

WHAT ARE THE EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISM
WHO ATTEND A RESIDENTIAL SCHOOL? AN EXPLORATORY STUDY USING
INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

by

Jayne Tansley

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ABSTRACT

Children with autism and additional complex needs experience difficulties in social interaction and communication which are often manifested by extremely challenging behaviour that is difficult to manage at school and within the home. Identifying appropriate educational provision for this group, which may involve the controversial category of residence, can create a dilemma for the responsible Local Authorities, operating within a dominant discourse of inclusion and can lead to a difference of opinion with parents. For parents, the decision for residence is profound and life-changing.

Six parents, both mothers and fathers, of children with autism and challenging behaviour who attend a residential school, participated in semi-structured interviews exploring their lived experiences before, during and after the decision for residence.

Interpretative Phenomenological Analysis (IPA) was used to analyse the data and four super-ordinate themes emerged: enduring loss; the family versus the system; the extreme parent; and the relief of residence. The super-ordinate and sub-themes were described and discussed in relation to the research questions and the extant literature. The lived experience of parents in this study transcended ideological concerns. Implications for practice focus on the need for professionals to gain a better understanding of parental experiences.

Dedication

To my husband, Neil, and to my children, Matthew and Lorna. Thank you all for your continued belief in me, for your patient support and encouragement, throughout the process.

To my parents, who, unknown to them, inspired me to achieve through their own unconditional love.

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Table of Contents

Chapter 1	Introduction	1
1.1	The focus of the research	1
1.2	The rationale and context of the research	1
1.3	The research aims	4
1.4	The research questions	5
1.5	The structure of the study	6
Chapter 2	Literature Review	8
2.1	Introduction	8
2.2	What is autism?	8
2.2.1	Identification and Diagnosis	9
2.2.2	Aetiology	11
2.2.3	Psychological theories of autism	11
2.2.3.1	Theory of Mind	12
2.2.3.2	Executive Function	12
2.2.3.3	Central Coherence	12
2.2.3.4	Intersubjectivity	13
2.3	Educational provision – interventions and placement	14
2.3.1	Interventions	15
2.3.2	Implications for placement	19
2.3.3	Outcomes	20
2.3.4	Inclusion	21
2.3.4.1	Historical	21
2.3.4.2	Inclusion	22
2.4	Residential education	25
2.4.1	Introduction	25
2.4.2	The 24 hour curriculum	26
2.4.3	The decision making-process for placing a child in residential education	29
2.4.3.1.	Criteria for placement	30
2.4.3.2	Parental views of the process	33
2.4.4	The contribution of educational psychologists	35
2.4.5	Outcomes of residential education	37
2.4.5.1	Parental satisfaction	37
2.4.5.2	Transitions	38
2.5	Parental experiences of raising a child with autism	39
2.5.1	Introduction	39
2.5.2	Why is it important to know about parental experiences?	40
2.5.3	What are the families’ experiences?	42
2.5.4	Why do these experiences occur?	44
2.5.4.1	Coping	44
2.5.4.2	Stress and psychiatric disorders	45
2.5.4.3	Isolation	46
2.5.4.4	‘Heightened experience of parenting’	46
2.5.4.5	Finding a diagnosis	47
2.5.4.6	Respite care	48

2.5.4.7	Transition into adult services	49
2.6	What should be done? – the contribution of the present study	49
2.7	Research aims	51
Chapter 3	Methodology	52
3.1	Background to the present study	52
3.2	Rationale for the methodology	52
3.3	Interpretative Phenomenological Analysis	58
3.4	Research Design	64
3.4.1	Ethical considerations	64
3.4.1.1	Ethical approval	64
3.4.1.2	Informed consent	65
3.4.1.3	Dissemination of results	66
3.4.2	Recruitment of participants	67
3.4.3	The sample	69
3.4.4	Data collection	72
3.5	Procedure	72
3.5.1	Design of the IPA questionnaire and interview schedule	73
3.6	Analysis	76
3.7	Validation and reliability	79
Chapter 4	Findings	81
4.1	Introduction	81
4.2	Rationale for the super-ordinate and sub-themes	81
4.2.1	1 st super-ordinate theme – enduring loss	81
4.2.2	2 nd super-ordinate theme – the family versus the system	82
4.2.3	3 rd super-ordinate theme – heightened parenting	82
4.2.4	4 th super-ordinate theme – the relief of residence	82
4.3	Reflections on the findings from the individual analyses	86
4.4	Super-ordinate theme – enduring loss	88
4.4.1	Sub-theme – loss of the expected child	88
4.4.2	Sub-theme – loss of the expected life	90
4.4.3	Sub-theme – loss of identity	92
4.4.4	Sub-theme – the impact of diagnosis	95
4.4.5	Sub-theme – the impact of the decision for residence	96
4.5	Super-ordinate theme – The family versus the system	99
4.5.1	Sub-theme – frustration	99
4.5.2	Sub-theme – abandonment	105
4.5.3	Sub-theme – conflict	107
4.5.4	Sub-theme – isolation	108
4.6	Super-ordinate theme – heightened parenting	111
4.6.1	Sub-theme – the expert parent	111
4.6.2	Sub-theme – the sacrificial parent	116
4.6.3	Sub-theme – the reconstructed parent	118
4.7	Super-ordinate theme – the relief of residence	121
4.7.1	Sub-theme – restoration	122
4.7.2	Sub-theme – acceptance	126
4.7.3	Sub-theme – community	129

Chapter 5	Discussion	133
5.1	Key Findings	133
5.2	1 st research question - What are the experiences of a parent of a child with autism who attends a residential school?	135
5.3	2 nd research question - How is the current situation with regard to provision, placement and support from professionals perceived by these parents?	136
5.3.1	Super-ordinate theme – the family versus the system	137
5.3.1.1	Sub-theme – frustration	137
5.3.1.2	Sub-theme – isolation	142
5.3.1.3	Sub-theme – abandonment	144
5.3.2	Super-ordinate theme – heightened parenting	145
5.3.2.1	Sub-theme – the expert parent	146
5.3.2.2	Sub-theme – the sacrificial parent	147
5.4	3 rd research question - How is the construct of ‘inclusion’ understood by these parents?	148
5.4.1	Super-ordinate theme – enduring loss	148
5.4.2	Super-ordinate theme - the family versus the system	151
5.4.3	Super-ordinate theme – heightened parenting	152
5.5	4 th research question - What are the effective features of a residential placement from a parent’s perspective?	155
5.5.1	Super-ordinate theme – the relief of residence	155
5.5.2	Super-ordinate theme – heightened parenting	161
5.6	The role of fathers	162
5.7	Conclusion	163
Chapter 6	Conclusions	164
6.1	Reflexivity – introduction	164
6.1.2	A personal reflection of the research interview process	164
6.2	Critique of the research design	167
6.2.1	Critique of the research questions	167
6.2.2	Critique of the methods and procedures	171
6.3	Suggestions for future research	173
6.3.1	Autism-specific residential research	173
6.3.2	Triangulation of data	174
6.3.3	Increased use of IPA	175
6.4	Implications for practice	176
6.4.1	The epistemological level	176
6.4.2	The ideological level	177
6.4.3	The operational level	178
6.5	Conclusion	179

References

Appendices

LIST OF ILLUSTRATIONS

Figure 1.	Pictorial representation of super-ordinate themes	85
Figure 2.	Patterns of polar sub-themes	85

LIST OF TABLES

1. Selected interventions for autism	18
2. Family experiences of the residential placement process	34
3. Negative factors associated with parenting a child with autism	43
4. How parents make sense of the experience of raising a child with a life-long condition	44
5. Details of the sample	70
6. Further participant information	71
7. Timeline of procedure	74
8. The IPA Analysis	77
9. Excerpt from IPA process of analysis of interview with ‘Brian’	78
10. Parental experiences of having a child with autism in residential education - emergence of super-ordinate and sub-themes	84
11. Summary of main emergent themes from individual accounts	87
12. Features valued by parents in a residential school	159
13. Distribution of super-ordinate themes across the research questions	169

CHAPTER 1 - INTRODUCTION

1.1 The Focus of the Research

This thesis is concerned with exploring the lived experiences of parents who have a child with autism attending a residential school. This is a relatively small, discrete group of parents and is a poorly understood and under researched area. It is however an important field for Educational Psychologists (EPs) to consider, for several reasons, which are outlined below. For clarity, the term ‘child’ is used to represent ‘child’ or ‘young person’ throughout the thesis and similarly the term ‘autism’ is used as an umbrella term to refer to all autistic spectrum disorders.

1.2 The Rationale and Context of the Research

Having a child with a pervasive developmental disorder such as autism, frequently with associated challenging behaviour and other complex needs, is likely to have an impact upon family life and challenge perceptions of parenting and of what might constitute ‘normality’. In addition, then making the decision, as parents, for a child to attend an often geographically distant residential school, marks a significant life event. Moreover, when the child has the additional difficulties of communication and interaction associated with autism, the decision is likely to be of even greater magnitude. An important consideration is to explore how parents experienced such a separation and how a residential school would address this, particularly with reference to the psychological construct of attachment. The aim of this present study is to explore the ‘lived experiences’ of such parents, considering their earliest concerns about the development of their child, through the diagnosis process, experiences of local educational provision, the decision for a residential school, their subsequent quality of

life following a placement and finally their hopes for the future. It is believed to be of value and of interest to psychologists, involved with supporting such children and families at pivotal stages in their life path.

The prevalence of autism (at least in the growing numbers of those diagnosed) is increasing amongst children and young people and the need for appropriate educational and social care provision is a growing concern for Local Authorities (LAs) and for parents (Wing and Potter, 2002, Baird et al, 2006). The individuals, within the target group of this present study, who have the greatest levels of need, and who are deemed to require residential provision, will almost inevitably, in time, progress into adult services. The high cost of this specialist provision is likely to become an increasing concern for the LAs (who are currently responsible for the cost), in the current economic climate of financial austerity. Therefore developing the knowledge base surrounding this, particularly with regard to the efficacy and outcomes of particular provision types and interventions, is desirable for all parties. The present study aims to contribute to this field.

The construct of ‘residential education for children’, is contentious in three main areas: politically (due to financial demands to resource the invariably expensive provision and the not infrequent friction between publicly funded and privately sourced provision); ethically (due to long-held psychological views on attachment and the importance of children remaining with their parents) and ideologically (due to the prevailing political stance of ‘inclusion’, that is, the rights of children to have equal access to local education and to live within their local community, as well as parental rights to have their own preferences regarding their child’s education acknowledged). The role of the residential school, which

becomes pivotal in the lives of these families, will also be interesting to explore, particularly in identifying the features that are valued by parents.

As practitioners, EPs are often key professionals whose opinions are sought in complex cases where disputes over appropriate provision for children with autism are involved.

Unfortunately, parents within the extant literature, frequently report dissatisfaction with the professionals whom they meet during the process, including EPs, with regard to their knowledge and expertise of autism and their restricted autonomy in sharing local information, when it is available. This can often be similarly frustrating for the practitioners themselves. Therefore, developing a better understanding of this area, particularly of the values and belief systems of parents, should enable EPs to provide a more informed, and effective role in this process.

Of the small body of existing research into residential education, in general, the main focus has been on the experiences and outcomes of the children and young people themselves, rather than on the impact upon their parents. Moreover, when parental views have been sought, it has been mothers, as the more usual main carer, that has been the target. The present study looked to include fathers to add a further dimension to the data. Additionally, there is limited research in all of these areas, available within the United Kingdom (UK), therefore international studies have also been considered in an attempt to gain as broad a picture as is possible, whilst acknowledging that there are likely to be difficulties in generalising cross-culturally.

Finally, there is a related research stream concerned with the impact of raising a child with a significant, lifelong disability, (of which autism is one), including studies of parental

methods of coping, levels of stress and of adjustment. These data are considered very important to the present study as it provides an insight into potential shared issues, with regard to parental emotional well-being as well as any that may be unique to parenting a child with autism. More specifically, there is a small number of studies that has used a phenomenological and hermeneutical methodology to explore these experiences, which through the data has produced rich insights into parental experiences. This was felt to be particularly suitable to the conceptual framework of the present study.

The methodology used for the study was Interpretative Phenomenological Analysis (IPA) – a qualitative research approach committed to the examination of how people make sense of their major life experiences. It is phenomenological in that it explores experiences in their own terms. It requires participants to engage in a considerable amount of reflection on their own experiences. IPA is also concerned with interpretation, the belief that the participants, as social beings, will try to make sense of (interpret) their own experiences as they relate them to the researcher. IPA uses a reflexive approach, or double hermeneutic so that the investigator also contributes to the research findings by interpreting the interpreted experiences of the participants.

1.3 The Research Aims

The aims of the research are to explore issues including:

- the values and belief systems of parents
- parental experiences of the diagnosis process and of living with a child with autism
- how parents make decisions about the placement of their children
- how parents are supported during the placement process

- how parents maintain their role once their child has moved to residence
- the impact of residence on the future parent-child relationship
- the impact of attachment issues in general (between parents and children and carers and children) and specifically in relation to pupils with autism
- the inclusion debate, i.e. whether children with complex needs should be educated within mainstream or specialist placements
- the role of Local Authorities in relation to residential placements

It is not the aim to claim generalisation of any knowledge gained. Nevertheless, the research will be valuable in its own right in recognising, validating and illuminating the experiences of these parents. It could also have additional merit in being used to inform future practice of the particular school the children are attending; to reveal good practice for consideration by a wider range of residential schools; to raise issues for consideration by LAs who are responsible for devising local policy for placement of children with autism; and to inform practitioners, including EPs, with regard to what these parents value and need, in order to best support their children.

1.4 The Research Questions

The research questions were:

- What are the experiences of parents with a child with autism who attends a residential school?
- How is the current situation, with regard to provision, placement and support from professionals perceived by these parents?

- How is the construct of inclusion understood by these parents?
- What are the effective features of a residential placement, from a parent's perspective?

The stages of the data collection and analysis were as follows:

- Obtain data via semi-structured interviews with six parents (mothers and fathers) of children with autism who attended the same residential school
- Audio tape and then transcribe the interviews
- Rigorously analyse the data thematically, following the model suggested for IPA by Smith et al, (2009)
- Discuss the findings at length, with reference to the original research questions and the emergent super-ordinate themes

1.5 The Structure of the Study

The study is arranged as follows:

Chapter 2 is concerned with a review of the current literature including consideration of the nature of autism, educational provision for children with autism including interventions and placements, residential education and parental experiences of raising a child with a life long disability (including autism). Finally the contribution of the present study to this field is addressed.

Chapter 3 describes the rationale for the chosen methodology of IPA, particularly the model of analysis from Smith et al, (2009). The research design is outlined, including a description

of the ethical considerations, details of the sample, the procedure for data collection (which involves a semi-structured questionnaire delivered in a face-to face interview) and finally a description of the analysis.

Four super-ordinate themes emerged from analysis of the transcripts. These were:

- enduring loss
- the family versus the system
- heightened parenting
- the relief of residence

The findings are presented and supported by extensive use of direct quotations from the parents in the study.

Chapter 4 is the discussion of the findings. The data were discussed with reference to the original research questions, the super-ordinate themes that emerged and to the extant literature.

Chapter 5 contains the conclusions and recommendations. These include a personal reflection of the interview experience given the particular feature of the double hermeneutic of IPA, a critique of IPA as the chosen methodology, recommendations for future research, implications for practitioners and concluding remarks.

CHAPTER 2 - LITERATURE REVIEW

2.1 Introduction

The aim of the present study is to explore the experiences of parents who have a child with autism that attends a residential school. The literature that will be reviewed will involve an overview of autism as the underlying condition of concern; provision and placement regarding these young people; inclusion, as the prevailing discourse around special educational need; residential education as a phenomenon and the experiences of parents with children with life-long conditions, including autism. Finally the role of the EP, as it relates to this area, will be considered.

2.2 What is Autism?

Autism is a complex, pervasive developmental disorder. There is a considerable body of literature within the academic field, as well as ‘insider accounts’ from those directly affected (individuals with autism and parents of children with autism). These latter accounts have contributed greatly to the understanding of autism as it is ‘experienced’. There is also an on-going debate over the construct of ‘autism’ linked with the wide-ranging discussion concerning ‘labelling’, diagnosing’ and ‘pathologising’ children, as influenced by the medical model. Detractors of this view warn that this is something to be cautiously considered and even actively resisted, holding as they do to a more social constructionist viewpoint and drawing on the values of community psychology (Billington, 1996, 2006; Fox and Prilleltensky, 1997; and Goodley and Runswick-Cole, 2012).

This argument is of current concern, following the recent publication of the American Psychiatric Association (APA), Diagnostic and Statistical Manual of Mental Disorders (5th

ed.) (DSM-5) (APA 2013). The impact of this publication on practitioners (especially educational psychologists) has been critiqued by, amongst others, Gillum (2013). Since the 1980s and the publication of the 3rd edition, this manual has been widely presented as a means of providing criteria for the classification of mental disorders and to improve the reliability of diagnoses. The underlying assumption of the manual is that of the concept of a ‘mental disorder’ that is caused by factors within an individual. This belief disregards, or at best reduces, the impact that other factors (e.g. environmental, cultural, social) may have upon the behaviour of an individual. It is therefore in opposition to those holding a social constructionist view who consider all of the circumstances of an individual’s life, rather than reducing them to a single, medical diagnosis, which can then close off creative avenues for support and intervention (Traxson, 2010), Gillum (2013).

2.2.1 Identification and Diagnosis

Against the background of the ongoing debate around the identity of ‘autism’, discussed above, lies the phenomenon itself.

Autism was first identified separately by Leo Kanner and Hans Asperger in the 1940s. It has transformed from Kanner’s narrow description through a broader *continuum* until arriving at the current accepted construct of a *spectrum* of related conditions, or subgroups, including individuals with average and above average intellectual ability (Wing, 1981a, Wing, 1996).

It is however agreed that regardless of the broad spectrum of disorders within autism, for a diagnosis to be secure, all individuals must share a triad of impairments, described over thirty years ago by Wing and Gould as:

- Impairment of social interaction
- Impairment of social communication
- Impairment of social imagination, flexible thinking and imaginative play/thinking

(Wing and Gould, 1979)

Much has been learned about autism since Kanner and Wing's classifications, which have led to refinements in the understanding of how the 'triad' impacts differentially on individuals and it should always be acknowledged that there will be a sensitive interaction between 'abilities and disabilities and the learning environment' (Jordan, 1999 p26).

How individuals are identified as having autism today, will reflect the prevailing view within the clinical assessment team, which in the UK is largely based within the Health Authority. However, there is a growing trend for Local Authorities to recognise and value the input of other stakeholders, including professionals in education and most importantly, families (Moran, 2010). There is a range of diagnostic tools (rating scales, checklists and questionnaires), relying on trained and careful observations over time and in different settings that are available to be used alongside more prescribed and medicalised frameworks such as that of the DSM-V (Appendix 1). Use of such diagnostic tools are claimed to produce 'one of the most reliable and valid diagnoses in child psychiatry' their strength depending upon the skill of the practitioner rather than the availability of a reliable tool (Jordan, 1999 p43). Increased use of these tools help in varying degrees, to a move away from the construct of autism as a 'disorder' to a more wide-ranging, interactive and socially constructed phenomenon.

2.2.2 Aetiology

Given the above debate about the nature of autism, a consideration of the aetiology is not straightforward. The extant research into the aetiology of autism has found it to be a complex and multi-factoral disorder. Psychological models are useful in understanding and explaining observed behaviours. However, these findings need to be considered alongside ongoing scientific research, involving neuroscience which is already mapping cognition onto brain function (Blakemore and Choudhury, 2006) and genetics (Bailey et al, 1995), as a highly integrated approach is likely to be required in order to fully understand the phenomenon. However, as autism is so closely bound up with social interaction and social communication, it is likely that environmental factors (relating to parents and caregivers in particular) will play a key role in how autism presents in an individual and, most importantly, how an individual responds to intervention.

Important to this study is the the impact of the uncertainty that *not* being able to identify a definitive ‘cause’ for such an important life event as having a child with autism, may have upon families. This may add to the frustration that parents may feel about adequate services and provision and also to their feelings of guilt or responsibility relating to their unfounded belief that they may have been the ‘cause’ of their child’s autism.

2.2.3 Psychological Theories of Autism

The three most current and prominent psychological theories of autism, include Theory of Mind, Executive Dysfunction and Central Coherence. They are areas that demand detailed examination but the main points only are summarised below in order to provide context for this study.

2.2.3.1 Theory of Mind

An ability to understand other people's points of views – their beliefs, motivations and goals - is essential, it is argued, for successful social interaction. This phenomenon of 'mentalising' has been called the Theory of Mind (ToM). This theory has been developed in relation to autism most notably by Baron-Cohen (1993, 1995,) and Frith and Happe (1994). Their studies over the last 20 years have found that there is an association between individuals with autism and deficits with ToM both in clinical trials and in neurological testing.

2.2.3.2 Executive Function

Executive Function refers to behaviours frequently associated with autism, including restricted, repetitive behaviours, inflexibility and a lack of planning. Executive functions, as described by Ozonoff (1995) are skills associated with the capacity to generalise learning, by the use of internal, mental processes. Many individuals with autism have persistent difficulties with behaviours that need discrimination and those that need to be generalised. It is a useful theory in that it helps to explain both the cognitive and motor behaviours observed in many individuals with autism. However, as Jordan (1999) points out, what is required from this theory in order for it to be more helpful in explaining autism, is to show how a presumed disorder of executive functioning leads to the errors observed in individuals with autism. More crucially, it needs to explain how these systems normally develop and what is different in individuals with autism (Jordan,1999).

2.2.3.3 Central Coherence

Central Coherence refers to the ability to integrate information to form coherent 'wholes' from partial information. In individuals with autism this has generally been found to be weaker (Frith, 1989a, 1993; Frith and Happe 1994). The implications of this theory for

development affect the areas of generalisation of learning, understanding context and incidental learning, which are required skills in successful learning and socialisation. Again, there is not universal agreement of this theory as an explanation for autism (Jordan, 1999).

2.2.3.4 Intersubjectivity

Intersubjectivity is a way of explaining how an individual with autism has difficulties with interaction and communication, and although not a psychological theory, is helpful in furthering the understanding of the theories described in brief above. It is primarily associated with the work of Hobson, (2002) who expanded his thinking on the importance of babies and young children learning to understand that there are other people with minds and that these people are separate from themselves. He asserts that this knowledge is acquired through relationships with other people and is bound up with emotions. His research demonstrated that babies and young children with autism found it much more difficult to engage in behaviours that facilitated the development of emotional engagement with others and were therefore hindered from the very beginning, in the task of developing social communication and eventually language (Hobson, 1990a; 1991). This has obvious links with the Theory of Mind. Moreover, a difficulty with imitation of social interactions (due to a difficulty with motor movements) has been advanced by others as a link between intersubjectivity and executive function (Rogers and Bennetto, 2000).

The introduction of the intersubjectivity approach has led to others developing a more person-centred focus to programmes of language development for those with autism (Prizant et al, 2000). This has developed partly in response to the formalising of the intuition that there is a qualitative difference in the emotional understanding and engagement in those with autism, provided by Hobson's work (Jordan, 1999). Understanding the importance of the social

transactional process between individuals during communication and interactions therefore demands that any programme of intervention also recognises this and moves from a purely behavioural approach of ‘teaching a sequence of speech or non-verbal behaviours’ (Prizant et al, 2000, p 218). This has been formalised into the SCERTS model (social-communication, emotional regulation and transactional support) (Prizant et al, 2000). Underlying the model is the belief that, ‘the development of trusting and secure relationships is both a foundation for and a product of success in social communication with others.’ (Prizant et al, 2000). Therefore, enabling parents, carers and educators to provide this nurturing environment will be a vital consideration of any educational intervention. This assumes even greater significance within residential provision.

The uncertainty in the research regarding aetiology and psychological models of autism has important implications for the present study, as the claims are often used as a justification for the wide range of educational provision and intervention programmes provided for those with autism. As will be discussed below, these are often lacking in a clear and coherent rationale, in terms of matching the particular model on which the intervention is based, with the particular manifestation of the spectrum with which an individual may be presenting. This is likely to further influence the confidence level of parents, and indeed supporting professionals, in decision-making, including that involving residential provision, which is the focus of this present study.

2.3 Educational Provision –Interventions and Placement

As there is no ‘cure’ for autism, interventions are focused on alleviating the behavioural manifestations of the condition and promoting maximum progress in learning and development. Therefore, identifying the most appropriate style of intervention, is vitally

important, not least to the confidence of parents. However, variations in types of setting (placement), intervention programmes, degrees of ‘autism’, parental preference and LA practice, amongst others, means that mapping provision for those with autism is very difficult. An additional layer of complexity is that there can be a relationship between a specific intervention and a placement, but this is not a uniform practice across LAs.

2.3.1 Interventions

The variations of research findings into the efficacy of individual intervention programmes and on comparative studies adds to the confused picture. A recent study, extensively reviewing the international data on empirical research and expert evidence, found that interventions in use with children with autism included a variety of both eclectic and specific approaches and there was certainly no evidence of one dominant or preferred approach, (Parsons et al, 2011). An additional difficulty these researchers highlighted was in the confidence of measuring the efficacy of interventions, given the highly individual and pervasive nature of autism, making it difficult to isolate the effects of specific interventions on specific areas of development. It was therefore not possible for them, as reviewers of this evidence-base, to make any firm recommendations regarding the efficacy of one study (or approach) over another but rather to recommend an eclectic approach, based on personalised learning. This echoed the earlier findings of Jordan et al, (1998).

This lack of clarity is also due to the inherent ‘spectrum’ nature of autism, with its highly variable manifestations, meaning that it is very unlikely that a universally appropriate provision will be found to meet the needs of all those identified as having autism. Parsons et al, (2011) found that decisions about provision were often based upon factors that are not able

to be neatly quantified, including ideological issues (social justice, inclusion), the knowledge of the practitioners involved (which may be idiosyncratic rather than uniform), practical considerations (e.g. the availability of provision in the locality), financial, and not least importantly, family considerations (Parsons et al, 2011).

However, despite the difficulty in neatly mapping provision with category of need, there is a growing evidence base for some forms of intervention. Parsons et al, (2011) were able to identify evidence for the efficacy of some specific approaches, including early intervention and the use of a key worker. Both of these approaches have benefits associated with involving parents and for practitioners to take into account the individual situations of each family, including, importantly, patterns of interaction within the families. A key recommendation of the study was for families to be closely involved with the intervention programmes and to be provided with good quality information (Parsons et al, 2011).

There was also some evidence that structured approaches can help the development of specific skills, but this was cautiously presented. This is a further warning of the danger of over-generalisations and the need for individualised approaches, as children with autism are not a homogenous group (Parsons et al, 2011).

Table 1 contains a selection of interventions available for children with autism. It is not the aim of this literature review to evaluate the effectiveness of all interventions advocated for use with pupils with autism. However, the evidence base for the 24-hour waking day curriculum will be considered in more detail, as it is in use, albeit in different forms, in specialist residential schools and therefore it is of particular interest to this study.

It is important at this point to distinguish between *approaches* and *interventions*, such as those described in Table 1, and the *places* in which the interventions occurred. The Autistic Spectrum Disorder Good Practice Guidance (ASDGPG, 2002), also noted that there was a wide range of these settings ranging from: local mainstream schools, with or without additional support; special units within mainstream schools; specialist schools for children with general learning difficulties; specialist schools that are autism specific; and residential specialist schools, both generic and autism specific, that offer provision outside of the normal school day (adapted from ASDGPG, 2002, p14). The vast majority of these schools are within the maintained sector, but there are also a number within the non-maintained and independent sector. There is also a small group of children who are educated at home, primarily as a result of parental choice.

