction of an SLT. Direct intervention is more common in special schools and indirect intervention is more common in mainstream schools. Dockrell et al. (2006) described that children with more severe and complex speech and language needs are more likely to be educated in special schools and received direct intervention. Children with milder SLD are more likely to be educated in mainstream school and receive indirect intervention.

Recently, there has been a preference towards inclusive education for children with SLD; this has been driven by the belief that the correct approach is to include rather than to segregate (Lindsay, 2007). Furthermore, most children with SLD are currently supported in mainstream school with specialist provision. There has also been a shift towards indirect intervention with children with SLD. However if more children with severe and complex speech and language needs start to be educated in mainstream school then this may need to be re-evaluated (Dockrell et al., 2006).

This has led to the debate surrounding a child's right to be educated in mainstream education and the right to receive the most appropriate educational placements for their needs. Dockrell and Lindsay, (2008) interviewed and compared the views of education staff and SLT services. Education staff emphasised inclusive education while SLT services emphasised the need for specialist provision, highlighting a difference in opinion about what is best for children with SLD. However, Lindsay (2007) evaluated the research evidence in support of inclusive education and showed little evidence for its success despite its current popularity. Subsequently, Dockrell and Lindsay (2008) found that inclusion is not simply about location but process, as a child can still be excluded from the classroom in mainstream school or from appropriate support in specialist education. In conclusion, it is the quality and appropriateness of the provision that is more important than where the provision takes place (Conti-Ramsden, Botting, Knox and Simkin 2002; Dockrell and Lindsay, 2008).

1.3.2 The School in the Present Project

This project followed-up ex-pupils of a residential special school for specific speech, language and communication needs in the north of England run by the charity ICAN. The school was originally opened in 1974 and at the present time caters for children aged 5-19 years with severe and complex communication difficulties whose needs cannot be met by the mainstream school setting. It provides its pupils with education, SLT and care at a level to suit their needs, aims to maximise their educational achievements, gain as much independence as possible and ultimately prepare them for life in the adult world when they leave. Pupils get referred to the school via their Local Education Authority (LEA) and it is typically the LEA that funds placements at the school. In addition, the school also aims to engage the parents of its pupils in active partnership to benefit the social, intellectual and academic development of its pupils (The school's prospectus, summer 2008).

The school has a large catchment area that spans across England, Scotland and Wales due to the very specialist nature of the provision offered. It provides also residential care for pupils who travel far from home to attend. The care setting aims to ensure the emotional and physical well-being of its pupils as well as providing additional support with education and independence skills. Communication between the pupils, the families and the school is also encouraged (The school prospectus, summer 2008). The pupils seen in this project either attended the school as day pupils who did not board, weekly boarders who returned to school

each Monday and returned home every Friday, and fortnightly boarders who spent alternate weekends at school and home; the fortnightly boarding option was phased out during the data collection period of this project. In addition, its broad catchment area also means it caters for individuals from a range of SES backgrounds.

The school originally opened as primary school in 1974 and catered for children aged 5 to 10 only. The school's popularity and demand increased and in 1987 a secondary department was also opened (Haynes and Naidoo, 1991). In September 2004 the school opened a Further Education (FE) department to cater for pupils aged 16-19 wishing to continue their education beyond the compulsory years. The FE department provides pupils with access to a wide range of courses at a local college suitable to pupil's ability levels and interests. FE pupils ideally spend at least 50% of their time at college completing their courses and the remaining time at the school's FE department where they have continued support with education, SLT and independent living skills for the future.

1.3.3 The Pupils who Attend the School

The school's pupils are a heterogeneous cohort who present with a combination of difficulties in the following domains: articulation, phonology, syntax, semantics, pragmatics and literacy. In general they have better nonverbal than verbal skills, however some pupils will also experience nonverbal difficulties in addition to their communication needs (Haynes and Naidoo, 1991). The school does not typically accept children with global cognitive impairments, significant hearing loss or psychiatric disorders.

The school has always aimed to support children with primary language problems that prevent them from fulfilling their potential in mainstream school. However, the focus within this area has changed with time, originally it focused more specifically towards speech difficulties and other language and communication impairments. Now it caters for a broader spectrum of difficulties that includes some difficulties on the autistic spectrum. The ex-pupils seen in the project attended the school between 1974 when the school opened and 2007. All had histories of severe and complex communication needs that met the criteria for admission to the school and are from varied SES backgrounds.

1.4 The Structure for the Remainder of this Thesis

This thesis will be presented in three parts follow-up by a general discussion that will discuss the boarder findings across the three parts. Each part will address a different aspect of the project.

1.4.1 Part 1 – Language, Literacy and Cognitive Outcomes (chapters 2 – 3)

Part 1 will be concerned with the nature of SLD over time according to psychometric testing. It will measure the ex-pupils' language, literacy and cognitive outcomes in adulthood, map longitudinal trajectories for the ex-pupil's language, literacy and cognitive abilities over time using archive data and current psychometric assessment scores, and compare the ex-pupils' performance on psychometric testing to that of nonlanguage impaired siblings.

1.4.2 Part 2 – Psychosocial Outcomes and the Impact of SLD on Families (chapters 4 - 6)

Qualitative interview data will be presented. This aimed to identify the ex-pupils psychosocial outcomes in a series of life domains: education, independence, personal lives and perception of SLD and also examine the relationship between persistent SLD and psychosocial outcome.

Interview data was also collected from some ex-pupil's parents and siblings to gain a family perspective on SLD, broader insight into the ex-pupils lives, and also to validate the ex-pupils reports.

1.4.3 Part 3 – Experiences of Young Adult with Speech and Language Difficulties in Further Education (chapters 7 and 8)

Part three aimed to examine the experiences the school's further education (FE) pupils before they make the transition into the adult world. The views of FE pupils, the parents of the FE pupils and FE staff were collected and compared.

Part 1

Language, Literacy and Cognitive Outcomes

Part 1 of this thesis concerns outcomes in adulthood and lifelong trajectories of language ability, literacy and nonverbal ability in individuals with severe and persistent SLD. It comprises 2 chapters. Chapter 2 reviews the literature on the nature of persisting SLD in adolescents and outcomes in adulthood. Chapter 3 presents a follow-up study of ex-pupils from a residential special school for pupils with SLD; this examined their language, literacy and cognitive outcomes in adulthood.

This piece of research is divided into three small studies.

- Study 1 examined the ex-pupils language, literacy and cognitive outcomes in adulthood.
- Study 2 combined archive data from childhood with the follow-up data collected in study 1 to map longitudinal trajectories for language, literacy and cognitive ability.
- Study 3 compared the ex-pupils' performance on psychometric tests at follow-up with their siblings at a case study level; who had no known history of SLD. This was to control for genetics and family environment.

Chapter 2 - Persisting Speech and Language Difficulties in Later Life: A Literature Review

2.1 The Long-term Effects of Persisting Speech and Language Difficulties

2.1.1 Speech and Language Difficulties in Adolescence

Follow-up studies have established that if early childhood SLD are not resolved by around 5 years of age they are likely to persist in to adolescence. Aram, Ekelman and Nation (1984), examined the long term effects of SLD into adolescents. They followed-up 20 individuals (aged 13;03-16;10, mean age 14;10) with previous childhood labels of language disorder and reported that most individuals continued to present with language difficulties in adolescence, as well as behavioural problems, social difficulties and poorer academic ability than their peers. Similarly, Haynes and Naidoo (1991) studied a cohort of 118 ex-pupils who attended the same school as that presented in this thesis during the time it was a primary school only. At follow-up they were making the transition from compulsory education. They entered the school with a range of SLD (e.g. articulation, phonology, syntax, semantics, pragmatics and literacy (also see 1.3.3 for a further description of the pupils who attend the school). At the time of the study, all individuals were still experiencing some level of difficulty with language, though this was minor in some cases. Individuals with more complex co-morbid difficulties effecting speech and language experienced poorer outcomes on measures of language at follow-up than those with speech difficulties only.

Stothard, Snowling, Bishop, Chipchase, and Kaplan, (1998) followed-up a cohort of 15 year olds originally identified by Bishop and Edmundson (1987) when they were aged 4-5;6 years (see 1.2.4). The original study had identified 3 groups of children:

- resolved-SLI who had resolved their difficulties by 5;6 years
- persistent-SLI who were experiencing persistent difficulties beyond 5;6 years
- general delay who were characterised by a nonverbal IQ of 70 or below

At 15 the resolved-SLI group were not significantly poorer than nonlanguage impaired controls on language measures, although they performed slightly poorer on tests of vocabulary, picture naming and reception of grammar. They did perform significantly less

well on sentence repetition, nonword repetition and spoonerism tests however. The persistent-SLI group performed significantly lower on tests of language compared to both nonlanguage impaired controls and the resolved-SLI group. They were also indistinguishable from the general delay group on tests of receptive and expressive vocabulary and language comprehension. This suggests a risk of long standing language difficulties for individuals who do not resolve their difficulties by 5;6 years.

Conti-Ramsden and Durkin (2008) followed-up 120 adolescents with SLI (aged 16 years) and compared their psycholinguistic profiles to a 118 typically developing aged matched controls. This cohort had originally been identified by Conti-Ramsden et al., (1997) at age 7 and previously followed-up at age 11 (Conti-Ramsden et al., 2001). The SLI cohort performed significantly poorer than the controls on measures of language suggesting continuing difficulties, and 59 of the SLI were felt to still meet the criteria for SLI (e.g. performance IQ of 80 or more and receptive and/or expressive language score of 85 or less). Of remaining member of the original SLI group 15 presented with language and nonverbal skills in the normal range and 41 presented with both language and nonverbal difficulties.

Beitchman, Wilson, Brownlie, Walters, and Lancee (1996) followed up 215 adolescents aged 13 who were previously screened for speech and/or language impairments (Beitchman, Nair, Clegg and Patel, 1986). This cohort was divided into cluster groups based on their performance:

- high overall performance
- articulation difficulties only
- comprehension difficulties
- pervasive difficulties effecting articulation and comprehension

Participants were assessed on linguistic measures and it was found that individuals experiencing the most pervasive SLD experienced the most persistent difficulties at follow-up. The comprehension difficulties only subgroup also experienced substantial difficulties though to a lesser extent than the pervasive language difficulties subgroup. Those with articulation difficulties only experienced fewest difficulties and performed at a level similar the high overall outcome subgroup. Rescorla (2005) followed up 28 children at 13 years of age who had been identified as late talkers at 24-31 months. While these individuals have less severe difficulties than those seen in Stothard et al., (1998) and Conti-Ramsden and Durkin (2008), they still scored significantly lower than controls on measures of vocabulary,

grammar, verbal memory and reading comprehension. The authors concluded that delayed language development in early childhood was associated with a weakness in language-related skills in adolescents.

In summary, there is strong evidence that suggests children who do not resolve their SLD in early childhood are at high risk of experiencing further difficulties with language in adolescence. These may present as obvious or more subtle residual difficulties. Furthermore those with more pervasive difficulties that effect comprehension risk greater persisting difficulties than those with milder or articulation difficulties only.

2.1.2 Speech and Language Difficulties in Adulthood

The pattern of research findings for persistent SLD in adolescence have also be found to extent further into adulthood. For example, Tomblin, Freese and Records (1992) followed-up a group of adults (age range 17-25 years) with a history of SLI and compared them to age matched controls. They reported that these adults still performed more poorly than controls on language measures.

Studies by Clegg, Hollis, Mawhood, and Rutter, (2005) and Mawhood, Howlin and Rutter, (2000) also provide strong evidence for persisting SLD in adulthood. These studies followed up the cohorts originally identified in childhood by Bartak et al. (1975) (previously discussed in 1.2.3). These cohorts had childhood histories of DLD and Autism. Mawhood et al., (2000) reassessed the language skills of both cohorts in their mid 20's; they followed-up 20 participants of the DLD cohort (mean age 24;10) and 19 participants of the Autism cohort (mean age 23;9). Both cohorts were found to be experiencing persisting difficulties; however the overall language competence of the group with Autism was much poorer than the DLD cohort. The Autism cohort also had poorer conversational skills, possibly because the Autism cohort were less inclined than the DLD cohort to use their language socially and therefore had less opportunity to develop their language abilities. Despite this, both groups still experienced significant difficulties according to language measures. More recently, Clegg et al., (2005) followed-up 17 of the DLD cohort in their mid-30's (mean age 36;2) and compared their performance to both sibling and a performance IQ matched control groups. The authors reported significantly impaired levels of language compared with controls again suggesting that language difficulties can persist in to adulthood.

Aboagye (2001) followed-up 4 ex-pupils (aged 33;2-44;1) of a residential special school for SLD very similar to the one that participated in this thesis. Standardised psychometric tests revealed that all four these adults experienced residual SLD greater than would be expected relative to the general population. She also compared retrospective archive data from each ex-pupil's time at the school and compared this with the data collected at follow-up in adulthood. This analysis was limited in terms on the quantity of archive data available, however she was able to conclude that individuals with pervasive difficulties affecting both expressive and receptive language are likely to continue to experience the greatest level of difficulty in adulthood; this was similar to the previous findings by Haynes and Naidoo (1991).

The findings by Beitchman, et al. (1996) that individuals with pervasive language difficulties have poorer language outcomes than those with articulation difficulties, also extend into adulthood. Johnson et al. (1999), followed-up the SLI cohorts from the Beitchman and colleagues' studies aged 18-20 years (Beitchman et al., 1986; Beitchman et al., 1996) (previously described in 2.1.1). They found that the participants with pervasive and comprehension difficulties still experienced more difficulties than those who initially presented with articulation difficulties alone. In a similar study, Hall and Tomblin (1978) followed up 36 participants with childhood language ($n = 18$, mean age 22) and articulation ($n = 18$, mean age 23) difficulties. Nine of the language impaired participants continued to have communication difficulties as adults compared to only 1 of the articulation impaired individuals.

Overall, it can be said that SLD that have persisted into adolescence are highly likely to continue to persist in to adulthood. This is also the case for type of difficulty as again those with the most severe and pervasive difficulties are highly to continue to have the most severe and pervasive difficulties.

2.1.3 Literacy Difficulties in Later Life

Section 1.2.4 presented evidence that children with SLD are likely to experience difficulties with literacy acquisition (Bird et al., 1995; Bishop and Adams 1990; Catts 1993), particularly if these have not resolved by 5;6 (Bishop and Adams, 1990; Nathan et al., 2004). In turn, literacy difficulties routed in childhood are likely to persist further into adolescence and adulthood.

Leitão and Fletcher, (2004) followed-up 14 adolescents with histories of speech difficulties aged 12-13 years. All these individuals were previously identified as having difficulties with literacy and phonological awareness at ages 5-6 years. At follow-up these individuals were still experiencing literacy difficulties, including difficulties with reading accuracy, phonemic decoding, and spelling. Similar findings were reported by Stothard et al., (1998) and Snowling, Bishop and Stothard (2000). They assessed the literacy and phonological skills of the cohort originally seen by Bishop and Edmundson (1987) at ages 4-5;6 and reported that those with persistent SLI or general delays performed significantly worse on tests of literacy and phonological skills than those who had resolved their SLI by age 5;6. However, those who had resolved their SLI still performed significantly worse on tests of literacy and phonological skills compared to controls. A recent study by Dockrell, Lindsay and Connelly (2009) followed the writing skills of 58 individuals with histories of SLI from ages 8 to 16 years. They reported that literacy development, especially writing, was a specific area of difficulty for these individuals whose writing skills decreased with age relative to population norms.

Like language impairments, literacy difficulties are also likely to persist into adulthood. Felsenfeld, Broen and McGue (1992) reported reading difficulties in adults (aged 32-34 years) with histories of phonological disorders in childhood, and Clegg et al., (2005) reported literacy difficulties also in their DLD cohort when followed-up in their mid 30's. The severity of the literacy difficulties in adulthood have also been shown to be related to persisting SLD. Johnson et al. (1999) showed adults with both comprehension and expressive language difficulties experience greater literacy difficulties rather compared to those with articulation difficulties alone.

Overall there is strong evidence to suggest a relationship between SLD and phonological awareness difficulties and subsequent literacy difficulties. Furthermore individuals who appear to have resolved otherwise their SLD are still likely to experience persisting literacy difficulties in later life, though to a lesser extent than those with persisting SLD.

2.1.4 Changes in Nonverbal IQ Over Time

The relationship between SLD and nonverbal IQ is not fully understood. In some cases individuals with SLD can have lower nonverbal IQ abilities compared to typically developing peers; this can occur in both children (Lundervold, Posserud, Sorensen and Gilberg, 2008; Silva et al., 1987) and adults (Tomblin, Freese and Records, 1992). However, it is not necessarily the case that all individuals with SLD will also have nonverbal difficulties.

Cowan, Donlan, Newton and Lloyd (2005) compared the number skills of children (age 7-9) with SLI ($n = 60$) with age matched typically developing controls and younger typically developing children matched on language ability. They found children with SLI performed below their typically developing peers on number skills suggesting that children with SLI also risk difficulties with number. Viging, Price, Spinath, Bishop, Dale and Plomin (2003) investigated the genetic and environmental origins of the comorbidity between language and nonverbal impairments. They recruited twins (160 monozygotic (MZ) and 131 same sex-dizygotic (DZ) twin pairs) at 4 years of age to test how much language impairment in one child predicted the nonverbal ability in their twin. Four-hundred and thirty-six of these children were identified as language impaired, and it was found that language impaired probands also suffered significant impairments in nonverbal ability. The study found evidence that language problems in one twin predicted poor nonverbal ability in the co-twin much more so for MZ twins than DZ twins. They argued this suggested a genetic factor that includes both language and nonverbal difficulties. Both studies show strong evidence for a link between language impairment and nonverbal ability; however some language impairments still happen in the absence of nonverbal difficulties.

Longitudinal research suggests that individuals with SLD may be at risk of falling nonverbal ability with age; in other words children with SLD that do not have nonverbal difficulties may risk developing these with age. Conti-Ramsden et al., (2001) found that 50 of 177 11 year old children originally diagnosed with SLI at age 7 had nonverbal-IQs 2 SD below the mean. This deficit had not been present when they were originally assessed and by definition should not have been present at all (Conti-Ramsden et al. 1997); this also raises questions for the diagnostic criteria for SLI longitudinally (as previously discussed in 1.2.2-3). Botting (2005) investigated falling nonverbal IQ for this cohort between age 7 and 14. She observed a mean drop of 23 IQ points over this time with nearly 75% of the cohort scoring at

least 1 SD below the mean at 14 years of age. In addition, individuals who experienced the drop in nonverbal IQ were also having difficulties with narrative at age 14;3 (Wetherell, Botting and Conti-Ramsden, 2007). Botting (2006) therefore proposed that cognitive impairments are likely to co-occur with language impairments rather than the difficulties being isolated.

Conversely, Stothard et al., (1998) found no difficulties with nonverbal IQ in their follow-up suggesting that the drop in nonverbal IQ with age is not seen in all persistent cases of SLI. However, their findings could have been skewed for 2 reasons. Firstly, 19 cohort members were excluded in early childhood by the original study and placed in the general delay group thus removing those with the poorest nonverbal ability from the cohort (Bishop and Edmundson, 1987). Secondly, a standard score of 70 (equivalent to 2 S.D. below the mean) was employed as the cut off point to identify the presence of nonverbal difficulties. In contrast, Botting (2005) used a cut off point of 85 (equivalent to 1 S.D. below the means). Therefore some of those diagnosed with SLI in the Bishop and Edmundson (1987) follow-up could have had general delays according to criteria outlined by Botting (2005). This methodological difference would mean that smaller losses in nonverbal ability were detected by Botting (2005) that would have been missed by the criteria used by Stothard et al. (1998).

The issue of falling nonverbal ability with age was complicated by findings from the follow-up studies of the DLD cohort originally identified by Bartak et al., (1975). Mawhood et al. (2000) reported a drop in nonverbal IQ when the cohort was seen in their mid 20s. However, this finding was not replicated by Clegg et al. (2005) who found the same cohort's nonverbal IQ to be equivalent to the level originally reported by Bartak et al. (1975) by the time they reached their mid 30's. Both studies had used the same measure of nonverbal ability; the WASI-R (Wechsler, 1992). The earlier study had used the childhood equivalent; the WISC (Wechsler, 1949). These inconsistent findings could be due to 2 reasons. Firstly, they could reflect genuine fluctuations in levels of IQ showing a true drop in nonverbal IQ in early adulthood that resolved again in later life. Alternatively it could have been caused by the cohort finding the WASI more difficult than the WISC but then improving again in later life. This is unlikely because the WISC and WASI are designed to be equivalent to one and other, although the cohort was an atypical population.

However, despite the lack of clarity regarding falling nonverbal ability, Clegg et al. (2005) also found evidence that the DLD cohort had significantly lower nonverbal abilities than siblings who acted as a control for genetics and family environment. This still suggests

that individuals with language impairments experience greater difficulties with nonverbal ability compared to those without language impairments despite the DLD cohort's apparent recovery. However, in this case, the difference between the DLD cohort and their siblings could have been amplified by a high performing sibling cohort rather than poor performance in the DLD cohort. It is unknown if the DLD cohort members would also have high levels of nonverbal IQ had they never experienced DLD like their siblings.

Overall, it can be said that there is strong evidence for a relationship between nonverbal and language ability; though this is not yet fully understood. There is also evidence that some individuals with language impairment who do not experience nonverbal difficulties in childhood risk falling nonverbal IQ with increasing age.

2.2 Different Methodologies used in Follow-up Research

2.2.1 Retrospective and Prospective Follow-up Studies

Follow-up studies of adults with developmental SLD date back to the 1960s and 1970s (Garvey 1970; Griffiths, 1969; Hall and Tomblin, 1978) and can be retrospective or prospective in their approach (Ruspini, 2002). Traditionally, follow-up studies have taken a retrospective approach. These are typically cross sectional meaning taken from a single point in time and studying a cohort once (as in (Aboagye, 2001; Records et al, 1992)). In such studies the follow-up is the first and only time of data collection. For example, a cohort with a known history of SLD would be recruited as adults rather than recruiting children with SLD and tracking them through into adulthood. Some more recent studies have also been retrospective in their approach (Aboagye, 2001; Records et al, 1992).

Other studies have used a prospective approach (Billstedt, Gillberg and Gillberg, 2005; Clegg et al., 2005; Conti-Ramsden, and Durkin, 2008; Johnson et al., 1999; Snowling et al., 2006). These are usually part of larger longitudinal studies that revisit the same cohort several times over the course of many years. Both methodologies have their strengths and weaknesses; these are summarised in table 2.1. Overall, prospective studies are significantly more difficult to carry out, but are ultimately superior to retrospective studies as they produce rich longitudinal data sets.

The largest prospective studies are the National Cohort studies. These studies collect large and rich longitudinal databases on a national scale. The 1958 National Child Development Study (NCDS) and the 1970 British Cohort Study (BCS70) are examples of

Table 2.1 - The advantages and disadvantages of retrospective and prospective follow-up studies.

	Retrospective studies	Prospective studies
Length of time	Advantage – Relatively quick as the cohort will only be visited once.	Disadvantage – Very slow, projects could take the lifespan of the participants and researcher as cohort members will be seen multiple times over many years.
Cost	Advantage – Relatively cheap as only 1 study will require funding.	Disadvantage – Relatively expensive as multiple studies will require funding.
Workload	Advantage – Relatively low as only 1 study will be carried out.	Disadvantage – Relatively high as many studies will be carried out. Larger longitudinal studies are typically carried out by large research teams or organisations.
Attrition of the sample	Advantage – No attrition as a cohort will be seen once.	Disadvantage – It is highly likely that increasing numbers of original cohort members will withdraw from a project over time.
Changing research interests	Advantage – None, as the study will be a snapshot and relevant to the research interests of the time.	Disadvantage – It is highly likely that the research interests will have changed by the end of a longitudinal project. This could mean a project will have different aims and focuses at different times as the knowledge in the field increases and theory progresses.
Longitudinal research questions	Disadvantage – Cannot address issues such as causality, risk factors or resilience with time.	Advantage – Can address issues such as causality, risk factors or resilience with time.
Examining the effects of age	Disadvantage – Difficult to distinguish the effects of age from other factors.	Advantage – Can distinguish the effects of age as the same factors can be measured at a range of ages over the lifespan.
Data quality	Disadvantage – May require participants to recall things from the past. Some individuals may struggle with this and memories can become distorted with time.	Advantage – Will document participants' life experiences of the time.

such data bases. The NCDS recruited everyone born between the 3rd and 9th of March 1958 and collected information regarding their physical, psychosocial and educational progress in a series of follow-up studies at ages 7, 11, 16, 23, 33, 42 and 46 years. The BCS70 recruited children born between the 5th and 11th of April and followed them up at ages 5, 10, 16, 26, and 30 years. Data was collected on their health, education, social and economic circumstances (Schoon, Ross and Martin, 2007).

2.2.2 Psychometric Assessments

Psychometric assessments are quantitative test batteries specifically designed to measure performance within specific domains relative to normative data; examples of domains are cognitive, language or literacy. For example, the WASI- R (Wechsler, 1981) is designed to measure verbal and nonverbal IQ of ages 6-89. There are difficulties associated with their use: for example, they are typically standardised in 1 country; they can be subject to performance on the day; and individuals can become familiar with assessment batteries with repeated exposure. Also most assessments designed to detect SLD are designed for children and the norms do not extend to adulthood. Thus such assessments may lack the sensitivity to detect more subtle difficulties which can persist into adulthood. In addition, they do not measure functional language such as that used in everyday situations. How to interpret psychometric assessments can also vary, for example when defining what identifies the presence of a difficulty; such as, the disagreement over the cut off point that distinguishes SLI from typical development (Rice, 2000) (previously discussed in 1.2.2). Even so, psychometric assessments are commonly used in follow-up research (as in, Clegg et al., 2005; Johnson et al., 1999; Stothard et al., 1998).

2.2.3 Archive Data

Archive data can be utilised through document research and used to inform retrospective follow-up studies. Documents can be written text, audio recordings or visual images and can have historical content (Bowling, 2002). The content of documents can be collected, coded, analysed and used to inform a research project. In a retrospective study documents have the advantage of capturing an earlier time point that the researcher wishes to study. This is unlike human memories that will become distorted with time (Ruspini, 2002) (see table 2.1). However, archive documents can be subject to biases imposed by their

original authors, and document research can be biased by the researcher's interests that will influence what material might be selected.

A small number of follow-up studies have used archive data to help inform their findings (Aboagye, 2001; Schery, 1985; Shriberg and Kwiakowski, 1988). The method used by Aboagye (2001) was similar to the present project. She followed-up 4 ex-pupils of a residential special school for SLD and was able to use archive data from the ex-pupil's time at the school to compare with her own data collected at follow-up for each of her case studies. Shriberg and Kwiakowski (1988) collated data from the school records of 55 children with special educational needs (SEN) and was able to map trajectories of their SEN between ages 4 and 8. Finally, Schery (1985) gathered data over an 8 year period for 718 with language disordered children between the ages of 3;1 and 16;4 years. These data were organised into categories: demographics, physical development, social development, language and academic characteristics. From this the characteristics of the participants who showed the most progress could be drawn: for example the child's age (the younger the better the outlook); nonverbal IQ; maternal education; clarity of child's speech; behaviour and the child's sociability.

2.2.4 Siblings as a Control Group

SLD can aggregate in families (Viging et al., 2003). A strong source of evidence for this comes from studies on the KE family. Gopnik and Crago (1991) collected data from 22 of the 30 members of this family spanning three generations; 16 of these participants had developmental dysphasia. The family members with dysphasia presented with grammatical errors in both expressive and receptive language. These errors indicated difficulties using plural forms and with tense markers. The family members without dysphasia did not show these errors. Examination of the KE family's profiles suggested that some had caused by a specific deficit with learning language. This research eventually led to the discovery of a gene for language known as FOXP2; a mutation which in this gene was thought to cause the severe language difficulties in the KE family (Lai, Fisher, Husrt, Vargha-Khadem and Monaco, 2001). While this might seem like a breakthrough discovery, the idea that FOXP2 is really a gene for language and the cause of SLI was later treated with caution. Marcus and Fisher (2003) argued that it was just one genetic element that contributes to language development and that it was unclear whether its role is special or unique; notably FOXP2 can be normal in many cases of SLI. Further research has suggested that SLI could also be

associated with genes on chromosomes 16 and 19 that potentially cause individuals to be at a genetic risk of developing SLI (The SLI Consortium, 2002).

Barry, Yasin and Bishop (2007) reported more difficulties with nonword repetition in parents of children with language impairment compared to those without language difficulties; they argued that nonword repetition could serve as a marker of family risk for language difficulties. Tallal et al. (2001) also reported the risk of language difficulties to be significantly higher in families of probands with SLI than matched controls; mothers and fathers were equally affected but brothers were significantly more likely to be affected than sisters. There is now a consensus that language impairment can be inherited.

These findings question of the validity of using siblings and other family members as nonlanguage impaired controls in research into language difficulties. However, Clegg et al., (2005) successfully used siblings to control for upbringing and the family environment in their follow-up study of adults with DLD; siblings performed significantly better on language measures suggesting they were not affected by SLD (as described in 2.1.2). Pratt, Botting and Conti-Ramsden (2006) also reported that mothers of children with SLI were no more likely to have language difficulties than those in the general population. Overall this suggests that siblings can be used as a control group successfully, however the literature into family heritability suggests researchers should be cautious as family members may also have some level of SLD of their own. Psychometric assessment can help to confirm if this is the case.

2.2.5 Case Studies

Case studies and cohort studies are also complementary methodologies that follow-up research has utilised. A case study can be a detailed study of an individual, an organisation, a process, a neighbourhood, an institution or an event. Single or multiple cases studies can be examined by a research project (Yin, 2003). They allow detailed and rich data sets to still be drawn from only one or a few individuals.

Case studies in the follow-up literature have focused on individuals. Clegg and Henderson (1999) examined the economic outcomes for adults with persistent SLD. Within their cohort they were able to pick out the case of TH, a 34 year old male diagnosed with DLD in childhood. Aboagye (2001) is an example of a follow-up study that used 4 case studies to examine the outcomes of 4 adults with SLD in detail. The multiple case study design meant she was able to make direct comparisons between her cases. Studies of this type

have the advantage that they are able to provide a rich detailed data analysis of the research area that can include both quantitative and qualitative information. They have the disadvantage that their findings are specific to those who participate, which limits their generalisability to other populations. As individuals with SLD are relatively few they can be challenging to locate and recruit; a case study design can therefore be advantageous when studying individuals with SLD as only small numbers need to be recruited.

2.3 Summary

Individuals who do not resolve their SLD by 5;6 years risk lifelong difficulties (Clegg et al., 2005; Stothard et al., 1998); these can present as more obvious or subtle difficulties. Furthermore, those with the most pervasive or multi-factorial difficulties risk the poorest outcomes in later life (Aboagye 2001; Haynes and Naidoo, 1991; Johnson et al., 1999). Secondly, literacy difficulties are also extremely prevalent in those with persisting or resolved SLD (Snowling, et al., 2000; Stothard et al., 1998) have a strong tendency to endure into adulthood (Clegg et al. 2005; Felsenfeld et a., 1992). Thirdly, there is also a risk that individuals with long term SLD will experience falling nonverbal skills with age (Botting, 2005; Mawhood et al., 2005); however the relationship between language impairments and cognitive impairments is currently not well understood (Botting, 2006).

In the light of this chapter 3 will present a follow-up study of ex-pupils of a residential special school for severe and complex SLD, which aimed to investigate the themes outlined above. This was a retrospective study that utilised data collected at follow-up and archive data from the participants' childhood. Themes in the data could be examined across the cohort, in small subgroups or at a case study level. Siblings with no known histories of SLD were also recruited for comparative purposes.

Chapter 3 - The Ex-pupil Follow-up; Language, Literacy and Cognitive Ability

3.1 Aims and Research Questions

This chapter presents a retrospective follow-up study of adults with persistent, severe and complex SLD. It will examine their cognitive, language and literacy outcomes, map trajectories of these skills over the life span, and compare their performance on these to their siblings.

The research questions will be addressed by 3 separate studies and are as follows:

- Study 1: What are the ex-pupils' language, literacy and IQ outcomes in adulthood?
- Study 2: What can we learn from the longitudinal trajectories of these individual's cognitive, language and literacy difficulties?
- Study 3: How do the ex-pupils' psychometric outcomes compare to that of their nonlanguage impaired siblings?

3.2 Methodology

3.2.1 Design

a. Study 1

This used psychometric assessments to measure the ex-pupils cognitive, language and literacy outcomes at follow-up. The severity and pervasiveness of the ex-pupils' difficulties was identified. Ex-pupils were then organised into subgroups based on their profiles in adulthood.

b. Study 2

This collected archive data from when the ex-pupils were children and compare their speech and language profiles with their performance on psychometric tests in adulthood across specific domains: nonverbal ability; verbal ability; expressive language; receptive

language; reading ability, and spelling ability. Scores from both time periods were combined to map longitudinal trajectories over the lifespan. This was similar to Aboagye (2001).

c. Study 3

This recruited the siblings of 3 ex-pupils to act as non-language impaired comparisons; again this was similar to Clegg et al., (2005). Siblings were chosen because they shared the same family environment, upbringing and gene pool but did not attend a residential special school for SLD. The siblings and ex-pupils were compared on cognitive, language and literacy ability at a case study level.

3.2.2 Participants and the Recruitment Process

a. Studies 1 and 2

Due to the school's wide catchment area ex-pupils are spread throughout the UK. Recruiting participants for the project was a complex process. The last known addresses for ex-pupils were stored in a record book at the school. Seventy-two ex-pupils had already been sent letters from the school inviting them to participate in an earlier and related research project; 18 had responded positively and eventually 9 took part (Clegg, unpublished). This left another 9 ex-pupils who could potentially participate in the present project. These 9 ex-pupils were sent new letters from the school informing them about the present project and inviting them to take part. These letters also included an information sheet about the project, a response slip and stamped addressed envelope. Six of these 9 ex-pupils were successfully recruited to the present study, but the remaining 3 had moved away.

At the same time a different batch of letters were sent from the school to contact another 78 ex-pupils who had not been contacted for either study previously. These letters invited the ex-pupils to take part in the project and included the same information sheet, response slip and stamped addressed envelope. Eleven of these ex-pupils responded positively, however 1 of these eventually withdrew from the study, 1 could not be contacted again after the initial contact, and 1 could not agree on a time to meet. There were also a further 8 negative responses. This left 8 ex-pupils who could take part in the project. Thus, a cohort of 14 ex-pupils (6 male; 8 female) aged between 21 and 38 were recruited; these all attended the school between 1975 and 2004 and all had left the school before it opened its FE

department. The 2 oldest cohort members attended the school when the statutory leaving age was 12 rather than 16.

A final set of 12 letters were sent out to younger ex-pupils who had attended the FE department at the school. Again these explained the nature of the study and contained an information sheet, response form and stamped addressed envelope. As a result, three younger more ex-pupils were recruited (2 male; 1 female) aged between 18 and 19 who previously attended the school between 1998 and 2007. All attended the school's FE department for at least 1 academic year. The final number of participants seen in this study was 17 (8 male; 9 female). Table 3.1 presents descriptive information about each participant.

The overall response rate from the letters was low and therefore the rate of successful recruitment was poor. There are a number of potential reasons for this: letters were sent to ex-pupils' last known addresses and it was unknown how many still lived at or had source of contact at their last known addresses; ex-pupils may have lacked the motivation or interest to return the letters; ex-pupils could have negative feeling towards the school and therefore not wished to be involved, finally some ex-pupils may have felt that they wanted to move on from their time at the school. Thus, the recruitment method may have produced a selection bias as ex-pupils with more positive feelings towards their time at the school might have been more inclined to help. Also, as initial contact was made using last known addresses there was an inevitable bias towards younger ex-pupils as older ex-pupils were more likely to have moved away. In many cases the last known address was the ex-pupil's parental home and letters were passed on to ex-pupils. It should also be noted that the gender ratio in this project is not representative of the school as similar numbers of male and female ex-pupils were recruited; in reality many more males attend the school compared to females.

Table 3.1 - Descriptive information for ex-pupils

Ex-pupil	Gender	Age on Entry	Age on leaving	Age at follow-up	Residential	Medical problems	Diagnostic label on entry
Dennis+	Male	5;07	12;04	35;11	Initially then day pupil	Convulsion as infant	Severe speech deficit and expressive language delay
Robin	Male	11;05	16;03	27;09	Fortnightly	Glue ear	Speech and language difficulties
Julian	Male	6;11	16;05	23;11	Weekly	None reported	Severe speech and language disability
Toby	Male	11;10	16;09	23;04	Fortnightly	Dysarthria and hearing loss	Specific speech problems with some language involvement
Steven	Male	11;07	16;04	21;11	Weekly	Other not relevant	Severe and complex multifactorial language disorder
Darren	Male	8;8	16;5	21;10	Day pupil	Hearing loss	Speech and language difficulties
Jack*	Male	13	17;07	18;04	Day pupil	None reported	Receptive language impairment & social communication difficulties with characteristics of ASD
Lewis*	Male	12;02	19;00	19;07	Fortnightly	None reported	Severe dyspraxia affecting motor control & articulation.

+ Attended the school when the statutory leaving age was 12

* Also attended the FE provision at the school

Table 3.1 (continued) - Descriptive information for ex-pupils

Ex-pupil	Gender	Age on Entry	Age on leaving	Age at follow-up	Residential	Medical problems	Diagnostic label on entry
Jacky+	Female	6;05	12;06	38;02	Weekly	None reported	Developmental expressive dysphasia
Karen	Female	7;05	16;03	26;09	Fortnightly	None reported	Receptive and expressive language difficulties
Grace	Female	11;11	16;09	26;03	Fortnightly	None reported	Semantic pragmatic disorder
Fiona	Female	8;05	16;02	25;00	Weekly	None reported	Pervasive language difficulties
Freya	Female	n/a	n/a	24;10	Fortnightly	n/a	Semantic pragmatic disorder
Jodie	Female	5;08	15;11	24;06	Day pupil	None reported	Expressive language difficulties
Lauren	Female	7;09	n/a	23;02	Fortnightly	None reported	Severe speech disorder
Kirsten	Female	11;05	16;03	21;11	Day pupil	Glue ear	Severely delayed expressive language skills
Emma*	Female	9;10	19;01	19;08	Weekly then fortnightly	Near cot death at 10 weeks	Severe specific & complex speech and language disorder.

+ Attended the school when the statutory leaving age was 12

* Also attended the FE provision at the school

b. Study 3

Once each of the ex-pupil above had completed their part in the project they were asked if they would be willing to allow their sibling to participate in the project; this had to be a sibling with no known language impairments. If their response was positive they were asked to provide a contact address for their sibling or were given a letter to pass on to the sibling. These letters explained the nature of the project, that their relative had already taken part and contained an information sheet, response form and a stamped addressed envelope. Unfortunately, siblings also proved difficult to recruit and only 3 (1 male; 2 female) agreed to take part. Table 3.2 presents descriptive information for the ex-pupils' siblings.

The original purpose of the siblings had been to form a comparison group to control for the ex-pupils genetics, family background and upbringing (as in Clegg et al. 2005). However, this was not possible as numbers were so low. Siblings were difficult to recruit for a number of reasons: initial contact required the consent of the ex-pupil and not all ex-pupils were comfortable with the researcher meeting their siblings; not all ex-pupils still got along with their siblings; not all ex-pupils had an appropriate sibling for the researcher to contact, and not all siblings gave positive responses to the researchers invitation to take part in the project. The siblings were therefore used as comparisons at a case study level due to their limited number.

Ideally the sibling comparisons would not experience any SLD themselves. However there is a genetic risk they will also experience SLD, though to a lesser extent than the ex-pupils (Gopnik and Crago 1991; Lai et al., 2001; Viging et al., 2003). Such scenarios will be identified by the cognitive assessments and subsequent analysis. Siblings who had known SLD similar to the ex-pupils were not recruited to this comparison group.

Table 3.2 – Descriptive information for siblings.

Siblings	Gender	Ex-pupil	Sibling age at follow-up
Thomas	Male	Freya	29;05
Petra	Female	Robin	26;07
Emily	Female	Grace	24;06

3.2.3 Ethics

This study was approved by the University of Sheffield ethics committee in the department of HCS prior to any contact with participants (see appendix A4.1). Participants had the nature of the project explained to them before they agreed to take part. Participants were also given the opportunity to ask questions before and after taking part. They were made aware that: the researcher would have access to their school records if they agreed to participate; that anonymity would be maintained, and that they could withdraw at any time.

3.2.4 Materials

a. Studies 1 and 3: The Ex-pupils and Siblings

Ex-pupils and siblings were assessed on a range of psychometric assessments that assessed verbal and nonverbal IQ, grammatical understanding, receptive and expressive language, reading and spelling.

Wechsler Adult Intelligence Scales – Revised

The Wechsler Adult Intelligence Scales – Revised (WASI-R) comprises 4 subtests which measure verbal and nonverbal IQ. It has the advantage of being fast to administer and reliable in estimating general cognitive functions (Wechsler, 1981). The WASI-R was selected because it provides standardised scores of verbal and nonverbal IQ and can be used on adults up to the age of 89 years. In addition, many of the ex-pupils had Wechsler Intelligence Scale for Children (WISC) scores from childhood available in their archive files. The WISC is designed as the childhood equivalent to the WASI-R so scores can be compared. The shortened 4 subtest was favoured for its speed and ease of use as administering the full assessment battery (WASI full); the ex-pupil testing sessions were already time consuming.

Verbal IQ: this measure comprises of 2 subtests: vocabulary and similarities. The vocabulary subtest requires an individual to verbally define word meanings, and the similarities subtest requires an individual to verbally define what two words have in common. Items increase in difficulty as the subtests progress. Both tasks require word knowledge and measure verbal ability.

Nonverbal IQ: this measure comprises of 2 subtests: block design and matrix reasoning. The block design subtest requires an individual to copy a block pattern from a

picture book using six sided blocks (either 4 or 9 blocks depending on the difficulty level) as quickly as possible. The matrix reasoning subtest requires the individual to complete a picture sequence by selecting the appropriate picture from an array of 5. Items increase in difficulty as the subtests progress. Both measure nonverbal ability.

Test for Reception of Grammar: version 2

The Test for Reception of Grammar: version 2 (TROG-2) (Bishop, 2003) is a receptive language test that measures understanding of English grammatical contrasts marked by inflections, function words and word order. It assesses knowledge and understanding of both simple and complex grammatical structures. Participants are presented with 4 pictures and hear a sentence allowed by the researcher. Their test is to select the picture that corresponds to the sentence. Items increase in grammatical complexity.

The upper age limit of the TROG-2 is 12 years. However, as some ex-pupils still had SLD it was felt the TROG-2 would be able to highlight ex-pupils who were still experiencing receptive language and grammar. There are no other measures of receptive grammar that can measure performance for adults with developmental SLD that would have been more appropriate.

An alternative would have been to use assessments designed to measure language skills in adults with aphasia. This was decided against as these are designed to measure language impairments in adults with acquired difficulties such as traumatic brain injury or dementia rather than developmental language difficulties.

Expression, Reception and Recall of Narrative Instrument

The Expression, Reception and Recall of Narrative Instrument (ERRNI) provides measures of a person's expressive language and story comprehension (Bishop, 2004). The upper age limit on this is also 12 years. Again as some of the ex-pupil still had SLD it was felt this would still detect if they were still experiencing difficulties with narrative of other aspects assessed by the ERRNI.

Expressive story telling: participants are shown a series of pictures. Then they are asked to tell the story portrayed by the pictures in their own words. In the story the central character has a false belief. Narratives are then transcribed and scored according to the manual based on the number of elements mentioned from the pictures. The ERRNI is a

relatively flexible assessment of expressive language and it does not require specific vocabulary knowledge like the WASI.

Comprehension: A series of comprehension questions follow the narrative section of the ERRNI. These assess how well the individual has understood the themes in the main narrative. It also assesses whether the individual has understood the false belief element of the narrative.

Mean length of utterance (MLU): The MLU can be calculated from the narrative transcripts as an additional measure of expressive language. This is the average number of words used in each utterance. A higher MLU suggests the production of longer and potentially more complex utterances.

An audio recorder was also required to record the expressive elements of the ERRNI for later transcription and analysis.

The Wide Range Achievement Test

The Wide Range Achievement Test (WRAT-3) (Wilkinson, 1993) measures single word reading and spelling accuracy in adults. It was chosen as a reliable measure of adult literacy and is quick and easy to administer.

Reading: This measures single word reading accuracy. Participants are shown a list of single words and asked to read them as accurately as possible. All words are real English words and increase in difficulty as the assessment progresses. There are no time restrictions. The assessment is scored on number of items read accurately.

Spelling: This measured single word spelling ability. Participants listen to a list of words spoken by the tester and were asked to spell them as accurately as possible. All words are real English words. Each word is first read alone, then used in a sentence, and then repeated again. Items increase in difficulty as the assessment progresses and there are no time restrictions. The assessment is scored on number of items spelt accurately.

b. Study 2: The Archive

Sixteen of the 17 ex-pupils still had between 1 and 3 archive files held at the school; Freya's files were unfortunately not available. The archive files contained a wealth of information about the ex-pupils time at the school, for example: psychometric assessment scores; SLT reports; school reports; medical reports, and informal or anecdotal comments from parents and other professionals. These were accessed following the ex-pupils informed

consent. The archive data provided psychometric assessment scores that could be compared to the scores collected at follow-up.

3.2.5 Procedure

a. Study 1: The Ex-pupils

The first study measured the ex-pupils language, literacy and cognitive skills at follow-up. An appointment was arranged with each ex-pupil who had responded positively to the recruitment letters (the recruitment process was outlined in 3.2.2). As the ex-pupils lived all over the UK they could elect to meet the researcher in the Department of Human Communication Sciences at the University of Sheffield, at the school or in their own homes. A quiet room was found for the session to take place in each case.

At the start of each session the ex-pupil was given another copy of the information sheet sent out with the letters and a consent form to sign if they agreed to take part. An additional copy of the information sheet was provided at this point to make sure each ex-pupil had read and fully understood the information regarding the project. They were also given the opportunity to ask questions and were put at ease before the study began. In some cases the researcher was required to carefully read through the information sheet and consent form with the participant if their literacy difficulties prevented them from doing this themselves. Ex-pupils then completed the assessment battery outlined in 3.2.4. Testing sessions typically lasted about an hour and participants were offered breaks if they needed them. Once the session was complete the ex-pupils were given another opportunity to ask questions if they had any.

b. Study 2: The Archive

This study used archive data to compare the cognitive, language and literacy skills of each ex-pupil in childhood and adulthood, and map longitudinal trajectories (similar to Schery, 1985). First of all the ex-pupils were divided into subgroups based on their performance on psychometric testing at follow-up. This meant ex-pupils with similar outcomes in adulthood could have their childhood SLD compared retrospectively.

The archive data was a record from each ex-pupil's time at the school and had not been collected for the purpose of a follow-up study. The data available for each ex-pupil was inconsistent and varied in volume, quality and relevance to the project. The relevant

information needed to be identified (see table 3.3) and then coded (see table 3.4) to make it consistent so it could be compared to the psychometric scores collected at follow-up. The files were initially examined for assessment scores that provided evidence for the presence or absence of a history of specific difficulties in a series of domains for each ex-pupil: nonverbal IQ; verbal IQ; expressive language; receptive language; decoding, and spelling. Data was regarded as missing if no evidence for an ex-pupils' ability within a certain domain was available. Once identified this information was coded so that all the data was in the same format (see table 3.4). The coded scores identified the presence of a difficulty previously experienced by each ex-pupil in each domain, and whether the difficulty was mild or severe.

The coding system was also applied to the assessment scores collected at follow-up as the data from both time points was in a consistent format. This made comparisons between individual's cognitive profiles in childhood and adulthood possible. At follow-up only one score for nonverbal IQ, verbal IQ, decoding and spelling was used. Expressive and receptive language were both measured using assessments not standardised on adults and therefore two scores were used to identify the presence of a difficulty at follow-up; the lower of the two scores was taken to represent the presence of a difficulty in both cases. Expressive language ability was measured according to performance on the ERRNI expressive language and MLU scores, and receptive language was measured according to performance on the ERRNI receptive language and the TROG.

Firstly standard scores could not be used because the archive sometimes reported a range of different and non-comparable assessments to measure the same domain across the cohort. It also commonly provided age equivalent scores only. Secondly the ex-pupils were assessed at different ages in childhood and this was inconsistent between participants. The coding system help combat this by converting the data into a consistent format, and a broad time frame that covered the time the ex-pupils attended the school was adopted; however this compromised the richness of the data.

Table 3.3 - Assessments available in the archive.

Ex-pupil	Exp. Lang.	Recep. Lang.	Reading	Spelling	Nonverb IQ	Verbal IQ
Grace	CELF	CELF	NARA	Vernon	BAS	BAS
Steven	CELF	CELF	BAS	BAS	BAS	BAS
Darren	-	-	NARA	Vernon	-	-
Jack	Bus story	TROG	WORD	WORD	-	-
Dennis	-	-	NARA	Vernon	WISC	WISC
Freya	-	-	-	-	-	-
Robin	-	-	NARA	-	BAS	BAS
Jodie	Reynell	Reynell	NARA	Vernon	BAS	BAS
Karen	CELF	CELF	-	-	-	-
Jacky	Reynell	Reynell	Not listed	-	WPPSI	WPPSI
Julian	CELF	CELF	NARA	-	BAS	BAS
Kirsten	CELF	CELF	NARA	Schonell	BAS	BAS
Emma	CELF	CELF	NARA	Vernon	WISC-III	WISC-III
Lauren	-	-	Graded n.w. read.	-	-	-
Lewis	CELF	CELF	NARA	Vernon	BAS	BAS
Toby	CELF	CELF	WORD	WORD	WISC	WISC
Fiona	CELF	CELF	NARA	Vernon	BAS	BAS

Table 3.4 – The coding system used to make the archive data systematic.

Data type	Order of preference	No difficulty	Mild difficulties	Severe difficulties
Standard score from relevant assessment	1 st	A score over or equal to 85.	A score between 70 and 84 or equal to 70.	A score below 70.
Age equivalent score from relevant assessment	2 nd	Not more than 1 year behind CA.	Between 1 and 2 years behind CA.	More than 2 years behind CA.

c. Study 3: The Siblings

Once each ex-pupil had participated the researcher asked if it would be possible to invite a sibling to also take part. If the ex-pupil agreed they were either given letters to pass on or provided the researcher with a contact address so the sibling could be sent the letter. These letters explained the nature of the project, the fact that the ex-pupil had already participated and invited the sibling to take part. They also contained an information sheet, a response form and a stamped address envelope (this recruitment process was outlined in 3.2.2). An appointment was arranged with each of the positive respondents. As siblings lived

all over the UK, they were also given the choice to meet the researcher at the Department of Human Communication Sciences at the University of Sheffield, at the school or in their own homes. A quiet room was found for the session to take place in each case. The sibling sessions followed the same format as the ex-pupil sessions outlined above.

Originally the siblings had been recruited to act as a control group, however, due to the limited number successfully recruited, this was not possible. Instead the performance of three ex-pupil and sibling pairs were directly compared at a case study level. This analysis included 2 ex-pupils from the RD subgroup and one ex-pupil from the PD subgroup.

3.3 Results

3.3.1 Study 1: The Ex-pupils' Psychometric Outcomes

The psychometric assessment scores provided eight measures on different aspects of the ex-pupils cognitive, language, and literacy skill at follow-up. The standard scores were used to highlight the presence of a difficulty in each domain: no difficulty was determined by a standard score of 85 or above. A mild or residual difficulty was determined by a standard score between 84 and 70, this was equivalent to 1 S.D. from the mean. A severe difficulty was determined by a score of 69 or less, this is equivalent to 2 S.D or more below the mean. This system was also used to highlight individuals with pervasive difficulties where multiple domains were affected. Differences across the cohort were compared at an individual level and overall trends could be identified. In addition, the ex-pupils were also classified on the basis of their cognitive ability at follow-up.

Ex-pupil's psychometric scores are presented in table 3.5 with the presence and severity of difficulties highlighted. The scores indicate that only 1 ex-pupil, Grace, had resolved her SLD by follow-up. The remaining 16 ex-pupils all displayed some residual or persisting difficulties in one or more of the domains. All ex-pupils, apart from Grace, had literacy difficulties affecting one or both subtests of the WRAT and 10 of these were experiencing severe difficulties. Twelve ex-pupils had some level of difficulty with WASI verbal IQ and this was a severe difficulty in eight cases. Eight ex-pupils were experiencing difficulties with receptive grammar and this was severe in 2 cases. Ex-pupils experienced the least difficulty with the ERRNI; however 3 experienced difficulties with the narrative and comprehension questions and 7 experienced difficulties with MLU. Fiona, had no scores for the ERRNI as

she did not engage with the test during her session. In addition, eight ex-pupils were also experiencing nonverbal difficulties at follow-up and this was severe in six cases.

Table 3.6 compares the pervasiveness and severity of the ex-pupils SLD.

Pervasiveness is represented by the number of domains affected and severity by whether a domain was mildly or severely affected. In general, those who experienced the most pervasive difficulties also experienced the most severe difficulties in the domains effected (Emma, Lauren, Lewis and Toby). Those who only experienced mild difficulties never had more than 4 domains affected (e.g. Steven, Darren, Jack, Dennis and Freya). The most severe case (Toby) had 8 domains severely affected. Kirsten was an exception who had 6 domains affected, but 5 were only mildly affected.

Table 3.5 – Ex-pupils' assessment scores at follow-up.

Ex-pupil	Gender	Age	WASI n. verb	WASI verb	ERRNI Exp	ERRNI MLU	ERRNI recept	TROG	WRAT reading	WRAT spelling
Grace	Female	26;03	93	99	103	115	106	95	105	119
Steven	Male	21;11	127	97	109	117	106	99	82*	99
Darren	Male	21;10	93	85	100	126	116	95	77*	80*
Jack	Male	18;04	96	95	81*	72*	100	95	89	80*
Dennis	Male	35;11	79*	78*	114	93	100	95	92	70*
Robin	Male	27;09	109	70*	105	93	106	99	62**	67**
Freya	Female	24;10	93	72*	108	84*	85	90	79*	80*
Jodie	Female	24;06	99	71*	100	80*	106	90	52**	67**
Karen	Female	26;09	88	59**	105	105	113	81*	73**	67**
Jacky	Female	38;02	102	63**	-	-	106	76**	60**	58**
Julian	Male	23;11	84*	58**	111	103	113	818	54**	52**
Lauren	Female	23;02	64**	60**	116	87	113	81*	60**	60**
Kirsten	Female	21;11	57**	86	74*	74*	83	95	71*	80*
Emma	Female	19;08	66**	63**	97	77*	100	76*	61**	61**
Lewis	Male	19;07	67**	60**	95	69**	75*	67**	55**	58**
Toby	Male	23;04	65**	62**	75*	79*	72*	71*	47**	63**
Fiona	Female	25;00	57**	64**	-	-	-	55**	64**	65**

* Indicates a mild or residual difficulty or standard score between 70 and 84

** Indicates a severe difficulty or standard score less than 70.

- Missing data

Table 3.6 – The pervasiveness and severity of ex-pupils SLD.

Ex-pupil	Gender	Age	No. domains affected	Mild vs. Severe
Grace	Female	26;03	0	0;0
Steven	Male	21;11	1	1;0
Darren	Male	21;10	2	2;0
Jack	Male	18;04	3	3;0
Dennis	Male	35;11	3	3;0
Robin	Male	27;09	3	1;2
Freya	Female	24;10	4	4;0
Jodie	Female	24;06	4	2;2
Karen	Female	26;09	4	1;3
Jacky	Female	38;02	4*	1;3*
Julian	Male	23;11	5	2;3
Lauren	Female	23;02	5	0;5
Kirsten	Female	21;11	6	5;1
Emma	Female	19;08	6	2;4
Lewis	Male	19;07	7	1;6
Toby	Male	23;04	8	4;4
Fiona	Female	25;00	5*	0;5*

* Participant had some missing data so to numbers may have been higher had complete data sets been available.

3.3.2 Study 2: The Trajectories

The first stage of this analysis involved dividing the cohort into subgroups at follow-up. Although this cohort was small, it was still possible to divide them into 3 subgroups based on their assessment scores at follow-up. These 3 subgroups are presented in table 3.7. Once the subgroups were established it was possible to compare the subgroup's archive data retrospectively to identify any emerging themes from childhood.

a. The Resolved/Residual Difficulties Subgroup

The resolved or residual difficulties subgroup (RD) was the highest performing subgroup and contained those individuals who experienced the least difficulties at follow-up. Importantly, none experienced any severe difficulties in any domain, however most experienced some mild persisting difficulties; five experienced some mild literacy difficulties, two showed mild difficulties WASI verbal IQ, and two also showed mild difficulties on either the ERRNI or WASI nonverbal IQ tests. Between zero and four domains were effected in any one individual. Overall these ex-pupils experienced few difficulties as adults although some mild difficulties remained.

b. The Persisting Difficulties Subgroup

The persisting difficulties subgroup (PD) also experienced more severe or pervasive levels of persisting language or literacy difficulties than those in the RD subgroup. These ex-pupils all experienced severe literacy difficulties affecting both decoding and spelling, as well as mild or severe difficulties in verbal IQ. Four also experienced further difficulties in other domains. Importantly none experienced severe difficulties in nonverbal ability, however Julian did fall one IQ point shy of having nonverbal abilities in the normal range. Overall the PD subgroup experienced more severe and pervasive difficulties than the RD subgroup but these were still mostly specific to language and literacy.

c. The Complex Difficulties Subgroup

The complex difficulties subgroup (CD) experienced the most severe and pervasive difficulties in adulthood. The defining feature of this subgroup was severe difficulties with nonverbal IQ. Most were also experiencing severe difficulties with decoding, spelling and verbal IQ, mild or severe difficulties with the TROG, and three also experienced difficulties with the ERRNI. Fiona may also have experienced difficulties with the ERRNI however no data was available for her as she could not begin to engage with the test.

Kirsten was difficult to place as she was the only ex-pupil to be experiencing severe difficulties with nonverbal ability in the absence of any severe language or literacy difficulties, although she still have mild/residual difficulties in 5 of the language/literacy domains. She was placed in the CD subgroup as she had severe difficulties with nonverbal IQ, a characteristic not present in the PD or RD subgroups. In addition, her difficulties were still more pervasive than the RD and PD subgroups even though they were less severe than the other CD subgroup members. Overall these individuals had the most pervasive difficulties. These profiles suggested more general difficulties, in addition to SLD and literacy difficulties, as nonverbal IQ was also impaired.

d. Mapping the Trajectories

Having established the 3 subgroups, this analysis aimed to map trajectories showing the progression of nonverbal IQ, verbal IQ, expressive language, receptive language, decoding and spelling ability from childhood to adulthood. The results are presented in figures 3.1-6. Each line depicts an ex-pupil's movement, if any, between having severe,

Table 3.7 – Ex-pupil subgroups

Ex-pupil	Age	Gender	WASI n. verb	WASI verb	ERRNI Exp	ERRNI MLU	ERRNI Recept	TROG	WRAT reading	WRAT spelling	
RD subgroup	Grace	26;03	Female	93	99	103	115	106	95	105	119
	Steven	21;11	Male	127	97	109	117	106	99	82*	99
	Darren	21;10	Male	93	85	100	126	116	95	77*	80*
	Jack	18;04	Male	96	95	81*	72*	100	95	89	80*
	Dennis	35;11	Male	79*	78*	114	93	100	95	92	70*
	Freya	24;10	Female	93	72*	108	84*	85	90	79*	80*
Median	23;07		93	90	105.5	104	103	95	85.5	80*	
PD subgroup	Robin	27;09	Male	109	70*	105	93	106	99	62**	67**
	Jodie	24;06	Female	99	71*	100	80*	106	90	52**	67**
	Karen	26;09	Female	88	59**	105	105	113	81*	73**	67**
	Jacky	38;02	Female	102	63**	-	-	106	76**	60**	58**
	Julian	23;11	Male	84*	58**	111	103	113	818	54**	52**
Median	26;09		99	63**	105	98	106	81*	60**	67**	
CD subgroup	Kirsten	21;11	Female	57**	86	74*	74*	83	95	71*	80*
	Emma	19;08	Female	66**	63**	97	77*	100	76*	61**	61**
	Lauren	23;02	Female	64**	60**	116	87	113	81*	60**	60**
	Lewis	19;07	Male	67**	60**	95	69**	75*	67**	55**	58**
	Toby	23;04	Male	65**	62**	75*	79*	72*	71*	47**	63**
	Fiona	25;00	Female	57**	64**	-	-	-	55**	64**	65**
Median	22;06		64.5**	63.5**	95	74*	83	73.5*	60.5**	62**	

* Indicates a mild or residual difficulty or standard score between 70 and 84

** Indicates a severe difficulty or standard score less than 70.

mild or no difficulties in each domain. It should be noted that the lines have been displaced for visibility purposes. The colours depict the subgroup the ex-pupil belonged to at follow-up; green for RD, yellow for PD and red for CD.

e. Expressive Language

Figure 3.1 presents the trajectories for expressive language. All the ex-pupils with complete data had histories of severe expressive language difficulties apart from Grace (RD subgroup), who had mild difficulties. All ex-pupils with complete data showed an improvement in this domain by follow-up, with the exception of Lewis (CD subgroup). Jack and Freya were the only RD subgroup members to show mild expressive language difficulties at follow-up; notably, Jack's difficulties had been severe in childhood. Lauren was the only CD subgroup member to show no expressive language difficulties at follow-up; however her childhood was missing in this domain so it was unclear if she experienced difficulties with expressive language in the past. All other CD subgroup members showed persisting mild or severe difficulties. Three PD subgroup members showed improvements from childhood;

Karen and Julian had resolved their difficulties, and Jodie had mild difficulties. Overall, most ex-pupils started with severe difficulties in childhood and, managed to fully or partially resolve these by adulthood.

f. Receptive Language

Figure 3.2 presents the trajectories for receptive language. All ex-pupils with complete data had histories of severe receptive language difficulties apart from Grace (RD subgroup), Jodie (PD subgroup) and Fiona (CD subgroup); the majority of ex-pupils still showed an improvement with time; apart from Fiona who showed a severe drop in receptive language and Lewis whose severe difficulties persisted. It is unclear what caused Fiona's apparent drop in performance. However archive suggested she went on to develop receptive language difficulties in later life; a previous area of strength (see appendix A1.6).

All members of the RD subgroup resolved their difficulties and all members of the PD subgroup showed a mild improvement apart from Jodie who had no difficulties at either time. Three members of the CD subgroup showed a mild improvement (Kirsten, Emma and Fiona) and Lauren also presented with mild difficulties at follow-up. Fiona and Lewis both presented with severe difficulties at follow-up and Fiona had experienced a severe drop in ability since childhood. The trajectories for expressive and receptive language both suggest a trend that difficulties improve or resolve with time unless the individuals experience pervasive difficulties at follow-up.

g. Decoding

Figure 3.3 presents the trajectories for decoding. All ex-pupils with complete data had histories of severe difficulties with decoding in childhood, apart from Grace (RD subgroup) who had no history of difficulties with decoding¹. Three RD subgroup members presented with no decoding difficulties at follow-up (Grace, Jack and Dennis), the remaining RD subgroup members showed mild difficulties (Steven, Darren and Freya) as did Karen (PD subgroup) and Kirsten (CD subgroup). Kirsten was the only ex-pupil outside the RD subgroup to show an improvement with decoding at follow-up.

¹ Although, according to the archive, she did have a hyperlexic profile as a child. This is associated with difficulties with reading comprehension rather than decoding (see appendix case reported).