Table 1

Intervention	Reference
<ul style="list-style-type: none"> • Applied behavioural analysis (ABA) (including Lovaas and Verbal Behaviour) • Circle of friends • Daily Life Therapy (24-hour curriculum) • EarlyBird programme • Hanen (ASD-specific adaptation) programme • Intensive interaction • Music therapy • Musical interaction therapy • Option (Son Rise) programme • Picture Exchange Communication System (PECS) • Portage programme • SPELL – Structure, Positive approaches, Empathy, Low arousal and Links • Social stories • SCERTS – social-communication, emotional regulation and transactional support • Treatment and Education of Autistic and related Communication handicapped Children (TEACCH) 	<p>Lovaas, O.I. (1987)</p> <p>Whitaker, P. et al (1998)</p> <p>Quill, K. et al (1989)</p> <p>Shields, J. (2001)</p> <p>Sussman, F. (2012)</p> <p>Nind, M. (1999)</p> <p>Storr, A, (1993)</p> <p>Christie, P. et al (1992)</p> <p>Kaufman, B.N. (1994)</p> <p>Bondy, A. and Frost, L. (1994)</p> <p>Bluma, S.M. et al (1976)</p> <p>Mills, R. (1999)</p> <p>Gray, C. (1994)</p> <p>Prizant et al (2000)</p> <p>Lord, C. and Schopler, E. (1994)</p>

Selected interventions for autism

2.3.2 Implications for Placement

Some interventions have a much clearer relationship with and implications for placement. Examples of such, and with particular relevance for the present study, are those having a holistic approach, that merge care and education into a 24-hour curriculum, often known as a ‘24-hour waking day curriculum’. This method, as its name suggests, depends upon a placement that can offer intervention over and above that normally provided in a school day and therefore will tend to require a residential setting. There are specific programmes advocating a 24-hour waking day curriculum that are autism specific, such as the Higashi/Daily Life Therapy approach (Kitahara, 1984). However, it more usually refers to a more generic, yet highly specialised approach, reserved for those with the most complex and challenging needs, requiring both educational and social provision. The families of these children with autism (as the 24-hour curriculum is not uniquely an autistic provision) are the focus of this current study. The particular characteristics of the 24-hour waking day curriculum, especially as they relate to the aims of this study, will be discussed later in section 2.4.2, within the context of residential provision.

It is important to be aware of the fluidity in terms of provision and placement for pupils with autism, as this is an important issue, in the absence of any nationally agreed criteria for access to particular placements and approaches. The ASDGPG 2002 audit found that in most specialist settings, a diagnosis of autism was required to secure a place, but not in all – although generally a diagnosis and/or a statement of special educational need was perceived to be important in accessing more specialist provision. Access to highly specialised provision, particularly residential, is more carefully controlled by LAs (who generally are

responsible for the high cost of funding of such places) although there is still confusion around precise numbers and criteria for places (ASDGPG, 2002).

2.3.3 Outcomes

The apparently simple task of identifying what is meant by ‘effective’ in relation to autism provision creates additional problems, requiring as it does a consideration of whether this includes the development of some or all of the following skills: academic, social, emotional and independence. Is it effective for the pupils themselves or for their families, or for the school or for the LA? It is likely that the answer will depend upon many factors, but is unlikely to be the same for each individual, which adds to the complexity of the situation with regard to meeting such a wide range of needs and expectations. In particular, it is likely that the parents involved in the present study, who have children with the most complex needs, including most limited communication skills, have concerns over and above academic progress, valuing the more basic needs of safety, love, belonging and positive well-being, following Maslow’s hierarchy of need (Maslow, 1943). In a recent study examining the outcomes for children and young people with autism (Wittemeyer et al, 2011) the views of parents (amongst other stakeholders) were obtained and a clear recommendation emerged that parents should have the individual needs of their child recognised. In addition, contrary to what professionals may have previously assumed, parents also stated clearly that a successful outcome for them, of any intervention, was for their child to have a meaningful and happy life. Therefore, strong emotional health and independent living skills were favoured over progress in academic attainments or more formal measures of progress.

The challenge of providing appropriate and effective provision for individuals with autism is also closely linked with the ideological concept of inclusion.

2.3.4 Inclusion

2.3.4.1 *The historical and socio-political background to inclusion*

Until the 1960s the received wisdom within the United Kingdom and most of western society was that children with special educational needs were better served by segregated special schools than in trying to educate them alongside their typically developing peers. This view reflected the psychological theory of the time, which was concerned with psychological testing and the *fixed* notion of ‘intelligence’. However, following changes in psychology, to consider a more fluid view of ‘intelligence’ and changes within society as a whole (not just in education) of the desire for equality, the movement to at first *integrate* children into local mainstream provision began to form and gain momentum. This was enshrined in policy in the UK in the Warnock Report of 1978 into the construct of Special Educational Needs. The language of this report is a reminder of the fact that prior to The 1970 Education Act many children in the UK were deemed ‘in-educable’ and as such were the responsibility of Health Authorities rather than education departments. Children with autism (diagnosed and undiagnosed) were likely to form a sizeable part of this former group. One of the main outcomes of the Warnock Report was the total re-organisation of the special education system, to include all children, even those previously excluded, by identifying a category of children with ‘special educational needs’. However, not all agree that this development was a move towards the goal of inclusion. Some saw this as a backward step in identifying a group of individuals as having ‘special needs’, separating them out and labelling them so that their differences could be addressed and changed, to more closely fit the ‘norm’, rather than valuing them as individuals, as the wider notion of inclusion would advocate (Billington, 1996).

Within the UK, the inclusion movement took hold, enshrined in legislation and guidance, from the 1981 Education Act, moving onto the 1993 Education Act and the subsequent Code of Practice for Special Educational Needs (DfE, 1994), through to the present day and the latest Children and Families Bill (DfE, 2013).

However, inclusion is not a simple construct. It poses demands upon the receiving body (school, organisation, society) to alter and adapt in order to accept and embrace individuals with a diverse range of attributes, and for those attributes to be celebrated as part of the individual. It therefore often requires significant changes of attitudes and practice.

Considering specifically educational practice related to severely autistic pupils, a group who, formerly, were not even in school, effective inclusive practice is bound to be a challenge.

To add further to the confusion, one other very important human right that is raised within the debate is the right to *choose*. This extends to the right for parents (within the Special Educational Needs Code of Practice, 2001) and the right for children (within the spirit of the Children Act, 2004) to select their educational provision. This ‘right to choose’ may not be readily available to the children of concern in this study, given their challenges with communication (Tilstone et al, 1998, Preece, 2002) and this concern is reflected in recent guidance encouraging the need for children with limited communication to have a means of expressing their ‘voice’ (NICE, 2011, Lamb Report, 2009, Wittemeyer et al, 2011, Children and Families Bill, 2013). In these cases it is more usually parents (or other responsible adults) who assume an advocacy role. Parents may have to weigh up the advantages and disadvantages of inclusive education over ‘peace of mind’ and make difficult decisions about their child’s education that may not reflect inclusive practice in its expected sense.

2.3.4.2 Inclusion and autism – what is the evidence base?

The category of ‘autism’ includes pupils with severely limited language, communication and interaction needs and additional cognitive difficulties (the group that this study is concerned with) that severely limit their opportunities to easily access the mainstream environment and interact with their peers. There is also a second group of pupils with Asperger Syndrome who have more skills to enable them to access a mainstream curriculum but who also have other, subtle but significant difficulties. However, there is also a very wide variation of children who fall between these two extremes and whose needs also have to be met within the educational system. Therefore, what is considered to be appropriate and effective inclusion is likely to vary from one group, indeed one individual, to another. Studies to evaluate effective inclusive practice for pupils with autism are therefore usually situation specific and it is difficult to generalise.

There are some studies that explore inclusion in relation to pupils with autism. For some whose special educational needs can be successfully managed within mainstream, with various support and differentiation, inclusion has provided an opportunity for them and their families to be part of the local community, with all of the accompanying social benefits (Carpenter, 2000, Frederickson et al, 2007). For others, there is a story of unsuccessful experiences particularly related to bullying and social exclusion, (Little, 2002, Reid and Batten, 2006), with the statistic of 21% of pupils with autism having at least one exclusion from school (20 times higher than those without an identified special educational need) adding to the worrying picture (Barnard et al, 2000).

Humphrey and Lewis (2008) carried out an exploratory small-scale qualitative study, using a case-study approach to examine this further. The study was conducted in four secondary

schools in the UK examining the effectiveness of inclusive education for pupils with autism in mainstream and how far government policy was being followed. They collected data via interviews with staff, pupils and parents, observations of a variety of lessons, examination of school policies and also examined entries from pupil diaries in order to obtain an in-depth understanding of the subject, within the context of the individual schools.

Their findings were mixed in that they identified some positive examples of inclusion as well as examples of less effective practice. But what was of most concern was that the gap between the inclusion rhetoric present in the schools and the classroom reality of the daily experience of pupils with autism was found to be very wide. In addition, they discovered that organisational factors such as school ethos and communication were important determining factors in effective outcomes, rather than specific pedagogy. This is important in the context of the present study as although these pupils were not presenting with the same learning and behavioural challenges as the proposed target group for the present study, this research suggests that nevertheless effective practice for students with autism still has a strong association with factors other than an autism-specific approach to teaching, which will be valuable to explore.

These findings may be seen as a caution against the practice of simply exposing autistic pupils to a mainstream curriculum, which could be seen as the default option in most schools, but which studies have shown is not always an effective one (Jordan and Powell. 1995, Anderson et al, 2004). Increased training, knowledge and expertise of autism and its relationship with effective pedagogy, are recommended repeatedly (ASDGPG, 2002, Mesibov et al, 2005, Frederickson et al, 2007, Parsons et al, 2011). However, it is more likely that a

combination of autism-specific knowledge and effective generic inclusive practices are required.

2.4 Residential Education

2.4.1 Introduction

Residential education for children and young people in the UK is a controversial subject associated as it is with views of negative labelling and social segregation against a changed world-view of social and educational inclusion. Historically, children with a wide range of disabilities and learning difficulties were often deemed non-educable and were segregated in residential schools far from where they lived, with the emphasis on care rather than education, and with the Health Authority (HA) having responsibility rather than the then, Local Education Authority. Other residential provision was for 'corrective' behaviour or the traditional 'children's homes' for those in the care of the LA and supervised by social workers. It is an area that has shrunk over the last ten to fifteen years, mainly due to changes in national policy with the emphasis of recent governments on promoting educational and social inclusion through improved and better resourced local provision. This has reduced the need for distant and expensive residential provision as pupils are reintegrated from schools outside of the LA. A second reason, especially in more recent years, is that of financial austerity measures, which have been a strong driver for LAs, who are largely responsible for funding this provision, to reduce the number of expensive places, with national government pressure to reduce local government spending (Gershon Review, 2004).

There are two ideologically distinct groups of children and young people who attend residential schools – firstly, those for whom it is seen as a positive, proactive and privileged

choice, funded (mainly) privately by parents and who are described as attending boarding schools and secondly, those for whom residential education is often perceived as a last resort, for hard to place children, when all other provision has failed and funding is (mainly) by LAs. The present study is focused on the second group, and within this, the subgroup of children with autism who are deemed to require a residential placement. However, given the very limited research specific to this group, the search is widened to include children with other special educational needs and disabilities, as very often it is difficult to isolate the target group from within the existing research.

2.4.2 The 24-hour curriculum

A ‘24-hour curriculum’ or ‘waking day curriculum’ (the terms are interchangeable within the literature) is frequently referred to within the field of residential specialist provision as a benefit or ‘value added’ component. Professionals and parents often cite this as a reason for requesting this particular provision (Abbott et al, 2000) and it is positively recognised by OFSTED (Davies, 2002). However, data on schools that provide a 24-hour curriculum in the UK are very limited and difficult to interpret because it is incomplete and unclear, with practice between and within LAs regarding this area varying considerably (Abbott et al, 2000).

At its simplest, a 24-hour curriculum refers to 24-hour provision, including therefore, a considerable element of care outside of the school day, particularly, but not exclusively, for those pupils who have a 52-week placement. The ‘care’ package varies according to the designated need of the school, but typically involves extra-curricular activities and a

therapeutic component. Some schools promote the benefits of consistency of approaches, particularly with regard to behaviour management (Davies, 2002).

Within the field of autism, it is recognised that for some children, with the most complex and severe difficulties, a 24-hour specialist provision is required (National Autism Plan for Children, 2003). Those autism-specific residential schools within the UK that offer a 24-hour curriculum describe a holistic approach, recognising the pervasive impact of autism. This is very different from and more common within the UK, than the singular approaches provided by the proponents of specific regimes such as the Daily Life Programme (DLP) (Kitahara, 1984), which is an intensive form of an autism-specific, 24-hour curriculum, delivered in the Higashi schools in Japan, the USA and, more recently, the UK. However, there are no scientifically reliable studies of its effectiveness available (Jordan et al, 1998), although there is a positively evaluated US State Inspection Report (2003), which notes that the school has a 'significant and positive impact' on the pupils (Massachusetts Department of Education, US, 2003, p5). The features highlighted within the report include a positive ethos, good communication, good relationships between staff and pupils and a systematic approach to pupils' progress. Many parents also report anecdotally that they see progress in their children (Hodge, 2008) and there has been further development of the approach within independent schools in the UK, which could be seen as testament to the satisfaction that parents experience. However, there has also been concern expressed over the rigour of the approach and the impact of the Japanese cultural phenomenon of valuing the group over the individual (Jordan et al, 1998).

One notable 24-hour curriculum programme in the UK is the Sunfield Integrated Education and Care Curriculum Approach (SIECCA, Carpenter et al, 2001). This approach is

predominantly but not wholly autism-specific. It promotes the notion of a 'transdisciplinary approach' whereby the unique needs of each pupil are addressed by a team of professionals, by providing an individual programme, but where the roles of each professional are flexible, for maximum effectiveness (Pagliano, 1999). This is combined with the use of a very structured approach, the TEACCH model (Treatment and Education of Autistic and Related Communication Handicaps, Mesibov et al, 2005) which allows for a highly consistent delivery of teaching and care, whereby skills learned in one setting are more easily transferable to another. All staff, including care staff, are trained in the approach and parents are also familiar with it, to reinforce the importance of a consistent approach.

Parental views were surveyed by the developers and found to be positive, highlighting specific factors such as high levels of care, valuing the student, an understanding of the students' ASD and good whole school communication (Chatwin and Harley, 2007). This has links with the earlier findings by Humphrey and Lewis (2008) who also noted that communication and ethos were important for effective inclusion of children with autism in mainstream schools, and of the claims of alternative 24-hour provision such as DLP (Kitahara, 1984). It also acknowledges the 'autism- specific' element, by noting the value of professionals understanding the unique condition.

There is additional, if limited, supporting evidence of the potential gains from the 24-hour curriculum for other areas. It was found to be particularly valued by parents of children with autism, with regard to a means of providing a consistent behaviour management programme and socially, by providing a peer group, although no details of the actual programmes or schools were available for comparison (Abbott et al, 2000).

Similarly, a further review of residential provision in the UK (not autism- specific) including those offering a 24-hour curriculum, found support from parents for the consistent behaviour management and out of school activities that the programme provided (Davies, 2002).

However, it is not clear in any of these studies whether parents are reporting positively as a response to the relief they are experiencing due to their (typically) pre-placement stress and dissatisfaction, rather than to any objectively measured progress as a result of the specialised placement (McGill et al, 2006). More specific research on the efficacy of these placements is therefore required, not least because it is the most expensive form of provision for students with autism but also as it is the most invasive intervention in terms of potential psychological impact, involving as it does removing children from their home and family. The present study is therefore important in exploring parental views of the placement experience, which may provide more information regarding what parents value and find effective in this provision.

Given the significance of the decision to place a child in residential provision, not least for the families involved, the next section considers what is known about the decision making process.

2.4.3 The Decision-making Process for Placing a Child in Residential Education

Placing a child in a residential school is a very important decision but it is an area of public policy with many gaps in information. Incomplete data, which blights this whole area, again makes it difficult to be clear about any generalisations on the subject. Two areas with particular pertinence for the present study are:

- Criteria for placement
- Parental views of the process

2.4.3.1 *Criteria for placement*

The decision to place a child in residential education is taken by LAs, usually with a joint panel from partner agencies (Social Care, Health, Education). This follows the shared responsibilities (including financial) of each agency. The pupil would be likely to have a statement of special educational need, to reflect the significance and complexity of this need and the corresponding required provision.

Most placements to residential schools take place at the transition from the primary to the secondary phase. This is likely to reflect both the gap in specialised provision at Key Stage 3 as well as the frequent escalation of need noted during adolescence, particularly of challenging behaviour, frequently associated with children with autism (National Autism Plan for Children, 2012).

Abbott et al (2000, 2001) undertook a large-scale study examining, amongst other issues, criteria for placement of children into residential schools, from the point of view of social service departments, being the primary department involved. This study took place before the restructuring of LAs into multi-agency Children's Services. As the present study is set following this change, it will be valuable to note any comparisons or changes.

Abbott et al's study had two phases: the first involved surveying the views of 21 local authorities within the UK to obtain broad knowledge about the criteria for placements in residential schools, via semi-structured, face-to-face interviews and attendance at decision-

making panel meetings. The second phase was more focused and looked more closely at decision-making. It also gathered information about parental experiences in just 4 of the original 21 local authorities.

Generally, the reasons for placement this study identified include:

- A requirement for a 24-hour curriculum with consistent provision
- Parents admitting that they could no longer cope with the demands of their child
- The child exhibiting challenging behavior
- The child had been excluded from local provision

It is interesting to note that only one of these criteria represents a positive choice, generated by a logical, educational or clinical reason. Rather, the rest are responses to negative, socially driven outcomes. The needs of parents are not the prime responsibility of LAs, but in the case of parents of very challenging and complex children, where they find themselves under immense pressure, the respite provided by residence is frequently viewed as an important advantage, which may outweigh any potential disadvantages.

Given the anticipated high levels of stress and challenges placed upon families and local provision from such situations, effective and empathetic support from the professionals charged with meeting them is desirable. However, Abbott et al's findings were very disappointing and make worrying reading for those concerned with effective partnership-working between agencies and between professionals and parents. They conclude:

‘the decision-making process that led to a boarding school placement was usually characterised by conflict between parent and authority, and often conflict between the education and social services authority’.

(Abbott et al, 2000 p26)

They report widespread dissatisfaction concerning the lack of clear criteria concerning the reasons for residential placement and varying practices between LAs. This is also noted in other studies (Pinney, 2005, McGill et al, 2006). They found that the decision could be based upon subjective factors, including an officer holding a principled opposition to residential education, or a positive bias towards inclusion, as well as pragmatic factors such as financial considerations.

In particular, one criticism levelled at the process is that of the chief decision makers finding themselves removed from the individual case. Whilst this may be seen as advantageous in terms of making an objective decision, Abbott et al's criticism is that in such complex and unique cases such as those under consideration here, a detailed understanding of each child's particular needs is required in order for a suitable decision to be made, rather than relying on general criteria or the priority being the stated agenda of the LA.

There was also a deep sense of dissatisfaction reported by many of the practitioners involved (social workers and EPs) as they reported being caught in a dilemma of being advocates of the child and working as 'officers of the authority', with a very clear view of the preferred inclusion policy of their managers. This also led to confused messages being transmitted to parents, regarding the appropriateness of provision. Abbott et al's study also found a more undesirable approach used by some LAs, who appeared to support a 'bullying' stance by threatening parents of the stigma of their child being taken into care, if they pursued their course for requesting a residential placement. Parents spoke of feeling 'attacked' and 'persecuted'. Unsurprisingly, the vast majority of parents found the decision making process a very negative experience.

2.4.3.2 *Parental views of the process*

In McGill et al's 2006 study, the typical 'child' was found to be a 15 year old boy with autism, challenging behaviour and an additional disability (therefore with direct relevance for the present study). The method used was a postal survey, followed up by a more detailed telephone interview with fourteen parents. The focus was to obtain information regarding the experiences of families prior to the residential placement, the perceptions of the quality and care provided by the school and the concerns of the families for the future. McGill et al, like Abbott et al earlier (2000, 2001), describe a negative and stressful experience for families who are involved in the process of securing a placement for their child in a residential school (summarised in Table 2).

Abbott et al note that only one parent described the decision making process as a positive experience (Abbott et al, 2000) and the negative experiences of these parents were very similar to those found by McGill et al including feelings of isolation and exclusion, a lack of information and adequate professional guidance and the frustration that their views were not taken into consideration, if indeed they were ever sought (McGill et al, 2006).

The parents in both McGill et al's and Abbott et al's studies reported a different, more positive experience of life post-placement. They cite a sense of relief and of the chance to resume normal family life as positive outcomes (Abbott et al, 2002). There was concern expressed by some parents over the high turn over of staff, inexperience of staff, the quality of care and difficulties with communication in both studies, but the clear impression gained overall was that of relief from very difficult circumstances.

Table 2

Dissatisfaction with: expertise of professionals involved, particularly in relation to autism local support availability of respite care exclusions from school quality of local provision experienced isolation and exclusion	Reasons for residential place: 24-hour care required – for management and consistency unable to cope at home escalation of challenging behaviour excluded from local provision
Gaining a place: a negative and stressful experience arbitrary decision – not based on the individual needs prior inappropriate placements suggestions made by supporting professionals were ‘informal’ conflict with the local authority	Expectations of the future: high levels of concern dreading the process again planning left by the local authority to the last minute worry that the next placement would be inappropriate funding concerns hoped that the next placement would be linked to their existing provision – for continuity

Family experiences of the residential placement process (based on Abbott et al, 2000, 2001 and McGill et al, 2006)

It may be therefore, that parents are willing to tolerate some level of concern about the placement, in exchange for respite from a previously intolerable situation. However, this may not be a wholly healthy situation as it could lead to complacency on the part of parents and professionals, both not wishing to disturb the status quo, for different, but equally understandable reasons. Further information on this complex relationship would be valuable, as would a consideration of ways to better facilitate communication and trust.

Overwhelmingly, the findings from these two important studies are that parents would prefer local provision for their children, but due to the challenges and pressures that their complex needs bring to family life, residential education is frequently the only option. Abbott et al also found that the parents in their study sometimes found themselves in the humiliating position of having to admit they could not look after their child and sensing a feeling of cynicism amongst professionals regarding their motives. Interestingly this study found that there was a marked difference between the views attributed to parents by social service managers and the actual views of the parents themselves, regarding placement. The managers tended to believe that parents had made an early, positive decision for residential education rather than it being the very painful, 'last resort' decision reported by the majority of parents. This illustrates again the important gap in understanding and trust between parents and professionals and the lack of data in the area of parental values and belief systems. Both Abbott et al and McGill et al conclude with a comprehensive list of recommendations for future research in order to improve the situation for children in residential education and in particular, with relevance for the present study, to better support parents through this challenging process.

2.4.4 The Contribution of Educational Psychologists

The main focus of the above discussion has been upon social workers as a professional body. It will be useful to add to this area by exploring in more detail the potential contribution of EPs.

The role of the EP is an evolving one, and one invariably determined by the current socio-political climate (Fallon et al, 2010). During the 1990s the role became narrowed and

dominated by statutory work, but more recently, following the Education Act of 2004 leading to the creation of Children's Services (a multi-agency organisation including social services and education) and the Every Child Matters agenda (ECM), there is now the potential for opportunities to become involved in a wider range of activities and to apply psychology in the community, rather than being largely confined to schools. EPs can be involved in more multi-agency work and preventative and therapeutic work. This could lead to more opportunities to work directly with parents and families in such ways and indeed there is a growing body of research evidence available to demonstrate that this is beginning (Farrell et al, 2006).

This could be viewed as the positive outcome of legislative change. However, it should be remembered that these changes arose directly from a very negative experience – that of the failure of services to work together to safeguard children (Department of Health, 2003). The subsequent report from Lord Laming identified six main points of concern for professionals, four of which are directly applicable to the frustrations that parents of children with autism cite, that is:

- Poor co-ordination of services
- A failure to share information
- Lack of effective training for professionals
- Absence of strong accountability

(adapted from Laming Inquiry, 2003)

Therefore, it is hoped that this present study, considering as it does autism and residential education, can help to contribute to an understanding of the 'distinctive contribution', as

described by Cameron (2006), that an EP can make as a skilled and sensitive interviewer, as an expert in the dynamics of families and systems and as a facilitator within consultations involving the most complex children and their needs. In this way EPs could stake a valid professional claim within an area (residential education) that historically has been the domain of colleagues within health and social care and make a ‘distinctive contribution’ to this important field at a time of increased national awareness.

2.4.5 Outcomes of Residential Education

The discussion of ‘outcomes’ regarding education is very wide-ranging and residential education is no exception. Measures include value for money and progress of pupils, parental satisfaction and success of transitions (Audit Commission, 2007). Here, the latter two areas, selected as two outcome measures having particular pertinence to the current study, will be considered.

2.4.5.1 *Parental satisfaction*

Some studies have attempted to seek levels of parental satisfaction (Carpenter et al, 2003, McGill et al, 2006,). Some report positive views directly related to the provision (Carpenter et al, 2003) whilst others suggest that it is not clear whether the positive reports are due mainly to a sense of relief from the overwhelmingly stressful situation *pre*-placement (Abbott et al, 2000, 2001, McGill et al, 2006). Of the available evidence on efficacy of residential schools, the following have been identified as factors associated with positive outcomes:

- Clear leadership
- Good relationships between children and staff

- Coherent ethos
- Good organisation

(Abbott et al, 2001, Clough et al, 2006, McGill et al, 2006, Berridge et al, 2012)

2.4.5.2 *Transitions*

Successful transition from one phase or type of education to another has particular importance in residential education, the operational elements being potentially more complex and the implications of failure, greater. In McGill et al's study, parents expressed concern and anxiety over what would happen to their child when they reached the age of 19 (McGill et al, 2006) and this was echoed in other studies that found there was no planning for post 19 education, (Smart, 2004, Audit Commission 2007, DCSF, 2009, Wittemeyer et al, 2011).

One of the recommendations from the Audit Commission (2007) is for there to be a longer term view at the start of any residential placement, which would acknowledge the strong possibility that many of the children and young people with the most complex difficulties (which would include the present study's target group) would continue to require specialist, residential provision post-19. The need to hold a longer-term view at the start of residential placements is called for, which should include more work on parents' perceptions. As the size of this group is growing, it is likely also that there will be a need for more adult places in the very near future. This has strategic and financial implications for LAs, again, highlighted by the Audit Commission (2007), but is also the proposed pathway for the larger group of children with special educational needs, in the most recent government legislation (DfE, 2013)

2.5 Parental Experiences of Raising a Child With Autism

2.5.1 Introduction

It is not an unreasonable assumption to make that raising a child with any life-long disability is likely (though not inevitable) to put families at risk of experiencing a negative impact.

Moreover, the particular nature of the impairments within autism, affecting as they do social interaction, social communication and a lack of flexibility in behaviours and thinking, places a particular strain upon parents (and the wider family) as it interferes with expected patterns of interactions between parents and children (Blacher and McIntyre, 2006, Schuntermann, 2007). Challenging behaviour is a frequent outcome reported by families and the review of literature into residential education has already highlighted this as a major factor in the decision making process for a child with autism to enter residential provision, the context of the present study.

It is therefore important to examine the available research into parental experiences in order to clarify why they are important, what these are, why they might occur and what action may need to be taken in the light of this information. This area has recently achieved a higher public profile and is influencing future policy, with calls for more information regarding parents' perceptions of living with a child with a disability, particularly identifying parents of children with autism, to inform policy and increase effectiveness of interventions and provision (Audit Commission, 2007, DfE - Support and Aspiration, 2012). These findings resonate with the recommendations of the Lamb Inquiry (2009), calling for much greater

involvement of parents in the special needs process, to restore their proclaimed lost confidence in the system (DCSF, 2009).

2.5.2 Why is it important to know about parental experiences?

Studies, based on an ecological theory of child development (Bronfenbrenner, 1979), holding that the socio-psychological status of parents has a direct influence on how they interact with their children, have found that when parents are experiencing high levels of stress they are likely to be less effective at parenting and responding to interventions and this may also negatively affect the behaviour of their children, regardless of any disability or additional need (Webster-Stratton, 1990, Anthony et al, 2005, Osborne and Reed, 2008). Studies specific to the parents of autism have also found this (Osborne and Reed, 2009).

As noted above, aggressive and challenging behaviour, leading to increased levels of stress within families, has been identified as a key factor in determining the placement of a child with autism in a residential school (McGill et al, 2006). Therefore, the more that professionals understand about how families in these challenging situations are functioning, including what their world-view and belief systems are, the better the chances of engaging with them and of implementing a successful intervention.

One study to explore this was carried out in Scotland wherein the author, as a result of using a Grounded Theory approach in a study of the perspectives of 10 families raising a child with autism (two of whom were in residential school), found that these parents held a range of sometimes opposing views (Tams, 2001). In particular the author cited the importance of ascertaining whether parents have ‘accepted’ their child’s diagnosis or are still ‘fighting’ in relation to how successful future interventions might be. Understanding parents’ belief

systems and how they have made sense of this life experience is vital, the author argues, if interventions are to be effective.

In a longitudinal study by Gray (2002) in Australia of 35 parents of children with autism, the difference between the perceptions and beliefs of a child's situation, held by parents and professionals, was highlighted. A common difference was that parents attributed a more positive and optimistic interpretation to their child's behaviour than did the professionals. Moreover, Gray found that this belief was important to motivate parents and to keep them involved in intervention programmes (Gray, 2002).

However, the danger of attempting to over-generalise and to make assumptions about parental belief systems from one family to another is also highlighted in this study, which found that although there were similarities between the families' reported experiences, they still perceived their own child's needs as unique. The differences in these parents' experiences were sometimes subtly different, but in other cases very different. The present study is aware of this and therefore does not attempt to generalise but rather to offer parents an opportunity to tell their own unique story. It is unlikely that one approach to intervention would be equally suited or successful with families with differing belief systems, although this may be the prevailing assumption in current autism-specific provision with a 'one size fits all' model.

There is evidence that when parents are more involved in decision making processes and when their views are taken into account they are more likely to engage successfully with interventions, to maximise their effectiveness and to be active participants rather than passive recipients (Beresford, 1994, Rosenbaum, 1998, Tams, 2001). This has also been replicated in

a study of parents of autistic children (Whittaker, 2002). There is currently a strong national drive to seek the views of service users and to develop genuine working partnerships with parents (DCSF, 2009, DfE, 2012). However, there is criticism that in the past attempts to obtain parental views may have lacked conviction. For example, parental views may have been sought, but often retrospectively in order to evaluate services, rather than pro-actively influence them (Wolfendale, 1998). If the recommendations of the new legislation are implemented robustly then it could be argued that the parental voice will have a much greater influence and the complexion of the special educational needs field look very different.

2.5.3 What are the families' experiences?

Autism is a pervasive life-long disorder that has a significant impact on the lives of families raising such children. The manifestations of autism, given its unique but idiosyncratic nature, vary greatly and therefore it is to be expected that there would be a correspondingly wide range of effects on individual families. The research in this area is limited and the studies that are available include those carried out in Canada, the US and Australia, as well as in the UK. However, only a minority of parents involved in these studies had children attending a residential school and the research methods ranged from telephone interviews to in depth interpretative conversations. Interestingly, despite the varied geography and methodology, the findings regarding the nature of the parental experiences have been found to be largely consistent and, disappointingly, overwhelmingly negative. Although many parents do also identify positive aspects of their parenting experience, these are almost always separated from external factors and associated with their love for their child and the richness they have brought to their families (Tams, 2001, Moore, 2004, King et al, 2006, Jardine, 2008).

A useful and positive contribution to the body of parental literature is that of Fleischmann (2005) who researched the experiences of many parents of children with autism from a trawl of parent-support websites. He compared the journey that these parents embarked upon as similar to the stages identified by Catford and Ray as ‘The Hero’s Journey’ (Catford and Ray, 1991). This is an empowering view of parents and describes them as moving from a period of adjustment following diagnosis, to a readiness for action. Following these stages, all parents reported viewing their own position and their child in a more positive light. Moreover, they felt able to support other parents in similar positions, but at an earlier stage in their ‘journey’.

Amongst the negative experiences described by many parents, frustration is a recurring theme. This and other experiences are summarised in Table 3.

Table 3

Negative factors associated with parenting a child with autism
the long and frustrating process of obtaining a diagnosis
the permanency of autism
frustration due to the lack of public knowledge of autism
frustration due to the lack of acceptance of autistic behaviour by society and sometimes by family members
very low levels of social support
extremely disruptive antisocial behaviour

Negative factors associated with parenting a child with autism (based on Tams, 2001, Moore, 2004, King et al, 2006, Jardine, 2008).

2.5.4 Why do these experiences occur?

2.5.4.1 *Coping*

One study (King et al, 2006) was conducted in Canada with parents of children with Down Syndrome and with autism. This involved interviewing parents in focus groups and exploring their belief systems and world-views, following the birth and/or diagnosis of their child. Fifteen parents were involved, their interviews transcribed and thematically analysed. The major findings were that four recurring themes emerged (Table 4).

Table 4

Recurring Themes			
Initial reactions to living with a child with a disability	Adapting over time	Changes in world views and values	Changes in priorities
lost dreams	being spurred to examine beliefs	stronger values	giving up trying to 'fix' the child
a life-changing experience	the importance of hope and seeing possibilities ahead	broader world views	refocusing on the needs of other family members
	gaining a sense of control and empowerment	areas of personal growth	
		learning what is important in life	

How parents make sense of the experience of raising a child with a life-long condition, from King et al, (2006) p358

King et al found that these parents, over time, adapted and changed their views of parenting and their expectations, which supported their levels of resilience and coping. This also appeared to help them to view their situations in a more positive light (a changed world-view that professionals may not have assumed) as well as enabling them to clarify their priorities, and empower them to make decisions in a more informed way. However, unfortunately, the study does not differentiate between the views of the two groups of parents, so any unique

findings in relation to parenting a child with autism are not available. Also, it is not clear about the nature of the autism of the children, nor if any attended a residential school. The present study is designed to explore these specific areas.

2.5.4.2 Stress and psychiatric disorders

Unsurprisingly, the studies that have been carried out on parental experiences have found a high incidence of stress and related psychiatric disorders. One UK study involving interviewing 68 mothers of children with autism, found that 50% faced serious psychiatric distress, which was associated with low levels of informal family support and high levels of challenging behaviour (Bromley et al, 2004). This study carried out individual interviews with mothers using structured schedules and checklists, which were then statistically analysed rather than using a qualitative analysis of the conversations. It is not clear whether any of the children attended a residential school and only mothers were interviewed. The present study aims to address these areas as they are identified as gaps in the body of research.

King et al's 2006 findings supported an earlier US study when higher levels of stress were found in mothers of children with autism than in mothers of children with cystic fibrosis, which is also a life-long disability (Bouma and Schweitzer, 1990). The difference appeared to be associated with the higher levels of challenging behaviour reported by the mothers of the children with autism (Bouma and Schwietzer, 1990). A second more recent US study found that mothers of children with autism had increased levels of stress when compared with mothers of typically developing children, again apparently related to the particular nature of autism as a disorder (Hoffman et al, 2009).

2.5.4.3 *Isolation*

Another frequently reported experience of parents of children with autism was that of isolation. One consistent theme from McGill et al's 2006 study to emerge was that of isolation, described by the authors as:

‘the overriding sense is of their being isolated, excluded and left to get on with a task (parenting) which is too difficult or beyond the expertise of the qualified professionals’. – McGill et al, (2006) p612.

This theme of isolation was also supported in a Canadian study, exploring how autism affects parenting, when 16 families of children with autism were interviewed, using a hermeneutic phenomenological approach (Woodgate et al, 2008). Three themes emerged (‘vigilant parenting’, ‘sustaining the self and family’ and ‘fighting all the way’) with the overarching experience of a feeling of isolation. The strength of the authors’ understanding of this theme is seen as they extend it to the analogy of the parents sharing their child’s *own* experience of ‘living in a world of their own’, created by their autism (Woodgate et al, 2008). The chosen methodology of Woodgate et al’s study, that of hermeneutic phenomenology, enabled parents to share their lived experiences in detail, to help make sense of them and to value them. The present study aims to pursue this further, but with a focus on children in residential education, a group not included in Woodgate et al’s original study.

2.5.4.4 *‘Heightened experience of parenting’*

This heightened experience of parenting is evident in many of these related studies (Abbott et al. 2000, 2001, Fleischmann, 2005, Dale et al, 2006, King et al, 2006, Woodgate et al, 2008)

and is also included in the findings from the study by McGill et al (2006), specifically examining the experiences of parents of children in residential schools, some of whom also had autism. The authors found that those parents in the study who had children with autism and challenging behaviour had a particularly heightened parenting experience. Pertinent to the present study, Abbott et al (2000) reported such parental experiences specifically related to having a child at residential school, for example:

‘I still cry after two weeks when I’ve had her home. I’m still standing at the doorstep crying my eyes out. And I don’t think that’ll ever change. I miss her very much ... it’s very wrenching but we have to do what we feel is best for Rachel as well as what’s best for us’. Abbott et al (2000) p74.

2.5.4.5 *Finding a diagnosis*

Frustration by parents over obtaining a diagnosis of autism is frequently cited in the research (Nissenbaum et al, 2002, Whittaker, 2002, Osborne and Reed, 2008). This is not limited to the experiences of parents in the UK (Quine and Pahl, 1987, Smith et al, 1994). However, within the UK, this frustration is associated with the fact that despite national guidance and local protocols, the process for the identification of autism still varies greatly (NICE, 2011). The most stressful time reported by parents was between them noticing the difference in their child’s development and the subsequent diagnosis (Piper and Howlin, 1992, Hutton and Caron, 2005). Parents report frustration over the actual delay, a sense of their concern going unrecognised, as well as with the procrastinations and apparent lack of expert knowledge amongst the professionals involved (Howlin and Moore, 1997, Whittaker, 2002, Gray, 2003). However, this is despite the fact that studies have found that the earlier the diagnosis the better parents were able to come to terms with the diagnosis and their changed situation (Gray, 2003) and to plan for the provision for their child (Piper and Howlin, 1992).

Many studies report very strong reactions to diagnosis from parents, including – confusion, despair, blame, guilt and depression – although most also report a sense of relief, that they have something to explain their child’s condition and that their concerns as parents have finally been vindicated (Abbott et al, 2002, Gray, 2002, Whittaker, 2002, Hutton and Caron, 2005).

2.5.4.6 *Respite care*

Respite care is the term given to the facility to provide a break for parents from caring for their child with additional needs. This might take place in the home or involve a residential facility. In the UK it is usually funded by Social Care as well as from charities or sourced privately. A limiting factor is frequently financial, however, the particularly challenging nature of autism also makes finding appropriate respite care difficult, as it requires specialist carers and specialist provision. This lack of respite care, which can lead to an unrelentingly difficult experience, is a further area of frustration for parents and a factor in increased isolation and stress reported repeatedly by families (Abbott et al, 2000, Barson, 1998, Loynes, 2000, Bromley et al, 2004, Hutton and Caron, 2005). This point is important in relation to the present study as often, as the literature has shown, it is the difficulty of parents in coping with their children at home (the additional *social* need associated with the complex educational needs) that is a driving force in the recommendation for a residential placement (McGill et al, 2006). It has been argued that if more creative solutions could be devised, including extensive local respite facilities, then the need for residential placements could be reduced (Abbott et al, 2000) as well as reducing the stress levels within these families. The lack of respite facilities was identified and has been addressed in the recommendations

contained within several policy and guidance documents although there is no review of the outcomes of these currently available (DfE, 2007, NICE, 2011).

2.5.4.7 Transition into adult services

The transition from one sector of provision to another, particularly from child to adult provision is frequently cited as a source of frustration for parents of children in residential schools, and has already been mentioned above. It is noted that there are additional barriers to a smooth transition for those individuals with autism, out of the larger disabled population (DH, 2009). Factors that were identified included:

- Difficulties in planning due to the geographical distance of social workers
- Many schools are independent and as such operate outside of national guidance
- Difficulties in accessing the views of the young people
- Difficulties in inter-agency working

This area is highlighted for attention within the most recent national guidance (NICE, 2011), which in turn refers to previously published guidance from the Departments of Health and of Education on transition processes from child to adult services for disabled children (DH, 2006, DfE, 2007).

2.6 What Should be Done? – The Contribution of the Present Study

There are many recommendations for good practice that arise from the literature amongst parents of children with autism, considered in this review. These include those at the

strategic and the operational level. One consistent recommendation is to increase parental involvement in order to obtain a better understanding of their unique experiences. This would be helpful in tailoring services with an increased chance of a successful outcome, as well as valuing and empowering the status of parents. Moreover, specifically in relation to families of children in residential schools, this could inform more effective early intervention programmes, which could then in turn reduce or delay the need for a residential place in the future – an outcome that is overwhelmingly regretted by parents in the extant literature and frequently regarded with professional unease by practitioners, challenging as it does the prevailing discourse of inclusion as the desired outcome for children with special educational needs. The quantitative data on such families is sparse and unclear. The limited qualitative data, that is available, including the narrative and interpretative accounts of parental experiences, provide a richer source of information, though as a group their needs and views are still largely unknown. The present study will add to this body of research, by specifically focusing on the experiences of these under-researched families. This will be useful to parents, their children and professionals, as well as contributing to the continuing debate on inclusion.

Moreover, the evidence from the extant literature points to the experiences of parents of children with autism in a residential school being complex, multi-faceted and concerned with profound feelings, beliefs and life-events. Therefore, the methodology required to elicit and facilitate an analysis of this rich data, needs to be carefully suited to the task. Woodgate et al's study, described in section 2.5.4.3 used a hermeneutical phenomenological approach and surfaced a wealth of rich data from parents of children with autism (Woodgate et al. 2008). Therefore, it is anticipated that within the present study, adopting a similar methodology, this will also be likely to help to uncover data of similar depth and quality. These data will be

both unique to the parents in the study, but have resonance and bring value to the larger special educational needs pedagogy, autism and inclusion discussions. In addition, the chosen methodology is likely to facilitate an exploration of the behaviour and decision-making of parents as well as their responses to the interactions within the education, health and social care systems.

2.7 Research aims

Following this extensive review of the relevant literature, several areas have emerged as worthy of further research and will be explored via the following research questions:

1. What are the experiences of a parent of a child with autism who attends a residential school?
2. How is the current situation with regard to provision, placement and support from professionals, perceived by these parents?
3. How is the construct of 'inclusion' understood by these parents?
4. What are the effective features of a residential placement, from a parent's perspective?

CHAPTER 3 - METHODOLOGY

3.1 Background to the Present Study

The primary aim of this present study is to give a voice to the parents of children with autism in residential schools. Their levels of frustration with the current system, of having their views misunderstood and/or dismissed, if indeed they were ever sought, have emerged powerfully from the review of the literature. In addition, the frustration of both professionals and parents over the incomplete knowledge of what comprises 'residential education for children with autism' and of how the construct of 'inclusion', in these situations, is experienced by the different parties, is a strong theme. Therefore the present study aims to explore the experiences of parenting a child with autism, in particular, the steps leading up to the decision for a residential placement, their interactions with professionals and their experiences post-placement. This will include their values, beliefs and hopes for the future, as well as exploring the direct impact of this significant life event on their own lives as parents, alongside the impact on the lives of their children and on their wider family.

This chapter will consider the rationale for the methodology for the present research, an overview of the theoretical basis of the methodology and the study design. Given the subjective nature of the reflective process involved in the chosen methodology, it was judged appropriate for the next section to be written in the first person.

3.2 Rationale for the Methodology

Examining the lives and experiences of others, in order to foster a shared understanding of their motives, beliefs and values, is a key purpose of psychology. Considering individuals as

they are positioned in their lives, in a holistic way, is also a vital component. More specifically, proponents of community psychology advocate the need for listening directly to the views of the people concerned in order to better inform those working in the field (Orford, 1992, Nelson and Prilleltensky, 2005). Therefore, I judged that a qualitative methodology was appropriate for the present study, as it would allow for the many contradictions of the rich and profound experiences contained within the everyday lives of the participants (parents of children with autism) to be explored in sufficient detail so as to respect and maintain their unique status. A qualitative paradigm is also in fitting with my epistemology as a social constructionist, that is:

‘...a view that social properties are constructed through interactions between people, rather than having a separate existence.’

(Robson, 2011, p25)

Moreover, qualitative research is complementary to phenomenological and hermeneutic approaches, both of which I considered to be necessary components of the analysis of the present study, if the complexity of the data were to be accorded appropriate rigour and respect.

The specific methodology therefore, that I have chosen for the present study is Interpretative Phenomenological Analysis (IPA) – a qualitative research approach committed to the examination of how people make sense of their major life experiences. It is phenomenological in that it explores experiences in their own terms. It requires participants to engage in a considerable amount of reflection on their own experiences. The present study is phenomenological in design, dealing as it does with the lived experiences of individuals, as

uniquely understood by themselves, within their contexts and within their existing life experiences.

IPA is also concerned with interpretation, that is, the belief that the participants, as people existing in the world, will try to make sense of (interpret) their own experiences as they relate them to the researcher. IPA encourages participants to be thoughtful and interpretative. Indeed, IPA uses a reflexive approach, or double hermeneutic, which is, that the investigator also contributes to the research findings by interpreting the interpreted experiences of the participants. I judged this to be vital for the present study for several reasons. Firstly, that I wanted to openly acknowledge that it would be naïve of me to present my analysis as if there had been no influence from my own experiences, in terms of my personal views and prejudices, stated or otherwise. Secondly, and more positively, I wanted to celebrate the experiences that I have acquired, during over 20 years as a practitioner, much of which has been involved with families and individuals with autism. Therefore, instead of attempting to justify or deny my personal interpretations of the participants' life events, which is a likely outcome of analysis of this nature, IPA allows for this to be an additional analytic tool.

However, an interpretivist paradigm may be enriching, but it is also open to the danger of over-simplification or naivety. Holloway and Jefferson caution researchers to be alert to the error of assuming 'truth' in what interviewees provide, citing the fact that in everyday conversations, listeners are always interpreting what is heard and making attributions and judgements based upon their particular experiences (Holloway and Jefferson, 2000). This is particularly true knowing, as a psychologist, the influence of such factors as power relationships, gender, the desire to please and interviewer/interviewee expectations, which are likely to be present in qualitative studies such as the one in question. They argue that, in

research interviews, this subtlety of analysis may be lost and as a result unfounded generalisations may be made. Cognisant of this warning, in the present study I have deliberately selected a methodology, in IPA, that is sensitive to this accusation and is transparent about the influence of interpretation, indeed, embraces this element as a positive contribution to the analysis.

Moreover, the present study acknowledges the value of allowing individuals to tell their story, in a free, narrative way, rather than imposing a structure, and thereby dictating the course and content of the conversation. I therefore chose a methodology that recommends a semi-structured interview technique, but with encouragement to allow divergence from this albeit loose, framework, as the interaction evolves.

Finally, some of the studies critiqued within the Literature Review for the present study also used a hermeneutic phenomenological approach which shared many features of IPA but were routed in disciplines other than psychology. These studies revealed rich and insightful information from parents who share some of the same lived experiences as the parents in this present study (Gray, 2006, King et al, 2006, Osborne and Reed, 2008, Woodgate et al, 2008). This hermeneutic paradigm elicited a very powerful parental voice from within the academic research, which was a model that I wanted to replicate in my own study.

I have argued for the rationale for IPA as the most appropriate tool for this research. However, alternative methodologies, such as Grounded Theory and Narrative Approaches could also have yielded similar data. These approaches were considered but rejected for the following reasons.

Grounded Theory has many qualities that make it attractive as a methodology for the present study. First emerging in the 1960s and explained in the influential text by Glaser and Strauss (Glaser and Strauss, 1967), Grounded Theory is a qualitative approach that is useful for, 'analysing data that is novel and has no pre-existing theories' (Robson, 2011 p146). It usually uses an interview technique and is systematic, but can also be flexible. Analysis of the data involves an inductive approach to coding and extracting themes, by repeated comparisons. This is in order to build a conceptual framework for the phenomenon in question, until saturation level is reached, achieved by a time consuming cycle of repeated returning to the data, advocated by the proponents, as the data in question is frequently complex and puzzling. It uses a purposive sample and is alert to the need for interpretation of the data.

Many of these features are highly suitable for the research aims of my study. However, Grounded Theory does not place the same emphasis on the position of interpretation, as found within IPA. This is in contrast to the defining element of the 'double hermeneutic' aspect of the IPA framework, which openly acknowledges and embraces the inevitable interpretation that the researcher imposes onto the data. I judged the double hermeneutic element to be particularly important for the present study for the following reason. I will be assuming a dual researcher/practitioner role, and my existing knowledge of the parents in the target group in the present study will be limited. This could lead to possible preconceptions or negative attributions, arising from the influence of the inclusion paradigm, under which as a practitioner I work on a daily basis. In this respect, and for this study, IPA is judged to provide as 'honest' a methodology as is available, and is therefore preferable to Grounded Theory.

Moreover, the defining element of Grounded Theory is that it sets out to create ‘theory’, albeit within a constructionist epistemology. However, this is not compatible with my aim in this present study, which was not to seek a new theory, nor to claim any generalisation of the findings to other, similar, but essentially different situations. The stated aims of this study are to consider individual ‘lived experiences’ as a valid phenomenon, unique to each individual, whilst allowing for comparison and contrast with others within the sample. I considered therefore, that an alternative methodology, such as IPA, encompassing many of the valuable fundamental qualities of Grounded Theory, but with essential additional facets, would be better suited to the aims of the present study.

I also considered a Narrative Approach, as it is attractive to the present study, allowing as it does for participants to freely tell their story, with minimum interference from the researcher. ‘Narrative Approaches’ is a broad descriptor for the methodology of the collection and analysis of data based upon the stories individuals use to describe and understand their lives (Cresswell, 2007). There is no particular set of procedures by which to undertake narrative research. It involves obtaining a transcript of the participants’ stories and then coding the data in a non-specified way. One criticism of Narrative Approaches may arise from this freedom, as it could be considered to be focused more on description and to be lacking in analysis (Atkinson and Delmont, 2006). A further criticism is that it relies on memory, which is fallible (Holloway and Wheeler, 2002). However, this is a criticism that could be levelled at all methods, including IPA and Grounded Theory, that involve interviews with people about events in the past and is indeed an inevitable by-product of a social constructionist paradigm. As the researcher, I am aware that it is my responsibility to be sensitive to this during the analysis.

IPA may however, go further to address this potential short-coming of Narrative Approaches (and Grounded Theory) by emphasising the importance of the double hermeneutic element, which demands a very stringent analysis, including a need for reflection and to be reflexive, of the data. Perhaps more importantly, however, IPA is not purporting to achieve ‘a perfect data collection’ nor to achieve a version of events which is ‘the truth’, rather, it is, ‘aiming to understand our participants’ perspectives as best we can’ (Smith et al, 2009, p55).

A more detailed examination of the methodology involved in IPA will now be considered, including the philosophical underpinnings and the practicalities of the particular model selected for this study.

3.3 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is a methodology that emerged in the 1990s, from within the field of health psychology and is one that is increasing in popularity amongst educational psychologists (Crowley et al, 2001, Brocki and Wearden, 2006, Smith et al, 2009 Hefferon and Gil-Roderigues, 2011). It has an epistemology firmly rooted in philosophical principles, specifically phenomenology, hermeneutics and idiography. Key influences include Husserl (1900/1970), the founder of modern phenomenology. Phenomenology is the philosophical approach that knowledge and understanding arises from everyday experiences. This is attractive from a psychological perspective as, phenomenology allows for a purposeful and rigorous examination of the lived experience. However, as Smith et al caution, whilst Husserl had a grand aim of seeking the explanation of the essence of experience, IPA has the, ‘more modest ambition of attempting to capture particular experiences as experienced for particular people,’ (Smith et al, 2009 p16). This is an attractive feature for my own research,

which does not seek to generalise but rather value the unique experiences of each individual's lived experience.

The second strand of IPA, interpretation, or hermeneutics, is vital to counteract the criticism from positivists that phenomenology is inherently a singular experience. The work of Heidegger is very influential here, as his approach was to describe phenomenology as essentially bound up with hermeneutics (Heidegger, 1962/1927). To Heidegger, it is impossible to escape using an interpretative approach when considering any lived experience. He expanded this to include the concept of 'being there', which is his construct of how an experience has to be embodied, and the body to be in the world to constitute knowledge. Therefore, there has also to be a context in which the experience is interpreted and that this context will be different for each individual. IPA not only demands an open acknowledgement of interpretation within an analysis, as the way to understand how sense and meaning is applied to an experience, but also reinforces the value of such by including the 'double hermeneutic' of reflexive interpretation, whereby the researcher reflects on their own interpretations, sense and meanings, of the original, interpreted, lived experience. This demands a spirit of openness from the researcher, to be aware of any previously held beliefs, views or prejudices and to critically consider how these might influence subsequent attempts at ascribing meaning to an experience. As explained above, this makes IPA particularly attractive for the present study.

Finally, the third epistemological element within IPA is that of idiography. This is the study of knowledge concerned with the particular, or individual. This is in contrast to most psychological research which is looking for patterns, or for data that is able to be generally applied to groups or larger populations. IPA, by contrast, is concerned with the *individual*

detail of the lived experiences, therefore demands a very rigorous analysis of the data at this micro-level. However, it is idiographic in a second sense because it is concerned with the *particular* experiences of individuals as a whole, how they are experienced by that individual, in that specific set of circumstances. Therefore, IPA values cases in their own right and does not seek generalisations. It is confident and satisfied with the new knowledge that research by this method can generate, in allowing for a thorough examination and by providing illumination of substantive life experiences.

A further important reason why I chose IPA as a methodology was that once I was satisfied about the paradigm within which I wished to conduct my research, I was concerned to carry through the research with appropriate rigour in order to ensure the findings were of the highest quality. I was therefore reassured to follow, as a beginner to the field of substantive academic research, a guide, such as that advocated by Smith et al (2009). This model does not differ in any substantial way from other good quality presentations of IPA studies.

Rather, they have sought to encompass existing good practice and provide a coherent model, particularly for novice IPA researchers. However, within their model, although there are strong recommendations for how to conduct IPA research, there is sufficient encouragement for the use of individual judgement depending upon the particular context of each piece of research to prevent it from becoming prescriptive. Moreover, Smith et al's model is fully in keeping with the accepted recommendations of other IPA practitioners and answers many of the criticisms of those who caution against a less rigorous and systematic approach (Reid et al, 2005, Brocki and Weardon, 2006, Hefferon and Gil-Rodriguez, 2012).

The procedure that Smith et al (2009) recommend is as follows. As the most important starting point, the research question under investigation must be worthy of such a detailed

examination that IPA demands, in that it must be a substantial life-changing experience that is likely to yield rich and detailed personal accounts. Such sensitive topics elicit emotions and cognitions that are both ‘hot’ and ‘cool’ (Eatough and Smith, 2008), that is, ‘those matters in a person’s life which are burning, emotive and dilemmatic’ and ‘those involving longer-term reflection across the life course’ (Smith et al, 2009 p186). Previous research findings described in the review of the literature for the present study, are evidence that parenting a child with autism does elicit such strong emotions and experiences (Dale, 2006, Osborne and Reed, 2008, Woodgate et al, 2008,) and also from first-hand ‘insider’ accounts (Moore, 2004, Ariel and Naseef, 2006, Rollison and Wright, 2012).

The requirement of engaging with such an emotive topic demands that the participants are willing and able to articulate and reflect upon their experiences during the interview process. Unless there is this depth and complexity of interaction, there is no data to analyse.