Figure 3.1 - Trajectories for Expressive language

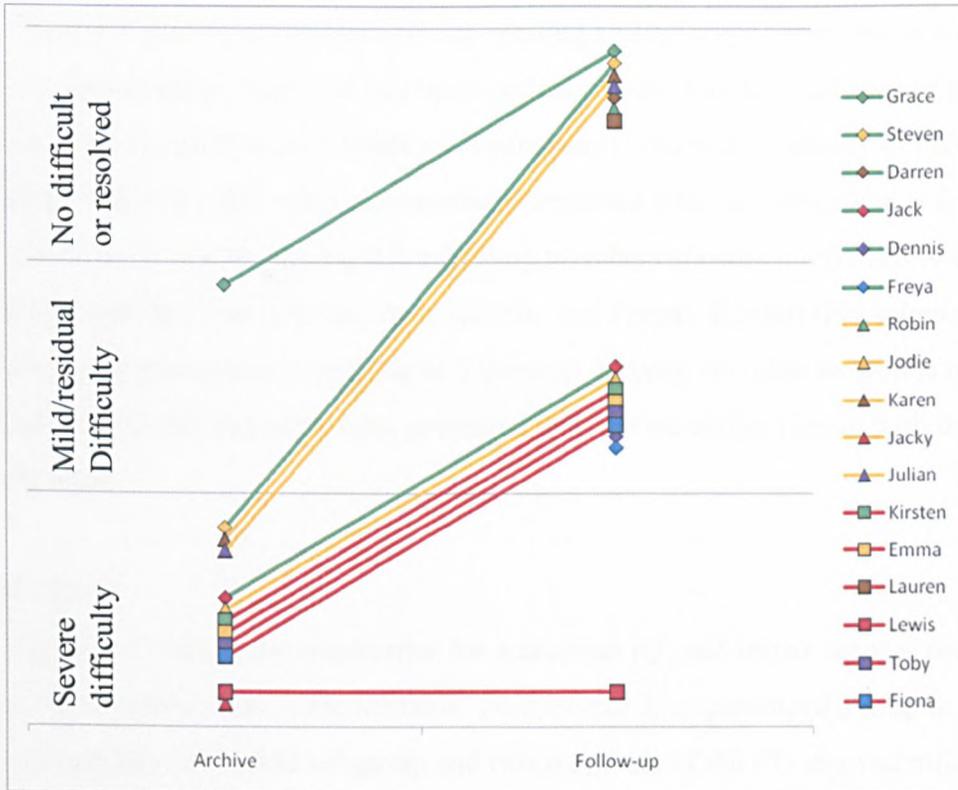
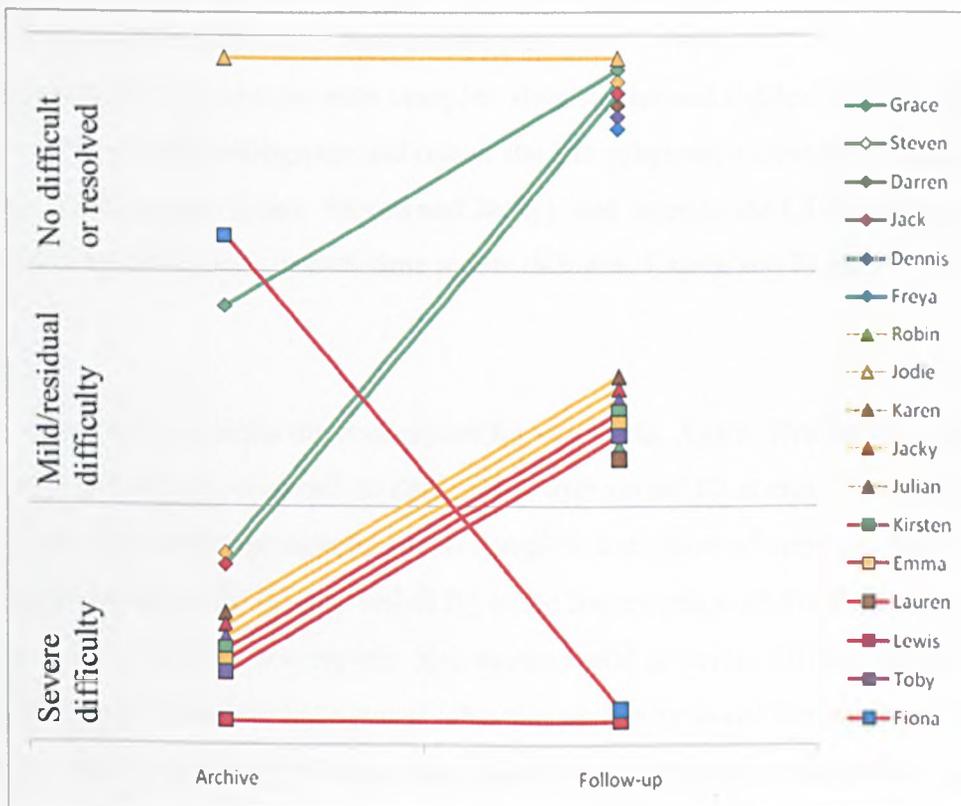


Figure 3.2 - Trajectories for Receptive language



h. Spelling

Figure 3.4 present the trajectories for spelling ability; these were similar to the trajectories for decoding. Again all ex-pupils with complete data had histories of severe difficulties, with the exception of Grace (RD subgroup) who had no history of difficulties with spelling. Only two RD subgroup members presented with no difficulties at follow-up (Grace and Steven). The remaining RD subgroup members showed a mild level of improvement with spelling (Darren, Jack, Dennis, and Freya). Kirsten (PD subgroup) also showed a mild improvement in spelling at follow-up. Finally, all other ex-pupils in the PD and CD subgroups with complete data presented with severe difficulties in both domains at both time points.

i. Nonverbal IQ

Figure 3.5 present the trajectories for nonverbal IQ, and shows some scores were stable over time while others were unstable. Four ex-pupils experienced a drop in nonverbal ability: one member of the RD subgroup and two members of the PD showed mild drops in nonverbal ability (Dennis, Jodie and Julian), and one CD subgroup member showed a severe drop (Toby). However, another PD subgroup member (Robin) showed the opposite pattern and resolved his mild difficulties from childhood.

The remaining ex-pupils with complete data all showed stable nonverbal IQ scores with time; two of the RD subgroup and one of the PD subgroup's nonverbal IQ scores stayed within the normal range (Grace, Steven and Jacky), and three of the CD subgroup all showed severe persisting difficulties at both time points (Kirsten, Emma and Fiona).

j. Verbal IQ

Figure 3.6 presents the trajectories for verbal IQ. Again, Grace (RD subgroup) was the only ex-pupil that experienced no difficulties with verbal IQ at either time point. The remaining two RD subgroup members with complete data showed opposing trajectories; Dennis experienced a mild drop in verbal IQ while Steven resolved his mild difficulties. All the remaining ex-pupils with complete data showed mild or severe difficulties at both time points apart from Kirsten (CD subgroup) who remarkably resolved her severe childhood difficulties. Jacky and Robin (PD subgroup) also showed opposing trajectories; Jacky's mild difficulties became severe in adulthood and Robin's severe difficulties became mild. All the remaining cohort members showed a stable profile over time; Jodie (PD subgroup) had mild

Figure 3.3 - Trajectories for Decoding Ability

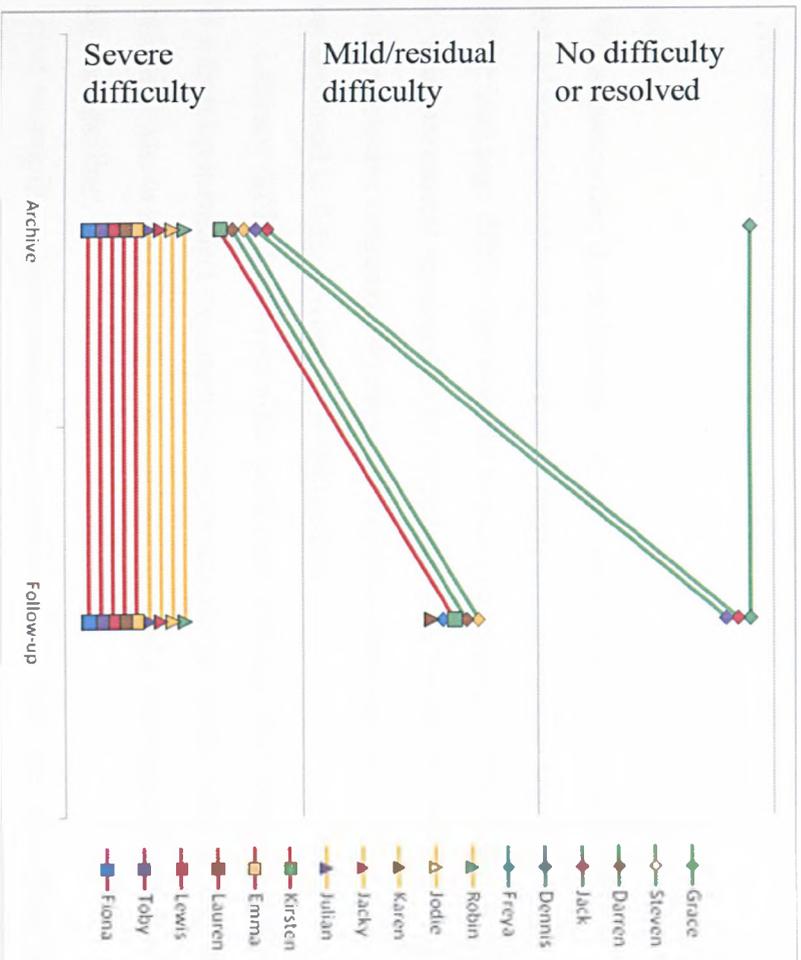
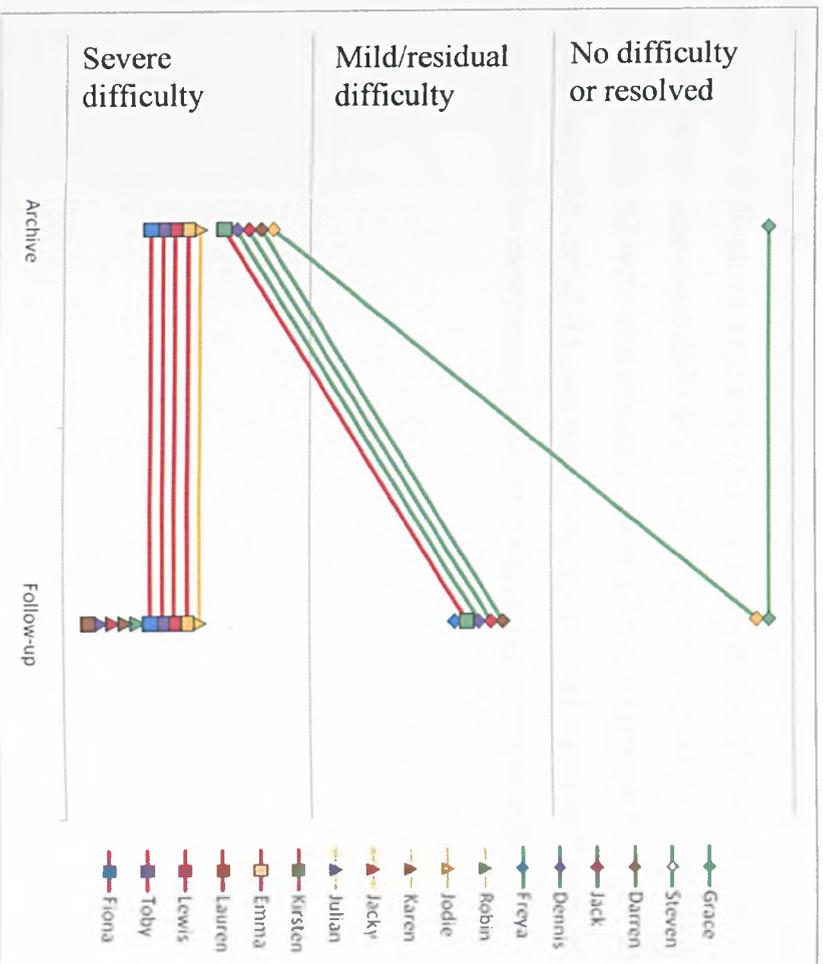


Figure 3.4 - Trajectories for Spelling Ability



difficulties and the other four had severe and persistent difficulties; Julian (PD subgroup), Emma, Toby and Fiona (CD subgroup).

k. Summary

When comparing the trajectories for the two language measures, there appeared to be a stronger relationship between ex-pupils' subgroup membership and improvement over time for receptive language difficulties than for expressive language difficulties. In other words the level of improvement appeared to be interchangeable for the RD and PD subgroups in the domain of expressive language. Whereas for receptive language difficulties only the RD subgroup appeared to fully resolve their difficulties.

Literacy difficulties were more persistent with age than language difficulties and only RD subgroup members experienced improvements in literacy ability, with the exception of Kirsten who was in the CD subgroup and also showed a mild improvement in both decoding and spelling.

Four ex-pupils experienced a drop in nonverbal IQ with age; these were spread across the subgroups, however the most severe drop was experienced by a CD subgroup member. Six other cohort members did not experience changes in nonverbal IQ: those in the RD and PD subgroups remained in the normal range and those in the CD subgroup consistently experienced severe difficulties. One PD subgroup member also showed a gain in nonverbal ability suggesting in some cases difficulties with nonverbal IQ can be resolved. The trajectories for verbal IQ were also unstable across all the subgroups: five ex-pupils experienced changes in verbal IQ over time; two experienced losses and three experienced gains. Six ex-pupils also experienced consistent verbal IQ scores with age.

Figure 3.5 – Trajectories for nonverbal IQ

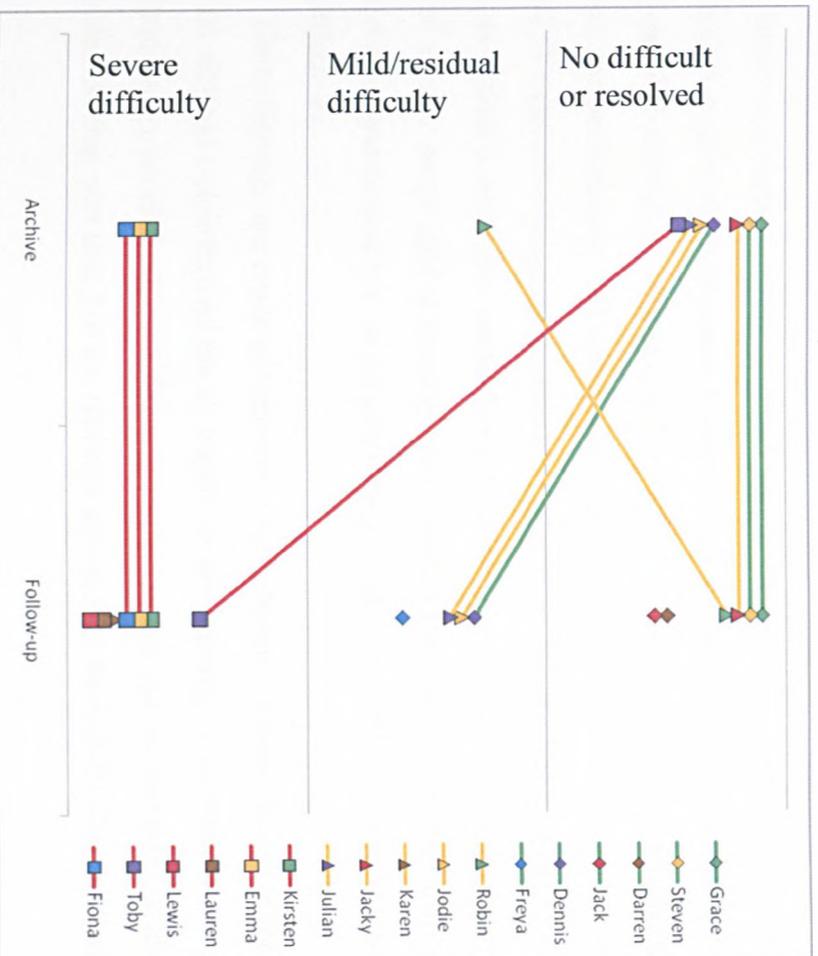
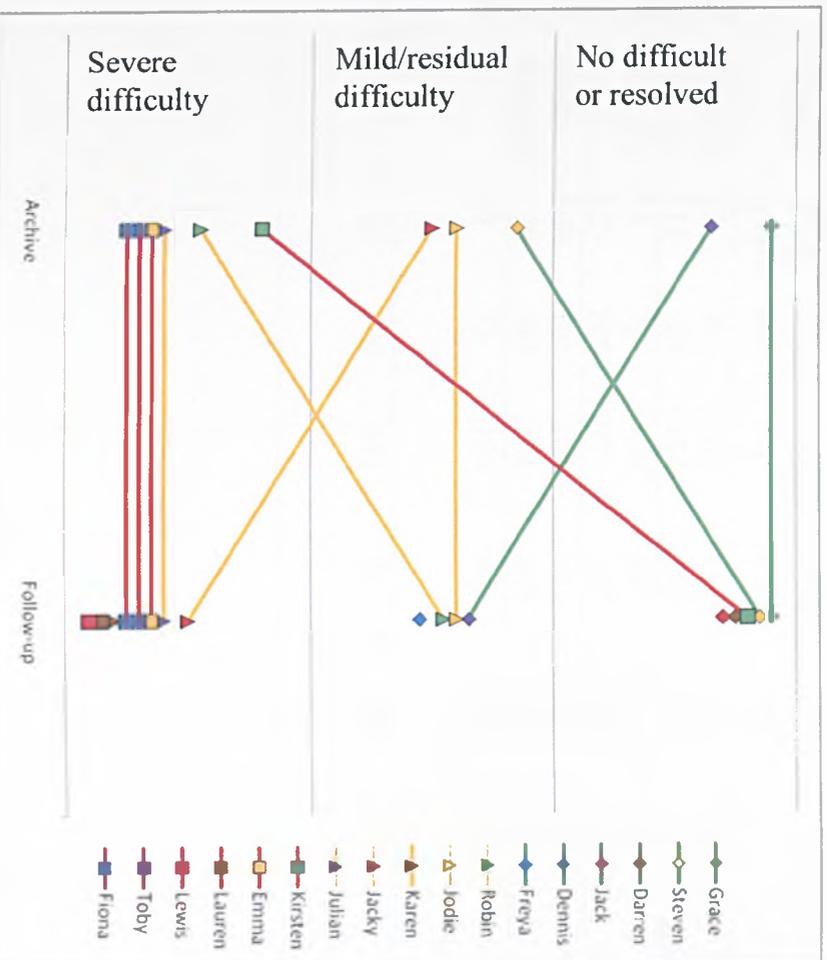


Figure 3.6 – Trajectories for Verbal IQ



3.3.3 Study 3: The Siblings

Direct comparisons of the standard and median scores suggest a trend that siblings outperformed ex-pupils on all domains. Grace was the most able member of the cohort and the only ex-pupil to display no apparent difficulties according to the assessment battery.

However, her performance was substantially poorer than her sister's on verbal and nonverbal IQ, ERRNI expressive language and reading. However, her spelling and MLU were similar to her sisters. Robin's sister also outperformed him on all the assessments; however she also appeared to have some mild difficulties with verbal IQ and MLU herself. Lastly, Freya's brother also outperformed her, on all assessments apart from MLU where he also appeared to have difficulties.

These findings are crude as numbers were extremely limited however they suggest a trend that siblings outperformed the ex-pupils on the majority of assessments even when ex-pupils had shown no difficulties within a specific domain. An undesirable but also not unexpected finding was that 2 of the siblings appeared to have difficulties of their own.

Table 3.8 – The ex-pupil and sibling comparisons

Ex-pupil	Age	Gender	WASI n.verb	WASI verb	ERRNI exp	ERRNI MLU	ERRNI recept	TROG	WRAT reading	WRAT spelling
Grace	26;03	Female	93	99	103	115	106	95	105	119
Emily	24;06	Female	111	121	112	115	126	104	120	118
Freya	24;10	Female	93	72*	108	84*	85	90	79*	80*
Thomas	29;05	Male	123	100	97	75*	126	104	116	104
Robin	27;09	Male	109	70*	105	93	106	99	62**	67**
Petra	26;07	Female	100	79*	121	81*	119	99	86	104
Ex-pupil Median scores	26;03		93	72	105	93	106	95	79	80
Sibling Median scores	26;07		111	100	112	81	126	104	116	104

3.4 Discussion

3.4.1 Study 1: What are the ex-pupils' language, literacy and IQ outcomes in adulthood?

a. Language Difficulties

The ex-pupils all had histories of severe and complex SLD that extended beyond 5;6 years. It would therefore be predicted that all the ex-pupils would experience persisting language difficulties in adulthood (Bishop and Adams, 1990; Nathan et al., 2004a). While this was the case for most ex-pupils at follow-up, three had managed to resolve all their language difficulties. There are two possible explanations for this unexpected finding. The first is that some individuals with SLD may be able to resolve their childhood language difficulties with the right intervention, even in cases where their initial difficulties were severe (Dockrell and Lindsay, 2008). All the ex-pupils had received intensive and specialist provision for SLD at the school for several years during childhood (see table 3.1 for entry and leaving ages for the school); this could have provided enough support for three ex-pupils to resolve their language difficulties. Notably, Haynes and Naidoo (1991) and Aboagye (2001) also reported that individuals who experienced a similar education to the ex-pupils in the present study go on to experience heterogeneous language outcomes; in some cases their ex-pupils also showed mild or residual language difficulties as adults. Furthermore it is also important to acknowledge the severity of the ex-pupils childhood language difficulties. The school specifically caters for severe and complex cases of SLD (The school's prospectus summer, 2008), and therefore it is likely that their childhood SLD would have been more severe than other cohorts where persisting SLD were reported in adolescence and adulthood (e.g. Conti-Ramsden and Durkin, 2008; Stothard et al., 1998).

However, the second explanation is that the assessment battery used at follow-up was not sensitive enough to identify persisting difficulties in those three cohort members. Two of the assessments used (ERRNI and TROG) are not designed for use with adults and thus maybe unable to detect more subtle difficulties in older participants. However, as the WASI-R is designed to measure verbal IQ in adults and also failed to detect any language difficulties in these individuals, these unexpected findings are less likely to be due to the assessment battery. However the WASI-R does measure different aspects of language skills than the ERRNI and the TROG.

b. Literacy Difficulties

Literacy outcomes were poorer than language outcomes, and all the ex-pupils experienced persistent literacy difficulties at follow-up; apart from Grace who had no history of difficulties with spelling or decoding. In general, the ex-pupils with pervasive difficulties experienced greater difficulties with reading and spelling than those with resolved or residual language difficulties. This pattern of result was similar to Stothard et al., (1998) and Snowling, et al., (2000) who both found persistent literacy difficulties in adolescents with histories of SLI. This was even the case for those who had their SLI resolved by 5;6 years, though individuals with persistent-SLI experienced more severe literacy difficulties than those with resolved-SLI. These results also support Johnson's et al (1999) findings that adults with pervasive difficulties also experience the poorest literacy outcomes, however there were no obvious differences between those experiencing receptive or expressive language difficulties in the ex-pupil cohort at follow-up. Nathan, et al. (2004a; b) also reported that those with articulation difficulties have fewer literacy difficulties than those with more complex SLD; however articulation difficulties are likely to cause difficulties with spelling. The present study did not measure articulation difficulties at follow-up, however no real differences between reading and spelling difficulties were apparent. Overall, it is known that individuals with a history of SLD are at high risk of severe, persistent and lifelong literacy difficulties (Aboagye, 2001; Clegg et al., 2005; Dockrell et al., 2009; Felsenfeld et al., 1992; Leitão and Fletcher, 2004; Snowling, et al., 2000). The present findings show this is also the case for the ex-pupils.

c. Nonverbal Difficulties

Cognitive impairments occurred amongst the ex-pupils with the most severe and pervasive difficulties; this was similar to previous research findings by Catts et al. (2002). Decoding, spelling and verbal IQ were also severely impaired in these cases. The exception was Kirsten who had severe cognitive difficulties accompanied with mild literacy and mild expressive language difficulties only. There was also a trend that only those who experienced nonverbal difficulties also experienced difficulties with narrative. Wetherall et al., (2007) previously reported similar findings for adolescence with SLI who experienced a drop nonverbal IQ with age.

Botting (2006) proposed that there is a relationship between language and nonverbal IQ that is not yet fully understood, and that cognitive impairments often occur with language

difficulties. These findings suggest that those who experienced the most severe and pervasive SLD in adulthood are likely to also experience difficulties with nonverbal ability.

Furthermore there appeared to be a relationship where only those with nonverbal difficulties appeared to experience difficulties with narrative.

d. Conclusions from Study 1

The results suggest a trend that individuals who experience the most severe difficulties also experience the most pervasive difficulties; this supports previous findings that have reported this pattern of results (Aboagye, 2001; Haynes and Naidoo, 1991; Johnson et al., 1999). Literacy difficulties were the most prevalent type of difficulty in this cohort and these were more severe in pervasive cases. Verbal IQ was the second most frequently effected domain: this was sometimes affected in individuals with mild or residual difficulties (RD subgroup) and always affected for individuals with more severe difficulties² (PD and CD subgroups). The ex-pupils with the most severe and pervasive SLD at follow-up risked impairments with nonverbal IQ and narrative (CD subgroup).

3.4.2 Study 2: What can we learn from mapping the longitudinal trajectories of these individual's cognitive, language and literacy difficulties?

The critical age hypothesis states that SLD will persist if not resolved by 5;6 years (Bishop and Edmundson, 1990; Nathan et al., 2004a). However, the findings from study 1 suggest more potential for some individuals to resolve their SLD than this (see 3.3.1). Study 2 adds further weight to this as the longitudinal trajectories show that several ex-pupils were able to fully or partially resolve their difficulties having experienced severe SLD in childhood. The ex-pupils with the most pervasive difficulties continued to experience the poorest outcomes longitudinally. This is similar to the findings by Johnson et al. (1999) and suggests a relationship between pervasive and severe difficulties that causes a high risk of persistent difficulties over the life span.

In addition, the trajectories also suggest a trend that receptive language difficulties have a greater chance of being resolved if the individual's difficulties are not pervasive, though this did not appear to be the case for expressive language difficulties. Two ex-pupils with comprehension difficulties in childhood were able to resolve their language difficulties

² With the exception of Kirsten.

in the absence of other pervasive difficulties, although some literacy difficulties still remained (Steven and Jack). This goes against the findings by Johnson et al. (1999) who found comprehension difficulties to be more difficult to resolve than expressive language difficulties. This could reflect a difference between the two cohorts as Jack and Steven resolved their comprehension difficulties in the absence of other pervasive difficulties. Furthermore this finding was at a case study level and Johnson et al. (1999) examined outcomes at a group level.

Study 1 also showed literacy difficulties to be more prevalent in the ex-pupil cohort at follow-up than language difficulties. Study 2 suggested that severe childhood literacy difficulties are harder to resolve than severe language difficulties. Furthermore only 1 ex-pupil with severe difficulties showed any improvement with literacy since childhood; this was Kirsten whose profile was atypical at follow-up because her greatest difficulties were with nonverbal IQ rather than language. All the other ex-pupils with severe or pervasive difficulties at follow-up experienced lifelong severe difficulties with literacy.

Four ex-pupils experienced a drop in nonverbal ability with age. Falling nonverbal IQ did not appear to be related to pervasiveness as drops were experienced in all three subgroups; however the ex-pupil who experienced the most severe drop belonged to the CD subgroup. Six other ex-pupils experienced stable nonverbal ability over time; three of these had been experiencing stable, severe and persisting nonverbal IQ difficulties since childhood (all CD subgroup members). The other 3 ex-pupils with stable nonverbal IQ scores had always scored in the normal range and all belonged to the RD subgroup. There was one ex-pupil who also experienced a gain in nonverbal ability.

These findings therefore support the idea that individuals with persisting SLD risk a drop with nonverbal IQ with age (Botting et al., 2005; Conti-Ramsden et al., 2001; Mawhood et al., 2000; Tomblin et al., 1992). They also suggest a trend that individuals with the most pervasive language difficulties are likely to also experience difficulties with nonverbal IQ, however these may be present from childhood and to not necessarily develop with age. This also supports the idea that cognitive impairments are likely to occur alongside language impairments rather than the difficulties being discrete (Botting, 2006; Viging et al. 2003). However, further conclusions on the risk factors that can lead an individual to experience a drop in nonverbal IQ is still unclear. In addition, the impact of the intensive provision the ex-pupils received at the school is also unknown; it may have prevented more ex-pupils from experiencing greater losses.

3.4.3 Study 3: How do the ex-pupils' psychometric outcomes compare to that of their nonlanguage impaired siblings?

This analysis showed siblings outperformed ex-pupils on the majority of assessments, suggesting that severe and complex childhood SLD also cause persisting difficulties with language, literacy and cognitive ability when controlling for genetics and family environment; this agrees with finding by Clegg et al., (2005). Notably, the siblings were a relatively high performing set of individuals as all three scored about the normal range in at least one domain. This could have skewed the results as ex-pupils were being compared to high scoring individuals rather than the normal distribution. However, these siblings still shared the same genetics and family environment as their sibling with SLD.

Although the study aimed to recruit siblings with no histories of SLD two siblings also presented with mild difficulties. This is not surprising given the evidence for heritability (Barry et al., 2007; Gopnik and Crago, 1991; Lai et al., 2001; Tallal et al., 2001). Robin's sister also experienced difficulties but these were not as severe as Robin's, and she still experienced a better outcome overall. Freya's brother's difficulties may need further investigation as he scored more poorly on MLU compared to his other assessments. Even so, each sibling still outperformed their ex-pupil pair on the majority of formal assessment suggesting that their language impairments are less.

Part 2

Psychosocial Outcomes and the Impact of SLD on Families

Section 2 of this thesis examines and identifies the psychosocial outcomes for individuals with severe and persistent SLD and the impact SLD have on families over the course of the life span. It comprises 3 chapters. Chapter 4 is a literature review that examines the psychosocial impact of longstanding SLD have on those who experience them and their families, and the issues surrounding quality of life in research methods.

Chapter 5 will present the second study in this thesis. This used semi-structured interviews to examine the ex-pupils psychosocial outcomes, their perceptions of their own quality of life, and their experiences at the school. Secondly, it also examined the relationship between the psychometric data presented in chapter 3 and psychosocial outcomes identify any emerging themes. Thirdly the ex-pupils' psychosocial outcomes were compared to their nonlanguage impaired siblings who controlled for genetics, upbringing and family environment.

Chapter 6 will present the third study in this thesis. This used semi-structured interviews to examine the views and experiences of the ex-pupils parents and siblings having had a member of their family with severe and complex SLD who attended the school. It also aimed to clarify the ex-pupils' reports in chapter 5 through the use of a proxy measurement provided by the parents.

Chapter 4 -The Quality of Life and Psychosocial Outcomes for Individuals with Persisting Speech and Language Difficulties and the Impact on Family Life: A Literature Review

4.1 Quality of Life

4.1.1 Defining Quality of Life

Quality of life (QoL) is a multi-dimensional construct with multiple approaches (Diener and Suh, 1997). The World Health Organisation (WHO) defined QoL as:

“an individuals’ perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment”.

(WHO QoL Assessment Group, 1993). There are a broad range of concepts and approaches associated with QoL. For example, Brock (1993) defined three ways of defining the concept of QoL:

- religious or philosophical ideals, for example the belief that a good life is dictated by religious values and principles
- personal satisfaction and preferences, for example QoL can be determined by an individual’s ability to obtain what they desire
- personal experiences, e.g. how much a person experiences feelings of joy, pleasure and contentment

Eiser and Morse (2001) proposed that a good QoL occurs when the hopes of an individual are matched and fulfilled by experience, and defined a range of contexts for what QoL can refer to:

- synonymous with happiness
- symbolise material wealth
- relationships with others
- economic factors

Multiple contexts led the authors to propose different approaches to examining QoL:

- The economic approach which refers to an individual's acquired wealth.
- The sociological approach which refers to an individual's perception of personal circumstances and relationships with others.
- The psychological approach which refers to self-esteem, happiness and fulfilment.
- The medical approach which refers to quality of medical care and quantity of life. This final approach is often referred to as health related QoL (HRQoL).

The range of concepts and approaches to QoL pose a problem for researchers, as the principle of QoL can vary and different researchers may use the term with reference to the different topics above.

4.1.2 The Psychology of Quality of Life

Theories have been put forward for the psychological processes that generate QoL. Cummins (2000) proposed that QoL is determined by levels of self-esteem and control. Self-esteem has been shown to be a strong predictor of life satisfaction (Diener and Diener, 1995), therefore high levels of self-esteem are likely to facilitate QoL. This is thought to be especially true of Western cultures. Most recently, Marriage and Cummins (2004) argued the case for a link between primary control³ and perceived well-being. Therefore, when an individual has more direct control over their situation, they are more likely to experience higher levels of perceived well-being and therefore QoL. In situations where primary control is not possible, an individual can use internal control⁴ or secondary control to reduce the negative psychosocial impact of uncontrollable events (Band and Weisz, 1990). Again in this instance, an individual with greater internal control will experience greater personal well-being.

Albrecht and Devlieger (1999) put forward a framework for QoL. They proposed that a good QoL involves establishing and maintaining a sense of balance between the body, mind and spirit within the individual's social context and environment. They argue that high levels of perceived QoL can still be achieved in situations where an external observer may assume a

³ Primary control refers to control over existing physical, social or behavioural realities, (Schulz and Decker, 1985).

⁴ Internal control refers to control over the perception or internal feelings over existing realities.

less than desirable standard of living; e.g. a person living with a disability. An individual's perception of QoL can also change over time if internal standards, values and conceptualisation of QoL shift. Shifts can occur if an individual's life circumstances change (Spranger and Schwartz, 1999).

4.1.3 Measuring Quality of Life

The literature has debated how best to measure QoL. A range of measuring tools have been devised that reflect the different definitions and contexts for QoL (as discussed 4.1.1). Traditionally, standardised objective instruments have been used. Typically these target and evaluate QoL in terms of specific life domains and produce ordinal measurements. QoL assessments include the *Health Utilities Index* (HUI) (Feeny, Torrance and Furlong, 1996; Furlong, Feeny, Torrance and Barr, 2001), the *Quality of Well Being Scale* (QWB) (Sieber, Groessl, David, Ganitats and Kaplan, 2004) and the TNO-AZL⁵ *Pre-school Children's Quality of Life-questionnaire* (TAPQOL) (Fekkes et al., 2000). The largest and most influential contribution was put forward by the World Health Organisation (WHO) (WHOQOL Group, 1995; 1998). This started as a project that aimed to identify the different elements that underlie QoL cross-culturally. Four broad, universally accepted domains were identified as relevant to QoL: physical health; psychological well-being; social relationships, and environment (WHOQOL, 1999). This led to the formulation of the WHOQOL-100 and WHOQOL-BREF, which measure QoL according to these domains.

However, Avis and Smith (1998) criticised conventional measurements of QoL as they can be confounded by concealment and social desirability. There is contention as to whether QoL should refer to objective standards determined by a person's circumstances and environment, or to an individual's perceived satisfaction levels (Hendry and McVittie, 2004). Objective measures of QoL (for example, measurements of QoL according to wealth, standard of living, health or personal achievement) have been criticised by authors who favour more subjective approaches to QoL. Carr, Gibson, and Robinson (2001) criticised objective assessment methods as they carry the risk of being confounded by the participant's life expectations and cannot measure QoL according to individual perception. Perceptions of QoL can vary between different individuals, so participants with different expectations will

⁵ Netherlands Organisation for Applied Scientific Research Academic Medical Centre.

report different QoL in the same circumstances. Hendry and McVittie (2004) argue that subjective measurements (for example, perceived satisfaction) are favourable because they:

- can account for context, experiences and perceptions at an individual level.
- have no definite criteria, such as status within a life domain, for example marital status, employment status, income and education
- can allow for ambivalence which rigid measures may not
- do not require normative data

Carr and Higginson (2001) made the case for patient-centred QoL measures and argued they are not affected by the same restrictions as conventional objective assessment methods. They put forward the *Schedule for the Evaluation of Individualised Quality of Life* (SEIQOL). In this, individuals are asked to specify five areas of life that are important to them and rate their current status in each of these to provide a quantitative account of an individual's perceived QoL. Similarly, Records, Tomblin and Freese, (1992) also devised a tool to measure subjective QoL; the *Subjective Well-Being* measure.

Subjective measurements of QoL can also be criticised for lacking clearly defined mechanisms and being vulnerable to researcher and participant biases at the data collection and analysis phases (Allan, 2003). Furthermore, they can be confounded by concealment and social desirability in the same way as objective methods (Avis and Smith, 1998). Finally, Diener and Suh (1997) argued the case for using subjective well-being measures as a means to evaluating and extending the findings from objective measures of QoL.

4.1.4 The Relationship Between Quality of Life and Disabilities

Individuals with disabilities report mixed experiences of QoL. However, there is mounting evidence to suggest that individuals with disabilities do not necessarily experience a poorer level of QoL than individuals without disabilities. Albercht and Devlieger (1999) proposed that many individuals with persisting disabilities or long-term illnesses reported a good or excellent level of QoL even though external observers may assume a less desirable level of QoL. They found that 54.3% of those with a moderate to serious disability reported high levels of QoL compared with 80-85% of people without disabilities. This suggested a discrepancy between objective QoL and QoL as perceived by the participants. Similarly, Shelly et al. (2008) argued that levels of QoL are more dependent on psychosocial aspects of life than functional limitations. Therefore an individual with a severe or long term disability

will still experience good levels of QoL if their perceived QoL is high. Shelly et al. (2008) reasoned that as QoL is often confused with function this often leads to the expectation that an individual with a disability will experience a poorer QoL than an individual without a disability. For example: Klugman and Ross (2002) reported a poor QoL for individuals with multiple sclerosis based on the functional limitations of the illness alone. They did not measure the participants' perceived QoL and therefore it is not known how these participants perceived their QoL. In comparison, O'Dickinson et al. (2007) reported that children aged 8-12 with cerebral palsy perceived similar levels of perceived QoL to children without disabilities, and thus both groups of children perceived their QoL as high. Shelly et al. (2008) provided further evidence to support this. They also examined QoL in children with cerebral palsy and found that while they commonly reported negative feelings towards the physical and functional aspects of their disabilities, this did not prevent them from achieving positive scores for the psychosocial aspects of QoL. This was also highlighted by Rosenbaum, Livingston, Palisano, Galuppi and Russell (2007) when they compared different assessment tools measuring the level of functioning and QoL in young people with cerebral palsy; a weak relationship between the functioning and perception was found, with functioning accounting for little of the variance in QoL between individuals.

In conclusion, QoL can be measured in terms of function or perception; however there are cases where these measures can produce opposing results. This can be especially true of those with disabilities. Both measurements are valid when examining QoL and arguably the results from both types of measurement can be triangulated to build the most complete assessment of QoL.

4.2 The Impact of Speech and Language Difficulties on Psychosocial Functioning and Quality of Life

Speech and language skills are an important prerequisite for psychosocial functioning, psychosocial outcomes and QoL (Clegg, 2006). The literature has reported mixed psychosocial outcomes and QoL for adults with childhood histories of SLD. The following sections will discuss the impact of long-term SLD on psychosocial functioning and QoL.

4.2.1 Educational Achievement

a. Formal Qualifications

Children who enter school with SLD will be disadvantaged as they will lack the building blocks necessary to develop the literacy and numeracy skills required to access the curriculum (Dockrell and Lindsay, 2008). Children with persistent SLD are likely to perform more poorly at school than their typically developing peers (Glogowska et al, 2006; Nathan et al, 2004b). The literature has reported mixed but predominantly negative findings for educational attainment and gains in formal qualifications for adults with persistent SLD (Clegg et al., 2005; Felsenfeld et al., 1994; Young et al., 2002).

Several studies have reported that adolescents with histories of SLD experience less academic success than those with no such history. For example, Young et al. (2002) followed-up the speech and language impaired cohort originally identified at 5 years of age by Beitchman et al. (1986) when they were 19 years of age. When nonverbal IQ was controlled they found that those with language impairments experienced greater difficulties academically than those with a history of speech difficulties only who performed at a similar level to controls with no histories of SLD.

Snowling, Adams, Bishop and Stothard, (2001) highlighted the potential impact of early SLD on performance in examinations during adolescence. They followed-up the cohort originally identified by Bishop and Edmundson (1987) aged 4 years when they were 16-17 years of age. They found a direct relationship between an individual's history of SLD and the number and grade of GCSEs they obtained. Those with resolved-SLI were less successful than those with no history of SLD, however they did perform better than those with persisting-SLI and general delay. Haynes and Naidoo (1991) interviewed 34 ex-pupils (26 males and 8 females) aged 18 years from the same school as the one now used in this thesis before it opened its secondary education department. Thirteen ex-pupils completed the interviews over the telephone, one by letter. A parent of the ex-pupil completed a telephone interview in 15 cases and both the parent and the ex-pupil contributed information in 6 cases. Twenty-two ex-pupils had gained CSEs; five had gained O levels; 3 had gained A levels, and thirteen had no formal qualifications. Aboagye (2001) also reported some formal qualifications amongst her four case studies. These adults (aged 33;2-44;1) with childhood histories of severe and complex SLD who attended school similar to the one the ex-pupils attended in this thesis. Furthermore, she noted a relationship where those with more complex and pervasive SLD also experienced the poorest academic outcomes. Felsenfeld, Broen, and

McGue, (1992) also reported lower grades for adults with histories of SLD and found they had completed fewer years of formal education compared with nonlanguage impaired controls.

Conversely, a relatively recent wave of studies has reported mixed findings. Dockrell, Lindsay, Palikara and Cullen (2007) found 54 adolescents with SLD experienced greater relative success at the end of compulsory education than previous reports (Aboagye, 2001; Haynes and Naidoo, 1991; Snowling et al., 2001); the majority gained a mean of five GCSEs at grades D-G and 13% gained five GCSEs at grades A*-C. However, only 3% gained both Mathematics and English A*-C. However, high levels of individual differences were also found and a minority of participants had limited academic success. Notably, most of these individuals attended mainstream schools and could therefore have had less severe SLD than the cohorts seen in the other studies; the participants seen by Aboagye (2001) and Haynes and Naidoo (1991) were all ex-pupils of residential special schools for SLD.

Durkin, Simkin, Knox and Conti-Ramsden (2009) followed-up 120 adolescents with SLI and 121 typically developing controls aged 17;4; originally identified at 7 years (Conti-Ramsden et al, 1997). At follow-up 75% were in special school while 25% were in mainstream school; this meant any differences between those in mainstream and special school could be examined in more detail. Their findings were similar to Snowling et al. (2001): those with resolved SLI performed worse than typically developing individuals but better than those with persisting SLI. Also, those in mainstream school gained more qualifications than those in special school. This was a likely consequence of those in special school having more severe difficulties and a difference in policy for exam entry between the types of school.

Durkin et al. (2009) also found that the SLI and typically developing cohorts both reported the same satisfaction levels with their academic outcomes even though the cohort with SLI performed more poorly than their typically developing peers. Similar levels of satisfaction for lower academic achievement in adults with SLD were also reported by Felsenfeld, Broen and McGue (1994). However, Durkin et al. (2009) suggested that the findings could indicate that individuals with SLI had lower expectations for themselves and therefore experienced high satisfaction levels.

b. Post-16 education

Outcomes at post-16 have been mixed but predominantly poor. Haynes and Naidoo (1991) reported that almost two thirds of their group went on to post-16 education; eight attended Technical colleges; 3 attended University; and 7 attended youth training schemes. In addition, twelve followed vocational courses: e.g. brick laying. Howlin et al. (2000) documented the educational achievements of the DLD ($n = 20$) and autism ($n = 19$) cohorts in their early 20's; originally identified by Bartak et al. (1975). Findings were relatively poor; none of the DLD cohort had gained post-16 qualifications, although six of the young adults with autism had. This was despite the fact the group with autism appeared to have more difficulties with cognitive tasks (Mawhood et al., 2000). However, a more positive outcome was reported for the DLD cohort when Clegg et al. (2005) saw them in their mid 30's; six had gone on to gain post-16 qualifications since the earlier studies. Records et al. (1992) reported that fewer young adults aged 17-25 years with SLD were enrolled in post-16 educational placements compared to nonlanguage impaired age matched controls.

However, again other studies have reported more positive success at post-16. Durkin et al., (2009) reported that adolescents with SLD are just as likely to pursue post-16 education as those with no history of SLD; however success in chosen post-16 placements can be more heterogeneous and a minority of individuals will still experience limited academic success at post-16. Dockrell et al., (2007) also reported most of the individuals they saw went on to post-16 placements. A minority of participants sort employment rather than FE after compulsory education, these tended to be those with the poorest academic success.

c. Social Difficulties and Victimisation

The educational attainment of children with SLD can be further hindered by the behavioural problems as these children are more likely to be disruptive in the school environment and social difficulties inhibit their ability to access education (Lindsey and Dockrell, 2000). Children and adolescents with SLD may have social and behavioural problems. Conti-Ramsden and Botting (2004) followed up 242 adolescents aged 14 years who were part of the cohort originally identified at age 7 by Conti-Ramsden et al. (1997). They found that adolescents with SLD were at greater risk of bullying, victimisation and social isolation than peers without SLD. They followed-up 242 of the original cohort and concluded that this may be the result of poorer social skills and behavioural problems. In turn this increased the likelihood that they were singled out by their nonlanguage impaired peers.

Huaqing Qi and Kiaser (2004) integrated the behavioural characteristics of 32 children aged between 3-4 years with SLD. These children exhibited poorer social skills and more behavioural problems than children with typical language development.

Children 10-13 years with persisting SLD have also been shown to have a more negative self perception of their competence at school, peer group acceptance and behaviour compared to their typically developing peers and younger children with similar difficulties according to self report questionnaires (Jerome, Fujiki, Brinton and James, 2002). Overall, the evidence suggests children with SLD are at risk of experiencing serious disadvantages at school compared to their peers.

4.2.2 Levels of Independence

SLD and associated literacy difficulties in childhood have been shown to be related to the level of independent functioning achieved in adolescence. Conti-Ramsden and Durkin (2008) followed-up 120 adolescents aged 16 years with a history of SLI; this cohort was originally identified at 7 years old (Conti-Ramsden et al. 1997). According to both parental and self reports many were less independent than their non-language impaired peers. Levels of independence were found to be associated with levels of language and literacy performance. Furthermore, individuals with histories of SLD are susceptible to poorer employment outcomes, often related as a result of poorer academic achievement (Snowling et al., 2001). In turn, poorer employment outcomes affect financial outcomes which are necessary for to independent and autonomous living (Clegg et al, 2005).

a. Employment outcomes

The potential consequences of poorer academic achievement are severe, as it can limit subsequent opportunities for FE and employment (Conti-Ramsden et al., 2008; Snowling et al., 2001). Follow-up studies have reported limited success with employment for adults with childhood histories of SLD (Billstedt et al., 2005). Howlin et al. (2000) reported poor employment outcomes for the cohorts with both DLD and autism in the early 20s follow-up of the cohorts identified by Bartak et al. (1975). However, employment outcomes were worse for the autism cohort as none of 19 individuals followed-up were in employment compared with 12 of the 20 members DLD cohort who were employed. This was despite greater academic success amongst the autism cohort (previously reported in 4.2.1). When Clegg et al.

(2005) revisited the DLD cohort in their mid 30's only 10 were still employed, however only 17 of the original cohort were followed-up at this time. They also reported unstable employment histories among the cohort, with some having been dismissed from work in the past. The same was not reported for a sibling control group. Similar, results were found by Hornby and Kidd (2001). They followed up a cohort of 24 young people (aged 18-25, mean age 22 years) with moderate learning difficulties and reported that 17 of this cohort were unemployed⁶.

In contrast, Aboagye (2001) found all four of her case studies had gained full time employment, though one had become unemployed five months prior to follow-up. Felsenfeld et al. (1994) found no differences in levels of employment for individuals with a history of SLD and nonlanguage impaired controls. However, those with SLD typically had less skilled jobs than controls. Records et al., (1992) also found similar levels of employment and income for adults with SLD compared with nonlanguage impaired controls. However, the control group were more commonly in part-time employment than the SLD group, albeit on the same income. This may have been because more of the controls were attending further or higher education and therefore not taken up full time employment.

Haynes and Naidoo (1991) also examined the employment outcomes for their ex-pupil cohort at 18 years of age and found mixed results. Twenty-five were employed including two who were in part time employment. However, five participants were unemployed, and 8 who were employed had experienced periods of unemployment in the past lasting up to 18 months. Six ex-pupils also expressed dissatisfaction with their jobs. The remaining ex-pupils were still in further or higher education at the time of follow-up.

Howlin, Alcock and Burkin (2005) demonstrated the success of a supported employment scheme that helped adults with a clinical diagnosis of Autism into work. One hundred and ninety-two clients of the project were found work over an 8-year period; this was a success rate of 68%. The majority of jobs were permanent and in administrative, technical or computing work. High satisfaction levels were reported by the clients in the scheme. The research highlighted how beneficial supported employment can be; however running the scheme came at a high financial cost (Mawhood and Howlin, 1999).

⁶ However, 2 of these 17 had found their own ways to earn money and demonstrated entrepreneurial skills. One kept ferrets to catch rabbits which he sold to the local butcher, and the other bought old bicycles cheaply to repair and sell for a profit.

b. Financial difficulties

Little is known about the economic impact of SLD on the individuals who experience them. Difficulties gaining and maintaining employment are likely to cause financial difficulties. Clegg and Henderson (1999) described the case of TH, a 34-year-old male with a history of DLD, who experienced severe financial difficulties, caused by difficulties gaining employment. TH had only had one paid job for two years since the age of 17, and therefore relied on his family to support him. Clegg et al. (2005) reported similar findings in their study of the 17 DLD cohort members, 11 had received welfare benefits and all of the seven adults who were living independently were living in accommodation rented from local authorities. In such cases, the estimated financial and economic cost of supporting individuals with SLD over their lifespan is high (Clegg and Henderson, 1999; Mawhood and Howlin, 1999). Expenses included funding for specialist educational provision in childhood, and housing and living benefits in adulthood, and is most costly in cases where the individual struggles to become financially independent. Clegg and Henderson (1999) estimated benefits claimed for DLD individuals to be around £66,000 over their lifespan compared with £23,000 for sibling controls.

c. Independent living

Levels of independent living have typically been reported to be poor for adults with childhood histories of SLD or DLD (Clegg et al., 2005; Haynes and Naidoo, 1991; Howlin, 2000) though not in all cases (Aboagye, 2001). Billstedt et al. (2005), reported very poor outcomes for a cohort of 108 adolescents and adults aged 17-40 years (mean 25;5 years) with autism⁷ and reported that only four were living independently; three of these led isolated lives and only one lived with a partner. This demonstrated very low rates of independent living, with the overwhelming majority of the cohort either living with their parents or in care homes. Howlin et al. (2000) also reported poor levels of independent living in their DLD cohort. Six of the 20 adults with DLD and 3 of the 19 members of the autism cohort were living independently or semi-independently in their mid 20's. A marginal improvement was shown when Clegg et al. (2005) revisited 17 of the DLD cohort in their mid 30s and found that seven were living independently, though the other 10 were either still living with their parents or in supported accommodation. Only 1 of the sibling control group was still living

⁷ Notably this was a group of adults with very severe difficulties and by the authors own admission were not representative of individuals with a diagnosis of autism or Aspergers syndrome more generally.

with their parents and this was because they were still in full time education. Haynes and Naidoo (1991) found 29 of their cohort to still be living with their parents; two of these had tried independent living but returned how because they were lonely and for financial reasons.

Again, not all studies have reported negative findings. For example, when Aboagye (2001) interviewed her four case studies regarding their life experiences, all reported they were living independently. Records et al. (1992) also reported positive findings for independent living; there were no significant differences in living situation between their cohort of young adults with SLD and aged matched nonlanguage impaired controls. In addition, both reported the same levels of perceived happiness with their living.

4.2.3 Personal Lives

a. Friendships

Adults with persisting SLD are also at risk of social difficulties and isolation. For example, Howlin et al. (2000) reported that the cohorts with DLD and autism⁸ had difficulties with friendships, however the autism cohort experienced greater difficulties overall. Clegg et al. (2005) reported mixed findings for the DLD cohort when followed-up in their mid 30s; ten had a normal number of acquaintances while the remaining seven still experienced difficulties. Overall, the DLD cohort still had poorer social outcomes when compared with the sibling control group. Johnson et al. (1999) also found that the adults with histories of SLI had persisting difficulties with friendships in later life. Beitchman et al., (2001) also reported on this cohort at the same time and found that individuals with language disorders displayed more antisocial personality traits than those with no history of language disorders. Haynes and Naidoo (1991) also found friendships to be an area of difficulty for their ex-pupil cohort; although 20 reported going out regularly with friend, 14 reported going out rarely and 9 only had friends within the family. Only 7 had friends of the opposite sex. This was also highlighted an area of specific concern for the ex-pupils' parents who felt their children risked social isolation. Furthermore, parents also felt the boarding element of special schooling had a negative impact on family life and that ex-pupils were often immature for their age.

Again, in contrast, Aboagye (2001) described more positive social outcomes for her case studies. All four cases were members of social clubs or societies or had hobbies that

⁸ Both cohorts also had difficulties forming peer relationships in adolescence (Cantwell et al., 1989).

surrounded their social lives. This meant they had a group of friends they could meet regularly at their chosen organisation. They reported high satisfaction levels with their social lives. Hornby and Kidd (2001) also reported low levels of friendship groups for adults (aged 18-25, mean age 22 years) with moderate learning difficulties, most of whom reported having either one or no friends.

Durkin and Conti-Ramsden (2007) found heterogeneous outcomes for social relationships for individuals with SLI in a cohort aged 16 years ($n = 120$). Furthermore they found that language ability accounted for some of the variance in outcome when other factors known to influence friendship quality were controlled for; e.g. behavioural problems. These findings lead them to conclude that SLI is a risk factor in poorer friendship development.

Overall, the research findings suggest that individuals with long term SLD risk poorer levels of friendships in adulthood compared to those with no such histories; this is especially the case for those with more severe SLD.

b. Relationships

The literature has tended to report negative outcomes for relationships in adults with SLD. Clegg et al. (2005) found only two of the 17 members of the DLD cohort were married when they were seen in their mid-30s; though this number had dropped from four marriages since their mid 20s as two had divorced (Howlin et al., 2000). Three of the DLD group had children by the time of the mid 30's follow-up. Billstedt et al. (2005) found 1 member of their cohort of 108 (aged 17-40) had a partner whom he lived with. Hornby and Kidd (2001) also found few relationships amongst their cohort of individuals with moderate learning difficulties; one was living with her partner but none of the cohort were married. Two participants also had children but they did not live with them.

Once again, Aboagye (2001) reported relatively positive findings compared to the larger group studies. Three of her four case studies were married and the other had a partner. Two of these relationships were described as happy, and two of these individuals had two children each, but there was growing concern that three out of these four children now had SLD of their own. In addition, Records et al. (1992) found no differences in the relationship between their cohort of young adults with SLD and nonlanguage impaired controls. However, the finding that the majority of participants in this study were single may merely reflect their age: all were in their early 20s.

4.2.4 Personal Awareness of Speech Language Difficulties

Few studies have measured the personal perceptions of adults and young people with SLD. Palikara et al., (2009) followed-up 54 young adults with histories of SLI during their first year of post-16 education. When interviewed, the majority of participants showed an awareness of their difficulties and could provide an accurate representation of their needs. Furthermore participants viewed the support they received in a positive light. Haynes and Naidoo (1991) found that only 3 of their cases were felt to no longer have any difficulties as perceived by their either themselves or their parents; however the authors anecdotally reported that one of these individuals was perceived to be difficult to understand by the research who interviewed them. The participant did not perceive this as problem. In general perceptions of persisting difficulties were high in this cohort and it was felt this could be partly due to a heightened self-awareness and self-criticism. It was also noted that parents tended to report more perceived difficulties than the ex-pupils.

In a similar study, Owen, Hayett and Roulstone (2004) interviewed 12 children (age range 6-11 years) with communication difficulties about their views of SLT. The children reported an awareness of expressive language difficulties and social difficulties. They also expressed concerns about friendships and academic achievement in the future. In general, the children in this study did not feel stigmatised by support and were accepting of it.

4.3 Family Experiences of Speech and Language Difficulties

4.3.1 Caring for Children with Speech and Language Difficulties

A recent wave of studies has examined the impact of SLD on the family environment. Parents are likely to become aware of their children's SLD in early development; this could either be the result of noticeable developmental differences compared with siblings or peers, or because a professional has identified them (Glogowska, 2002). Furthermore, parents have been shown to be able to accurately predict developmental difficulties in young children prior to referral for SLT (Rannard, Lyons and Glenn, 2004; 2005); sometimes in cases where a professional has not already identified a problem (Tervo, 2005). Rannard, et al., (2004; 2005) interviewed 40 parents of children with SLD (aged 6;10-16-16;9) who had been integrated into mainstream education from language units. These parents reported an awareness of their child's SLD from an early age and were often the first to become aware of their children's difficulties.

In early childhood, parents often try to make sense of their children's SLD as soon as they start to suspect something is wrong. Parents are also likely to have their own ideas about their causes; for example, medical reasons, the parents' own actions, family background, and qualities internal to the children. Some parents may report feelings of guilt and responsibility for their children's SLD despite the fact that they are unlikely to be the cause (Glogowska, 2002). In cases, where early SLD do not resolve parents typically become concerned for the future especially with regard to beginning school (Woodcock and Tregaskis, 2008).

If SLD continue to persist into later life then parental concerns will also continue, though the nature of the concerns change. Pratt et al., (2006) recruited the families of 52 of the SLI cohort (mean age 14;3 years), who were originally identified by Conti-Ramsden et al., (1997) when they were 7 years of age. Mothers expressed serious and wide ranging concerns regarding their children's personal characteristics and social skills but generally not their SLD directly. The number or type of concerns held also bore no apparent relationship with the young person's difficulties. In a similar study, Conti-Ramsden, Botting and Durkin, (2008) recruited parents of 120 adolescents (aged 16 years) with SLI and 118 typically developing adolescents (aged 16 years) originally identified by Conti-Ramsden et al. (1997). The parents completed a questionnaire about the concerns for their children. Parents of the SLI cohort expressed more negative expectations for their children's psychosocial outcomes than parents to typically developing adolescents. Parents of both sets of individuals expressed concerns towards the future, employment opportunities, and socialising with other people, however the parents of the SLD cohort did so to a greater extent. In addition, the parents of the individuals with SLD had further concerns that their children could be taken advantage of or bullied at school, that there was a lack of community resources to meet their needs, and that they may experience restricted work choices in the future. Antle, Mills, Steel, Kalnins and Rossen (2007) interviewed the parents of 15 adolescents aged 11-16 with physical disabilities (e.g. cerebral palsy; spina bifida and muscular dystrophy). These parents also expressed concerns for the future and how their children would progress.

Lastly, Glogowska, (2002) also found that access to information regarding children's SLD is important to parents as it helps them to understand and make sense of their children's difficulties. Importance is also placed on there being a need for greater level of knowledge of SLD in the public domain.

4.3.2 Raising children with Speech and Language Difficulties

A wealth of studies have reported that both mothers and fathers of children with disabilities experience greater levels of stress (Mugno, Ruta, D'Arrigo and Mazzone, 2007; Dyson, 1997; Floyd and Gallagher 1997; Ricci and Hodapp 2003) and depression (Hastings, 2003) than parents of typically developing children who do not. The level of parental stress also increases if the child has behavioural problems, but does not necessarily correlate with the level of disability experienced by the child directly. For example, Baker, McIntyre, Blacher, Crnic, Edelbrock and Low (2003) showed there was a direct relationship between parental stress levels and children's behavioural difficulties in families of children with developmental delay (aged 36-48 months). As children with SLD are more likely to develop behavioural problems than typically developing children (as discussed in **Error! Reference source not found.**) then this also suggests further risks of increased stressed levels for parents to children with. Bringing up a child with SLD has also been shown to have a negative effect on parents' social lives as caring for the child can be demanding on the parent's time (Emerson, 2003).

In addition, caring for a child with disabilities is likely to be more time consuming, expensive, and physically exhausting than caring for children without disabilities. The burden of responsibility will also increase with the number of other children in the family (Green, 2007). A child's care may require a rigid routine (Mulroy Robertson, Aiberti, Leonard and Bower, 2008), which can impact on employment (Green, 2007). Parents, especially mothers, of children with disabilities work fewer hours due to the demands of caring for the child (Seltzer, Greenberg, Floyd, Pettee and Hong, 2001) and have diminished financial resources (Mulroy et al., 2008). Thus, caring for children with any disability is also likely to come at a financial cost to families.

Furthermore, children are more likely to experience SLD among families with low SES who are likely to have more limited financial means putting these children and families at greater disadvantage (Emerson, 2003). For example, Glogowska (2002) reported the case of a mother who was upset because she felt the SLT who was supporting her child expected her to be able to afford to pay for materials that she was unable to afford to help supplement the SLT sessions.

If a child's SLD persist then parental responsibility and the provision of continuing care are likely to continue even into adulthood (Floyd and Gallagher, 1997). As parents get older they may also become more fearful for the future when they are no longer around to

care for their child (Grant, Ramcharan and Flynn 2007). There is a likelihood that families will still be supporting their children financially in adulthood (Clegg and Henderson, 1999).

However, not all research findings have reported negative effects of bringing up a child with disabilities (Hastings and Taunt, 2002) and raising a child with SLD can also make families stronger (Green, 2007). Parents are likely to experience an initial period of emotional distress at the time of the child's birth or diagnosis but after this parents typically adjust to the challenges of raising their child successfully (Flaherty and Glidden, 2000; Green, 2007). Conti-Ramsden et al., (2008) found that while families of children with SLD are likely to experience more stress relative to families of children without SLD, they are also able to adapt and cope. Grant et al., (2007) provide further support for this in a review paper that examined how families raising children with disabilities cope. They proposed that families are more resilient when they are able to find meaning in their situation and are able to embrace it, achieve a sense of control, and maintain their personal values and goals. Families who successfully achieve and maintain these goals are more positive, and demonstrate more resilience in the face of adversity when caring for a child with disabilities. Finally, Seltzer et al., (2001) also suggest that families that have supported an individual whose difficulties persist into adulthood may be more successful at supporting their children's needs because they will have developed more stable patterns of coping as a result of prolonged experience supporting their child.

4.3.3 Parental Experiences of Support Services

Parents ultimately make the decision whether to take their child to SLT and what type of intervention to follow (Marshall, Goldbart and Phillips, 2007). Parents of children with persisting SLD are usually keen for their child to be referred to SLT so they can gain the benefits (Glogowska, 2002), but may also try their own methods to help support their children before seeing relevant professionals (Marshall et al., 2007).

Glogowska and Campbell (2000) compared the views of parents of preschool children who either received SLT immediately with those who would receive SLT the following year; watchful waiting. In general, parents preferred for their children to receive SLT as soon as possible and felt their children's progress might be compromised if they did not. However, parents who favoured watchful waiting did so because they felt their children would find SLT more beneficial when they were older. Enthusiasm for SLT dwindled when parents felt it was

not beneficial. Parents also preferred to have their role made clear and to have a part in the SLT process. Overall the study showed parents viewed SLT positively. This was accompanied by feelings of relief that their child was going to receive support and having a more active role in supporting their child. In addition, Woodcock and Tregaskis (2008) reported that parents valued well informed professionals who spend time with them and were able to relate to them and their children.