The sample for the research must be purposive, that is, it must not be a random sample but be representative of the group with which the research is concerned and be deliberately recruited on these lines. It should also be homogenous. The reason for both of these criteria is to ensure that the sample, ‘grants access to a particular perspective on the phenomenon under study,’ and that they, ‘represent a perspective rather than a population,’ (Smith et al, 2009, p49).

The recommended sample size is always small, to allow for sufficient detailed analysis of the data generated. A sample size of between four and eight is suggested as a guide for the depth of analysis required by the present study as this provides sufficient ‘meaningful points of similarity and difference between participants,’ but does not generate an overwhelming

amount of data, which can then be difficult to manage. (Smith et al, 2009 p51).

IPA requires a method of data collection that yields rich and detailed conversations.

Therefore face-to-face interviews are recommended, with a minimum of structure, to allow for the narrative to flow in the direction that seems most relevant. This requires a level of skill on the part of the interviewer, as, by definition, the areas that are explored within these conversations are intensely personal, meaningful and almost inevitably will arouse strong emotions, as participants reflect upon such life-changing events. I felt that my experience and expertise gained from my practice as an EP, would equip me to successfully carry out the data collection in this way.

Additional data collection, in order to contextualise the main data obtained via the interviews, is also suggested, but is not essential. This may be drawn from a variety of sources including participant observation, questionnaires/interviews with other relevant people, participant diaries and reflective notes by the researcher. However, what is essential is for there to be a verbatim record of the interviews, which enables detailed scrutiny and analysis and also provides a rich bank of direct quotations from the participants, by which to further contextualise the findings.

Smith et al (2009) describe a detailed process for data analysis, which involves very rigorous reading and re-reading of the individual interview transcripts, before attempting to analyse the content and to then conceptualise the findings. The content of the transcript is analysed in two initial ways. Firstly, by looking for ‘exploratory comments,’ which includes, descriptive, linguistic and conceptual comments. This is a way of obtaining what matters to the participants. This body of subsequent additional notes is then further scrutinised to reveal

‘emergent themes,’ achieved by a process of data saturation, by visiting and re-visiting the initial notes in the ‘exploratory comments,’ in an attempt to reduce the content whilst retaining the complexity of the interactions. These ‘emergent themes’ are described by Smith et al as, ‘usually expressed as phrases which speak to the psychological essence of the piece and contain enough particularity to be grounded and enough abstraction to be conceptual,’ (Smith et al, 2009 p92). Finally, these emergent themes are distilled into ‘super-ordinate themes’, through a variety of non-prescriptive methods, which could include abstraction, subsumption, polarisation, contextualisation, numeration or function (Smith et al, 2009 p 97-98). This is in order to draw together the emergent themes and to produce a structure which allows a clear view of the most important aspects of the participants’ accounts. The final step is in looking for any patterns that may emerge across the cases. Smith et al highlight this desirable higher order level of analysis as it points, ‘to ways in which participants represent unique idiosyncratic instances but also share higher order qualities’ (Smith et al, 2009 p101). The resulting analysis should provide a new and enlightening understanding of a particular lived experience, and should, ‘have a satisfactory sense of completion’ (Smith et al 2009, p103).

One long-standing criticism of qualitative research is that it has questionable value because it does not follow a traditional scientific, quantitative method (Robson, 2011). With regard specifically to IPA, there is criticism of it being at risk of being too descriptive and with an insufficient complexity of analysis (Heffron and Gil-Rodriguez, 2012). Proponents of IPA, including Smith et al (2009) defend this accusation by employing Yardley’s four broad principles for assessing the quality of qualitative research (Yardley, 2000). These are: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. Providing the IPA research is conducted with skill and with reference to the

recommendations for the methodology, it is argued that IPA has a sufficiently developed methodology to withstand this scrutiny (Eatough and Smith, 2006, Smith et al, 2009, Hefferon and Gil-Rodriguez, 2012). Specifically, Smith et al defend their model by citing the following: IPA has sensitivity to context because it recommends prolonged engagement with the data, additional data collection, and reflexivity. Moreover, often the nature of the whole research demands and demonstrates an awareness of a need for sensitivity when engaging with participants and with their stories. IPA has commitment and rigour, it is argued, as demonstrated by the interviewer's commitment to the whole interview process and of their awareness of the skills that are required in order to carry this out in a successful way. It is rigorous as the recommended stages of data collection and analysis are substantial, systematic and thorough. It has transparency and coherence as it is recommended that for transparency, a clear audit trail is maintained and presented, and that the final thesis contains many direct quotations from the participants. It can show coherence in several ways, including having a logical framework that produces a coherent whole and by the thesis demonstrating coherence with the chosen methodology of IPA by embracing a phenomenological and hermeneutic approach. Finally, IPA can be consistent with research having impact and importance. In many ways this may be a subjective decision, but Smith et al encourage IPA researchers to aspire to producing research that is 'interesting, important or useful' (Smith et al, 2009 p183).

3.4 Research Design

3.4.1 Ethical Considerations

3.4.1.1 *Ethical approval*

Ethical approval was obtained from the University of Birmingham Ethics Committee. Areas

considered included consent, withdrawal, confidentiality and elements of risk. Appropriate action was taken to minimise these risks, as detailed in the Application for Ethical Review, contained in Appendix 2. Alongside the procedural accounts of the ethical considerations, I have also included, where appropriate, more personal reflection on each stage, in the spirit of IPA. There is also further detail on my experience of the interview procedure in particular, in section 6.1.2.

3.4.1.2 *Informed consent*

Consent was obtained via a letter (Appendix 3) sent to all parents in the school and inviting them to opt in to the research. If there were additional needs such as language or intellectual ability, they were ascertained via information from the head teacher of the school and an alternative format for the letter could have been devised. Once participants were identified, I held a telephone conversation (Appendix 4) to explain that the interview will be searching and in depth, and will have a focus on exploring their feelings. I explained that the results would be published in my thesis, although the participants as individuals will not be identified. I explained that I would be seeking background information about their child from the school, which may involve discussions with their child's teacher. I sought their permission to read appropriate reports on their child, held by the school, as a means of obtaining relevant background information.

Reflection – All parents I approached were willing to take part in the research as described and none asked any questions or indicated any concern over what the outcome of the interview may be, in terms of possible emotional disturbance. As a result of this I experienced some disquiet as to whether I had fully explained the depths to which I was

expecting them to explore during the interview. It was difficult to obtain the correct balance of fully explaining and pre-warning them of the possible emotional impact of the interview and maintaining a factual, objective stance. One particular concern I held was that by asking parents to reflect in such detail on their experience and the decision for residence, it could lead them to reconsider their decision and to possibly disturb the placement. In this respect, I judged that parents would be free to make this decision and that my responsibility was to ensure that the interview was conducted as fairly and balanced as possible. However, no parent expressed any regret immediately following the interview nor when given the opportunity to comment on the summary of my initial interpretation of their interview, which was reassuring.

3.4.1.3 *Dissemination of results*

Feedback was given to the participants via an initial invitation to comment upon my write-up of their interview, which was a synthesis of the proceedings. I sent a written copy to them with an invitation to contact me with their comments, positive or negative. One parent responded indicating their agreement with my summary and I had no response from the other parents. Following the completion of my study I intend to post out to them and to the headteacher of the school, a brief summary of the study, written in plain English, of approximately 1000 words.

Reflection – Writing the summary of the interview was a very challenging task. I felt considerable responsibility to be accurate with facts (as understood by me) but more importantly, I was aware that I was taking the first steps in putting my own interpretation on their experiences. I was extremely apprehensive before posting out the summaries, as I felt

that I had been entrusted with valuable information and I did not want to be clumsy in my handling of it. I wondered how a formal written report would be received, away from the context of the security of the interview room. I was also apprehensive from a researcher perspective, as I was unsure how I would proceed if any parent had questioned my interpretation or had been distressed by it. According to IPA, my interpretation, so long as I had been competent in my practice, would be valid, yet it would be at the very least uncomfortable, if this had been a negative experience for any parent. As reported, only one parent responded to the summary and this was positive. However, this also led me to wonder why other parents had not responded in any way and whether I should follow this up. My eventual decision was to adhere to the original procedure rather than inadvertently put any additional pressure on the parents by making further contact. Inevitably, the completion of the research project has been lengthy and therefore parents are still waiting for the promised summary of the research findings. I am aware that this may seem unreasonable to parents who may wonder whether there was any purpose to their contribution. I did consider making interim contact with the parents, but judged this to be possibly intrusive as this had not been part of their initial agreement. However, I have maintained regular contact with the headteacher of the school, keeping her informed of the progress of the research.

3.4.2 Recruitment of Participants

The inclusion criteria for the participants were that they were parents of a child with autism attending an identified residential special school in the East of England who were judged (by the headteacher of the school) to be intellectually and linguistically able to engage in the interview process. I identified the participants from a list of all parents (twelve families in total) at the school, obtained from the headteacher. These criteria fulfilled the

recommendations for an IPA study, as the sample was purposive and small. I first wrote to all of them (Appendix 3), in order to obtain an expression of interest. The letter outlined the general purposes of the research and invited them to opt into the first stages of the research on an informal basis. The headteacher sent out this letter on my behalf as an indication of her support for the research and as a way of providing an initial indirect contact with the parents, none of whom were previously known to me. I received positive responses from six families. One of these families had a child that attended on a daily basis (a new arrangement in the school of which I was not previously aware) so was thanked for their expression of interest but not included within the main research as this would not have met the essential criteria of involving a residential placement. I informed the headteacher of the identity of the remaining consenting parents and she confirmed that they would be able to take part in the interviews, according to previously mentioned criteria. I then contacted these parents a second time, initially by telephone conversation (Appendix 4) and followed this up with a letter (Appendix 5), providing a detailed explanation of the research and their commitment, should they agree to participate. Parents from all of the remaining five families agreed to participate and a date was fixed with them to conduct the interview. Each parent was given the choice of venue of either their home or their child's school. Each parent chose the family home. I sent out a written copy of the consent form for them to read, sign and return to me on my visit and also enclosed a brief demographic questionnaire (Appendices 6 and 7).

Before meeting the parents I chose to have no prior knowledge of them nor their child in residence, other than that they attended the target school. This was to minimise the risk of forming any preconceptions before the interview. However, I had spent a day shadowing a member of staff at the school so although I did not have any knowledge of specific children, I was able to gain an understanding of the complexity of the needs of the children attending the

school.

Each parent was given the choice (at the time of arranging the visit and a further reminder of this option at the time of the visit) to be interviewed either alone or with their partner (whether this was the child in residence's natural parent or not).

Reflection – I was surprised by the willingness of each parent to participate in this potentially intrusive activity and to share so intimately with a stranger. My decision not to have any prior knowledge of their child meant that, at the beginning of the interview, the initial exchanges were awkward. In retrospect although I had made the decision for methodological reasons, it may have appeared discourteous to the parents, who all chose to view their child as the focus of the interview, even though for my purposes, it was they themselves who were the focus.

3.4.3 The Sample

Details of the sample are found in Table 5. The sample of parents was made up of five families: four mothers and two fathers, with a total of six children in residence. One family had twins attending the school. I considered this as a single interview as the participant for the research was the parent and not the child. One family had an additional child with a diagnosis of autism, but not attending the school. The second child was not specifically the focus of the interview, although inevitably this contributed to the parent's overall experience. This was representative of the prevalence of autism within families found in the general population.

All of the parents were in stable relationships, two with partners that were not the child in

residence's natural parents. Five of the parents (representing four of the families) had additional children, including children from other relationships. This sample is indicative of the complexity of family life in 21st century Britain, although there were no lone parents, which might have been expected. Of the children, four were boys aged 19 (including twins) and one aged 14. One was a girl aged 17. All of the children had additional identified difficulties including severe learning difficulties and extreme challenging behaviour. Other difficulties identified included Tourette's Syndrome, severe anxiety, epilepsy and Attention Deficit Hyperactivity Disorder. Only one of the children had some degree of functional spoken language. This fitted the requirement of being a representative sample as the ratio of boys to girls with autism in the general population is 4-1 and the largest group of children with autism in residence are teenage boys with autism, additional identified difficulties, typically severe learning difficulties and challenging behaviour.

Table 5

Family 1	Mother (Jo), step-father, two younger brothers (one with autism), child in residence , male aged 14 (Taylor)
Family 2	Father (Paul), step-mother, three younger sisters, child in residence , male aged 19 (Connor)
Family 3	Mother (Julie), father (Stuart), two older siblings, child in residence , male aged 19 (Nick)
Family 4	Mother (Lesley), father, children in residence , male twins aged 19 (Sam and Ben)
Family 5	Mother (Sue), father (Brian), one older daughter, child in residence , female aged 17 (Becky)

Details of the sample (all names used are aliases)

Three mothers chose to be interviewed separately. One mother initially chose to be interviewed separately but then invited her partner (the child in residence's natural father) to

join mid-way through the interview. One father initially chose to be interviewed separately but then allowed his partner (not the child in residence's natural mother) to join the interview early in the proceedings. One set of parents (both the child in residence's natural parents) agreed to be interviewed separately. This resulted in six separate interview transcripts.

I chose to include this variety of participants within the interviews to gain a broad view of parental experiences. Particularly it was advantageous to include fathers, both within joint and single interviews as theirs are points of view that are lacking in the literature. Step-parents were also included as their experiences were judged to be relevant as a comment on the recent and current experiences, even if they were not involved in the earlier phase of the family.

Table 6

Category	Information
Ethnicity	Caucasian
Age of parents	Range: 34-59 years
Work status of main carer	Full time =1, Part time =3, Does not work =2
Pattern of interview	Lone mother = 3, Lone father = 1 both parents = 2
Time taken to reach school from home	Range: 0.5 – 1.5 hours
Length of time child has been in residence	Range: 2-4 years
Statement of Special Educational Needs?	All children in residence
Number of Local Authorities represented in the sample	4

Further participant information

3.4.4 Data Collection

Prior to the formal IPA interview process I made preparations which included familiarising myself with the literature on parental experiences of raising a child with autism, as directly reported from ‘insider accounts’ (Moore, 2004, Ariel and Naseef, 2006) as well as drawing upon my experience of over 20 years experience as a practitioner, much of which has involved a specialism within autism and working with parents of children with a range of other complex needs. This was in order to further develop my sensitivity to issues that families may be experiencing as well as developing my empathy with their situation. I also carried out preliminary pilot work to provide contextual information with regard to the school, which included designing and administering a semi-structured interview for use with the headteacher to explore her views of parental involvement and also a self-completion teacher questionnaire exploring perceptions of parental involvement within the school.

IPA encourages the collection of data other than that obtained directly from the interview with the key participants. There was a risk that in familiarising myself with the school I may have unknowingly allowed myself to be influenced by the views of the staff and the ethos of the school, which could have affected my ability to be open to the parents and their experiences in their interviews. However, I attempted to be explicit about this danger and to openly acknowledge it during the analysis. I felt that the additional contextual information that I gained from the interviews outweighed the risk.

3.5 Procedure

A summary of the whole research procedure, including collection of data and analysis is presented as a timeline, in Table 7.

3.5.1 Design of the IPA Questionnaire and Interview Schedule

The length of the interviews lasted from 50 minutes to 1 hour 15 minutes and were conducted in the participants' own homes for their convenience, comfort and security, given that the topic of conversation was of a potentially sensitive nature. All interviews were audio recorded and later transcribed verbatim. Semi-structured questionnaires are recommended as the most useful tool for conducting IPA research as they allow the participant to share their stories in detail and to elicit thoughts and reflections about their emotions and experiences (Reid and Batten 2005, Smith et al, 2009).

Table 7

Date	Activity
March 2010	Contacted headteacher of school expressing initial interest
June 2010	Conducted the pilot study, including the semi-structured interview with the headteacher and the self-completion questionnaire by a member of the teaching staff
June 2011	Explained the research proposal to the headteacher
June 2011	Contacted the owners of the school to explain the research and secure their approval
June 2011	Invitation offered to explain the research to the staff at the school via a meeting (this offer was declined as the headteacher preferred to introduce the research herself, using a provided script)
June 2011	Letters sent out to all parents in the school inviting them to express an interest in the research
July 2011	Expressions of interest received from 6 families (one family not included as did not fulfil the essential criteria of child being in residence)
August 2011	Ethics form submitted to University of Birmingham and agreed
August 2011	Semi-structured questionnaire designed
September 2011	Telephone conversations with representatives of the five remaining families to explain the research and their commitment in more detail
September 2011	Written details of the research, consent forms and demographic questionnaire sent out to families
October-December 2011	Interviews took place
December 2011-March 2012	Interviews transcribed and analysed
March 2012	Summary of interview findings (pre-analysis) sent to each family and their comments invited
August 2012	Preliminary findings presented to EP colleagues for moderation

Timeline of Procedure

They provide a structure as a guide, but are sufficiently flexible to encourage deviation from this if the participant's responses require it and to allow for particular areas to be probed further, as required. They are easily managed, encourage rapport between the interviewer and participant, allow participants to think speak and be heard and are conducive to the rich discussion that such complex subjects demand (Reid and Batten, 2005).

A copy of the interview schedule used in the study is in Appendix 8. The questions were designed to be open-ended and to elicit factual ('How did your child arrive at the school?'),

reflective ('What are your hopes for the future?') experiential (Tell me about your child's experiences of school before going to residential school?') and contextual ('What do you like about how the school works?') information relevant to my research questions. There were a total of eighteen questions in the schedule, including a broad open-ended introductory question ('Tell me about (child's name)'). This was included to allow the participant to set the scene rather than the interviewer, as recommended by Smith et al, 2009. There was also a general concluding question encouraging reflection on the interview experience itself ('How have you found the experience today?'), included to check for any potential distressing consequences as well as to gain feedback on my own performance. Each question had additional prompt cues, to use to clarify the original question ('Can you remember how you felt at that time?' 'Can you tell me a little more about that time?') and to enable the participant to provide as much information as they were willing and able to share.

I was aware of the need to put the participant at ease in the interview by reminding them at the start of the process that I was interested in their own experiences and that there were no right or wrong answers to the questions. The participants were encouraged to take their time over their responses and to feel comfortable in returning to previous questions if they had additional comments to make.

The order and nature of the questions were designed to be chronological in nature, in an attempt to apply structure to a complex situation, although these could be varied if the situation demanded. The schedule was reviewed by a colleague and modified for clarity prior to administration.

Immediately after the interview I made contemporaneous notes of my impressions of the

interview, to be used as additional contextual material when completing the analysis (Appendix 9).

Reflection – I was not prepared for the level of emotion present within the interviews and at times I was concerned that I had intruded into highly personal areas and that possibly I was ill-prepared to deal with the consequences. I was profoundly moved by the depth of feeling that many parents expressed. This was possibly a reflection of my pre-judgment as to how the parents would view their situation – of relief and satisfaction rather than of the extreme trauma and on-going painful adjustment that was their reality. I was also aware that I was a very fleeting visitor who would be leaving each family to manage the ‘shift in equilibrium’ resulting from the interview process on their own, as I left with my ‘data’. This led me to reflect on the wider ethical issues associated with such intrusive research. However, each parent commented positively or at least neutrally about how they had felt about the interview which provided me with some reassurance as to the impact of the experience.

3.6 Analysis

The data were analysed using IPA and specifically following the model described by Smith et al, 2009 (Table 8).

Each transcript was analysed individually before any consideration of a comparison with other cases was made. This was in order to respect and value the worth of the findings from each individual, one of the main aims of IPA. Each audiotape was transcribed personally, which involved considerable engagement with the material prior to analysis, as well as firmly establishing the participant’s ‘voice’ in my head, both literally and metaphorically.

Table 8

STAGES OF ANALYSIS
Individual level
Transcribe the interview from the audio tape
Analyse each transcript individually
Note any points of interest
Code the transcript using the headings of exploratory, linguistic and conceptual comments
Emergent themes are identified
Super-ordinate themes emerge
Repeat the process with the remaining interviews
Whole study level
Look for patterns across the cases
Identify to what extent super-ordinate themes apply to each participant

The IPA Analysis

During this time, anything of interest regarding the interview, was noted. I was not attempting to conduct a detailed discourse analysis of the material, but linguistic aspects such as pauses, tone of voice, visible emotion and movement in or out of the room, which provided additional context, were included. Once the transcript was complete, I followed the model of coding described by Smith et al (2009). This is a move from the descriptive to the interpretative and an excerpt is included in Table 9 for illustrative purposes.

The exploratory comments were further subdivided into three: descriptive, linguistic and conceptual comments – in order to thoroughly examine the content and begin the analysis process. Following this, by using the original transcript, the first stage of analysis gained from the ‘exploratory comments’ and an overall growing knowledge of the interview as a whole through initial noting, the third stage is reached, that of identifying emergent themes.

Table 9

Exploratory comments	Original Transcript	Emergent themes
<p><i>Intuition, 'there was something not right'</i> <u>Running away with the story, did it seem like things were happening fast then? As if they were losing control, handing over to professionals?</u></p> <p>Becky was diagnosed early – <u>was this due to connections in the air force?</u></p>	<p>I -When you were wondering about things...?</p> <p>B -There was something not right, but we didn't, I mean we didn't at the time suspect at all that it was autism as I say at first we thought she's got a hearing problem, but after that was tested, well we were up in (air base) at the time I was in the air force and we were stationed up there and it started to be investigated and we told the doctor in the hospital about it and we got posted down to (new county) and she happened to know a doctor in the local hospital and she actually referred her to that doctor, the doctor who gave the diagnosis that she was autistic and she was able to do it at a very young age, she said normally you can't diagnose this until I think she said about 4</p> <p>I -Yes, around then</p> <p>B -But she said, 'I've no doubt she's showing <i>all</i> the traits'. She did think that she would probably have speech, but unfortunately she never really had and she said the chances are she'd be a bit eccentric</p> <p>I -Right</p> <p>B - But again, it's been somewhat worse than that</p>	<p>Parent intuition</p> <p>The journey of autism</p> <p>Loss of expected child</p>
<p>The diagnosis was not very accurate and may have given Brian false hopes</p> <p>Understated, <i>'it's been somewhat worse than that'</i></p>		

Excerpt from IPA process of analysis of interview with 'Brian'

Key: I = Interviewer, B = 'Brian' (parent). Plain text – descriptive comments, Italics – linguistic comments, Underlined text – conceptual comments

This is when interpretation is becoming more to the fore and the influence of my knowledge of the impact of autism and of having a child in residence on the family is more visible. The emergent themes should capture the essence and understanding of what is said within chunks of narrative, whilst retaining a sense of belonging to the 'whole' – they should reflect the participants' own words as well as my interpretations – thus illustrating the interpretative and phenomenological elements of the process.

The final part of IPA analysis of the individual transcript is to find the super-ordinate themes. This is where the double hermeneutic element of IPA is introduced into the analysis, when I as the interviewer, make my interpretation of the participant's experiences. It is a way of mapping out how all of the emergent themes fit together. To do this I listed each of the emergent themes separately on paper and physically moved them around until those that were attracted to each other, or were in opposition to each other, suggested an over arching or super-ordinate theme to capture the essence of that group. Themes were not decided upon solely by their frequency, but also by their intensity and richness.

This process was then repeated in the same way with the other five transcripts.

Once a collection of super-ordinate themes for each participant was obtained I looked for patterns across the cases. I did this by looking across at each set of super-ordinate themes for 'key objects of concern such as relationships, processes, places, events, values and principles' (Smith et al, 2009 p83).

Once this was obtained I was able to consider to what extent each super-ordinate theme applied to each participant in the study, by taking each theme in turn and looking for evidence

from each participant to support each theme. This was in order to present, ‘a clear and full narrative account’ of all I had learnt about the participants, as recommended (Smith et al, 2009 p110).

3.7 Validation and Reliability

I had regular contact with an external supervisor experienced in qualitative analysis and a colleague experienced in discourse analysis who were able to help me to review the analysis and provide input into the coding process. I presented my findings to a group of EPs, for their comments on the above, but in addition, on the ‘face validity’ of the findings and my analysis, to borrow a term from quantitative research, in order to check that my interpretations had resonance with their own professional experiences.

Finally, I invited my participants to comment on my interpretations of their interview by sending them a summary of the initial interview. This was prior to any formal analysis but did include my initial interpretations. This was following recommendations in IPA research, including from Willig (2001) that participant involvement is a mark of quality for qualitative research. This is also consistent with the ethos of community psychology (Orford, 1992) that advocates collaboration in research with participants and also as an acknowledgement to the recent calls to increase parental involvement with the special needs system, referred to in the literature review for the present study (Lord Laming Review 2009, DfE 2012).

CHAPTER 4 – FINDINGS

4.1 Introduction

Four super-ordinate themes emerged from analysis of the transcripts. These were:

- enduring loss,
- the family versus the system,
- heightened parenting
- the relief of residence

In all cases the temporal context had a decisive role as eventually, the families moved from a negative pre-residence stage into an overwhelmingly positive post-residence experience.

However, for all, there were already the signs of a regression to the pre-residence negative experience as parents contemplated the next stage of their child's education, into adult services.

4.2 Rationale for the super-ordinate and sub-themes

4.2.1 1st super-ordinate theme – enduring loss

The construct of 'enduring loss' is taken to express the intense and on-going experience of loss, described by all parents. This began with the first suspicions about their child having some difficulty, to the decision for them to go into residence. Therefore, it is a 'loss' in physical or tangible terms, that is, the absence of their child from the family home or loss of income due the constraints of caring for their child. However, it is also symbolic, in terms of loss of the 'expected' child and life and a loss of identity, that parents reported as having experienced, at different times and to varying degrees. This was seen in accounts from parents who felt they were not perceived, or did not perceive themselves, as being a 'full'

parent, that is, one who takes care of their child and does not cede parental control to another. Emergent themes that contributed to the formation of this super-ordinate theme included unresolved loss, isolation, conflict of emotions, regret, despair, sense of loss, guilt and devastation.

4.2.2 2nd Super-ordinate theme – the family versus the system

This construct is designed to capture the on-going ‘battle’ that all families reported in their dealings with authority (including practitioners and professionals in positions in power). Their comments had a very strong theme of ‘us against them’ that continued throughout the narratives, even after residence. Emergent themes that led to the formation of the super-ordinate theme included frustration, battle, anger, pragmatism, defensive, advocate, isolation and sacrifice.

4.2.3 3rd Super-ordinate theme – heightened parenting

The construct of ‘heightened parenting’ is chosen to reflect the intense, enhanced and amplified experience that parenting a child with autism is, as described by these parents. It represents the ‘super’ parenting that is required, whereby extreme vigilance, effort and attention is required in order to fulfill the parenting role. Emergent themes that led to the formation of this super-ordinate theme include ‘expert’ parent, sacrifice, abandonment, advocate, frustration, pragmatism, determination, reconstruction and protection.

4.2.4 4th Super-ordinate theme – the relief of residence

The construct of ‘the relief of residence’ captures the enormous change in the lives of the families, as they describe their experiences post-residence. Each narrative had two distinct

parts, pre and post-residence, and relief was the overwhelming emotion expressed. Emergent themes that led to the formation of this super-ordinate theme include empowerment, relief, community, restoration, acceptance and hope.

Within each super-ordinate theme certain of the sub-themes that emerged overlapped the super-ordinate themes, which added to the complexity of the analysis, as illustrated in Table 10. In addition, although each of the super-ordinate themes emerged as separate entities, their full resonance can only be appreciated by considering them as they interact within the overarching context of the impact of autism, parental unconditional love for their child and of the intense and enduring nature of each parent's experience (Figure 1).

Some strong themes, such as 'transition', emerged from all the narratives, but were not included as a separate super-ordinate or sub-theme. In the case of 'transition' it was considered more effective to address this under the super-ordinate themes of 'the family versus the system' and 'heightened parenting' where the underlying affects of fear, frustration and sense of abandonment, for example, associated with the anticipation of the transition process, could be explored. Some sub-themes within these super-ordinate themes arranged themselves along opposite poles, moving in a positive direction post residence. These included isolation-community, conflict- restoration, frustration-relief and abandonment-acceptance. Additional non-polar sub themes included identity, the impact of diagnosis, the impact of residence, loss of expected child and family life, abandonment, the 'expert' parent and the 'sacrificial' parent. Many of these sub-themes crossed over the super-ordinate themes in different guises, depending upon the context (Figure 2).

Table 10

Super-ordinate themes	Sub-themes
enduring loss	loss of the expected child loss of the expected life the impact of diagnosis the impact of residence identity
the family versus the system	frustration conflict abandonment isolation
heightened parenting	'expert' parent 'sacrificial' parent 'reconstructed' parent
the relief of residence	relief restoration acceptance community

Parental experiences of having a child with autism in residential education - emergence of super-ordinate and sub-themes

The Impact of Autism

Unconditional Love

Intense and Enduring

Having a child with autism in residence

```
graph TD; A((Enduring loss)) <--> B((The family versus the system)); A <--> C((Heightened parenting)); B <--> D((The relief of residence)); C <--> D;
```

Enduring loss

The family versus the system

Heightened parenting

The relief of residence

Figure 2

	Pre - residence (negative)	Post - residence (positive)
Sub - themes	Isolation	Community
	Conflict	Restoration
	Frustration	Relief
	Abandonment	Acceptance

85

4.3 Reflections on the Findings from the Individual Analyses

As noted in the methodology, all of the interviews were analysed individually before being integrated to find the super-ordinate themes. However, it was important in this process that the unique experience of each family was not subsumed in the macro-analysis. The super-ordinate themes previously considered, were present in all accounts. However, they were more evident in some than in others, due to the particular life experiences of each family. This created some difficulty in deciding which should have the most prominence. Similarly, some emergent themes were an important component of some accounts but not of others and a decision was therefore made not to include them in the main analysis as a super-ordinate theme. It was also important to maintain the clarity of the analysis whilst balancing the complexity of both the breadth of individual themes and those that were identified as super-ordinate. Therefore, in order to include the idiographic element, key to a successful IPA full transcripts of all of the interviews are contained in Appendix 10. In addition, the individual themes that emerged in each interview, are reported in brief here in Table 11, but are also recorded in full in Appendix 11, showing their relationship to the super-ordinate themes. Finally, a summary of one interview, identifying key themes, in a narrative form is found in Appendix 12 and a full transcript of the interview is found in Appendix 13, showing the stages of IPA – the exploratory comments and emergent themes. These are included as it grounds the data in the human story, that could otherwise be lost as the analysis drifts further away from the original source, even an analysis that has sought to be rich in direct quotations.

Table 11

Individual accounts of parents	Main emergent themes
Lesley	unresolved loss isolation sacrifice conflict of emotions empowerment advocate frustration regret battle relief
Paul	frustration anger despair sense of loss regret conflict of emotions battle relief
Jo	pragmatism determination defensive frustration battle unresolved loss relief
Brian	guilt unresolved loss advocate conflict of emotions frustration battle relief
Sue	pragmatism determined advocate frustration sense of loss conflict of emotions relief
Julie and Stuart	unconditional love sense of loss conflict of emotions protection devastation frustration relief

Summary of main emergent themes from individual accounts

It is important to keep these individual stories in mind as the IPA macro-analysis unfolds and is described in detail below.

For information, each quotation is identified by number, and can be referenced in the full transcripts contained in Appendix 10

4.4 Super-ordinate theme – Enduring Loss

‘... but you just feel a failure as a parent because you feel well, I should be able to cope, ‘cos she’s our child and why, why have we had to resort to this?’ *Sue (84)*

All parents identified loss at different times during their experiences. It began with the painfully recalled loss of their expected child, to the loss experienced as a result of their decision for residence. Sometimes this loss was tangible, as when their child was physically separated from the family or when a marriage broke up or a job was sacrificed. More often it was powerfully symbolic, associated with loss of identity and expectations, illustrated in the lives of the families in a myriad of ways.

4.4.1 Sub-theme – Loss of the Expected Child

This sub-theme was present in all families:

‘cos you have expectations don’t you when children are born don’t you and then suddenly all those expectations change, they’re no longer like the normal ones, leave school, go to uni, get married or whatever, that’s never going to be the case, so all your hopes had sort of tumbled down around your ears, so all you could hope for now was that they had all the help that they needed, that they would be happy, safe, you know and actually have some purpose’. *Lesley (210)*

Lesley is also speaking about how her ambitions for her boys diminished, following the realisation that they had autism, abandoning previous hopes of an independent life with a family and a career, for the more fundamental needs of safety, positive well-being and to ‘have some purpose’.

These were echoed by Jo, whose hopes were linked to her job as a nursery nurse:

Really, I don't know cos I suppose a bit disillusioned, because I had all these, because I'm a nursery nurse, well, I still am, I had all these plans and all these ideas in my head about how we were going to do things, and we were going to read together and we were going to do this activity, and none of that was happening, so I was really, really you know, severely disappointed, totally upset and I still am now. I have not coped with losing that baby that I had. *Jo (18)*

Lesley's comments also capture the conflict of emotions and confusion that all parents shared at the realisation of their altered situation:

Initially we couldn't (understand) because they were our own only children, and I felt we'd done something wrong, I felt like that to begin with, 'cos I thought was it something we'd done cos I didn't know what autism actually was. *Lesley (210)*

Paul's loss was linked with the hopes that he had, as a father for his 'first born son'.

Devastated, more so than anybody.....first born wasn't it? *Paul (35)*

Four parents shared an element of denial in the days pre-diagnosis:

Distraught I think (laughing) cos although I knew, Martin (husband) knew as well I think, although we both tried to sort of, erm, put it aside sort of thing, until a professional rubber stamps it, you've always got hope haven't you, that you're wrong, but we both knew that we were right. *Lesley (22)*

There was something not right, but we didn't, I mean we didn't at the time suspect at all that it was autism as I say at first we thought she's got a hearing problem. *Brian (2)*

Yeah, if you speak to people now they'll say, 'Yeah well if you remember he was a bit too good as a baby and if you remember he did this and he did that', so yeah, there were earlier indications that we think there might have been a problem, but he was my first baby and I wasn't sure about babies... I'd never seen babies... *Jo (2)*

Sue, like the other parents, had an intuition that something was wrong, but had yet to admit it to herself:

...and then they diagnosed Becky as being autistic, which we kind of knew at the back of our minds. *Sue (1)*

Stuart's comments encapsulate this acknowledged underlying discourse of denial, but which was only articulated in a powerful but simple way as an enduring wish, by he and Julie, as Nick's parents:

...well, we've always thought that we'll go to sleep one day and he'll wake up normal haven't we....? *Stuart (389)*

4.4.2 Sub-theme - Loss of the Expected Life

In the early stages, all the families were pre-occupied with the immediate needs of their child. However, as they began to come to terms with the loss of their expected child, they also began to realise that they had lost their expected family life, especially for those with other children:

Everybody was suffering, these (Paul's daughters) couldn't have friends round, or have a proper nights sleep, everything was fractured. *Paul (119)*

I think the other two got left out quite a lot to be quite honest, Nick always needed me more. *Julie (358)*

...but it's not all about Taylor, I've got two other children as well. *Jo (58)*

We couldn't let Emma (sibling) have sleepovers here when, you know, when she was younger, so we did feel bad. *Sue (71)*

...but he was being aggressive towards him (Taylor's younger sibling). *Jo (58)*

Several families talked about the arrangements and compromises they were forced to make in order to manage the needs of their child – taking them further away from their expected family life. Jo describes Taylor's increasingly difficult behaviour:

...and he was getting aggressive towards me, he was getting quite destructive at home, and it was the slightest change, I mean even if something like just going into town or to

go to a supermarket, which some people could do quite easily, it wasn't easy anymore. *Jo (58)*

Paul's partner describes how they had to split the care for their children, a coping arrangement also described by Jo and Sue:

...it was Paul looked after Connor and I looked after the girls, really wasn't it? *Paul's partner (336)*

...erm, when she has outbursts, she'd have them good and proper, and what would happen is that if Brian was at home, then me and Emma would go upstairs and Brian would deal with Becky and try and calm her down, we just got out of the way. *Sue (65)*

Holidays in particular were a difficult time:

... but we decided after this year we're never doing it again. If we take Taylor out, we'll take Taylor out alone, and if we go on holiday and Taylor needs a holiday, we'll take him alone. *Jo (73)*

I mean you'd see that taking him on holiday wasn't really a holiday with three young kids – and Nick as well, it was just all systems go...we couldn't do it now because of our age, we could not do what we used to do I mean when he went to sleep everyone went to sleep, to catch up with him, 'he's recharging, quick!' *Julie and Stuart (251-253)*

It was that bad and we were so worried 'cos we didn't know whether they'd actually let us on the aeroplane (laughs) and we thought, 'oh god', and we thought, 'well, we'll not, never take her again.' *Sue (75)*

Christmas is a terrible time, Christmas is always a terrible time, I hate Christmas cos you can't have decorations up or anything' cos they tear them all down. We used to have a Christmas tree and they'd just pull it down. *Lesley (39)*

The pathos in these remarks is also starkly contrasted with the expected joy that events such as holidays and festivals normally bring.

In only one family, was the impact of having a child with autism cited as leading directly to marital breakdown:

Well, that's why we're not together, 'cos he's (Taylor's father) never really accepted....(the diagnosis) *Jo (35)*

In one family the parents have separated but there is no evidence that this was directly related to having a child with autism and for the three other families, both parents have remained together and share in the care of the child.

4.4.3 Sub-theme – Loss of Identity

Loss was also experienced in terms of the identity as parent and advocate for their child.

This was sometimes as a consequence of other agencies becoming involved and holding the power for making important decisions affecting their children. For Sue, it was the special school Becky was attending:

...and then they said in 2002 that it wasn't the school for her, and to look around for something else, that was at the annual review they told us, so that was a bolt out of the blue... *Sue (3)*

In Julie and Stuart's case, it was the police and social services who had to deal with Nick when he was experiencing severe challenging behaviour:

It was really, really frightening, it was awful, I mean the house would be in tatters and I'd call social services 'cos I didn't have a social worker at this stage, or didn't know who they were anyway and then they started coming onto the scene and I'd phone them up when he'd had these 'nutties' and they couldn't come out or whatever or it was the wrong time of day or night or something and they told me I had to call the police, which I had to, because I was here on my own a lot of the time and I couldn't handle it and the police would come, and of course they had no idea what they were dealing with, how they were going to handle it, they were almost ready to give him an ASBO and cart him off, you know... *Julie (34)*

For others this loss of identity as a parent was experienced as helplessness and failure:

... but you just feel a failure as a parent because you feel well, I should be able

to cope, 'cos she's our child and why, why have we had to resort to this (residence)?
Sue (54)

For Paul, coping on a nightly basis with Connor's double incontinence, he described this loss of identity as a painful moment of realisation:

It was 4 o'clock in the morning and I just said, 'I can't do this.' *Paul (102)*

For others, guilt was also involved:

Initially we couldn't (tell our family) because they were our own only children, and I felt we'd done something wrong. *Lesley (210)*

Paul felt very strongly that he had lost his identity as Connor's father as a result of the residence and regretfully described himself as a:

...part time dad now, – towards him (Connor). *Paul (408)*

Four parents vividly described the loss of identity of their child when the impact of their autism appeared to transform them into another individual:

The real Nick is a very, very happy child, difficult, he's obsessed with videos, I think most of them with autism are, obsessed with like Disney videos and things and whilst things are going Nick's way, and he can more or less do what he wants to do, he's the happiest child, he's gorgeous, he's lovely. *Julie (6)*

This is contrasted with the description of Nick when he is in a rage, associated with his autism:

...then he goes completely berserk and then he attacks people attacks me, attacks anybody who's near him, people, staff, us.... and then he'll calm down and he's our Nick again, cos he isn't Nick while he's in one of those things, he isn't Nick at all.
Julie (3-4)

Paul movingly describes the contrast between the 'real' Connor and the Connor that is seen when he is agitated and distressed:

Very loving, loves contact, loves being around people. *Paul (7)*

In the beginning, he only hurt himself mildly, you could manage it, but when he approached puberty he went nuts, it must have been the hormones, or something...and he was just intent on hurting himself all the time. *Paul (11-13)*

Jo needed considerable prompting to recall any particular strengths of Taylor's:

Strengths, I don't...that's a hard one really...he's got this strength, it's like a photographic memory, or like a good long term memory that comes out now. At the time he can't tell you what's happened, but years later he's recalling things, when he's three or four, and I've forgotten all about them. *Jo (4-6)*

She was however able to recall many distressing incidents, when the impact of Taylor's autism was evident:

Well, all hell broke loose, he's screaming he's in his bedroom, he's banging windows, throwing everything around in his bedroom... *Jo 155*

Sue describes how Becky could be calm and enjoy the experience of flying on a family holiday:

...so it was quite easy and she liked the aeroplane and she liked, you know the whole, you know, being in the pool at the other end... *Sue (78)*

But this changed as she reached puberty and demonstrates similarly very challenging behaviour, as related by all of the other parents in the study:

...and she just went berserk and it was only because there was like an ex policeman that helped restrain her and we managed to like get her into a wheel chair and she was just like grabbing all the time she'd been pulling Brian's ear, she'd gone through it a few times, she'd gone for his ears, and it was all cut at the back and his face was all cut and when he got back to work people thought he'd been in a car accident. *Sue (75)*

The matter of fact way that these distressing episodes are related is symbolic of the distance the parents have travelled away from 'normality', that they no longer appreciate the impact of these statements on those not also living their experiences.

4.4.4 Sub-theme - The Impact of Diagnosis

The impact of diagnosis emerged as a separate sub-theme from the loss of the expected child, as there were manifestations of 'loss' specifically associated to the way the diagnosis process was experienced. Four parents described a perceived subterfuge by professionals, leading to a loss of control for the parents, at the time of the diagnosis, when they felt that they were not given a clear diagnosis or prognosis.

Paul's experience was one of growing dread and he describes his feelings during that period of uncertainty prior to the diagnosis as:

...gutted, absolutely gutted, I knew something was wrong because he wouldn't say, the consultant wouldn't say.... They never said, they'd never say, 'don't worry, it'll be something he'll grow out of, it was always a case of, 'you'll have to bring him back for more tests.' *Paul (31-33)*

Julie and Stuart shared a similar experience:

...we took him to the doctors and they didn't really want to say anything, but they did tests on him and things and it became clear, though they said he was on the autistic spectrum, or that he maybe, you know, and I didn't, I thought, oh, autistic tendencies, that's not very much. *Julie (12)*

Brian recalled what the consultant said and, like Julie, also had false optimism as a result of his interpretation of the prognosis. His ironic comment on the eventual outcome for Becky is powerful and experienced more sharply as a loss, as a result of the initial hope he had been given:

She (the consultant) said, 'I've no doubt she's showing all the traits (of autism)'. She did think that she would probably have speech, but unfortunately she never really had and she said the chances are she'd be a bit eccentric, but again, it's been somewhat worse than that... *Brian (10-12)*

Lesley's experience with her twins was with a cautious health visitor:

They actually passed their 18 month check, the health visitor passed them which I was amazed as I thought they needed a fair few words but she said, 'well they're premature, they're boys, they're twins, they'll be slow.' *Lesley (10)*

Lesley and Julie reported a loss of skills in their child in the early days:

...but oddly enough it was only when my sister said, she said, 'they don't look at you any more...' *Lesley (12)*

But Julie was the only parent who also mentioned a possible trigger for the onset of autism (the MMR vaccination):

...but it was around the time of the MMR... *Julie (8)*

...no, he seemed fine, for his first year or so, he seemed just to be doing the normal things, then, I can't say it was over night, but it was certainly over a short space of time, the things he had been doing, just disappeared. I think he was just starting to say 'mum' and 'dad' and things like that. *Julie (16)*

For Sue, having the diagnosis was a relief, and she used it in a pragmatic way to help her cope:

...but we got the diagnosis which we were quite pleased about because it's very difficult to actually get a diagnosis but if you don't have a diagnosis you can't then get the help. *Sue (1)*

4.4.5 Sub-theme - The Impact of the Decision for Residence

All parents experienced a conflict of emotions regarding their decision for a residential school. Sue spoke of guilt and failure:

Guilty, you feel very, very guilty, because you just think you've failed as a parent...
Sue (80)

These feelings were shared by Brian, her husband, explaining his feelings at the time of deciding about residence. For he and Sue, friends acted a source of social support for their decision:

To a certain extent devastated (about the decision) and I mean in many respects I still am, you know, there's an element of guilt there, I think that you know, and to a certain extent (you) are feeling a little bit of a failure, you know you can't look after your own child..., but the reality is I mean most of the people I've talked to since, they've said we don't see how you coped as long as you did. *Brian (40)*

Julie also wrestled with the conflicting feelings of loss and guilt:

...you feel guilty, you feel like, I felt like I'd betrayed him, he was never going to go away, but.... *Julie (193)*

But she and Stuart also received social support:

I mean my mate, and sort of people we know, turned round and said, 'how you cope with that, I don't know'. *Stuart (303)*

These feelings were echoed by Jo, who actively sought the reassurance of friends over her decision:

I was, well, it was heartbreaking for me, 'cos I'm thinking, 'O my god, I'm sending him away, I'm sending him away,' then I spoke to friends and they said, 'you're doing what's best for him and you've got to take you out the equation completely.' *Jo (94)*

All parents described in very emotional terms the impact of the loss as they took their child to the school for the first time, and their experiences in the early days of residence:

We were distraught, the pair of us, I was just a wreck, it was awful it was like the worst feeling. *Sue (92)*

Lesley's grief and loss is palpable:

It felt like a loss actually, I don't know whether that's the right thing to say and I just miss 'em, I miss 'em during the week, sometimes, don't laugh, sometimes I'm sitting here right, and I'm feeling, I'm really, really missing 'em and I just have to hold my breath. *Lesley (170)*

...and we had to hang around and I was...I was...in bits really, not happy at all. I think it was very hard the first couple of weeks until we took her out the first time and that was probably the hardest, the house just seemed so empty, quiet...*Brian (86-90)*

...and we went home and we just sat in a lay by and just bawled our eyes out, didn't we, we went hysterical didn't we the pair of us, just stopped in a lay by and just cried and cried... *Julie (177)*

Jo's distress was also concerned with the uncertainty of the placement and the effect it would have on Taylor and on the family if it were not successful:

I was just upset, really, really upset, anxious...how it's going to be if he doesn't take to it and education decide it's not for him? *Jo (100)*

Paul's recollection of that time was such that he was too distressed to speak about it, mentioning, that he had felt 'lost' and a need to be constantly 'ringing them up' to check on Connor's well being.

All parents became very emotional at the recollection of this time, which for some had been almost three years ago but was recalled with great clarity and force. Julie and Stuart recall their very strong feelings of loss several weeks after Nick had moved to Ash House:

...well I remember when we went to the beach on our own, I think we'd been to see Nick and we went to the beach on our own and we sat on the beach and we said, 'this isn't right' it's just because it was just the two of us and we didn't have to hare around, we just felt completely and totally lost, didn't we? *Julie (250)*

Brian shared some of this same feeling of guilt at the perceived loss of his role as a parent:

I think now, it's a little bit less, because, we've kind of, as time's gone by, again, you normalise things, it's because sometimes you'll think to yourselves, well she's coming home this weekend, God, I haven't thought about her for... I haven't given her a second thought, for the past week, the truth of the matter is you probably have, lots of times.

Brian (100-102)

Several parents made attempts to restore their loss of their parenting role by ensuring that they still carried out tasks for their children, once in residence, such as collecting them from school for visits, attending reviews and meetings and being their strong advocate:

Ash House have said, 'we'll bring her if you want, we'll transport her if you want', but we've said, 'you know, it's only 20 miles up the road', it's not a great burden for us to go and collect her and take her back so it means that we pick her up normally on a Friday afternoon, take her back on a Monday morning, on the way off to work. *Brian (76)*

4.5 Super-ordinate theme: The Family Versus the System

'You have to fight for your child all the time, when they were diagnosed I never in a million years thought I would have to fight as hard as that and all the time for every little thing for them...' *Lesley (220)*

All parents spoke in passionate terms of their, almost wholly, negative relationship with professionals (both individuals and corporate bodies), conceptualised as 'the system', which here is taken to refer to all outside agencies that came into contact with the families, other than Ash House.

4.5.1 Sub-theme: Frustration

All parents described a great sense of intense and enduring frustration with events and forces outside of their control. There were numerous examples of frustration with professionals and the perceived rigidity of procedures, from the very first days of concern for their child, to the present days, as some are now caught up in the anxiety of the transition into adult services.

Lesley describes an early experience concerned with diagnosis and her sense of powerlessness due to the perceived procrastination from professionals:

Well they had to be diagnosed at the CDC (Child Development Centre) and that's not what the system is now, but then you had to wait for an appointment, you had to have an appointment at the child development centre and it was the doctors there, the paediatricians there that actually diagnosed autism. *Lesley (26)*

Paul and his partner share this feeling very strongly:

They're just sat in a corner waiting for someone to contact them, and then asking. They don't say, 'don't you know about this...?' It's a load of... *Paul (204)*

Jo was frustrated over the apparent reluctance of professionals to state their true views, due to an obligation to work within 'the system', first in mainstream education:

I was really cross with her so I said look, you know what it's like, you know how I'm being treated and yet you're not standing my corner and I met her years later and she said she was going with what the Head wanted. *Jo (41)*

And again later when Taylor was in a specialist provision:

...so the Headmistress kind of, of Downs Road (local specialist provision), said to me, 'I feel he needs that kind of placement (residential) but my hands are tied because who you're fighting against, is my boss', and it's, the county council, the city council, so they couldn't be seen to be rocking the boat too much, they could put in 'Taylor would benefit from a waking day curriculum', but they couldn't really say.... how that was going to be, how it should really be administered. *Jo (79-81)*

Others felt they were not provided with sufficient information with which to make a decision regarding their child, nor that they were made aware of what was available. Paul and his partner shared this conversation, which had a conspiratorial edge:

Paul: There's families out there that haven't found out what we've found out you know they're not aware of places like Ash House, there not aware of what they're entitled to from social services...

Partner: ...they're not aware of the allowances...

Paul: ...They don't make you aware, that's the thing... Paul (200-202)

For some, they perceived it as sheer chance that they had discovered Ash House. Sue described a conversation she had at work with a colleague:

...and I was just chatting to her and I was saying about the problems Becky was having and she said there's a place (in the next town), Ash House, which is residential, for autistic children so I went on the website and had a look and just got some background information about it... *Sue (154)*

Paul shares this experience and is bitter that the LA did not make this known to him, even though they had other pupils placed there. He describes the accidental way he found out about the school:

...I stumbled across Ash House. *Paul (169)*

All families described frustration with the lack of specialist knowledge and experience of professionals:

In my opinion, the council, the social workers or what ever didn't know what they were doing. *Stuart (136)*

Lesley echoed this view, referring to professionals, with frustration:

But they're not always right, they're not always right and this is the thing.
Lesley (119)

Brian agreed with this view, talking of the time when Becky was out of school while the county identified an appropriate provision and the inadequate support workers the Local Authority identified as appropriate to meet Becky's needs:

...the county put 2 carers in, after half a day they were gone because they went, 'this is well beyond our ...' *Brian (30)*

Paul speaks with ill -disguised contempt of the CAMHS workers that were sent to advise him on ways to manage Connor's challenging behaviour:

Yes, and they (CAMHS workers) come into the house to set up some routines so that we could tackle some of his behaviours. They just weren't specific enough. It was just impossible, we couldn't apply it 24-hours... *Paul (173)*

This also leads to other comments about the perception that professionals were not listening to parents and believing their stories of the extent of the difficulties at home:

...no, and that's when I decided, right I can't cope with it 'cos his behaviour was just getting.... and I actually filmed, I filmed on an old phone, I felt that, I would keep a record of how he was... *Jo (59)*

I've always said to anyone working with Connor, come and see him, when they've seen him for five minutes, they know... *Paul (441)*

They wouldn't listen to us... do you know what, if we could have coped with her for weeks at a time, we would have her for weeks at a time, we wouldn't be putting her into residential care. *Sue (27)*

Stuart relayed this painful conversation when he was trying to convince the authorities about the urgency of the situation with Nick:

'...we're really not coping and although we don't want to, we think he's going to have to go into care'. 'Oh no, he can't go into care, do you know how much it costs?' (mocking professional tone). I didn't give a damn at that time. *Stuart (200)*

These comments also have echoes of the persistent call from parents for others to see their child as an individual and not as part of a homogenous group called 'autistic children'.