However, Paradice and Adewusi (2002) highlighted that the referral process is not always straight forward for parents and there is a high risk they will encounter difficulties. The authors used focus groups to explore the views of 51 parents on educational provision for children with SLD. Worryingly provisions were viewed to be scarce and gaining access to them was dependent on luck and parents' ability to fight the local authorities. Furthermore, Rannard, et al., (2004; 2005) reported that children with obvious neurological delays or no speech were more likely to be referred to SLT quickly than those with less obvious symptoms. There was often a considerable gap between the parents first noticing their children's difficulties and the child being referred, which made the parents feel health professionals did not take them seriously. Parents reported frustration if the referral process took too long.

The findings are further complicated by other findings by Rannard and colleagues also found parents also associated SLT with fears and anxiety to confirmation of their child's disability, despite parents' strong sense of needing to get their child referred as early as possible. Some parents may be concerned that attended SLT is stigmatising for their child (Glogowska, 2002). Furthermore, Green (2006) reported that the referral process can be an overwhelming time for parents as they have to deal with many different professionals; e.g. medical, educational and social services. Parents may also need emotional support to help them cope with their children's difficulties (Glogowska, 2002)

Glogowska and Campbell (2000) also reported that parents ultimately wanted their children to be able to attend mainstream schools like their nonlanguage impaired peers but were uncertain as to whether this would be achievable. SLT was seen as a means of enabling their children to begin school when they reach the right age. However, this preference may change if SLD persist in school age children. According to Rannard et al., (2004) parents of older children with SLD are more likely to favour placements in language unit rather than mainstream schooling; these parents felt not enough SLT was provided in mainstream education and the more intensive support offered in language units was appropriate. The

parents seen by Paradice and Adewusi (2002) also felt happier if their children were receiving support in a special unit or special school rather than in mainstream school.

4.3.4 The Impact of Raising a Child with SLD on their Siblings

Having a child with SLD also has an impact on the other children in the family. Therefore, knowledge of how disabilities can affect siblings is beneficial for parents and health professionals; parents can anticipate the effect on their family and clinicians can use the knowledge to provide support (Mulroy et al., 2008).

Studies examining the impact of having a child with disabilities has on siblings have reported mixed findings. Negative findings have found some children experience a less close relationship with their affected sibling (Osmond and Seltzer, 2007); and that parents can have less time to spend with their unaffected children due to the demands of caring for the child with disabilities (Mulroy et al., 2008). Other negative experiences are: exposing the sibling to parental stress; the additional burden on the sibling to assist with care; having to deal with peer misconceptions regarding their siblings' difficulties; embarrassment caused by their sibling's behaviour at public events, and missing out on some family experiences (Mulroy et al., 2008).

However, positive findings have also been reported. For example, having a sibling with disabilities can enrich the lives of the other siblings in the family. This includes developing a greater understanding of living with disabilities, thus removing prejudice against others different to themselves (Green, 2007); having a greater level of admiration for the sibling and having less quarrels with the sibling (Kaminsky and Dewey, 2001); having an increased sense of responsibility towards their siblings, more compassion, care, patience and kindness, more maturity than peers, and being good at assisting their parents (Mulroy et al., 2008). Selter, Greenberg, Krauss, Gordon, and Judge, (1997) surveyed and contrasted the views of siblings (aged 21-63) of adults with learning difficulties (329 families participated) and adults with mental illnesses (61 families participated). They found that the siblings of adults with learning difficulties were significantly more likely to report a closer more positive relationship with their sibling than those whose siblings had mental illness.

Orsmond and Seltzer (2007) compared the impact of having a sibling with Down's syndrome (DS) to having a sibling with ASD. They found that siblings of individuals with ASD were more pessimistic about their sibling's future than those with siblings with DS.

They also reported a more distant relationship and spent less time with their siblings. Siblings of individuals with ASD were also more likely to report their relationship with their parents had been affected but this was viewed as positive rather than negative. This study also reported that sisters tend to use more emotional coping strategies while brothers used more practical coping strategies and that the brothers' coping strategies were more effective overall. The sibling's coping skills are important because they influence the quality of the relationship with their disabled family member.

In later life siblings may also become responsible for their siblings' care. Damini (1999) showed that siblings are also likely to worry about the future and caretaker responsibilities once their parents are no longer able to care for them. Caring for a disabled sibling can be challenging as it inevitably involves the sibling supporting the sibling's needs while managing their own lives (Orsmond and Seltzer, 2007).

4.4 The Methodologies used in Studies of Psychosocial Outcomes

4.4.1 Qualitative Measures of Outcome

Qualitative analysis aims to gain a holistic overview of a study area and is conducted through intense and prolonged contact with the field (Miles and Huberman, 1994). Qualitative data can take many forms (e.g. interviews, focus groups, documents, or video data), and can be analysed using qualitative techniques. Grounded theory (Glaser and Strauss, 1967) is a form of qualitative analysis that is an inductive approach that begins with the data and aims to generate hypothesis that 'fit' the data based on themes that emerge from the data. The researcher should come to the data with no perceived ideas or hypothesis. Generating a grounded theory is a meticulous process that involves:

- coding the data
- collecting the codes into concepts
- grouping similar concepts into categories to generate a theory
- using the themes from the analysis to explain the theory and subject of the research

Grounded theory can be controversial as it works in the reverse order to experimental research methods that begin with a hypothesis and set out to collect data to support it. Allan, (2003) criticised grounded theory because it lacks clearly-defined mechanisms and will

inevitably be subject to researcher biases and preconceived ideas at the data collection and analysis phases.

Content analysis (Weber, 1990) is another form of qualitative analysis. This involves a similar process to grounded theory, but allows the researcher to have some assumptions such as specific research questions when they come to carry out the analysis (Miles and Huberman, 1994).

Qualitative methods have the advantage of being applicable at an individual level as they do not have to conform to discrete criteria that could be inapplicable or inappropriate at an individual level. They can also allow for ambivalence when rigid measures may not (Hendry and McVittie, 2004). Skeat and Perry (2008) advocate the use of qualitative methods in SLT research as they can provide the researcher with a broader understanding of a complex research area. However, qualitative analysis has the disadvantage of no normative comparisons and is extremely time consuming to carry out.

Relatively few studies have adopted exclusively qualitative approaches to measuring QoL or psychosocial outcomes for individuals with SLD (Markham and Dean, 2006; Ronen, Rosenbaum, Law and Streiner, 2001); these studies have typically used semi-structured interviews (Hendry and McVittie, 2004) or focus groups (Markham and Dean, 2006; Ronen et al., 2001).

4.4.2 Mixed Methods

A third research method is the 'mixed methods' paradigm (Tashakkori and Teddlie, 2003). This combines quantitative and qualitative methods to utilise their relative strengths, and provides a more complete approach to conducting research. Historically, mixed research methods have come under criticism from purists who argue that the two methods are incompatible. Quantitative purists argue that social science should be treated as a natural science and that behavioural observations should be treated as entities free of context (Nagel, 1986). Qualitative purists argue that behavioural observations are bound up in context and cannot be treated as a natural scientist would treat physical phenomena (Guba, 1989). Both sides of the debate argue that the two methods are incompatible. Howe (1988), amongst others (e.g. Greene, Caracelli, and Graham, 1989; Onwuegbuzie, 2002), argued against this, stating that there is no incompatibility between the two methods and that they share many commonalities at the levels of data, design, analysis and interpretation. Furthermore, the two

methods are typically associated with different research questions and interests (Howe, 1988). Advocates of mixed methods argue that quantitative and qualitative methods are not incompatible and can inform one another (Johnson and Onwuegbuzie, 2004) and a mixed methods approach can be tailored as the researcher requires (Leech and Onwuegbuzie, 2009). In conclusion, a mixed methods approach can be viewed as a compromise in the quantitative/qualitative debate, and researchers should be free to use the methodology that is most appropriate for their research questions (Johnson and Onwuegbuzie, 2004).

Mixed methods research is now becoming more common. For example, Lindsay and Dockrell (2004) followed up quantitative questionnaires with qualitative semi-structured interviews to further inform the findings. Records et al., (1992) also used a mixed approach that measured outcome quantitatively and collected feelings towards psychosocial outcomes. Therefore, the most complete method for assessing an individual's life outcomes would arguably be a mixed methods approach. This would measure an individual's levels of success and life achievements objectively, but within the context of the individual's subjective perception. This approach also has the advantage of removing any methodological biases that could arise as a product of a single methods approach.

4.4.3 Mixed Findings for Psychosocial Outcomes as a Result of Different Methodologies?

The follow-up literature for adults with longstanding SLD have reported mixed results. For example, the studies by Aboagye (2001) and Records et al. (1992) both reported more positive findings when compared other studies (Billstedt et al. 2005; Clegg et al., 2005; Howlin, 2000). This may well reflect a genuine difference between the cohorts in the different studies, notably the sample seen by Aboagye (2001) was small and therefore may not be representative of adults with SLD generally. However there is also a possibility that this difference in research findings could have a methodological origin. More qualitative studies have typically measured outcomes according to an individual's perception or personal appraisal within a domain (e.g. Aboagye, 2001; Records et al., 1992). Quantitative studies have typically measured outcome according to achievements within certain life domains according to objective criteria. This difference in the methodologies used could contribute to some of the differences between studies.

Therefore, the current project will adopt a mixed methods approach (Tashakkori and Teddlie, 2003) to document both the objective life successes and achievements of the ex-pupils as well as their subjective views, experiences and personal perspectives on their life circumstances. This methodology will provide the most complete measurement of psychosocial outcome for the ex-pupils seen in this project and will therefore provide an accurate account of QoL for adults with childhood histories of SLD.

4.4.4 Using Interview data

The following 2 chapters will utilise interview data. Interviews involve talking to participants about the research topic and can be structured, semi-structured or unstructured. They can be used to collect quantitative and/or qualitative data as required. Structured interviews are typically quantitative and consist of questions with pre-coded responses. Semi-structured interviews involve structured questions, but these are open-ended and do not use response codes. Unstructured interviews are qualitative and explore a topic area following a format closer to a conversation. Looser interview formats are most beneficial when little is known about a topic area. More structured formats are beneficial when the researcher wishes to address very specific questions (Bowling, 2002). A mixture of the different types of question can be used in the same interview as required. Previous follow-up studies that have used interview data to measure outcomes include Aboagye (2001), Beitchman et al. (2001), Clegg et al. (2005), and Snowling et al. (2006).

4.4.5 Proxy Measurements by Parents or Primary Caregiver

Some individuals may lack the necessary language or cognitive skills to be able to provide a complete and reliable account of events or have long-term views; this will limit their ability to perform in an interview or complete a questionnaire (Theunissen et al., 1997); for example, young children or participants with communication difficulties. In such cases, proxy by parents or the primary care giver can be a useful alternative; as it allows one individual to speak on behalf of another. It has the disadvantage, however, that the representative may have their own biases. Even so, there may be cases where there is no alternative to proxy. Theunission et al., (1997) compared the HRQoL for children between ages 8 and 11. The sample consisted of 1105 parent-child pairs. Parents and children both completed parallel questions that measured the children's levels of HRQoL. They found that

parental reports may be a reliable substitute for their children's reports but that large differences in proxy agreement can occur. Parents also tended to report more extreme views than children, for example extreme pessimism or optimism relative to the child's perspective.

Markham and Dean (2006) aimed to collect HRQoL data for children with SLD using qualitative data collected from focus group meetings of parents to children with SLD, SLTs and other relevant professionals (such as health visitors or education staff). This methodology showed that parents could provide reliable measurements of QoL for children with SLD using a qualitative methodology. Nunes, Pretzlik and Ilicak (2005) also successfully used a proxy measurement to assess how cochlear implants affect children's lives according to their parents' perceptions. These studies suggest that parental reports can provide reliable data. Ronen et al., (2001) argue against the use of proxy measurement stating that valid responses can still be collected in cases where proxy may be the preferred assessment choice.

An alternative use for a proxy measurement could be to further inform a data set. For example, parental views could be used to validate the perception of an individual who may or may not be able to provide an accurate account themselves. Agreement would strengthen the data and disagreement would highlight areas for further investigation.

4.5 Summary

This chapter discussed the risks poor psychosocial outcomes faced by adults with persisting SLD: poorer academic achievement; poorer employment outcomes; economic difficulties; difficulties achieving independent living, and difficulties with social and personal relationships (see 4.2). It also discussed the strengths and weaknesses of objective and subjective measures of QoL (see 4.1.3).

In the light of this chapter 5 will present a study that examined the psychosocial outcomes of same 17 adults with persisting severe and complex SLD as seen in chapter 3; all attended a residential special school for SLD. A mixed methods approach will be used to measure the ex-pupils' levels of objective success and subjective perceptions of different aspects of their lives (Tashakkori and Teddlie, 2003). Their performance will also be compared to three nonlanguage impaired siblings to control for genetics, upbringing and family environment.

Section 4.3 discussed the effects of raising a child with disabilities on the family. Chapter 6 will present a qualitative study that sort the views and experiences of the ex-pupils

parents and siblings having had a family member experience severe SLD and go away to school; this was to examine these theme further in families to children with SLD. In addition a proxy measure (as in Theunissen et al., 1997) was also collected from the parents to confirm or enlighten the ex-pupil reports in chapter 5 further.

Chapter 5 - The Ex-pupil Follow-up; Psychosocial Outcomes

5.1 Research Questions

This chapter will present another follow-up study of adults with persistent, severe and complex SLD.

The following research questions will be addressed:

1. What are the psychosocial outcomes for adults with childhood histories of severe and complex SLD?
2. How do the ex-pupils' perceived levels of QoL compare to their psychosocial outcomes?
3. What are the ex-pupils' views on special schooling and mainstream education?
4. Is there a relationship between the psychometric data presented in chapter 3 and psychosocial outcomes?
5. How do the ex-pupils' psychosocial outcomes compare to that of their nonlanguage impaired siblings?

5.2 Methodology

5.2.1 Design

This study used a mixed though predominantly qualitative methods approach (Tashakkori and Teddlie, 2003). Semi-structured interviews were used to measure the ex-pupils and siblings' levels of success and achievements within a range of psychosocial domains as well as to document their views and perceptions of their QoL.

Both quantitative factual information (e.g. how many GCSEs did each ex-pupil gain during their time at the school) and qualitative perceptual and emotional information (e.g. how ex-pupils felt about the GCSEs they gained) were collected using the semi-structured interviews.

5.2.2 Participants

The participants were the same ex-pupils and siblings as those seen in chapter 3. The recruitment process was outlined in section 3.2.2. Section 3.3.2 presented study 2 which had divided ex-pupils into three subgroups based on their performance on psychometric testing at follow-up. In the present study the psychosocial outcomes of these three subgroups were also compared to see if any themes could be identified. To recap, the three subgroups were as follows:

- The resolved or residual difficulties subgroup (RD) was the highest performing subgroup. None experienced any severe persisting difficulties however most had mild persisting language or literacy difficulties.
- The persisting difficulties subgroup (PD) experienced severe and persisting language and literacy difficulties.
- The complex difficulties subgroup (CD) experienced the most severe and pervasive difficulties in adulthood. The defining features of this subgroup were severe difficulties with nonverbal IQ, in addition to other persisting difficulties with literacy and language.

Table 5.1 – Ex-pupil subgroups

Ex-pupil	Age	Gender	Boarding status at the school	Subgroup
Dennis	35;11	Male	Boarded/then day pupil	RD
Grace	26;03	Female	Fortnightly	RD
Freya	24;10	Female	Fortnightly	RD
Steven	21;11	Male	Weekly	RD
Darren	21;10	Male	Day pupil	RD
Jack*	18;04	Male	Day pupil	RD
Jacky	38;02	Female	Weekly	PD
Robin	27;09	Male	Fortnightly	PD
Karen	26;09	Female	Fortnightly	PD
Jodie	24;06	Female	Day pupil	PD
Julian	23;11	Male	Weekly	PD
Fiona	25;00	Female	Weekly	CD
Toby	23;04	Male	Fortnightly	CD
Lauren	23;02	Female	Fortnightly	CD
Kirsten	21;11	Female	Day pupil	CD
Emma*	19;08	Female	Weekly/then fortnightly	CD
Lewis*	19;07	Male	Fortnightly	CD

* Stayed at the school for FE

Table 5.2 - The siblings

Siblings	Age of sibling	Gender	Ex-pupil pairs
Thomas	29;05	Male	Freya
Petra	26;07	Female	Robin
Emily	24;06	Female	Grace

The siblings provided additional comparisons at a case study level that controlled for genetics and family environment.

5.2.3 Ethics

This study was approved by the University of Sheffield ethics committee in the department of HCS prior to any contact with participants (see appendix A4.1). Participants had the nature of the research project explained to them before they agreed to take part. Participants were also given the opportunity to ask questions before and after taking part. They were made aware their anonymity would be maintained, and that they could withdraw at any time. They were also advised that it would be helpful if they agreed to be recorded during the study session and given the option to be video recorded or audio recorded or not recorded at all. No participant was pressured to be recorded if they felt uncomfortable. Each participant was also given the choice whether to allow the use of their comments and/or interview recording in research presentations. Their response to these questions did not affect their participation in the project.

5.2.4 Materials

A semi-structured interview schedule was used to measure life outcomes and experiences. This was originally modified from an interview schedule devised by Rutter, Couteur, Lord, MacDonald, Rios and Folstein (1988) by Clegg et al. (2005), and then further adapted for use in the present project. The original interview schedule was comprised of closed questions only, these yielded responses that were coded according to numerical scores. For the present project the interview schedule was adapted to include open ended qualitative questions and questions on the school, support services, perceptions on current communication, technology and hobbies. The inclusion of open ended questions was important as they allowed rich qualitative data to be collected (see appendix A5.4).

The ex-pupil interviews covered a range of topics and life domains: living arrangements; employment; education; current communication; friendships and social

relationships; relationships and children; finances; hobbies, and life expectations. The sibling interviews covered a similar but not identical list of topics: early childhood; living arrangements; employment; education; current communication; friendships and social relationships; relationships and children; finances; hobbies, and life expectations. The semi-structured interviews were designed to elicit factual information from closed questions and qualitative information from open-ended questions.

During the interviews each topic was discussed in as little or as much depth as the participant wished. Participants were made aware that they did not have to answer any questions they did not want to. The interviewer had a series of prompts to steer the interview to elicit relevant information when needed. The interview format was also flexible enough for the participants to talk about topics of their choosing.

5.2.5 Procedure

The data presented here were collected at the same time as the psychometric data presented in chapter 3. The ex-pupils and siblings completed the semi-structured interviews with the researcher once they had completed the psychometric assessment battery presented in chapter 3. The interviews lasted between 45 minutes and two hours depending on how much the participant wanted to say. The participants were also offered breaks as and when they needed them.

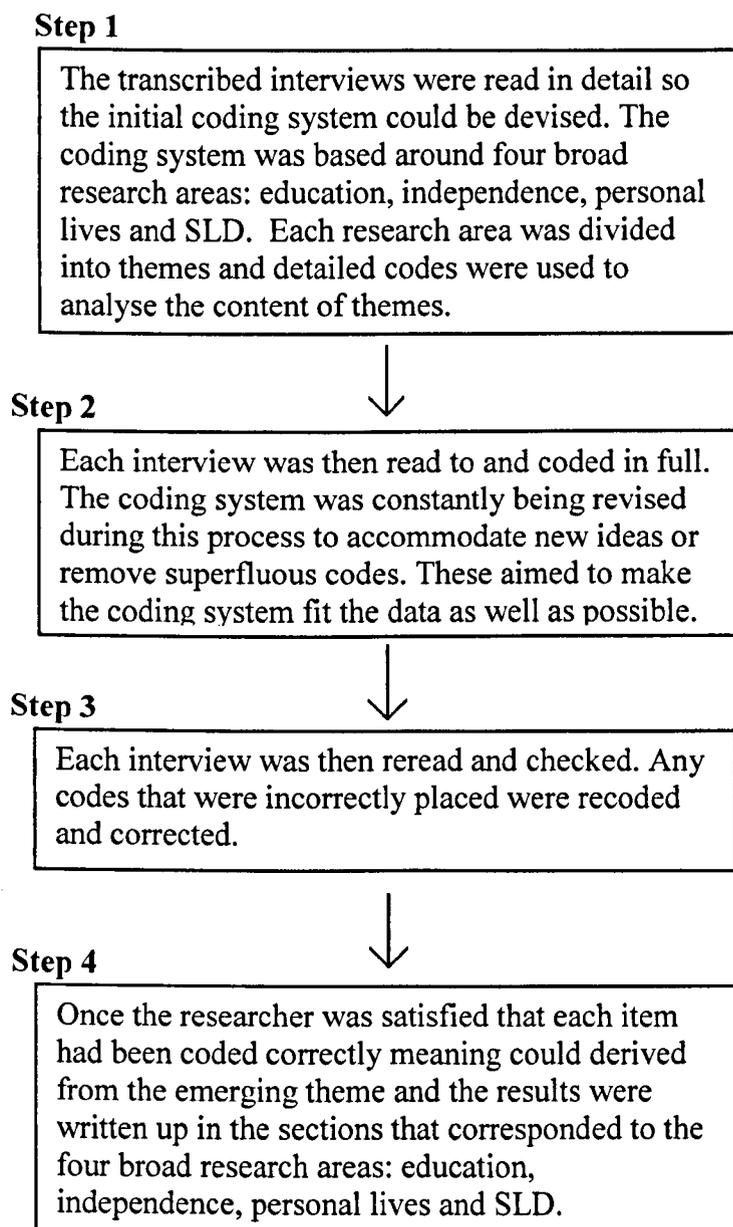
Before the interviews began the researcher briefed the participants about the interview and gave them another opportunity to ask questions. The interview sessions were either video or audio recorded for later transcription purposes. The recording method was the participant's choice and the majority gave consent for this, however two participants refused to be recorded in any form (one ex-pupil and one sibling) because it made them feel uncomfortable. In these instances the researcher took careful and detailed notes during the interviews; this meant these sessions were more time consuming.

5.2.6 Data analysis

The interview recordings were transcribed in full to prepare them for the analysis. The interview notes taken from the two participants who did not consent to recording were also typed up and treated as interview transcripts. The steps taken to prepare and carry out the data analysis are outlined in figure 5.1. The qualitative analysis used content analysis (Weber,

1990) and was conducted using NVivo (NVivo qualitative data analysis software, 2008). Content analysis was used because it allowed the researcher to address the research questions outlined in 5.1 specifically. The full data analysis, including transcription time, was a meticulous and time consuming process. Once the analysis was complete a 2nd coder scored 2 full interviews using the final coding system; interrater reliability was shown to be 92.13%. See appendix A2.1 for the final coding system and A3.1 for a worked example.

Figure 5.1 – Methodology used to devise the coding system used to analyse the interview data.



5.3 Results

The findings from the semi-structured interviews are presented in this section. The themes that emerged from the qualitative analysis are presented in four sections: education, independence, personal lives, and speech and language difficulties. Descriptive and factual quantitative results are presented in tables.

5.3.1 Education

a. Educational placements

Ex-pupils attended different types of educational placement before the school for children with severe and complex SLD (see table 5.3⁹). Those who attended mainstream schools typically reported negative experiences. Five ex-pupils (Robin, Freya, Emma, Steven and Jacky) struggled at mainstream school; mainly because the work was difficult. Three also felt they struggled due to their SLD (Robin, Emma and Freya); one was moved down an academic year on two occasions (Emma); and two felt the staff had not understood their difficulties (Steven and Freya). Jacky reported being turned away because her mainstream school could not cope with her needs. The only positive comments concerned having good social relationships with mainstream peers (Jack and Emma).

Four ex-pupils (Grace, Steven, Lewis and Fiona) attended language units attached to mainstream primary schools and felt this was a positive experience. One commented that her language unit was able to support her (Grace).

Lastly, two ex-pupils attended other special schools. Jacky's special school catered for general learning difficulties and disabilities including physical disabilities. Her experiences from this time were traumatic. Karen attended a similar residential special school to the one in this project.

There was an overall consensus that ex-pupils favoured the residential special school for SLD to mainstream school. They reported smaller class sizes (Grace and Emma); more support (Jack and Jodie); less bullying than in mainstream school (Jack and Steven), and felt more able to keep up academically (Jack).

⁹ In some cases responses from ex-pupils were unclear, so further clarification was sought from the archive data or parental interviews.

Table 5.3 - Educational placements prior to the ex-pupil's time at the school, and the ex-pupils entry and leaving ages to the school.

	Ex-pupil	Mainstream school	Language Unit	Other special school	Entry age	Leaving age
	Grace	Until year 3	Until year 7	-	11;11	16;9
	Steven	Until year 6	Until year 7	-	-	11;7
RD Subgroup	Darren	Missing data	-	-	8;8	16;5
	Jack	Until year 9	-	-	13;?	17;7
	Dennis	Missing data	-	-	5;7	12;4
	Freya	Until year 7	-	-	(11;3)	n/a
PD Subgroup	Robin	Until year 7	-	-	11;5	16;3
	Jodie	Went straight to the school from nursery			5;8	15;11
	Karen	Missing data *	-	-	7;5	16;3
	Jacky	In reception	-	Until year 3	6;5	12;6
	Julian	Missing data	-	-	6;11	16;5
CD Subgroup	Kirsten	Unsure of type of school before attending the school **			11;5	16;3
	Emma	Private school 3 till 9	-	-	9;10	19;1
	Lauren	Unsure of type of school before attending the school **			7;9	n/a
	Lewis	-	Until year 11*	-	12;02	19;0
	Toby	-	-	Until year 6	11;10	16;9
	Fiona	-	Until year 3	-	8;5	16;2

The shaded bars are used to highlight cases where the types of educational placement listed at the top of the table were not applicable.

* Were a year older in academic years when they entered the school; Karen spent an extra year in nursery and Lewis spent an extra year in primary school.

** Spent a time out of education before attending the school.

() Estimate from interview data. No archive data available.

Table 5.4 – The types of schools the siblings attended before compulsory education.

Ex-pupil	Mainstream school	Language Unit	Other special school	Entry age	Leaving age
Emily	Until year 11	-	-	n/a	n/a
Petra	Until year 11	-	-	n/a	n/a
Thomas	Until year 11	-	-	n/a	n/a

All three siblings attended mainstream education (see table 5.4) and all gave positive reports of their time at school: for example; an enjoyable, fun experience; receiving the right education, and being prepared for life. None of the siblings reported receiving any extra support at school, and all three felt mainstream school had been the right choice for them.

b. Education at the Residential Special School for Speech and Language Difficulties

Memories from the school were mostly positive and 11 ex-pupils explicitly reported an enjoyable experience. Pupils felt staff were understanding and supportive (Jodie and Lewis) and the school did everything a mainstream school would at a manageable pace (Darren). Five pupils described a mixed experience of the school. These pupils felt it was a positive experience overall, but also expressed some negative feelings towards it. Negative comments included: traumatic boarding experiences (Jacky); difficulties with peer relationships due to their SLD (Freya and Jack); limited opportunities to form friendships outside the school (Jack and Steven), and being frustrated with their SLD (Dennis). Lauren was the only ex-pupil who reported a solely negative experience from her time at the school¹⁰. This included not getting along with teachers or peers and being disciplined frequently.

Support at the school was seen as readily available. This included help with SLD, behaviour, work in lessons, literacy skills and visual learning strategies. Comments included: the support was useful (Freya); staff made sure pupils understood a topic in the class before moving on¹¹ (Jack); staff understood what a pupil was trying to express (Dennis); and the staff were approachable (Fiona). Only Lauren reported negative feelings towards support at the school, stating that it could be inconsistent.

c. Speech and Language Therapy at the Residential Special School for Speech and Language Difficulties

Ex-pupils received SLT at the school alongside the curriculum and there was a consensus that this had been beneficial. This supported pupils with all aspects of their SLD.

Researcher: Was (SLT at the school) helpful to you... ?

Jodie: Oh yes::: ... coz ... I suppose I wouldn't be the same person would I.

More critical comments included: SLT was boring (Darren), and the disruption of having to change therapist regularly (Grace). However, as adults both Darren and Grace appreciated the SLT they received. All ex-pupils felt SLT had been beneficial.

There was a consensus amongst ex-pupils that special school had been right for their needs and had provided them with the right education. Reasons included: focusing on SLD

¹⁰ Additional evidence in the archive supported her report and suggested she was very unhappy at the school.

¹¹ This was seen as a better teaching system then compared with mainstream school where the whole class move to the next topic together.

(Jodie), provided them with skills to progress in the adult world (Darren), and it made it possible for them to gain employment (Freya).

Darren: And I think if I didn't go to (the school) I'd just be like a vegetable at home.

Steven: I don't think there coulda been another school that could have helped me out like, I definitely woulda been walked over in mainstream.

Two ex-pupils reported feeling that boarding school had been the wrong school for them at the time because it limited opportunities to form friendships at home (Jack) and made them feel different (Dennis). Notably, Jack's reasoning was more specific to boarding school rather than special school.

Jack: I had friends (at school) but when I went home like you know you see all the kids around the streets just like going to the park and stuff and I didn't really know any of them ... I was too shy to go and ... see if I could go and join in stuff.

Despite this, both ex-pupils now felt the school had been right for them. However, both ex-pupils reported hiding the fact that they had attended a residential special school from their friends and colleagues as adults. In contrast, Grace and Lauren felt the school had not been the right school for them on reflection. Grace now felt she would have preferred to have attended a language unit (similar to her previous educational placement) closer to home for secondary school. She also felt the school had stifled her academically. Lauren felt it had been the wrong school for her because she did not get on with her school peers, however she also felt she got the right education there.

Ex-pupils described things they would have liked at the school. Several would have liked to study subjects in more detail or to study additional subjects such as business studies (Steven) or psychology (Darren). Two ex-pupils wanted the opportunity to study more GCSEs (Grace and Steven). In addition, ex-pupils would have liked more work on life skills (Grace), better careers advice (Darren and Steven¹²), and to have learned more about strategies for gaining employment (Julian). Eight ex-pupils felt that there was nothing additional the school could have offered.

¹² Darren might have chosen to study for an apprenticeship had he been aware of them. Instead he studied for a sports degree he did not complete. Steven felt he initially had made the wrong career choice when he left the school and might have chosen something different with more knowledge.

d. Experiences of Boarding

Ex-pupils had different residential statuses: day pupils who went home each day, weekly boarders who went home at weekend or fortnightly boarders who went home every other weekend (see table 5.1). In some cases, ex-pupils lived so far away and stayed with other relatives nearer the school some weekends (Freya and Grace). Many boarders found it upsetting and reported feeling homesick, isolated and missing their families. Jacky reported perhaps the most difficult boarding experience.

Jacky: I'll always always remember ... the first couple of years ... going to school on Sunday night crying and holding my mum's hands. When we got to ... school I'd locked myself in the car ... I would try to grab my Mum and Dad and the housemothers (used) to pull me off ... it was upsetting. ... the first couple of days I was upset, but I'd always every week write letters to my Mum and Dad or we'd have a telephone call ... once I had that telephone I was so happy and I peeked up again.

Freya: It was good for me but ... it did take me away from my parents it did take me away from my family coz I had to go a long way and ... mum and dad knew they had to do it but they were very upset ... I was still crying ... when I was sixteen and they left me.

These feelings were most severe when ex-pupils were new to the school.

Grace reported additional negative experiences of boarding such as feeling uncomfortable in someone else's care and regretting that her parents missed out on her growing up. Despite their views ex-pupils ultimately understood the necessity of boarding.

However, not all reports of boarding were negative. Three ex-pupils reported they preferred being away from their parents (Lewis, Steven and Toby). Steven also enjoyed the extra independence.

Steven: I liked the fact that I was away from home actually ... it's sort of like a bit of a buzz like going to camp.

Researcher: You didn't miss your family?

Steven: No not a bit actually.

Lewis and Emma both enjoyed boarding because they liked spending time with their friends. Emma also enjoyed learning about life skills in care in the FE department. Notably, these were both ex-pupils who stayed on for post-16 education so their experiences of boarding could have been different to the older cohort members who did not have this opportunity.

Furthermore, boarding was seen as 'different' for Freya's brother as he also went to boarding school as their family lived in a remote part of the UK. Unlike Freya, he did not mention any negative consequences of boarding and saw it as necessary for getting the best education he could. He also felt it had provided him with more independence skills than a regular school.

Thomas: It was actually quite good, I was certainly much better prepared than anyone else at University. I mean going in to halls some people couldn't cook for themselves, some people couldn't look after themselves couldn't do the washing ... couldn't cope with being away from home and just fuffed and did stupid things.

e. Friendships at the Residential Special School for Speech and Language Difficulties.

Sixteen out of 17 ex-pupils reported having friends at school and 12 had a best friend. Julian and Lewis described their friends as being their favourite part of their experience at the school, and eight other ex-pupils agreed that boarding helped them make friends. Jack commented that it was easier to make friends at the school as his peers all had similar difficulties. Only Dennis did not report having friends because he could not remember.

Difficulties with friendships also occurred. Emma and Lewis lost friends during the transition from the secondary department to the FE department, because not all pupils decided to continue. Lauren stated that she did not get on with many of the other pupils and had only a few friends. Freya felt she never had her own space.

There were also difficulties maintaining friendships after leaving. Ten ex-pupils had lost all contact with their friends after leaving the school. Twelve ex-pupils also said they had no friends at home while they were attending the school. This was due to geographical distance and meant ex-pupils were at risk of social isolation after leaving as many lost their school friends and then had no other friends at home.

Julian: Yeah I made quite a few friends ... only thing is that I lost touch with loads of them. ... ever since I left (school) coz like they're all over the place.

Toby, Lauren and Fiona reported still having contact with friends from the school but saw nothing of those friends. Emma and Lewis who were recent ex-pupils of the FE were also reported having contact with their friends, however it was still early days for them as they had only been out of school for less than a year. Their contact with friends was minimal; e.g. occasional text messages.

Ex-pupils gave mixed reports of bullying at the school. Seven ex-pupils reported they were bullied and a further three said that others were bullied but not themselves. Only Freya admitted to being a bully, although she had also been on the receiving end. Some reports of bullying appeared to be mutual fighting rather than victimisation (Steven and Julian). Overall, ex-pupils felt the school dealt with bullying well apart from Lauren, who felt the punishments for bullying had no effect.

All siblings reported friendship groups at school and Robin and Freya's siblings reported they still had occasional contact with school friends, but this was limited. Grace's sister was no longer in touch with any school friends and had a new group of friends. All the siblings also experienced mild bullying in their mainstream schools. Freya's brother saw being bullied as a normal part of school.

f. Education after Leaving the Residential Special School for Speech and Language Difficulties

Once ex-pupils entered the school they all stayed there until the statutory leaving age. Ex-pupils' leaving ages are shown in table 5.3. For twelve ex-pupils this was until 16 years. However, Jacky and Dennis, who were the eldest cohort members, attended the school when the statutory leaving age was 12; Dennis was therefore also the only ex-pupil who returned to mainstream education before 16 years of age. He felt that this had been right for him and that returning to mainstream education made him feel he had returned to the real world and did not report the same negative experiences as the ex-pupils who attended mainstream schooling before entering the residential special school for SLD. The three youngest cohort members had the option to remain there for post-16 education and stayed there for one (Jack) or three additional years (Emma and Lewis).

Most ex-pupils agreed the school had prepared them for life as adults. Ex-pupils reported learning a range of life skills: interview skills, domestic skills and budgeting. Emma also said that she had matured during her time at the school and this helped her with self-confidence and independence. Ex-pupils who felt it had not prepared them for life gave their reasons why: boarding meant they had less access to learning about life skills in the family environment (Freya and Grace), and the environment was overprotective and this had sheltered them from the world outside (Steven and Jacky¹³).

All ex-pupils reported attending some kind of post-16 educational placement after completing their compulsory education. The 14 older ex-pupils did this outside the school. The three younger ex-pupils who stayed for FE attended college courses as part of the provision provided by the school, and then attended additional FE courses after leaving the school. Emma and Lewis were still attending these post-16 placements at follow-up.

¹³ Jacky left the school at 12 and went on to attend another residential special school. In her cases this difficulty could have partly been the responsibility of her subsequent school as well as the school.

Fifteen ex-pupils attended mainstream college placements, although two attended residential colleges similar to the FE department (Fiona and Freya). Three ex-pupils attended multiple colleges placements; Karen and Freya did this because they wanted to study certain courses and Julian had to move colleges for personal reasons.

Five ex-pupils reported difficulties at college: for example difficulties with examinations (Emma); no access to additional support or allowances for SLD (Emma); and failure to complete a course (Darren, Dennis, Steven and Jack). Reasons for not completing a course included choosing the wrong course (Darren and Steven), failing to find a work placement for a component of the course (Dennis), and wanting to pursue another career (Jack and Steven). Arguably, Steven experienced the most success at post-16 education; he was awarded a competitive scholarship to study dance, but he eventually left to pursue another career in retail.

During interviews the 14 older cohort members were given a brief description of the new FE facility and asked if they felt they would have stayed to attend the FE provision had it been available. Responses were mixed. Eight ex-pupils felt they would have continued; two specifically felt they would have found the life skills element useful (Grace and Lauren). Jacky also wished FE had been an option for her despite her strong wish to leave residential school aged 16. Four ex-pupils felt they would not have chosen to stay. Reasons included wanting to move on and make new friends (Darren and Steven), and not needing the further support and knowledge on the life skills that FE offered (Robin). Freya also felt that she would have wanted to leave, but that the final decision would have been made by her parents.

The three younger cohort members all stayed for FE. Lewis attended FE so he could continue improving his literacy skills, and he appreciated learning about life skills. Emma enjoyed the extra freedom in FE and learning about life skills; however she disliked arguments between pupils and staff. Jack found the support with college work helpful and felt that staff at FE had motivated him. He was not concerned with life skills because he felt he had a good knowledge of them without further support from FE. When asked what they would have done had FE not been available, Emma and Lewis were not sure, and Jack said he would have attended his local college.

In comparison, the siblings also reported attending post-16 placements, but at a higher level than the ex-pupils. Grace and Freya's siblings both completed A-levels and degrees and Petra studied an intermediate level GNVQ. Robin's sister also studied for the advanced level GNVQ, but did not complete all the elements of the course.

g. Formal qualifications

The ex-pupils reported achieving a range of formal qualifications gained from compulsory, at post-16 and as part of employment; these are presented in table 5.5. The siblings formal qualification are presented in table 5.6 as a comparison. Table 5.7 present the total number of qualifications gained by the ex-pupil subgroup and siblings.

Table 5.5 – The ex-pupil's formal qualifications

	Ex-pupil	Compulsory education	At post-16	As part of employment
RD subgroup	Darren	None reported	Did not complete course	Life guard certificate
	Grace	3 GCSEs B-G, YAS bronze & silver	GNQV 1 GCSE E (Appendix for more)	Basic chemistry
	Freya	2 GCSEs D-G	2 GCSEs C – D	None reported
	Steven	5 GCSEs C-D	AS level (B) BTEC (Merit)	None
	Dennis	None reported	Did not complete course	Life guard certificate, First aid
	Jack *	None reported	BTec	None reported
PD subgroup	Jacky	1 O-level level 4+	Duke of Edinburgh Award - silver Catering certificate (Appendix for more)	Catering certificate Health and hygiene certificate
	Robin	None reported	FE award City and Guilds qualification (Appendix for more)	None reported
	Karen	2 GCSEs Grades not disclosed	City and Guilds Mathematics and English, CACHE levels 1 & 2, (Appendix for more)	None reported
	Jodie	3 GCSEs E-G	2 NVQs	None reported
	Julian	1 GCSE E YAS (silver and bronze), AQA English	None reported	None reported
CD subgroup	Fiona	Pre-GCSE in science	NVQs in horse care levels 1 and 2	None reported
	Toby	None	NVQ level 1	None reported
	Lauren	2 GCSEs F – G	Attended college but no further information	None reported
	Kirsten	None reported	Hairdressing course no formal mentioned	None reported
	Emma *	None reported	Beauty NVQ Sport and recreation	n/a
	Lewis *	None reported	None reported	n/a

* Previously studied at the department FE

+ Qualification gained at 16 from a different school to the one in this project because ex-pupil attended when they statutory leaving age was 12 years.

Table 5.6 - The siblings' formal qualifications

Sibling	Compulsory education	At post-16	As part of employment
Emily	8 GCSEs	International history and politics degree 2:1 3 A-levels A-B	None reported
Petra	8 GCSEs C-D	2 GCSE retakes D GNVQ business intermediate.	None reported
Thomas	8 GCSEs	4 A levels A-B Physics degree	None reported

Table 5.7 - Total number of qualifications gained by ex-pupils and siblings

Subgroup or cohort	Compulsory education	At post-16	As part of employment
RD	12	7	4
PD	10	10	1
CD	3	5	0
Sibling	32	12	0

5.3.2 Independence

a. Employment

Tables 5.8 - 5.10 present the ex-pupils' employment statuses at follow-up, any training they were required to complete, employment history, periods of unemployment, difficulties in the workplace and future employment plans across the three subgroups. In total, eleven ex-pupils were employed at follow-up, one was a voluntary worker, three were unemployed and two were still in full-time education. Eight ex-pupils had jobs that required specialist training and four ex-pupils reported needing no specialist training for their jobs.

Of the ex-pupils who were employed or in voluntary work, nine reported enjoying their work and eight felt they were good at it. Two ex-pupils disliked their jobs: one experienced difficulties in the workplace (Freya)¹⁴, and one had been passed over for promotion (Dennis). Grace had mixed feelings towards her job; she enjoyed the work but disliked the politics within her workplace.

Eight ex-pupils reported relatively stable employment histories in that they reported no prolonged periods of unemployment. Jacky and Robin both reported periods of

¹⁴ Freya had been disciplined at work for reasons that were unclear. She felt this had happened because other staff members had not been pulling their weight. This had resulted Freya being moved to the laundry department in the care home and so she was no longer in the care role that she had been employed to do.

unemployment following redundancy and dismissal from work respectively. Despite her redundancy, Jacky had worked at her present job in a stable post for fifteen years at the time of follow-up. Robin experienced more difficulties and had been sacked or made redundant from several previous jobs and experienced a six-month unemployment period. Julian had never been in paid employment and was looking to gain work in a supermarket, but had experienced little success. He had also previously worked voluntarily in a charity shop and as a refuse collector for a wage, but was dismissed from both positions. Fiona had never been in paid full-time employment and was enjoying her voluntary work, but consequently had no motivation to gain paid work in the future. Lauren had also never been in paid employment. Toby was seeking employment and had recently become unemployed as a result of moving away following the breakdown of his relationship (relationships will be discussed in 5.3.3). However, he also reported hating his previous work.

Thirteen ex-pupils reported future employment plans. Darren and Jack were planning changes of career in the near future; Darren was due to start a new job in a DIY shop and Jack was planning to give up his football career to get a job working in a prison (where his father also worked) and to live with his partner. Grace and Dennis reported difficulties changing careers as they could not access the jobs they wanted, they felt this was possibly due to their SLD. Dennis wanted a job as an ambulance driver but struggled at interview because he misinterpreted the questions that were asked of him and Grace wanted a full-time position at her workplace but had been turned down numerous times. The three unemployed ex-pupils all discussed future employment ideas: Julian was seeking work in a supermarket but without success, Toby had been seeking employment following the breakdown of his relationship possibly as a factory worker, and Lauren wanted employment but was unsure what she would be able to do.

Five ex-pupils also mentioned future training to enhance their careers. Steven was attending a training programme provided by his employer that would increase his chances of future promotions. Kirsten was considering studying childcare so she could enter that profession in the future. Lewis wanted to become a gamekeeper and therefore learn to shoot. Lauren wanted to gain further qualifications to enhance her future employment options; however she was not confident of her academic ability or sure what she wanted to study. Lastly, Robin wanted to learn to drive in order to get a job using this skill.

Table 5.8 – Employment outcomes for the RD subgroup

Ex-pupil	Current Employment	Wages	Formal Training	Previous employment	Periods of unemployment	Difficulties at work	Future employment plans
Grace	Part-time microbiologist	Not disclosed	Scientific methods	Carer in residential care home. Lab technician	None	Unable to climb career ladder	Full-time microbiologist
Steven	Part-time sales business professional	£12,000 per year + commission.	None	Awarded scholarship to study dance	None	Regretted previous career choice	£30,000 per year job
Darren	Swimming and gym instructor	£985 per month	Fitness instructor training, first aid	Always had same job	None	None	DIY shop or fire service
Jack*	Caterer and low-league footballer	Football £250 per week, Catering £5.65 per hour	Football training	Saturday job in shop while at secondary school	None	None	Work in a prison
Dennis	Swimming instructor and first aid trainer	Not disclosed	Fitness instructor training, first aid	Always had same job	None	Failed to get preferred job	Ambulance driver
Freya	Laundry assistant	£6.38 per hour	None reported	Hospital cleaner, carer in residential care home	None	Disciplined	Move to another residential care home**

* Previously studied at the department FE

Table 5.9 – Employment outcomes for the PD subgroup

Ex-pupil	Current Employment	Wages	Formal Training	Previous employment	Periods of unemployment	Difficulties at work	Future employment plans
Robin	Helping with deliveries	£5.67 per hour	None	Printing shop, clothes shop	For 6 months	None	Driver
Jodie	Care worker for the elderly	£6.50 per hour	First aid	Worked in 2 different care homes previously	None	None	No plans
Karen	Nursery assistant	Not disclosed	CACHE*	Fast food shop	None	None	None
Jacky	Part-time caterer in conference centre.	£450 per month	Health and hygiene	Worked in factory	For 12 weeks when made redundant	Infrequent bullying	No plans
Julian	Unemployed	n/a	None	Voluntary work in charity shop, 1 day as refuse collector.	Mostly unemployed since leaving school	None	Supermarket

* Council for Awards in Children's Care and Education

Table 5.10 – Employment outcomes for the CD subgroup

Ex-pupils	Current Employment	Wages	Formal Training	Previous employment	Periods of unemployment	Difficulties at work	Future employment plans
Kirsten	Part-time cleaner	Not disclosed	None	Only had 1 job	None	None	Childcare
Emma*	Full-time education	n/a	None	n/a	n/a	n/a	Own a restaurant or pub
Lauren	Unemployed	n/a	None	Never been in paid employment	Yes - never employed	n/a	Wanted employment, work with computers
Lewis*	Full-time education and voluntary work in a garden centre	n/a	None	Voluntary work	n/a	None	Game keeper or gardener
Toby	Unemployed	n/a	None	Cinema, Supermarket	At follow-up	Did not enjoy previous jobs	Seeking employment as a packer (factory work)
Fiona	Voluntary work in stables	n/a	None	Never been in paid employment	n/a	None	Continue with voluntary work or be a jockey

* Previously studied at the department FE

Ten of the 12¹⁵ ex-pupils in employment reported they got along with their colleagues and bosses, and four reported socialising with them outside work. Grace and Freya gave more mixed reports; both got on well with their colleagues however they both felt they experienced prejudices because of their SLD. Relatively few cases of bullying in the workplace were reported explicitly. Jacky was the only ex-pupil to report bullying-type behaviours from her colleagues because of her SLD. She described this as infrequent but upsetting.

Jacky: Sometimes (they) say like 'oh you didn't say that word properly' ... little things now and again I hate it ... I hate it ... 'oh you said that word wrong'.

However, Jacky also reported that her boss was very understanding and supportive of her difficulties. Grace felt that she had been intimidated by a male boss at a previous job but this was due to sexism and not her SLD.

Overall the ex-pupils in the RD subgroup all experienced relatively stable employment histories with no prolonged periods of unemployment. Three of the PD subgroup reported a period of unemployment (Jacky, Julian and Robin); this had occurred on several occasions in Robin's case. Julian was yet to successfully maintain a job having left education. Three of the CD subgroup also had unstable employment histories (Lauran, Toby and Fiona) and two were not employed as they were still in full-time education (Lewis and Emma).

Jobs that required specialist training were most common amongst the RD (4 ex-pupils) and PD subgroups (3 ex-pupils). Four reported no specialist training for their jobs; one was from the RD subgroup and three were from the PD subgroup. Only 1 ex-pupil in the CD subgroup had completed specialist training, however she was also the only subgroup member for specialist training to be relevant as the others were either unemployed or in full time education.

Of the thirteen ex-pupils who reported future employment plans this included all members of the RD and CD subgroups and 2 members of the PD subgroup. The three remaining ex-pupils expressed no future plans. Two ex-pupils were planning a change of career in the near future; Darren was due to start a new job in a DIY shop but actually wanted to join the fire service. Jack was planning to give up his football career to get a job working in a prison (where his father also worked) and to live with his partner.

The sibling data for employment is presented in table 5.11 for comparison. All the siblings were in paid employment; Robin and Freya's siblings enjoyed their jobs but Grace's

¹⁵ This includes Fiona's voluntary work placement.

Table 5.11 – Employment outcomes for the siblings

Sibling	Employment	Wages	Training	Previous employment	Periods of unemployment	Difficulties at work	Future employment plans
Emily	City council	n/a	Technical training and dealing with public	Same job since leaving University	10 weeks between University and present job	None	Wanted to change job in the future
Petra	Sales assistant	£5.50 per hour	None	Supermarket	Yes – when she moved house	None	None
Thomas	Business analyst	+ £65,000 per year	Mostly self-taught IT skills, but also health and safety training	Multiple past jobs	None – always found work	None	Have his own company.

sister was less satisfied and saw her job as temporary. Robin and Freya's siblings both reported changing jobs in the past, but neither had experienced unstable employment histories or prolonged periods of unemployment. Grace and Freya's siblings felt they would change jobs in the future. None of the siblings reported any difficulties with prejudice or bullying at work.

b. Independent living

Of the 17 ex-pupils, three were living independently, one was in supported accommodation and 13 were living with their parents (see table 5.12). The three ex-pupils living independently had all moved in with partners. Julian, who was in supported accommodation, had also achieved a level of independence although it was unclear how much support he was receiving. Dennis was one of the 13 ex-pupils living at home, however he was still relatively independent as he had his own area of the house for which he was responsible, was financially independent and contributed to the running costs of the house. The remaining 12 ex-pupils living with parents were less independent however seven expressed a wish for independent living in the future. Two were planning to buy or rent a house with their partners (Darren and Jack); two wanted to buy or rent houses with friends (Emma and Steven), one was seeking supported living (Lewis), and the remaining two were looking to rent (Grace and Kirsten). Three of these ex-pupils planned to achieve independent living over the coming year (Darren, Jack and Kirsten), three had more vague plans for independent living (Grace, Emma and Steven), and Lewis was waiting for his application for supported living to be processed before he could move. Four of the 12 ex-pupils living with parents expressed no plans to move out in the future and were content with their situation (Dennis, Jodie, Karen and Fiona). Lastly, Toby had been living with his partner's family but he had returned to the family home when this relationship broke down. His levels of independence while living with his partner were unclear, as they had been living with her parents. Toby was reliant on his parents for support again, but wished to move out in the future.

Four ex-pupils were living away from the family home and three were fully independent and had left home to live with partners (Freya, Jacky and Lauren). One owned their house (Jacky), one was renting (Freya), and one was fully supported by her partner and living in his home (Lauren). A fourth ex-pupil was living in supported accommodation (Julian). Ex-pupils who had achieved independent living preferred it to living at home, but

Table 5.12 – Ex-pupils’ living situation and confidence with life skills at follow-up.

Ex-pupil	Status at follow-up	Satisfaction	Preference	Future plans	Domestic skills	Financial independence	
RD subgroup	Grace	Living with parents	Satisfied	Independent living	Independent living	Yes	Expressed Concerns
	Steven	Living with parents	Dissatisfied	Independent living with friends	Independent living with friend	Yes	Expressed Concerns
	Darren	Living with parents	Satisfied	Independent living	Owning home with partner	Yes	Expressed Concerns
	Jack*	Living with parents	N/A	Independent living with partner	Independent living with partner	Did not answer question	Yes
	Dennis	Living with parents	Satisfied	Living with parents	None	Fine – but not good at it	Yes
Freya	Independent living with partner	Felt isolated	Owning home with partner	Looking to buy rather than rent	Yes	Experienced Difficulties	
PD subgroup	Robin	Living with parents	Satisfied	Living with parents	None	Yes	Fine
	Jodie	Living with mother	Satisfied	Living with mother	None	Yes	Expressed Concerns
	Karen	Living with parents	Satisfied	Independent living	None **	Yes	Expressed Concerns
	Jacky	Independent living with family	Satisfied	Independent living with husband	None	Yes	Experienced Difficulties
	Julian	Supported living	Felt isolated	Supported living	None	Yes	Unclear

* Previously studied at the department FE

** No future plans reported at follow-up but mother revealed plans for supported living in her interview.

Table 5.12 (continued) – Ex-pupils' living situation and confidence with life skills at follow-up.

Ex-pupil	Status at follow-up	Satisfaction	Preference	Future plans	Domestic skills	Financial independence	
CD subgroup	Kirsten	Living with parents	Dissatisfied	Independent living	Independent living	Yes	Financial support from
	Emma*	Living with parents	Satisfied	Independent living with friends	Independent living with friends	Expressed Concerns	Expressed Concerns
	Lauren	Independent living with new partner	Felt isolated	Living independently	None	Yes	Unclear
	Lewis*	Living with parents	Satisfied	Living independently	Supported living	Expressed Concerns	Expressed Concerns
	Toby	Returned to parents' home	Dissatisfied	Living independently	None	Yes	Yes
	Fiona	Living with parents	Satisfied	Living with parents	None	Expressed Concerns	Unclear

* Previously studied at the department FE

also expressed feelings of social isolation not reported by those living at home (Freya, Lauren and Julian). Only Jacky was fully satisfied living independently. Although, none felt they would return to the family home in the future.

Ex-pupils expressed few concerns with the domestic demands of running a household; 13 ex-pupils felt they had or would have no difficulties. Financial independence and management was a greater area of concern for ex-pupils. Only three ex-pupils felt confident managing their own finances (Dennis, Jack and Toby). Six ex-pupils expressed concerns about bills (Darren, Jodie and Steven), not understanding taxes (Steven), getting a mortgage or the financial cost of independent living (Darren, Dennis, Grace and Steven), poor financial management skills (Lewis), and overspending (Grace). Of the four ex-pupils who lived independently, two had gone on to experience financial difficulties, either in the past or at follow-up (Jacky and Freya). Kirsten reported that she would still have financial support from her parents if she was to move out in the future. In general, concerns with finances came with independent living.

Overall, incidents of independent living were spread reasonably evenly across the subgroups: each of the three ex-pupils living fully independently belonged to a different subgroup (Freya, Jacky and Lauren) and the ex-pupil in supported accommodation belonged to the PD subgroup (Julian). Satisfaction levels were varied in all three subgroup but were perhaps slightly higher for the PD subgroup. Mixed levels of confidence with financial management were also expressed in all three subgroups, however only ex-pupils in the CP subgroup expressed concerns for the domestic demands of running a house hold (Emma, Lewis and Fiona): notably both Emma and Lewis spent time at the school's FE department where they would have been taught about this skills specifically.

The data for the siblings' living arrangements presented in table 5.10 All the siblings were living independently; two lived with partners and one lived in a shared house, and all were renting. All were satisfied with their living arrangements and felt they would not return to their parents' homes unless their circumstances changed significantly. Grace's sister was the only sibling to report feelings of social isolation. None of the siblings reported experiencing financial difficulties or difficulties with financial management. None of the siblings expressed any concerns with the domestic demands of running a household.

Table 5.13 – Siblings' living situation and confidence with life skills at follow-up.

Sibling	Status at follow-up	Satisfaction	Preference	Future plans	Domestic skills	Financial independence
Emily	Independent living with partner	Satisfied	Living independently	None	Yes	Yes
Petra	Independent living with family	Satisfied	Living independently	None	Yes	Yes
Thomas	Independent living with housemates	Satisfied	Living independently	None	Yes	Yes

5.3.3 Personal lives

a. Friendships in Adulthood

Twelve ex-pupils reported being part of a friendship group. Two more reported having one good friend rather than a group of friends, and one reported having no friends at all (see table 5.14). Of the 14 who reported friendships, eight were happy with their social lives. For example, Jack reported feeling popular despite his SLD. Five ex-pupils reported that they were unhappy with their social lives, and three of these felt this was because they lived in isolated areas (Freya, Julian and Lewis). Lauren reported that she did not care about her social life.

Of the three ex-pupils who reported having no friends, two were bothered by this and wanted to make new friends. Fiona found making friends difficult and felt this was due to her SLD. Grace felt that friendships were rare and difficult to find. She did have a close friend in the past but they no longer got along. Dennis also reported no real friends but was happy with this situation.

Ex-pupils also talked about loneliness. Eight ex-pupils reported never feeling lonely. These were the same ex-pupils who were also satisfied with their social lives, apart from Kirsten. Nine ex-pupils reported they felt lonely at times; two felt this was a rare occurrence but it still happened occasionally (Jacky and Jodie), two felt lonely when they were away from friends (Steven) or their partner (Lauren), and five reported feelings of social exclusion (Fiona, Freya, Julian, Lewis and Grace).

Julian: Coz like (shakes head) round here everybody hates me ... I don't know why ... I just like I can't get along with anyone.

Seven ex-pupils reported using clubs or social groups as a means to meet people. These groups were an important part of these ex-pupils' lives. Karen had recently reached the upper age limit of her social club and was setting up her own club for older individuals.

Overall, outcomes for friendships were varied across the subgroups. However, there was a pattern that ex-pupils in the CD subgroup more commonly used social clubs or groups to meet friends than ex-pupils in the other subgroups. The CD subgroup members who did not use social clubs tended to report more isolated social lives. However, two ex-pupils in the RD and PD also reported using social clubs and groups to meet people (Grace and Karen).

Table 5.15 presents the siblings' friendship outcomes. All reported being part of a friendship group and were content with their social lives. Only Emily reported being part of a

Table 5.14 – Ex-pupils' friendships in adulthood

	Ex-pupil	Friendships	Satisfied with social life	Loneliness	Social clubs/groups
RD subgroup	Grace	No real friends	Dissatisfied	Some reported	Voluntary work
	Steven	Friendship group	Satisfied	Some reported	None
	Darren	Friendship group	Satisfied	None	None
	Jack *	Friendship group	Satisfied	None	None
	Dennis	No real friends	Did not care	None	None
	Freya	Friendship group	Dissatisfied	Some reported	None
PD subgroup	Robin	Friendship group	Satisfied	None	None
	Jodie	Friendship group	Dissatisfied	Some reported	None
	Karen	Friendship group	Satisfied	None	Youth club
	Jacky	Friendship group	Satisfied	Some reported	None
	Julian	1 friend	Dissatisfied	Some reported	None
CP subgroup	Kirsten	Friendship group	Dissatisfied	None	None
	Emma *	Friendship group	Satisfied	None	Youth club
	Lauren	1 friend	Did not care	Some reported	Theatre group
	Lewis *	College friends only	Dissatisfied	Some reported	None
	Toby	Friendship group	Satisfied	None	Youth club
	Fiona	No real friends	Dissatisfied	Some reported	Several clubs

* Previously studied at the department FE

Table 5.15 – Siblings' friendships in adulthood

Sibling	Friendships	Satisfied with social life	Loneliness	Social clubs/groups
Emily	Friendship group	Yes	Rarely	Political group
Petra	Friendship group	Yes	None	None
Thomas	Friendship group	Yes	None	None

club or organisation, but she attended this for personal interest and not as a means to meet people.

b. Relationships and Children

Outcomes for relationships were also varied (see table 5.16). Six ex-pupils reported being in relationships; one had been married for 15 years (Jacky); one was engaged (Freya), three were in non-married relationships (Darren, Jack and Karen), and one was married but living with a new partner (Lauren). Three were living with partners (Freya, Jacky and Lauren) and two were planning to move in with partners in the near future (Darren and Jack). Of the six ex-pupils, two described their relationships as happy (Darren and Jacky). Freya reported difficulties in her relationship; her partner had pressured her to move away from

family and friends and this contributed to her feelings of social isolation. Karen declined to talk about her relationship¹⁶.

Ten ex-pupils reported having relationships in the past; six were not in relationships at follow-up, six reported unhappy experiences and four reported difficult break-ups (Kirsten, Steven, Lauren and Toby). Toby had been living in his partner's parental home and their break-up had forced him to return to his own parental home. Lauren got married at 18, but by 21 she had separated from her husband and was living with a new partner. She wanted a divorce but had not started legal proceedings. Two ex-pupils reported their past relationships were unhappy (Jacky and Freya). Freya's ex-partner had used her for money and eventually stole a substantial sum of her money. Two other ex-pupils reported that their past relationships were at school or college (Fiona and Robin). Robin only reported past relationships from his time at the school, and Fiona reported past relationships at college¹⁷.

Four ex-pupils had never been in relationships (Dennis, Grace, Julian and Lewis). Dennis reported he was happy with this situation and never expected it to change. Julian was unhappy and felt he would never meet a partner; he put this down to having no means to meet new people.

Overall relationships were mixed across the three subgroups, however if Karen and Fiona's relationships are discounted (this were later dismissed by their parent in 6.3.3) then they are perhaps most common in the RD subgroup. The only ex-pupil who was married with children belonged to the PD however.

Jacky was the only ex-pupil to get married and also the only ex-pupil to have a child. She had a 7-year-old son who had been diagnosed with special educational needs: autism and SLD. He also suffered from fits and required medication. His language was limited to a few words, but he had been taught sign language with some success. He was attending a language unit attached to a mainstream school but was experiencing difficulties. This was extremely upsetting for Jacky, as she saw herself in her son and was desperate for him to start talking properly. She was adamant that he would never go to boarding school and that they would move to live near him if the situation arose. However, Jacky also felt there was more support available to her son than she had had as a child due to greater understanding of SLD, more support organisations, and developments in modern technology.

¹⁶ Her mother later confirmed this was not a real relationship (this will be presented in section 6.3.3).

¹⁷ Her also parents dismissed this relationship (this will be presented in section 6.3.3).

Table 5.16 - Ex-pupils' relationships and children

	Ex-pupil	Relationship status	Past relationships	Children
RD subgroup	Grace	None	None	None
	Steven	None	Past relationship	None
	Darren	Unmarried relationship	Past relationships	None
	Jack *	Unmarried relationship	None	None
	Dennis	None	None	None
	Freya	Engaged and cohabiting	Past relationships	None
PD subgroup	Robin	None	Past relationships	None
	Jodie	None	Past relationships	None
	Karen	Unmarried relationship	Past relationships	None
	Jacky	Married	Past relationships	1 son
	Julian	None	None	None
CP subgroup	Kirsten	None	Past relationships	None
	Emma *	Refused to disclose	Refused to disclose	None
	Lauren	Cohabiting with new partner	Still married to ex-partner	None
	Lewis *	None	None	None
	Toby	None	Past relationships	None
	Fiona	None	Past relationships	None

* Previously studied at the department FE

Table 5.17 – Siblings' relationships and children

Sibling	Relationship status	Past relationships	Children
Emily	Unmarried cohabiting relationship	None	None
Petra	Married	Past relationships	1 daughter
Thomas	None	Past relationships	None

Table 5.17 presents the sibling comparison data. Two of the siblings were in married or long-term relationships (Emily and Petra) and one had experienced a long-term relationship in the past (Thomas). Petra was the only sibling who had a child. Her daughter had not experienced any SLD; however if she did, Petra stated she would make sure her daughter got the help she needed but would be devastated if that meant boarding school.

c. Spare time

Ex-pupils talked about how they used their spare time and whether they had social or solitary hobbies. Ten ex-pupils reported social hobbies. These included going out with friends (Darren and Jacky), sports (Darren, Jack, Lauren and Steven), participating in a youth group or similar organisations (Emma, Fiona, Karen and Toby), and hiking (Jacky and Lauren). Nine ex-pupils also reported more solitary hobbies: dog walking (Dennis), surfing the

internet (Fiona), yoga (Grace), swimming (Grace), watching television and DVDs (Lewis, Robin and Toby), computer games (Lewis, Robin and Toby), and listening to music (Toby).

5.3.4 Perceptions of Speech and Language Difficulties

a. Speech and Language Difficulties in Childhood

Ex-pupils were asked to describe their childhood memories of their SLD. They either reported personal experiences (eight ex-pupils), named their diagnostic label without personal reflection (Darren, Toby and Jodie), or stated that they could not remember (six ex-pupils). Ex-pupils who described personal experiences reported not being able to talk properly (Dennis, Jacky, Robin and Julian), frustration through not being able to express themselves (Dennis), difficulties understanding language and the world around them (Freya and Steven), difficulty remembering instructions (Steven), having tests and assessments (Jacky and Steven), feeling different (Dennis, Jack and Steven), difficulties with self-confidence and shyness (Grace), crying and having tantrums (Jacky), and literacy difficulties (Robin).

Jack: I've got autism, I don't really know much about it to be honest with you ... but it's just like your brain thinks differently to other people and stuff.

Only three ex-pupils remembered receiving support for their difficulties before attending the school. Freya had infrequent SLT at primary school and Jack and Jodie had classroom assistance. Grace and Jacky did not report specialist support as such, but did report an awareness of the fight their parents needed to go through when trying to get them assessed and get access to appropriate provision (parental perspective to be discussed in section 6.3.3).

b. Speech and Language Difficulties in Adulthood

Ex-pupils also talked about their SLD at follow-up. Five ex-pupils felt they were no longer bothered by their SLD in everyday life (Darren, Jack, Karen, Kirsten and Toby). Darren and Jack both felt confident with all elements of their jobs and that their SLD did not interfere with their performance. However, both felt they still had some difficulties with literacy, but they were able to hide these. Three ex-pupils felt they still had some persisting difficulties with literacy but nothing else (Jodie, Lauren and Robin). Kirsten and Karen felt their SLD had completely resolved. Toby also felt all his SLD had gone, but then acknowledged some persisting difficulties with understanding and speaking.

Other ex-pupils acknowledged persisting difficulties. Steven felt he struggled with not knowing certain vocabulary at work, but this was business vocabulary he had not been

exposed to before, rather than a direct result of his SLD. Dennis also felt he had some mild difficulties remaining; these were with pronouncing words and understanding accents.

The remaining ex-pupils reported more persisting SLD. These difficulties were with expression and understanding. Expressive difficulties included difficulties with speech (Lewis), using long words or sentences (Jacky), making themselves understood to others (Jacky), getting words mixed up when emotional (Jacky), and difficulties speaking in a group (Emma). Receptive difficulties included understanding, words and sentences (Julian, Fiona and Grace), ambiguous situations (Grace), understanding people (Freya), and college work (Emma). Three ex-pupils reported persistent literacy difficulties (Jacky, Dennis and Lewis). Additional consequences of SLD included getting frustrated with SLD (Freya), lacking confidence (Emma), difficulty making friends (Fiona), difficulty with eye contact (Fiona) and barriers to employment (Freya and Grace).

Nine ex-pupils reported needing to talk to members of the public as part of their job. Most found this easy despite their histories of SLD, but two still reported mild difficulties. Dennis disliked speaking on the telephone and preferred e-mail, and Jodie reported occasions where she found talking to people difficult, but this was rare. In addition, 16 ex-pupils reported finding it easy to do things such as asking for directions or asking for things in shops that involved speaking to someone they had not met before; the exception was Toby who reported that he would not talk to strangers.

Ex-pupils' perceptions and awareness were varied across the subgroups. All were shown to have a level of persisting difficulties with language in chapter 3 with the exception of Grace. This was not always perceived by ex-pupils. Grace still felt she had difficulties despite showing no difficulties on the assessment battery in chapter 3 (see 3.3.1). Conversely, Karen (PD subgroup), Kirsten and Toby (CD subgroup) also reported having resolved all their previous difficulties despite presenting with mild to severe and persisting language difficulties in chapter 3. Furthermore Kirsten and Toby also presented with severe nonverbal difficulties.

c. Reading in adulthood

Only four ex-pupils reported reading for leisure; this is perhaps unsurprising given their literacy difficulties (previously reported in 3.3.1). Darren, Dennis and Kirsten reported reading a small number of fiction books every year, usually between one and three. Lewis

and Steven also read books but these were factual rather than novels. Toby also reported reading books but then described this as reading the jobs section of the newspaper each week.

d. Support for Speech and Language Difficulties after Leaving the Residential Special School

Only five ex-pupils reported having access to support after leaving the school. This included, support teachers (Dennis, Jodie and Steven), SLT (Dennis and Fiona), support with literacy (Jodie), support with exams (Jacky), and free computer equipment (Steven). Jacky also went to night school to improve her literacy skills but did not consider this as extra support.

The remaining 12 ex-pupils reported no additional support after leaving the school. Only three of these reported they would have benefited from support; Lewis and Emma both wanted continued access to SLT and their families were fighting for this, and Lauren would have liked help with her literacy skills. The remaining ex-pupils all reported not needing any more support, however there could have been a reluctance to admit to support in later life, as it requires admitting to persisting difficulties. For example, Freya reported no additional support since leaving the school despite attending a specialist residential college for SLD after the age of 16 years. There was also evidence in Toby's archive file that his family had been fighting for extra support for his needs at college.

e. Siblings' perceptions of their own language and literacy difficulties

None of the siblings reported any difficulties with SLD in childhood or adulthood, and all felt they had good communication skills. The siblings all reported reading books regularly and enjoying them. They reported reading between 4 and 30 leisure books per year.

f. Technology

Sixteen¹⁸ ex-pupils reported using a computer was easy. Dennis enjoyed using computers because he felt he could compensate for his poor handwriting. Lewis also enjoyed using computers, but struggled with typing accurately because of his dyspraxic difficulties.

All 17 ex-pupils owned mobile phones. Sixteen reported having them for personal use and four reported also using them for work (Darren, Dennis, Jodie and Steven). Toby reported having a phone as something he could use in an emergency only. Eleven of the 16

¹⁸ Julian had no access to a computer at follow-up and this made him feel unqualified to answer any questions regarding his computer use.

ex-pupils used their phones for personal use reported finding writing text messages easy, however five reported this was difficult and this was because of spelling difficulties (Dennis, Julian, Lewis, Lauren and Robin). The three siblings also reported that using computers and mobile phones was easy.

g. The future

Finally, ex-pupils talked about their hopes for the future. Seven wanted to get new jobs and earn more money, two wanted to live independently (Emma and Steven), one wanted a better social life (Grace) and two wanted to get married and have a family (Jodie and Jack). The remaining ex-pupils either reported that they were happy with everything or did not know what they wanted from the future. Finally, Jacky talked about her wish for a 'normal' child, but knew that this was something she could not resolve.

5.4 Discussion

5.4.1 What are the Psychosocial Outcomes for Adults with Childhood Histories of Severe and Complex Speech and Language Difficulties?

The ex-pupils' psychosocial outcomes were varied. Eight ex-pupils gained GCSEs mostly in the D-G range, all ex-pupils attended some kind of post-16 educational placement and eleven gained formal qualifications from this; these were typically vocational (see table 5.5). Dockrell et al. (2006), reported similar wide ranging performance and grades at GCSE for individuals with similar but less severe difficulties. Many of these individuals also went on to FE after finishing compulsory education. Other follow-up studies have reported poor academic performance for individuals with persisting SLD (Clegg et al., 2005; Snowling et al., 2001; Young et al., 2002). This suggests a relatively positive outcome for the ex-pupils and the school.

Furthermore the finding that all the ex-pupils enrolled in post-16 education is also more positive than some previous research findings. Records et al. (1992) reported fewer individuals with SLD enrolled in post-16 education than those without SLD, and in Howlin et al.'s (2000) study none of the DLD cohort went on to post-16 education. This is also a higher enrolment rate than reported by Haynes and Naidoo (1991); almost two thirds of their ex-pupil cohort went on to post-16. This suggests more ex-pupils of the school now attend post-16 education than in the past. Although it should be noted that Haynes and Naidoo (1991) had a larger ex-pupil cohort and therefore a more powerful estimate of the proportion of ex-

pupils that go on to FE. Even so, these findings suggest more individuals with SLD now attend post-16 education than in the past. This idea has recently been suggested by Dockrell et al. (2006) and Durkin et al. (2009). The current research lends further support to these findings.

The ex-pupils' employment outcomes were also relatively positive and similar to the findings by Aboagye (2001) and Felsenfeld et al. (1994); findings were relatively positive when compared to other previous research (e.g. Clegg et al., 2005; Howling et al., 2000). The majority of ex-pupils were in paid employment and their jobs ranged from skilled full-time paid work to unskilled work. This suggests more employment opportunities for individuals with SLD than previously speculated (Conti-Ramsden et al., 2008; Snowling et al., 2001) but that there is also a risk of poor employment outcomes for individuals with SLD. However, four ex-pupils did report difficulties at work that left them feeling either discriminated against because of their SLD or unable to progress their careers. Two of these were more career-driven cohort members. This suggests that while the ex-pupils did experience relative success the most driven cohort members still encountered some closed doors (as in Snowling et al., 2001). Even so, ex-pupils got along well with colleagues and bosses and there was only one case of bullying at work. This was more positive than findings by Clegg et al. (2005), who reported more frequent incidence of bullying at workplace.

Cases of independent living in this cohort were few; only four ex-pupils were living away from home and just one was a home owner. Individuals with SLD risk poorer levels of independence in later life (Conti-Ramsden and Durkin, 2008) and therefore poorer performance in this domain could be predicted. These findings are similar to Clegg et al. (2005) who reported mixed independent living outcomes for adults with DLD; success was slightly higher among their cohort, however their average age was also higher and therefore would have had longer to achieve independent living. Aboagye (2001) also reported all four of her cohort achieved independent living; these individuals were more like the cohort seen in this project but of an age similar to the DLD cohort seen by Clegg et al. (2005). Therefore more ex-pupils may have achieved independent living by their mid 30's.

Financial independence and management appeared to be the biggest obstacle preventing the ex-pupils from achieving independent living; ten ex-pupils reported difficulties or uncertainties with managing money. Few studies have reported on the economic outcomes for individuals with SLD however, Clegg and Henderson (1999) suggest

it is likely to be an area of difficulty. This was an area where many ex-pupils were likely to need ongoing support.

Fourteen ex-pupils in the current study reported friendships, eight were happy with their social lives and six ex-pupils also used social clubs or group to meet people. Again this was similar to findings by Aboagye (2001) who reported all her cases to have active social lives. Other findings in the literature have report poorer outcomes social relationships for individuals with SLD (Beitchman et al., 2001; Clegg et al., 2005; Howlin et al., 2000; Johnson et al., 1999). However, the present findings showed more variance in friendship outcomes than Aboagye (2001) as five ex-pupils still felt socially isolated.

Relationships were perhaps the area where ex-pupils experienced the least success. Six were in relationships at follow-up (but it was unclear if one was genuine) and only two of these were happy. A further six reported unhappy experiences in the past, and four reported having never been in relationships. The literature predicts very poor outcomes for close committed relationships for those with persisting SLD (Billstedt et al., 2005; Clegg et al., 2005; Howlin et al., 2000) although others have reported more positive findings (Aboagye, 2001; Records et al., 1992). These findings suggest this to be an area of difficulty for adults with persisting SLD. However, again the relatively poor findings could have been due to some of the cohort members being too young to have had the opportunity to start serious relationships or get married. In support of this the oldest cohort member, Jacky, was the only ex-pupil to be happily married, although conversely, Dennis (the second oldest cohort member) had never been in a relationship.

From these findings we can conclude that the ex-pupils experienced relatively positive though varied outcomes across the different life domains. Overall as a cohort the ex-pupils experienced more positive outcomes in some of the achievement domains (e.g. academic achievement and employment) than the personal domains (e.g. relationships); however outcomes for independent living were still relatively poor and outcomes for friendship were more positive than may be expected and therefore did not conform to this. Ex-pupils experienced greatest difficulty with independent living, financial management and relationships. Therefore it is likely that these will be an area of potential difficulty for adults with persisting SLD.

5.4.2 How Do the Ex-pupils' Perceived Levels of QoL Compare to their Psychosocial Outcomes?

The present research findings highlighted some cases where the disability paradox occurred (Albrecht and Devlieger, 1999): this is when individuals with disabilities perceive high levels of QoL for themselves while external observers may perceive something less positive. For example, four ex-pupils were still content living at home with their parents and showed no motivation to gain independently in the future. Fiona was also content with her voluntary work and had no plans to obtain paid employment in the future despite the advantages of having an income. Dennis was happy with a solitary social life, limited network of friends and having never had a partner at almost 36 years of age. These are situations where society will assume a reduced level of QoL while the individual may perceive themselves to have a high level of QoL. This is comparable to findings by Shelly et al. (2008) and Rosenbaum et al., (2007) that children and young people with cerebral palsy perceive high levels of QoL for themselves despite poorer levels of functioning.

There is also a theory that individuals with SLD may learn to expect less for themselves. This was suggested by Durkin et al., (2009) to explain why adolescents with SLD who experience poorer academic outcomes still report high levels of satisfaction with the achievements. Although this is a positive finding the authors expressed a concern that this was due to individuals with SLD expecting less for themselves. The present findings may suggest that lower expectations can occur in multiple life domains.

However, examples of the reverse situation also occurred; some ex-pupils who experienced greater success expressed less personal satisfaction towards this. For example, three of the four ex-pupils living independently reported feelings of dissatisfaction even though eight ex-pupils living with their parents were striving to achieve this. Four ex-pupils who were employed expressed a level of dissatisfaction with their jobs.

In conclusion, the present findings show some support for the disability paradox (Albrecht and Devlieger, 1999). However, it did not appear to apply to all ex-pupils especially the higher achieving cohort members. Furthermore, there is a potential danger that some individuals with persisting SLD may set lower expectations for themselves in adult life (as in Durkin et al., 2009). These findings also show that perceived QoL and levels of functioning are different and should be measured separately to gain a complete measure of QoL (as in Shelly et al. 2008).

5.4.3 What are the Ex-pupils' Views on Special Schooling and Mainstream Education?

The ex-pupils in this project reported an overwhelming preference for special schooling or language units over mainstream schooling. Ex-pupils also reported experiencing more difficulties accessing education and forming peer relationships while at mainstream educational placements prior to their time at the school; Dockrell and Lindsay (2008) identified these as risk factors for children with SLD entering mainstream education. None of the ex-pupils favoured mainstream schooling, apart from Dennis who had been the only ex-pupil to return to mainstream schooling for after entering the residential special school.

Furthermore, ex-pupils also felt the support they received at the school was appropriate for their needs, that it was the right school and that it prepared them for life as adults. Dockrell et al., (2006) reported that children with the most severe and complex SLD are more likely to be educated in special schools and received direct intervention for their needs. This was the case for the ex-pupils in this project and the majority felt this had been appropriate.

However, attending special school came with costs. Boarding was a difficult and upsetting experience for many ex-pupils. They also lost contact with friends once they left and several felt that this contributed to their limited friendship groups as adults. A minority of ex-pupils also reported that while it had prepared them for most aspects of life as adults, the school failed to prepare them for some things because it had an overprotective ethos; this was due to limited experiences of the world outside the school and had made the world outside feel more threatening when they left. A minority of ex-pupils also felt attending a special school meant they were taught a more limited curriculum and had fewer opportunities to gain GCSEs. Even so, specialist education was still favoured over mainstream schooling by the majority of ex-pupils.

Twelve ex-pupils did return to mainstream education after finishing compulsory education; five ex-pupils began to experience further difficulties with mainstream education once again. The FE department was seen as a positive and necessary addition to the school by all, however, not all the ex-pupils felt it would have been right for their needs at that time. These tended to be the ex-pupils who felt ready to move on with their lives. The three ex-pupils who did stay found it an extremely positive and beneficial experience. These findings therefore lead support to those who advocate special school over inclusive education (e.g.

Dockrell and Lindsay, 2008; Lindsay, 2007). This is the case for both the compulsory education years and post-16 years.

5.4.4 Is there a Relationship Between the Psychometric Data Presented in Chapter 3 and Psychosocial Outcomes?

The ex-pupils were divided into subgroups based on their performance on psychometric testing at follow-up in chapter 3: the RD subgroup, the PD subgroup and the CD subgroup. This chapter compared the psychosocial outcomes of these three subgroups. There was a pattern where the ex-pupils with the most severe and pervasive SLD at follow-up also experienced the most difficulties with educational achievement and employment. There was also a pattern that members of the CD subgroup more frequently belonged to social clubs or groups.

The RD subgroup had the most qualifications while the CD subgroup had gained the fewest. This suggests a pattern that individuals with more pervasive and persistent difficulties will perform more poorly academically and is comparable to the findings by Aboagye (2001). This is perhaps not surprising, as children who enter school with SLD will be disadvantaged academically (Dockrell and Lindsay, 2008; Nathan, et al, 2004b) and therefore risk of poorer educational attainment in later life (Snowling et al., 2001; Young et al., 2002). These findings support that of Snowling et al., (2001) who showed that individuals with persisting-SLI performed more poorly at GCSE than those with resolved-SLI. Dockrell et al (2007) also showed high levels of individual differences at GCSE for adolescents with SLD, and also found that those with the most severe levels of SLD were less likely to go on to post-16 education. This may also be due to poorer academic performance as a result of more severe and pervasive SLD. Overall, these research findings show support for there being a relationship between levels of persisting SLD and academic achievement.

The RD subgroup also had the best employment outcomes, the most stable employment histories and tried harder to progress their careers compared to the PD and CD subgroups. Furthermore, all members of the RD subgroup all had jobs that had required them to complete specialist training, compared with half the PD subgroup and none of the CD subgroup; though 2 of the CD subgroup were still in full time education. Thirdly, none of the RD subgroup had experienced a period of unemployment. This therefore suggests a further relationship between the severe and pervasive SLD and later employment success. This could be the result of employment opportunities being dictated by academic success (as in

Snowling et al., 2001). This could also confirm concerns reported by Conti-Ramsden et al., (2008) that individuals with persisting SLD may have more limited employment opportunities available to them. Furthermore, limited employment opportunities could also be due to some individuals to experiencing more difficulties gaining and keeping employment as a result of their persisting SLD.

It should be noted, that the CP also had the youngest median age and two subgroup members were still in full time education making it the only subgroup to have members still studying. This could therefore skew the results as two CP subgroup members would not have had the chance to gain employment by the time of follow-up. A similar issue was reported by Records et al (1992) as their cohort was still relatively young and may not have had time to achieve certain life goals.

There were no clear patterns for friendships across the subgroups specifically: however attendance at a social club or group was most common in the CD subgroup. This may suggest that the CD subgroup were more reliant on organisations to build up social networks than the RD and PD subgroups. Durkin and Conti-Ramsden (2007) suggested a link between the severity of an individual's SLD and their risk of poor social relationships. Therefore the CD may have more difficulty in forming social relationships compared to the other subgroups but are able to compensate for this by using social clubs or groups to meet people. Aboagye (2001) also reported similar findings for her cases; they experienced full and active social lives and also belonged to a range of social clubs and groups. Overall, friendships were equally varied across all three subgroups. Poor friendship outcomes appeared to be most closely related to whether ex-pupils lived in isolated areas and the ex-pupil's perceptions on how important a social life was to them, rather than the severity and pervasiveness of their SLD.

There were no other patterns to suggest potential relationships between subgroup membership and psychosocial outcomes: for example in independent living; financial management, or relationships. This suggests that these outcomes were more likely to be determined by other factors such as personal circumstances.

5.4.5 How do the Ex-pupils' Psychosocial Outcomes Compare to that of their Nonlanguage Impaired Siblings?

The findings that can be drawn from the sibling and ex-pupil comparisons are limited due to the small number of siblings and should therefore be treated with caution. However, they suggest that the siblings experienced more success at outcome than the ex-pupils. Similar findings were reported by Clegg et al. (2005) for employment and independent living, and by Durkin et al. (2009) when comparing the academic outcomes of adolescents with persisting SLD with their nonlanguage impaired siblings.

In the present study each sibling experienced more success academically than their respective ex-pupil pair. Furthermore two siblings had gained university degrees compared with none of the ex-pupils. All three siblings were in paid full time employment, two of these were skilled jobs and none had experienced any difficulties at work and all had relatively stable employment histories. Freya's brother in particular had experienced high levels of success in employment compared with his sister. Like Grace, her sister also expressed some dissatisfaction with her job at follow-up and that she wanted to move jobs in the future; however this was on a much smaller scale to the difficulties Grace experienced at work. All the siblings were living independently, however none owned their own homes. Freya was the only respective ex-pupil pair to have also achieved independent living. All the siblings were happy with their social lives compared with just one of the respective ex-pupil pairs: Robin. Both Grace and Freya has reported a level of unhappiness with their social lives and feelings of social isolation. Finally, two of the three siblings were in relationships and all had experience serious relationships in the past. Freya was the only ex-pupil with a sibling pair in a serious relationship at follow-up: Grace reported having never been in a serious relationship and Robin reported no serious relationships since attended the school and therefore none in his adult life.

In conclusions, these findings tentatively agree with findings by Clegg et al. (2005) the adults with persisting SLD are likely to experience poorer psychosocial outcomes when controlling for genetics and family environment. However, these findings would need to be replicated on a larger scale before more confident conclusions can be drawn.

Chapter 6 – Parents and Siblings’ Perspective on having a Family Member with Speech and Language Difficulties

6.1 Research Questions

This chapter presents the findings from interviews with the parents and siblings of the ex-pupils followed-up in chapters 3 and 5. The primary aim of these interviews was to gain a family perspective of the lives of the ex-pupils and compare that to their ex-pupils’ perspective.

The research questions for the family study are as follows:

1. What is the impact of having a child with SLD on the family?
2. What are parents’ views on support services and special schooling?
3. To what extent do the findings from the interviews with the family member match those from the interviews with the ex-pupils?

6.2 Methodology

6.2.1 Design

The study employed a qualitative methodology to understand the perspectives of the ex-pupils’ parents and siblings. The participants all completed semi-structured interviews that aimed to elicit the participants’ views, perceptions and experiences of a range of topics concerning the ex-pupils’ childhood and time at the school. The parents were also asked for their perceptions of the ex-pupils’ psychosocial outcomes in adulthood. The siblings were not asked to provide their perceptions of the ex-pupils’ psychosocial outcomes as the parents already provided a proxy measurement and the siblings had previously been interviewed regarding their own psychosocial outcomes reported as chapter 5.

6.2.2 Participants

The parents and siblings were recruited through the ex-pupils. Once each ex-pupil had completed their part in the project they were asked if they would be willing to consent to have a parent and a sibling to participate in the project. If their response was positive they

were asked to provide a contact address for a parent and a sibling or were given letters to pass on to their family members. These letters explained the nature of the project, that their family member had already taken part and contained an information sheet, response form and stamped addressed envelopes. Positive responses were follow-up with a telephone call and a meeting with the researcher was arranged.

The parents of 9 of the ex-pupils were recruited; this came to a total of 12 parents overall (8 mothers and 3 fathers) because both parents were interviewed together in 3 cases (see table 6.1). One of the 8 mothers seen was the mother of an ex-pupil who took part in the pilot study for the FE project that will be presented in chapter 8. She wanted to communicate views regarding many of the topics covered in the interview and was very keen to participate.

Table - 6.1 The families who took part in the project

	Family member	Ex-pupil	Ex-pupil age	Ex-pupil cohort	Other siblings who did not participate
Parents	Mary (M)	Jacky	38;02	21-38 years ex-pupils	Younger brother
	Amanda (M)	Dennis	35;11	21-38 years ex-pupils	Three older brothers
	Trevor (F)				
	Edith (M)	Karen	26;09	21-38 years ex-pupils	Older brother
	Jenny (M)	Grace	26;03	21-38 years ex-pupils	None
	Dawn (M)	Fiona	25;00	21-38 years ex-pupils	Older brother (deceased)
	Robert (F)				
	Rachel (M)	Freya	24;10	21-38 years ex-pupils	Youngest brother
	Samantha (M)	Emma	19;07	19-21 years attended FE	Older sister
Siblings	Sandra (M)	Lewis	19;08	19-21 years attended FE	Younger brother
	Roy (F)				
	Stacey (M)	Jason**	16;##	Not ex-pupil attending FE	Two older brothers
Siblings	Petra (S)	Robin	27;09	21-38 years ex-pupils	Youngest sister
	Emily (S)	Grace	26;03	21-38 years ex-pupils	None
	Thomas (B)	Freya	24;10	21-38 years ex-pupils	Youngest brother
Other*	Nigel (B)	Dennis	35;11	21-38 years ex-pupils	One of Dennis's three older brothers

* Like Dennis Nigel also attended the school but did not participate in the project. However, their parents discussed both sons at interview. Therefore reference will be made to Nigel in the results.

** Was recruited for the pilot study for the FE study reported in chapter 8. Change if decide not to report M = mother, F = father, B = brother, S = sister.

Her data is presented in this section with the other parents but her son's data is unlike the other ex-pupils and reported earlier in this thesis.

Siblings for 3 of the ex-pupils were recruited. These were the same siblings that were reported in chapters 3 and 5. In addition, the chapter will make occasional reference to a fourth sibling: Nigel. This is Dennis's older brother who also attended the school but could not be recruited to take part in the study. Dennis's parents, made many references to Nigel during their interview and these are also presented.

Recruiting family members proved difficult as it required the consent of both the ex-pupil and the relative. The eventual numbers were small as it was often difficult to gain consent from both parties, especially when recruiting siblings. In addition, not all ex-pupils had a sibling who could be approached to take part.

6.2.3 Ethics

This study was approved by the University of Sheffield ethics committee in the department of HCS prior to any contact with participants (see appendix A4.1). Participants had the nature of the research project explained to them before they agreed to take part. Participants were also given the opportunity to ask questions before and after taking part. They were made aware that: that their anonymity would be maintained, and that they could withdraw at any time. They were also advised that it would be helpful if they agreed to be recorded during the study session and given the option to be video recorded and/or audio recorded or not recorded at all. No participant was pressured to be recorded if they felt uncomfortable. Each participant was also given the choice whether to allow the use of their comments and/or interview recordings in research presentations. Their response to these questions did not affect their participation in the project.

6.2.4 Materials

The parental interview schedule used in this study was modified from the ex-pupil interview schedule (see chapter 3). It was adapted to elicit a proxy perspective on the ex-pupils lives, and also included an additional section about the ex-pupils' childhood. The sibling interview schedule used in chapter 6 was shorter than the parental interviews (as siblings completed long interview schedules as part of chapter 5) but were also modified from the ex-pupil interview schedule. The ex-pupil interview schedule was originally modified from an interview schedule devised by Rutter, Couteur, Lord, MacDonald, Rios and Folstein

(1988) by Clegg et al. (2005), and then further adapted for use in the present project (this was detailed in 5.2.3).

The parental interviews included: experiences of being a parent of a child with SLD; childhood language development; education at the school and at other schools and colleges; post-16 educational provision; the nature of ex-pupils SLD in adulthood; employment; friendships; relationships; grandchildren; independent living, and finances. The siblings were asked for their views on the ex-pupils' lives and what they could remember about them attending the school. These interviews covered the siblings own psychosocial outcomes, this was previously reported in chapter 5.

During the interviews each topic was discussed in as little or as much depth as the participant wished. Participants were made aware that they did not have to answer any questions they did not want to. The interviewer had a series of prompts she could use to steer the interview to elicit further relevant information. However as the interviews were semi-structured it was possible for the participants to talk about other relevant topics of their choosing.

6.2.5 Procedure

As the participants lived all over the UK they were given the option to meet the researcher either at the Department of Human Communication Sciences at the University of Sheffield, at the school, or at their own homes. A quiet room was found for the interviews to take place in each case.

At the meeting each participant was given copy of the information sheet to remind them of the purpose of the study and a consent form to sign. Care was taken to make sure that each participant understood the nature of the study, given the opportunity to ask questions and was put at ease before the interview began. The interviews lasted between 45 minutes and 2 hours depending on how much the participant wanted to talk. The participants were also offered breaks if they needed them. Once the interviews were completed participants were offered a further opportunity to ask questions if they had any.

6.2.6 Data analysis

These interviews were analysed using NVivo following the methodology described in 5.2.6. See figure 5.1 for the methodology used to devise the coding system used in this analysis. Once the analysis was complete a 2nd coder scored 2 full interviews using the final

coding system; interrater reliability was shown to be 80.00%. See appendix A2.2 for the final coding system and A3.2 for a worked example.

6.3 Results; Family Case Studies

The themes that emerged from the qualitative analysis are presented in three sections: family experiences of SLD; experiences of the residential special school and other support services, and perspectives on the ex-pupils' psychosocial outcomes. This third section will present both the parents' and the ex-pupils' perspectives for comparison.

6.3.1 Family experiences of Speech and Language Difficulties

a. Parental Views on the causes of their Children's Speech and Language Difficulties

This concerned experiences surrounding early childhood and child development. Three parents reported a specific underlying cause for their children's SLD; incidents in early infancy that were believed to have resulted in a lesion to the brain (Emma and Karen), and the MMR vaccine (Jason).

Samantha: (Emma) was a (near) cot death baby so I knew there was damage.

Parents also reported a range of developmental delays (see table 6.2, page 142), and that the ex-pupils displayed obvious developmental differences compared with their siblings when they were growing up (Fiona and Freya).

Rachel: With the ... retrospectoscope as they say it was very obvious from the word go that she didn't communicate ... she was very different to her big brother.

In addition, Grace's sister reported an awareness when they were growing up that her sister had difficulties that she did not.

b. Early Speech and Language Difficulties

The parents of 8 ex-pupils reported that their children experienced speech delays (see table 6.2).

Dawn: She (Fiona) couldn't speak one word when she first started school.

Three ex-pupils reportedly displayed some pragmatic/social difficulties, e.g. echolalia.

Jenny: I would say 'would you like?' ... And she (Grace) would say 'you like' ... back to you.

Motor co-ordination difficulties were also noted (Dennis and Grace) reportedly. Emma was

felt to have experienced a more general cognitive delay rather than a delay to her speech and language, however she did experience word finding difficulties.

Dennis's parents commented that his SLD had been greater than his brother Nigel's and they had an impact on his ability to write and draw. Grace's mother (and sister) commented her reading and writing skills were advanced for her age and that she had taught her sister to read and write before she started school.

c. Childhood Behavioural Difficulties and Frustration

Seven parents described behavioural difficulties associated with their children's difficulties (see table 6.2). For example, Dennis (and his 3 brothers), Jason, Karen and Grace were said to be frustrated as children because they had difficulties expressing their needs, which became manifested in poor behaviour. Similarly, a child psychologist concluded Fiona was also frustrated however her parents felt she did not display behavioural difficulties and disagreed. Jason displayed extreme behavioural difficulties; these eventually resulted in his mother losing access child care for him and family no longer visiting the house.

Stacey: (Jason) was the most bizarre erratic child and he used to scream all the time he wouldn't sleep he wouldn't eat he refused food he use to throw the food that I gave him everywhere erm we couldn't go to play groups or anything like that because he was a monster he use to attack other children ... he use to climb he was completely unaware of any danger at all not a bit concerned at and all just do wild things ... absolutely had to watch him twenty four hours a day seven days a week cause he doesn't sleep either.

Freya, Jason and Grace were also said to be frustrated as children; this was because they had difficulty understanding the world around them associated with comprehension difficulties. This also had implications for discipline and keeping the children out of danger as well the appearance of poor behaved. Lastly, Dennis (and his 3 brothers) and Lewis were said to display hyperactive behaviours rather than frustration.

d. Parental Coping Strategies

Parents implemented various strategies to try and support their young children in the home. These strategies included: structuring their children's time (Freya); talking to and teaching their children about the world (Emma); encouraging the child to express when they had not understood (Fiona); practicing SLT exercises at home (Lewis); using pictorial communication aids (Lewis); explaining the consequences of difficult or challenging

behaviour (Freya), and controlling the environment to minimize stressful situations that could trigger behavioural difficulties (Jason).

e. Experiences of Boarding at the Residential Special School

All the ex-pupils whose family members took part in the project had been boarders apart from Jason. Most parents only commented on the negative aspects of boarding. Several parents found having their children living away from home emotionally challenging (Amanda, Samantha, Mary, Dawn and Robert and Edith).

Mary: But I used to ring and I used to say 'hello (Jacky) are you alright' and she used to be crying ... course she couldn't tell me what's wrong ... it were just heart breaking.

Samantha: And we felt she was growing up in a different environment ... it was hard.

Negative feelings towards boarding included: finding it difficult to have someone else looking after their child (Dawn and Samantha); feeling someone else would not be able to look after their child as well (Jenny); opposing sending their child to boarding school (Robert), experiencing a family feud caused by a relative who strongly disagreed with sending the family member to boarding school (Samantha).

Samantha: I've got a sister who didn't agree at all with going to boarding school ... she sort of said I don't know why you've had children if you've sent them away to school ... and obviously just didn't understand.

However, Jacky and Karen's mothers both felt it had been the right decision to send their children to a boarding school overall.

Grace, Fiona and Dennis's mothers talked about their children returning home at weekends, but this was not described as a positive experience. Grace's mother found it 'surreal' as her daughter was away so much of the time. She also felt that Grace found weekends at home with family boring as the weekends at the school were spent doing activities. Fiona's mother reported their family had no social lives at weekends because their time was taken up with Fiona's activities. Dennis's (and Nigel's) mother tried to organise activities for her children when they came home but soon realised that this was not what they wanted.

Amanda: And I think I must have been a bit thick because when (Nigel) came home we used to plan all sorts of treats ... and it took me months to realise that all he actually wanted was to be home ... he wanted to have his cat with him he wanted to go in his bedroom and very often he'd just go in his bedroom by himself and just be by himself because they don't get much space to themselves in those sort of schools ... he liked to have his own sort of space.

Conversely, Freya's mother did not find boarding upsetting as all three of her children attended boarding schools because they lived in a remote location. Lewis's parents were the only parents to report positive aspects of boarding; they felt Lewis enjoyed it and appreciated the rest from his care when he went away.

Eventually Dennis' parents relocated so he could become a day pupil. Jacky's family also considered moving closer but this was not practical. Jason's mother felt relieved that they lived close enough to the school for him to be a day pupil and that he could not have coped with boarding. Parents also expressed negative views on how they felt their children experienced boarding. Dennis and Nigel had disliked the communal living and Emma found it difficult being one of very few girls.

Parents also commented on the journeys to and from the school as many families lived far from the school. Some ex-pupils had funded taxis or transport that took them to and from school (Freya, Jason, sometimes Dennis) but other families had to do the travelling themselves (Fiona, Emma, Jacky and Fiona, sometimes Dennis); this was either because there was no funding for taxis or because they chose to spend the journey with their child. These journeys were costly to families in terms of time and money, and often affected parent's working hours. Jacky and Fiona's mothers described taking their child back to school as emotionally challenging.

f. The siblings' Perspective

Freya's brother was older and had been aware of his sister's difficulties as a child and described that he would sometimes 'translate' her speech as he understood what she was trying to express better than their parents did as they were closer in age. Grace and Robin's sisters were both younger and did not report the same level of awareness of their sister's SLD and described feeling their siblings were no different from them when they were growing up. Robin's sister first became aware of his SLD when he started attending the residential special school and not because she noticed them specifically. She also felt this had been especially

Table 6.2 - Summary of ex-pupils' difficulties as reported by the parents

Ex-pupil	Physical cause	Milestones	Speech	Cognition	Pragmatic and social difficulties	Behavioural difficulties	Family History of SLD or Lit. difs.
Dennis	None	Delayed	Delayed	Not reported	Not reported	Hyperactive	Yes
Fiona	None	Not reported	Delayed	Not reported	No imaginative play	Frustrated?	No – true fam. hist. unknown
Freya	None	Not reported	Delayed	Not reported	Not reported	Frustration	Yes
Grace	None	Not delayed	Not Delayed	Not reported	Echolalia	Frustration	Yes
Jacky	None	Not delayed	Delayed	Not reported	Not reported	None	Not before Jacky
Karen	Stroke	Not reported	Delayed	Not reported	Not reported	Frustration	No
<i>Nigel</i>	<i>None</i>	<i>Delayed</i>	<i>Delayed</i>	<i>Not reported</i>	<i>Not reported</i>	<i>Hyperactive</i>	<i>Yes</i>
Robin	None	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
Emma	Near cot death	Not delayed	Not delayed	General difficulties	Not reported	None	Yes – but unrelated
Lewis	None	Delayed	Delayed	Not reported	Not reported	Hyperactive	No
Jason	MMR Vaccine	Not reported	Delayed	Not reported	No eye contact	Severe	Yes

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Lydia Anson

upsetting for their younger sister.

Siblings also found boarding difficult because they missed the ex-pupils when they went away (Grace and Robin).

Petra: I know I was upset every time he went coz (Robin) was upset coz he didn't wanna go and I don't think any of us wanted him to go but we knew that at the end of the day it was the best thing for him.

Again, Freya's brother did not feel this as all the children in the family attended boarding school. In addition, Karen's mother commented that Karen's brother did not want her to go to boarding school. These findings suggest that boarding also difficult for parents and siblings as well as for ex-pupils.

As adults the ex-pupils and siblings experienced mixed relationship outcomes. Positive experiences included, Grace and Robin's sisters both felt they had been normal with their siblings as adults. Freya and her brother independently agreed they got on as adults, as did Grace and her sister. However, with hindsight Grace's sister wondered if she might have formed a stronger bond with Grace had she not gone away to school. Karen's mother also felt her son was now very protective of Karen as an adult because of the time she had from home. Negative outcomes included two cases of sibling jealousy; Dennis and an elder brother and Jacky and her younger brother. This was based on parental reports as these siblings did not participate. Dennis and Nigel's mother felt this had been caused by boarding and they got more attention when they came home. Jacky's brother reportedly never told his school friends she had SLD. This upset Jacky's mother because she felt he was ashamed of Jacky.

Mary: Something that (Jacky's brother) did say that really hurt me he never told anybody where he use to go on the Sundays ... never told his mates ... so that quite hurt me coz I says 'oh never be ashamed ... of our (Jacky)'.

Grace's sister also never told her peers that her sister went to a different school but this was to protect Grace from being bullied.

g. Knowledge, Information and Understanding of Children's Speech and Language Difficulties

Parents felt there was a general lack of information or understanding of children's SLD. This meant people might assume their children lacked intelligence (Dennis and Jason), were poorly behaved (Grace, Freya and Jason) and or that they were deaf (Fiona and Jason). Fiona's mother also commented that a professional had wrongly assumed Fiona would never learn to drive.

Jenny: If you were as a group of young mums with your children playing together ... it was a little bit hard ... because you know that it isn't your child that's being naughty ... they can't help it.

Overall there was a consensus that SLD were little understood, not publicised and that few people knew how to cater for children with such difficulties. Jason's mother stated:

Children they do that every day ... the times I've heard it ... because it's not obvious
Stacey: We wouldn't say to a child in a wheelchair right come on get up ... but with Autistic.

Parents also talked about the difficulties they had finding information for themselves. Freya's mother reported that she had no information until Freya received her diagnosis of Semantic Pragmatic disorder. Grace's mother did not understand how Semantic Pragmatic disorder manifested itself when Grace was diagnosed. Jason's mother also reported a similar naivety when Jason had been younger.

However, there was also a consensus that there was more information and understanding at the present time compared with in the past and that this had a direct effect on current support services. Parents felt that the reasons for this included: an increased understanding of SLD (Fiona and Dennis's parents); more resources available to families today than in the past, and that children with difficulties are picked up earlier (Jacky and Freya's mothers). Jacky's mother made a direct comparison between the services available when Jacky was a child and the services available to her grandson. Despite this parents still felt more needed to be done.

Another development was the increased amount of assistive technology available, Dennis and Jacky's mother both felt that their children had this. Dennis and Nigel could both use spell check well as part of their jobs. Jacky's mother could directly compare the technology that was available when Jacky was a child to that available to her grandson now. She felt that Jacky would have benefited from computers as a child.

6.3.2 Experiences of the Residential Special School and other Support Services

a. Experiences of Support Services before Ex-pupils Attended the Residential Special School

Parents reported mixed experiences of support services from before their children attended the school. All the ex pupils had received SLT apart from Emma who had been referred but no provisions were made available. Four parents reported positive experiences

with regard to: early identification of SLD (Karen and Grace); prompt placement at the residential special school following diagnosis, and having access to a skilled SLT (Dennis and Nigel).

However, these parents felt they had been lucky because they considered their positive experiences unusual. This was strengthened by the fact that more negative experiences were reported than positive. Some negative experiences concerned acquiring a diagnosis of SLD. Lewis and Jacky's SLD were both reported to health professionals during early childhood, however both were turned away as they were felt to be slow developers. Dennis's mother reported an educational psychologist had tried to label Dennis and Nigel as having general learning difficulties which she felt was inappropriate. Five parents reported inadequate SLT provisions (Jason, Fiona Emma, Jacky and Lewis), and Jason's mother also had difficulty accessing all support services for Jason because her Local Education Authority (LEA) was underfunded and his behavioural difficulties were so severe that nobody wanted to work with him.

b. Statementing

Parents viewed statementing as crucial as it forced the LEA to provide support for their children (Fiona, Emma and Lewis's parents). Furthermore, parents also felt it was important to get children statemented as early as possible so they could start getting the right support they needed (Jacky, Karen, Jason and Fiona's parents).

Dawn: But when (Fiona) was statemented so they (The LEA) had to pay.

All ex-pupils went through this process, however this was often not straightforward. Parents reported obstacles to getting their child statemented: the statementing process was confusing (Grace); not understanding their child's difficulties (Grace); difficulties with formal diagnosis as their child had not fully fitted the criteria for any diagnostic labels (Grace); requiring multiple assessments (Jason); having to wait a long time for the statement to be written (Karen); having to pay for additional statements (Emma and Fiona), and having to fight to have SLT provision included as a compulsory element of the statement (Lewis). Two parents also described initially being referred to schools they felt had been inappropriate for their children's needs (Grace and Jason). Freya's mother was an exception and the only parent to find the statementing process experience.

c. The Fight for Access to Support Services

All parents stressed the need to fight to get the right support for children with SLD. Five families reported having an especially difficult time with support services (Jason, Fiona, Lewis, Grace, and Dennis). Parents needed to be persistent and assertive to gain access to support and this was stressful and upsetting. Three parents felt their local education authorities (LEAs) were reluctant to help due to cost (Stacey, Robert and Roy). Parents typically had to find out what support services were available themselves as information was often not offered freely.

Jason's mother experience was especially traumatic. She felt that the LEA had taken advantage of her lack of knowledge when Jason was a young child and denied him support he would have been entitled to. Getting Jason a place at the school had also been a hard fight that went to tribunal. Following her own experiences she had become proactive in her local community and was actively helping other parents of children with SLD fight the LEA.

Conversely, Freya, Grace and Karen's mothers were all relatively satisfied with their LEAs and reported that they had not had to fight with the authorities. Grace and Karen's mothers both felt this was because their children were identified and got into the system early. All three mothers felt that they were in a minority and their good fortune had not been typical.

The parents of 4 ex-pupils reported feelings of exhaustion when raising their children due to the demanding nature of their children's care (Lewis, Jason, Freya and Grace). Fiona's parents also reported exhaustion but attributed this to their continuing fight with support services. Emma's mother had felt desperate and unable to cope with her daughter before she had support from the school. She also felt isolated at the time because she did not have access to state services because Emma was attending a private school. This was followed by feelings of relief when Emma finally went to the school.

d. Experience of the Residential School for Speech and Language Difficulties

Parental experiences of the school were largely positive. Parents felt the school had been right for their children's needs (Dawn and Robert, Samantha, Rachel, Mary and Stacey) and this was more important than having their children stay at home (Samantha, Rachel, and Mary). Emma, Jason and Jacky's mothers also all mentioned how much their children appeared to enjoy their time at the school.

Stacey: The first day (Jason) actually started full time he came home and he'd had the most lovely day of his entire life and his said 'I love it there I'm just like everyone else' which upset me because I didn't realise that he knew he wasn't like everybody else.

Mary: Yes that was absolutely marvellous ... yeah I've got nothing bad to say about that school other than it being far away.

Samantha: It was wonderful absolutely wonderful ... I felt she was being understood ... I felt everyday she would be getting the appropriate teaching she was making progress she was happy she'd made friends erm she just fitted in she adored it ... coz she adored it I was happy.

Lewis's father felt there was good communication between the school and home.

Negative experiences were mostly associated with boarding (as described in 6.3.1), however, with hindsight Grace's mother felt she would have preferred for her daughter to have attended a language unit in a local secondary school closer to home. She also felt Grace had been a high achiever and that attending a special school had stifled her academically. She was the only parent to report feelings of this type.

Three parents had also considered other residential special schools when choosing a school for their children but these were felt to be not appropriate (Fiona, Grace and Emma).

Dawn: (That school) was ... youngsters that had got ... behavioural problems ... so that was the wrong school for (Fiona).

e. Ex-pupils' Speech and Language and Literacy Difficulties while at the Residential Special School

Parents tended to comment on the consequences of their children SLD while at the school and made relatively few comments about their nature. For example; Lewis and Fiona had difficulties telling their parents what happened at school or reporting important information. Freya and Jacky suffered academically because of their difficulties. Only Fiona's parents talked about her difficulties directly. They reported that Fiona had large gaps in her knowledge and understanding of the world and vocabulary at this time.

Parents also reported the impact of literacy difficulties while at the school. Freya's parents communicated with her via letter but this was problematic for Freya as she had reading comprehension difficulties. Jacky's mother felt Jacky's literacy skills were delayed because she began her literacy instruction late due to her SLD.

f. Education and Support at the Residential Special School

Most parents made positive comments about the education their children received at the school (Amanda, Dawn, Mary, Stacey, Edith and Roy).

Stacey: They just took (Jason) right back to the very beginning and corrected all the ... gaps in his education, spelling, reading, numbers the whole lot really ... needed revising and starting again which they did.

Only 3 parents made negative comments, these mostly concerned the broadness of the curriculum (Amanda, Jenny and Edith), however Grace's mother was also concerned her daughter received sex education before she was emotionally ready; this had been against her mother's wishes and resulted in Grace finding it upsetting.

The support ex-pupil's received for their SLD at the school was also seen as positive. Parents felt their children were being understood (Samantha, Dawn, Edith, Roy and Sandra) and that the SLT had been appropriate for their children's needs (Roy and Sandra, Jenny and Dawn).

Roy: The whole school ... is all involved in their speech therapy ... everybody knows what each child's been working on and they all work together and sort of have the speech therapy and then its carried on throughout the classroom and care and everywhere.

Jacky's mother also commented that the school had been able to give her additional advice on looking after Jacky at home. Furthermore, three parents reflected that the school had been the only source of support while their children were growing up as there had been very limited support outside the school (Dawn, Stacey and Mary).

g. FE provisions at the Residential Special School and in the Mainstream Environment

There was a consensus that opening the FE department had been an important addition to the school, but views were mixed as to whether parents would have liked their children to have attended. Fiona and Jacky's parents would have liked for their children to have been able to stay for FE, however Dennis's parents felt that he (and Nigel) would not have stayed as they were able to return to mainstream education. The remaining parents were unsure and saw the benefits of both scenarios.

The parents of the 3 ex-pupils who did stay for FE felt the system where pupils could access college courses worked well and that pupils would have struggled to achieve the same success at post-16 without additional support for the FE department (Emma, Lewis and Jason). Furthermore, Jason's mother also felt she would have been in a difficult situation had FE not been opened because she would not have known how else to provide for him.

Stacey: I don't know actually what would have happened I presume (Jason) would have gone to local college and I presume he wouldn't have been able to cope heh heh very well ... And I presume then he would have been unhappy but fortunately that didn't happen.

Few parents criticized the FE department. Emma's mother felt she struggled as her year group had been very small and she had not had many female peers. Freya's mother made a similar prediction had Freya stayed on for the FE provision.

Parents expressed dissatisfaction with other college provision for various reasons. Fiona's college was not allowing her to study her chosen course NVQ level three as they felt it would be too challenging for her; however her parents believed she would be able to complete the course. Freya disliked her college placement because the staff had not understood how to support her needs, and Emma was denied support at college because it was felt her difficulties were not severe enough to warrant it. Karen also experienced difficulties at college because they failed to give her the correct allowance for her difficulties in examinations.

h. Ex-pupils' Maturity

One of the goals for the FE department was to prepare pupils for life in the future after they leave the school. The older cohort members did not have access to this; Grace and Karen's mothers felt that although the secondary department had also helped prepare their daughters for adult life, both were still immature when they left and therefore less able to make the transition into the adult world. But they did not view this as the fault of the school. Moreover, Grace's mother felt Grace had not been ready to leave the school at 16 years of age. Similarly, Karen's mother felt Karen was still like an adolescent even though she was in her mid 20's. In addition, Lewis's parents felt that although he was still immature for his age he had become more independent and matured during his time in FE.

Roy: He did mature didn't he big time.

Sandra: Yes he grew up.

...

Roy: I think a lot of it was to do with the way they were treated in FE.

Sandra: Yes they were treated more like adults weren't they ... at the end of the day there were adults.

Roy: Which is what the FE was trying to achieve wasn't it.

i. Mainstream School and Special Education

Parents talked about the advantages and disadvantages of both mainstream and special education. Parents favoured special schools over mainstream schools and highlighted a range

of difficulties they encountered at mainstream schools. These included; lack of expertise with specific learning needs (Freya, Fiona, Emma and Jason), large class sizes (Grace), a lack of individual attention (Rachael), being unable to cope with behavioural difficulties (Dennis and Jason), the ex-pupils being unable to cope with what was expected of them (Dennis), having a label was stigmatising (Dennis), and mainstream school focused on academic achievement rather than supporting children with special needs (Fiona). Nigel and Dennis were the only individuals who returned to mainstream education before age 16 years. Nigel floundered academically and was bullied on his return. However, by the time Dennis returned to mainstream education the school had previous experience supporting his brother and Dennis had a better experience.

Even so, parents also discussed difficulties with their children attending a special school. The curriculum was more limited than in mainstream school and much of the focus was taken up with SLT (Grace and Karen). Grace's mother also felt her daughter left school with few qualifications (Grace).

k. Support Services for Adults with Speech and Language Difficulties

Karen's mother reported the most positive experience with support services since her daughter left the school; good careers advice, support when gaining access to employment and having a social inclusion officer. Lewis also benefited from a supported employment scheme. Jacky and Dennis received extra time and readers in examinations, and Dennis's parents felt he had not really needed this. Fiona also needed support from a reader when she took her driving theory test.

Other experiences of support services had not been so positive. Emma was no longer receiving support for her SLD since starting college and her mother felt this was because she appeared more able than she actually was due to good coping strategies. Similarly, Jason's LEA refused him access to a social worker or to supported employment as they felt he had too many GCSEs to be counted amongst those with the greatest need. Further problems with support at college included: not received specific support for SLD at college (Grace and Freya). Fiona's mother reported that Fiona was having difficulty accessing the college course she wanted to study because the college felt she would be unable to complete it. She also had a negative experience with a careers adviser who had not understood SLD. Lewis's parents stated that he still required SLT for his difficulties but that he had not been able to access this since leaving the school due to a general lack of SLT provision for adults. His parents were

concerned that his speech had regressed since he left the school and he was in the process of having his statement redone.

6.3.3 Perspectives on the Ex-pupils' Psychosocial Outcomes

a. Speech and language difficulties in adulthood

All parents felt that their children had a level of persisting language difficulties including both expressive and receptive language difficulties. Expressive difficulties included: word finding difficulties (Dennis, Nigel and Emma); pronunciation difficulties (Lewis, Dennis and Jacky), and difficulties talking about emotions (Karen). Receptive language difficulties: included not always understanding social situations or the world around them (Freya, Grace, Fiona and Emma). Other difficulties reported were: memory difficulties (Emma) visual difficulties (Dennis); hyperactive behaviour (Jason) and being treated differently by other people (Jason).

Parents also made additional comments on the ex-pupils' SLD. Freya preferred to explain to people out right about her difficulties to avoid potential misunderstandings; however she was still prone to get upset in social situations because of her difficulties. Grace had become more aware and able to recognise situations when she had misunderstood. Lewis was good at compensating for his speech difficulties by rephrasing sentences when he was not understood or by explaining things in a visual way. Fiona preferred to talk to people on the telephone rather than in person because she did not like to make eye contact. Emma was good at masking her difficulties but this was often to her detriment as people assumed she was more able than she was. Dennis had become a confident public speaker as a result of his job even though he still sometimes pronounced words incorrectly.

Parents also reported persisting literacy difficulties (Dennis, Nigel, Emma and Jacky) but did not consider this to have a detrimental effect on ex-pupils' lives. Only Emma's mother was concerned as Emma was still completing her college courses. Jacky had chosen a career path (catering) that meant it was not necessary for her to have more than basic literacy skills. Similarly, Dennis used computers for writing reports which hid his poor spelling and handwriting.

Amanda: If (Dennis) is writing a report and he can't think how to spell a big word he can think of how to choose a smaller word ... you find ways round it don't you.

In general, the parental and ex-pupil reports on SLD in adulthood agreed. For

example: Dennis also reported pronunciation difficulties; Jacky reported difficulties with making herself understood, and Grace and Freya experienced difficulties understanding some situations. However, one area of discrepancy arose as Karen reported resolving all her SLD while her mother described a level of persisting SLD. Furthermore, Karen also reported receiving no further support for her SLD after leaving the school while her mother reported the Karen had received additional support at this time.

b. Employment

Parents commented on employment opportunities open to their children after they left education. Positive comments included: Nigel gaining a high powered job, and Dennis having a job that required good public speaking skills. Negative comments included: Dennis being turned down at interview several times and passed over for promotion at his present workplace (his mother felt this was partly due to him not having the right qualifications); Nigel was paid less than a colleague with better qualifications despite having a higher position within the company; Fiona had a careers advisor who had not understood her difficulties and made impractical suggestions for work, also Jacky, Freya and Grace's mothers felt their daughters' SLD had caused them to experience difficulties at work.

Jenny: People make assumptions that you know a certain amount so they only need to tell you a little bit, well sometimes with (Grace) it's the whole lot.

Fiona, Karen and Freya had also experienced a period of unemployment directly after leaving school but not since.

Parental reports largely matched the ex-pupil's, however some changes in employment status had occurred since the ex-pupil interviews. Freya and Grace had changed jobs and both were said to be much happier since they were previously seen in phase 1. Neither Karen nor Freya reported the previous periods of unemployment their mothers did. Other parental reported confirmed the ex-pupils

Parents also talked about future employment plans. Emma wanted to become a youth group leader in the future. Lewis's parents felt he would be most suited to an outdoor job in the future, such as gardening. Jason's mother felt he could work in retail in the future and was seeking supported employment for him. In addition, Grace's mother talked about the importance of pushing to get better things for Grace and felt she could have a more demanding and responsible job.

c. Financial Management

Nigel, Dennis and Jacky were reported to be completely financially independent while the other ex-pupils still required support: 4 ex-pupils had difficulty budgeting (Freya, Grace, Emma and Fiona); 2 had difficulties counting money (Lewis and Fiona), and 2 did not have their own bank accounts (Emma and Jason).

These were similar to the ex-pupils' concerns: Grace also felt she had difficulties with budgeting; Freya did not report difficulties budgeting but did express more general financial difficulties, and Emma and Lewis also expressed concern. The parental report also clarified that Fiona did experience difficulties managing her finances, this was unclear in chapter 5.

Parents also reported barriers to their children achieving financial independence. For example: while Lewis and Jason could understand spending with cash, they may misunderstand paying by card to complete because they might not understand this represented the money coming directly out of their bank accounts. They were not allowed cards for this reason. Lewis had been short changed before as he had difficulties counting coins. Freya experienced difficulties when her ex-partner had conned her into giving him a large sum of money. In contrast, Grace's mother reported her daughter was fully responsible for her credit card and experienced no difficulties. However, she was still concerned that she could be an easy target for criminals that may want to con her.

d. Independent Living

From the parental reports, Nigel and Jacky appeared to be the most independent and it was felt neither would return to live at home or require any support. Dennis was living at home but still relatively independently in that he made his own contribution towards the family's living costs and required no help from his parents. Freya was also living independently and her mother felt she was happier being independent and capable of handling the responsibilities. Grace's mother felt that Grace wanted to be independent but was living at home because she lacked the financial means. Lastly, Karen and Lewis were both waiting to move into supported accommodation in the future; their families were optimistic about this but were finding the application process slow.

These reports agreed with the previous ex-pupils reports: Jacky (and Nigel) was the only home owner; Freya also lived independently but was not fully satisfied with this because she felt some feelings of social isolation; Dennis lived with his parents but contributed his far

share to the running of the household, and Lewis was looking to moving into supported living. The only development was Karen was now also applying for supported living; she had expressed a desire for independent living in chapter 5.

However, parents also expressed more concerns about their children's chances of achieving independent living in the future. Both Emma and Jason's mothers felt their children would need support with independent living and that it was something they were working towards. Jason's mother had additional worries about his ability to perform domestic tasks and manage a household. Fiona's parents were pessimistic about her prospects for independent living and were concerned she would need to be taught about running a household. Fiona herself had no desire to move out as yet. Karen and Fiona's mothers were worried about the future and who would support their daughters when they were no longer around.

Edith: And you know we've got to prepare (Karen) for that because we're not going to be around forever she's going to have to make that move really.

e. Social Lives

According to parental reports, Nigel and Jacky lead quite active social lives and had no real difficulties. Emma was also outgoing and had friends at college. Dennis, Fiona and Grace lead less active social lives and only had friends within the contexts of their workplaces. Jason's mother felt he had difficulties with friendships, but was finding it easier to make friends at college because he was attending college as part of the FE provision at the school. Again these findings largely agreed with the previous ex-pupil reports.

Some parents were worried about the quality of their children's friendships. Freya's mother was concerned that Freya could only get on with others at a superficial level. She expressed concerns that her daughter's friends were not intellectually challenging and possibly manipulative.

Rachel: (She gets on with others) superficially yes ... tea party chit chat ... she's not so good at ... understanding how people tick.

Parents also confirmed reports of ex-pupils losing touch with their friends from the school. Grace and Fiona's mothers mentioned this in particular.

Jenny: (Grace) has ... on more than one occasion said 'because you sent me away to school I don't have any friends'.

Parents remarked on their children's involvement with social clubs and organisations. Grace had friends at a voluntary work placement but only ever saw them in this context. This

was similar for Karen and Jason. However, Karen's mother was worried her daughter only had opportunities to meet people who also had difficulties and would have preferred Karen to also have opportunities to meet a broader spectrum of people.

Chapter 5 reported findings that Karen had formed her own social club after she had been forced to leave her youth club when she reached the upper age limit (see section 5.3.3). However, by the time her mother was interviewed this project had failed as the rent for venue had been too expensive. Her mother had encouraged Karen to continue but Karen had lost interest. This was partly because Karen had started working with a new inclusion officer who had given Karen new opportunities to meet people, which she lost when she could no longer attend her youth club.

Finally, parents were worried about their children becoming socially isolated. Rachel was worried Freya was living in an isolated area and had few opportunities to meet up with her friends who lived far away. Lewis's parents were concerned that Lewis had no opportunities to meet people of his own age and had hopes this would change when he moved into supported accommodation. Freya and Lewis described these feelings in chapter 5.

g. Relationships

Parents reported confirmed the ex-pupil's relationship statuses in all cases but one. Jacky and Nigel were in married relationships and Freya was engaged. The marriages were described as happy; however Freya's mother disliked her daughter's fiancée and described him as manipulative and unsupportive. She was also concerned they had become engaged but that Freya had not fully understood what that meant.

The parents reported the other ex-pupils to be single at this time. This was despite Karen reporting a boyfriend (see 5.3.3). Karen's mother explained that the boyfriend was not a boyfriend in the conventional sense but a boy that was her friend who she met once a week at her social group.

Edith: She will occasionally tell me that she's got a boyfriend ... and I think at the moment there is a boy that she sees at this disco¹⁹ who she describes as her boyfriend but they don't see each other in between the disco ... and they probably communicate by text message or phone ... but she hasn't really got a boyfriend in the sense that you or I would think of as having a boyfriend.

Dennis's mother felt he would never get married but did not see this as a problem. Similarly, Jason's mother also felt her son would never get married because he felt it was too

¹⁹ This was a weekly event Karen attended.

complicated for him. She also had additional worries that if Jason did get married it could be to somebody else with difficulties and she could end up responsible for them both. Emma had never had what her mother described as a 'true' relationship. Grace, Fiona and Lewis's parents also reported their children had never been in relationships. Grace's mother felt Grace was not mature enough for one but did not rule it out for the future.

6.4 Discussion

6.4.1 What is the Impact of having a Child with SLD on the Family?

This question sort to identify the effects a child with SLD has on the rest of the family over the course of the life span. Mixed but predominantly negative findings were reported. Families faced many challenges with the ex-pupils' care and getting them the support they needed:

- Challenging behaviours in childhood.
- Developing strategies to facilitate the ex-pupils care and communication needs.
- Five families needed to fight their LEA to access support.
- Lack of awareness, understanding, knowledge and information about children's SLD in the public domain.
- Mixed effects on relationships with siblings in family life.
- Boarding strained family life.

In childhood the ex-pupils displayed a range of behavioural difficulties associated with receptive and expressive language difficulties; this made their care challenging for parents. These parents experienced stress associated with the ex-pupil's care in childhood. This agreed with the several previous studies that caring for children with disabilities is stressful for parents (Baker et al., 2003; Diego et al., 2007; Dyson, 1997; Hastings, 2003; Ricci and Hodapp 2003) and that behavioural difficulties can also increase parental stress levels (Baker et al., 2003; Floyd and Gallagher, 1997).

Jason's care had been so demanding his mother had given up her job. But it is perhaps surprising that higher incidence of parents giving up work were not reported; for example Seltzer et al. (2001) showed mothers to children with disabilities worked fewer hours due to the demands of their children's care. However, Jason's mother able to return to work after he

began at the residential special school. It could therefore be that these parents had some of their responsibilities associated with their child's care relieved once their children entered the school. For example, Lewis's parents appreciated the break from his care when he went to school. Therefore the school may have had further benefits for the whole family.

There was also a reoccurring theme that parents had to battle their LEAs to access the support their children needed before gaining a place at the school; this supports the findings by Paradise and Adewusi (2002). This added further stress to family life and placed extra demands on families' time and resources.

The parents also reported feeling frustrated and upset due to a general lack of awareness, knowledge and understanding of children's SLD in the public domain; this supports similar findings by Glogowska (2002). This was true for personal acquaintances and professional the parents encountered outside specialist and specific provisions for SLD and meant people made incorrect assumptions about their children. Furthermore in the early childhood years parents often felt they also lacked knowledge on their children's SLD because there was no information available to them. This was therefore another stress burden on family life.

As adults some ex-pupils experienced good relationships with their siblings while others no longer got along with them. Having a sibling with disabilities has been shown to both enrich the lives of siblings (Mulroy et al., 2008; Selter et al., 1997) or reduce the quality of relationships within the family (Mulroy et al., 2008). Examples of both instances occurred in these cohorts. For example: Karen's relationship with her brother was said to have been enhanced, however Dennis and Jacky both had siblings they no longer got along with. Furthermore it is also likely boarding school also contributed to the quality of sibling relationship in adulthood. Attendance at boarding school was shown to have a negative impact on siblings at the time as they missed the ex-pupils while they were away and some felt jealous of the attention they received from the parents on their return. The aftermath of this was still felt in adulthood. This is similar to findings by Haynes and Naidoo (1991) who also found parents felt boarding had a negative impact on family life.