Paul's partner referred to this, speaking negatively of the rigidity of the system and her frustration of the way the system seemed to want to deal with the unique situation of Connor:

It's not a tickbox. (*Paul's partner*) *Paul* (192)

All parents raised the issue of the constraints of funding, believing that, although never stated, this was always the main factor in the system's decision-making process for residence:

Paul: Yes, yes, it was the money, everything's money

Partner: it's the bottom line innit? *Paul* (195-196)

I just feel that the authorities don't have the best interests of the children in mind, I think that the only thing that they worry about is the budget and the funding. *Lesley* (220)

It's not something that you do lightly, and then you think, 'Is it just down to money?', and they were going, 'No it's not,' but obviously it is, down to money, you know what I mean? *Sue* (29)

Finance was similarly identified by Jo in her experience of the tribunal procedure she had to attend to secure Taylor's placement:

We had to have other reports to make sure that he got in there and luckily, I think it would have cost them more for him to...for the court battle, than for them to just agree... and they agreed... *Jo* (90)

and by Julie in her pursuit of appropriate provision for Nick:

...it all came down to money in the end but in the end there were so many people who were saying that we couldn't cope with him, I mean we just couldn't cope with him. *Julie* (302)

Brian is prepared to offer a more magnanimous interpretation when considering the actions of the LA with regard to post-19 provision:

'Cos I've no doubt that they'll try and offer something that they'll think is appropriate and it's not because they don't care, it's because they've got financial burdens and so they've got to and we've got to sort of fight the case to get the very best care that we can for Becky. *Brian* (58)

The comments about finance echo the theme of subterfuge that has been earlier identified in connection with frustration with the system. Parents were made to feel guilty and greedy for needing this, as if they were expecting preferential treatment for their child. Paul summarises how he resolved these uncomfortable feelings:

My conscience was clear, 'cos throughout all this, when they were explaining about the money, 'cos for all them years they never spent a penny on him, 'cos he'd been at home, so all that time, he needs this, it's his last chance. *Paul (193)*

and Sue found comfort in the positively re-framed explanation from the head teacher of Ash House:

...but as (the Head of Ash House) said, if you had a gifted child, that was offered say a music scholarship, you wouldn't think twice, you would just say, you know, 'there you go' *Sue (82)*

There were just two positive comments about professionals, pre-residence:

Stuart, speaking about their current social worker, whom he feels is better informed than her previous colleagues:

She really knows her stuff and she's helping us with some forms and this that and the other and you can't knock her, very professional, and a nice woman. *Stuart (299)*

and Paul, recalling a previous social worker:

I said to Mark North, 'come on, I want this now', he pointed me in a few directions... he was very good Mark North. He was the best social worker Connor ever had. *Paul (175)*

Some parents spoke of their frustration of lack of understanding about autism from society:

We get annoyed when we see things like Rainman, they (society) think they're all like that, but Nick isn't. *Stuart (450)*

...and I mean you've got this like toddler (referring to Kyle, Taylor's younger sibling) throwing himself down and having a fit or pulling something off the shelves, but he is a naughty little toddler, but when you've got this 9 year old, that's doing exactly the same and I mean you're getting all the tuts and you know people are looking... *Jo (61)*

Frustration was expressed by all at the length of time it took to secure a residential place:

...and I don't understand as well why it's so long drawn out why it can't be a quick process or why there is (not) a time limit , you know, it just seems to drag on. *Jo (103)*

Paul feels this strongly and his frustration is also combined with regret and guilt at not having secured the provision at an earlier time for Connor:

It's doubly frustrating 'cos he's learned to do that and what else could he have learned to do? And what more could he have learned if he'd had that from the age of three, that input? Oh, frustrating! *Paul (366)*

4.5.2 Sub-theme – Abandonment

This theme was evident in all of the narratives, and is interlinked with frustration with 'the system'. Paul talked about it in the most forthright way, in this quotation referring to Connor's time in his first specialist school:

He was abandoned there...Never had a social worker, never had nothing - any of the contact with any professionals came from me or his mum. *Paul (47-49)*

And here describing the ongoing process of securing appropriate provision for Connor:

And that is the most frustrating thing about anything to do with autism, is the fact that you're abandoned and left to fight for yourself, rather than have access to these places... *Paul (59)*

Jo and Paul refer to a feeling of abandonment associated with having a child with autism:

You're just left out to dry – just get on with it. *Paul (206)*

...and no-one seems to want to give you any information, you know, at the end of the day it's your child that they're discussing and you should be at the forefront of everything but you don't seem to be. *Jo (103)*

Many parents felt they were given limited, if any information and guidance to look for an appropriate placement for their child and were forced to look for the provision themselves:

Well, I was just given by social workers or somebody a list of all the schools in the city and told to go and look for one and I'd gone to sort of normal schools.... *Julie (121)*

Yes, and that's the only support we had (referring to a small amount of speech and language therapy). *Lesley (28)*

Yes, and you'll laugh at this...we've had no contact with social services, whatsoever.... I've had to pre-empt the next stage, I mean he's 19, what're they doing? ... *Paul, recounting with frustration and disbelief the transition arrangements for Connor. (216-218)*

Several parents strongly believed that the type of provision that a child received was often due to the amount of pressure that parents were able to exert and were uncomfortable about the perceived inequality of this system:

But you just think, erm, I'm not being funny but if you didn't have as much about you, if you weren't as geared up, you would just, you would just think that you'd have to do what they wanted you to do, the education authority and social services. *Sue (112)*

There's families out there that haven't found out what we've found out, you know, they're not aware of places like Ash House, there not aware of what they're entitled to from social services. *Paul (200)*

The thought of being abandoned still haunts Julie and Stuart even as Nick is settled at Ash House:

I mean he'd have just got left and as the years gone by...and nobody seeing him, and it's a horrible thought that we've got now, that when we're gone I don't know who'll go (to visit). *Julie (269)*

4.5.3 Sub-theme – Conflict

A very strong sub-theme of ‘conflict’ was evident in all accounts. The language of war and fighting was very common. This was symbolic, in the case of parents speaking of a ‘battle’ with ‘the system’:

It was more important for us to fight for Ash House. *Sue (86)*

...you get the diagnosis so that’s why I was so intent on getting the diagnosis because I wanted to be like fully armed and ready to go. *Sue (55)*

‘It’s what you could do without, this battle.’ *Paul (441)*

You have to fight for your child all the time, when they were diagnosed I never in a million years thought I would have to fight as hard as that and all the time for every little thing for them. *Lesley (220)*

No, but I mean the school all fought on our behalf and they got a person for me, who was a legal person for me and she actually fought everyone’s corner. *Jo (88)*

Every single school that we’ve gone to we’ve had to fight with social services and the education authority. *Sue (106)*

But ‘conflict’ was also based painfully in reality, when parents had to physically ‘battle’ with their child during episodes of challenging behaviour and the language of war and fighting was again frequently used:

Brian would deal with Becky and try and calm her down, we just got out of the way ‘cos she would just grab anybody in sight, anybody that was passing, anybody, you know, you would get it basically, and if you weren’t quick enough she could get you by the hair and she could actually pull you down to the ground, she was very, very strong. *Sue (65)*

And he’d just go into these (outbursts) and you didn’t know when, there didn’t seem to be a trigger for them or anything and then he’d just smash the whole house up and if you tried to go near him then he would attack me. *Julie (32)*

Well, all hell broke loose, he's screaming he's in his bedroom, he's banging windows, throwing everything around in his bedroom... *Jo* (155)

Brian in particular directly compared his experience with Becky and her challenging behaviour to his time on active service in the Gulf:

Brian: I was in the airforce and I was in the first Gulf conflict and the airfield I was at was one of the ones that was most heavily targeted with scud missiles and we, the first time the sirens went off, everybody was a bit...but then it changed and you became tense until the sirens went off and once the sirens had gone off, you were calm, you were happy then...

Interviewer: It was the waiting...?

Brian: Yes, when you first went in the shift you knew what was going to happen, pretty much, so it was a little bit the same (at home with Becky), the tension, you were waiting all the time, for the outburst, once the outburst came, you could cope with it.

Brian (94-96)

Other parents also described the tension of waiting for the challenging behaviour:

I mean I used to sit here at night and if there was a bang on the ceiling and you'd think he was going to go...You'd sit here and like shake and think, 'do I go up there?' but if I go up there and speak to him he's going to get worse, 'cos any sort of contact...he wants to be on his own. *Julie* (76-78)

...you were tense every time she came home in the taxi, it was like, 'oh god, what kind of mood is she going to be in?'.... and sometimes she'd be alright and sometimes she wasn't and you always had that knot in your stomach, and you were just waiting for the back lash. *Sue* (63)

4.5.4 Sub-theme – Isolation

Isolation was a strong sub-theme that had different guises depending upon circumstances.

All parents experienced a sense of isolation as a result of the constraints the challenging behaviour of their child brought to their everyday lives:

...so we're going to meet friends tonight, which we couldn't do (before residence) because we couldn't have people to the house. *Sue (122)*

...but at that point any thing, decisions that we made it was, 'how's it going to affect the boys?' erm, and that's just what we did and in the end we just ended up staying here (laughing) not going anywhere, occasionally people would drop around but you had to say, 'not too many, not all at once'. *Lesley (39)*

In addition, all of the children experienced isolation, not only as a direct result of the inherent constraints of their autism:

...we couldn't...do anything with him you know, he was just watching videos all the time and if we tried to take them away, then... *Julie (169)*

and she'd come flying through the door, just take her shoes off, have some snack, go and take herself next door, which was like basically her domain and go and watch her videos. *Sue (63)*

but also because of their challenging behaviour, which resulted in exclusion from their local special school for three of the six children and lengthy times out of school waiting for a suitable placement to be found, for all of them. During these periods both parent and child were virtually isolated from the rest of society, and these are described as some of the hardest times:

There was a period, I can't remember exactly how long it was, while she was suspended yes, when she was at home and we were having to take time off ... *Brian (30)*

Sue describing the same time:

...it was 24/7 before and we were just so tired and worn down and we're just waiting for the next one (outburst) to come... *Sue (144)*

Paul, Julie and Stuart and Lesley describe the extreme impact this had on day-to-day life:

...the personal experience that we had with Connor at that time was, he was doubly incontinent, he wasn't on any medication so his mood swings were high and low and flitting between the two quite quickly, and he was double incontinent which means, he made a lot of mess... *Paul (96)*

...we really weren't coping. I mean it was at the stage when he wouldn't have his hair cut, but that's not the end of the world. His teeth were having to come out because he couldn't clean them, we couldn't cut his finger nails, we couldn't get near him to do any of the practical things that you needed to do. *Julie (167)*

It was awful, I mean, I love 'em to bits but I was stuck in the house 24 hours a day with them, no respite, no school for them to go to, I was just at the end of my tether, I really was. I mean I love 'em to bits but I thought, 'this is killing me.' *Lesley (93)*

Sue also described the physical isolation of their child, due to her challenging behaviour:

...but she was a danger to other pupils because they had to basically, when the smaller pupils went through, they had to lock her in the headmaster's office. *Sue (13)*

The taxi people had also said there'd been problems, she'd been attacking them and in the end they had to get a taxi with three rows of seats and put her at the back and not have anybody sitting next to her so that she couldn't reach out and grab. *Sue (17)*

Lesley's twins were isolated as they were the last two pupils to be found alternative provision when their school was closed down following a poor inspection:

So they were in a class with just each other, that was it, and I thought there was no social development whatsoever. How could there be? They weren't going out into the community anymore because of their behaviour so they were actually just confined to the school, occasionally they'd go on a bus ride around the town. *Lesley (61)*

Several parents articulated their sense of isolation as a result of their lack of knowledge in the early days of autism:

But I had no idea what autism was at that stage and I'm sort of baffled with it, I still am... *Julie (48-50)*

Lesley and her husband made a decision not to talk about the autism to their family, as they knew so little about it themselves, which led to their social isolation:

... ‘cos one of the reasons was because we didn’t know anything about it, we didn’t know much, we knew it was autism, but we thought, ‘well, what is autism?’ And we thought, we’re not prepared for all the questions, ‘cos we don’t know anything ourselves so we can’t tell anybody else so we thought we’d leave it and we kept it amongst ourselves... *Lesley (200)*

4.6 Super-ordinate theme: Heightened Parenting

‘At the end of the day this is your child and you have to do what you think is best for your child’. *Sue*

All of the narratives contained frequent references to a heightened experience of parenting. Parents demonstrated this as they developed their role as expert for their child as they became so finely tuned to their child’s needs, through intuition, experience and latterly in some cases developing their own theoretical knowledge. A strong sub-theme was also one of the sacrificial parent as the very demanding needs of the child became paramount. Heightened parenting was also characterised by the readjustment of expectations and goals for their children and of celebrating simpler milestones and achievements, as parents reconstructed their own identity as a parent of a child with additional needs, as a result of their experiences.

4.6.1 Sub-theme – The Expert Parent

All parents were confident to demonstrate their expert knowledge of their children, often with a sense of urgency, by narrating their ‘story’ in great detail and with little encouragement required. This also conveyed the extent of the impact of their experience, as many events that had occurred up to 19 years ago, were recalled clearly and described with a depth of emotion which gave them a sense of immediacy. This role of expert parent contrasted starkly with their disappointment in the lack of expertise in the professionals around them.

All parents reported that they were the first to notice that something was different with their child:

Oh yes, I started to get uneasy when it got to the point about 15 months, I started to feel uneasy because I wasn't hearing, I was hearing sounds, that sounded like words, but no words at all. *Lesley (10)*

There was something not right, but we didn't, I mean we didn't at the time suspect at all that it was autism. *Brian (8)*

... maybe I knew at the back of my mind that it was more than...deafness. *Sue (31-33)*

But it would be around the 9-10 month age, 'cos he wouldn't play with toys properly, everything went to mouth and he had to lick everything, that was the first concern. *Paul (15)*

As the realisation of the impact of the diagnosis became apparent, all parents adopted the role as expert and advocate for their child. Jo describes a distressing initial assessment by a health visitor:

...and she was getting quite angry with him 'cos he wouldn't do what she wanted and I said, 'look, stop... I think I've got some concerns,' and I told her what he was doing and how he was being. *Jo (16)*

Sue adopted a pragmatic approach to dealing with the situation:

Yes, like I say, I wanted the diagnosis because I knew it would take a long time to get the ball rolling, to get people involved and I didn't want her starting school, in mainstream school and then them saying, erm, 'there's a problem.' *Sue (47)*

The 'expert' parent was frequently concerned with securing the most appropriate provision for their child. Once Paul had discovered Ash House, he was forthright in his determination to secure a place for Connor:

So I started looking, I went to Ash House, straightaway I thought, ‘this is good, I wouldn’t mind him being here’ and everything else they said...I just blocked, cos I wanted him to go to Ash House. *Paul (175)*

Jo showed similar determination, from an early stage:

It wasn’t until the actual statement was put in place that he got 1-1 support at his nursery, but I’d already made my mind up then, he was going to a special school... *Jo (22)*

Lesley used her growing knowledge of her sons to obtain the most appropriate early support for them, here describing a crèche attached to the local college:

...and I took them along there...and it was ideal ‘cos they had 2 classrooms, with about 8 children in each, and if I took them on particular days, I think they went twice a week, 2 mornings a week, there would only be about 4 children in each room, which was good, because I noticed then they didn’t like to be with a lot of people, they didn’t like a lot of noise, you know a lot of stuff going on around them, you know that would upset them. *Lesley (32)*

She continued her active involvement, as the boys’ needs changed as they became older and their behaviour more challenging, and it became clearer to Lesley that they required a residential provision:

... but then we thought about it and we thought no, they’re not going to cope with that, going backwards and forwards everyday, they just wouldn’t, they need a 24-hour curriculum and that’s when we got in touch with people, approached the authorities and said that’s what we want to do and we asked for a reassessment of their needs... *Lesley (61)*

Many parents felt the need to be their child’s advocate when they began to encounter opposition from the system, particularly when this threatened or questioned their potential to learn. These comments also captured the sense of urgency that all parents shared, of ‘seizing the moment’ and maximising their life chances, almost as if by waiting, it would be too late and the opening would have passed. This was vividly conceptualised by Paul as:

...last chance saloon... *Paul (305)*

and expanded later in his story:

I think you just don't know what they're capable of, but you feel gutted that you don't try...until you try you don't know and I think they all deserve...that amount of support. *Paul (320-324)*

Lesley shared this view of the need to act now and with vigilance:

...and in the meantime the boys are suffering, it's all time, their time, they only have one chance and you know you've got to give 'em the best that you can. *Lesley (75)*

Yes, and that's why any hint of a crack appearing, needs to be sorted, pounced on immediately and dealt with immediately, because if you leave it...and if you leave it for other people to sort out then it doesn't get done, it's left you have to push for it, they're big lads now, we've wasted enough time I think. *Lesley (196)*

Sue's comment captures the views of all parents:

at the end of the day this is your child and you have to do what you think is best for your child. *Sue (112)*

This vigilance in advocacy is continuing for many parents as they prepare for the transition to adult services, as Sue and Lesley illustrate as they speak of future provision for their children:

...and I just said to the social worker at the last meeting, I said, 'I want her to stay here, at Ash House, for post 19 and believe you me we will be fighting, so I'm just giving you warning, we're used to doing it, she will stay where we think she needs to be, where we think she'll get the best care, where we think she wants to be...oh well, you might as well know, you don't think you're going to be fobbing us off.' *Sue (113)*

Yes, I decided it wasn't going to happen again, I wasn't going to listen to people who thought they knew it but actually didn't. I was going to empower myself, if you like, with knowledge about autism and how that affected my boys. *Lesley (111)*

Several talked about trusting their own child's intuition about particular schools, which supported their identity as expert and also suggested an almost symbiotic relationship between child and parent:

Not that it (Ash House) was the only school we looked at, it was the only school where she seemed happy. *Brian (30)*

... they seemed to adore him, (the staff at Ash House) and he seemed to know...he wanted to go there, he didn't want to come out... so that was...thank goodness...
Julie (176)

There's something about it (an alternative school), I'd taken her a couple of times and I thought, 'I'm not sending my child there, there's just something she doesn't like about it, she's not going.' *Sue (112)*

Many parents commented, with anger, regret and frustration on the lack of expert provision their children had been given prior to Ash House, recognising it as respite rather than teaching:

All to do with Connor's schooling I felt it was to give him something to do with his day rather than to tackle his difficulties. I've always felt that. *Paul (81)*

But she actually hadn't been taught at all and she obviously caused a lot of disruption but they just realised they couldn't cope with her any more. *Sue (!!)*

...and looking back, I think he didn't learn a lot at school, it was more of a babysitting service and somewhere for him to actually go and be placated by what they were doing and not actually learning anything. *Jo (43)*

Two of the accounts include comments about parents purposefully deciding to seek out more information regarding autism, in order to benefit their child. Lesley talks at length about the research she has undertaken and the conferences she has attended, since her children have been in residence. Even prior to that, she familiarised herself with information about communication and language development, as she felt that the professionals did not have this information:

...and we had this argument with the school and we said, 'you'll have to find something else' and in the end we looked at PECS and we read up about it and we thought let's try

it for now and the school wouldn't let 'em do it. The school, said, 'no, we're not going to use that, this is what we use here.' but I said, 'yes but it's not working so you've got to try something else'. *Lesley (115)*

Yes, I always tell 'em (Ben and Sam), cos their understanding of verbal language is miles better than their actual expressive language and communication and you can say, as long as you keep to simple words, concrete words and 3 or 4 at the most, then give 'em time to process the instruction, then they'll actually, you know, do as you say. *Lesley (118)*

Julie and Stuart took Nick to the Son-Rise project in the US and spoke about this, apparently as an after thought, when the formal interview was over. They commented that they had learned such a lot about autism and about Nick, and contrasted this with their perception of the very limited specialist knowledge of the professionals with which they were dealing.

4.6.2 Sub-theme – The Sacrificial Parent

The sub-theme of sacrifice was present in every narrative although it emerged strongest in Lesley's account, possibly as she had the needs of two very challenging children to consider.

All parents adopted their lifestyle to suit the needs of their children:

So we stopped going out at that point, we felt, for the sake of them, 'cos it was actually causing them a lot of anxiety. *Lesley (34)*

and referring to Christmas:

So I have to say to people, 'don't all come at once, stagger it, don't stay for very long', you know, all that kind of thing, which you know, cuts all the joy out of it you know... *Lesley (41)*

and aspects of normal family life were sacrificed:

...but we decided after this year that we're never doing it again. If we take Taylor out, we take Taylor out alone (emphasised) and if we go on holiday and Taylor needs a holiday we will take him alone and try to find something for the other two to do, or one of us goes, because its just too much, too much stress. *Jo (73)*

All parents made accommodations for the complex needs of their children, but Lesley described in detail the physical alterations she made to her house to help her children:

We arranged all the furniture so it was all around the room and nothing in the middle so they didn't have to negotiate anything and we changed all the décor, so all the walls were plain 'cos we used to have floral paper (laughs) I can't believe it but we changed all that 'cos we thought the least amount you know the less busy the environment...
Lesley (47)

A most persistent and poignant phenomenon was that of parents being forced to fight for an outcome (residence) that, under any other circumstance, they would never choose. In these situations, they sacrificed their own needs for the sake of their children:

... but Ash House, she just, she just seemed to slot in and that was fine, erm, so we did feel a bit more comfortable but obviously we weren't, you know, it wasn't the ideal thing to do because, like I say, you feel such a failure, but we felt that was the best option for her. *Sue (86)*

We knew he had to go, we had to fight for him to go, because we knew we weren't coping, we really weren't coping...and when he did go into care, well, it was the worst day of my life ... and to have to fight for something you didn't really want was horrendous... *Julie (204)*

Lesley spoke at length about how she had had to come to terms with sacrificing her needs for the good of Sam and Ben:

.... I've seen how it benefits them, they need it, it's as simple as that, I mean that was one of the things I had to overcome, my needs as opposed to their needs. *Lesley (226)*

and of learning to ignore the possible criticism of others regarding her decision:

I thought that (there would be criticism) to begin with but you get to a pitch where it doesn't matter any more. It's like somebody dying of cancer, you get to the point where the pain is so bad you just wanna die. It's the same sort of thing, you get to a point right and you just can't do it any more and they're suffering most of all and you have to do something about it. *Lesley (234)*

Paul's decision was also affected by his awareness of the conflicting needs of his other children:

Yes, enough's enough is what I felt, as much as I loved himerm I started thinking of the others now... *Paul 146*

...it's not to do with how I feel about things, it's what's suitable for him. *Paul (424)*

Many parents were forced to make a sacrifice in terms of their career and livelihoods:

When she was younger, you know, when people could cope, my wife's mother would look after the children, she'd come and look after the children for a couple of weeks during the summer holidays, we would take time off separately, effectively, that wasn't available as far as Becky was concerned we would need specialist (care), so, it would mean that effectively one of us couldn't have a proper job... *Brian (46)*

Paul was forced into making the decision to leave his job, after describing how his mother supported him with Connor after his marriage broke up:

'Cos I worked in (neighbouring town). She'd be working 'til 5, get a bus here, look after these while I went off to work, then I'd come back in the morning and she'd go off to work. And I could see it taking a big toll on her she was getting tired and not doing stuff which she always did and I thought, 'that's enough' so I gave up work. *Paul (349)*

Jo recounted the dilemma of having a child with autism, and how this impacts onto her decisions regarding the wider family:

... if I were a stay at home mum and we didn't need my money and blah blah blah, and it was just Taylor here, then the possibility would, yes I could have him home, but it's not all about Taylor, I've got two other children as well. *Jo (198)*

4.6.3 Sub-theme – The Reconstructed Parent

This sub-theme emerged as a response to the 'journey' that all parents embarked upon as a result of their unique situations, from their first suspicions of autism, through to residence.

They eventually found other means by which to value and enjoy their parenting, as they came to terms with their experiences and reflected on their experiences. In this way their belief systems were altered. This was illustrated in their comments about recognising simple pleasures and as they recounted tales about their children, often with loving humour:

Music, yes, he loves music...loves transport and water, they're his three main things, he loves water, so his baths, showers and swimming, he absolutely loves it! *Paul (123-125)*

We've had laughs, we've had to laugh at some of the things, my mates always said, 'if he burns the house down, it's only Nick!' *Stuart (236)*

...and we used to go on the beach with him, because he loves the sea, he's got a way of walking along the shore, but he only likes going one way! (laughing). *Julie (241)*

They're still my little boys, I always refer to them as my boys, but I mean they're adults now, only in law, but they're really children in an adult's body, just little boys in an adult's body and they'll always be my babies, whatever age they are (laughing). *Lesley (170)*

But generally she's a lot calmer and she's making fantastic progress at the school, although she doesn't do the same sort of things at home (laughs). *Sue (116)*

Alternative, small steps of achievement are celebrated:

They've got her own bathing routine and she's brushing her teeth... and she's doing like household chores, she's hoovering, helps prepare all the food... *Sue (118)*

He does do bits for himself, he tries to do bits for himself, he seems to have a bit more understanding, and they manage to cut his hair and cut his toenails and he shaves himself and, which he didn't need to do before he went, but he does now, he shaves himself and he cleans his teeth and I think they have to help him with all of that. *Julie (276)*

He goes toilet now – and that's something I never thought I'd see in my life time.... *Paul (316)*

... he'll sit calmly for longer, and I've noticed he takes a lot more interest in what he's looking at rather than it being fleeting... *Paul (381)*

Some achievements were almost too ephemeral to be noticed, but they were still valued:

There was a sparkle, they were actually enjoying being there (at Ash House), which was never before, because they never had anything for them to do. *Lesley (81)*

...the fact that she's a lot more settled, she seems happier. *Brian (144)*

This reconstruction of what is important in life was never more apparent than in the responses to questions about their hopes for the future. Lesley was not prepared to think any further ahead than the present:

For the moment I'm just hoping that this (Ash House) is gonna work out.
Lesley (194)

Julie also had not thought any further ahead than the current provision:

Yes, I think we hope that he'll stay where he is 'cos we can't imagine anywhere better for him. *Julie (390)*

Jo shared this wish, but also voiced her fears for the future:

God only knows! We try not to think about that....so we're hoping that he'll be able to continue to stay there (Ash House), but the way government cuts are going and blah blah blah, we don't know what the future holds, but it looks a little bit brighter now 'cos they do keep them 'til way into their old age now. *Jo (196)*

Many voiced a very simple, yet fervent hope for their child, of safety and positive well-being.

In this respect the parents also reconstructed or redefined what they saw as a successful outcome from a placement – providing basic human needs rather than pedagogical excellence:

...that he's happy, that he's looked after, with the best... *Paul (419)*

...my priority is that people respect him... *Paul (424)*

...but some sort of place where she's cared for and allowed to develop to the extent that she can *Sue (152)*

This is in contrast to the earlier fear that Sue had voiced:

... and I know there won't be any abuse of Becky which is always at the back of my mind, always... *Sue (126)*

...my fear was putting her somewhere where she was going to be put in a corner and they'd drug her up. *Sue (150)*

This fear of abuse was also, reluctantly mentioned by Paul, as if the act of speaking it aloud, made the possibility more real:

... 'cos he can't communicate his feelings – you don't know how he'd be, I wondered if they'd look after him properly... *Paul (233)*

This was not overtly stated by other parents, but the vigilance by which all parents monitored their children once in residence, was a strong indicator of the presence of this unspoken fear.

4.7 Super-ordinate theme: The Relief of Residence

'...oh we were terrified, we couldn't, I couldn't imagine that he could go anywhere and anyone could love him like his parents...but we're so glad he went there...' *Julie and Stuart (163)*

The immense relief that residence brought to all parents was an undeniable super-ordinate theme in every narrative. There was an almost palpable change of emotion during the interviews between the stress and chaos of the pre-residence period and the calm and order that prevailed post-residence. Three sub-themes emerged, which were the positive polarities associated with the pre-residence sub-themes of conflict, abandonment and isolation – namely, restoration, acceptance and community. These captured the range of experiences of each family and helped to illustrate the idiosyncratic way the relief of residence was manifested. Thus, some aspects were more highly valued or received more prominence than others, depending upon individual circumstances.

However, despite this variation in experiences, all parents were unanimous in their satisfaction with their choice of school, and with their decision for residence, even though all of them had previously expressed concern and uncertainty. Their comments confirmed their satisfaction:

...because she's in the best place. *Sue (102)*

...and we realised that he really was in the best place. *Julie (179)*

...and he's been absolutely fine, he loves it. *Jo (96)*

Ash House was perfect, cracking place, good care, I was convinced by the teaching side of it as well. *Paul (179)*

4.7.1 Sub-theme - Restoration

Restoration was conceptualised as the antithesis to conflict, as there were frequent references within all of the accounts to the restoring of order as a result of residence. Restoration of confidence, relationships and identity were themes also present.

Many parents spoke of the calm that was restored to their child through residence:\

Oh yes, definitely, she's a lot calmer. *Sue (116)*

When we go to visit, he's ever so cool, calm, and collected and I tell you something that I've not seen in a long, long, long, long, long time, is an outburst. *Paul (371)*

But he seems more content, he seemed a lot more content, after he'd been there for a while. *Julie (278)*

...but then I could quickly see how happy they were and how different they were, just in the couple of weeks they'd been there. *Lesley (79)*

Many parents spoke of the restoration of normal family routines following residence:

It's made it a lot easier 'cos like I've said, when Taylor's not here, we can have a sense of normality. *Jo (13)*

Oh much more relaxed (at home). *Sue (122)*

Yes, I mean you go out a bit more, see your family a bit more, I've got quite a lot of family so I'm able to see them a lot more than I used to, and some friends we used to have, there's a quiz night down the road we go to once a month and we couldn't do any of those things, so we've been able to have a social life again. *Lesley (132)*

It's a normal family atmosphere now, whereas before, it was a battlefield, and erm...er and despite how much you love someone, the frustration is within, and it's to do with that stuff, cleaning up, walking on egg shells, trying not to upset him... every aspect of it. *Paul (331-333)*

The routine and predictability that residence brought, was highlighted by many as contributing to the changes in their child:

As it turned out she settled in, pretty much immediately and now she's in a very good routine. *Brian (64)*

She's happy to go back, yes, she's happy on Monday morning, she's happy to go back and I think she likes that routine, to be honest. *Sue (90)*

Jo, Paul and Brian each identify the 24-hour curriculum that Ash House provides as a key factor in meeting their children's needs:

I like the fact that he's got a carer and a teacher and he's got this team around him, that can cater to him, for everything, you know, I know that's not what life is all about, we can't get what we want, but the fact, because of Taylor being like he is, he needs that, he needs someone who's gonna be there all day and tell him exactly what's happening, whereas I can't predict what's happening in an hours time, or whatever, here, you just can't. *Jo (151)*

They've applied the 24-hour routine that he needs. *Paul (316)*

Particularly for autistic children, the educational method, this two days, a day off, two days, the weekend off, that they use, is by far the best because they don't have... autistic children need routine and they have this routine it's bang bang bang, it's there, and it doesn't have a 4 week break, or a 6 week break over the summer. *Brian (176)*

Jo, Lesley and Paul spoke about the restoration of their own identities, following residence.