However, even though the families faced many adversities while the ex-pupils were growing up, the parents described feelings of pride towards the ex-pupils and their achievement. Parents felt their children displayed a level of resilience towards their SLD and this associated with feelings of positivity. The families may have also built up a level of resilience to the hardships they encountered when raising their children. Grant et al, (2007)

suggest that families are more resilient when they are able to find meaning in their situation, can embrace it, achieve a sense of control, and maintain their personal values and goals. Families who achieve this are more positive and demonstrate more positivity in the face of adversity when caring for a child with disabilities. Furthermore as the ex-pupil cohort had now reached adulthood it was also likely the families had become experts in their care. This is similar to findings by Seltzer et al., (2001) who suggest that families to children with life long disabilities that have reached adulthood are likely to be more successful at supporting their children's needs than families to children who become disabled in later life because they will have developed more stable patterns of coping as a result of prolonged experience supporting their child.

In summary, parents experienced a range of challenges associated with raising their child, but also displayed a level of resilience in the face of adversity. The findings also suggest parents will benefit from support, in this case the school was able to supply this. Parents to children with SLD are also likely to benefit from support with the child's care, increased access to support services and increased public knowledge of SLD.

6.4.2 What are Parents' Views on support services and special schooling?

a. Support Services

Gaining access to support for children with SLD is potentially challenging for families. The parents reported an early awareness of their child's SLD (as in Glogowska, 2002), however not all parental concerns were taken seriously in early childhood. This supports findings by Rannard et al. (2005) that parents can accurately identify if their children have difficulties that require special attention and are likely to become frustrated when professionals do not take their concerns seriously. This therefore suggests a risk that children who need support may be turned away. Some parents also reported using their own methods to try and support their children's SLD when they did not know what else to do. This was similar to Marshall et al., (2007) who also reported parents may experiment with their own methods of intervention before seeking advice from a professional; however the parents in the present project had resorted to this when they had nothing else they could do.

Gaining access to support, and SLT, was seen as highly desirable (as in Glogowska and Campbell, 2000) and parents placed importance on gaining a diagnosis early so children are able to start receiving support as soon as possible. However positive experiences support services were few and having to fight for access to support was seen as normal (as in

Paradice and Adewusi, 2002). One factor that did appear to ease the referral process was if the child had an obvious and undisputable medical cause for their SLD; e.g. damage to the brain during infancy. These children were picked up by the support system in early childhood and stayed in their records. However, for other families access to support proved to be a long and tiring struggle; 5 families came up against barriers within the system. This typically resulted in a long, tiring, stressful and time consuming battling with their LEA. Importance was also placed on statementing; this was seen as a crucial element to winning the fight with the local authorities as it secured access to support. Parents also felt LEAs were reluctant to spend money on providing support services but having a statement forced them to provide funding.

Parents also often need to fight to get the ex-pupils a place at the residential special school; however barriers to support were no longer an issue once the ex-pupil entered the school. However, parents also reported further barriers to support once the ex-pupil left again; e.g. gaining access to a support worker. Conti-Ramsden et al., (2008) also described parents to children with SLI expressed a similar concern for a lack of community resources to support their children's needs after full time education.

These findings highlight a need for improved access to support; having to fight for access to support was a major area of stress for families. They also demonstrate the inconsistent nature of accessing support as some parents had to fight while others did not. Overall they suggest a need for a change in how support is accessed to make the process easier, clearer and more accessible to parents.

b. Special Schooling

There was a consensus amongst parents that special schooling had been the right choice for their children over mainstream education; the ex-pupils also expressed this opinion in chapter 5. Similar to Rannard et al., (2004), these parents felt that an education specific to the needs of children with severe communication needs and were mostly very accepting of their child's placement in special education. Glogowska and Campbell, (2000) suggested some parents view special education as a temporary platform to support their children in overcoming their difficulties enough to return to mainstream education; in this case mainstream education was favoured by parents. This was not the case for the parents in the present study as they felt their children would be unlikely to ever cope in mainstream education; more importantly parents also felt their children's needs would not be properly

catered for in mainstream school (as in Rannard et al., 2004). It is likely that ex-pupils experienced relatively severe SLD compared with the children of the parents interviewed by Glogowska and Campbell (2000), and therefore would have had less potential to return to mainstream education. Furthermore the parents in the present study had the perspective of hindsight, which the parents in the study by Glogowska and Campbell (2000) did not have as their children were preschool age. These parents greater experience in catering for their children's needs may have also changed their opinion (as in Seltzer et al., 2001).

Parents also favoured the residential special school as they felt their children could make friends more easily and would have been at greater risk of bullying in a mainstream school. Furthermore, two of the three siblings never told their mainstream peers about their sibling's SLD because they feared a negative response. These concerns are justified as children with persisting SLD are more likely to experience difficulties forming peer relationships compared to children with no such difficulties (Jerome et al., 2002) and adolescents with SLD are also at increased risk of victimisation by nonlanguage impaired mainstream peers (Conti-Ramsden and Botting, 2004). However, bullying also occurred at the special school though this was felt to be to a lesser extent.

Parents also expressed some negative feelings towards specialist education, though these were fewer overall. Parents were concerned special education could have compromised the broadness of the curriculum the ex-pupils studied as well as opportunities to gain qualifications at the end of compulsory education. Durkin et al. (2009) suggested these worries are justified and that individuals who attended specialist education gained fewer qualifications than those educated in mainstream school. However these findings were likely to be skewed by those in special schooling having more severe difficulties requiring greater specialist attention, and therefore also risk poorer educational outcomes (Felsenfeld et al., 1992; Snowling et al., 2001). Despite this parents still viewed getting the right support as the biggest priority. Only Grace's mother speculated special schooling may have been wrong for her daughter as she had been a high achieving pupil at the school.

Boarding was also viewed as negative because it put an emotional strain on family life. Difficulties arose when ex-pupils went away (e.g. family members missed them; transportation difficulties) and when returned (e.g. sibling rivalry). However boarding was also seen as a necessary sacrifice to allow ex-pupils to have access to the education that was right for them.

All the parents recognised the necessity of opening the FE department at the school. This was despite some parents feeling it would not have been necessary for their child because it was time for their children to move on. These parents felt the school had done a good job at preparing them for the adult world outside already. The parents of the ex-pupils who did attend the FE provision unanimously felt it was a positive experience; ex-pupils were seen as immature relative to their peers at 16 and FE was seen as an opportunity that gave them more time to mature. The only criticism of FE provision was that only a small number of girls attended.

In summary, these findings suggest the families felt a strong preference for special schooling over mainstream education. This suggests that special education had been the right choice for ex-pupils. This is of significance as places at the school often needed to be fought for and currently inclusive education is often viewed a preferable (as discussed in 1.3.1). Overall these findings suggest some individuals may find special schooling more beneficial and support the idea that the appropriateness of the provision is more important than where the provision takes place (Dockrell and Lindsay, 2008).

6.4.3 To what Extent do the Findings from the Interviews with the Family Members match those from the Interviews with the Ex-pupils?

This aspect of the present study used a proxy measurement expand upon the findings on the ex-pupils psychosocial outcomes presented in chapter 5 and also to confirm the ex-pupil reports in chapter 5. Theunissen et al. (1997) showed parents can be reliable informants but that some disagreement between parents and children occurred; therefore this method also allows areas of disagreement between ex-pupil and parental reports to be highlighted.

All parents felt their children had persisting SLD as adults. All the ex-pupils agreed with this in section 5.3.4 apart from Karen who felt she no longer experienced any difficulties while her mother felt this was not the case. Parents also reported the ex-pupils received slightly more support after compulsory education than mentioned by the ex-pupils. One explanation for this is that some ex-pupils were reluctant to admit to still be receiving extra support as it may be viewed as admitting to still be experiencing difficulties. Furthermore some ex-pupils also reported hiding the fact they attended a special school from their friends and acquaintances as adults (e.g. Darren and Jack). Alternatively ex-pupils and parents may have interpreted the word 'support' differently.

The parental reports for employment mostly confirmed the ex-pupils'. In addition, parents were concerned that their children experienced limited employment opportunities (as reported by Conti-Ramsden et al., 2008); for example 2 parents felt their children had encountered difficulties progressing their careers due to their SLD. Parents were also concerned persisting SLD could contribute to ex-pupils experiencing difficulties in the workplace. The literature would suggest that these concerns are likely to be justified as adults with persisting SLD risk poorer employment outcomes (Billstedt et al., 2005; Clegg et al., 2005; Howlin et al., 2000) and prejudice or bullying in the workplace (Clegg et al., 2005).

Two areas of discrepancy arose in the employment domain. Karen's mother reported her daughter was unemployed for several months after finishing college; Karen had failed to report this previously, this could have been a reluctance to admit to something seen as negative. Fiona also felt happy with her voluntary work and therefore showed no motivation to gain paid employment. However, her parents were anxious she gained work in the future so she could support herself in the future when they were no longer around (as in Grant et al., 2007).

Parents expressed concerns towards the ex-pupils' financial management skills and felt the ex-pupils needed more support managing their finances than reported by the ex-pupils themselves (see 5.3.2). Parents reported difficulties with budgeting, making transitions, counting out money and being vulnerable to crime; e.g. being 'ripped off'. Clegg and Henderson (1999) showed that adults with persisting SLD risk financial difficulties and often require ongoing financial support from their families. Here the parents gave examples of the potential pitfalls of financial management. The ex-pupils' difficulties with financial management all related to understanding therefore could be related to persisting comprehension difficulties. Financial management is included in the life skills training now taught in the new FE provision at the school.

The parental accounts mostly confirmed to the ex-pupils' reports of independent living. Lewis and Karen's parents were helping them into supported accommodation thus working towards their aspirations for independent living; this was a development since Karen's interview. However, similar to findings for employment, Fiona was content living in the parental home and had no motivation for independent living in the future. However, her parents did not see this as a permanent solution and feared for Fiona's future. In addition, Karen and Fiona's parents were concerned about their daughters' ability to manage the domestic demands of running a household; however, Karen previously reported confidence

with this. Again, parental concerns are justified as adults with persisting SLD risk difficulties achieving independent living (Clegg et al., 2005; Howlin, 2000). Again domestic skills are now taught as part of life skills in the new FE provision at the school.

Parental reports also suggest schemes to help adults with persisting SLD gain employment or live more independently can be of great benefit. Howlin et al., (2005) demonstrated the benefits of supported employment schemes, however they also proved to be very expensive to fund. Similarly, Karen's mother felt applying for supported living was slow process and this was likely to be due to limited community resources (as in Conti-Ramsden et al., 2008).

In general, the parental reports confirmed ex-pupil reports for friendships, and this included ex-pupils' attendance at social clubs. Adults with persisting SLD risk social isolation (Beitchman et al., 2001; Clegg et al., 2005; Howlin et al., 2000; Johnson et al., 1999). However some of the ex-pupils with the most severe difficulties that were most at risk of social isolation used social clubs and groups to meet new people. Even so, parents were still concerned for the quality of their children's friendships and wished they had more opportunities to meet new people in a variety of contexts. This was because some ex-pupils appeared to only have friends with difficulties similar to their own. Despite this, the ex-pupils did not express this dissatisfaction with their friendship groups. Conti-Ramsden et al. (2008) also found parents to adolescents with SLD expressed similar concerns about their children experiencing social difficulties as a result of their SLD. It could therefore be the case that while social clubs can provide individuals with a place to meet people, there are still limitations to the benefits they provide.

Adults with persisting SLD also risk difficulties with relationships (Beitchman et al., 2001; Clegg et al., 2005; Howlin et al., 2000). In general, the parental reports also confirmed ex-pupils reports about relationships. Two parents felt their children would never marry (Dennis and Jason) and three more reported their children had never been in relationships before (Grace, Fiona and Lewis). Disagreement occurred between Karen and her mother both of whom interpreted this relationship different ways; Karen felt he was her boyfriend and her mother felt he was a boy who was her friend. This was either down to Karen having a misconception of what a boyfriend was, possibly caused by her SLD, or that her mother had misinterpreted the relationship. It is difficult to confidently determine whose perception is accurate without collecting more information. Similarly, Fiona had reported having a boyfriend in the past at college but her parents also dismissed this. The research findings

suggest this is a great area of difficulty for individuals with persisting SLD exacerbated by social difficulties, limited opportunities to meet people and being immature relative to chronological age.

Part 3

Experiences of Young Adult with Speech and Language Difficulties in Further Education

Part 3 will be presented chapters 7 and 8. Parts 1 and 2 were concerned with outcomes in adulthood for individuals with severe and complex communication needs. Part 3 aimed to build on these findings by examining the transitional period of life between finishing compulsory education and entry to the adult world.

Chapter 7 will present a literature review on the potential difficulties for adolescents with persisting SLD, the experiences of parents and professionals who work with adolescents with persisting SLD, and transitions into the adult world.

Chapter 8 will present a study that sort the views and from current pupils of the residential special school's recently opened FE provision, their parents and the school staff who worked with them in FE. This study examined the pupils' experiences of FE at the residential special school, the views and experiences of the pupils' parents and FE staff, and to identify any areas of potential risk and difficulties for individuals with persisting SLD at post-16 and beyond?

Chapter 7 - The impact of SLD on the transition from compulsory education into post-16 and beyond;

Literature Review

7.1 Persisting Speech and Language Difficulties in Later Adolescence and Consequences for Academic Achievement

7.1.1 Persistent Speech and Language Difficulties

If childhood SLD persist beyond around 5 years of age they are likely to persist into later life (previously discussed in section 2.1). For example, Haynes and Naidoo (1991) followed-up 118 ex-pupils who attended the same residential special school as that presented in this thesis as they made the transition out of compulsory education; all were found to be still experiencing some level of persisting language difficulty, though this was minor in some cases. Similarly, Conti-Ramsden and Durkin (2008) followed-up 120 adolescents with SLI (aged 16 years) and found they performed significantly poorer than nonlanguage impaired age matched controls ($n = 118$) on measures of language. Overall, there is strong evidence to suggest children who do not resolve their SLD in early childhood are at high risk of experiencing further difficulties with language in adolescence.

7.1.2 Consequences for Academic Achievement

Adolescents with persistent SLD also risk longstanding academic achievement and performance in examinations (see 4.2.1 for previous discussion). For example, Snowling et al., (2001) identified a direct relationship between resolved and persistent SLI and the number and grade of GCSEs obtained. Those with persisting SLI performed more poorly than those who had resolved their SLI, however both groups performed more poorly than those with no history of SLD.

Studies that have examined the formal qualifications gained by cohorts similar to the pupils who attended the residential special school presented in this thesis have shown success levels to be mixed. Haynes and Naidoo (1991) found varied success in their ex-pupil cohort: 22 ex-pupils gained CSEs; five gaining O levels; 3 had gained A levels, and thirteen had no formal qualifications. Success was more consistent among the four ex-pupils seen by

Aboagye (2001); all gained CSE (grades 1-4) or O-levels (grades A-E), and one gained three A-levels (grades A-B). Dockrell et al., (2007) also documented mixed academic outcomes of 54 adolescents with SLD as they completed compulsory education; the majority gained a mean of five GCSEs at grades D-G, 13% gained five GCSEs at grades A*-C although only 3% gained both Mathematics and English A*-C. Notably this cohort had less severe difficulties than those seen by Haynes and Naidoo (1991) and Aboagye (2001).

Durkin et al., (2009) compared the academic performance of 120 adolescents with SLI and 121 typically developing controls aged 17;4. They also found that the cohort with SLI performed more poorly than typically developing controls; however the cohort with SLI still reported high satisfaction levels despite experiencing less success. Durkin et al. (2009) proposed that this could indicate some individuals with SLI have lower expectations for themselves.

7.1.3 Pursuing Further Studies After Compulsory Education

Leaving compulsory education is a significant and challenging time of transition in the life of any adolescent (Blacher, 2001). It is typically followed by beginning new post-16 educational placements. However, adolescents with persisting SLD may experience greater challenges associated with post-16 education and success has been shown to be heterogeneous (previously discussed in 4.2.1).

Speech and language needs can be met in the mainstream or special school environment at post-16. Few studies have reported on FE provisions available to those with persisting SLD. In general, there is a short fall in the availability of specialist FE provisions and places are limited. For example, Dockrell et al. (2006) found that around 4% of individuals with persisting SLD were having their needs provided for in special schools while around 9% were having their needs met in mainstream school. These numbers are still very low over all when the numbers of young adults with persisting SLD that are not having their needs met at post-16 are taken into consideration. Conti-Ramsden et al., (2008) also showed parents to adolescents with persisting SLI expressed concerns towards the lack of provision available at post-16. Worryingly, Durkin et al., (2009) found adolescents with SLD are just as likely to pursue post-16 education as those with no history of SLD; this suggests a likely shortfall in provision. Dockrell et al., (2007) also reported most of their cohort went on to post-16 placements. Durkin et al., (2009) found 75% of their SLI cohort were in special school while 25% were in mainstream school. The cohort with SLI performed more poorly

than typically developing controls, and those in mainstream school gained more qualifications than those in special school. This was likely to be the result of those in special school having the most severe difficulties to begin with and a difference in policy for examination entry between the types of school.

Outcomes at post-16 have been mixed. Haynes and Naidoo (1991) reported that almost two thirds of their cohort went on to post-16 education; eight attended Technical colleges; 3 attended University; and 7 attended youth training schemes. Twelve others followed vocational courses: e.g. brick laying. Howlin et al. (2000) documented the educational achievements of two cohorts of adults with childhood histories of DLD ($n = 20$) and autism ($n = 19$) in their early 20's. Findings were relatively poor; none of the DLD cohort had gained post-16 qualifications, although six of the young adults with autism had. However, this situation improved in later life when Clegg et al. (2005) followed up the DLD cohort in their 30's and found six had gone on to gain post-16 qualifications since the earlier study.

In a recent study, Palikara et al., (2009) interviewed 54 individuals with SLI during their first year of post-16 education on their experiences. The interview format used both structured and semi-structured elements to collect specific pieces of information and to allow their participants to explore some of the issues in their study. Fifty-one participants chose to continue into FE. The most common reason for this was for personal interest and enjoyment, but other participants also reported reasons relating to future employment. The remaining cohort members had started work. Nearly half reported difficulties since leaving full time education; most of these occurred in FE, some also occurred in work. The most common difficulty was dealing with the increased academic demands; however victimisation in FE or the workplace were also problems. Participants reported a level of familial support; 4/5 received help with their academic studies from a family member. All participants reported friendship was important to them and most got on well with their peers at post-16, only 1 reported not making any new friends. Most participants also still reported positive feelings towards the support they received at school.

7.2 Persisting Speech and Language Difficulties and Social Difficulties in Later Adolescents

Adolescents with persisting SLD are also at increased risk of experiencing behavioural problems and social difficulties (Conti-Ramsden and Botting, 2004). Snowling, Bishop, Stothard, Chipchase and Kaplan, (2006) showed support for this. They compared 17 adolescents aged 15-16 years with preschool histories of SLI and 49 age match controls. They reported that 10 of the clinical sample had attentional difficulties, 11 had social difficulties and 8 had a combination of both. Lindsay, Dockrell and Strand (2007) also found persisting levels of behavioural, emotional and social difficulties in children with SLD between 8 and 12 years according to parental and teacher reports. Beitchman et al., (2001) compared the psychiatric outcomes for young adults (aged 19 years) with histories of speech difficulties only, SLD and controls with no histories of any difficulties. They found higher rates of anxiety disorder and social phobia among those with speech difficulties and SLD than the controls and these were highest for those with the more pervasive SLD.

Adolescents with persisting SLD are also at increased risk of experiencing bullying and victimisation (see 4.2.1 for previous discussion). For example, Conti-Ramsden and Botting (2004) followed up 242 adolescents with SLI at age 14 years and compared them to nonlanguage impaired controls. The social difficulties of both cohorts were measured based on teacher judgments. They found that adolescents with SLD were at greater risk of bullying, victimisation and social isolation than peers without SLD, and concluded this may be the result of poorer social skills and behavioural problems. In turn this increased the likelihood that they were singled out by their nonlanguage impaired peers. However, mixed findings were reported by Durkin and Conti-Ramsden (2007). They examined the quality of friendships in 16 year olds with (n=120) and without a history of SLI (n=118); those with SLI experienced a poorer quality of friendships overall. However, findings were heterogeneous in the SLI cohort with over half the group still experiencing a good quality of friendship and high levels of popularity despite their difficulties.

7.3 Experiences of Parents and the Professionals who Work with Individuals with Persisting Speech and Language Difficulties

7.3.1 Parental Perspectives

Raising a child with SLD is likely to put a strain on family life (see 4.3.2 for previous discussion). Parents are at risk of experiencing raised stress levels (Baker et al., 2003; Mugno et al., 2007; Dyson, 1997; Floyd and Gallagher, 1997; Ricci and Hodapp, 2003), mental health problems (Hastings, 2003), reduced rates of employment due to the demands of the child's care (Green, 2007; Seltzer et al., 2001) and extra financial costs for parents (Glogowska 2002; Mulroy et al., 2008). Furthermore, parents to children with SLD may have other sources of stress and anxiety associated with having to fight for access specialist provisions to support their children's needs (as in Paradice and Adewusi, 2002).

If SLD persist in to adulthood then parental care and responsibilities are likely to continue also (Clegg and Henderson, 1999; Floyd and Gallagher, 1997). As parents get older they may also become more fearful for the future when they are no longer around to care for their child (Grant et al., 2007). Therefore transitions are also a significant time for the families of individuals with persisting SLD as gains in independence will help relieve families of some of the responsibilities associated with the individual's care. Conti-Ramsden et al., (2008) interviewed the parents of 120 adolescents with SLI and the parents of 118 nonlanguage impaired adolescents all were attending the final year of compulsory education (age 16 years). During the interviews parents discussed their concerns for their children's futures. Parents of adolescents with SLI expressed more concerns for their children's futures, employment opportunities, and their social skills compared to parents of adolescents without SLI; however parental concerns were still expressed in both groups. There was also more variance in the level of worry for parents to children with SLI and a concern about the lack of educational resources for adolescents with SLD.

7.3.2 Experiences of the Education Staff and Professionals who Work with Individuals with Persisting Speech and Language Difficulties

Few studies have documented the views and experiences of the education staff that work with children and adolescents with SLD. The studies that have done so have focused on mainstream settings. Dockrell and Lindsay (2001) interviewed the teachers of 69 children aged 8 years. Fifty-nine of the children were attending mainstream education and 10 were

attending special schools. The teachers completed semi-structured interviews regarding their knowledge and understanding of children's SLD. Responses were mixed and many teachers had limited understanding of children's SLD, felt there was little training available to help them support children's needs and that they were unable to provide the right support and adequate provision. SLTs were seen as key professionals but were limited in number and by accessibility. Seventy-eight percent of the teachers raised concerns for the children's future progress and being able to meet their needs.

A similar study by Sadler (2005) investigated the knowledge and attitudes of 89 mainstream school teachers who had children with a preschool diagnosis of moderate to severe SLD. These teachers all taught classes from reception to year 2. The mainstream teachers reported limited knowledge of SLD but confidence in their abilities to cater for the educational needs of children with SLD. Mainstream school was seen as favourable over specialist education although some disadvantages with inclusion were reported: e.g. lack of time for individual attention. Even so, the benefits of being educated in the mainstream environment were seen to outweigh these.

Marshall, Ralph and Palmer (2002) measured the expectations of 268 PGCE students towards working with children with SLD in the future using questionnaires and interviews. Findings were positive on the surface with participants mostly expressing feelings of interest and willingness to accommodate children with SLD in their class. However, concerns were also expressed; e.g. it would not be fair on the other children?, or I'd be worried the child would be stretched from the work. The participants also reported feelings of nervousness, apprehension, anxiety, panic or feeling underprepared, however these reports were infrequent. Notably these individuals were yet to experience working with children with SLD so their opinions have changed once they started work. Findings by Greenwood, Wright and Bithell (2006) also suggest that the profile of SLT as a profession needs to be raised. Six hundred and fifty one students (with a minimum age of 16;1 years and range of ethnic backgrounds) were recruited from schools and colleges and completed questionnaires about future career choices and familiarity with SLT as a profession and as a degree course. They found SLT was not well known amongst students with around a third of students having not heard of it, and therefore less students may consider it as a profession.

Dockrell et al., (2006) used questionnaires to investigate the views of SLT service providers. They reported a lack of provision and resources to cater for children's needs, particularly post-16 and that placing some children was difficult, e.g. children who display

the symptoms of both SLD and ASD. It was also felt that parents can influence the support given to children with 'pushy' or more knowledgeable parents being more likely to gain access to support.

Teacher perceptions of an individual's difficulties can also differ to parental perceptions. These perceptions may also change over time. De Ruiter et al., (2008) compared teacher and parental judgements of emotional and behavioural problems for individuals with intellectual disorders through ages 6-18 years. Teachers reported consistent difficulties over time while parents reported a reduction in difficulties. This could reflect situational differences and the increasing academic demands of the classroom.

7.4 After Further Education

Leaving education is also a significant time of transition. This can either occur after compulsory, further or higher education depending on the individual's life choices and experiences. This is typically followed by gaining employment and increased levels of independence leading to independent living. Once again, adolescents with persisting SLD may experience greater challenges associated with this.

7.4.1 Entering Employment

Academic difficulties associated with persistent SLD can lead to few formal qualifications being gained at the end of compulsory education and at post-16 (as discussed in 7.1). Formal qualifications are important as they open subsequent opportunities for post-16 studies and poorer outcomes can limit these (Conti-Ramsden et al., 2008; Snowling et al., 2001).

Adults with histories of SLD are susceptible to poorer employment outcomes (see 4.2.2). Follow-up studies have reported limited success with employment for adults with childhood histories of SLD (Clegg et al., 2005; Howlin et al., 2000), and that they may also be a increased risk of unstable employment histories and bullying at work (Clegg et al., 2005). However, research findings have also been mixed and other studies have reported more positive findings that individuals with histories of SLD can experience relative success with employment (Aboagye, 2001; Felsenfeld et al., 1994; Records et al., 1992).

Supported employment schemes have also been shown to be potentially beneficial in helping individuals with SLD gain employment and maintain their jobs (Howlin et al., 2005; Mawhood and Howlin, 1999). Such organisations can provide further support after leaving education to individuals who still require it, thus limiting the impact of potential difficulties associated with SLD.

7.4.2 Becoming Independent

Adult with histories of SLD also risk more limited levels of independence (see 4.2.2). Employment outcomes have a relationship with financial outcomes (Clegg and Henderson, 1999) which are a prerequisite to independent and autonomous living (Clegg et al., 2005). Independent living has also been shown to be poorer for those with histories of SLD (Clegg et al., 2005; Howlin et al., 2000), although again some individuals still experience relative success (Aboagye, 2001; Records et al., 1992).

Conti-Ramsden and Durkin (2008) showed adolescents with SLI experience poorer levels of independence than those without language impairment. They followed up 120 SLI adolescents (mean age 15;9) and 118 nonlanguage impaired adolescents (mean age 15;11 years). Both the adolescents and the adolescents' parents rated the adolescents' levels of independence. The SLD cohort was rated by both parental and self report as less independent than peers without SLD. The parents also rated poorer levels of independence for the adolescence compared to how the adolescents rated their own independence; this was true of adolescents both with and without SLD. Language and literacy were also found to be better predictors of independence than nonverbal ability for both groups.

7.5 Why is it important to study FE provision at the school?

The evidence suggests children who do not resolve their SLD in early childhood are at high risk of experiencing further difficulties with language in adolescence (Stothard et al., 1998). The academic achievements of these individuals are varied but poorer than those with no histories of SLD (Dockrell et al., 2007; Durkin et al., (2009) and adolescents with persisting SLD risk poorer psychosocial outcomes than those without language impairments (Clegg et al., 2005).

Specialist provisions at post-16 that cater for SLD specifically are limited (Dockrell et al. 2006) despite evidence to suggest adolescents with SLD are just as likely to pursue post-16 education as those with no history of SLD (Durkin et al., 2009). However, in September 2004 the school presented in this thesis opened an FE department to cater for its pupils needs at post-16. There are three components to this provision: access to college course at a local college with support from a learning support assistant (LSA); time in FE learning about life skills (ASDAN²⁰) and having additional support with college work, and work based placement designed to get pupils work experience.

Chapter 8 will present a study that examined the experiences of pupils completing their post-16 education at the new FE department at the residential special school studied in this thesis. It will also aim to highlight the areas of potential risk or difficulty for these individuals in the future after they leave the school. Furthermore it will also aim to document the views and experiences of these pupils' parents and the education staff who work supporting the pupils in the FE department. Parental views were sort because transitions can be a time of anxiety for the future (Conti-Ramsden et al., 2008; Grant et al., 2007). Staff views were also sort to add a third dimension and because few studies have documented the views of education staff who work with children and adolescents with SLD in the special school environment: most previous studies have done this in a mainstream setting (e.g. Sadler, 2005).

²⁰ Award Scheme Development And Accreditation Network

Chapter 8 – Post-16 Provisions for Individuals with Persisting Speech and Language Difficulties in a Special School Setting.

8.1 Research Questions

The pupils who attend the FE department recently opened at the school presented in this thesis have three major components to their studies:

1. The FE department works in partnership with a local mainstream college that provides a full range of vocational courses. Pupils ideally spend at least 50% of their time at college completing a qualification of their choice. They are also allocated an LSA to help support their needs while they are in the college environment.
2. Most pupils spend the rest of their time in the FE department. This time is used to complete college coursework, to study towards their ASDAN qualifications, and provides the pupils with continued access to SLT.
3. Currently a small minority of FE pupils also attend work based placements to gain work experience. These tend to be pupils who experience less success at college.

This third and final phase of data collection was devised to examine the lives of the school's FE pupils, their hopes for the future and their experiences in FE. This was also devised in the light of findings from the studies presented in part 2 of this thesis as the 3 youngest ex-pupils also attended this provision. They felt it had been a beneficial experience with no alternative. The parents of two of these ex-pupils' also gave similar reports. In addition, this study also aimed to gain a staff perspective on FE. This was of significant interest because as far it is known to the researcher no other studies have reported on the views of the education staff who work with children and adolescents with SLD outside the mainstream school setting.

This study asked the following questions:

1. What are the pupils' experiences of FE at the residential special school?

2. What are the pupils' parents' experiences of having their child with SLD attend FE at the residential special school?
3. What are the experiences of the staff who work with the FE pupils?
4. What are the areas of potential risk and difficulties for individuals with persisting SLD at post-16 and beyond?
5. Are there areas of discrepancy between pupils, parents and staff in their reports of FE?

8.2 Methodology

8.2.1 Design

In order to address the questions in 8.1 data was collected from: pupils attending the residential special schools FE department (n = 16); the parent of the FE pupils (n = 5), and LSAs that worked with the pupils (n = 8). The pupils and parents completed structured interviews and the staff completed semi-structured interviews; these were used to investigate the participant's views and experiences of FE and their hopes for the future.

The pupils and LSAs completed their interviews with the researcher face to face, while the parents completed their interviews over the telephone due to geographical distance. Interviews and questionnaires can be completed face-to-face or over the telephone. Telephone interviews are often felt to be an inferior method to face-to-face interviews, however they can have the same accuracy rates. They are most effective for closed questions and questionnaires and less effective for open questions or semi-structured interviews. They also have the advantage of being faster and more cost effective than face to face interviews (Bowling, 2002).

8.2.2 Participants

a. Pupils

The pupils were all currently attending the FE provision at a residential special school for children with severe and complex SLD. There were 27 pupils in the FE department at the school, of these 16 agreed to participate, the remaining pupils either declined to take part or were unavailable at the time of the project. One female participant became too distressed during the session to continue and her data was discarded; this was due to external events earlier that day unrelated to the project. Therefore the final cohort was made up of 15 pupils (5 females and 10 males) at the FE department. See table 8.1 for details of the FE pupils.

Table 8.1 - Descriptive information about the FE pupils

FE Pupils	Gender	Age	Entry Age	FE year	Boarding
Joe	Male	19;09	10	14*	Weekly
Dominic	Male	19;04	10	14*	Weekly
Phillip	Male	19;00	11	14*	Fortnightly
Dylan	Male	18;11	11	14*	Day pupil
David	Male	18;10	7/8	13	Fortnightly
Mathew	Male	18;06	14	13	Day
Shane	Male	17;11	13	13*	Weekly
Morgan	Male	17;11	11/12	13	Weekly
Andrew	Male	17;10	12	12	Day pupil
Leo	Male	17;09	12/13	12	Weekly
Miriam	Female	19;07	8	14*	Fortnightly
Selina	Female	18;11	8	14*	Weekly+
Alexia	Female	18;02	12	13*	Weekly
Lilly	Female	17;04	8	12	Weekly
Sofia	Female	16;11	12	12	Weekly

* Indicates that it was a pupil's final year in the FE department.

+ But this went down to 2 or 3 nights a week when Selina started FE.

b. Parents

Five parents (4 mothers and 1 father) were successfully recruited and interviewed. See table 8.2 for details of the parent and pupil pairs.

Table 8.2 Parents of FE pupils seen

Parent	Relation	Pupil	Boarding	Pupil still in FE by parent interview?
Ben	Father	Joe	Weekly	No
Gwen	Mother	Selina	Weekly*	No
Lia	Mother	Shane	Weekly	No
Jasmine	Mother	Mathew	Day	Yes
Jessica	Mother	Andrew	Day	Yes

* Went down to 2 or 3 nights a week in FE.

c. Learning Support Assistants

All 8 LSAs who worked with the pupils in FE were successfully recruited to take part (5 females and 3 male). Some LSAs also had additional responsibilities at the school. See table 8.3 for details of the LSAs.

Table 8.3 Descriptive information for FE staff

Name	Gender	Role	Providing support at college?	Worked at before FE was opened?
Isaac	Male	LSA	Yes	No
Nicholas	Male	LSA	Yes	No
Nathan	Male	LSA and school tutor	Yes	No
Alison	Female	LSA	Yes	Yes
Camilla*	Female	LSA	Yes	Yes
Molly	Female	LSA and IT technician	Yes	No
Maria	Female	LSA and Diagnostics	Did previously	No
Rose	Female	LSA	Yes	Yes

* Camilla was an ex-pupil of the school herself who had gone on to work as an LSA there. She was therefore able to provide a unique insight into her experiences working at the school. She was willing to participate in phase 3 of the project but declined to take part in phase 1.

8.2.3 Ethics

This study was approved by the University of Sheffield ethics committee in the department of HCS prior to any contact with participants (see appendix A4.2). Participants had the nature of the research project explained to them before they agreed to take part and were given the opportunity to ask questions before the start of the interviews. There were also made aware that they could withdraw at any time and that they would remain anonymous. They were also asked if the sessions could be audio recorded but were given the option not to be recorded at all if they did not wish to. No participant was pressured to be recorded.

8.2.4 Materials

a. Pupils

Originally the pupils were going to complete questionnaires rather than structured interviews. These were designed with the help of two SLTs who worked at the school and knew the pupils but did not participate in the study. They advised how to make the questionnaires as accessible to pupils as possible. It was felt some pupils were likely to experience difficulty completing a written questionnaire and decided that the researcher would be present to support the pupils and the questionnaires would take the form of structured interviews instead. Structured interviews and questionnaires are similar and they can both have structured and unstructured elements (Bowling, 2002). The structured interviews involved the researcher supporting the pupils with reading and understanding the questions, and writing their written answers. Some pupils were also highly distractible and needed to be refocused on the task. In addition, some questions used a linear scale to indicate

emotions; these were presented in a written format. The staff suggested that the researcher also kept a pictorial representation of the linear scale in cases where pupil found the written form difficult to understand

The final structured interview was divided into 9 sections: personal detail; experiences at school and in FE; boarding; college and education; life after FE; independent living; employment; communication, and friends. They also contained a mixture of: closed questions; open questions; linear scale questions, and tick box questions. The linear scales all involved the pupils rating their emotion on a scale between 0 and 10 with 5 being the average. Closed questions have precoded response formats and are appropriate when researching a topic where much is already known. Open questions do not have precoded responses and are useful when little is known about a topic (Bowling, 2002). A combination of the two types of questions was used to gain a more holistic data set. Closed questions were followed by open ended questions, these aimed to establish the reasons why a participant chose a specific response to the closed question (see appendix A6.3 for the interview schedule). An audio recorder was also required if the participant consented to be recorded.

b. Parents

The parental structured-interviews followed a similar format to the pupils. These contained closed questions; open questions, and tick box questions. They did not contain any linear scale questions as there were felt to be impractical over the telephone and tick boxes were used instead. These structured-interviews were divided into 9 sections: personal details; experiences of the school; boarding; college and education; life after leaving the school; independent living; employment; communication, and friends (see appendix A6.3 for the interview schedule). A telephone recorder was used to record these sessions if the parent agreed.

c. Learning Support Assistants

The LSAs were given short semi-structured interviews that took around 30 minutes to complete. These were similar to those used in section 2 but much shorter and covered three main topic areas: working in the school's FE department; personal experiences, and the future for the FE department and the pupils who leave. They took the form of a series of prompts the researcher could use to steer the interview however the structure was also loose and

allowed leeway so the LSAs could also add comments if they wished (see appendix A6.3 for the interview schedule). An audio recorder was used to record the interview sessions.

8.2.5 Procedure

a. Pupils

The researcher spent two weeks in the school's FE department during the summer term of 2008. During this time FE pupils were approached and invited to participate in the project. A quiet room was found where the researcher explained the nature of the project and gave the pupils a copy of the information sheet and consent form to sign. Care was taken to make sure each pupil understood the information sheet and the consent form, and each was given the opportunity to ask questions. In some cases this meant the researcher read through the information sheet and consent form with the participant. It was also made clear that if a participant took part they did not have to agree to be recorded as well.

Before the sessions began the audio recorder was started with the participant's consent. Then the participant and researcher completed the structured-interview together. This involved the researcher facilitating the pupil to complete the structured-interview in the form of a questionnaire. The researcher helped read the questions, make sure the pupil understood the meaning of any questions they felt unsure of and recorded the responses in a written format. The researcher took care to remain neutral and not influence the pupils' responses. Additional comments captured on the recordings were also part of the data and were later transcribed. Once the session was complete the participant was given another opportunity to ask questions.

b. Parents

After the pupils had participated a letter was sent to each of their parental homes inviting a parent to take part. The parents were sent an information sheet outlining the details of the project, a response form to sign and a copy of the structured-interview in the post. A stamped addressed envelope was provided so the response form could be returned and positive responses were also designed to be signed consent forms. No responses were followed up with a second letter.

The parents were recruited and participated after the pupils had taken part in the school summer holiday of 2008. Once a positive response was received from the parent the

researcher contacted them by telephone and arranged a time to call them again to complete the structured-interview together.

The procedure was kept as similar as possible to that used with the pupils as the data for parents and pupils so the data could be analysed in pairs. Any comments made by the parents were included in the transcriptions of the sessions. It was made clear that the parent did not have to agree to be recorded. One parental session could not be recorded due to equipment failure.

The researcher called the parents from a quiet private room. The parent was put at ease from the beginning and asked if s/he had read and understood the information sheet and given the opportunity to ask questions. If s/he had not read the information sheet the researcher went through it with them. When they were ready to start the researcher began the audio recorder with the participant's consent and informed the parent of this. Then the parent and researcher completed the structured-interview together. Once the session was over the parent was given another opportunity to ask questions if they wished.

c. Learning Support Assistants

The semi-structured interviews with the LSAs were carried out during the same 2 week period as the FE pupil sessions. During this time LSAs were invited in person to participate in the project. The researcher explained the nature of the project and gave the LSA a copy of the information sheet and consent form to sign. Again it was also made clear that the participant did not have to agree to be recorded.

At the beginning of each session the audio recorder was started with the participant's consent; in this case all LSAs agreed to having their interviews recorded. The researcher then completed the semi-structured interview with the LSA. The responses were also recorded in writing at the time. Once the session was complete the participant was given another opportunity to ask questions if they wished.

8.2.6 Data Analysis

The analysis of the pupil and parental questionnaires utilised a mixed methods approach (see 4.4.2), while the staff semi-structured interviews were analysed using a qualitative approach (see 4.4.1).

a. Pupils

Closed questions were used to collect descriptive information; e.g. the name of the pupil's college course. Tick box questions were used where questions had a selection of multiple choice answers: e.g. do you think you'll keep in touch with your friends when you leave? The results of these are presented in tables throughout section 8.3.1. Pupils' responses to the open ended questions were transcribed and collated; these results are presented in the text. It is also indicated in the text where more than one pupil gave the same answer. The mean, standard deviation and range scores were calculated for the answers to the linear scale questions; e.g. how do you find getting on with other people? These results are presented in table 8.4.

b. Parents

The data analysis for the parental structured interviews followed the same format as that for the pupil questionnaires. However, there were no linear scale questions in the parental interviews as these were felt to be impractical over the telephone.

c. Learning Support Assistants

The semi-structured interviews completed by staff were analysed with NVivo, using the qualitative methodology outlined in 5.2. Once the analysis was complete a 2nd coder scored 1 full interview using the final coding system; interrater reliability was shown to be 85.71%. The results are presented in 5 sections that arose from the qualitative analysis: views and experiences of the FE department; views and experiences of the pupils; boarding; pupils' friendships, and leaving further education and the future (see appendix 0 for a summary of the codes and A3.3 for a worked example).

8.3 Results

8.3.1 The Findings from the Pupil Data

a. Experience of the Special School and the FE Provision

Table 8.4 suggested most pupils rated themselves as relatively happy in the school, however the large range suggests some pupils felt unhappy. On average pupils felt slightly happier in FE (mean 2.37, range 0-6) than in the primary and secondary department at the

Table 8.4 – Questions that used a linear scale to rate emotions. Pupils gave scores between 0 and 10.

Question	Mean	S.D.	Range
How do you feel about your communication skills now? 0 was the happiest and 10 was the unhappiest	1.67	1.91	0-5
How do find getting on with other people? 0 was the easiest it could be and 10 was the hardest	1.70	1.63	0-5
Has being at the school helped you feel ready for life in the future? 0 was the most the FE department could have helped and 10 the least	1.97	1.93	0-5.5
How much do you enjoy being at college? 0 was the happiest and 10 was the unhappiest	2.21	2.76	0-10
Have the staff at school helped you with your communication? 0 was the most the FE department could have helped and 10 the least	2.27	2.02	0-5
In general how do you feel in the FE department? 0 was the happiest and 10 was the unhappiest	2.37	2.56	0-6
How do you feel about Maths now? 0 was the happiest and 10 was the unhappiest	2.40	2.64	0-8
Do you make new friends easily? 0 was the easiest it could be and 10 was the hardest	2.70	2.61	0-10
How do you feel about your reading now? 0 was the happiest and 10 was the unhappiest	2.93	2.74	0-8
What is it like living at the school?*	3.19	2.25	0-6
0 was the best it could be and 10 was the worst it could be			
How ready do you feel to start work? 0 was the most prepared they could feel and 10 the least	3.30	2.06	0-7
How do you feel about your spelling now? 0 was the happiest and 10 was the unhappiest	3.30	2.88	0-8
How ready do you feel to start something new? 0 was the most prepared they could feel and 10 the least	3.30	2.59	0-8
Do you ever miss your family at home? 0 was the most they could possibly miss their families and 10 was not at all	3.54	3.41	0-10

* Only applied to boarding pupils (n=12).

Table 8.4 - Continued

Question	Mean	S.D.	Range
In general how do you feel when you are at school? 0 was the happiest and 10 was the unhappiest	3.63	2.37	0-8
One day you will have to leave The school. How ready do you feel for this? 0 was the most prepared they could feel and 10 the least	3.73	2.40	0-10
How ready do you feel to live independently? 0 was the most prepared they could feel and 10 the least	4.10	1.88	1-7

school (mean 3.63, range 0-8). Positive qualitative comments about the FE department included: favourite subjects; going to college; work placements; FE staff members; friends; break times; experiencing independent travel; specific activities in the residential provision; being able to bring possessions from home to school (e.g. games consoles or DVD players), and using the computers in FE. Pupils also FE was a better option than returning to mainstream school for post-16 education.

Pupils reported fewer negative comments than positive overall. Negative comments included: the limited independence that came with living in FE; the school's overprotective nature; staff assuming pupils did not know what they were doing; drinking alcohol was not allowed in FE even though they were the legal age (2 pupils); disliking the school food; short break times; boys outnumbering girls; arguments with other pupils; slow internet; poor laptops, and having to do the work.

b. Boarding at the school

Twelve of the FE pupils were boarders. As a group they were reasonably happy living in FE however again the range suggest some pupils were less happy (mean 3.19, range 0-6). On average pupils did not report a great sense of missing their families at home, however the range for this answer covered the full spectrum of answers so some pupils missed their families much more than others (mean 3.54, range 0-10). Pupils also gave qualitative comments about living in FE. They liked: going out in the evenings²¹; playing games and sports organised in FE; spending time with friends; having their own rooms, and not having to travel between home and the school every day. In addition, pupils also reported enjoying certain activities related to learning about independent living: exploring the community; help

²¹ This was dependent on getting permission from staff.

with cooking washing and ironing; cooking their own meals once a week, and also having more freedom than they had done in the past when they lived in the main part of the school. Pupils also made some negative comments about boarding. Pupils disliked: conflict between pupils and the care staff (3 pupils); being away from their families (3 pupils); having chores (2 pupils); house meetings in care (2 pupils)²²; not being allowed to visit the pub; being bullied; not having time to themselves; strict discipline; being made to participate in evening games and activities; being made to go to bed earlier²³ than preferred, and poor food (3 pupils).

Twelve pupils commented on being away from home and two pupils explicitly felt this was negative. Pupils reported: missing their families (5 pupils); it was upsetting; missing pets; missing home cooking; missing their own beds and possessions, and not having the same level of freedom as they would do at home. However, pupils also liked: having space away from home; spending time with friends, and feeling responsible for themselves.

c. Education in the Further Education Department

Pupils reported mostly positive, though some negative, feelings towards being at college (mean 2.21, range 0-10). They also made qualitative comments about the support they received from FE at their external placements. Six pupils reported an LSA came to college to support them. Pupils also described the support in FE itself: receiving help with coursework; literacy skills; remembering things from their courses and getting help as required.

The majority (11 pupils) preferred spending time at their placements and none favoured FE (see table 8.5). Pupils favoured college because: they preferred doing their chosen courses (2 pupils); they were working towards qualifications; they were treated more like adults (2 pupils); they felt more respected; college was less overprotective (2 pupils); they had more freedom (4 pupils); they had more personal space; they were allowed to smoke; they liked having different tutors; the college had more students; they had friends at college (5 pupils), and the food was better (2 pupils).

Pupils also described what they felt they had got out of going to college: improving skills e.g. using computers (4 pupils); the courses (3 pupils); qualifications (3 pupils); knowledge of their subject areas (5 pupils); friendships (4 pupils); access to the college tutors (2 pupils); getting better at using public transport (2 pupils), and more independence.

²² These occurred when a problem arose in care and were seen as a negative occurrence.

²³ Bedtime in FE was reported to be 9:45pm.

Table 8.5 - Pupils' placements and courses, whether they reported having an LSA support them at college and whether they felt college was useful.

FE Pupils	Placement	Course	LSA	Placement useful	Preference
Alexia	College	Art, Design and Media	Yes	Yes	College
Andrew	College	Media and Design	Yes	Yes	College
David	Both	ICT and Work placement	Yes	Yes	College
Dominic	College	Multi Media	Yes	Yes	Same
Dylan	WBP	Gardening	Yes*	Yes	Work
Joe	WBP	Local shop	Yes*	Yes	D/K
Leo	College	Performing Art	Yes	Yes	College
Lilly	College	Horse care	Yes	Yes	College
Mathew	College	Media	Yes	Yes	Same
Miriam	College	Multimedia	Yes	Yes	Same
Morgan	College	Painting and Decorating	Yes	Yes	College
Phillip	College	Multimedia	Yes	Yes	College
Selina	College	Horse care	Yes	Yes	College
Shane	College	Sport and ICT	No	Yes	College
Sofia	College	Health and social care	No	Yes	College

* Support was during a previous college course and not at the work placements.

WBP Work based placement

Reasons for staying in FE included: staying with friends (7 pupils); the education offered (5 pupils); access to college courses (4 pupils); wanting qualifications; wanting work experience; pressure from parents (2 pupils); staying was more easier than moving on (2 pupils); extra support; help with maths and literacy (2 pupils); SLT; not feeling ready to leave, and thinking it would help them get the best out of life.

d. Life After Special School

As a group the pupils felt reasonably ready to leave, however the results indicated a broad range of responses and overall it was an area where pupils expressed relatively low confidence (mean, 3.73, range 0-10). Pupils felt slightly more ready to begin the next thing after leaving the school e.g. employment or more studies (mean 3.30, range 0-8). Pupils also strongly felt FE had helped them feel more ready for life in the future (mean 1.97, range 0-5.5).

Pupils preferences for what they wanted to do after FE are reported in table 8.6: employment (7 pupils); further education (2 pupils); studying and work placement (2 pupils),

Table 8.6 - What pupils preferred to do in the future when they leave FE.

FE Pupils	After FE
Alexia	Studying and work placement
Andrew	Undecided
David	Job
Dominic	Studying
Dylan	Studying and work placement
Joe	Job
Leo	Job
Lilly	Job
Mathew	Job
Miriam	Undecided
Morgan	Job
Phillip	Undecided
Selina	Studying
Shane	Job
Sofia	Undecided

or undecided (4 pupils). Pupils wishing to pursue further studies wanted: to start a new college course (4 pupils); to finish elements of a course they had begun in FE at alternative colleges in their local area (2 pupils), and to get qualifications. Pupils who wanted to start work talked about: the jobs they wanted to do; wanted an income (4 pupils), or were bored of studying. Two pupils also wished to start a work experience placements alongside their future studies.

Only three pupils suggested additional things the school could have done for them: help with romantic relationships; help with navigating unfamiliar places; more careers advice, and more opportunities for work placements. Overall, the pupils felt FE had been successful at preparing them for when they leave.

e. Independent Living²⁴

Pupils were least confident of the future chances of achieving independent living of all the items in the interview (mean 4.10, range 1-7). Ten pupils felt they would achieve independent living in the future and 5 were unsure; all pupils felt this would happen in their early to mid 20's (see table 8.7). Pupils commented on what they expected to find positive: more freedom (6 pupils); more independence; being your own boss; experiencing adulthood; having your own home (2 pupils); peace and quiet; meeting new people; getting to know a

²⁴ Living independently was explained pupils as moving away from the school and from their parents but that they might live with friends if they wished.

Table 8.7 – Pupils' wishes for future independence

FE Pupils	Wish for independent living	Age predicted by pupil
Alexia	D/K	22
Andrew	Yes	21
David	Yes	D/K
Dominic	D/K	23
Dylan	Yes	21
Joe	D/K	23
Leo	Yes	20
Lilly	Yes	D/K
Mathew	Yes	20
Miriam	Yes	Early 20's
Morgan	Yes	D/K
Phillip	Yes	20-22
Selina	Yes	25
Shane	D/K	22
Sofia	D/K	23

D/K – Did not know, or did not express

place; having a big house; having a car (2 pupils); learning to drive; having pets; buying what you want; finding a partner; getting a job and earning money, and having fun. Four pupils suggested tasks they would 'have' to do rather than would 'like' about independent living; needing to do domestic chores (4 pupils) and 'needing' to get a job.

Pupils also gave comments about what they would find negative or difficult about independent living. Comments included: paying bills (4 pupils); working for money (2 pupils); having too much responsibility (2 pupils); being away from home; missing families (5 pupils); cooking for themselves (2 pupils); getting up in the mornings, looking after themselves, and living alone.

Pupils gave comments about the life skills they had learnt in FE and how these could help them in the future. Pupils were taught about: ASDAN (6 pupils); washing and ironing (5 pupils); using public transport; shopping; paying bills (4 pupils); cooking; cleaning; tidying up; appropriate and inappropriate behaviour; personal hygiene and homework. Pupils were also allowed out in the evenings and 1 individual found this useful for building up independence skills. Overall, pupils were perhaps least confident about their future chances of achieving independent living than other domains examined.

f. Future employment plans

Pupils rated how ready they felt for employment (mean 3.30, range 0-7) and described the jobs they wanted to have in the future (see table 8.8). Most reported choosing specific jobs because there was an element they felt they would like: e.g. being creative (3 pupils); using machinery; working outdoors; meeting staff and customers (3 pupils); working with animals (2 pupils); competing; to do an activity they enjoyed doing (3 pupils); they wanted to follow a career path, or because they wanted to help others. Other comments included: making money (3 pupils); skills or qualities pupils felt they possessed²⁵; skills or awards pupils wanted to gain²⁶, or because pupils felt their ideal job matched their life style.

Pupils reported any training they would need to do to get their desired future job. Eight pupils mentioned specific training for their employment ideas, e.g. David getting a forklift truck licence. Nine pupils mentioned more general types of training: e.g. literacy and numeracy skills. Leo commented that he would need to train to be a dentist but showed no awareness of how to achieve this.

Table 8.8 - Pupils' future job ideas

FE Pupils	Future job choice
Alexia	Potter
Andrew	Unspecified office work
David	Warehouse worker
Dominic	Working with animals
Dylan	Gardener
Joe	Retail
Leo	Dentist
Lilly	Jockey/entering the Olympics
Mathew	Shop assistant
Miriam	Art or photography
Morgan	Musician
Phillip	Media or IT
Selina	Working with horses
Shane	N/A*
Sofia	Care assistant

* Refused to disclose information

g. Communication

Pupils' reported feelings towards the support they received at the school for the SLD (mean 2.27, range 0-5), their SLD (mean 1.67, range 0-5), reading (mean 2.93, range 0-8),

²⁵ Fixing computers; researching on the internet; patience; past experience with a job; passion; caring for people and, team working skills.

²⁶ Experience; qualifications; winning medals or trophies, and working on the tills.

spelling (mean 3.30, range 0-8) and mathematical ability (mean 2.40, range 0-8) at the time of the study. On average pupils felt happy and confident in their abilities and that staff had been able to help them. SLD was also reported to be the greatest area of confidence for the FE pupils.

Pupils found some aspects of FE easy. Eleven pupils mentioned academic subjects or skills they liked and 3 pupils mentioned other activities they enjoyed: working on a laptop; living in the care environment; expressing themselves; talking to new people; making friends; problem solving tasks; college, and sports.

Areas of difficulty were also reported. Ten pupils named academic subjects or skills they found difficult, other reports included: not understanding college work; difficulties keeping friends; difficulties with memory; difficulty understanding people; difficulty speaking in a group; difficulty with romantic relationships, and staying out of trouble.

h. Friendships

In general, pupils reported getting along with others and that they made friends easily, however getting along with others was slightly easier than making friends. Table 8.9 shows the numbers of friends pupils reported they had and that all the pupils felt they would keep in touch with their FE friends when they leave. Overall, the greatest number of friendships were reported in FE.

Table 8.9 - Numbers of friends reported by the pupils.

FE Pupils	Friends in FE	Friends at College	Friends at Home	Keeping in touch with FE friends in the future?
Alexia	10+	2 to 5	2 to 5	Yes
Andrew	2 to 5	2 to 5	10 +	Maybe
David	2 to 5	5 to 10	0	Maybe
Dominic	10+	2 to 5	5 to 10	Yes
Dylan	10+	10+	5 to 10	Yes
Joe	5 to 10	2 to 5	1	Yes
Leo	10+	2 to 5	0	Yes
Lilly	10+	2 to 5	0	Yes
Mathew	2 to 5	2 to 5*	5 to 10	Maybe
Miriam	10+	2 to 5	0	Yes
Morgan	10+	10+	5 to 10	Yes
Phillip	10+	5 to 10	0	Yes
Selina	10 +	10 +	2 to 5	Maybe
Shane	10+	2 to 5	2 to 5	Yes
Sofia	10 +	5 to 10	1	Yes

A choice of 5 tick boxes were available 10+ was the maximum and 0 was the minimum.

* But 2 – 5 of the same friends that he knew in FE

8.3.2 The Findings from the Parental Data

a. Experiences of Further Education

Overwhelmingly positive experiences of FE were reported by the parents (see table 8.10). Parents felt the education in FE was appropriate for their children's needs and saw combined SLT in to the curriculum as positive. FE was also seen as crucial because the same standard of provision received at secondary school could now be carried on to post-16 and because 16 was viewed as too young to withdraw support.

Parents felt the main objectives of FE were providing a transition and preparing pupils for the real world (3 parents); providing a transition from secondary school into FE (2 parents); facilitating learning at college; helping pupils pass exams; identifying what pupils could do in the future; providing continuing SLT; continuing the support provided at secondary school; ASDAN (3 parents); helping students to reach their full potential (2 parents); improving confidence; and behaviour; supporting pupils with personal problems, and to provide a safe environment for pupils to learn in. Joe's family had been concerned as to what he would do after completing secondary education but fortunately FE was opened in time for him to move in to the first year of FE. Mathew's mother also felt that she had been lucky that FE was opened.

There was a consensus that the school understood SLD and had expertise to help support their children's needs because the staff had specialist knowledge and understanding of pupils' SLD (3 parents) and SLT was built in to the education at the school.

Jasmine: (The school) had the expertise, experience and knowledge to address the needs of communication disorders.

Gwen: Language is built in to everything and the development of language is constantly a theme all the time.

Three parents felt that having specialist SLTs and LSAs who could offer one to one support was important.

FE was seen to be a caring and supporting environment for pupils. This included support with: college courses and coursework (2 parents); life skills; behavioural difficulties (2 parents); self confidence; social difficulties (3 parents), and personal issues. Also, as FE catered for relatively small numbers of pupils support could be tailored to pupils' individual needs more easily; this included the care environment for the boarding pupils. Lia felt FE had helped her son in every way possible.

Table 8.10 - How well did the school cater for the pupils' needs?

Parents	How well did the school before FE cater for your child's needs?	How well has FE catered for your child's need?
Ben	Very well	Very well
Gwen	Very well	Very well
Jasmine	Very well/Quite well	Very well/Quite well
Jessica	Very well	Very well
Lia	Very well	Very well

There were 5 possible choices: very well; quite well; adequately; quite poorly, and very poorly.

In summary, FE was seen as a crucial addition to the school as it provided pupils with continuing quality education and specialist support at post 16. This was a vital addition to the school as 16 was seen as too young to withdraw support. FE was viewed to provide a successful and appropriate provision for pupils, and staff were seen to have a good knowledge and understanding of SLD and how to support the pupils.

b. Current Communication

Table 8.11 reports how parents' felt towards the pupil's SLD and the support they received. All parents felt their children had made improvements during their time at the school and in FE. For example, Selina's mother felt her daughter had improved significantly; she had been able to say very few things when she entered the school. Other positive reports included: gaining self confidence (2 parents); confidence when speaking; understanding own needs; improved communication (2 parents); using language in the right context; being able to say when they had not understood; better understanding of what is expected; better understanding of social interaction, and learning to control anger.

Even so, parents still felt pupils had difficulties caused by their SLD. These included: getting tenses and situations wrong; choosing not to talk; persisting SLD; difficulty understanding facial expressions and body language, and poor dexterity. Parents also felt the school had helped pupils with their literacy, this included reading, writing, spelling (4 parents), and confidence with literacy. However, parents also felt that pupils still struggled with literacy. For example, Joe's father felt his son struggled during his GCSE mathematics examinations because the questions had been written in words rather than mathematical symbols; as a result he had not realised his potential in this exam.

Table 8.11 - Parents satisfaction with pupils' communication.

Parent	1. How happy is parent with child's communication	2. Did FE help with child's communication	3. Did FE help with child's literacy
Ben	Quite unhappy	Yes a lot	Yes a lot
Gwen	It's okay	Yes a lot	Yes a lot
Jasmine	Quite happy	Quite a lot	Quite a lot
Jessica	Completely happy	Yes a lot	Yes a lot
Lia	Quite happy	Yes a lot	Yes quite a lot

1. There were 5 possible choices completely happy with it; quite happy with it; it's okay; quite unhappy with it, and very unhappy with it.

2 & 3. There were 5 possible choices: yes a lot; yes quite a lot; only a bit; no not much, and no not at all.

In summary, parents felt that FE had been successful in helping pupils resolve some of their difficulties, however they also felt that pupils still had some persisting difficulties remaining. Despite this parents still felt overwhelmingly positive towards the support that had been provided.

c. Education in Further Education

Table 8.12 compares the parent and pupils' reports on college and extra support received. Shane and his mother disagreed on whether he received support. In addition, parents reported on the positive and negative aspects of the college placement element of FE. Positive comments included: access to college courses and the college environment; good communication between the college and FE (2 parents); support with college work (2 parents); having an LSA attend college (2 parents); help with transport (2 parents), and making friends with mainstream peers. Parents also reported difficulties with college: struggling at college due to SLD; college was time consuming, and difficulties finding the right courses (2 parents).

Four parents spontaneously commented on the life skills learned in FE. Teaching life skills in FE was seen as positive by parents. However, three parents felt that boarding pupils had an advantage over day pupils as they got to study extra life skills in care. Of these pupils, Joe was the only pupil who attended a work based placement at a local shop. His father felt this was important as it provided him with a reference that would be beneficial when applying future employment.

Table 8.12 - Pupils placements and whether extra support from LSAs was reported.

Child's college course	Extra support reported by parents	Extra support reported by pupils
Work Placement	Yes* (Ben)	Yes* (Joe)
Horse care	Yes (Gwen)	Yes (Selina)
Media and Multimedia	Yes (Jasmine)	Yes (Matthew)
Media and Design	Yes (Jessica)	Yes (Andrew)
Sport and ICT	Yes (Lia)	No (Shane)

*Support was during his previous college placement. Joe did a Sport diploma in year 12 and a Leisure and Tourism diploma in year 13 before his work based placement in year 14.

d. Boarding

Parents' comments on boarding were more positive than the previous ex-pupil reports in section 6.3.2 (see table 8.13). Two parents reported that their children were 'fine' boarding at the school despite initial apprehension. These parents also reported no detrimental effects of boarding on siblings at home. Only Selina's mother reported an especially negative experience with boarding as she felt it had affected her relationship with her daughter. Joe's father felt the communication between the school and home had been superb and this helped making boarding easier for the families.

Table 8.13 - Parents feelings towards boarding

Parent	How do you feel when your child is away from home?	Does it have an impact on their siblings?
Ben	I don't worry about them much	No, I don't think it effects them at all
Gwen	Very hard and upsetting	It affects them by they get on ok
Lia	I don't worry about them much*	No, I don't think it effects them at all

There were 5 possible choices for question 1: I don't worry about them much; I worry about them a little bit; Sometimes I'm ok and sometimes I find it hard; I find it quite hard, and I find it very hard and upsetting. There were 5 possible choices for question 2: Absolutely – I know they find it hard; I think it affects them a bit but they get on okay; No I think it affects them at all; I can't be sure either way, and S/he is an only child.

* But did worry when he first went away.

e. Perceptions of Mainstream School and Specialist Provision at Post-16

Only two parents reported their children had attended mainstream schools in the past, however all felt special school had been the best option because of the expertise offered (2 parents) and the smaller class sizes (2 parents). Three parents reported negative feelings towards mainstream education: no specific knowledge; peers may treat their child differently; lack of specialist provision; pupils not being able to cope; pupils being disruptive in lessons, and not understanding the lessons.

Ben: No chance. I'm a teacher in the mainstream school he would have gone to and there is no way he would have coped.

Lia: (Shane) would have been excluded from primary school ... disruptive in lessons ... (struggled to) understand lessons ... (and) wouldn't have learnt anything.

Reasons why parents chose for pupils to stay for FE included: the SLT; the specialist support; it was an easy transition; because there was no alternative (2 parents); to take advantage of the opportunity FE offered; the familiar environment (2 parents), and because pupils already had friends there.

Parents felt that there had been no alternatives to FE that would have been able to cater for their children's needs at post 16 (2 pupils). Selina's mother felt she would have been in a 'dire situation' had FE not been available, and Mathew's mother hypothesised her son would have stayed at home and his behavioural difficulties would have increased. Two mothers suggested their sons could have gone to local technical colleges but they would have received general support and may not have coped.

f. Friendships

Parents viewed pupils' friendship more negatively than the pupils themselves (see table 8.14). They made few qualitative comments and these were mostly negative. They felt pupils had few friends at home due to; pupils not having the opportunity to meet new people at home; people not accepting pupils, and because boarding limited their time at home. Selina's mother hoped that her daughter would make friends at home after FE.

g. Life After FE

Parents felt that FE helped pupils to make the transition from life in FE to life outside because it helped with life skills, and provided guidance for the future. Parents also felt pupils had matured during their time in FE and this had helped pupils gain confidence (2 parents).

By the time parents were interviewed three pupils (Selina, Joe and Shane) had left FE. Selina was planning to carry on with her horse care course at a local college with nonspecific learning support; going to college in FE meant she found it easier to start at her new college. Joe had started work in a warehouse, this was a job his father helped him get. Joe also benefited from a careers liaison officer at the school before leaving. It was unclear what Shane was going to do next. The parents of the two pupils still in FE were also asked about

Table 8.14 - Parents' views on pupil's friendships and a comparison of parent and pupil views.

1. Do they get on with others	2. Do they make friends easily	3. No. of friends a home - parents' views	4. No. of friends a home – pupils' views	5. Keeping in touch with friends when pupils leave – parents' view	6. Keeping in touch with friends when pupils leave – pupils view
Very well	It's quite hard	1-5 (Ben)	1 (Joe)	It's unlikely (Ben)	Maybe (Joe)
Quite well	Quite easily	0 (Gwen)	2 to 5 (Selian)	Would like to, but it could be difficult (Gwen)	Yes (Selina)
Quite well	It's quite/very hard	1 (Jasmine)	5 to 10 (Matthew)	Unlikely (Jasmine)	Maybe (Matthew)
Very well	Very easily	5 to 10 (Jessica)	10 + (Andrew)	Yes definitely (Jessica)	Maybe (Andrew)
Quite well	Quite easily/Okay	0 (Lia)	2 to 5 (Shane)	Would like to, but it could be difficult (Lia)	Yes (Shane)

1. There were 5 possible choices: S/he gets on with them very well; s/he gets on with them quite well; sometimes s/he gets on with them; s/he doesn't really get on with them, and s/he doesn't get on with them at all
2. There were 5 possible choices: very easily; quite easily; okay; it's quite hard for him/her, and it's very hard for him/her.
3. There were 5 possible choices: more than 10 friends, between 5 and 10 friends, between 2 and 5 friends; one good friend, and s/he doesn't have any friends.
4. There were 5 possible choices: more than 10 friends, between 5 and 10 friends, between 2 and 5 friends; one good friend, and I don't have any friends.
5. There were 3 possible choices: yes definitely; I think s/he would like to, but it might be difficult, and it's unlikely.
6. There were 3 possible choices: yes definitely; I would like to, but it might be difficult, and it's unlikely.

Table 8.15 - Parents' feeling towards pupils leaving FE

Parent	1. Is your son/daughter ready to leave FE?	2. Are you confident child is ready to move on?	Preference for what they do next?
Ben	My child is nearly ready	Not confident	Employment
Gwen	My child is nearly ready	Quite confident	Employment
Jasmine	Not sure	Quite confident/Not sure	Employment
Jessica	Not sure	D/K	Further Education
Lia	My child is nearly ready	Completely confident	He can choose.

1. There were 5 possible choices: my child is completely ready and could leave now; my child is nearly ready and will be ready when the time comes; I'm not sure if my child will be ready to leave when the time comes or not; my child will not be ready to leave when the time comes, and I can't ever see a time when my child will be ready.

2. There were 5 possible choices: I'm completely confident my child could do this; I'm quite confident my child could do this; I'm not sure if my child could do this; I'm not confident could do this and, I think this would be very difficult for my child.

D/K - Did not know

the future: Andrew's mother felt he would need support to gain access to work, and Mathew's mother felt he would be able to do part time work that did not require academic ability.

Parents talked about what jobs they felt their children might do in the future (see table 5.16) but expressed concerns for the future and their children finishing at FE. Concerns for the future included: difficulties gaining and maintaining employment; accessing further college courses, and no more specific support or SLT.

Concerns specific to gaining employment included: poor local facilities²⁷; limited employment opportunities; feeling unsure of pupil capabilities, and being disadvantaged when competing for jobs because of their SLD. Concerns with maintaining employment included: pupils having a limited work rate; not being able to take orders or keep on task without reminders, and behavioural difficulties associated with SLD.

h. Independent Living

Parents were unsure whether their children would achieve independent living in the future (see table 8.17). For example, Selina's mother felt Selina would need a motivation to move out; e.g. if she met someone she wanted to move in with. Joe had been given the opportunity to try living with his sister but he had declined this offer his father was unsure if Joe would ever want to live independently.

²⁷ E.g. careers service, support services, the job centre, the poor local transport system and employment opportunities (Ben).

Table 8.16 - Parent and pupils' views on starting employment

Parent	Future job/parents	Future job/pupils	Ready to start work?	Did pupil talk about future job?	Did parent have concerns?
Ben	Was working in a warehouse by Ben's interview	Retail – this was before he started his subsequent job.	N/A	N/A	Yes
Gwen	Horse care or animal care	Horse care	Quite ready	No	Yes
Jasmine	Shop assistant	Shop assistant	Not really sure/not very ready	Yes – clothes shop	Yes
Jessica	Office based work	Office based work	Not ready at all	Yes – designing computer games	Yes
Lia	Gardener/something outside	*	Quite ready	Yes	Yes

* Refused to disclose information but assured the researcher that he knew what he wanted to do in the future.

Table 8.17 - Parent and pupils' independent living in the future.

1. Will I.L. be achieved – Parents	Will I.L. be achieved – Pupils	At what age? – Parents	At what age? – Pupils	Parental concerns?	1. Will they need support from the family?	2. Will they need support from the organisations?
Not sure (Ben)	D/K (Joe)	D/K (Ben)	23 (Joe)	Yes	He will always need some support	Yes – if it was available locally
Not sure (Gwen)	Yes (Selina)	25+ (Gwen)	25 (Selina)	Yes	She will always need some support	She will always need some support
Not sure (Jasmine)	Yes (Matthew)	Not a priority (Jasmine)	20 (Matthew)	Yes	He will always need some support	He will always need some support
Not sure (Jessica)	Yes (Andrew)	D/K (Jessica)	21 (Andrew)	Yes	He will need very little support.	He will need very little support.
Yes (Lia)	D/K (Shane)	D/K (Lia)	21 (Shane)	No	He will need support at first	No

I.L. Independent living

1. There were 5 possible choices: Yes my child will always need regular support from the family; Yes my child will always need some support from the family; Yes my child will need support when they first start living independently; Yes my child will need support when they first start living independently, and No my child won't need any support from the family.

2. There were 5 possible choices: Yes my child will always need regular support from support organisations; Yes my child will always need some support from support organisations; Yes my child will need support when they first start living independently; My child will need very little support from support organisations, and No my child won't need any support from support organisations

Parents expressed concerns with pupils living independently in the future: e.g. pupils could become vulnerable 'being taken advantage of'; it would be difficult to achieve if the pupil still needed support, and pupils may struggle with domestic tasks associated with independent living. Shane's mother was the most optimistic towards her son's chances of achieving independent living and felt he had become quite independent because he had learnt to cook and use public transport in FE. Parents were also concerned pupils would struggle with managing the financial side of independent living: e.g. difficulties with budgeting (2 parents) and needing help managing their finances. Joe's father felt finances could have been addressed better in FE.

8.3.3 The Findings from the Staff Data

a. Views and Experiences of the FE department

The LSAs strongly agreed that opening FE had been important because: it helped prepare them for life in the future and aided the transitions into the adult world (6 LSAs); provided continuing education at post-16; helped pupils' gain qualifications and experience (2 LSAs); it get them time to catch up with their mainstream peers, prepared pupils for employment and gave them more time in the school. One LSA felt FE gave the younger pupils something additional to aspire to in the future. Another mentioned the financial implications as FE had brought extra sources of funds into the school.

The three LSAs who had worked at the school since before FE was opened (see table 8.3) felt that FE had a minimal impact on the rest of the school as it was a separate entity. One LSA reported some FE pupils would help out with the younger pupils and both parties usually enjoyed this. Another felt that the addition of FE could make the school more appealing to prospective pupils.

Staff acknowledged challenges associated with pupils attending external college courses; this was complex to organise as different pupils had different timetables and went off site with different LSAs at different times and days. Each pupil was allocated an LSA to help support their learning at college. LSAs were allocated to fit pupils' needs based on their expertise. Further difficulties with pupils attending college courses included: making sure pupils chose the right courses; making sure pupils were capable of completing college courses before taking them on (2 LSAs); the college lessons being much longer than the lessons in FE and pupils finding this a struggle; the rewards and punishments used in FE were

juvenile compared with the college environment; the larger environment was stressful, college staff not understanding SLD or why pupils needed an LSA for support. The positive consequences of pupils going off site to attend college courses included less behavioural difficulties at college and access to a new peer group.

The second component of FE concerned building life and independence skills to help pupils function in society in the future. LSAs felt that this was an important part of pupil's education at FE; however day pupils were seen as disadvantaged because boarding pupils got to learn more about independent living skills in the care setting. They felt there was a case for all pupils to board a few nights a week so all could benefit from this.

There was a consensus among staff that work based placements should become a compulsory element of FE as they helped pupils gain work experience and references to help them gain future employment. Work based placements could be completed either alongside a college course during a day that pupils would normally be in FE or during a third year in FE. One LSA also felt pupils could benefit from voluntary community work.

LSAs talked about the successes in FE and found this rewarding (3 LSAs). Examples of success included: passing exams, gaining self confidence (4 LSAs); growing emotionally (2 LSAs); gaining skills for independence²⁸ (2 LSAs), or overcoming a difficulty such as challenging behaviour. Three LSAs also talked about successes in building relationships with the more challenging pupils and resolving challenging behaviour. This was felt to be a very challenging but also rewarding element of the job.

Maria: You know that if you say to them you know you really didn't ought to be doing that ... and they'll almost be yeah your right ... it's like a woah oh my god ... that is a light bulb moment they've actually whether or not they always take it on board but if you just make one little indentation in somebody's life you've succeeded really ... you've done your job well.

LSAs reported some with the limitations of the FE department. A small minority of pupils failed to complete or pass their college courses: for example, one pupil failed an element of his course and therefore failed to gain the qualification. One LSA commented that sometimes FE had difficulty supporting all the college courses pupils wished to study as some required specific expertise the LSAs did not have. Inevitably an LSA will be more disposed to help with their specific area of expertise. One LSA felt some pupils had to leave FE before they were ready as they had completed the full 3 years. She felt that some pupils

²⁸ E.g. catching a bus for the first time.

could benefit from longer ongoing support and that the maximum age should be 25 rather than 19.

Rose: It's so important for students and I would love to see the funding extended even to twenty-five ... but a bit biased ... I'm sure some of our students would benefit from at least another couple of years.

b. Staff Views and Experiences of Pupils in FE

Staff members talked about the range of different difficulties FE pupils experienced: communication difficulties; Aspergers syndrome; dyslexic difficulties; dyspraxia, and learning difficulties. Pupils had difficulties with: using language; empathy; literacy; self confidence; motor control; behaviour, and presenting themselves to others e.g. volume when speaking. Problem areas were specific for individual pupils and LSAs gained different experiences working with individual pupils. The LSAs felt some pupils were able to make significant progress during their time in FE while others experienced more persisting difficulties (2 LSAs). LSAs also felt there was a small minority of high achieving pupils who might fare better in mainstream school rather than special school. These were pupils who appeared to have relatively few 'visible' SLD.

Many of the behavioural difficulties seen in FE were part of pupils SLD and exacerbated by the fact that pupils were not as mature as other 16 year olds. However, in FE pupils were treated like adults and therefore expected to behave accordingly. Often their behavioural difficulties meant they behaved younger than their chronological age. Three LSAs felt FE lacked strong enough discipline to deal with poor behaviour and stronger boundaries needed to be set so pupils could learn the consequences of their actions in the world outside FE. Disciplining the pupils in FE was difficult because juvenile behaviour was typically punished accordingly; this meant the methods of discipline used in FE were often juvenile compared to the pupils' age and the college environment. However, at college pupils seemed to recognise there were more severe consequences of poor behaviour (e.g. being removed from the course) and also displayed less behavioural difficulties at college.

Six LSAs reported that many pupils matured during their time in FE and two LSAs felt this was the most rewarding part of working in FE. Maturing referred to pupils blossoming and becoming more confident within themselves or displaying fewer behavioural difficulties.

Alison: You see a lot of them sort of coming in quite timid and scared and then you get them going out the other end you know really quite cocky and confident.

Nathan: When I first started (Shane) made my life hell ... got a really really good relationship now ... to the point where I can get him to do things that other people can't ... that type of thing gives me a buzz.

This therefore this made FE a critical part of preparing pupils for the future as FE gave them extra time in FE helped them to catch up with their mainstream peers. One LSA also commented that all successes for FE pupils were important: e.g. being able to hold down a job: becoming self sufficient, or possibly finding a partner. Unfortunately she felt success stories were uncommon among school leavers.

c. Boarding in FE

LSAs felt boarding was advantageous as pupils learnt additional life skills in care. One LSA had attended a boarding school during his education and felt that it had taught him to be more independent. Few disadvantages of boarding were reported overall. One LSA felt that sometimes parents overcompensated when pupils returned home and therefore some of the parents' discipline of pupils could be poor. Another felt that boarding prevented pupils from becoming part of their communities at home. One LSA, who was also an ex-pupil herself, did describe her own difficulties with the emotional hardship of being away from families at home as a child.

d. Friendships in FE

Staff also commented on pupils' friendships. Four LSAs commented that boarders had access to a good social life because they lived with their friends, however, one felt that boarding sometimes came at the expense of having no friends at home. Another LSA felt pupils found it difficult to maintain friendships once they left FE. Three LSAs felt that college helped with social skills as pupils also got to socialise with mainstream peers; however, one LSA also felt pupils could be vulnerable or taken advantage of at college.

e. Leaving FE and the Future

FE was felt to provide a transitional period to prepare pupils for leaving the school by providing them with the opportunity to gain qualifications, experience, life skills and confidence for when they leave FE (2 LSAs). LSA expected that the majority of FE pupils would go on to further college courses and a minority go on to employment (3 LSAs). LSAs felt unsure about the future for many of the pupils and there was a consensus that there would

be a large spectrum of outcomes which could not be generalised. Parents were felt to have a heavy influence on pupil success after they left FE and played an important supporting role after pupils leave FE. One LSA felt pupils benefitted from having proactive parents and pupils with less proactive parents were more likely to experience poorer outcomes. Two LSAs also felt some pupils were anxious about finishing and leaving. LSAs were concerned FE was a safe protective environment that did not provide pupils with a realistic view of the world outside (3 LSA).

LSAs expressed concerns towards levels of understanding, knowledge and awareness of SLD in the outside world; this could cause the pupils difficulty in the future. Some pupils were reported to be good at hiding their difficulties, and people not be aware of their SLD. LSAs were concerned that the pupils who could mask their difficulties could be vulnerable in the outside world as people may assume they are more able than they are. More generally it was felt that people unfamiliar with SLD do not understand how they affect the individuals who have them. Another commented that people assume SLD refers to people who cannot speak or stammer. This could therefore cause difficulties for the pupils in the future.

8.4 Discussion

8.4.1 What are the Pupils' Experiences of Further Education at the Residential Special School?

Many pupils that stayed for FE had not felt ready to leave the school at 16. Pupils felt FE had successfully prepared them for life as adults because: it provided continued access support for SLD; it provided access to college courses and support with these, it taught them about life skills for the future, and it helped them gain greater levels of independence, self confidence and maturity. Having access to post-16 provisions for SLD put the pupils in a fortunate minority as this is rare at post-16 (Dockrell et al., 2006). Not only did this include support with accessing further studies but it also meant ongoing access to SLT. The pupils appreciated the opportunities FE had provided and had few suggestions on how to improve their experience. Overall, FE was viewed as highly beneficial Palikara et al., (2009) also found similar findings that individuals with persisting SLD valued and appreciated the support they received.

While pupils felt happy in FE, they preferred spending time at college because they felt they were allowed more freedom and were treated more like adults than in FE. Furthermore, in the FE pupils could not be allowed certain privileged because they were not

appropriate on the school site; e.g. smoking and drinking alcohol despite being the legal age. While pupils appreciated FE, the mainstream environment was still more appealing. Adolescents with SLD are likely to experience more limited levels of independence than others their own age without SLD (Conti-Ramsden and Durkin, 2008). This study suggests support for this; however it also shows individuals with SLD greatly value the independence they do have. It also highlights an area where pupils favoured mainstream education over the residential special school.

8.4.2 What are the Pupils' Parents' Experiences of having their Child with SLD Attend FE at the Residential Special School?

Parents felt FE had been a positive and crucial addition to the school. Conti-Ramsden et al., (2008) showed that access to specific post-16 provisions is important to parents and lack of provision can be a source of anxiety. FE was seen as a stepping stone that supported their children in making the transition between compulsory education and the adult world. College and work based placements were viewed as successful; however some parents were concerned that some placements may be too difficult.

Parents also felt that FE had the expertise and knowledge to support their children and offered the right provision. They felt the pupils showed an improvement with their SLD, literacy, confidence, social skills and maturity during their time in FE; however, parents still reported some persistent SLD.

Parents also reported feelings of anxiety for what would have happened had FE not been available. This highlights how critical opening FE had been for pupils and their families. Parents also reported feelings of fear for the future and having nowhere to go when their children leave FE. This was similar to findings by Grant et al. (2007).

Parents all favoured FE for their children over returning to mainstream school and were concerned about how their children would have coped in mainstream education. Overall, FE was viewed as a successful provision by parents.

8.4.3 What are the Experiences of the Staff who Work with the FE Pupils?

The LSAs also felt FE had been a positive and crucial addition to the school. They also felt it provided pupils with the means to progress into the adult world. They saw success in FE as pupils making steps towards independence and overcoming their difficulties. LSAs felt successes like gaining paid employment or achieving independent living were positive

outcomes for pupils and the school. Many of the FE pupils were immature for their age when they entered FE. As they progressed they matured, increased in confidence and displayed fewer behavioural difficulties.

However, FE was a complex organisation to run. LSAs reported difficulties with pupils attending college placements; they struggled with longer lessons times, and the college staff at college did not understand the pupils' needs. Furthermore, some pupils struggled with the demands of their college courses. Dockrell et al., (2007) reported heterogeneous academic outcomes for adolescents in SLD at 16 years of age. A minority of their cohort did experience poor academic outcomes. This was also the case of the FE pupils. The potential causes for this may be: e.g. persisting SLD (as in Aram et al., 1984; Snowling et al., 2001); pupils choosing the wrong courses; courses being too demanding, or they did not receive enough support. The latter is unlikely as support in FE was abundant.

LSAs also reported areas for improvement in FE. They wanted to see work based placements become a compulsory element of the FE provision. This would provide pupils with experience of employment and a stronger foundation and increased level of confidence to go find employment in the future. This is important as the pupils may risk poor employment outcomes in the future (Clegg et al., 2005; Howlin et al., 2000) and similar schemes, such as supported employment schemes, have been shown to be of benefit to individuals with SLD seeking employment (Howlin et al., 2005; Mawhood and Howlin, 1999). LSAs also wanted for some pupils to be able stay in FE beyond three years as some pupils still left before they were ready.

8.4.4 What are the Areas of Potential Risk and Difficulties for Individuals with Persisting SLD at Post-16 and Beyond?

Leaving compulsory education is a significant and challenging time in the life of any adolescent (Blacher, 2001). Parents and LSAs expressed fears for the future when the pupils leave FE. There was a consensus that outcomes were more likely to be negative than positive. They also felt that FE was a safe protective environment that did not provide pupils with a realistic view of the world outside. In the future this could mean pupils are vulnerable because they lacked life experience. Parents are likely to express concerns for the future, particularly at times of transition, and these have been shown to be more severe in parents to children with SLD (Conti-Ramsden et al., 2008).

More pupils expressed a wish to start employment after FE rather than pursuing more studies. However, employment is potentially a potential area of difficulty for the pupils. Some follow-up studies have reported limited success with employment (Clegg et al., 2005; Howlin et al., 2000) while others report more positive outcomes (Aboagye 2001; Felsenfeld et al., 1994; Records et al., 1992). It is difficult to predict how this cohort will fair but it is most likely their outcomes will be heterogeneous; the LSAs predicted mixed but predominantly negative outcomes for the FE pupils based past experiences of school leavers.

Most FE pupils felt they would achieve independent living in their early to mid 20's. Adolescents with SLD are likely to have more limited levels of independence than their typically developing peers (Conti-Ramsden and Durkin, 2008). They also literature reports mixed outcomes for independent living (Aboagye, 2001; Clegg et al., 2005; Howlin, 2000). In addition, some pupils expressed concerns towards their ability to look after themselves despite the extensive life skills work they completed in FE. This suggests that pupils may still struggle to meet their predicted targets for independent living unless they receive some additional support e.g. supported living.

The LSAs described some social difficulties among the pupil cohort; immature behaviour; poor behaviour, and difficulties with college peers. In addition, LSAs and parents both felt pupils were likely to lose contact with their friends in FE after leaving the school. These findings suggest the FE pupils may risk of social difficulties in the future. It is most likely that friendship outcomes for the FE pupils will be heterogeneous: for example, Conti-Ramsden (2007) reported heterogeneous friendship outcomes in 16 year olds with SLI. The literature also suggests pupils could be at risk of social isolation if they are not able to form new friendships (Beitchman et al., 2001; Clegg et al., 2005; Durkin and Conti-Ramsden, 2007; Howlin et al., 2000; Johnson et al., 1999).

8.4.5 Are there Areas of Discrepancy between Pupils, Parents and Staff in their Reports of FE?

Some areas of discrepancy arose between the reports of pupils, parents and LSAs. The first related to employment. The majority of pupils wanted to go into employment directly after leaving. However, staff reported that the majority of school leavers go on to further studies rather than employment. This highlights a difference between the pupils' wishes for the future and what could be a different outcome. It is unclear why so many pupils continue

to study after FE, however this was not necessarily seen as positive by parents and LSAs who would prefer to see them go into work after leaving FE.

The second area of discrepancy was with the discipline and the way pupils felt treated in FE. The pupils felt discipline was strict, compromised their freedom in FE and made them feel they were being treated younger than their age. Conversely the LSAs felt discipline in FE was not strict enough and that pupils were not being taught the potential consequences of their actions in the 'real world'. Both parties agreed that the discipline was too juvenile in FE, but staff felt this was difficult to avoid when pupils behaved immaturely. Both parties also felt that the discipline was more relaxed at college. The LSAs also felt it was more effective in college because the consequences were more severe, e.g. being thrown off the course. In turn, the pupils reported that they preferred the college environment because they felt more respected. These findings highlight a conflict between the pupils' desire to be treated as young adults and immature behaviour caused by persisting SLD.

Thirdly, as a group the pupils were relatively confident about their chances of achieving independent living in the future; most felt they would do so in their early to mid 20's. However, parents were less confident about their children's future chances of achieving independent living. Based on the literature and previous research findings there is a risk that this cohort will struggle with independent living (Clegg et al, 2005), this is also of concern to parents as they may have to continue providing their children with accommodation and financial support in adulthood (Clegg and Henderson, 1999).

Fourthly, Shane and his mother disagreed as to whether he received support at college. It could therefore be the case that pupils received more support than they disclosed. It is difficult to know whether pupils' failure to disclose was due to pupils misunderstanding the question or to a reluctance to admit to still needing support.

Chapter 9 - General Discussion

9.1 The Aims of this Thesis

This thesis aimed to explore the outcomes of ex-pupils of a residential special school for developmental SLD in adulthood, examine the views and experiences of their families and conducted a prospective study of younger post-16 pupils with the same educational needs. This was to see what could be learnt about the persisting nature of SLD over the lifespan, the impact persisting SLD have on the lives of the individuals who experience them and their families.

Four main research questions were asked of this thesis. These were as follows (also see **Error! Reference source not found.**):

- How stable are SLD, literacy difficulties and nonverbal abilities in individuals with severe, complex and persisting developmental SLD over time?
- What challenges to achieving positive psychosocial outcomes are faced by adults with persisting, severe and complex developmental SLD?
- How important is access to specific support for individuals with lifelong speech and language difficulties?
- What are the challenges for families to children with SLD?

9.2 How Stable are SLD, Literacy Difficulties and Nonverbal Abilities in Individuals with Severe, Complex and Persisting Developmental SLD Over Time?

9.2.1 The Nature of Persisting Language Difficulties in the Ex-pupil Cohort

Part 1 of this thesis examined the stability of different aspects of SLD over time in a cohort of adults with persistent, severe and complex developmental SLD. As all the ex-pupils experienced persisting SLD beyond 5;6 years it was expected that all would be experiencing a level of persisting language difficulty in adulthood as it has been shown children who do not resolve their SLD in early childhood experience persisting difficulties (as in Bishop and Adams, 1990; Nathan et al., 2004a). These are likely to be lifelong (Tomblin et al., 1992; Clegg et al., 2005). However, three ex-pupils managed to resolve all their language difficulties according to the assessment battery they completed. This was an unexpected

finding and two possible causes were suggested: 1. the intensive provision the ex-pupils received at school helped them to resolve their SLD more than expected, or 2. the assessment battery administered in part 1 was not sensitive enough to detect any persisting language difficulties in these three individuals.

Furthermore, in part 2, ex-pupils' perceptions of their SLD were not necessarily equivalent to their performance on psychometric testing. Of the three ex-pupils who resolved their language difficulties, only one (Darren) actually perceived himself to be no longer affected by SLD in adulthood. Grace, who was the highest performing ex-pupil on the psychometric assessments, felt she still struggled with receptive language difficulties associated with semantic pragmatic disorder; e.g. understanding irony or being over-literal. This was despite her good performance on tests of language. This account was also confirmed by Grace's mother.

Steven also felt his SLD still affected him. However, his difficulties were not primary consequences of language difficulties, but may have been caused by his history of SLD and attending the school; e.g. having not previously encountered some specific vocabulary used in the workplace.

In contrast one ex-pupil, Karen, who did present with some severe and persisting language difficulties at follow-up felt her adult life was unaffected by them. This suggests that she lacked awareness of her SLD or she felt her language difficulties did not impact on her life style, or that she did not want to admit to still having language difficulties in adulthood. Her mother did feel Karen's language difficulties persisted and were a cause for concern.

Overall, these findings showed heterogeneous language outcomes for the ex-pupils at follow-up in adulthood. However, some individuals with childhood histories of severe and persisting SLD were also able to resolve their language difficulties more than previously predicted by the critical age hypothesis (Bishop and Adams, 1990; Nathan et al., 2004a). This was an unexpected finding and may have been due to the specialist provision the ex-pupil received at the school. A further follow-up study that compared the language outcomes for adults who attended different types of educational placement in childhood would need to be carried out to examine if this was the result of the ex-pupils attending special schooling.

9.2.2 The Relationship between Severity and Pervasiveness in Persistent Language Difficulties

Part 1 also revealed a trend where the ex-pupils with the most pervasive difficulties also had the most severe difficulties in adulthood. This is similar to findings by Johnson et al., (1999) that those with pervasive difficulties will also experience the most severe difficulties; theirs was a prospective study that showed this relationship between severity and pervasiveness had been present from childhood and persisted all the way through into adulthood (Beitchman et al., 1986; Beitchman et al., 1996). However, these studies also showed that individuals with persisting comprehension difficulties showed poorer outcomes than those with expressive SLD. The ex-pupil cohort in the present study experienced more complex expressive language difficulties as children that related to multiple aspects of expressive language; e.g. difficulties structuring sentences, word finding difficulties and/or pragmatic difficulties. The longitudinal trajectories suggested that some childhood language difficulties may be easier to resolve in cases where the initial difficulties are less pervasive. More specifically comprehension difficulties may be easier to resolve in less pervasive cases as two ex-pupils with only mild and residual difficulties in other domains at follow-up had fully resolved previously severe comprehension difficulties (Steven and Jack). The same did not appear to be the case for expressive language difficulties as two ex-pupils with severe persisting difficulties in other domains managed to resolve their expressive language difficulties (Karen and Julian).

In conclusion, these findings support the literature that suggests a relationship between pervasiveness and severity (Johnson et al., 1999). Furthermore they also suggest there may be a longitudinal relationship between comprehension difficulties and pervasiveness where comprehension difficulties are harder to resolve in more pervasive cases.

9.2.3 Persisting Literacy Difficulties in Adults with Histories of Severe and Complex Speech and Language Difficulties

Literacy difficulties proved to be most stable longitudinally of all the potential difficulties examined in chapter 3. All ex-pupils presented with a level of persisting literacy difficulties at follow-up; with the exception of Grace who had no history of difficulties with decoding or spelling. This suggests literacy difficulties are the hardest to resolve of all the domains examined in part 1. The ex-pupils with severe and pervasive difficulties at follow-up

also experienced the most severe literacy difficulties. The remaining ex-pupils with mild or resolved language difficulties experienced milder literacy difficulties. It has been shown that individuals with persisting language difficulties tend to experience the poorest literacy outcomes. Individuals who resolve their language difficulties are also likely to develop literacy difficulties but to a lesser extent (Johnson et al., 1999; Snowling, et al., 2000; Stothard et al., 1998).

Language difficulties will inhibit a child's ability to develop literacy skills if they remain when a child begins literacy instruction (Dockrell et al., 2009). The findings from this study add to the existing evidence that childhood literacy difficulties are highly likely to persist into adulthood (Clegg et al., 2005; Felsenfeld et al., 1992; Johnson et al. 1999); this is even the case when previous language difficulties have been resolved (Snowling, et al., 2000).

In addition, when explicitly asked, only four ex-pupils viewed reading as something they would do for leisure suggesting it was still not an enjoyable activity. This is likely to be because their literacy difficulties make reading a more taxing activity, which the ex-pupils are therefore more likely to avoid. This was not the case for the ex-pupils' siblings.

These findings therefore add to an already existing body of literature that literacy difficulties are likely to be the greatest area of persisting difficulty for those with childhood histories of SLD. Furthermore they also suggest that intensive specialist provision cannot help eradicate literacy difficulties.

9.2.4 Is there a Relationship Between Language Difficulties and Nonverbal IQ?

Part 1 also found that the ex-pupils with the most pervasive difficulties tended to also experience difficulties with nonverbal ability (as in Catts et al., 2002; Wetherall et al., 2007). Decoding, spelling and verbal IQ were also severely impaired in these cases and there was a trend that only ex-pupils who experienced nonverbal difficulties also experienced difficulties with narrative; similar findings were also reported by Wetherall et al., (2007). Four ex-pupils also experienced drops in nonverbal IQ with age, however falling nonverbal IQ did not appear to be related to pervasiveness (as in Botting et al., 2005; Conti-Ramsden et al., 2001; Mawhood et al., 2000; Tomblin et al., 1992). Even so the ex-pupil who experienced the most severe drop of the four also presented with the most pervasive difficulties.

Botting (2006) proposed that there is a relationship between language and nonverbal IQ that is not yet fully understood but that cognitive impairments often occur with language

difficulties. These findings support this theory as the ex-pupils who experience the most severe and pervasive language difficulties also experienced severe difficulties with nonverbal ability either in childhood or at follow-up. Furthermore, as only one ex-pupil managed to show an improvement with nonverbal ability over time (compared to more ex-pupils in the domains of comprehension $n = 9$, expression $n = 10$ and verbal IQ $n = 3$) they also suggest that once present nonverbal difficulties are harder to resolve than language difficulties. They also suggest some individuals with persisting SLD risk a drop with nonverbal IQ with age (Botting et al., 2005; Conti-Ramsden et al., 2001; Mawhood et al., 2000; Tomblin et al., 1992) although this is not the case for all individuals with persisting SLD and the other risk factors that determine this are still unclear.

9.3 What Challenges to Achieving Positive Psychosocial Outcomes are Faced by Adults with Persisting, Severe and Complex Developmental SLD?

9.3.1 When Pupils Leave the School

This project studied two cohorts of individuals that attended the same residential special school for SLD; the ex-pupil cohort and the FE pupil cohort. Most of the ex-pupil cohort left the school at 16 years of age having finished compulsory education ($n = 12$); however the three youngest ex-pupils stayed for FE and the 2 oldest cohort members left at 12 years of age. The transition where they left the school was viewed as a difficult time for pupils because they had to leave a safe and familiar environment. In part 3 both parents and LSAs expressed fears for the pupils' futures then they leave FE and there was a consensus that outcomes were more likely to be negative than positive; this was similar to findings by Conti-Ramsden et al., (2008) that parents to children with SLD expressed more concerns for the future than parents to typically developing children.

In part 2 the ex-pupil's psychosocial outcomes were mixed, and not as successful as their nonlanguage impaired siblings at a case study level (as in Clegg et al., 2005). These findings agreed with predictions made by the LSAs in part 3 for the FE pupil cohort. The LSAs viewed success as pupils making steps towards overcoming their difficulties, and becoming more independent, self-confident and mature. The LSAs defined positive outcomes as successes, e.g. gaining paid employment or achieving independent living. However, the LSAs also felt negative psychosocial outcomes were most common among school leavers. This suggests either a selection bias in the ex-pupil cohort where the most successful ex-

pupils were most inclined to reply or that the LSAs took a more cynical perspective on the FE pupils' outcomes.

9.3.2 Academic Achievements

Academic achievement was mixed among the ex-pupil cohort (Dockrell et al. (2006): eight had gained GCSEs (mostly gained grades at D-G), all attended post-16 placements, and eleven had gained formal qualifications from this; these were mostly vocational courses. There was also a pattern that the ex-pupils with the least persistent difficulties at follow-up also had the most qualifications while those with the most persistent difficulties gained the fewest. This suggested those with the most pervasive and persistent difficulties risk the poorest academic outcomes. In addition, the siblings still experienced greater academic success at a case study level, and 2 siblings had University degrees compared to none of the ex-pupils (as in Clegg et al., 2005).

These findings were relatively positive compared to other studies that have documented poorer academic achievement in those with persisting SLD (Clegg et al., 2005; Snowling et al., 2001; Young et al., 2002) and that fewer individuals with persisting SLD will enrol in post-16 education (Howlin et al., 2000; Records et al. 1992). They also support previous findings that have shown a relationship between the severity of persisting SLD and academic achievement (Dockrell et al., 2007; Snowling et al., 2001).

Furthermore the addition of the FE department has allowed pupils to access post-16 qualifications through the school aided by support specific to their needs with the view to improving their success rates at achieving qualifications at post-16.

Overall this suggests those with persisting SLD may be at risk of poorer academic outcomes compared to those without a history of SLD. However some individuals can also achieve relative success and academic outcomes can also vary between different individuals with persisting SLD.

9.3.3 Subsequent Employment Opportunities

Employment outcomes were also relatively positive but mixed. Eleven were in paid employment and their jobs ranged from skilled to unskilled work, nine of these also enjoyed their jobs, however six reported unstable employment histories and four encountered difficulties at work including one incident of bullying. Once again the ex-pupils with fewer persisting difficulties associated with SLD experienced best employment outcomes while

those with the most persistent SLD experienced the poorest outcomes. This may have been the result of the ex-pupils with the fewest persisting difficulties also having the most academic qualifications and the most drive to progress their careers. In addition, all three siblings were in paid full time employment, two of these were skilled jobs and none had experienced any difficulties at work and all had relatively stable employment histories.

As a cohort ex-pupils' employment outcomes were relatively positive as eleven were in paid employment (similar to Aboagye, 2001; Felsenfeld et al., 1994), although a minority of individuals experienced poor outcomes (similar to Clegg et al., 2005). While this does highlight success for some cohort members it also suggests others may struggle gaining and maintaining employment (as in Snowling et al., 2001).

The FE pupil cohort all expressed future employment aspirations although arguably not all of these were realistic, e.g. famous musician. The LSAs and FE pupils' parents expressed concerns that the FE pupils may experience difficulties with employment in the future, this was similar to findings by Conti-Ramsden et al. (2008). Furthermore the ex-pupil's parents confirmed these worries; they felt the ex-pupils had experienced more limited employment opportunities. They also felt supported employment schemes to help adults with persisting SLD gain employment were beneficial. Howlin et al., (2005) demonstrated the benefits of supported employment schemes, however they also proved to be very expensive to fund.

Overall, the conclusions for employment outcomes are similar to academic achievement. This may suggest the two are related as academic achievements can influence later employment opportunities. In conclusion, those with persisting SLD may be at risk of poorer employment outcomes but can also be relatively successful. Outcomes can also vary at an individual level and are poorer compared to those without a history of SLD.

9.3.4 Financial Management and Independence

Ten ex-pupils reported difficulties or uncertainties with managing money. Financial management and independence was an area of overall difficulty for the ex-pupil cohort and the biggest obstacle to independent living.

Few studies have reported on the economic outcomes for individuals with SLD however, Clegg and Henderson (1999) suggest it is likely to be an area of difficulty. They also found that families may end up supporting their children financially into adulthood. Parents of the ex-pupils felt this was an area of great difficulty for them and felt they

experienced a range of difficulties: budgeting, making transitions, counting out money and being vulnerable to crime; e.g. being 'ripped off'. There was also a consensus that these difficulties are associated with the ex-pupils underlying SLD.

The FE provision at the school teaches pupils about financial management as part of life skills in an effort to address this. However, the parents of two of the ex-pupils who attended FE still felt they experienced difficulties with finances despite the support they had received. These feelings were also echoed by the parents of the FE pupils: one explicitly felt that the financial management skills taught were not adequate for the pupils needs.

Overall, individuals with persisting SLD are at a high risk of experiencing difficulties with financial management in adulthood. These findings therefore highlight an area where greater support is needed. They also add to a currently small body of knowledge about the economic outcomes for individuals with persisting SLD.

9.3.5 Independent Living

Cases of independent living in this cohort were few. Four ex-pupils were living away from the parental home; one was a home owner, two were in rented accommodation, and one was in supported living. In contrast all of the siblings were living independently and were therefore self sufficient, however none were home owners either. Ex-pupils felt limited finances were the biggest obstacle to achieving independent living. Conti-Ramsden and Durkin, (2008) found individuals with SLD risked poorer levels of independence in later life and therefore poorer performance in this domain could be predicted. These findings are also similar to Clegg et al. (2005) who found mixed independent living outcomes for adults with DLD.

Most FE pupils felt they would achieve independent living in their early to mid 20's, however, their parents were less confident about their future chances of achieving this. The ex-pupil findings further suggest the FE pupils may struggle. In addition, the ex-pupils' parent felt supported live schemes could be beneficial to adults with SLD. Achieving independence is also important for the families of individuals with persisting SLD as they are likely to remain responsible for their family members if independence and self sufficiency is not achieved (Clegg and Henderson, 1999).

Overall these findings suggest that independent living is also likely to be an area of difficulty for many individuals with persisting SLD, however some individuals do

experience relative success. Independent living is also another domain where more support maybe required.

9.3.6 Friendships

Fourteen ex-pupils reported friendships and eight were happy with their social lives, however five reported feeling of social isolation. In addition, six ex-pupils used social clubs or groups to meet people and this was most common among the ex-pupils with the most pervasive SLD at follow-up.

The literature has predominantly reported poorer social relationships for individuals with persisting SLD in adulthood (Beitchman et al., 2001; Clegg et al., 2005; Howlin et al., 2000; Johnson et al., 1999). However, Aboagye (2001) found relatively positive friendship outcomes for her four case studies. The present research found varied social outcomes for the ex-pupils. Durkin and Conti-Ramsden (2007) suggested a link between the severity of an individual's SLD and their risk of poor social relationships; however in the present study the ex-pupils with the most severe difficulties may have been using social clubs as a means to compensate for this. The evidence for this is further supported by Aboagye (2001) as her case studies also attended social clubs, this could have contributed to her positive findings.

Despite these positive findings the ex-pupils' parents were still concerned for the quality of their children's friendships and their opportunities to meet people as some ex-pupils appeared to only have friends with difficulties of their own. Conti-Ramsden et al., (2008) also found parental concerns towards the social lives of children with SLD at 16 years of age.

In FE the pupils were all confident they would keep in contact with friends from school. The FE pupils parents and the LSAs did not share this confidence; findings from the ex-pupil follow-up supported their concerns as the ex-pupils all lost contact with their friends within the first few years of leaving the school. This may also contribute to some ex-pupils experiencing more negative outcomes for friendships as they are unable to maintain friendships from school.

Overall, the outcomes for social relationships were mixed and appeared to be more related to personal circumstance than levels of persisting SLD. However, some ex-pupils did experience poorer social outcomes suggesting individuals with persisting SLD do risk becoming socially isolated in adulthood. The findings also suggest that access to social groups may be used to help compensate for any difficulties with establishing social networks.

9.3.7 Relationships

Outcomes for relationships were relatively poor among the ex-pupils. Six were in relationships at follow-up, however only two of these were happy and another may not have been genuine. This is in comparison with the siblings where two of the three siblings were in long term and happy relationships. The literature has found some very poor outcomes for close committed relationships for individuals with persisting SLD (e.g. Clegg et al., 2005; Howlin et al., 2000) although other studies have reported more positive findings (e.g. Aboagye, 2001; Records et al., 1992).

The present findings suggest relationships were the area of greatest difficulty for adults with persisting SLD. Relationships also appeared to be less strongly related to persisting SLD at follow-up and were perhaps more strongly influenced by other factors, such as personal circumstances.

9.4 How Important is Access to Specific Support for Individuals with Lifelong Speech and Language Difficulties?

9.4.1 Mainstream and Special School

There was a consensus across the cohorts seen in part 2 that special schooling was favoured over mainstream education and that ex-pupils had attended the right educational placement for their needs. None of the ex-pupils favoured mainstream schooling, apart from Dennis who had been the only ex-pupil to return to mainstream schooling after entering the residential special school.

Reasons why the school was seen to provide the right support included:

- access to specific provision for SLD
- providing the education that was right for the pupils and ex-pupils
- providing SLT that was built into the curriculum
- having an appropriate peer group
- preparing pupils for life in the future

This supports findings by Lindsay (2007) who showed little support for inclusive education, and Rannard et al., (2004) who found parents to children with SLD favoured special schooling. However, Glogowska and Campbell (2000) found opposing findings when they interviewed parents of preschool children with SLD who stated a preference for mainstream education. The present findings did not support this and this could have been

because these parents had the perspective of hindsight. In addition, the ex-pupils themselves were likely to have experienced more severe difficulties than the preschool children seen by Glogowska and Campbell (2000). Also, Dockrell et al., (2006) stressed that children with the most severe and complex SLD are more likely to be educated in special schools, and Dockrell and Lindsay (2008) stressed the importance of children being in the correct educational placement for their needs. In this case the ex-pupils had histories of severe SLD and the correct educational placement was at special school.

Ex-pupils who attended mainstream school before entering the special school experienced a range of difficulties that further demonstrated why mainstream education was the wrong choice for their needs:

- accessing education
- forming peer relationships
- being unable to cope
- having a label was stigmatising
- mainstream school focused on academic achievement rather than support for SLD.

This supports findings by Dockrell and Lindsay (2008) who identified these as risk factors for children with SLD entering mainstream education.

Even so, part 2 also showed the right education to come at a cost. Thirteen of the ex-pupils boarded at the school and this came with emotional hardship for them and their families. It was also often felt to have lasting effects on the relationships ex-pupils had with their siblings in adult life, e.g. Dennis's mother felt he no longer got along with one of his elder brothers because the brother was jealous when Dennis returned home. However, despite this being a strong theme in part 2 this finding was not replicated in part 3. The FE pupils were relatively content boarding at the school because it made them feel more independent and they enjoyed spending time with friends. This may reflect the fact that this cohort were older boarding pupils, and that these pupils may have become accustomed to boarding as they would have boarded for many years prior. Boarding in FE may also be a more preferable experience to boarding in the primary and secondary departments at the school as pupils are older and treated more like adults.

Boarding had consequences for ex-pupils' social relationships; all ex-pupils lost contact with their school friends within the first few years of leaving and some struggled to

form new social networks as adults (e.g. Julian and Grace). A small number of ex-pupils also reported hiding the fact they had attended a special school from their acquaintances in their adult life as it made them feel stigmatised (Jack and Darren).

Part 2 also highlighted some additional elements the ex-pupils would have found beneficial but were not provided:

- More information on the options available at post-16; e.g. education and employment opportunities.
- The opportunity to gain more qualifications e.g. GCSEs.
- The curriculum was felt to be more limited than in mainstream education.

Importantly the school has since been able to address these issues with the addition of the FE department. This provides access to formal qualifications in the mainstream environment as well as careers advice for the future when pupils leave.

9.4.2 Specialist Provisions at Post-16

A demand for ongoing educational support at post-16 was expressed by the ex-pupils, parents and FE staff. Sadly there is currently short fall in the provision available at post-16 (Dockrell et al., 2006; Durkin et al., 2009). Despite this a majority of individuals with SLD will continue to study after compulsory education (Dockrell et al., 2007; Durkin et al., 2009). This is of concern as many may struggle without access to specialist support and therefore not achieve their potential.

The school became able to address this demand when it opened the FE department in September 2004. This was seen as a critical addition to the school by all participants in the 3 study phases as it provided its pupils with continuing provision, access to college courses with specific support, ASDAN, and work based placements at post-16. It also aimed to prepare pupils for life in the future. This a more positive findings than for the older ex-pupils in part 2 who experienced diminished access to support at post-16; something parents and a small number of ex-pupils felt was still necessary

However, the LSAs also expressed concerns that FE was a safe protective environment that did not provide pupils with a realistic view of the world outside. In the future this could mean pupils are vulnerable because they lacked life experience. It was supported by some ex-pupil reports in part 2; e.g. Jacky and Steven both describing feelings of the world outside being an intimidating place.

9.4.3 Importance of Ongoing Support in Adulthood

As concluded in 9.2, it is likely some adults with persisting SLD will still require ongoing support in various psychosocial domains. Evidence from parts 2 and 3 suggest families can provide a great source of support to individuals with persisting SLD when they reach adulthood. For example, twelve ex-pupils were still living in the parental home and others required financial support (as in Clegg and Henderson, 1999). Some parents also helped their children gain employment; for example, FE pupil Joe was able to gain employment with the help of his father soon after leaving the school. Furthermore LSAs also felt that parents usually had the greatest influence in shaping pupils futures after they leave FE. Therefore parental attitude is key for achieving good psychosocial outcomes and having proactive parents was seen as positive.

However, parents who were providing their children with support because they had not achieved self sufficiency did not view this as a permanent solution and also feared for the future. This supported findings by Grant et al., (2007) that as parents get older they start to worry about what will become of their children when they are no longer around. This therefore demonstrates further evidence for the importance of access to continued support with the various psychosocial domains as required by the individual; e.g. support at post-16; supported employment schemes; supported living, and access to social clubs. This was outlined in section 9.2.

Lastly, there was also a possibility that some ex-pupils were reluctant to admit to still needing support as adults. Only five ex-pupils reported having support at post-16 when directly asked. It is likely that more pupils had support at college than disclosed. It is difficult to know whether pupils' failure to disclose was due to pupils misunderstanding the question or to a reluctance to admit to needing support. However, a reluctance to admit to still needing support could be due to a reluctance to admit to still be experiencing SLD in adulthood. This could suggest another potential barrier to adults with persisting SLD accessing support at post-16 as they may reject help because they feel they no longer need it.

9.5 What are the Challenges for Families of Children with SLD?

The families in the present project faced various challenges associated with raising their children with SLD and three major areas of difficulty arose:

- difficulties associated with raising the child
- having to fight for access to support services

- general lack of awareness, knowledge or information on SLD in the public domain

In childhood the parent's found the ex-pupils' care challenging (as in Green, 2007). This was due to behavioural difficulties; hyperactivity; the ex-pupil not understanding the world in the same way as a typically developing child, and the ex-pupils not being able to understand discipline. This was stressful for families. Raising children with disabilities has been shown to be more stressful for families than raising children without disabilities (Dyson, 1997; Floyd and Gallagher 1997; Hastings, 2003).

Gaining access to the right provision was seen as crucial for supporting children's needs and was valued by parents. However, experiences with support services were mixed. Five families had to fight for access to support services. This was typically a time consuming struggle for parents accompanied with feelings of anger, frustration and worry when support could not be accessed (as in Rannard, et al., 2004; 2005; Paradice and Adewusi, 2002). Parent's also placed importance on getting children with SLD into the right provision as early as possible; this was similar to findings by Glogowska (2002). Getting a statement was seen as a key component to winning the battle with support services. In addition, two families who reported not having to fight for access to support felt they were in a fortunate minority.

The difficulty with limited knowledge and understanding of SLD appeared to be a problem for society. It affected parents on two levels. Firstly, it meant the parents struggled to understand their children's SLD in early childhood posing an additional problem with their care. Secondly, it meant other adults did not understand their children's SLD and consequentially made incorrect assumptions, for example the children were deaf or poorly behaved. This lack of knowledge reportedly spread to some but not all professionals the families encountered. Limited knowledge amongst professionals caused some parents to experience confusing and inconsistent support from one professional to the next; therefore this was another source of difficulty and frustration for parents.

These findings highlight how difficult it can be for parents of children with SLD. Although there was a consensus that on average, there is more support for parents now than in the past, there is still a need to further to make the support system more accessible, comprehensible and consistent from one LEA to the next. Families may also benefit from having support networks, such as the one set up by Jason's mother.

9.6 Methodological issues

9.6.1 Strengths and Limitations of the Samples

There were strengths and limitations of the samples recruited for this thesis. The ex-pupil and FE pupil cohorts were of reasonable size compared to other follow-up studies, e.g. Clegg et al. (2005). All were recruited from a specific population, i.e. all attended the same residential special school for SLD. Therefore all would have histories of severe and complex SLD. This made them a good sample to study to explore the longitudinal aspects of SLD in adulthood. There were also various challenges associated with recruiting the ex-pupil cohort (see 3.2.2). Furthermore the ex-pupil sample had archive data available at the school so detailed information could be collected from childhood and longitudinal trajectories could be mapped in part 1 even though this study utilised a retrospective design.

However, only a small sample of ex-pupils were successfully recruited from within the total pool of potential participants. A total of 162 letters were sent but only 17 ex-pupils eventually participated; therefore the ex-pupils seen in parts 1 and 2 may not be representative of all ex-pupils from this school.

Furthermore, the sibling sample size recruited in parts 1 and 2 was small. This limited the data analysis in study 3 (in chapter 3) and the comparisons that could be drawn between the ex-pupils and siblings psychosocial outcomes in chapter 5. This meant both cohorts were compared at a case study level when a comparison at a cohort level would have been preferable. This meant siblings were only compared to their corresponding ex-pupil pair and not the full cohort. Had a larger sibling cohort participated in the quantitative study it may have been possible to find more concrete patterns in the data instead of trends.

There was also a possible issue with biases in the selection process. As the project was associated with the school this could have caused a selection bias when the ex-pupils were recruited. Ex-pupils with positive memories of the school may have been more motivated to participate than ex-pupils with more negative memories. This could have caused the sample to report more positive memories of the school than the complete cohort would have done. Ex-pupils who experienced the most success after leaving the school may also have been more motivated to participate. This could have skewed the results for the psychosocial study making the ex-pupils appear more successful and supportive towards the school than the complete cohort. Notably, one LSA felt that more school leavers go on to experience more negative life outcomes than success, however they are more likely to hear back from ex-pupils who have been successful (see 8.4.3). In addition, the parent and sibling

cohorts are also subject to this bias as their selection was determined by the selection of the ex-pupil cohort.

The parents in the present project were also all parents to children that attended a special school rather than mainstream education. Therefore it is likely they could have been biased towards specialist education and may have also been pushy parents who were successful at gaining access support; a similar sample selection bias was proposed by Paradise and Adewusi (2002). There could be other parents of children who had not been allocated the right educational provisions or favoured inclusive education for their children. Another cohort of parents with children who did not attend specialist residential school may have provided a contrasting account.

9.6.2 Strengths and Limitations of the Assessment Battery used in Part 1

There were four standardised assessments used in part 1. Two were standardised on adults while two were only standardised on children and adolescents. The ex-pupil and sibling cohorts therefore exceeded the upper age limit on two of the assessments; the TROG and the ERRNI. These assessments were chosen because no equivalent tests have been designed to test developmental language abilities in adults. The highest age band was applied in both cases. This is problematic as it could limit test sensitivity. Even so, these assessments still successfully detected language impairments in the cohort members experiencing severe and persisting difficulties in the relevant language domains. The concern would be that some ex-pupils may have been experiencing more subtle persisting difficulties the assessment battery was not sensitive enough to detect, e.g. three ex-pupils resolved their language difficulties more than expected. The WASI and the WRAT-3 had been standardised on adults and also detected language impairments across the cohort.

9.6.3 Challenges using the Archive Data

There were numerous difficulties associated with using the archive data in chapter 3. While it contained a wealth of information from the ex-pupils' childhood years, its application was challenging. The archive had not been collected with the primary aim of informing this research project and was therefore not a consistent source of information. The data available for each ex-pupil was variable in terms of volume, quality and relevance to the project. Freya's files were also unavailable.

However, this study was able to find a meaningful way to use the archive data, and compare it with the data collected at follow-up. A coded system was applied to convert the data into a consistent format that could be compared with the data collected at follow-up (see table 3.4). Therefore, despite the limitations associated with using the archive this study was able to take advantage of data collected from the ex-pupils childhood without encountering the challenges associated with using prospective approaches (outlined in table 2.1).

9.6.4 Challenges using Interviews

The ex-pupil and FE pupil cohorts may have struggled in completing the structured and semi-structured interviews due to their SLD. There could have been occasions where participants misinterpreted questions due to comprehension difficulties. This study used parental accounts as a proxy measure to qualify ex-pupils accounts and there was agreement in most cases (areas of disagreement were critically discussed in 6.4.3). The high levels of agreement between ex-pupils and parents suggest the ex-pupils were able to provide accurate and valid accounts.

There could have been further issues associated with the researcher administering the interviews. The researcher always strived to make the questions as clear and understandable to the participants as possible, however there could have been occasions where the participants and the researcher misunderstood each other. Equally there were occasions where the researcher could not understand the participants' responses. This was caused by responses being unintelligible or out of context. On these occasions the researcher was able to clarify the response with the participant. The final impact of this is also impossible to quantify, but every effort was made to limit occasions where this went unnoticed by the researcher or confusions were left unresolved.

There is also a chance participants could have been biased when describing their lives, or their families member's lives. In other words some participants describe their lives to be more positive or differently than the reality because it is the way they wish to be perceived. Such biases cannot be quantified and any of the participants in the project could have displayed them.

Finally, the researcher assisted the FE pupils in completing their structured interviews in part 3 as their literacy difficulties were such that they were unable to complete them as questionnaires. There is therefore a chance the researcher could have influenced the pupils

responses when she discussed the questions with them. The researcher made every effort to remain neutral during these testing setting so as not to influence the participants' responses.

9.7 Future work

9.7.1 A Future Follow-up of the FE Pupils

In the future another follow-up study of the FE cohort could be carried out using the format outlined in sections 1 and 2 of this thesis; this could include both the quantitative and qualitative elements of the study. The ex-pupil and FE pupil outcomes could then be directly compared to examine the effects of the extra support the FE pupils received in the FE provision. If the FE pupils experience greater success than the ex-pupils then this would suggest that the FE department had a positive impact on these pupil's lives and show support for the importance of continuing access to support at post-16 for individuals with persisting SLD.

There would also be a possibility of recruiting the FE pupils' school peers who chose to leave the school at 16 years and not stay on for FE. This would provide a further age matched comparison group of individuals who experienced similar SLD and received the same support with compulsory education but did not have the same level of support at post-16 years.

In addition, the FE pupils aspirations reported in 8.4.1 could be compared directly with their actual outcomes in later life. Durkin et al. (2009) theorised that individuals with SLD may expect poor outcomes for themselves than those with no histories of SLD (Durkin et al., 2009) (discussed in 4.2.1). A study comparing the FE pupils' aspirations with their later outcomes would examine with further.

9.7.2 A Prospective Follow-up Study

A future follow-up study of ex-pupils could use a prospective approach (see 2.2.1) similar to other prospective studies (Billstedt et al., 2005; Clegg et al, 2005; Conti-Ramsden, and Durkin, 2008; Johnson et al., 1999; Snowling et al., 2006). This would recruit the ex-pupils in childhood when they entered the school. They could then be periodically assessed on specific standardised measures of language, literacy and nonverbal ability at the same ages over the course of their time at the school. This approach would remove the challenges associated with using archive data: inconsistent data for individuals that varied in volume, quality and relevance to the project, and missing data (see 9.3.3).

However, the school caters for children aged 5-19 so this phase of data collection alone could potentially take a minimum of 14 years to complete. Following this, further studies of the cohort could continue into adulthood to measure psychosocial outcomes (as in Billstedt et al., 2005; Clegg et al., 2005; Howlin et al., 2000; Johnson et al., 1999). This would produce high quality detailed longitudinal data on a cohort similar to that seen in the present project. However, prospective research projects are costly in terms of time and funding, and also have disadvantages that retrospective studies do not (as summarised in table 2.1).

9.7.3 A Follow-up on a Larger Scale

If this research were carried out in the future it would be possible to increase the scale on which it was done by increasing the sample size to either include a larger proportion of the potential ex-pupil cohort or to include more schools.

Recruiting a larger sample from the possible pool would increase the power of the research findings and firmer conclusions could be drawn for some of the trends that were identified in the quantitative study, however the practicalities of recruitment were discussed in 3.2.2 and are likely to be an issue for similar studies in the future.

Increasing the number of schools in the pool would increase the diversity of the cohort studied and the findings would be more applicable to other contexts. This could include other school similar to one in the present project, or other group of ex-pupils from other types of educational provision, for example language units and mainstream schools as a comparison group.

A particular limitation of the studies in parts 1 and 2 was the size of the sibling cohort. Parents and siblings proved to be of particular difficulty to recruit. It would have been desirable to have recruited one parent and one sibling for each ex-pupil who participated to produce three balanced matched cohorts. Again this would be difficult to achieve due to the practicalities associated with the recruitment process.

9.7.4 A Control Group of Mainstream School Pupils

An unexpected finding from this project was that three ex-pupils resolved their language difficulties more successfully than would be expected. One explanation for this finding was that it was down to the specific and intensive provision provided by the school (see 3.4.1 and 9.1.1). The true impact of the provision the ex-pupils received could be

measured if a control group was introduced to control for the type of education received. This would involve finding another cohort of individuals that could match the ex-pupils on the severity of their past SLD and age but attended a different type of educational provision: for example mainstream school; language unit, or a different type of special school not specific to SLD.

Furthermore investigating the outcomes for individuals with childhood histories of severe and complex communication needs that attended mainstream schools would also inform the debate surrounding inclusive education (see 1.3.1). There was a consensus from the participants seen in this thesis that special education had been the right choice for the ex-pupils and FE pupils. This findings may have been biased by the fact all the ex-pupils and FE pupils had attended the school. Recruiting ex-pupils who attended mainstream school and their families as a comparison group would provide a balanced perspective on this. However, it should be noted that some ex-pupils spent some of their years of compulsory education in mainstream schooling and this was more commonly viewed as negative and unsuitable for the ex-pupil's needs; therefore such a group may be difficult to locate and recruit.

9.7.5 Additional Control Groups

It would also be possible to recruit a control group of individuals with a different type of disability to control for the effects of disability in general; this would aim to identify aspects at outcome specific to individuals with SLD from aspects associated with disability in general. This could include individuals with other types of SLD or learning need.

An IQ matched control group would control for the effects nonverbal IQ. This would aim to recruit a group of individuals with the same nonverbal IQ scores as the SLD cohort but with not histories of SLD. This was a design used by Clegg et al. (2005).

Finally the studies presented in this thesis did not control for SES (as discussed in 1.3.3). The school has a nationwide catchment area and recruits pupils from a varied range of SES backgrounds, however this impact of SES was still not measured in this study. A match control from of individuals from the same SES background with no histories of SLD would control for this.

9.8 Conclusions

The main finding from this thesis were as follows:

- The ex-pupils comprised a heterogeneous group in terms of their language outcomes in adulthood. Three showed greater success at outcome than previously seen (Bishop and Adams, 1990; Nathan et al., 2004a).
- There was a relationship between the pervasiveness and severity of SLD at follow-up (as in Johnson et al., 1999).
- Literacy was the greatest area of persisting difficulty for the ex-pupils; these are likely to remain even when the individual has otherwise resolve their SLD (as in Johnson et al., 1999; Snowling, et al., 2000; Stothard et al., 1998).
- The ex-pupils who experience the most severe and pervasive language difficulties also experienced severe difficulties with nonverbal ability either in childhood or at follow-up.
- Some individuals with persisting SLD may risk a drop with nonverbal IQ with age; although this is not the case for all individuals with persisting SLD and the other risk factors that determine this are still unclear.
- There was a consensus that special schooling had been the right choice for the pupils and ex-pupils seen in this project; notably they all had relatively severe histories of SLD.
- Importance was placed on ongoing educational support at post-16.
- The ex-pupils experienced heterogeneous psychosocial outcomes; however some of these were relatively poor suggesting individuals with persisting SLD still risk poorer outcomes in adulthood.
- Levels of success with academic achievement and employment outcomes were varied and appeared to be related to levels of persisting SLD.
- Many ex-pupils struggled to achieve independent living and the majority were still living with their parents into their 20's or 30's.
- Limited finances and poor financial management skills were viewed as the biggest barrier to achieving independent living.
- Outcomes for social and romantic relationships were mixed and appeared to be more related to personal circumstance than levels of persisting SLD.

Relationships was the area where ex-pupils appeared to experience the least success.

- Some ex-pupils benefitted from access to social groups (as in Aboagye, 2001).
- Families provided a source of support to adults with persisting SLD; however there is a risk families will have to continue supporting their children into adulthood.
- There is a demand for continued support for adults with persisting SLD after they leave education to support them with psychosocial social outcomes.
- There is a demand for support for families with children who experienced long term SLD that persist over the lifespan.
- Having to fight for access to support services was viewed as typical (as in Paradice and Adewusi, 2002).
- There was a general lack of knowledge, awareness and understanding of SLD in the public domain.

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Appendices

A1 Ex-pupil Case Reports: Based on Finding from the Archive.

A1.1 Case 1: Jacky

Jacky was the elder of two children and was born on 2nd of August 1968. No SLD were reported in her family before her birth. Her mother's pregnancy and the birth were uncomplicated and her early development did not cause concern. Jacky had no history of hearing problems, babbled normally as a baby and responded to the speech of others. However, her mother became concerned when she was not talking at 1;6 years and she took her to their G.P who initially dismissed Jacky's difficulties. However, she was still not speaking by age 4 year, and could only say a few words by age 5 years. Jacky was then diagnosed with *developmental expressive dysphasia*. She presented with severe speech and language disorder but did not have other cognitive difficulties. Her language was so severely affected that she could not communicate sufficiently to carryout social independence.

When Jacky was 4 she began an infant school but required a lot of individual attention. She then began weekly SLT at age 5 years. She started attending the special school at age 6;7 year and was reported to be 'one of the most severally handicapped children ever admitted to the school'. She had marked problems with spoken language and therefore she:

- Had delayed development in articulation.
- Spoke in short simple sentences in a telegrammatic fashion.
- Had difficulties with grammatical structures and tended to express herself using one word sentences.
- Had word finding difficulties.

Jacky's comprehension skills were better than expressive skills but these were 12 months behind her chronological age. She still had good social skills and established good social relationships with adults and peers at school. She also attended as a weekly boarder. She had difficulties with this because she found upsetting and traumatic.

She left at age 12;11 as this was the upper age limit at the time. Some aspects of her disorder had improved and others had persisted:

- Her articulation had steadily improved although some immaturities persisted.
- Her vocabulary was still limited.
- She had difficulty in unspoken parts to language such as sarcasm.