Jo, as a confident, functioning person in her own right, not just the mother of a child with autism:

Yeah, I suppose I feel a bit better about me, a bit more 'me' time, not just thinking that I'm Taylor's mum, that I've got an autistic child to deal with...it's just less stressful, if you'd seen me before, I was on anti-depressants, leading up to him going to school. *Jo (122)*

Lesley as an empowered and knowledgeable woman:

...so I never had time to actually read or do anything like that (prior to residence) so one of the things we did once I'd got the house sorted out was started attending conferences about autism. *Lesley (109)*

and Paul with a new career:

...and when Connor went off to Ash House, my job weren't there no more... so I had to retrain so I've been college the last three years... so I'm a painter and decorator now. *Paul (353-355)*

The restoration of the parents' confidence in 'the system', but only as represented by Ash House, was very clear in all accounts:

I like the calibre of the staff, the staff are fantastic, they've obviously been really well trained and they know exactly what they're doing and I feel Becky's safe and secure there. *Sue (126)*

Now, I'm perfectly at ease and comfortable with how they care for him. I know all the staff, we talk to them and they're approachable and I'm 100% confident that if there's anything that happens to Connor, I'll know about it, so I don't have to worry and I don't worry, now, I don't. *Paul (377)*

Brian and Julie and Stuart refer to the confidence that previous experience and a level of expertise engenders in parents:

... and we've been very lucky, that the school is so fantastic and very understanding, I mean they have coped with all of this before. *Brian (82)*

But they're prepared for that aren't they, that's the thing. *Stuart (279)*

Similarly to the earlier comment by Paul regarding Connor's toilet training, the surprise Lesley expresses over this not unusual situation of a school being prepared for a new arrival, indicates the persistent disappointment and low levels of expectation to which the parents had previously been accustomed, when professionals had been dealing with their children.

The staff are obviously very good with them, they give them lots of support. I remember the first day they started there, the speech therapist and the educational psychologist were in the classroom that morning, they were ready to receive them and to start working with them, and I thought that was brilliant. *Lesley (81)*

Julie's description of their first visit to Nick captures the simplicity of the gradual transition and growth of confidence associated with residence, for both the child and parent:

I mean the first time we went to visit him we went up there and just sat in a room with him and he sort of looked at us a bit gingerly and he eventually he did come to sit on my lap and then they said it was his time for tea and we went home... *Julie (177)*

Finally, Lesley's description of the literal restoration of her house, following residence, was a powerful symbol of how her situation had altered and heralded a new chapter:

I mean, the house went to pot, I couldn't tidy it or do anything in it, it was a real mess, in fact that was the first thing I did, that's how I actually dealt with them being away, I redecorated the whole house. *Lesley (95)*

4.7.2 Sub-theme – Acceptance

All parents spoke about the openness and transparency of their residence experience, in sharp contrast to the perceived subterfuge of pre-residence.

Here, Paul firstly speaks of the open and trusting relationship he has with the staff, with regard to being kept informed about Connor's progress, and secondly about the 'open-door' policy they have with parents:

What I like about Ash House, is that every single one of them, to a man, is approachable. I said from day one, I don't want any...I don't want them to dress anything up. I want to know how it is – if it's bad – tell me, if it's good tell me, but don't feed me any bull and that's the number one thing I like about Ash House, straight down the line, tell it like it is. *Paul (393)*

This view is also shared by Sue and Brian:

Oh it's brilliant you can just pick up the phone if you've got any queries. *Sue (136)*

...and of course the other thing is and another thing which is a major plus as far as Ash House are concerned, we can go and see her any time, without notice, we're always welcome with open arms and we can collect her whenever we want...very, very open, there's nothing, well there isn't anything that.... you don't feel as if there's any possibility that it's hidden. *Brian (208-212)*

Julie values the very informal communication - which meets her needs - referring to the contact with staff when they bring Connor home for visits:

...but when we do see them they always have a lot (to say)...and when they bring him here to drop him off and that we always have a good chat and that...they usually have us in fits about something, strange things that he's said.... *Julie (346-348)*

Jo and Lesley describe the more formal arrangements for communication, but which also have an open and collaborative ethos:

Yes, fantastic, I mean they're really good, everybody sits round the table and everyone has an input whereas at other schools, you get a letter home. *Jo (186)*

You have to have a 12 week review after a change of placement, this is the authorities review, about the placement, to see how it's going and these issues were discussed, so we'll have another one in 6 months time, and depending upon how well it's going, a bit like a statement. *Lesley (164)*

Many parents spoke with satisfaction of the fact that the staff accepted each child as a unique individual and were prepared to offer a very individual curriculum. This took Paul by surprise, given his previous negative experiences with professionals:

Anyway, from Day 1 at Ash House he didn't wear them (incontinence pads) and they wouldn't let him wear a pad and they said, 'If necessary we'll follow him round with a mop and bucket,' which I thought was hilarious. *Paul, describing the immediate plan to toilet train Connor (298)*

Jo refers to the efforts that the school has gone to in meeting the different needs of Taylor:

They've gone out of their way to accommodate Taylor completely, so they've not kind of just lumped him in with all of the others... *Jo (176)*

Away from the specifics of the curriculum, all parents valued the total acceptance by staff, of their child, just for who they were:

I like their attitude, that these children can do anything if you give them the chance. I like the fact that they have high expectations of them, which I felt where they were before, they didn't, I like the fact that they take them out places, which is what they need, otherwise, how do they become confident going out into the community? *Lesley (148)*

For Stuart, the relief that someone else understood, respected and accepted his son, was greatly appreciated:

...well, it was just er...he said he wouldn't go, and there's one thing with Nick, if you try to force him, then there's only one winner and that will be Nick and which is the way they deal with him at Ash House, I mean all of them, they'll just ask Nick and if Nick doesn't want to do it then they'll, if they can, leave it, they won't push him. *Julie and Stuart (156-159)*

The accommodating and caring ethos of the staff, contributing to the experience of total acceptance, was also valued:

So I mean, nothing's too much trouble. *Jo (178)*

I think the staff are lovely, they're really committed to the children, they care about them... *Lesley (148)*

They're all approachable, if I want to get something for Connor, they'd do it, if I said I want to do something for Connor, they'd do it for Connor, no questions asked and the other thing I noticed, they care about the kids... *Paul (397)*

Brian, Sue, Jo, Julie and Stuart all relate detailed stories of when staff from Ash House supported them at home, in very challenging circumstances. The gratitude that the parents have for this help is powerful, not just for the practical assistance provided, but for what it represented in terms of valuing, accepting and understanding the needs of the families. This is one example from Jo:

...and I had these tickets that were given to us for Legoland (from a charity) and I said, 'we're not taking Taylor', I said, 'we can't do it', I said, 'we'll take the little ones 'cos it's more geared up for them' and I said, 'we'll take Taylor another time' and I rang school to see if they'd have Taylor for the day and they said, 'what about if we sent some workers to support him at Legoland, would you be able to take him then?' And we said, 'well yes, if there's the extra support', so that's what they did. They rang up Legoland to secure two carers' passes so they didn't have to pay and they brought Taylor all the way to Legoland and spent the day with us... *Jo (165-166)*

This is starkly contrasted with the position with regard to support from Jo's true extended family:

...my mum is terrified of him (Taylor) because she doesn't know how to calm him down... *Jo (156)*

4.7.3 Sub-theme – Community

As their children joined Ash House, so also the parents joined the larger community that residence offers. Thus, instead of experiencing the extreme isolation and lack of understanding, pre-residence, they were able to call upon an extended network or support. Many described this experience as 'family':

...it's like having that, that extended family, that extended support. *Jo (157)*

...they come with us all the time she (Becky) has appointments (at the regional hospital), which is absolutely brilliant, because it's just great to have that extra pair of hands. *Sue (136)*

It's like a family, which is nice... *Lesley (148)*

So we did realise, after he'd been there for a while, that he was in the best place and they, in their own way, they do seem to love him... they do, I think they're almost like a family there... *Julie (183-185)*

...as soon as you come in you're taken in and everyone speaks to you... yeah, family, they look after us as well as looking after Nick when we go there. I couldn't say that there's one person there who you couldn't say isn't a part of your family... *Julie (309-310)*

All the staff are fantastic, they're all very caring, they've made it as much like a family environment for the children as they possibly can and it, I think the children appreciate that. *Brian (176)*

This construct of 'family' was limited to the relationship between staff and individual families. No inter-parent relationships were mentioned, although very occasional comments suggested that families did have some awareness of one another, as in this comment from

Brian, demonstrating his strong views about the importance of extended families and acceptance:

Yes, to my mind, without naming any names, we know why some of the children are there (on Christmas Day) and we think that those families are, it's not that they don't want their children on Christmas Day, it's that the extended family can't cope with their children and in my opinion, if the extended family can't cope, that's their problem, that's the way that we feel. I mean luckily for us, our extended family would think there was something wrong with us if we didn't have Becky with us. *Brian (188)*

And Julie commenting on a past pupil:

...and apparently, this lad, well he's left now, his mum took him out, which I think is a great shame... *Julie (327)*

This phenomenon, of apparent isolation between families, was not commented upon either positively or negatively in any account.

Distance was important to all parents and mentioned as a factor in their choice of school.

This reflected their need to be close enough to be there in an emergency and also to 'feel' near to their child. Many parents expressed a negative view about the schools they were offered as alternatives to Ash House that were geographically distant:

....there's another home in (the south west) but we didn't really bother to go it, we didn't want him to go to (the south west) 'cos how could you get to (the south west) and back in a day? *Stuart – Julie and Stuart (267)*

There were a couple of places and they were all a long way off...there was no way he was going. Ash House was perfect...and it was nearby, within an hour, it's only a 50 minute drive. *Paul (179-181)*

...and then they said, 'well, we're considering sending her to a special school in (the north east),' so we both said, 'we don't want that,' so we did a massive, great big report... *Sue (108)*

Distance also seemed to be connected to the expressed wish of all families to remain the main carer for their child. This was experienced in different ways and to different extents by the families. All parents talked about their insistence of attending reviews and other formal events as a means of remaining in touch with their child and maintaining control.

All except Julie and Stuart talked in some detail about this, Jo, for example:

We go over for the Christmas play and if anyone, I mean if the doctor wants to see me then I go over, also every six months social services need to see me at the school and him at the school, so I go for that, I don't miss any of them... *Jo (188)*

Julie and Stuart, however, needed prompting to mention this aspect and it was not a prominent discourse in their narrative:

...and they say he's doing really well and they got a fantastic Ofsted report. *Julie (324)*
- referring to Nick's most recent review

Parental control was also expressed via other means, often through the decision making process around care and medication:

...'Cos as I say she has epilepsy so I say if she ever has any fits, we want to know no matter what time of day or night we want to be advised. *Sue (136)*

There's a procedure laid down that if there's anything prolonged (a seizure), then I have to be notified. *Paul (375)*

This comment from Brian, referring to Ash House's stated philosophy, summarises the prevailing view of all families, regarding the sensitive relationship between school and family and one which was deeply appreciated:

‘We’re looking after her for you, you make all the decisions, you make the decisions on her behalf, we’ll do whatever you ask.’ *Brian (206)*

Paradoxically, therefore, it was as if, as a result of residence, parental power and advocacy was restored, rather than removed. Paul’s comments are typical of all the parents’ experiences of the very real sense of community for the children at Ash House and the satisfaction that this brings to the parent:

...and Connor’s happy, you can see that. They do far more there than they would do anywhere else, with regards giving them something to do in the day...swimming one day, gardening another day, trip over to the seaside another day, shopping, they do things, they’re not just sitting down in front of the telly all the time. *Paul (379)*

Residence provided many associated, indirect benefits for each family. It allowed all of the families to cope with the still difficult times of home visits, knowing that they had the support of a community to call upon:

I think it’s better because I think we’re more relaxed so when she does have an outburst we can cope with it more whereas it was 24/7 before and we were just so tired and worn down and we’re just waiting for the next one to come and it’s only whereas now, you think, ‘well, she’s going off on one, but we can cope with it.’ *Sue (144)*

The other advantage of course of her being in residential school, is if she comes home, you know, we see an end to it, we know it’s only going to be for the weekend, if she has a particularly bad weekend. *Brian (160)*

Jo’s affectionate comments capture the mixed emotions of a weekend visit:

...but by Sunday I’m pulling my hair out... so by the time he’s ready for school I’m ready for him to go back, I’m like, ‘for god’s sake, just take him!’ *Jo (190)*

as does Julie and Stuart’s poignant conversation, epitomising the acceptance that has finally been achieved, through post-residence community:

Stuart: ...we have him, we have him for a weekend, on Sunday when he goes out the door...

Julie: ...we’re exhausted...

Stuart: ...he gets in the van and we both look at each other and the house is like a...

Julie: ...like a bomb site...

Stuart: ...and we say, let's leave it until Monday!' *Julie and Stuart (336-342)*

CHAPTER 5 - DISCUSSION

5.1 Key Findings

The main aim of the present study was to use an interpretative phenomenological approach to explore the following four research questions:

- What are the experiences of a parent of a child with autism, who attends a residential school?
- How is the current situation with regard to provision, placement and support from professionals perceived by these parents?
- How is the construct of inclusion understood by these parents?
- What are the effective features of a residential school from a parent's perspective?

Four super-ordinate themes emerged as a result of the analysis of the data, these were:

- enduring loss
- the family versus the system
- heightened parenting
- the relief of residence

The main findings within these super-ordinate themes will be considered with reference to the original research questions and to the extant literature.

5.2 1st Research Question - What are the experiences of a parent of a child with autism who attends a residential school?

The overall aim of the present study was to explore the experiences of parents of children with autism in residential schools, thus, this first research question is overarching and requires the subsequent, more specific research questions in order to allow for the full exposition of the phenomenon. Therefore, analysis of the points of ‘convergence and divergence, patterning but also individual nuance’, as predicted by Smith et al sit more comfortably within the analysis of the subsequent questions, and this is where the majority of the discussion will take place (Smith et al, 2009 p166). Thus the attention given to the discussion of the first research question is therefore less detailed than that of research questions two, three and four, serving rather as an introduction to the major exposition.

The experience of a parent with a child with autism in a residential school is one that is profoundly meaningful and life-changing. It forces parents to re-examine their core beliefs and values and to discover what, for them, are the most important aspects of family and of a fulfilled life. In this respect, the findings from the present study reflected many of the previous findings in the research concerning families of children with autism, children in residential schools and children with life-long disabilities. However, the present study also makes an original contribution to knowledge as there is no extant literature that precisely explores this area, that of exclusively autistic pupils in residence, using a phenomenological approach. Moreover, it also includes the views of fathers, which is an area that is neglected.

In the present study, many of the parents' experiences were indeed profound and multi-faceted. In addition, they also were in some ways unexpected, a feature Smith et al associate with IPA methodology, revealing considerably more within the abstract realm of feelings, emotions, values and beliefs than they did about intellectual or pragmatic parental insights into systemic operations (Smith et al, 2009). A significant finding was that the role of carer, both primary and secondary, emerged as more important to the parenting experience than that of gender, with all fathers providing an equally intense narrative as mothers. Moreover, the lived experiences of all of these parents need to be interpreted through the appreciation of the impact of the all-prevailing influences of their contexts, which in the present study were identified as: the impact of autism; unconditional love; and the intense and enduring nature of the phenomenon in question. Finally, there are also some common themes with 'The Hero's Story' (Catford and Ray, 1991), as applied to parents of children with autism by Fleischmann (2005), as the parents in the present study moved through the stages of loss and adjustment, to a position of acceptance and reconciliation.

5.3 2nd Research Question - How is the current situation with regard to provision, placement and support from professionals perceived by these parents?

The constructs of provision, placement and support from professionals were not clearly delineated either in the interview questions or in the responses. This was due to the deliberately open nature of the interview questions which allowed the participants maximum opportunity to describe their story. Therefore they will be discussed together under the individual super-ordinate themes, present in the research question.

The super-ordinate themes most clearly present in this question were: the family versus the system and heightened parenting.

5.3.1 *Super-ordinate theme – The family versus the system*

The parents' perceptions of interactions with professionals in the present study regarding provision and placement were almost wholly negative and captured by the sub-themes of frustration, conflict, abandonment and isolation. These findings mirror those experiences represented in the extant literature concerning parents of children with autism, with life-long disabilities and in residence (Abbott et al, 2000, Dale et al, 2002, Whittaker, 2002, Bromley et al, 2006, Gray, 2006, King et al, 2006, McGill et al, 2006, Osborne and Reed, 2008, Woodgate et al, 2008 and Wittemeyer et al, 2011). Indeed, the similarities between the experiences of the parents in all of these studies, was marked.

5.3.1.1 i) Sub-theme - frustration

Parental experiences included frustration with the system with regard to securing appropriate provision for their child, with all parents expressing dissatisfaction with placements prior to residence. Specifically, the parents in the present study shared the frustration of those in Billington et al (2000) by reflecting with regret and frustration about lost opportunities for their children, as a result of inadequate provision that had provided merely an 'exercise in containment' (Billington et al, 2000 p 68) rather than a robust curriculum. This is likely to have arisen due to the particularly challenging and complex nature of the children in the present study, where schools appeared to be focused on accommodation, protection of the other pupils and appeasement, rather than education, as their behaviour became increasingly violent and physical.

There were many similarities with the decision-making process for residential school, in this and previous studies. The same requirements for placement as Abbott et al (2002) identified were corroborated in the present study, namely:

- a need for a 24-hour curriculum with consistent provision
- parents admitting they could not cope
- child exhibiting challenging behaviour
- child excluded from local provision

Moreover, the apparent lack of any clear criteria for residential placements led to conflict with the system, as both the studies of Abbott et al (2000) and McGill et al (2006) identified. The parents in the present study were not aware of any clear criteria and the decision-making seemed to them to be arbitrary. More frustratingly, their strong perception was that the primary concern was financial. One parent, Paul, identified financial constraints directly and spoke with anger and contempt about this. For others, finance was always suspected to be a main factor, although they may not have had direct proof of this. Introducing finance into the decision making process was hurtful to all parents as they saw this as a way of putting a value on their child – and one that initially the system was, apparently, not prepared to pay. This led them to assume an aggressive position, as they felt they were left with no option but to fight for that to which they felt their child was entitled. This was also linked with the call for every child to be seen as having unique needs, and not to be subsumed under one generic provision – also raised by Abbott et al. Smith et al, in their guidance for carrying out IPA, encourages the researcher to engage in a consideration of the complexity, ambiguity and variability within the decision-making process of the participants, during an IPA analysis.

However, it appeared in the present study that most parents shared a very similar experience regarding this most important decision of residence. All felt that they were left with little choice as they described in detail the extreme behaviour and challenges they were dealing with on a daily basis, with very little, if any, external support. If the need to make the decision for residence was unambiguous, then the actual experience of the process was very complex. All parents experienced a conflict of emotions and a need to justify their decision, definitely to the professionals in the system, which added to their frustration and fuelled their perception of conflict, and possibly also, as they narrated their story, to the interviewer, who would be viewed not only as an outsider, but could also be perceived as part of the wider 'system'. This facet of the present study, of the conflict of emotion, proved to be one of the defining features of the research.

However, these findings are overtly acknowledged to be from the parental perspective and this study did not aim to speak to the professionals involved, the views of whom are likely to be very useful in adding to the understanding of this complex situation.

Unfortunately, prior to any actual experience of residence, the present study also had residential provision associated with the 'last resort' option, rather than a positively sought pro-active provision. This was the case as the decision for residence was taken after all other alternatives had been tried and found to fail and was perceived by parents as not only the last chance for their child, but also a regretful one, meaning as it did, the removal of their child from the family home. The 'last resort' perception was also reinforced, indirectly, by the reluctance with which most professionals appeared to view residence - in the present study and certainly in those of Abbott et al and of McGill et al – as an ideologically less desirable position, only to be sought when all other more inclusive options had been exhausted.

Moreover, the majority of reasons for the decision in the present study, as also found by Abbot et al, were negative (to relieve a stressful situation) rather than as a provision chosen for the positive benefits it would bring to the child. This is regretful, as it could be argued that a consistent 24-hour curriculum, applied before these very negative and traumatic behaviours became established, could prevent the appearance of this subsequent undesirable behaviour. This was certainly the view of the parents in the present study. It is not inevitable nor obligatory that families should endure such trauma, before residence is offered, yet, scrutiny of all available information, from this and previous studies, would indicate this is the more typical scenario. This has links with the claims of Prizant et al (2000), the view of autism as a transactional phenomenon and the important part emotional regulation has for individuals with autism. It could be argued that ensuring the emotional well-being of both parents and children, through early intervention, could lead to more favourable outcomes. It is interesting that with hindsight, all parents in the present study expressed a wish that they had been offered the residential provision at an earlier stage, as they began to appreciate the positive effects residence had both upon their own lives and those of their children. Thus, what had previously been viewed as an undesirable option by parents, through direct experience, had been totally transformed.

Frustration with the lack of forward planning for transition into adult services was a key theme of this study. In some participant's cases, this was postponed and possibly allayed, due to the very recent opening of an adult unit attached to the residential school, to which three of the students had entered and one was awaiting confirmation of a place. However, for the remaining two parents, this was an ever-present concern. Again, this confirms the findings from Abbott et al, McGill et al and Wittemeyer et al in the UK, mirrored in Gray's study in Australia, and gives backing to the recommendations of the 2007 Audit Commission

for consistent long-term planning for this group of students. If these changes were to occur, then they could bring more peace of mind to the parents in the present study and allow them to plan as a family, especially for older parents (such as Julie and Stuart), or those without other children to rely upon (Lesley) to assume the role of carer. It could be argued that it is not the state's responsibility to provide peace of mind for parents, yet in an inclusive society that purports to respect the lives of all, including those with additional needs and is a signatory to human rights legislation, it could be equally be argued that this is not an unreasonable expectation for parents to have.

Parents in the present study reported frustration with professionals who they perceived were constrained by their loyalty to their employer and were therefore unable to provide complete or effective information, but rather purveyed vague and informal advice– also identified by Abbott et al and commented upon by Jo and Paul in their accounts. Parsons et al, (2011) also found that decisions around provision were frequently linked to factors that were difficult to quantify, including ideological issues and knowledge of practitioners (which was not uniform). Abbott et al's study speaks of EPs having a concern for their professional integrity, in trying to remain neutral and not naming a particular school or type of provision, but many parents found this strangely contradictory, that those with the most knowledge were unable to give advice. They then found they had nowhere else to go other than taking the authority to tribunal.

Frustration was also experienced because the standpoint from professionals was often perceived by parents to be one against residential schools – yet they as practitioners also were forced to admit that there were no viable local alternatives. In this respect, the experiences of

parents in this study were that the needs of the child and family were routinely lost within an ideological battle with the professionals within the system.

The parents in Abbott et al's study found the decision making process a 'damaging and negative experience', unfortunately, a sentiment shared by all of the parents in the present study. Abbott et al spoke of this being a 'bullying' experience for their parents. Bullying was not overtly mentioned by the parents in the present study, but their experiences were of being made to feel routinely impotent, out of control and of their views being ignored or disbelieved - equally damaging experiences. This was especially true with regard to the distance of the school from their home. All parents held strong views about the proximity of the school as they wanted their children near to them, but their perception was that professionals saw the financial cost of this as superceding parental wishes. Parents also put value on their own view of the school and how they interpreted their own child's views of the school – but these were not perceived to be considered important, or at least were not acknowledged as such, by those making the decisions.

5.3.1.2 ii) Sub-theme – isolation

All of the participants experienced this at different times and in different guises prior to residence, as also described in other studies, including Billington (2000), Gray (2002), Woodgate et al (2008) and here, by McGill et al:

‘the overriding sense is of their being isolated, excluded and left to get on with a task (parenting) which is too difficult or beyond the expertise of the qualified professionals.’
McGill et al (2006) p612

Woodgate et al's construct of isolation for the families in their study was encapsulated by the theme, 'living in a world of our own,' and resulted from external sources, in particular the lack of understanding of autism from society. Whilst this was evident to some extent in the lives of the parents in the present study, it did not account for the whole experience of every parent. Woodgate et al attributed their findings to the fact that their parents were recruited from an empowered support group and therefore it could be inferred that they were more resourceful and resilient to internal stressors. However, the parents in the present study presented more like those in Gray's Australian study, who were recruited from a treatment centre and constructed as a more dependent group. This could be because the parents in the present study were not part of any 'group' at all and were coping on their own, in isolation. Gray also identified isolationism as a factor in his group and explored the coping mechanisms of his participants, as a way of exploring this construct further. He identified a range of strategies, some of which the parents in the present study shared in a limited way, including social support (Jo, Stuart), extended family (Sue and Brian) and activism (Lesley). However, the mechanisms, identified by Gray, that the parents in the present study mainly relied upon, and were present in every case, were: services (but only in a successful way following residence); normalisation (of the unusual family situation) and individualism (withdrawing into isolation). The latter was a necessary action following the disappointment of the expected support from the system.

A strong theme from this present study was of isolation as a form of survival. The participants did not identify with Gray's findings, that fear of stigmatisation was a predominant factor in their withdrawing from society. Rather, their motivation was of a more simple and urgent nature. This difference could be accounted for by the particular needs of the children in the present study, that were severe and challenging, whereas those in

Gray's study were more wide-ranging and included those with mild difficulties. As challenging behaviour has been identified as a major stressor in family dynamics by Gray and others (Bromley et al, 2004, King et al, 2006, Hoffman et al, 2009), this is highly likely to be an associated factor.

Isolation through lack of appropriate respite facilities, frequently previously identified by others (Barson, 1998, Abbott et al, 2000, Loynes, 2000, Bromley et al, 2004 and Hutton and Caron, 2005) was experienced by all the parents in the present study.

5.3.1.3 iii) Sub-theme – abandonment

Participants also felt abandoned at each stage of the process by the system, pre-residence and during the decision making process, as previously described, and also following the placement. Abbott et al in their study note that once a decision for a residential place had been agreed, the professionals then did not have much involvement with the choice of the particular school. The parents in the present study also found this, and were perplexed by this, occurring as it did at the time when they as parents became most concerned. They would have valued help and advice but felt that they received none. Professionals did not appear to have the time to get to know families in sufficient detail, yet these were the very families with the most complex needs who required an individual approach. The parents were therefore frustrated when professionals did not understand their world-view, as construed by King et al (2006) in their study, and were relieved to find support from other sources to meet this need – in the present study, this was positively provided by the residential school. However, there could be a need for caution in other similar situations, as, in the

absence of appropriate expert professional advice at this crucial time, less scrutable professionals or establishments may fulfill this role, with less satisfactory outcomes for both parents and families.

With further regard to the role of professionals, initially, it was thought that the present study may have a different perspective in relation to the prominent role of social services, within the decision making process (as in Abbott et al and McGill et al's studies) due to the formation of joint Children's Services in recent years. However, all of the decisions regarding placement in the present study had been made prior to this system change. Therefore, the criticism of parents in the present study was still largely directed towards this professional group.

Indeed, EPs were only directly mentioned twice, giving the impression that they were not influential in the process. This is likely to reflect the secondary role that EPs typically held with these complex families at that time, due to historical practice, as well as social workers having the major influence, as a result of the extreme social needs of the children in question. This situation may now have changed, due to the emergence and growing establishment of joint Children's Services and it will be interesting, from a professional-identity perspective, to investigate this.