She had become more aware of her difficulties and she was more prepared to ask others to repeat what they had said when she did not understand. She also showed advances in literacy skill and enjoyed looking at books at her equivalent reading age (7;9). Her small vocabulary meant that books at her chronological age were less accessible. She was also capable of producing some written sentences but these often mirrored the imperfections in her speech.

Initially Jacky attended a local comprehensive for secondary education but she was unable cope there. She then attended another specialist boarding school that was able to cater for her needs for the rest of her secondary school years. Following her secondary education she went on to study catering which became her vocation.

A1.2 Case 2: Dennis

Dennis was the fourth and youngest of four sons in his family; born on the 19th of March 1971. All four brothers experienced a level of SLD and/or perceptual problems. Dennis's birth was typical and the pregnancy was full term. He also attained his childhood milestones as normal. However, he had several convulsions as a young child. He was then diagnosed with histidinaemia at 2;6 year, which may have caused him to have speech problems later on. He was given a label of severe dyslalia aged 2;7 years and referred to SLT. At this time:

- His speech contained a great number of sound omissions, substitutions and letter reversals.
- He had virtually no spoken language.
- He had auditory perceptual difficulties with auditory attention, memory and poor discrimination.
- His co-ordination was clumsy in all aspects including articulation.

Initially his language difficulties were both receptive and expressive, however, his language comprehension caught up with his chronological age by 3;7.

Initially Dennis attended at mainstream school for the mornings only. He entered the residential special school aged 5;7. By this time he has a new label of *severe speech deficit and expressive language delay*. He had a range of expressive language difficulties:

- Primary difficulties were with articulation due to motor difficulties.
- His speech contained many omissions and immaturities.
- He had limited syntax caused by poor auditory memory.
- He had no apparent problems with language comprehension; although he did have difficulties with poor auditory discrimination and memory.

These difficulties did not hamper his social skills however and his vocabulary and information knowledge were within normal limits.

Dennis reached the ceiling age for the school at age 12;3. At this time:

- His articulation improved, he could make all sounds in isolation and only a few immaturities remained in single words.
- His auditory discrimination for spoken words improved.
- He had some persistent difficulties with complex syntax.
- Problems recalling words.

His literacy skills were developing, however, he still fell behind his chronological age. His spelling was also poor and full of errors due to imperfections in his pronunciation.

Dennis went to a mainstream grammar school for his secondary education and still needed remedial help with written language and maths. His earlier language difficulties were now mostly resolved but he was left with difficulties similar to dyslexia. At 16 Dennis went to college to study Agriculture and Engineering, but left and got a job as a pool life guard after the first year; a profession he's stayed in ever since.

One of Dennis's elder brothers, Nigel, also attended the residential special school. As a child Nigel had severe SLD and multi-perceptual problems. Initially he attended another ICAN school similar to the one in this project. His speech later resolved although his perceptual difficulties remained. He was then transferred to the residential special school seen in this project. Nigel was already attending the school before his brother joined.

A1.3 Case 3: Robin

Robin was born on the 17th of April 1980. There were no problems with his birth, the pregnancy was full term, he also reached all his milestones as normal and babbled as a baby. Even so, his speech development was delayed. He eventually said his first words at 5 years, was using two word phrases at 6 years, and full sentences at 7 year. His pronunciation was only clear to strangers at around 7 year. He also glue ear ages 6, 8 and 9 years. The fluid was drained and grommets were inserted at 6.

Initially Robin attended two different specialist language units for learning difficulties attached to mainstream schools. He also had SLT from 4 years old and was formally given a statement of special needs when he was 8. This indicated that he had *specific SLD*. His main difficulty was with comprehension and decoding incoming auditory information.

Robin entered the school aged 11;06 years. He had a perceptual phonological difficulty that impaired the development of his speech and expressive language. However, this improved during his time at there. In addition, Robin also suffered from low self-esteem and got emotional very easily. He had few close friends at school and found keeping friends difficult.

Robin left the school aged 16;03 years. He had improved in some areas and had persisting difficulties in others:

- His comprehension of spoken language was still poor.
- His understanding of grammar was impaired.
- His expressive language had improved and his speech was intelligible.
- He could make himself understood in everyday situations but suffered some false starts and or word finding difficulties when speaking.

He still had low self-esteem, which meant that he often gave up when he could not make himself understood. After leaving school Robin initially got a job at a printing shop, from which he was fired. He then studied horticulture, agriculture and floristry at a mainstream college before returning to work. His employment history had been unstable since.

A1.4 Case 4: Karen

Karen was born on the 4th of April 1981. Her mother reported she had a stroke on her first day of life as a baby and this was felt to be responsible for her subsequent SLD. A brain scan showed damaged to the left hemisphere.

Karen entered the aged 7;5 year. She presented with both receptive and expressive language difficulties. Her difficulties were with:

- Processing longer utterances
- Understanding certain syntactic structures and concepts
- Limited vocabulary
- Limited expressive language skills; reduced in content, form and use.
- Word retrieval and confused perceptually similar words.
- Sequencing her thoughts into sentences.
- Residual phonological immaturities in her speech.

Even so she was still intelligible to the listener.

Karen stayed the school throughout for Junior and Secondary school. Towards the end of her time there she showed some improvement and she could now produce complex utterances, though with some grammatical errors. However, she still had receptive and expressive difficulties:

- Poor auditory skills all though she worked on strategies to aid memory for information.
- She used short sentence structures in conversation only giving basic details.
- Continued difficulties with word-finding and a limited vocabulary.

Karen also had intermittent attention levels in the classroom. She was typically distractible in group situations and needed help and encouragement to persevere with difficult tasks. Socially she tended to be unwilling to contribute in individual or formal sessions but could be more forthcoming in relaxed situations, for example, chatting with peers. She eventually left the school aged 16;03.

A1.5 Case 5: Grace

There is no history of semantic pragmatic disorder or Autism in GW's family, however there is some history of dyslexia. Grace's mother as was well throughout her pregnancy and there were no complications with the birth. Grace was born on the 13th of October 1980. She had jaundice after she was born but no treatment was required. Her milestones were a little delayed and she sat at 8-9 months, crawled at 13 months and was walking at 21 months. This perhaps suggested early signs of developmental difficulties.

Initially Grace's language development did not cause concern; she babbled as a baby and had no difficulties with articulation. However, her parents noticed that she had problems understanding. She was given a label of *semantic pragmatic disorder* at age 6. At this time she had difficulties with both receptive and expressive language:

- Variable comprehension skills sometimes responding well to instructions but appearing unaware of what was expected of her at other times.
- Expressive language difficulties were specifically with structuring sentences.
- Reverting to echolalia at school.

Grace had specific difficulties with the unspoken parts of language and its social use. She had a tendency to over literalise everything and had comprehension difficulties in ambiguous situations. However,

other aspects of her speech, language and cognitive development appeared unimpaired hence her good articulation. She was placed in the language unit attached to the school for the final 3 years of her primary education.

Grace entered the residential special school aged 11;11 years. Her label of *semantic pragmatic disorder* remained and her primary difficulties concerned comprehension of verbal inputs at a reasoning and inferential level and the social use of language:

- Her social skills were very poor
- She was over literal and took a black and white view on things.
- She had difficulty maintaining eye contact
- She had little sense of humour.
- She was bossy with her friends.

Grace's difficulties were specific and she had strengths in most other areas of speech, language and cognition:

- Her speech contained no articulation errors
- She had no problems discriminating speech sounds.
- Her expressive language no longer containing syntactic errors
- Her comprehension was otherwise good
- Her vocabulary knowledge and syntactic abilities were average.
- Her literacy skills were very advanced (but not for comprehension).

Grace left the school aged 16;09 years but her difficulties with *semantic pragmatic disorder* remained. She had persisting with:

- Inferencing and verbal reasoning.
- A tendency to be very literal though this had improved since childhood
- Social interaction

However she had made good progress with her social skills. She was more confident and able to initiate conversation with people she was familiar with and was better at maintaining eye contact and initiating conversation. She also gained GCSEs in Maths, English, Art and Science and a silver Youth award scheme (YAS).

A1.6 Case 6: Fiona

Fiona was born on the 24th of April 1982. Her natural mother was 16 when she was born and had concealed the pregnancy up until the birth. Fiona was then adopted at 2 months old. As an infant she was responsive, alert, feeding well and reached all her motor milestones at a typical age. However, concerns for her language development began at very young age. She did not babble as a baby and no first words were reported. This was in the absence of any hearing loss.

At age 2;11 years Fiona was diagnosed with a *severe delay of language development*. This effected several domains:

- Primary difficulties where with severely delayed expressive language

- She had no intelligible spoken words, but was able to say, ma and da and used grunts and for communication
- Delayed in gross motor development
- Disruptive social behaviour

Her comprehension was less impaired and she was able to carry out commands, for example select objects. However, she did have difficulties with comprehension due to having poor attention and listening skills. By age 4;7 years Fiona also had reported difficulties with listening and memory limiting her ability to follow. However her speech improved and she could name most letter sounds and was beginning to blend CVC words and she was given a new label of *expressive language delay*.

Fiona attended nursery school from age 3;6 years where she was also exposed to Makaton sign language at the nursery from around 3;10 year. Her parents and brother also learned it and it became adopted in the family home. She then attended a language unit attached to a mainstream primary school from age 4;7 years and received regular SLT.

Fiona entered the residential special school aged 8;5 years as a weekly boarder. She now also had comprehension difficulties, which had previously been an area of strength:

- Her receptive vocabulary and concept understanding were delayed
- She had difficulties with syntactic comprehension
- Her attention span was limited and was easily distracted.
- Her auditory comprehension was delayed

It was concluded that Fiona had pervasive language difficulties and was given another new label of *delayed receptive and expressive language*. Her literacy skills were also developing slowly; she had difficulty organising ideas, constructing sentences and she had some difficulties with mechanics of writing as her fine motor skills were poor.

Fiona left the school aged 16;02 years. She still had persisting difficulties with her SLD. These were greater for language comprehension but also affected her expressive language:

- Her vocabulary developed slowly and she had difficulty learning and retaining new vocabulary
- She had difficulty understanding and producing complex grammatical structures
- She had word finding difficulties
- Her expressive difficulties were more evident in formal situations or when talking about unfamiliar subjects
- She continued to have difficulties attending fully to verbal input

However, her previous articulation difficulties had resolved and her speech was clear and easy to understand. She had also become less distractible compared with when she had started. Socially she remained immature and naïve. She was keen to gain attention, but did not always do so in an appropriate way. Sometimes she was highly sociable initiating greetings and making eye-contact and at other times she could behave very

immaturely being surly, petulant and show off. When Fiona left the school she went to another residential special needs school for her post-16 education.

A1.7 Case 7: Freya

Case notes missing from the archive

A1.8 Case 8: Jodie

Jodie's mother developed diabetes in the fifth month of her pregnancy and Jodie was induced at 38 weeks. She was born on the 2st of August 1982, but the birth was complicated and she became distressed during the birth and the monitor indicated a brief lack of oxygen.

Jodie went through She did babble as a baby but did not say her first words until 3-4 years old. Her expressive language development was delayed and she was using two word phases at 4 years and sentences of several words at 5-6 years.

Jodie attended a nursery school for 3 months at age 4, followed by a mainstream infant's school from age 5;1 years before joining the residential special school at age 5;8 years. At this time her difficulties were still primarily with expressive language. Her difficulties were with:

- Organising what she wanted to say.
- With remembering words.
- Phonological difficulties that often made her speech unintelligible.
- Bilateral hearing loss and ear ache (though this was quickly resolved when she started at school).
- Difficulties understanding concepts.

At school her speech had also quickly improved. Her main difficulties then were with word-finding and short-term memory. She also had difficulty learning and retaining new vocabulary. Socially Jodie communicated readily and was happy to initiate conversation. However, her difficulties with sentence organisation, grammar and vocabulary reduced her capacity to communicate fluently.

Jodie left the school aged 15;11 years. Her difficulties had shifted and she now had difficulties with comprehension and literacy rather than expressive language:

- Though listing skills were good but auditory memory remained limited.
- Her receptive grammar was delayed.
- Her expressive language had improved; although she still had word finding difficulties and sentence formation.
- She had difficulties with phoneme segmentation but had good phonological awareness skills with syllable and phonemic segmentation, rhyme detection and production.

However Jodie's social skills were an area of strength, she had good awareness of social cues and could work well with others. When she left school Jodie wanted to go to college to pursue her post-16 studies. She had a keen interest in child care and ambitions to explore this as a career.

A1.9 Case 9: Julian

Julian was born on the 22nd of February 1983, his birth and early development did not cause concern. His mother's pregnancy had been healthy and the birth was induced at 42 weeks and a normal delivery followed. Julian had slight jaundice on his second day, though no treatment was required. He reached all his motor milestones as normal and there was no early cause for concern.

Concern for Julian began when he had difficulties learning to speak. His difficulties were expressive effecting articulation, intonation and syntax. Many of his speech sounds were distorted and difficult to understand. His intonation was stereotyped and his sentence structures were very immature e.g. 'me do this'. He also had a specific difficulty with the perception and discrimination of speech sounds (though this was not documented until he entered the school). This manifested itself in delayed expressive language.

Even so JW still had strengths in other domains:

- His fine and gross motor co-ordination were unimpaired
- His social skills were relatively good despite his SLD and he was happy to mix with other children; although sometimes they could not understand him
- He was emotionally stable, had a positive self-image and seemed unaware of his difficulties

Julian went to a mainstream infant's school on a part time bases from age 4;7 until 6;11 when her entered the residential special school. During this time he received a help from different services:

- A local clinic once a week (unspecified time period)
- Help for his difficulties at school twice a day between ages 4 and 5
- Additional individual daily help with SLT by a special needs nursery

However, Julian's progress was during this period and he was eventually referred to the residential special school. At 6;11 year he was given a label of *severe speech and language disability*. His difficulties were said to now affect all linguistic levels of comprehension and expression and he that was generally at least 3 years behind his chronological age across all domains of language. His primary difficulty was a severe phonological disorder that impaired his ability to make contrasts between words. This had severe consequence for JW's speech and language development.

- His vocabulary and concept understanding were delayed
- His grammatical comprehension was poor and he confused longer sentences
- He found sentence production difficult
- He had word finding difficulties that hampered expressive language further

Even so, Julian's social skills were his strength during. He was a pleasant and polite child who got on well with his peers and was willing to work with others. He tried hard to communicate verbally but often had difficulty in expressing information. He was able to express basic needs, ask questions and give opinions.

Julian left the school aged 16;5 years. He had now resolved his difficulties with phonological discrimination, but still had considerable problems with language overall. His primary difficulties were now with memory and caused pervasive difficulties with language skills, particularly with expressive language:

- He had a memory span of 4 digits

- Difficulty with limited vocabulary and concept understanding
- Difficulty understanding complex sentences
- Word finding difficulties
- Difficulties remembering information

It is unclear from the archive when Julian's memory difficulties first became apparent but they were reported as a primary difficulty when he left this school. He had also experienced a severe delay with literacy development by this time and also suffered a substantial drop in nonverbal ability.

A1.10 Case 10: Toby

Toby was born on the 14th of September 1983 and was adopted at 9 weeks old. His biological mother had learning difficulties that were a result of a childhood illness. Toby was initially assessed for SLD aged 4 years. It was found he had a severe specific speech difficulty but his cognitive functioning was relatively unimpaired.

He started to infant's school aged 5 years at a school that had the resources to meet his needs. He progressed to the equivalent junior school position aged 7. At around age 8;4 it was reported that his receptive language had improved but not expressive language. This was the first time Toby's receptive language difficulties had been mentioned and their nature was unclear. He was then given a statement of special educational needs at around age 9. This report diagnosed him with a *severe speech and language disorder* and listed his difficulties:

- Speech and language skills
- Gross and fine motor skills
- Basic literacy
- Basic numeracy

Overall his difficulties were extremely pervasive affecting his speech, language, cognition, motor coordination and social development.

A similar report 2 years later when TD aged around 11 diagnosed him with a *severe receptive and expressive language disorder*, which constituted:

- Severe difficulty expressing himself with spoken and written and language
- Severe difficulties with comprehension and expression of higher level language
- Persisting speech problems due to dyspraxia, dysarthria and hearing loss
- Significant general learning difficulties
- Socially immature and appeared younger than his actual

It was therefore felt appropriate for him to attend the special residential school for his secondary education. He entered the school aged 11;10 years. His progress was slow and varied. His receptive language skills improved, however his comprehension was still hindered by poor short term auditory memory and slow processing made social situations difficult. Toby had made less progress with his expressive language, which remained immature. Socially he lacked confidence in groups. He tended to speak loudly when excited and

smiled in inappropriate situation, particularly when he did not understand. Overall his difficulties were still persistent and affected all areas of language, cognition and social functioning despite improvement in some areas.

Toby left the school aged 16;9 years. He still had significant difficulties with speech, language, weak short-term auditory memory and cognition. His memory problems caused him to have comprehension difficulties as he had problems keeping up with incoming verbal information. He had developed a compensatory strategy for this by following actions or answers of others which he did whether it was appropriate or not.

Toby then went on to attend a mainstream college. There had been potential for Toby to attend a residential college, which would have been able to provide for his special needs, but his parents had no means to fund his placement. It was felt that the mainstream college did not have the facilities Toby needed and there was also concern he would have no appropriate peer group at the mainstream College. His parents pursued funding from the local LEA and their case went to tribunal. The outcome of the case was unclear from the archive files however TD talked about going to the mainstream college in his interview.

A1.11 Case 11: Lauren

Lauren was born on the 20th of December 1984. No information was available for Lauren from before she entered the school, aged 7;9. At this time she had a label of *severe speech disorder* and had a restricted phonetic inventory as a result. Her speech difficulties were caused by a severe phonological disorder and much of what she said was difficult to understand if not unintelligible. She had no difficulty with non-speech oral movements and therefore was felt not have a dyspraxic difficulty.

Despite her articulation difficulties she did have some phonological skills for listening tasks. She was able to detect nonwords reliably and make rime judgements although she was very poor at detecting the onset of words. LP also had other expressive difficulties with severe word finding difficulties and grammatical difficulties. In summary, Lauren had a primary phonological disorder that impaired her articulation as well and other aspects of expressive language.

Lauren left the school aged 16 years. Many of her problems had persisted. It was reported this was partly due to Lauren's attitude at school. She had not accepted she had a problem, was unable to appreciate the need to change and her progress at school had been very slow. Lauren's articulation difficulties persisted throughout her time at the school, however, on leaving she was able to imitate most speech sounds and showed some improvement with her phonological skills.

Lauren's archive files also report she had severe behavioural difficulties at school due to feelings of anger. This anger was directed at a number of different sources:

- She was angry at her family. Her family situation was unusual not only because she was attending a boarding school but also because her grandparents were her primary caregivers. She had no contact with her father and rarely saw her mother who was not responsible for her.
- She specifically angry at her brother but equally loved him and wanted him to join her at school.
- She was angry at herself and her speech difficulties.

- She was angry at the school and had a strong desire to leave.
- She had low self-esteem and viewed herself as an angry person generally.
- She was aware of her difficulties and consequently did not like working on her communication skills.
- She was an uncooperative individual who did not respond to threats or punishments.

A1.12 Case 12: Kirsten

Kirsten was born on the 8th of April 1985. She was the fourth of five children in the family and had two brothers and two sisters. There was a history of SLD in Kirsten's family. One of her brothers was also stated as he had problem with his speech and one of her sisters had mild cerebral palsy. A medical record reported Kirsten's mother's pregnancy was normal until she was born in an ambulance 3 weeks early. The delivery was normal and her birth weight was 6lb 12oz. There were no problems at birth or obvious delays with milestones.

Kirsten started play group at 2;6. At this time her mother thought she was speaking reasonably well but a health visitor queried her speech development. She then started SLT at 3;0 years but was still not speaking in sentences by 7;0 years. There were also reports of medical difficulties that could have inhibited her speech and language development. Firstly, Kirsten had been unable to breathe through her nose properly and had a teeth brace fitted to her back teeth to widen her mouth and ease breathing. Secondly, she also needed grommets and had hearing aid for approximately two years between 8 and 10 years. In socially KM lacked confidence as a young child and was viewed as 'thick' by the rest of her siblings.

Her parents persistently tried to get her a place at the residential school and were eventually successful after 4 years. Kirsten eventually entered the school at 11;5 years when she presented with *severely delayed expressive language skills as well as delayed receptive language skills*. She also had specific difficulties with:

- limited vocabulary knowledge
- semantic knowledge
- word-finding
- sentence formulation
- significantly below average verbal and nonverbal abilities.

Kirsten then stayed at the school for the duration of her secondary education. Towards the end of her time there it was reported that her expressive language abilities had improved while her comprehension difficulties had remained more persistent. Her word finding ability and vocabulary knowledge had also improved and she now had coping strategies she used when speaking. Her primary difficulties were now with receptive language as these difficulties had been the more persistent. Importantly, her self-confidence had improved and could now stick up for herself and express her opinions; something would have been too shy to do aged 11;5. She still lacked confidence in her own abilities but this was improving. Kirsten left the school aged 16;03 years.

A1.13 Case 13: Steven

Steven's family had a history of literacy and mental health problems. His father and brother both had difficulties with spelling and learning to read but nothing was ever formally diagnosed. His grandmother on this mother's side had depressive symptoms and other relatives had agoraphobia and anxiety disorders.

Steven was born on the 18th of February 1985 and the birth was typical. He reached his the developmental motor milestones relatively normally, however there was concern that he severed from night terrors when he was a toddler. Initially Steven's language development appeared typical. He babbled as a baby and learned to say 'mum'. However, concern began at 18 months when her was referred to SLT and was monitored till age 3 years. By age 4 his vocabulary only contained 4 words. Early tests showed slight hearing loss at this time.

At age 7 year Steven complained he could not hear properly describing the speech of others sounding like 'mmmm...mmmm'. Even so, Steven attended a mainstream infants and junior school between ages 4 and 10, and then moved to a language unit attached for the final year of junior school. His language abilities were then reassessed and this showed he had large a discrepancy between his verbal and nonverbal ability; his verbal abilities were below average and his nonverbal abilities were above average. He was also given a label of *severe and complex multifactorial language disorder*.

The speech and language aspects of this disorder where:

- Auditory perception/discrimination problems
- Mispronunciation in speech
- Problems sequencing and blending sounds to make words
- Auditory memory and inference problems
- Difficulties manipulating and cross referencing semantic information
- Comprehension difficulties with abstract vocabulary, time and sequencing
- Problems organising and expressing thoughts with succinct appropriate content and structure
- Topic shift in discourse

The literacy aspects of the disorder were:

- Poor reading due to short term memory difficulties resulting in difficulty recall the story lines
- Poor spelling as he words he learned on visual basis and had difficulty recalling them
- Spellings often had bizarre appearance

Behavioural aspects:

- Hard working and keen to archive
- Sociable and got on well with peers, however, other children had started to notice his language difficulties
- Panic attacks, night terrors and phobias

Steven then started at the residential special school aged 11;7 years. During this time he had increasing problems with mental health and developed obsessive compulsive disorder (OCD) and anorexia due to a phobia of the school food. However, he still grew in confidence while at school and showed a great passion for dance and theatre performance.

Steven left the school aged 16;4 years. His difficulties had improved, however aspects of his disorder persisted due to his perceptual difficulties. His receptive language was poorer than his expressive language and he still had difficulties understanding complex verbal information as he was prone to forgetting parts of what had been said to him. His expressive language had shown a greater improvement however he had persisting difficulties with sentence formation and word finding.

A1.14 Case 14: Darren

Darren was born on the 26th of January 1985. A medical report stated his mother had been well throughout her pregnancy until 38 weeks when she developed high blood pressure. The birth was then induced. Darren had mild jaundice for 14 days following his birth. He went through his motor milestones without too many problems; he was sitting by 7-8 months and walking by 14 months (though this was a little clumsy) and toilet trained by age 2;6 years.

Concerns for Darren's language development started at a young age. He did babble but only as a very young baby. He also had a history of hearing problems as a young child and had his tonsils and adenoids removed. He developed an extremely limited vocabulary as a young child and started to receive sporadic speech and language therapy from the age of 2;6 years as a result. Despite these efforts he could still only say 'Ma' and 'Da' by the age of 5.

Darren then started to attend a specialist speech and language unit in 1990 where he received therapy 3 times a week. His problems with vocabulary persisted and by age 6 he could still only say a few single words. By 7;6 his language use had increased to simple 2-word phrases. Socially he was described as a timid child up until age 5 years when he grew into a more easy-going child.

His problems with his language development persisted and entered the school in September 1993 at the age of 8;8 years. He still had a small vocabulary and other SLD had also become apparent. He had poor understanding of sentence structure, something which also impaired his comprehension ability. His ability to decode written text was also impaired though he did have a small sight vocabulary that he could rely on. He also had further problems with word finding and verbal dyspraxia.

During his time at the school he managed to improve in many areas that he had initially found difficult. His vocabulary skills had improved dramatically and were later described as 'normal', however he still had difficulties when acquiring new words. His literacy also improved though this was still hindered by several factors. He had some comprehension difficulties with speech that affected his ability to decode. It was also thought that his speech problems had affected his spelling. It was also noted that there was quite a marked discrepancy between his knowledge in maths and science and his literacy skill. His overall language use had also improved but this was also hindered by his difficulties organising and formulating explanations or descriptions that required specific details. Darren was described as immature in group interactions and socially. He left the school aged 16;5 years.

A1.15 Case 15: Jack

Jack was born on the 10th of February 1900. The birth was said to be difficult. He was the older of 2 siblings and had very negative feelings towards his younger sister. As a baby he cried, smiled and gave eye-contact but did not babble. However, he became hyperactive between 6 and 18 months did not sleep. His speech development was slow and he started to talk at 3 ½ years. In addition, he was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) at age 6 years. This meant he could become very angry and kick, punch or throw himself down. Triggers shopping for this were and changes in routines. He needed clear boundaries to manage his behaviour and was prescribed Ritalin. He also suffered repeated ear infections that lasted 7-8 months until 7-8 years. His play was restricted to lining up cars, moving verticals along and bashing toys. He liked routines and needed forewarning if events were changing.

He received SLT at nursery at age 4, but when he came to start primary school aged 5 years he was still unintelligible to strangers on starting school. He had further SLT but struggled due to having no friends and the therefore spent a lot of time alone. This school was also said to be too big for him and he was transferred to a smaller school in 1998. He then transferred to secondary school in 2001, where he was supported by a teaching assistant.

He later entered the residential special school at around 13 years following the closure of his secondary school. At this time he was said to presents with *significant receptive language impairment and social communication difficulties with characteristics of ASD*. He did not fill true criteria for Asperger's syndrome as he also showed a language delay. There were also no longer signs of ADHD. A range of language difficulties were reported:

- Significant delays in verbal comprehension and the understanding and processing of spoken language
- Difficulty storing and retrieving new vocabulary
- Difficulties organising and sequencing sentences
- Difficulty understanding social interactions
- Dyslexic difficulties
- Dyspraxic difficulties
- Anxiety about his own limitations

He also stayed for one year which began in 2006.

A1.16 Case 16: Lewis

Lewis was born on the 30th of July 1988. No information on his birth or early development was available in the archive. He had one younger brother who he had lost contact with by the time he was seen at follow-up. This was due to a family rift. Lewis lived with his father and his brother lived with his mother.

The earliest report in Lewis's archive was a school progress report from when he was 9 years. He was said to have *severe dyspraxia affecting motor control and articulation* and particular difficulty with literacy and

numeracy. His classroom behaviour was also difficult. He was never deliberately disruptive, however he was impulsive and often could not remain in his seat during lessons, had difficulty with listening, was always chewing his belongings, and was very demanding of adult attention. His performance on all tasks was hampered by extremely impulsive behaviour, obsessionality and high degree of distractibility, however he was keen to cooperate and please. In 1998 it was thought he had ADHD and that medication would be beneficial. His father did not wish to start medication however, and felt he was more manageable at home. He was also held back a year at school.

Lewis entered the school in September 2000. He was said to have *severe articulatory dyspraxia*, literacy difficulties and fidgety behaviour. His spoken language was very difficult to understand. He omitted many consonant sounds from his speech, found consonant clusters extremely problematic, his vowel sounds were often inaccurate and his sentence structures were often poorly constructed. He also had moderate learning difficulties and presented with difficulties with non-verbal skills and numeracy skills. He also had significant difficulty with handwriting due to his dyspraxia.

In July 2007 Lewis left the school and was said to still have significant difficulties. This particularly affected his speech, listening and attention, language comprehension, expressive language and interaction and literacy. In addition, an occupational therapy report from this time reported Lewis had self harmed during his time at the school. This was not felt to be the result of difficulties with Lewis's mental health but because he used the self harm as a way of providing feedback and extra sensation to his body. This was felt to indicate that his senses were not working in the way they should.

A1.17 Cast 17: Emma

Emma's mother was said to be very ill during the pregnancy and Emma's birth. She was born on the 4th of June 1988 and there were otherwise no problems at birth. She reached all milestones as normal. However, Emma suffered a near-miss cot death as an infant which left her with a complex range of difficulties; SLD, moderate learning difficulties and night epilepsy.

Initially Emma attended a private school. However she struggled and was held back a year twice despite her parents paying for a class room tutor for her. In 1998 her statement reported she had significant and complex educational needs related to learning difficulties. She presented with severe specific and complex speech and language disorder and her primary difficulties were with semantics and syntax. She also had significant difficulties in receptive and expressive language and intellectual functioning. However she still had good social skills, a good motivation for work and applied herself in a positive and hard working way.

She then entered the school in April 1998 and stayed until July 2007 having completed three years in the school's FE department. During her time at the school she continued to have difficulties with processing language, word learning and retrieval, expressive language, inferential and higher level reasoning skills and social interaction. However, Emma was also aware of difficulties, sought advice and responded to support. She was also responsible, organised and a popular member of FE. Unfortunately at this time it also became apparent that the medication Emma had been taking for her epilepsy had damaged her peripheral vision and the family were seeking legal action in compensation for this.

A2 Coding systems for the Qualitative Analyses

A2.1 Coding system for the Ex-pupil Follow-up; Psychosocial Outcomes

Research area	Theme	Code	No. of items
Education	Educational placements	Mainstream education	13
		School before	31
		Support before	9
	Education at the school	Information	27
		Memories	46
		Preparing for life	18
		SLT	16
		Support	29
		Additional wants	31
		The right school?	21
	Boarding	Boarding	61
		Boarding and family	21
		Boarding and friends	13
		FE	32
		If no FE	3
	Friends at the school	Bullying	22
		Friends	28
		Maintaining Friendships	32
	Education after life at the school	Leaving at 16 - 19	5
		Leaving at 12	7
Post-16		48	
Qualifications		43	
Independence	Employment	Achievements	3
		Bullying	18
		Colleagues	22
		Employment history	34
		Employment	78
		Problems at work	3
		Future employment	38
		Unemployment	13
	Specialist training	21	
	Independent living	Finances	39
		Living arrangements	79
		Domestic tasks	14
		Financial management	23
Personal lives	Friendships	Clubs	7
		Friendships	93
		Social difficulties	25
	Relationships	Relationships	46
	Children	Children	4
		More support today	1
	Spare time	Hobbies	17
SLD	Childhood	SLD in childhood	32
	Adulthood	SLD in adulthood	31
		Support after the school	19
		More support today	1
		Talking in public	31
		Technology	25
	Adult literacy	Books	18
The future	Future plans	20	

A2.2 Coding system for Parents and Siblings' Perspective on having a Family Member with Speech and Language Difficulties

Research area	Theme	Code	No. of items	
Impact on Family	Parental views on the causes of SLD	Child development	49	
	Early SLD	Literacy difficulties before the school	8	
		SLD before DHS	55	
	Childhood Behavioural Difficulties and Frustration	Behavioural difficulties	33	
	Parental Coping Strategies	Coping strategies	18	
		Helping children with SLD	17	
	The effect of boarding on the family	Boarding	61	
	Siblings' Perspective	Siblings	54	
	Knowledge, Information and Understanding	Changing social attitude	17	
		Limited information	32	
		Technology	8	
	Table 6.2 only	Family history of SLD	16	
	The School and Support Services	Support before the school	Education before the school	65
			Support before DHS	58
Statementing		Statementing	33	
The Fight		Impact on parents	34	
		The fight	52	
Experiences of the school		Bullying	7	
		Experiences at the school	83	
		Friendships (childhood)	26	
SLD while at the school		Literacy difficulties at the school	3	
		SLD at the school	11	
Education and support at the school		Education at the school	27	
		Support at the school	18	
FE provisions		FE	22	
Maturity		Immature for age	19	
Mainstream vs. special school	Mainstream vs. Special schooling	35		
Support in Adulthood	Support after the school	60		
Ex-pupils' Psychosocial Outcomes	SLD in adulthood	Adult literacy difficulties	13	
		SLD in adulthood	54	
	FE outside the school	Post-16 provisions	72	
		Transitions	12	
	Employment	Bullying	2	
		Employment	46	
	Financial Management	Finances	26	
		Taken advantage of	4	
	Independent Living	Independent living	46	
	Social Lives	Friendships (adulthood)	39	
		Social club	6	
		Social isolation	3	
	Relationships	Children	37	
		Relationships	54	

A2.3 Coding system for the FE staff

Research area	Theme	Code	No. of items
FE staff	Views and Experiences of the FE department	Challenges in FE	27
		College	21
		Effect on rest of the school	11
		Failures	15
		Importance	10
		In FE	14
		Mainstream vs. Special school	4
		Objectives	13
		Role in FE	17
		Work placements	12
	Staff Views and Experiences of Pupils in FE	Behaviour	8
		Coping	2
		Maturity	18
		Parents	17
		Pupil's SLD	15
		Skills	12
		Successes	24
		Supporting The pupils	31
	Boarding in FE	Boarding	10
	Friendships in FE	Friends	11
	Leaving FE and the Future	Awareness of SLD	8
		Improving FE	26
Independence		5	
Protected		5	
The future Transitions		10 22	

A3 Worked example for the Qualitative Analyses

A3.1 Worked example of coding system for chapter 5

Code: Living arrangements

Researcher: O:k you think you did (.) o:k so do you think in the future you'd ever like to move out and live on your own?

Karen: Yeah (starting nodding) I would yeah.

Researcher: Ok and how long have you thought about that for?

Karen: Not very long.

Researcher: Not very long so that's a fairly resent

Karen: About a couple of months.

Researcher: A couple of months o:k (.) and do you think that would be a good experience?

Karen: A bit of both.

Researcher: A bit of both why do you think that?

Karen: It would be good to get the experience but I just like living at home.

Researcher: mmm

Code: Domestic takes

Researcher: Not really (.) what about things like cooking and cleaning and (.) house work?

Karen: Am quite good at that.

Researcher: Do you help with those things now?

Karen: Mmm (nods)

Researcher: Mmm so that would be ok?
 Karen: (nods)

Code: Financial management

Researcher: And what about budgeting?
 Karen: Am quite good at it but not that good.

Code: Employment

Researcher: Not that good (.) o:k (flips pages) and the next thing I want to talk about is employment so do you currently have a job at the moment?

Karen: (nods)

Researcher: You do and what is that you do?

Karen: I'm a nursery nurse

Researcher: Mmmm

Karen: at a nursery (.)

Researcher: mmm

Karen: in (name of the town where Karen worked)

Researcher: Ok (.) and what is it that you have to do there?

Karen: Erm (.) its:: (.) erm jus' look after you know the kids

Researcher:

mmm
 and see if they're alright.

Karen:

Researcher: How old are they?

Karen: Erm they come two and a half

Researcher: Two and a half.

Karen: and going four and a half.

Code: Talking to the public

Researcher: You do ok (.) and does that involve talking to parents and

Karen: Well I don't deal with that

Researcher: You don't

Karen: but people do::

Code: Employment

Researcher: Umhm ok and is it ok to ask how much you get paid for doing that or would you prefer not to answer?

Karen: I::: can't remember tee heh heh.

Code: Colleagues

Researcher: You can't remember that's fine (.) and how well do you get along with the other people that you work with there?

Karen: Yeah (nodding)

Researcher: Their all fine?

Karen: Yeah

Researcher: What about your boss?

Karen: Yep.

Researcher: Is that ok they're all easy to get along with?

Karen: Yeah

Researcher: And do you socialise with those people as well?

Karen: Yep

Researcher: You do (.) what about outside work?

Karen: Yep

A3.2 Work example of coding system for chapter 6

Code: Support before DHS

Edith: so she was referred initially for speech therapy she must only have been about two and a half or three or something like that h:: um (.) so (.) from that point of view there weren't all frustrations there

Researcher: Ok

Edith: erm: (.)

Researcher: Is your you experience of support services been generally good would you say?

Edith: h::::

Edith: Well (.) I mean we had a very good er she had a very good speech thera pist when she was little (.) h and then (.) she was referred to the (name) centre for speech and hearing.

Researcher: Mm

Edith: Erm (.) quite early on (.) she was four when we went there the first time (.) so (.) the fact that we got into that system that and she got their support meant that yes at that stage (.) the support we were getting was good (.) what wasn't so good was: was actually the support from (local) county at that stage (.)

Code: Statementing

erm the statementing procedure (.) was a nightmare heh:::: hah hah hah

Researcher: Ok what was that?

Edith: Well they started to write a statement for her she about four and then because when she was five

Code: Education before DHS

Edith : she was five she was went to the (place) erm you know the (place) unit the (place) centres?

Researcher: I don't know it I've heard of it

Edith: I don't know whether its still there to be honest

Researcher: Mm

Edith: Erm but it was a residential centre forh::: now I've got to remember now (.) how many children there were not very many (.) about ten many erm (.) and its actually technically it's a ward of the hospital but actually it's a little school for children with speech and language problems.

Researcher: And sh she

Code: Statementing

Edith: She was five when she went there (.) erm but when she the place there they stopped bothering to write the statement so when she left there two years later they still hadn't finished writing the statement which meant that actually identifying that she was gunna go to Dawn House and that they were gunna fund it (.) was quite a struggle because you know they hadn't actually (.) h:::eh heh

Code: Experiences at the school

Researcher: Ok I've forgotten how old (Karen) was when she went to Dawn House.

Edith: She was seven

Researcher: Seven

Code: Education before DHS

Edith: So sh she had (.) she went (.) well when she when she actually reached five what happened was that when she was four she went a local (.) nursery attached to one of the infants schools not the school she would been expected to go to er and she went there full time so locally I mean the sch that was good that we were actually offered that erm (.) and then at the time that she was five (.) they felt that she wasn't ready to go into the in the local infants school so in fact she technically went on to the role of the infants school the nursery was attached to but actually stayed in the nursery

Researcher: Ok

Edith: H::: erm and then I was during that sort of period from the Easter through to the summer that we were offered the place at the (name) unit.

Researcher: Ok

Edith: So er she went to (name) unit when she just over five.

Researcher: Ok do you think

Edith: Just over five and a half

Code: Mainstream vs. special school

Researcher: Do you think that was better that she went there then if she'd gone to erm a main stream primary school?

Edith: I think so I don't think she would have coped at that stage in mainstream she didn't have the ability to communicate sufficiently or to understand I think.

Researcher: Ok

Code: Childhood behavioural difficulties

Edith: Erm (.) and I think by that by the time she was five she was getting frustrated at the lack of

Researcher: mm

Edith: at not being able to communicate

Researcher: mm

Edith: getting cross with people from not knowing what she wanted hah heh::

Researcher: Ok

A3.3 Work example of coding system for chapter 8

Code: The future

Researcher: Ok erm and how do you think the pupils will get on when they do eventually leave Dawn House FE.

Molly: Well hopefully they'll get on well.

Researcher: Yeah what do you think they might be like?

Molly: Erm well hopefully they'll take away what they've learnt in FE away with them erm I know even now that some are leaving next week and erm they are quite worried.

Researcher: Ok

Molly: Because I think FE well Dawn House has been a safe environment for them.

Researcher: Yes some of them have been here a long time.

Molly: Yes and I think its those that been here a long time to go out there you know they feel a little bit insecure but you know but a lot of them are going on the colleges where they are where they live so hopefully they'll be ok.

Code: Transitions

Researcher: Do more go on to do studying or do more employment when they first leave?

Molly: A lot of them go on to college courses.

Researcher: Yes

Molly: So erm I think there's only on that may be going (.) I think he's doing an apprenticeship.

Researcher: Ok

Molly: So you know

Researcher: Ok

Molly: But a lot of them will continue at college near where they live.

Code: Independence

Researcher: What about things like independence?

Molly: Erm well we don't really see them outside of school time erm but I mean they're able to and get on a bus say where they want to go you know so they have got that independence it was care worked well with them because its care that have said right we're going shopping der der der they've gone.

Researcher: Ok

Molly: They're going to the picture you know they do that kind of thing we have done it with some of our students you know we get on a bus we want to go so and so that's it.

Code: Friends

Researcher: Um hm and what about more sort of social things?

Molly: Er again care deal with all that so.

Researcher: Ok

Molly: You know interacting barbeques at night time and you know activities that go off so.

Code: In FE

Researcher: Um hm ok erm how do you think Dawn House FE has prepared them for when they leave?

Molly: They can only preparing 'em as well as they're willing to let us prepare them so I mean if they don't you know if they say no that's it they put this barrier up and that's it you can't do anything.

Researcher: Sure

Molly: Hopefully they do get life skills

Researcher: Yes

Molly: and you know thing things like and obviously the curriculum that (FE coordinator) or the tutor delivers you know its all part of what happens in the outside world.

Code: Skills

Researcher: Yeah (.) you do do life skills and thing in FE.

Molly: Yes yes

Researcher: I thought you did

Molly: Yes

Code: Maturity

Researcher: Yeah ok erm (.) do you feel that pupils change with time?

Molly: Yes I do.

Researcher: Yeah

Molly: Yeah

Researcher: In what way?

Molly: I can see like (name) that's erm obviously he was very agitated that first months not being in college the as soon as he got there.

Researcher: Mm

Molly: Different child.

Researcher: Mm

Molly: Totally different you know it really surprised me and we've got that you instead of saying F off its thank you (staff member) thank you (MC) or please you know I have got something out of if and I think you know he's not sworn very much since we've had him so to speak you know erm excuse me language and that's all it will take and sorry.

A4 Proof of ethical approval

A4.1 Ethics approval for data collection phases 1 and 2

ETHICS REVIEWER'S COMMENTS FORM

This form is for use when ethically reviewing a research ethics application form.

1. Name of Ethics Reviewer:	Richard Body
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2. Research Project Title:	Follow-up of pupils from Dawn House School
3. Principal Investigator (or Supervisor):	Lydia Ansorge
4. Academic Department / School:	HCS

5. I confirm that I do not have a conflict of interest with the project application

6. I confirm that, in my judgment, the application should:				
Be approved:	Be approved with <i>suggested amendments</i> in '7' below:	and/or	Be approved providing <i>requirements specified in '8' below are met:</i>	NOT be approved for the reason(s) given in '9' below:
	✓			

7. Approved with the following suggested, optional amendments (i.e. It is left to the discretion of the applicant whether or not to accept the amendments and, if accepted, the ethics reviewers do not need to see the amendments):
--

- The Ethics Review Panel will need to have sight of a copy of the I-CAN permission for the researchers to have access to the DHS archive.
- Note typographical corrections on Information Sheets / Consent Forms
- Video Recordings The information on future use of video recordings needs to be made consistent and more accurate
 - Use of the phrase "I will allow my recordings ... to be shown anonymously". Although it is possible to make these anonymous in the sense of not giving biographical details, participants can still be identified from video. The wording needs to be changed to reflect this.
 - Parent Information Sheet says (of recording) "This will just be for my benefit." This is not consistent with the Consent Form.
 - Is it necessary to restrict Parent recordings to 'never being shown to members of the public?' Suggest rewording Consent Forms to give all participants options regarding the use of video recordings, e.g. none / for ease of transcription / for discussion with supervisors / for presentation in HCS / for presentation at conferences.
 - Use of the word 'mainly' (be shown to...) in Information Sheets is not specific. Reword.
- Questionnaires It would be a good idea to state at the beginning of the questionnaires that participants can decline to answer individual questions (rather than having a choice of continue or withdraw),
- Time estimate. Given the size of the questionnaires, it may be that the 3 hours mentioned on the information Sheets is optimistic. Discuss with supervisors.

8. Approved providing the following, compulsory requirements are met (i.e. the ethics reviewers need to see the required changes):

9. Not approved for the following reason(s):

10. Date of Ethics Review: 13.09.06

R. Body

ETHICS REVIEWER'S COMMENTS FORM

This form is for use when ethically reviewing a research ethics application form.

1. Name of Ethics Reviewer:	Dr Richard Body Dr Patricia Cowell Dr Anna Maria di Betta
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2. Research Project Title:	When children with speech and language difficulties grow up
3. Principal Investigator (or Supervisor):	Lydia Ansorge (Prof J Stackhouse)
4. Academic Department / School:	HCS

5. I confirm that I do not have a conflict of interest with the project application
--

6. I confirm that, in my judgment, the application should:			
Be approved:	Be approved with suggested amendments in '7' below:	and/or	Be approved providing requirements specified in '8' below are met:
	✓		NOT be approved for the reason(s) given in '9' below:

7. Approved with the following suggested, optional amendments (i.e. it is left to the discretion of the applicant whether or not to accept the amendments and, if accepted, the ethics reviewers do not need to see the amendments):
<ul style="list-style-type: none"> ▪ Pupil information sheet. Minor edits. (a) Rephrase the first sentence so that the word "about" is not used twice. Suggest "...a project that studies the lives..." (b) Under "what is involved" replace the question mark with a full stop. (c) Insert Prof and Dr for the supervisors' titles. ▪ Pupil/Parent/Staff consent forms. Insert the study title at the top of the sheet. ▪ Pupil questionnaire. Rephrase Question 5 to clarify that independent living is "not at Dawn House" and "not with your parents". ▪ Parent information sheet. Minor edits. (a) Delete the word "in" from line 2 of paragraph 2. (b) Insert Prof and Dr for the supervisors' titles. (c) Under "what is the project about" edit the last line to read "...parents' views." ▪ Parent questionnaire. Question 8 should read "...fared better..." ▪ Staff information sheet. Minor edit. (a) Insert Prof and Dr for the supervisors' titles.
8. Approved providing the following, compulsory requirements are met (i.e. the ethics reviewers need to see the required changes):
9. Not approved for the following reason(s):
10. Date of Ethics Review: 4 July 2008.
Dr Patricia Cowell

A5 Materials used in Phases 1 and 2

A5.1 Recruitment letters

Letter for first contact; sent on paper with the School letter head.

Dear

██████████ School, follow-up of ex-pupils

We are writing to you as an ex-pupil of ██████████ School. We are carrying out a follow up project in to the lives of ex-pupils to see if we can learn from their experiences to support our current pupils. We are being helped to do this by staff at the University of Sheffield who are, Joy Stackhouse, Judy Clegg and Lydia Ansonge.

We would like to invite you to take part in the project. The project will involve talking about your experiences of ██████████ School, and completing some routine assessments like the ones you did at school.

Please could you fill in your current address and telephone number and let us know if you are happy for us to contact you again. Please return the form in the stamped addressed envelope. If you have any questions, then you can contact either Lydia Ansonge (tel. 0114 2222416, e-mail l.ansorge@sheffield.ac.uk), or ██████████ School. We would be more than happy to discuss the project with you.

We would look forward to hearing from you

Yours sincerely

Lydia Ansonge
 Postgraduate Research Student
 Human Communication Sciences
 University of Sheffield

Letter for second contact sent to nonrespondents for the previous letter; sent on paper with the School letter head.

Dear

██████████ School, follow-up of ex-pupils

We are writing to you to follow-up our previous letter. We are still carrying out the follow up project into the lives of our ex-pupils to see if we can learn from their experiences to support our current pupils. We are being helped to do this by staff at the University of Sheffield who are, Joy Stackhouse, Judy Clegg and Lydia Ansonge.

We would still very much like to meet you and to invite you to take part in the project. The project will involve talking about your experiences of ██████████ School, and completing some routine assessments like the ones you did at school.

Please could you fill in your current address and telephone number and let us know if you are happy for us to contact you again. You can also return the form if you are NOT happy to be contacted again. Please return the form in the stamped addressed envelope. If you have any questions, then you can contact either Lydia Ansonge (tel. 0114 2222416, e-mail l.ansorge@sheffield.ac.uk), who is from the University of Sheffield, or ██████████ School. We would be more than happy to discuss the project with you.

We would look forward to hearing from you

Yours sincerely

Lydia Ansonge
 Postgraduate Research Student
 Human Communication Sciences
 University of Sheffield

Anne Jordan
 Head Teacher
 ██████████ School

Letter sent to the 9 ex-pupils recruited by Clegg (Unpublished) that did not participate; sent on paper with the School letter head.

Dear

██████████ School, follow-up of ex-pupils

Do you remember getting a letter in May 2005 from ██████████ School, ICAN and Judy Clegg about a project following-up ex-pupils of ██████████ School? Our records show that you were willing to be contacted about the project at the time. We are sorry that you were then not contacted again. This was because not everyone who responded could be seen at the time.

However, we would like to invite you again to take part in a similar project if you are still interested. This project is being carried out by ██████████ School, ICAN and Lydia Ansonge, who is from the University of Sheffield. The project will involve talking to Lydia about your experiences of ██████████ School, and completing some routine assessments like the ones you did at school.

Please could you fill in your current address and telephone number and let us know if you are still happy for us to contact you again. Please return the form in the stamped addressed envelope. If you have any questions, please do not hesitate to contact either Lydia Ansonge (tel. 0114 2222416, e-mail. l.ansonge@sheffield.ac.uk) or ██████████ School. We would be more than happy to discuss the project with you.

We would look forward to hearing from you

Yours sincerely

Lydia Ansonge
 Postgraduate Research Student
 Human Communication Sciences
 University of Sheffield

Returnable response form sent out with the 3 previous letters.

██████████ School Project

Please can you complete the following details and return the form in the stamped addressed envelope.

Name:
 Address

Telephone number:
 E-mail address:

Please complete the following to let us know if you would like to be contacted again about the project.

I would like to be contacted again about this project

Signed:
 Date:

I would NOT like to be contacted again about the project.

Signed
 Date:

Please return this form in the stamped addressed envelope

Letter sent to ex-pupils' parents: sent on University of Sheffield paper.

Dear

[REDACTED] School, follow-up of ex-pupils

We are writing to you as a parent of an ex-pupil of ours. We are carrying out a follow up project in to the lives of ex-pupils of **[REDACTED] School** to see if we can learn from their experiences to support our current pupils. We have already been talking to _____ about his/her experiences of the School and would be very interested to talk to you as his/her mother/father. _____ has nominated you as someone they feel they would like to take part.

The project is being carried out by **[REDACTED] School**, I CAN and Lydia Ansorge who is from the University of Sheffield. It will involve talking to Lydia about your experiences having had your child attend **[REDACTED] School**.

Please could you fill in your current address and telephone number and let us know if you are happy for us to contact you again. Please return the form in the stamped addressed envelope. If you have any questions, then you can contact either Lydia Ansorge, who is from the University of Sheffield (tel. 0114 2222416, e-mail l.ansorge@sheffield.ac.uk), or **[REDACTED] School**. We would be more than happy to discuss the project with you.

We would look forward to hearing from you

Yours sincerely

Lydia Ansorge
 Postgraduate Research Student
 Human Communication Sciences
 University of Sheffield

Returnable response form sent out with previous letter.

[REDACTED] School Project

Please can you complete the following details and return the form in the stamped addressed envelope.

Name of child who attended **[REDACTED] School**:

Your name:

Address

Telephone number:

E-mail address:

Please complete the following to let us know if you would like to be contacted again about the project.

I would like to be contacted again about this project

Signed:

Date:

I would NOT like to be contacted again about the project.

Signed

Date:

Please return this form in the stamped addressed envelope

Letter sent to ex-pupils' siblings: sent on University of Sheffield paper.

Dear

██████████ School, follow-up of ex-pupils

We are writing to you as the brother/sister of an ex-pupil of ours. We are carrying out a follow up project in to the lives of ex-pupils of ██████████ School to see if we can learn from their experiences to support our current pupils. We have already been talking to _____ about his/her experiences of the School and would be very interested to talk to you as his/her brother/sister. _____ has nominated you as someone they feel they would like to take part.

The project is being carried out by ██████████ School, I CAN and Lydia Ansonge who is from the University of Sheffield. It will involve talking to Lydia about your experiences having had your brother/sister attend ██████████ School and taking some routine tests like the ones your brother/sister did at school.

Please could you fill in your current address and telephone number and let us know if you are happy for us to contact you again. Please return the form in the stamped addressed envelope. If you have any questions, then you can contact either Lydia Ansonge, who is from the University of Sheffield (tel. 0114 2222416, e-mail l.ansonge@sheffield.ac.uk), or ██████████ School. We would be more than happy to discuss the project with you.

We would look forward to hearing from you

Yours sincerely

Lydia Ansonge
Postgraduate Research Student
Human Communication Sciences
University of Sheffield

Returnable response form sent out with previous letter.

██████████ School Project

Please can you complete the following details and return the form in the stamped addressed envelope.

Name of sibling who attended ██████████ School:

Your name:

Address

Telephone number:

E-mail address:

Please complete the following to let us know if you would like to be contacted again about the project.

I would like to be contacted again about this project

Signed:

Date:

I would NOT like to be contacted again about the project.

Signed

Date:

Please return this form in the stamped addressed envelope

A5.2 Information Sheets for Participants

Ex-pupil information sheet
Lydia Ansorge
Department of Human Communication Sciences
University of Sheffield

This information sheet is about a research project that will document the lives and experiences of ex-pupils of [REDACTED] School.

Please read this sheet carefully before agreeing to take part in this study. You will also be given the chance to ask any questions you might have if you are worried or confused about anything that isn't clear.

Who is involved in the project?

My name is Lydia Ansorge and I will be interviewing ex-pupils of [REDACTED] School to see how they are getting on as adults. I am a PhD student in the Department of Human Communication Sciences at the University of Sheffield. The project is supervised by Joy Stackhouse and Judy Clegg who are also in the Department of Human Communication Sciences.

Our contact details can be found at the end of this sheet.

We are working with [REDACTED] School and the charity I CAN who fund [REDACTED] School. Both are interested to see what happens to their ex-pupils when they leave.

What is the project about?

The project is looking at what happens to ex-pupils of [REDACTED] School when they grow up. Ex-pupils will be given the chance to talk about their experiences, thoughts and feelings having left the school.

What will I have to do?

If you choose to take part I will see you at a time that is best for you. First I would like to assess your thinking and language abilities. Then I would like to talk to you about your time at [REDACTED] School and your experiences now you have left. I would also like to record you talking about your experiences so I can listen to what you said afterwards. I can use either an audio or video recorder. You can choose which you would be most happy with, or you can choose not to be recorded at all.

I can see you in one long session or two smaller sessions, it's up to you. If you choose one long session it will last about 3 hours and will have breaks in the middle to stop you getting too tired.

If you choose to participate I would also like to look at your old school record. This will be used to look at what you were like when you were at [REDACTED] School compared to what you are like now.

What will happen afterwards?

No one will know who you are from the assessments or recordings. No identifying information about you, like your name or address, will be kept with these. Any information will be kept in a locked filing cabinet in a locked office.

The assessments and recordings will be looked at by my two supervisors and myself. I would also like to ask your permission to use some of your remarks or clips from your recordings anonymously in presentations to other researchers, students and professionals for discussions or teaching about the life experiences of people like yourself. If you don't want me to do this then that is okay and you can still participate in the project.

What if I don't want to take part or I change my mind?

If you don't want to take part then that is okay. If you do decide to take part but change your mind then that is also okay and your recordings and assessments will not be used in the study. You will not have to give a reason if you do not wish to take part anymore.

Contact details for if you have any more questions

Contact me at:

Lydia Ansorge
Department of Human Communication Sciences
31 Claremont Crescent
SHEFFIELD
S10 2TA

Tel: 0114 2222416
E-mail l.ansorge@sheffield.ac.uk

Or you can contact my supervisors,

Professor Joy Stackhouse,
Tel. 0114 2222429,
E-mail j.stackhouse@sheffield.ac.uk

Dr. Judy Clegg,
Tel. 0114 2222450,
E-mail j.clegg@sheffield.ac.uk

**[REDACTED] School Ex-pupil Project
Parent information sheet**

**Lydia Ansoorge
Department of Human Communication Sciences
University of Sheffield**

This information sheet is about a research project that will document the lives and experiences of ex-pupils of [REDACTED] School.

Please read this sheet carefully before agreeing to take part in this study. You will also be given the chance to ask any questions you might have if you are worried or confused about anything that isn't clear.

Who is involved in the project?

My name is Lydia Ansoorge and I have been interviewing ex-pupils of [REDACTED] School to see how they are getting on as adults. I am a PhD student in the department of Human Communication Sciences at the University of Sheffield. The project is supervised by Joy Stackhouse and Judy Clegg who are also in the department of Human Communication Sciences.

Our contact details can be found at the end of this sheet.

We are working with [REDACTED] School and the charity I CAN who fund [REDACTED] School. Both are interested to see what happens to their ex-pupils when they leave.

What is the project about?

The project is looking at what happens to ex-pupils of [REDACTED] School when they grow up. As part of this I would also like to talk to the parents of ex-pupils to find out about their experiences of [REDACTED] School and thoughts and feelings now their child has left the school.

What will I have to do?

If you choose to take part you will be seen by me at a time that is best for you. I would like to talk to you about your child's experiences, difficulties and time at [REDACTED] School. I would also like to record you talking about your experiences so I can listen to what you said afterwards. I can use either an audio or video recorder. You can choose which you would be most happy with, or you can choose not to be recorded at all.

What will happen afterwards?

No one will know who you or your child are from the interview. No information about you or your child, like your names or addresses, will be kept with these. Any information will be kept in a locked filing cabinet in a locked office.

The assessments and recordings will be looked at by my two supervisors and myself. I would also like to ask your permission to use some of your remarks or clips from your recordings anonymously in presentations to other researchers, students and professionals for discussions or teaching about the life experiences of people like your child. If you don't want me to do this then that is okay and you can still participate in the project.

What if I don't want to take part or I change my mind?

If you don't want to take part then that is okay. If you do decide to take part but change your mind then that is also okay and your recordings and assessments will not be used in the study. You will not have to give a reason if you do not wish to take part anymore.

Contact details for if you have any more questions

Contact me at:

Lydia Ansorge
Department of Human Communication Sciences
31 Claremont Crescent
SHEFFIELD
S10 2TA

Tel: 0114 2222416
E-mail l.ansorge@sheffield.ac.uk

Or you can contact my supervisors,

Prof. Joy Stackhouse,
Tel. 0114 2222429,
E-mail j.stackhouse@sheffield.ac.uk

Dr. Judy Clegg,
Tel. 0114 2222450,
E-mail j.clegg@sheffield.ac.uk

[REDACTED] School Ex-pupil Project
Sibling information sheet

Lydia Ansoorge
Department of Human Communication Sciences
University of Sheffield

This information sheet is about a research project that will document the lives and experiences of ex-pupils of [REDACTED] School.

Please read this sheet carefully before agreeing to take part in this study. You will also be given the chance to ask any questions you might have if you are worried or confused about anything that isn't clear.

Who is involved in the project?

My name is Lydia Ansoorge and I have been interviewing ex-pupils of [REDACTED] School to see how they are getting on as adults. I am a PhD student in the department of Human Communication Sciences at the University of Sheffield. The project is supervised by Joy Stackhouse and Judy Clegg who are also in the department of Human Communication Sciences.

Our contact details can be found at the end of this sheet.

We are also working with [REDACTED] School and the charity I CAN who fund [REDACTED] School. Both are interested to see what happens to their ex-pupils when they leave.

What is the project about?

The project is looking at what happens to ex-pupils of [REDACTED] School when they grow up. As part of this I would also like to talk to the siblings of ex-pupils to find out about their experiences, thoughts and feelings now their brother/sister has left the school.

What will I have to do?

If you choose to take part you will be seen by me at a time that is best for you. First I would like to assess your thinking and language abilities. Then I would like to talk to you about your own experiences of school, your experiences as an adult and a bit about your brother/sister. I would also like to record your interview so I can listen to what you said afterwards. I can use either an audio or video recorder. You can choose which you would be most happy with, or you can choose not to be recorded at all.

I can see you in one long session or two smaller sessions, it's up to you. If you choose to be seen in one session it will last about 3 hours and you can have breaks in the middle to stop you getting too tired.

What will happen afterwards?

No one will know who you or your brother/sister are from the assessments or interviews. No information about you or your brother/sister, like your names or addresses, will be kept with these. Any information will be kept in a locked filing cabinet in a locked office.

The assessments and recordings will be looked at by my two supervisors and myself. I would also like to ask your permission to use some of your remarks or clips from your recordings anonymously in presentations to other researchers, students and professionals for discussions or teaching about the life experiences of people like your child. If you don't want me to do this then that is okay and you can still participate in the project.

What if I don't want to take part or I change my mind?

If you don't want to take part then that is okay. If you do decide to take part but change your mind then that is also okay and your recordings and assessments will not be used in the study. You will not have to give a reason if you do not wish to take part anymore.

Contact details for if you have any more questions

Contact me at:

Lydia Ansorge
Department of Human Communication Sciences
31 Claremont Crescent
SHEFFIELD
S10 2TA

Tel: 0114 2222416
E-mail: l.ansorge@sheffield.ac.uk

Or you can contact my supervisors,

Professor Joy Stackhouse,
Tel. 0114 2222429,
E-mail: j.stackhouse@sheffield.ac.uk

Dr. Judy Clegg,
Tel. 0114 2222450,
E-mail: j.clegg@sheffield.ac.uk

A5.3 Consent Forms for Participants

Consent form

Please fill in this form if you agree to take part.

Name:.....

Please put a tick in each box if you agree with the following:

I have **read and understood** the information sheet for the project and have had the opportunity to ask questions.

I understand that I **do not have to take part** and I can change my mind if I am not happy without giving a reason.

I **agree/do not agree** (delete one) to take part in the study

If you agree to take part

I understand that **other people will NOT be able to tell who I am** from the study.

I understand that the researchers **will have access to my old school records.**

Please tick just one of the following

I would:

- be willing to be video and audio recorded
- be willing to be audio recorded only
- not be willing to be recorded at all

Please put a tick each box if you agree with the following:

You can still take part in the study if you do not agree to these.

I will allow some of my comments to be used anonymously by the researcher in presentations:

I will allow my recording to be used anonymously by the researcher in presentations :

Ex-pupil Signature:.....

Date: / /

Researcher Signature:.....

Date: / /

Consent form

Please fill in this form if you agree to take part.

Your name:.....

Your child's name:.....

Please put a tick in each box if you agree with the following:

I have read and understood the information sheet for the project and have had the opportunity to ask questions.

I understand that I do not have to take part and I can change my mind if I am not happy without giving a reason.

I agree/do not agree (delete one) to take part in the study

If you agree to take part

I understand that other people will NOT be able to tell who I am from the study.

Please tick just one of the following

I would:

- be willing to be video and audio recorded
- be willing to be audio recorded only
- not be willing to be recorded at all

Please put a tick each box if you agree with the following:
You can still take part in the study if you do not agree to these.

I will allow some of my comments to be used anonymously by the researcher in presentations:

I will allow my recording to be used anonymously by the researcher in presentations:

Parent Signature:..... Date: / /

Researcher Signature:..... Date: / /

Consent form

Please fill in this form if you agree to take part.

Your name:.....

Your brother/sister's name:.....

Please put a tick in each box if you agree with the following:

I have read and understood the information sheet for the project and have had the opportunity to ask questions.

I understand that I do not have to take part and I can change my mind if I am not happy without giving a reason.

I agree/do not agree (delete one) to take part in the study

If you agree to take part

I understand that other people will NOT be able to tell who I am from the study.

Please tick just one of the following

I would:

- be willing to be video and audio recorded
- be willing to be audio recorded only
- not be willing to be recorded at all

Please put a tick each box if you agree with the following:

You can still take part in the study if you do not agree to these.

I will allow some of my comments to be used anonymously by the researcher in presentations:

I will allow my recording to be used anonymously by the researcher in presentations:

Sibling Signature:.....

Date: / /

Researcher Signature:.....

Date: / /

A5.4 Semi-structured interview Schedules

Semi-structured interview for Ex-pupils

Instructions

This is a semi-structured interview which aims to elicit information about an individual's life, specifically in the areas of, independent living, employment, education, current communication, friendships, social relationships, finances, hobbies and life expectations. The interview follows a series of questions that the interviewer can use as prompts to elicit the relevant information from the individual.

The interview is semi-structured so any important information can be explored in depth scoring to the individual. Any responses should be recorded in detail (written/audio/video). The questions may need to be further re-phrased or simplified to ensure the individual is able to understand.

It is recommended that the interview is video/audio recorded for later analysis. This is so the interviewer does not have to record in detail the responses given during the interview and therefore the interview can flow more like a conversation. Completion of the interview will need the individual's written consent. Furthermore, video/audio recording will require additional written consent from the individual.

Note: The interview should be confidential and anonymous. If the individual does not wish to answer a question then this must be respected. This will be made clear at the start of the interview.

Living arrangements

1. Where are you living currently?

Establish if individual is living independently.

- a. Where do you live? Who with? Do you live with your parents?
- b. Do you live/Have you ever lived away from home? Is accommodation rented/owned?

2. Have you lived in different accommodation?

- a. Chronological list of different places lived.
- b. Did they enjoy living in each place?

If never lived independently go to 6

3. When did you start living independently?

- a. When did you move out of your parent's home?
- b. Why did you move away?

4. Do you prefer living independently?

- a. What is different about it?
- b. What you like/dislike about it?

5. Would go back home to live with your parents

Why

If currently living independently go to section 2

6. Wish for independence

If never lived independently

- a. Have you thought about living on your own (if never lived independently)?
- b. When did you start to think about this?
- c. What would be good/bad about it

If returned to live with parents

- a. Why did you come back to live with your parents?
- b. Do you prefer living with your parents?
- c. What is good/bad about it?
- d. Would you ever live independently again?

7. Problems leaving the parental home.*Can individual make realistic plans?*

- a. What would be different if you moved away from home?
- b. Do you think you could look after yourself?
- c. What would you have to do for yourself (*washing cleaning, shopping and budgeting*)?
- d. What might you find difficult?

Employment**1. Current work**

- a. Do you have a job at the moment?

If no go to 2

- b. What do you do?
- c. Do you enjoy your job?
- d. Does that involve talking to members of the public? What is that like?
- e. Can I ask how much you get paid?
- f. How well do you get along with colleagues/bosses? Are they easy to get along with? DO you socialise with colleagues?
- g. Do you think you are good at your job?

2. Can you tell me what jobs you have done in since leave [redacted]/full time education?

- a. Establish chronology of employment.

If never been employed then go to 5.

- b. Have any of your jobs required you to do any specialist training? What?

3. Changes in job placement

- a. Why have you had to change jobs in the past?
- b. How long have you been out of work for in the past?
- c. How many times have you had to change job? Why?

4. Future employment plans (if employed)*Establish plans for the future, recognition of practicalities in choosing work and extent to which goals are realistic.*

- a. Do you like your job?
- b. Do you think you would ever like to find another job?
- c. What would you like to do?
- d. How would you get a new job – what would you need to do?
- e. Would you need special training? Where could you train? (*both specific and general skills*)

5. Future employment plans (if unemployed)*Probe for attempts to gain work/advice about future work; plans for the future, recognition of the practicalities involved, and how realistic these goals are.*

- a. What job would you like to do?
- b. How would you get a new job?
- c. What would you need to do? Would you need any training/qualifications?
- d. Have you ever applied for any jobs?

Education**1. Attendance at [redacted] School ([redacted])**

- a. Can you remember the name of the school/s you attended before [redacted]?
- b. What were they like? Did you enjoy being at those schools? Why?

Try and establish chronological order and age at which schools were attended.

- c. Can you remember when you started and left [redacted]? How old were you?

When did individual start? Age?

When did individual leave? Age?

Till what age could they attend [redacted]?

Where did they go if they left before 16 years old?

Did you attend as a day pupil or a boarder (could have been weekly or fortnightly)?

2. Experience of [redacted] as a pupil

- a. How do you remember your time at [redacted]?

- b. Did you enjoy being at [REDACTED]?
- c. When you think back, was it the right school for you at the time?
- d. You think it offered you the right sort of education for you at the time?
- e. What subjects did you get to do? Which were your favourites/least favourites?
- f. Was there anything you would like to have studied but couldn't?
- g. Did the staff give you the help you needed to learn? Did they know what you found difficult?
- h. Did you like the other pupils at [REDACTED]?
- i. Did you have any particular friends/a best friend at [REDACTED]?
- j. Are you still in touch with any friends from [REDACTED] (if yes, ask to tell them about the project)?
- k. Did you have any particular friends/a best friend at home?
- l. Are you still in touch with these friends?
- m. Did you have any particular friends/a best friend at any of the other schools you attended (school other than [REDACTED])?
- n. Are you still in touch with these friends?

3. Experience of residential accommodation at [REDACTED]

- a. How long were you a residential pupil for? How old were you? What was it like?
- b. What was it like living away from home? Where there good things about it? Where there bad/difficult things about it? What was it like during the week/weekends?
- c. Did boarding at the school help you to make friends? Was it easy/difficult to get along with some of the other [REDACTED] pupils?
- d. What was it like being away from family at home?
- e. What was it like being away from friends at home?

4. Leaving [REDACTED]

- a. When you were at [REDACTED], could you stay till 12 or 16? Where did you go after you left [REDACTED] (name of subsequent school or left school aged 16)?
- What were your subsequent schools like?
- b. What did you do when you left school aged 16 (post 16 education/employment)?

5. Academic and educational qualifications

- a. Do you have any formal qualifications/certificates? When/where did you get these (Date obtained chronological order if possible)?

6. Opinion of post 16 years provision

- a. Did [REDACTED] prepare you for life as an adult when you left school? (Explain new post-16 provisions unit)
- b. If you could have stayed on at [REDACTED] after your were 16 would you have chosen to do so?
- c. If you had stayed what would you have liked to have studied? What lesson, activities, opportunities, skills etc would you have found useful.
- d. As an adult is there anything you wish the school had prepared you for before you left?
- e. In the post-16 unit current pupils get to live semi-independently so they can learn how to live independently when they are older. Staff at [REDACTED] are still there to help them if they need them. Would you have liked the chance to live semi-independently in the post-16 unit?
How would it have helped you?

Current communication

One of the reasons for attending [REDACTED] was because you had some communication difficulties when you were younger

- a. What were they? What was it like?
- b. What sort of help did you receive at [REDACTED] for these difficulties?
- c. Was this helpful to you
- d. Do you think you still have these difficulties?
- e. Have these communication difficulties changed since leaving school? How?
- f. Do you think you have any other communication difficulties now (finding it difficult to understand other, finding the right words, saying the wrong thing, making friends, speaking clearly)?
- g. How do communication difficulties affect your everyday life? Do you have any problems with literacy or maths?
- h. Do you ever/did you ever get annoyed/frustrated with your communication difficulties?
- i. Have you received any support, such and speech and language therapy since leaving [REDACTED]?

If yes describe/if no would it help?

Friendships and social relationships**1. Perception of acquaintances**

- a. How easy do you find it to get on with people?
- b. Do you ever start talking to people you don't know at social gatherings (*party/social*)? What might you talk about?
- c. Are there people/friends you know near where you live you would talk to?
- d. What about talking to strangers you have to speak to (*e.g. asking for things in shops/asking for directions*)?

2. Individual's description of current friendships (*establish if friends are specific to places e.g. Church and that friendships are reciprocal*)

- a. Do you have certain friends who you meet up with?
- b. Do you have any best friends who you meet up with?
- c. Where would you meet these friends?
- d. Are they a similar age to you?
- e. What kinds of things do you talk about?
- f. Where do you go in your spare time?
- g. Do you meet people/friends there?

3. Individual's Concept of friendship

- a. What is special about that friend?
- b. What does being a friend mean to you?

4. Loneliness

- a. Do you ever want to talk to people, but they don't want to talk to you?
- b. When does this happen?
- c. What does it feel like?
- d. Do you ever feel lonely?
- e. Do other people ever annoy you?

5. Teasing bullying

- a. Did you ever get teased or bullied at school (or other school)?
- b. Do you think boarding at the school made this better/worse?
- c. How did staff at other school deal with this?
- d. What did the bullies do then?
- e. Do you ever get teased or bullied now?
- f. Do people ever call you names or make rude comments?
- g. What do they say?
- h. Do you ever say things back to them?
- i. Has anyone ever said anything about the way you speak?
- j. How do you feel when people tease you?

Relationships**1. Marriage/co-habitation**

- a. Are you married or in a close/co-habiting relationship? For how long?
- b. How long have you been together?

2. Committed relationships

- a. Are you in a special committed relationship with anyone? Are you happy to talk about this relationship?
- b. Have you ever been in a special committed relationship with anyone? Are you happy to talk about this relationship?
- c. Have you ever been divorced or experienced a difficult break up? Are you willing to talk about this? What happened?

3. Children

- a. Do you have any children? How many?
- b. Do they live with you? Where do they live?
- c. How old are they?

- d. Do they go to school/nursery?
- e. How are they getting on at school (*if at school*)? Have teachers ever expressed any concern about any of you children's learning?
- f. Do you think any of them are having similar difficulties with their communication that are like the ones you had growing up?
- g. Have they been to see any professionals/experts about any problems (*especially speech and language therapy or special education*)?
- h. How do you feel about your child's educational progress?
- i. How would you feel about one of your children attending a school such as ?
- j. What do you think they might do/might be like when they grow up?

Finances

1. Do you look after your own money?

(Establish if the individual has a bank account)

2. Do you find it easy or hard to look after your money?

- a. Have you had any problems?
- b. What happened?
- c. Do you worry about money?

3. Do you need any help to look after your money?

- a. Do you ever need to borrow money (*friends, parents bank, loans*)?

Hobbies

- a. What things do you like to do in your spare time (*solitary/social*)?
- b. How much time do you spend doing that? What do you like about that?
- c. How much television do you watch (*hours a day*)? What programmes do you like to watch?
- d. Did you have a television as a child? Did you like watching television then?
- e. How much time do you spend reading books (*hours a day*)? What books? How many books have you read in the past year?
- f. Did you enjoy books as a child? What books? Did you get read to?
- g. Do you read magazines or newspapers? Which ones, how often?
- h. Do you have your own computer/have access to a computer? Do you use the Internet? Sending e-mails? Use it for work (*e.g. spreadsheets, word-processing*)? Playing computer games (*which ones? How often*)? Is using a computer hard?
- i. Do you own a mobile phone? Do you use it to call people, who? Do you use it to text people, who?
- j. How much time do you spend socialising (*hours a day*)?

Life expectations

1. Overall are you happy with your life now? Why?

- a. Job
- b. Money
- c. Social life
- d. Family
- e. Living arrangements
- f. Other

2. Is there anything you would change that would make life better? Why?

3. What would you realistically like to achieve in the future if anything?

Semi-structured interview for Ex-pupils who completed FE at [REDACTED]**Instructions**

This is a semi-structured interview which aims to elicit information about an individual's life, specifically in the areas of, independent living, employment, education, current communication, friendships, social relationships, finances, hobbies and life expectations. The interview follows a series of questions that the interviewer can use as prompts to elicit the relevant information from the individual.

The interview is semi-structured so any important information can be explored in depth according to the individual. Any responses should be recorded in detail (written/audio/video). The questions may need to be further re-phrased or simplified to ensure the individual is able to understand.

It is recommended that the interview is video/audio recorded for later analysis. This is so the interviewer does not have to record in detail the responses given during the interview and therefore the interview can flow more like a conversation. Completion of the interview will need the individual's written consent. Furthermore, video/audio recording will require additional written consent from the individual.

Note: The interview should be confidential and anonymous. If the individual does not wish to answer a question then this must be respected. This will be made clear at the start of the interview.

Modified from:

Rutter, M, Le Couteur, A, Lord, C, MacDonald, H, Rios, P, & Folstein, S, (1988), Diagnosis and sub-classification of autism: Concepts and instrument development. In E. Schopler & G. Mesbov (Eds.), *Diagnosis and assessment in autism*. New York: Plenum.

Similar to interviews used by:

Clegg, J, Hollis, C, Mawhood, & Rutter, M, (2005), Developmental language disorders – a follow-up in later adult life. Cognitive, language and psychosocial outcomes, *Journal of Child Psychology and Psychiatry*, 46, 128-149.

Living arrangements**1. Where are you living currently?**

Establish if individual is living independently.

- a. Where do you live? Who with? Do you live with your parents?
- b. Do you live/Have you ever lived away from home? Is accommodation rented/owned?

2. Have you lived in different accommodation?

- a. Chronological list of different places lived.
- b. Did they enjoy living in each place?

If never lived independently go to 6

3. When did you start living independently?

- a. When did you move out of your parent's home?
- b. Why did you move away?

4. Do you prefer living independently?

- a. What is different about it?
- b. What you like/dislike about it?

5. Would go back home to live with your parents?

Why?

If currently living independently go to section 2

6. Wish for independence

If never lived independently

- a. Have you thought about living on your own (if never lived independently)?
- b. When did you start to think about this?
- c. What would be good/bad about it?

If returned to live with parents

- a. Why did you come back to live with your parents?
- b. Do you prefer living with your parents?
- c. What is good/bad about it?
- d. Would you ever live independently again?

7. Problems leaving the parental home.

Can individual make realistic plans?

- a. What would be different if you moved away from home?
- b. Do you think you could look after yourself?
- c. What would you have to do for yourself (*washing cleaning, shopping and budgeting*)?
- d. What might you find difficult?

Employment

1. Current work

- a. Do you have a job at the moment?

If no go to 2

- b. What do you do?
- c. Do you enjoy your job?
- d. Does that involve talking to members of the public? What is that like?
- e. Can I ask how much you get paid?
- f. How well do you get along with colleagues/bosses? Are they easy to get along with? Do you socialise with colleagues?
- g. Do you think you are good at your job?

2. Have you had a job since leaving [redacted] or are you still in full time education?

- a. If not in full time education then establish chronology of employment.

If never been employed then go to 5.

- b. Have any of your jobs required you to do any specialist training? What?

3. Changes in job placement

- a. Why have you had to change jobs in the past?
- b. How long have you been out of work for in the past?
- c. How many times have you had to change job? Why?

4. Future employment plans (if employed)

Establish plans for the future, recognition of practicalities in choosing work and extent to which goals are realistic.

- a. Do you like your job?
- b. Do you think you would ever like to find another job?
- c. What would you like to do?
- d. How would you get a new job – what would you need to do?
- e. Would you need special training? Where could you train? (*both specific and general skills*)

5. Future employment plans (if in full time education/unemployed)

Probe for attempts to gain work/advice about future work; plans for the future, recognition of the practicalities involved, and how realistic these goals are.

- a. What job would you like to do?
- b. How would you get a new job?
- c. What would you need to do? Would you need any training/qualifications?
- d. Have you ever applied for any jobs?

Education

1. Attendance at Dawn House School ([redacted])

- a. Can you remember the name of the school/s you attended before [redacted]?
- b. What were they like? Did you enjoy being at those schools? Why?

Try and establish chronological order and age at which schools were attended.

- c. Can you remember when you started and left [redacted]? How old were you?

When did individual start? Age?

When did individual leave? Age?

Till what age could they attend [redacted]?

Where did they go if they left before 16 years old?

- d. Did you attend as a day pupil or a boarder (could have been weekly or fortnightly)?

2. Experience of [redacted] as a pupil

- How do you remember your time at [redacted]?
- Did you enjoy being at [redacted]?
- When you think back, was it the right school for you at the time?
- You think it offered you the right sort of education for you at the time?
- What subjects did you get to do? Which were your favourites/least favourites?
- Was there anything you would like to have studied but couldn't?
- Did the staff give you the help you needed to learn? Did they know what you found difficult?
- Did you like the other pupils at [redacted]?
- Did you have any particular friends/a best friend at [redacted]?
- Are you still in touch with any friends from [redacted] (if yes, ask to tell them about the project)?
- Did you have any particular friends/a best friend at home?
- Are you still in touch with these friends?
- Did you have any particular friends/a best friend at any of the other schools you attended (school other than [redacted])?
- Are you still in touch with these friends?

3. Experience of residential accommodation at [redacted]

- How long were you a residential pupil for? How old were you? What was it like?
- What was it like living away from home? Where there good things about it? Where there bad/difficult things about it? What was it like during the week/weekends?
- Did boarding at the school help you to make friends? Was it easy/difficult to get along with some of the other [redacted] pupils?
- What was it like being away from family at home?
- What was it like being away from friends at home?

4. Leaving [redacted]

- When you were at [redacted], did you stay till 16 or 19? Where did you go after you left [redacted]?
- What did you do when you left school?

5. Academic and educational qualifications

- Do you have any formal qualifications/certificates? When/where did you get these (Date obtained chronological order if possible)?

6. Opinion of post 16 years provision

- What made you decide to stay on at [redacted] for post-16?
- What was the post-16 FE unit like?
Did it help?
- What did you study while you were there?
Lessons, activities, formal qualifications
- What was a day like?
- What was living semi-independently in to post-16 FE unit like?
- Did get well with the other pupils/did you have many friends? Are you still in touch with these?
- What do you think you might have done if that had not been available?
- Did [redacted] prepare you for life as an adult when you left school?
Was there anything that [redacted] didn't do?
- What did you go on to do after that?
Employment of further post-16 placements; establish further Chronological history of post-16 education.

If still in education

- What made you decide to continue studying?
- How does that placement compare to post-16 experience at [redacted]?
- What do you think you might like to do next?

Current communication

One of the reasons for attending [redacted] was because you had some communication difficulties when you were younger

- a. What were they? What was it like?
- b. What sort of help did you receive at [redacted] for these difficulties?
- c. Was this helpful to you
- d. Do you think you still have these difficulties?
- e. Have these communication difficulties changed since leaving school? How?
- f. Do you think you have any other communication difficulties now (*finding it difficult to understand other, finding the right words, saying the wrong thing, making friends, speaking clearly*)?
- g. How do communication difficulties affect your everyday life? Do you have any problems with literacy or maths?
- h. Do you ever/did you ever get annoyed/frustrated with your communication difficulties?
- i. Have you received any support, such as speech and language therapy since leaving [redacted]?

If yes describe/if no would it help?

Friendships and social relationships**1. Perception of acquaintances**

- a. How easy do you find it to get on with people?
- b. Do you ever start talking to people you don't know at social gatherings (*party/social*)? What might you talk about?
- c. Are there people/friends you know near where you live you would talk to?
- d. What about talking to strangers you have to speak to (*e.g. asking for things in shops/asking for directions*)?

2. Individual's description of current friendships (*establish if friends are specific to places e.g. Church and that friendships are reciprocal*)

- a. Do you have certain friends who you meet up with?
- b. Do you have any best friends who you meet up with?
- c. Where would you meet these friends?
- d. Are they a similar age to you?
- e. What kinds of things do you talk about?
- f. Where do you go in your spare time?
- g. Do you meet people/friends there?

3. Individual's Concept of friendship

- a. What is special about that friend?
- b. What does being a friend mean to you?

4. Loneliness

- a. Do you ever want to talk to people, but they don't want to talk to you?
- b. When does this happen?
- c. What does it feel like?
- d. Do you ever feel lonely?
- e. Do other people ever annoy you?

5. Teasing bullying

- a. Did you ever get teased or bullied at school (*[redacted] or other school*)?
- b. Do you think boarding at the school made this better/worse?
- c. How did staff at [redacted] other school deal with this?
- d. What did the bullies do then?
- e. Do you ever get teased or bullied now?
- f. Do people ever call you names or make rude comments?
- g. What do they say?
- h. Do you ever say things back to them?
- i. Has anyone ever said anything about the way you speak?
- j. How do you feel when people tease you?

Relationships**1. Marriage/co-habitation**

- a. Are you married or in a close/co-habiting relationship? For how long?
- b. How long have you been together?

2. Committed relationships

- a. Are you in a special committed relationship with anyone? Are you happy to talk about this relationship?
- b. Have you ever been in a special committed relationship with anyone? Are you happy to talk about this relationship?
- c. Have you ever been divorced or experienced a difficult break up? Are you willing to talk about this? What happened?

3. Children

- a. Do you have any children? How many?
- b. Do they live with you? Where do they live?
- c. How old are they?
- d. Do they go to school/nursery?
- e. How are they getting on at school (*if at school*)? Have teachers ever expressed any concern about any of you children's learning?
- f. Do you think any of them are having similar difficulties with their communication that are like the ones you had growing up?
- g. Have they been to see any professionals/experts about any problems (*especially speech and language therapy or special education*)?
- h. How do you feel about your child's educational progress?
- i. How would you feel about one of your children attending a school such as [redacted]?
- j. What do you think they might do/might be like when they grow up?

Finances**1. Do you look after your own money?****(Establish if the individual has a bank account)****2. Do you find it easy or hard to look after your money?**

- a. Have you had any problems?
- b. What happened?
- c. Do you worry about money?

3. Do you need any help to look after your money?

- a. Do you ever need to borrow money (*friends, parents bank or loans*)?

Hobbies

- a. What things do you like to do in your spare time (*solitary/social*)?
- b. How much time do you spend doing that? What do you like about that?
- c. How much television do you watch (*hours a day*)? What programmes do you like to watch?
- d. Did you have a television as a child? Did you like watching television then?
- e. How much time do you spend reading books (*hours a day*)? What books? How many books have you read in the past year?
- f. Did you enjoy books as a child? What books? Did you get read to?
- g. Do you read magazines or newspapers? Which ones, how often?
- h. Do you have your own computer/have access to a computer? Do you use the Internet? Sending e-mails? Use it for work (*e.g. spreadsheets, word-processing*)? Playing computer games (*which ones? How often*)? Is using a computer hard?
- i. Do you own a mobile phone? Do you use it to call people, who? Do you use it to text people, who?
- j. How much time do you spend socialising (*hours a day*)?

Life expectations

1. Overall are you happy with your life now? Why?

- a. Job
- b. Money
- c. Social life
- d. Family
- e. Living arrangements
- f. Other

2. Is there anything you would change that would make life better? Why?

3. What would you realistically like to achieve in the future if anything?

Semi-structured interview for Parents of Ex-pupils

Instructions

This is a semi-structured interview which aims to elicit information about a parent's son or daughter with a history of developmental speech and language difficulties, specifically in the areas of, birth, early childhood, independent living, employment, education, current communication, friendships, social relationships, finances and hobbies. The interview follows a series of questions that the interviewer can use as prompts to elicit the relevant information from the individual.

The interview is semi-structured so any important information can be explored in depth. Any responses should be recorded in detail (written/audio/video). The questions may need to be further re-phrased or simplified to ensure the individual is able to understand.

It is recommended that the interview is video/audio recorded for later analysis. This is so the interviewer does not have to record in detail the responses given during the interview and therefore the interview can flow more like a conversation. Completion of the interview will need the individual's written consent. Furthermore, video/audio recording will require additional written consent from the individual.

Note: The interview should be confidential and anonymous. If the individual does not wish to answer a question then this must be respected. This will be made clear at the start of the interview.

This semi-structured interview was modelled around previous interviews devised by Rutter (1996) and Clegg (2006).

References

Clegg, J, (2006), Living with speech and language difficulties: reflecting on the past and lessons for the future, A fasc abstract.

Rutter, M, (1996), Social/Emotional functioning interview, London

1. What like being a parent to a child with speech and language difficulties?

- a. What makes you most proud about _____?
- b. What has it been like being a parent to a child with communication difficulties?
 - Are there things that are difficult about it? How do you remember _____'s childhood?
- c. What has your experience of support services been?
 - Was it positive or negative? What helped, what didn't? How did _____ compared to other services? Did you ever feel in the dark or like there wasn't enough information about your child's difficulties?
- d. Do you have any advice for other parents of children with similar difficulties?

2. Childhood language development

- a. Do you have any other family history of communication or literacy difficulties? Who else?
- b. What can you remember about _____ when was a young child?
 - Can you remember when they first started to speak? How old were they? What did they say? Was h/she outgoing or quiet?
 - Did parent notice anything that there was something wrong with their child's communication or was it another professional e.g. teacher? When? How old was the child? Did the parent notice they were different to their siblings?
 - Where they referred to any professionals such as Speech and Language Therapists? When? Where they given a diagnosis? What was that processes like as a parent? What did it feel like?
- c. Was there anything you did at home to help your child?
 - Helping the child to learn language/literacy skills? Reading to the child? Helping with homework? What was that like? Did they require more attention than siblings? What did this do?

3. Education

- a. What could you remember about _____'s schools before _____?
- Where did they go? Try and establish chronological order and age at which schools were attended.

- *How did the child get on in mainstream school/language unit? Did the child enjoy being at those schools? How did they get on with teachers/pupils? How did you feel communication difficulties have affected their education?*
- *Did teachers notice anything? What was this like for the parent?*
- *Did your child ever have any kind of help/support for their difficulties before attending [redacted]? Did they understand the child's needs?*
- b. What can you remember about _____ going to [redacted] School?
 - *How did they get referred to [redacted]? Did they try other things first? Who suggested [redacted]? How did they end up getting a place there?*
 - *Did they attend as a day pupil or weekly boarder? What was it like when they went away? How did it affect the family? How did it affect siblings?*
 - *Did they understand the child's needs? What sort of support did they provide for your child?*
 - *Was it the right school? Did it help them? Was it the right choice to send them to a residential school? Would it have been better if they had attended a school in the local area?*
 - *Did the child enjoy being at [redacted]? How did they get on with teachers/pupils?*

4. Opinion of post 16 years provision

- a. What _____ go on to do when they left school at 16?
Further education/employment?
 - *What extra support did they receive since leaving [redacted]? What? Was it what they needed? Did it help? Should they have had more help?*
- b. What about if they had been able to stay on at [redacted] for post-16?
 - *Would that have been better? Did [redacted] prepare _____ for life as an adult when they left school?*
- c. There is now a new FE unit at [redacted]. Do you think that would have been a good opportunity for your child?
 - *How would this have helped them? Would this have prepared them better for life as an adult? What do they think they might have studied?*

5. Adult language difficulties

- a. Do you think they still have any difficulties as an adult?
 - *What are they like now? Have these communication difficulties changed since they left school? How? Do you think they have any other communication difficulties now (finding it difficult to understand others, finding the right words, saying the wrong thing, making friends easily, speaking clearly)?*
 - *Do these difficulties affect their everyday life? Are they happy regardless?*
- b. What support have they received, such as speech and language therapy, since leaving [redacted]?
 - *If yes describe/if no would it help?*
 - *Should be more support services available to help adults such as your son daughter? E.g. employment social clubs.*

6. Employment

- a. Does your son/daughter have a job at the moment?
If employed
 - *What do they do? How do they find that? Are happy with their job? Would they ever like to find another job?*
- b. What jobs did they do in the past?
Establish employment history
- c. Have they ever been out of work?
 - *When? For how long? Why? Were they fired/made redundant?*
- d. Have they ever had difficulties at work?
 - *Do they find things difficult? Have they been bullied?*

If unemployed

- a. Have they have had jobs in the past?
 - *What jobs? When? For how long? Why? Were they fired/made redundant?*
- b. Have they been applying for jobs?
 - *What jobs?*

7. Friendships and social relationships

- a. Does _____ get on well with other people?
 - *Are they shy or outgoing? Do they find it easy to talk to people they don't know very well/strangers?*
- b. Do they have a group of friends?
 - *Are this friends or acquaintances? How many friends? What are they like how old are they? Do they have any best friends? Where would they meet?*

8. Relationships

- a. Is in a _____ married/special committed/co-habiting relationship? Are you able to tell me a bit about this?
 - *How long have they been together? Are they living together? What about the future?*
- b. Are you able to tell me about any special committed relationships in the past?
 - *Is parent happy to talk about this?*
 - *What happened?*

9. Children

- a. Do they have any children? Can you say a little bit about your grandchild(ren)?
 - *How many? How old are they? Do they go to school/nursery?*
- b. Do you think any of them are having similar difficulties to those _____ had growing up?
- c. Have they been to see any professionals/experts/SLTs)? What does _____ feel about that?
- d. Do any of your grandchildren go to school?
- e. How are they getting on? Have teachers ever expressed any concerns? How do you feel about your grandchild's educational progress?
- f. How would you feel about one of your grandchildren attending a school such as _____?
- g. What would it be like if your grandchild had to attend a residential school? What would _____ think?
- h. What would you like for your grandchildren when they grow-up?
 - *What might they do?*

10. Living arrangements

- a. Where does your son/daughter currently live?
 - *If living independently*
 - *Who do they live with? Do they live far away from parents? Do they ever need help e.g. domestic, financial?*
 - b. Do you think they would they ever come back home to live with you?
 - *What would you think about that? Would you prefer that?*
- If not living independently*
- a. Have they ever thought/talked to you about living on their own? What would be good/bad about it for your son/daughter? What would be good/bad about it for you? How would it be different?
 - b. Would they be able to look after themselves? What might they find difficult?

11. Finances

- a. How do they find looking after money?
- b. Have they had any problems? What happened? Do you ever need to help them e.g. lending money, help with budgeting.

Semi-structured interview for Siblings of Ex-pupils

Instructions

This is a semi-structured interview which aims to elicit information about an individual's life, specifically in the areas of, their relationship with their sibling in early childhood, independent living, employment, education, current communication, friendships, social relationships, finances, hobbies and life expectations. The interview follows a series of questions that the interviewer can use as prompts to elicit the relevant information from the individual.

The interview is semi-structured so any important information can be explored in depth according to the individual. Any responses should be recorded in detail (written/audio/video). The questions may need to be further re-phrased or simplified to ensure the individual is able to understand.

It is recommended that the interview is video/audio recorded for later analysis. This is so the interviewer does not have to record in detail the responses given during the interview and therefore the interview can flow more like a conversation. Completion of the interview will need the individual's written consent. Furthermore, video/audio recording will require additional written consent from the individual.

Note: The interview should be confidential and anonymous. If the individual does not wish to answer a question then this must be respected. This will be made clear at the start of the interview.

Modified from:

Rutter, M, Le Couteur, A, Lord, C, MacDonnald, H, Rios, P, & Folstein, S, (1988), Diagnosis and sub-classification of autism: Concepts and instrument development. In E. Schopler & G. Mesbov (Eds.), *Diagnosis and assessment in autism*. New York: Plenum

Similar to interviews used by:

Clegg, J, Hollis, C, Mawhood, & Rutter, M, (2005), Developmental language disorders – a follow-up in later adult life. Cognitive, language and psychosocial outcomes, *Journal of Child Psychology and Psychiatry*, 46, 128-149.

Early Childhood

- a. Are you younger or older than your brother/sister?
- b. Did you play together as children? What did you play? Did you talk about things
- c. Did you ever notice that there was anything different about their communication then? In what way (*understanding, how they expressed themselves, how they said sounds/words, could they talk to other people and express their desires and feelings*)?
- d. Can you tell me a bit about what it was like having a brother/sister with communication difficulties?
- e. Did you ever feel treated differently to your brother/sister?

School

- a. Can you remember what it was like when your brother/sister went to [redacted]?
- b. What was it like when they had to go away from home? Did you miss them while they were away from home? Was it a relief?
- c. Would you have preferred for them to go to school with you? How would that have been better/worse?
- d. How do you think it made your parents feel? How did it affect the family?
- e. Can you remember anything about the journey to and from [redacted]?
- f. Can you remember what it was like when your brother/sister left [redacted]?
- g. Did they come back to live with family? Was sibling living there too?
- h. How do you get along with your brother sister now?

I want to talk a bit about you now**Living arrangements****1. Where are you living currently?***Establish if individual is living independently.*

- a. Where do you live? Who with? Do you live with your parents?
- b. Do you live/Have you ever lived away from home? Is accommodation rented/owned?

2. Have you lived in different accommodation?

- a. Chronological list of different places lived.
- b. Did they enjoy living in each place?

*If never lived independently go to 6***3. When did you start living independently?**

- a. When did you move out of your parent's home?
- b. Why did you move away?

4. Do you prefer living independently?

- a. What is different about it?
- b. What do you like/dislike about it?

5. Would go back home to live with your parents?

Why?

*If currently living independently go to section 2***6. Wish for independence***If never lived independently*

- a. Have you thought about living on your own (if never lived independently)?
- b. When did you start to think about this?
- c. What would be good/bad about it?

If returned to live with parents

- d. Why did you come back to live with your parents?
- e. Do you prefer living with your parents?
- f. What is good/bad about it?
- g. Would you ever live independently again?

7. Problems leaving the parental home.*Can individual make realistic plans?*

- a. What would be different if you moved away from home?
- b. Do you think you could look after yourself?
- c. What would you have to do for yourself?
- d. What might you find difficult?

Employment**1. Current work**

- a. Do you have a job at the moment?

If no go to 2

- b. What do you do?
- c. Do you enjoy your job?
- d. Does that involve talking to members of the public? What is that like?
- e. Can I ask how much you get paid?
- f. How well do you get along with colleagues/bosses? Are they easy to get along with?
- g. Do you think you are good at your job?

2. Can you tell me what jobs you have done in since leaving full time education?

- a. Establish chronology of employment.

If never been employed then go to 5.

- b. Have any of your jobs required you to do any specialist training? What?

3. Changes in job placement

- a. Why have you had to change jobs in the past?
- b. How long have you been out of work for in the past?
- c. How many times have you had to change job? Why?

4. Future employment plans (if employed)

Establish plans for the future, recognition of practicalities in choosing work and extent to which goals are realistic.

- a. Do you like your job?
- b. Do you think you would ever like to find another job?
- c. What would you like to do?
- d. How would you get a new job – what would you need to do?
- e. Would you need special training? Where could you train? (*both specific and general skills*)

5. Future employment plans (if unemployed)

Probe for attempts to gain work/advice about future work; plans for the future, recognition of the practicalities involved, and how realistic these goals are.

- a. What job would you like to do?
- b. How would you get a new job?
- c. What would you need to do? Would you need any training/qualifications?
- d. Have you ever applied for any jobs?

Education**1. What schools did you go to when you were younger?**

- a. Name of schools and age attended in chronological order?
- b. What were they like?
- c. How do you remember your time at these schools?
- d. Do you think you got a good education at those schools? Were they right for you?
- e. What subjects did you get to do? What subjects were your favourites/less favourites?
- f. Was there anything you would like to have studied but couldn't?
- g. Did you ever have any difficulties at school of your own? Was there anything you found especially hard?
- h. How did you get on with other children? Did you have any special friends? Are you still in contact with any of them?

2. Opinion of post 16 years provision

- a. How well prepared for adult life do you think you were when you left school at age 16?
- b. Was there anything you feel you weren't prepared for that you wish you had?
- c. Did you stay on in further education? What (a-levels/higher degree)? Did you go on to get a job? What? (*If didn't stay on for Post-16 education do you wish you did?*)

Communication

- a. How would you describe your communication skills (*speaking, reading, and writing*)?
- b. Have you ever felt that you may have difficulties similar to those of your brother/sister? When? Can you provide a history of any difficulties you've had?
- c. If yes, have you ever received any specialist support (*speech and language therapy or special needs classes*) at any point in your life? When? Where? Did this help you? *Provide a history.*
- d. Do you think you still have these difficulties?
- e. Do you think they affect your everyday life? How?

Friendships and social relationships**1. Perception of acquaintances**

- a. How easy do you find it to get on with people?
- b. Do you ever start talking to people you don't know at social gatherings (*party/social*)? What might you talk about?
- c. Are there people/friends you know near where you live you would talk to?
- d. What about talking to strangers you have to speak to (*e.g. asking for things in shops/asking for directions*)?

2. Individual's description of current friendships (*establish if friends are specific to places e.g. Church and that friendships are reciprocal*)

- a. Do you have certain friends who you meet up with?
- b. Do you have any best friends who you meet up with?
- c. Where would you meet these friends?
- d. Are they a similar age to you?
- e. What kinds of things do you talk about?
- f. Where do you go in your spare time?
- g. Do you meet people/friends there?

3. Individual's Concept of friendship

- a. What is special about that friend?
- b. What does being a friend mean to you?

4. Loneliness

- a. Do you ever want to talk to people, but they don't want to talk to you?
- b. When does this happen?
- c. What does it feel like?
- d. Do you ever feel lonely?
- e. Do other people ever annoy you?

5. Teasing bullying

- a. Did you ever get teased or bullied at school?
- b. How did staff at the schools deal with this?
- c. What did the bullies do then?
- d. Do you ever get teased or bullied now?
- e. Do people ever call you names or make rude comments?
- f. What do they say?
- g. Do you ever say things back to them?
- h. How do you feel when people tease you?

Relationships

1. Marriage/co-habitation

- a. Are you married or in a close/co-habiting relationship? For how long?
- b. How long have you been together?

2. Committed relationships

- a. Are you in a special committed relationship with anyone? Are you happy to talk about this relationship?
- b. Have you ever been in a special committed relationship with anyone? Are you happy to talk about this relationship?
- c. Have you ever been divorced or experienced a difficult break up? Are you willing to talk about this? What happened?

3. Children

- a. Do you any children? How many?
- b. Where do your children live?
- c. How old are they?
- d. Do they go to school/nursery?
- e. How are they getting on at school (*if at school*)? Have teachers ever expressed any concern about any of your children's learning?
- f. Do you think any of them are having similar difficulties with their communication that are like the ones your brother/sister had growing up?
- g. Have they been to see any professionals/experts about any problems (*especially speech and language therapy or special education*)?
- h. How do you feel about your children's educational progress?
- i. How would you feel about one of your children attending a school such as [redacted]?
- j. What do you think they might do/might be like when they grow up?

Finances**1. Do you look after your own money?**

(Establish if the individual has a bank account)

2. Do you find it easy or hard to look after your money?

- a. Have you had any problems?
- b. What happened?
- c. Do you worry about money?

3. Do you need any help to look after your money?

- a. Do you ever need to borrow money (*friends, parents bank or loans*)?

Hobbies

- a. What things do you like to do in your spare time (*solitary/social*)?
- b. How much time do you spend doing that? What do you like about that?
- c. How much television do you watch (*hours a day*)? What programmes do you like to watch?
- d. Did you have a television as a child? Did you like watching television then?
- e. How much time do you spend reading books (*hours a day*)? What books? How many books have you read in the past year?
- f. Did you enjoy books as a child? What books? Did you get read to?
- g. Do you read magazines or newspapers? Which ones, how often?
- h. Do you have your own computer/have access to a computer? Do you use the Internet? Sending e-mails? Use it for work (*e.g. spreadsheets, word-processing*)? Playing computer games (*which ones? How often*)? Is using a computer hard?
- i. Do you own a mobile phone? Do you use it to call people, who? Do you use it to text people, who?
- j. How much time do you spend socialising?

Life expectations**1. Overall are you happy with your life now? Why?**

- a. Job
- b. Money
- c. Social life
- d. Family
- e. Living arrangements
- f. Other

2. Is there anything you would change that would make life better? Why?**3. What would you realistically like to achieve in the future if anything?**

A6 Materials for Part 3

A6.1 Information Sheets for Participants

Views of ██████████ FE
Pupil information sheet

Lydia Ansoorge
Department of Human Communication Sciences
University of Sheffield

This information sheet is about a project about the lives of pupils of Dawn House.

I would like to invite you to take part in the project. Please read this sheet carefully before you decide to take part. You will be given the chance to ask questions first if you are worried or confused about anything that isn't clear.

Who is involved in the project?

My name is Lydia Ansoorge and I will be talking to pupils of ██████████ FE about their experiences at school and about what they would like to do when they leave?

I am a PhD student in the Department of Human Communication Sciences at the University of Sheffield. I am working with Joy Stackhouse and Judy Clegg who are also in the Department of Human Communication Sciences. Our contact details can be found at the end of this sheet.

We are working with ██████████ School and the charity I CAN. Both are interested to see what happens to their pupils when they leave.

What is the project about?

The project is part of a larger project looking at what happens to ex-pupils of ██████████ School when they grow up. As part of this we are interested to talk to current pupils of ██████████ FE.

What will I have to do?

If you choose to take part I would like to ask you some questions about your experiences at ██████████ and about what you would like to do afterwards. This should take about 30 minutes. In that time we will complete a questionnaire together.

If it is okay I would also like to record our meeting in case I want to listen back to it later on. If you do not wish to be recorded then that is also okay. You can still take part.

What will happen afterwards?

No one will be able to find out who you are because you took part. Nobody will find out any identifying information about you, like your name or address. Any information will be kept in a locked filing cabinet in a locked office. The questionnaires will only be looked at by my two supervisors and myself.

I would like to ask you if it would be okay to use some of your remarks or clips from your recordings anonymously in presentations to other researchers, students and professionals. This would be for discussions or teaching about the life experiences of people like yourself. If you don't want me to do this then that is okay and you can still take part.

What if I don't want to take part or I change my mind?

If you don't want to take part then that is okay. If you do decide to take part but change your mind then that is also okay and your questionnaire and recording will not be used in the study. You will not have to give a reason if you do not wish to take part anymore.

Contact details for if you have any more questions

Contact me at:

Lydia Anson
Department of Human Communication Sciences
31 Claremont Crescent
SHEFFIELD
S10 2TA

Tel: 0114 2222416
E-mail l.anson@sheffield.ac.uk

Or you can contact my supervisors,

Professor Joy Stackhouse,
Tel. 0114 2222429,
E-mail j.stackhouse@sheffield.ac.uk

Dr. Judy Clegg,
Tel. 0114 2222450,
E-mail j.clegg@sheffield.ac.uk

**Views of ██████████ FE
Parent information sheet**

**Lydia Ansoorge
Department of Human Communication Sciences
University of Sheffield**

This information sheet is about a research project that has been documenting the lives and experiences of ex-pupils of ██████████ School and current pupils of ██████████ FE.

As a parent of a current FE pupil I would like to invite you to take part in the project. Please read this sheet carefully before agreeing to take part in and contact me if you have any questions (see end of sheet). You will also be given the chance to ask any questions you might have if you are worried or confused about anything that isn't clear. Once you have made your decision please complete and return the enclosed consent for indicating if you wish to take part. Please return this form even if you do not wish to take part so we know not to contact you again.

Who is involved in the project?

My name is Lydia Ansoorge and I am a PhD student in the department of Human Communication Sciences at the University of Sheffield. The project is supervised by Joy Stackhouse and Judy Clegg who are also in the department of Human Communication Sciences. We are working with ██████████ School and I CAN. Both are interested to see what their pupils go on to do when they leave.

What is the project about?

I have been interviewing ex-pupils of ██████████ School to see how they are getting on as adults. These are individuals who went to the school before your child did. As part of this we were also interested to talk to current pupils of ██████████ FE about ██████████ and what they might like to do after they leave. We have already been talking to your son/daughter about this. We would now also like to invite you to take part in the project as we are also interested in parent's views.

What will I have to do?

If you choose to take part I would like to ask you some questions about your experiences of ██████████. If you choose to take part then I would like to talk to you for about 30 minutes over the telephone. In that time we will complete a questionnaire together. The questionnaire is attached to this letter so you can see the questions in advance.

Also, if it is okay I would also like to ask you permission to record our conversation in case I want to listen back to it later on. If you do not wish to be recorded then that is also okay. You can still take part in the study.

What will happen afterwards?

No one will know who you or your child are because you took part in the study. Any information will be kept in a locked filing cabinet in a locked office. The questionnaires will only be looked at by my two supervisors and myself.

I would like to ask your permission to use some of your remarks or clips from your recordings anonymously in presentations to other researchers, students and professionals for discussions or teaching about the life experiences of people like your child. If you don't want me to do this then that is okay and you can still take part.

What if I don't want to take part or I change my mind?

If you don't want to take part then that is okay. Please indicate this when you return the form so we know not to contact you again. If you do decide to take part but change your mind then that is also okay and your questionnaire and recording will not be used in the study. You will not have to give a reason if you do not wish to take part anymore.

Contact details for if you have any more questions

Contact me at:

Lydia Ansorge
Department of Human Communication Sciences
31 Claremont Crescent
SHEFFIELD
S10 2TA

Tel: 0114 2222416

E-mail: l.ansorge@sheffield.ac.uk

Or you can contact my supervisors,

Prof. Joy Stackhouse,

Tel. 0114 2222429,

E-mail: j.stackhouse@sheffield.ac.uk

Dr. Judy Clegg,

Tel. 0114 2222450,

E-mail: j.clegg@sheffield.ac.uk

Views of [REDACTED] FE
Staff information sheet

Lydia Ansoorge
Department of Human Communication Sciences
University of Sheffield

This information sheet is about a research project that has been documenting the lives and experiences of ex-pupils of [REDACTED] and current pupils of [REDACTED] FE.

As a member of staff involved in [REDACTED] FE I would like to invite you to take part in the project. Please read this sheet carefully before agreeing to take part in and contact me if you have any questions (see end of sheet). You will also be given the chance to ask any questions you might have if you are worried or confused about anything that isn't clear.

Who is involved in the project?

My name is Lydia Ansoorge and I am a PhD student in the department of Human Communication Sciences at the University of Sheffield. The project is supervised by Joy Stackhouse and Judy Clegg who are also in the department of Human Communication Sciences. We are working with [REDACTED] School and I CAN. Both are interested to see what their pupils go on to do when they leave.

What is the project about?

I have been interviewing older ex-pupils of [REDACTED] School to see how they are getting on as adults, and younger current pupils of [REDACTED] FE to see what they might like to do when they leave. As part of this we are also interested to talk to staff members involved with [REDACTED] FE. We would therefore like to invite you to take part in the project as we are also interested in staff member's views.

What will I have to do?

If you choose to take part I will see you at [REDACTED] School. I would like to ask you some questions about your experiences as a member of staff at [REDACTED] and about [REDACTED] FE. This should take about 30 minutes.

Also, if it is okay I would also like to ask you permission to record our meeting so I can listen to it back to it later on. If you do not wish to be recorded then that is also okay. You can still take part in the study but it may take longer as I will need to make notes.

What will happen afterwards?

No one will know who you or anyone else are because you took part in the study. Nobody will be able to find out any identifying information about you, like your name or address. Any information will be kept in a locked filing cabinet in a locked office. The recordings will only be listened to by my two supervisors and myself.

I would like to ask your permission to use some of your remarks or clips from your recordings anonymously in presentations to other researchers, students and professionals for discussions or teaching about the life experiences of people like the [REDACTED] pupils. If you don't want me to do this then that is okay and you can still take part.

What if I don't want to take part or I change my mind?

If you don't want to take part then that is okay. If you do decide to take part but change your mind then that is also okay and your recording will not be used in the study. You will not have to give a reason if you do not wish to take part anymore.

Contact details for if you have any more questions

Contact me at:

Lydia Anson
Department of Human Communication Sciences
31 Claremont Crescent
SHEFFIELD
S10 2TA

Tel: 0114 2222416
E-mail l.anson@sheffield.ac.uk

Or you can contact my supervisors,

Professor Joy Stackhouse,
Tel. 0114 2222429,
E-mail j.stackhouse@sheffield.ac.uk

Dr. Judy Clegg,
Tel. 0114 2222450,
E-mail j.clegg@sheffield.ac.uk

A6.2 Consent Forms for Participants

Consent form

Please fill in this form if you agree to take part.

Name:.....

Please put a tick in each box if you agree with the following:

I have read and understood the information sheet for the project and have had the opportunity to ask questions.

I understand that I do not have to take part and I can change my mind if I am not happy without giving a reason.

I agree to take part in the study

If you agree to take part

I understand that other people will NOT be able to tell who I am from the study.

Please tick just one of the following

I would:

be happy to be recorded

not be happy to be recorded

Please put a tick each box if you agree with the following:

You can still take part in the study if you do not agree to these.

I will allow some of my comments to be used anonymously by the researcher in presentations:

I will allow my recording to be used anonymously by the researcher in presentations:

Pupil Signature:.....

Date: / /

Researcher Signature:.....

Date: / /

Consent form

Please complete both sides of this form and indicate if you would like to take part. Please return this form in the envelope provided. Please return the form even if you do not wish to take part so we know not to contact you again.

Your name:.....

Your child's name:.....

Please put a tick in each box if you agree with the following:

I have read and understood the information sheet for the project.

I understand that I do not have to take part and I can change my mind if I am not happy without giving a reason.

Please indicate if you would like to take part in the study:

I agree to take part in the study

I do not agree to take part in the study

Please complete if you agree to take part:

I understand that other people will NOT be able to tell who I am from the study.

Please tick just one of the following

I would:

be willing to be audio recorded only

not be willing to be recorded at all

Please put a tick each box if you agree with the following:

You can still take part in the study if you do not agree to these.

I will allow some of my comments to be used anonymously by the researcher in presentations:

I will allow my recording to be used anonymously by the researcher in presentations:

Parent Signature:..... Date: / /

Researcher Signature:..... Date: / /

If you agree to take part we will need to phone you at a time you are in.

Telephone number:

Please indicate the times you are most likely to be at home. Tick as many as are appropriate:

Times of the week you are likely to be at home and would be able to take a telephone call							
Time	Mon.	Tues.	Wed.	Thurs.	Fri.	Sat.	Sun.
Morning 9am-12pm							
Afternoon 12pm-5pm							
Evening 5pm-9pm							

Consent form

Please fill in this form if you agree to take part.

Name:.....

Please put a tick in each box if you agree with the following:

I have read and understood the information sheet for the project and have had the opportunity to ask questions.

I understand that I do not have to take part and I can change my mind if I am not happy without giving a reason.

I agree to take part in the study

If you agree to take part

I understand that other people will NOT be able to tell who I am from the study.

Please tick just one of the following:

I would:

I am happy to be recorded

I am not happy to be recorded

Please put a tick each box if you agree with the following:

You can still take part in the study if you do not agree to these.

I will allow some of my comments to be used anonymously by the researcher in presentations:

I will allow my recording to be used anonymously by the researcher in presentations:

Staff Member Signature:.....

Date: / /

Researcher Signature:.....

Date: / /

A6.3 Questionnaires and Interviews for Phase 3 of Data Collection

Post 16 questionnaires for FE pupils

Name _____

Gender Male
Please tick Female

Date of birth __/__/____

School year ____

1 [redacted] experience

1. How old you were when first you came to [redacted]? ____

2. Are you a fortnightly boarder, a weekly boarder or a day pupil?

Please tick one:

Fortnightly boarder
 Weekly boarder
 Day pupil

3. In general how do you feel when you are at [redacted]?

Put a cross on the line:

Very happy Very unhappy

4. In general what do you think of [redacted] FE?

Put a cross on the line:

Very happy Very unhappy

5. What do you like best about [redacted]?

List up to 3 points:

1 _____

2 _____

3 _____

6. What do you like least about [redacted]?

List up to 3 points:

1 _____

2 _____

3 _____

2 For boarders only

If day pupil then go to page 5

1. What is it like living at [redacted]?

Put a cross on the line:

Really good Really bad

2. Can you think of things you like about it?

List up to 3 points:

1 _____

2 _____

3 _____

3. Can you think of things you don't like about it?

List up to 3 points:

1 _____

2 _____

3 _____

4. Do you ever miss your family at home?

Put a cross on the line:

Yes a lot  No never

5. What is it like when you are away from your family?

List up to 3 points:

1 _____

2 _____

3 _____

3 Education

1. What college do you go to? _____

2. What course do you study? _____

3. How much do you enjoy being at college?

Put a cross on the line:

Really good  Really bad

4a. Do you get extra help while you are at your college?

Please tick one:

Yes
 No

4b. If Yes – what help do you get.

5. Which do you like best? College or [redacted]?

Please tick one:

- I like being at college better
- I like being at [redacted] better
- I like them the same
- I can't decide

6. What's better about [redacted] /College?

List up to 3 points

1 _____

2 _____

3 _____

7. Do you find going to college useful?

Please tick one:

- Yes
- No

8. What have you got out of going to college?

List up to 3 points:

1 _____

2 _____

3 _____

9. Why did you choose to stay at [redacted] for FE?

List up to 3 points:

1 _____

2 _____

3 _____

10. Have you taken any exams at [redacted] before you came to FE?

Please list them below with your grades:

Subject	Grade
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4 Life after [redacted]

In the future you will finish at [redacted]. This next section will talk about how you feel about leaving [redacted] one day.

1. One day you will have to leave [redacted]. How ready do you feel for this?
Put a cross on the line:

Completely ready Not ready at all

2. When you leave [redacted] you might get a job or continue with your education. How ready do you feel to start something like?
Put a cross on the line:

Completely ready Not ready at all

3. Has being at [redacted] helped you feel ready for life in the future?
Put a cross on the line:

Yes a lot No not at all

4. Would you prefer to get a job or continue studying?
Please tick one:

- Get a job
- Carry on studying
- I haven't decided yet
- Something else

5. Can you explain more? What job would you like to do/what would you like to study?
List up to 3 points:

1 _____

2 _____

3 _____

6. Can you think of anything [redacted] has done to help you do this?
List up to 3 points:

1 _____

2 _____

3 _____

7. Is there anything else [redacted] could have done to help you more?
List up to 3 points:

1 _____

2 _____

3 _____

5 Living

1. Would you like to live independently in the future? This means not at [redacted] and with your parents.

Please tick one:

- Yes
- No
- I haven't decided

2. How ready do you feel to live independently?

Put a cross on the line:

Completely ready Not ready at all

3. How old do you think you might be when you first live on your own? ____

4. What might you like about living independently?

List up to 3 points:

1 _____

2 _____

3 _____

5. What might you find hard about living independently?

List up to 3 points:

1 _____

2 _____

3 _____

6. Have [redacted] done anything to help you live independently if you wanted to?

List up to three points:

1 _____

2 _____

3 _____

6 Employment

When you have finished studying you may want to get a job.

1. What job would you like to do in the future? _____

2. Why do you think you would like that job?

List up to three points:

1 _____

2 _____

3 _____

3. How ready do you feel to start work?

Put a cross on the line:

Completely ready Not ready at all

4. Can you think of any training you would need to do to get a job?

List up to three points:

1 _____

2 _____

3 _____

7 Communication

The reason you came to _____ was because you had some difficulties with your communication

1. Have the staff at _____ helped you with your communication?

Put a cross on the line:

Yes a lot No not at all

2. How do you feel about your communication skills now?

Put a cross on the line:

Very happy Very unhappy

3. How do you feel about your reading now?

Put a cross on the line:

Very happy Very unhappy

4. How do you feel about your spelling now?

Put a cross on the line:

Very happy Very unhappy

5. How do you feel about Maths now?

Put a cross on the line:

Very happy Very unhappy

6. What kind of lessons or activities do you find easiest at _____?

List up to three points:

1 _____

2 _____

3 _____

7. What kind of lessons or activities do you find hardest at [redacted]?

List up to three points:

1 _____
 2 _____
 3 _____

8 Friends

1. How do find getting on with other people?

Put a cross on the line:

It's very easy _____ It's very hard

2. Do you make new friends easily?

Put a cross on the line:

It's very easy _____ It's very hard

3. Do you have many friends at [redacted]?

Please tick one:

I have more than 10 friends at [redacted]
 I have between 5 and 10 friend at [redacted]
 I have between 2 and 5 friends at [redacted]
 I have 1 good friend at [redacted]
 I don't have any friends at [redacted]

4. Do you have many friends at college?

Please tick one:

I have more than 10 friends at college
 I have between 5 and 10 friend at college
 I have between 2 and 5 friends at college
 I have 1 good friend at college
 I don't have any friends at college

5. Do you have many friends at home?

Please tick one:

I have more than 10 friends at home
 I have between 5 and 10 friend at home
 I have between 2 and 5 friends at home
 I have 1 good friend at home
 I don't have any friends at home

6. Do you think you will keep in touch with your friends from [redacted] after you leave?

Please tick one:

Yes definitely
 I would like to
 Probably not

7. How might you keep in touch with them?

Please all the things you might do:

- Visit them at home
- Have them visit you
- Phone them
- Text them
- E-mail them
- On social networking sites
- Internet chatrooms
- Write letters to them

8. What do you think is special about your friends?

List up to three points:

1 _____

2 _____

3 _____

Pictorial representation of linear scale



Questionnaire for parent/guardian of [redacted] FE pupil

1 Personal details

1. Name of parent/guardian _____

2. I am the child's: Mother
 Father
 Guardian

3. Name of child at [redacted] FE _____

4. Child's gender Male
 Female

5. Child's date of birth ___ / ___ / ___

6. Child's school year _____

7. How old was your child when s/he first went to [redacted]? _____

8. Is your child a fortnightly boarder, a weekly boarder or a day pupil?

Please tick one:

- Fortnightly boarder
- Weekly boarder
- Day pupil

2 [redacted] experience

1. In general how do you feel [redacted] has been able to cater for your child's needs?

Please tick one

- Very well
- Quite well
- Adequately
- Quite poorly
- Very poorly

2. Can you give reasons for your answer?

List up to 3 points

- 1 _____
- 2 _____
- 3 _____

3. How well has [redacted] FE been able to cater for your child's needs?

Please tick one:

- Very well
- Quite well
- Adequately
- Quite poorly
- Very poorly

4. Can you give reasons for your answer?

List up to 3 points

1 _____
2 _____
3 _____

5. What do you feel are the main goals of the [redacted] FE?

List up to 3 points

1 _____
2 _____
3 _____

6. What would you and your child have done if [redacted] FE had not been available when s/he completed secondary school there?

7. Do you think your child has fared better than s/he would have done in mainstream school?

2 For parent of boarders only

If your child is a day pupil then go to page 5

1. How do you feel when your child is away at [redacted] School?

Please tick one:

- I don't worry about them much
- I worry about them a little bit
- Sometimes I'm ok and sometimes I find it hard
- I find it quite hard
- I find it very hard and upsetting

2. Do you think that fact the one of your children lives away at [redacted] has an effect on his/her siblings?

Please tick one:

- Absolutely – I know they find it hard
- I think it affects them a bit but they get on okay
- No I think it effects them at all
- I can't be sure either way
- S/he is an only child

3. If so how?

List up to 3 points:

1 _____

2 _____

3 _____

4. What is it like when your child comes home again?

List up to 3 points:

1 _____

2 _____

3 _____

3 Educations

1. What college does your child go to?

2. What course do they study?

3. How do you feel your child is getting on in their current studies?

4. Do they get extra help while they are at college?

Please tick one:

Yes

No

5. If Yes – list help they receive college.

6. Why did your child choose to stay at _____ for post-16?

7. Did they take any exams at _____ before moving to post-16?

Please list any subjects with their grades:

Subject: _____ Grade: _____

4 Life after [redacted]

1. Do you think your child is ready to leave [redacted] and enter the adult world?

Please tick one:

- My child is completely ready and could leave [redacted] now
- My child is nearly ready and will be ready when the time comes
- I'm not sure if my child will be ready to leave when the time comes or not
- My child will not be ready to leave when the time comes
- I can't ever see a time when my child will be ready for life after [redacted]

2. Can you explain you answer?

3. Do you feel confident that your child will be ready to begin the next thing (start work or a new further education course)?

Please tick one:

- I'm completely confident my child could do this
- I'm quite confident my child could do this
- I'm not sure if my child could do this
- I'm not confident could do this
- I think this would be very difficult for my child

4. Can you explain you answer?

5. Do you think [redacted] FE did anything specific to help your child in the adult world?

6. Would you prefer to see your child get a job or continue studying when they leave?

Please tick one:

- Get a job
- Carry on studying

7. Can you explain more? What would you like to see them doing once they leave [redacted]?

5 Living

1. Do you think your child will achieve independent living in the future?

Please tick one:

- Yes
- No
- Not sure

2. How old do you think they might be when they first live away from home and [redacted]? ____

3. Do you have any concerns about whether your child will be able to live independently?

- Yes
- No

Can you explain your answer?

List up to 3 points:

- 1 _____
- 2 _____
- 3 _____

4. Do you think your child will still need ongoing support from the family?

Please tick one:

- Yes my child will always need regular support from the family
- Yes my child will always need some support from the family
- Yes my child will need support when they first start living independently
- My child will need very little support from the family
- No my child won't need any support from the family

5. Do you think they will still need ongoing support from support organisations?

Please tick one:

- Yes my child will always need regular support from support organisations
- Yes my child will always need some support from support organisations
- Yes my child will need support when they first start living independently
- My child will need very little support from support organisations
- No my child won't need any support from support organisations

6. Has [redacted] done anything to help them live independently if they wanted to?

List up to three points:

- 1 _____
- 2 _____
- 3 _____

6 Employment

1. What job might your child do in the future? _____

2. Do you feel your child is ready to start work?

Please tick one:

- Yes completely ready
- Yes quite ready
- Not really sure
- Not very ready
- Not ready at all

3. Does your child ever talk about what job s/he might like to do when s/he leaves [redacted]

- Yes
- No

If yes - what? _____

If yes - do you feel your child is likely to achieve this goal? Explain why.

4. Do you have any concerns about your child entering the world of work?

- Yes
- No

If yes what? _____

7 Communication

The reason your child came to [redacted] was because s/he had some difficulties with his/her communication.

1. How do you feel about your child's communication now?

Please tick one:

- Completely happy with it
- Quite happy with it
- It's okay
- Quite unhappy with it
- Very unhappy it

2. How has it changed since they entered [redacted] School?

List up to 3 points:

1 _____

2 _____

3 _____

3. Do you feel that [redacted] has helped your child with his/her communication difficulties?

Please tick one:

- Yes a lot
- Yes quite a lot
- Only a bit
- No not much
- No not at all

4. Can you comment on this?

List up to 3 points:

1 _____

 2 _____

 3 _____

5. Do you feel that [redacted] has helped your child with his/her literacy skills?

Please tick one:

- Yes a lot
 Yes quite a lot
 Only a bit
 No not much
 No not at all

6. Can you comment on this?

List up to 3 points:

1 _____

 2 _____

 3 _____

8 Friends

1. How would you say your child gets on with other people?

Please tick one:

- S/he gets on with them very well
 S/he gets on with them quite well
 Sometimes s/he gets on with them
 S/he doesn't really get on with them
 S/he doesn't get on with them at all

2. How easily does s/he make friends?

Please tick one:

- Very easily
 Quite easily
 Okay
 It's quite hard for him/her
 It's very hard for him/her

3. How many friends would you say your child has at home (not at college or [redacted])?

Please tick one:

- More than 10 friends
 Between 5 and 10 friends
 Between 2 and 5 friends
 One good friend
 S/he doesn't have any friends

4. Do you think s/he will keep in touch his/her friends from [redacted] after s/he leaves?

Please tick one:

- Yes definitely
 I think s/he would like to, but it might be difficult
 It's unlikely

Semi-structured interview for FE staff at [REDACTED] School

Staff member's role in FE:

Can you describe a bit about your role in [REDACTED] FE?

- a. What responsibilities do they have?
- b. When do they work with/interact with pupils

What do you feel the main objectives of [REDACTED] FE are?

- a. Are these personal objectives or objectives across the school?

How important was it to open [REDACTED] FE?

What are/have been the biggest challenges for [REDACTED] FE?

- a. What are these to do with? Individual pupils? Policy? Co-operation with colleges? Etc...

What are/have been the biggest challenges for you?

- a. Personal challenges?

How has the addition FE changed the dynamics of the school?

- a. What is it like having older pupils there staying at the school longer?
- b. How do these pupils get on with the younger pupils/Do they have much contact with them?
- c. What effect has this had on the school as a whole?