5.3.2 Super-ordinate theme – Heightened parenting

The super-ordinate theme of heightened parenting was strongly represented in this question as, overall, parents felt the need to be a strong advocate for their child, once they realised the many obstacles they were facing from all three areas –securing appropriate provision, placement and support from professionals. This theme reverberated with the previous constructs of, 'vigilant parenting' (Woodgate et al, 2008), 'parenting plus' (Ray, 2002),

‘extraordinary parenting’ (Rempel and Harrison, 2007), and ‘heightened experience of parenting’ (King et al, 2006) in studies of parents of children with a life-long disability. This also had points of contact with Fleischmann’s study and ‘The ‘Hero’s Story’ (Catford and Ray, 1991, Fleischmann, 2005).

All of these studies explore, in varying degrees, the lived experiences of the parents and by doing so help to make more explicit the values and belief systems of the families. King et al argue that the particular situation of living with a child with a chronic condition forces parents to examine their implicit belief system in a way that most parents do not. This is, they posit, to enable parents to take control and to feel empowered. In this way, they encounter the ‘heightened experience’ shared and vividly described by the parents in the present study.

5.3.2.1 i) Sub-theme - the expert parent

Woodgate et al describe a ‘system’ that was ‘inaccessible in many ways’ to the parents in their study (Woodgate et al, 2008 p1079). This was an experience shared by the parents in the present study, who consequently adopted the position of expert and advocate for their child to fill the vacuum left by the professionals. They go on to conclude that a product of this enforced isolation by the system, was a ‘diminished sense of hope’ within the parents, associated with the expected outcomes for their children (Woodgate et al, 2008 p1079). In order to cope with this negative emotion, they adopted roles similar to those that surfaced in the present study and captured by the sub-theme, expert parent. By contrast, Gray (2006) introduces the notion of optimism in relation to the parents in his study, claiming that they are more optimistic about their children’s attainments than the professionals. Pessimism, or low expectations from professionals was not overtly stated in the findings in the present study, but

it could be implied from their in-actions, in apparently not seeking out provision that could offer more than respite and thereby not recognising the potential of the children.

However, the parents in the present study are more accurately described as determined and vigilant (after Woodgate et al) in maximising their child's opportunities, than optimistic. In these ways, they were following Woodgate et al's parents who were seen as 'fighting all the way' in an advocacy role (Woodgate et al, 2008 p1081). However, the similarity between the two groups of parents did not extend to Woodgate et al's further observation of their group, in supporting other parents. Rather, in the present study, the parents were too isolated and pre-occupied with day-to-day survival to contemplate any altruistic actions, whereby, in contrast, Woodgate et al's parents were all engaged in a structured intervention programme (Applied Behaviour Analysis - Lovaas) and recruited from a support group, suggesting they were both empowered and confident. Moreover, the parents in the present study were largely unaware of any other families and possibly did not therefore have the immediate motivation to consider their needs.

5.3.2.2 ii) Sub-theme – the sacrificial parent

The sacrificial parent was a powerful sub-theme throughout the findings – becoming more visible when considering the parent's construct of inclusion. However it is still important to highlight where it is present in this research question, namely, within the parents' interactions with the issues of provision and placement, mediated by their contact with professionals during the decision-making process for residence. All of the parents in the present study experienced a painful conflict of interest at this time, culminating in a huge sacrifice of their own needs as a parent over the needs of their child. Abbott et al (2001) also recognise this

act of self-sacrifice amongst the parents of their study. The act had such resonance that it elicited the most emotional periods of discourse of the whole narratives in the present study, and the impact of this decision is clearly still very powerful, with evidence of residual guilt present in all accounts.

5.4 3rd Research Question - How is the construct of inclusion understood by these parents?

Inclusion is not a simple construct. It is usual to consider both social and educational inclusion, concepts which reverberated through the interviews from the parents in the present study. What emerged from these findings was that the parents experienced the ‘operational fall-out’ of an ongoing and complex ethical dilemma, preoccupying the professionals. This dilemma can be expressed as: should an ideological perspective and construct of inclusion take precedence over the practical needs of individuals?

It should be noted that nowhere in the parent’s narratives was the word ‘inclusion’ mentioned. However, three super-ordinate themes were represented in this question – enduring loss, the family versus the system and heightened parenting, which have been construed and interpreted as relating closely with this construct. Parental views of inclusion were therefore uncovered through an examination of their comments in a number of related areas, most notably from those relating to their belief systems, a conception viewed as highly relevant to this discussion, and particularly highlighted by King et al (2006).

5.4.1 *Super-ordinate theme – Enduring loss*

Before the realisation that their child had a life-long condition, none of the parents spoke of any direct experience of the special educational needs system nor did they have any need to

consider, in a personal way, ideological terms such as ‘inclusion ‘ and ‘segregation’. In the early days, when families were beginning to assimilate the impact of the loss of their expected child and of their family life, the primary concern was to procure appropriate early intervention. As it was very clear in five out of the six accounts, that their child had severe and complex needs and that therefore additional specialist provision was likely, the construct of educational inclusion was not a priority. Only Jo, whose son’s needs were more subtly presented, had a brief, unsuccessful episode of mainstream education, following which she quickly came to the conclusion that he required more specialist provision.

The predominant discourse of the early years of education, from the parent’s perspectives, was disappointingly, of accommodation and containment, rather than actively promoting learning. No parent expressed any regret over their child not being present in a mainstream school nor of having a restricted peer group. However, they did, in hindsight, express regret over the lack of specialist provision and of potentially lost opportunities, also echoed powerfully in the parental account in Billington et al (2000). When professionals were apparently pre-occupied with considering the ethical dilemmas posed by residential education, all of the parents in this study were convinced of the absolute necessity of this respite – despite their yearning to keep their child close to them, in the family home. Earlier in the process, parents also did not find useful the inclusion-driven policy of having the right to request any mainstream school in their area for their child. Julie was confused by this and found the experience humiliating and rejecting, when it was immediately obvious that Nick’s needs could not be met within such a placement. This was an example of a laudable approach having an undesirable effect –perhaps when ideology takes precedence over the needs of an individual?

Thus, it might be inferred from their actions that the parents in the present study were anti-inclusion. However, this would be too reductive and to dismiss the wealth of their experiences to a very narrow concept. Earlier studies have called for the belief systems of parents, (Tams, 2001, Gray, 2002 and King et al, 2006) to be better understood by professionals, and the findings of this present study concur with this view. Failure to adequately appreciate parental values can lead to conflict, as evidenced in this and other studies. The parents in both the studies of King et al and Fleischmann changed their belief systems as a result of their experiences and as a way of coping. Similarities can be seen in the present study. Just as King et al's and Fleischmann's parents set aside hopes of accomplishment and independence for safety and respect – so did these parents. By their actions and by their accounts, the parents in the present study demonstrated that they placed a higher value on the more basic human needs of acceptance, safety and positive well-being than they did on educational progress, a finding also present in Wittemeyer et al's most recent study (Wittemeyer et al, 2011). They eventually experienced this re-construct of inclusion when their children were fully accommodated and respected within the residential school – even though this was far away from their community, family and from their local peer group. Thus, to them, inclusion in the narrow sense of the neighbourhood mainstream school, was an irrelevant construct, rather, 'inclusion' had transcended into the wider concept of seeking and enabling opportunities to fulfill potential and to be fully included in life, via a highly individualised experience.

However, the parents, in all cases, eventually felt they had no other options available to them, other than residence, and in this respect, their chances of making a more inclusive choice of provision were nullified. McGill et al and Jones et al (2008) make a recommendation for

Local Authorities to consider a more creative, individual package of local support, crucially also including an effective and realistic respite component. If there were to be a commitment to this, then possibly, at least some of the parents in the present study may have had a viable alternative to consider and thereby enabled their child to remain part of the family and of the local community, at least for longer. Unfortunately, for all of the parents, the trauma of caring for their child, with inadequate support, during the very challenging years leading up to residence, had forced them to draw the reluctant conclusion that they could not imagine them ever living back in the family home on a permanent basis.

5.4.2 Super-ordinate theme – The family versus the system

Until the 1970s, the children in the present study would have been judged to be in-educable and would have been in hospital or social care facilities rather than within the education system. Following, changes in legislation, including the very significant Warnock Report (1978), education for all children, regardless of need, was introduced. However, after spending only a relatively short time within the education system, children with the most complex needs found themselves within a quickly changing agenda, following the introduction of the National Curriculum in the 1980s, with subsequent pressure on special schools to demonstrate their ability to continue the inclusion of such complex children. To remain part of the education system, schools have to demonstrate their adherence to the National Curriculum and also to all related government guidance concerning curriculum, achievement and inclusion. It is very difficult, without substantial attention, to include pupils with severe and complex needs within such an academically biased system. Parents in this study (other than Jo, whose son had slightly different needs) were calling for basic care, security, acceptance and a meaningful existence as well as continuing to progress, as far as

they were possible, with the development of independence skills and communication.

Inclusion for these parents involved being accepted within the education system as a whole, within the community of the residential school and its environs (which they equated with ‘home’) and for life-long learning opportunities. They wanted their child to be recognised as an individual with unique needs and for them to be helped to be included in everyday life experiences. These were much simpler requests than ‘access to the National Curriculum’ and can be seen as an indication of how far their very different, extreme experience of parenting, has forced them to drift away from that of their peers.

As a result, the parents in the present study made a very painful decision for residence, but as with those in McGill et al’s study, some of the professionals were perceived to view this decision with cynicism, apparently from a lack of understanding of individual circumstances, and because they did not (or could not) seek out parental views. This could be interpreted as professional arrogance – as if some professionals had a pre-conceived idea about what is right for the education of these complex children, that is, that inclusion within mainstream schools, or as near to that ideal as is possible, is always the preferred choice.

5.4.3 *Super-ordinate theme – Heightened parenting*

The parents in the present study needed to adapt in order to cope with their challenging lived experience. The super-ordinate theme, heightened parenting, captured the essence of this and provides an insight into their changing belief system, and how it relates to their changing view of the construct of inclusion.

Many of the observations from Woodgate et al's study and that of Fleischmann, find parallels with the parents in the present study, including learning to be more assertive with professionals, protecting their own well-being and re-evaluating what is important in life. There were similar cross-over points with King et al's study. Their parents thought it important to hold a positive view, as a way of coping, to strengthen their values and to use their experience as an opportunity for personal growth. Certainly after residence the parents in the present study showed more evidence of these qualities, through their stated determination to be assertive with professionals over post 19 provision, in seeking out knowledge regarding autism and in making positive adjustments in their new, reconstituted families.

However, where the parents in the present study deviated from the previous researchers was in their ability to benefit from or reflect upon their experiences in an altruistic and philosophical way. By illustration, Woodgate et al speak of their parents learning from their children, in that they began to recognise their strengths and qualities as they interacted with others. King et al write of their parents broadening their world-views and receiving positive recognition from society and Fleischmann of the parents in his study changing their perception to see autism as something that brought value to their lives. However, the more usual experience for the parents in the present study, certainly pre-residence, was of a shrunken world and of a smaller sphere in which they interacted. Thus, they learned of patience, acceptance, tolerance, perseverance and unconditional love – as did those described by King et al. However, the difference was that in the present study, their 'learning' was through an unsought necessity, with none of them describing this in positive terms, such as 'enlightening' or as an 'epiphany', as is the emphasis from King et al and Fleischmann and to a lesser extent also from Woodgate et al. Rather, for the parents in the present study, having

a child with autism, pre-residence, appeared to have left them traumatised, with limited capacity for existential deliberations. All of their spare energy was required to deal with the demands of the current situation and to be preserved for their frequently mentioned, anticipated future battles, on behalf of their children.

King et al talk about a transcendence experience for their parents as they move on with their life. However, although in many ways the parents in the present study had also journeyed, post-residence, (most notably with normalisation of family life) the impact of their child's complex needs was ever present, particularly so for Lesley, who was still heavily enmeshed with her sons' lives, three years into residence. One tentative explanation for the differing tone of these parental experiences could be linked with the pervasive and unrelenting impact of autism in conjunction with other chronic needs, that the children in the present study experienced, contrasted with, possibly, the lesser needs of the children in King et al's study (which included those with autism, still able to live at home, and those with Down Syndrome). Therefore, caring for these complex children, the parental role was perhaps more likely to be an intense and enduring one. For Lesley in particular, she had the added factors of twin boys with autism and no other children to command and divert her attention, which could have further intensified her experience. Importantly, it must also not be assumed that she, and the other parents, did not also positively choose to maintain a very close involvement with their children, as the context of unconditional love resonates clearly throughout all of their accounts.

5.5 4th Research question - What are the effective features of a residential placement from a parent's perspective?

The parents in the present study were asked directly about the positive and negative aspects of their particular experience of residence at Ash House, and as indeed several of them pointed out unprompted, they were aware residence may have been a very different experience, had the school itself been different. All of the parental accounts emphasised the specific impact that Ash House had on their experience, rather than residence per se, which was a clear finding from the study. Therefore, it would be unwise to attempt to generalise these findings to other establishments. Rather it may be more prudent to directly state that it is more likely that parental experiences will be determined by the nature of the particular school, such is the impact the establishment itself appears to have upon such vulnerable families.

Moreover, the parents needed no prompting to speak freely about their lives post-residence, in overwhelmingly positive terms. These responses have been interpreted as representing the features that were valued about residence and therefore likely to contribute to effectiveness, following the measure of parental satisfaction (Carpenter et al, 2001, McGill et al, 2006).

The features that were identified as valuable were categorised as operational (for example the communication system in the school) and ethological (for example the relationships between the family and the school).

5.5.1 *Super-ordinate theme – The Relief of Residence*

The relief of residence is the super-ordinate theme that is best represented in this research question. All parents in the present study experienced a profound sense of relief, post-

residence, similar to that reported by those in the studies of Abbott et al (2000) and of McGill et al (2006). They were able to gradually rebuild their lives and restore normality to their families. As a result of the transition into residence and the subsequent sense of total acceptance that all participants felt from the school, Ash House, although an external agency, was no longer perceived as part of the wider system – rather it had transcended into the realm of the extended family. This was apparent by the frequent direct comparisons by parents of the school staff as ‘family’ as well as by the indirect references to the ways in which the school supported the parents, the level of involvement and the mutual affection, trust and even love, that was described. The findings suggest that this transformation occurred as a result of the serendipity of two variables coinciding – the highly vulnerable state of all of the parents and the favourable ethos of the school, which seemed to precisely match their requirements at that precise time. Parents felt immense relief because without this option, several of them had disclosed that they were considerably stressed and finding it difficult to continue with their child at home. The relief did not come without conflicting emotions however, as all parents expressed guilt arising from the original decision for residence. Nevertheless, the relief did outweigh any negative emotions, and became more intensified over time, as the parents became more aware of the benefits of the school and also adjusted to life without their child at home.

Therefore, the affective and ethological aspects of the school emerged as the most immediate features that were valued by parents, rather than specific operational aspects of the school. Thus, the debates around autism-specific pedagogy, were not reflected in the comments from parents. They did all value the defining feature of the 24-hour curriculum, provided by the school but, as in previous studies, it was difficult to isolate the specific features associated with this, including any that were autism-specific. Rather, it appeared as if, for many

parents, they were largely unaware of the day-to-day functioning of the school, particularly with regard to the educational components. Lesley spoke about communication schedules for her sons and Jo briefly mentioned the specific teaching programmes that the school had introduced for her child (having some different needs from the rest of the cohort), but this was not a strong feature of the narratives. In this respect, the findings concur with those of others, as an example of parents transferring their previously held primary concerns of ‘accomplishments’ to acceptance and positive well-being, and of valuing social and emotional care above education (Abbott et al, 2000, King et al 2006, Wittemeyer et al, 2011).

Many of the features, both operational and ethological, identified directly and indirectly in the present study, were similarly valued by the parents in previous studies. However, there were some differences, most notably in the quality of the relationship between school and parent, which assumed a more prominent role for the parents in the present study, arguably as they had experienced a more traumatic pre-residence period as a result of the particularly complex needs of their children. These are summarised in Table 12.

The absence (or otherwise) of a peer group was not mentioned by any of the parents in the present study. This was thought most probably accounted for in the very limited communication skills of the children in the present study, compared with those in others. This could reduce the opportunities for interaction with peers and to therefore similarly reduce the importance of this, for parents. It might be thought more surprising that no parents specifically mentioned the importance of a key worker, a factor that has emerged strongly from the study of Parsons et al (2011). The impression that the findings gave of the arrangement in Ash House was of a larger group of adults having a very good knowledge of each child rather than designated individuals. However, this may warrant further

clarification. Certainly, there was no implied criticism of the current system and all parents spoke highly and confidently of the relationships of the staff with their child. Indeed, continuity of staff was mentioned as something of particular value, to the extent that when this was threatened (by the use of agency staff) this was a very rare moment of concern about Ash House, expressed by one parent.

Similarly, the findings in the present study did not reveal any specific references to such variables as 'clear leadership', yet in all of the narratives there was a strong discourse of satisfaction and confidence in the organisation and ethos of the school, factors positively identified by others in relation to autism specific residential provision, mentioned above, but also, interestingly, by the parents of children attending the Higashi school (Massachusetts Department of Education, US, 2003) and also as highlighted by Humphrey and Lewis in their study of the inclusion of children with autism in mainstream schools (Humphrey and Lewis, 2008). From this evidence then, it might be inferred that the leadership in the residential school was effective and valued. All parents spoke warmly of the good relationship between children and staff, which they valued highly. This seemed to qualitatively differ from an expected adult-child relationship, indeed it was referred to by all parents as a family relationship, and defined the residence experience. It was this supra-normal experience, of providing support over and above what could be expected, also highlighted by Abbott et al by their parents in residence, that enabled the parents in this study to be restored to effective and functioning individuals. The importance of this relationship, perceived by parents as a vital factor in the success of the provision, is also key when considering the intersubjectivity and transactional views of autism (Prizant, 2000, Hobson, 2002,), where social interaction and emotion are so important in successful outcomes.

Table 12

UNIQUE TO PREVIOUS STUDIES	UNIQUE TO THE PRESENT STUDY	COMMON FEATURES
peer group	trust	consistent behaviour management
good relationships with a key-worker	openness	high level of care
coherent ethos	approachability	valuing the child
	‘family’ relationship	good school communication
	high expectations of all children	respite
	highly individualised approach	reassurance from experts
		continuity of staff
		clear leadership
		parents able to maintain some degree of responsibility for their child
		emphasis on the social and emotional aspects of learning
		proximity to home

Features valued by parents in a residential school –based on findings from (Abbott et al, 2000, Carpenter et al, 2001, McGill et al, 2006 and Parsons et al, 2011)

As a result of this transformation, the parents in the present study, like those in Abbott et al’s, were willing to tolerate features that were not totally satisfactory (as seen in the narratives of Paul and Lesley) for the greater good of residence. Similarly, McGill et al talks of the ‘cost’

of residence, to which they are referring to the increased risk of abuse and the reduction of family contact. In the present study, Paul and Sue talked indirectly about their fear of harm and neglect. Similarly, reduction of family contact (through a distant placement) had been a frequently mentioned deciding factor in the choice of Ash House. Moreover, all were vigilant in maintaining contact with their child through formal and informal ways. It appeared therefore as the parents in this study had weighed up these costs and on balance were prepared to accept them, because they had an initial trust in the school, which grew over time into a strong sense of loyalty. This loyalty led them to appear reluctant to even appear to criticise the school. When the rare, ineffective features of residence were identified, the parents took great care to identify these not with the school, but with the wider 'system' from which they had firmly shifted Ash House.

However, there are alternative interpretations of the behaviour of the parents in the present study. It could be argued that they are likely to be hesitant in being seen to be critical of a body with which they have not only established a personal relationship, but also one to which they have entrusted their most vulnerable child. Also, there could be an element of enforced self-deception by parents, as by admitting that they had concerns over the placement, this would be at the least unsettling and at worst potentially devastating in terms of being forced to consider an alternative provision, when their recent history has demonstrated that this would be far from an easy process. This leads to the risk that as a result of the parents having such a close relationship with and dependency on the school, they may be prevented from exercising the same degree of rigour in their monitoring of the provision. Moreover, the usual practice of professionals in the home authority, who are responsible for maintaining and financing the placement, assuming this monitoring role, has been noted by McGill et al as being problematic. They found professionals faced several obstacles to carrying out this role

effectively, including the geographical distance of the school from the home authority, time constraints and unclear pathways of responsibility. Therefore, satisfactorily evaluating the effectiveness of residential placements, is similarly highlighted as a potential area of concern, from the present study. This area has most recently been highlighted by the publication of the Winterbourne View Report with recommendations for the care of individuals (in this case, adults) with complex needs, in residence (Department of Health, 2012).

5.5.2 Super-ordinate theme – heightened parenting

Within this research question there were also present elements of the super-ordinate theme, heightened parenting, as all were anticipating future ‘battles’ with the system in order to preserve the provision that they recognised as being most appropriate for their child.

Recent publications in this area, including the study of Jones et al (2008) the issuing of the Autism NICE guidelines (2011) and the recommendations of The Children and Families Bill (2013) raise the emphasis and value of parental perspectives, especially the importance of involving parents in decision making for more effective outcomes. Pre-residence, there is not evidence from this present study of parents having any involvement in the provision (through effective reviews, for example), but, by contrast, they greatly valued the opportunity to be involved post-residence and this was mentioned on several occasions. However, only one parent, Lesley actually spoke about being directly involved and this was perceived to arise from the school and not from other professionals. Therefore, in this respect, for these parents, there was still a sense of abandonment by and isolation from, the wider system, as had been experienced pre-residence.

5.6 The role of fathers

This was not a separate research question in the present study, but the opportunity to consider the specific experiences of fathers arose due to the particular composition of the sample. A full discussion of this area is not undertaken here but several important points can be made. Two fathers, Paul and Brian, provided individual interviews, with Stuart making a substantial contribution to that of Julie, his wife. All of their experiences mirrored those of the mothers, in terms of the strong representation of the four super-ordinate themes and the over-arching impact of the context of the impact of autism, the intense and enduring experience and unconditional love. For Paul, who was the primary carer for Nick, his son, his experience did not differ in quality or intensity from those of Lesley, Julie, Jo and Sue, who were also the primary carers for their children, suggesting that this is the key variable in defining the parental experience, rather than gender. Importantly, the present study also found that increased stress levels, previously attributed to mothers of children with autism and complex needs, were similarly present in fathers (Paul, in the present study), if they were the primary carer (Bromley et al, 2004, Dale et al, 2006, Hoffman et al, 2009). However, Brian and Stuart, who were secondary carers, in that they were both working and therefore absent from the family home for substantial periods, still narrated very powerful, life-changing experiences and both described their views of the major events – the initial realisation of a difficulty, diagnosis, early school experience, the decision for residence and post-residence – in the same emotionally powerful terms as the primary carers. They did however, acknowledge that they had reduced levels of stress, when compared with their partner, the primary carer. This suggests that the impact of the experience of having a child with such challenging and complex needs as autism, was such as to transcend the role of gender and of primary/secondary carer, but that the status of the carer was significantly associated with

levels of stress. There were some specific differences in experience which may be interpreted as being attributed to the traditional role of being a 'father', most notably when Paul referred to his perception of the loss of his 'first born son', and Brian spoke of his disappointment in not being able to provide all that was needed for his daughter, but overall, the findings from the present study did not surface any evidence of there being a significant difference in experience between mothers and fathers.

5.7 Conclusion

This chapter has considered in detail how the research questions for the present study have been reflected in the findings and particularly it has examined points of difference and similarity with the extant research. The next chapter is concerned with offering conclusions to the whole study, including making recommendations for future research and addressing possible implications for practitioners.

CHAPTER 6 - CONCLUSIONS

This chapter is concerned with a discussion of how far the present study achieved its stated aims and includes a consideration of the reflexivity element of IPA via a personal reflection of the research interview process, a critique of the methodology, suggestions for future research and implications for practitioners.

6.1 Reflexivity – Introduction

IPA encourages the researcher to adopt a reflexive stance. This is in open acknowledgement of the difficulty inherent in any interpretative phenomenological analysis, in separating out, for example, which are the participants' thoughts and which are those as interpreted by the researcher, influenced by their own life experiences. This celebration of the 'hermeneutic circle' within the research process, contributes to the transparency and integrity of the whole procedure (Smith et al, 2009 p35). One way of achieving reflexivity is to reflect on the thoughts and feelings associated with the interview experience. The following section outlines the reflexive experience of the researcher in the present study and is written in the first person to acknowledge the subjective nature of the process.

6.1.2 A personal reflection of the interview process

I am a very experienced practitioner and have conducted numerous interviews with parents of children with very complex needs, largely within the realm of assessment. However, prior to this study, I had never interviewed parents about such personal matters as their own experiences and as a novice researcher using IPA, my first reflective response to the interview process was one of professional humility. The content of my contemporaneous notes,

recorded after each interview, document my surprise at the openness, honesty and power of the emotions of the parents expressed within the interviews. The rawness of their emotions, conveyed through their narratives, encompassing grief, frustration, anger and unconditional love, gave a powerful voice and sense of immediacy to their experiences. The richness of the narratives reflected the powerful urge of the parents to tell their story. For some, this was the first time they had spoken about their unique and traumatic experience in any detail, and particularly to an outsider. For this, I felt a sense of privilege but also of responsibility, in my interpretation of their story.

Thus, their accounts were largely unknown prior to this research, particularly to the professionals who had previously been concerned with identifying and advising on provision for their children and who typically were constrained by time and resources. It is also not within the usual remit of such professionals, including EPs such as myself, to enter so closely into the lives of these families. Yet this is what the parents unanimously desired. I therefore felt a responsibility to use their rich insights in a way that would reflect their value and would maximise their impact.

This sense of responsibility also bore heavily upon me during the interview process. Smith et al defines the interviewer as the expert, who should be the guide during the interview. However, I was frequently surprised by the candour of the parents and did not always have the confidence nor the expertise to follow up specific comments, when it would have been helpful to clarify their thoughts on a particular area. At times I found it difficult to separate my usual role as a practitioner from the temporary role as an objective researcher. Therefore, on occasions the transcript reveals that I made leading comments or made gentle attempts to defend my profession when I felt it under attack. At other times it was difficult not to

attempt to distance myself from the 'system' when it was being so negatively portrayed, nor to use opportunities to show that I was not like 'them', by demonstrating my knowledge and understanding of autism, for example. Whilst analysis of the transcripts does not lead me to believe that this was a frequent nor a damaging feature of the interviews, it is impossible to be sure how this might have impacted upon subsequent comments from the parents.

Smith et al also talk of attempting to 'expose the obvious' and to 'reveal the strange in the familiar' during the interview process (Smith et al, 2009 p69). I felt that I was more successful in the latter as participants appeared to relax into the interview and then spoke freely, without inhibition, mentioning, unprompted, many powerful and personal experiences. With the former, I felt that my lack of assertiveness, due to my inexperience of the methodology, led to my not obtaining sufficient clarity on certain subjects, which did not become clear until the process of analysis. This was sometimes as a result of my reluctance to be seen to be probing into sensitive areas, but also in not clarifying meaning, when the parents made an assumption that I understood their situation, for example.

I was also constrained at times by the situation of being a guest in the parents' homes. Within this context, some questions, particularly about relationships with ex-partners, felt as though they would be too intrusive and personal, especially as this had not been a stated aim of the interview. I was also conscious that I was making just one visit and was not attempting to make any longer-term relationship with them, gaining personal information and then using it (largely) for my own purposes, which at times felt uncomfortable and possibly exploitative. I was therefore deliberately tentative in my approach, through a desire to be sensitive. I would have preferred to have developed a more collaborative relationship, but this may have affected the objectivity of the research.

However, overall, I believe that my previous experience as an interviewer and my knowledge of autism is reflected in the quality of the narratives shared by all of the parents. These had a rich and genuine quality, and subsequent analysis of the findings has revealed that they provided sufficient detail and insight into their lived experience to produce a study worthy of their inherent value.

The next section moves from the subjective consideration to an objective critique of the methods and processes of the present study.

6.2 Critique of the Research Design

6.2.1 Critique of the Research Questions

Any critique of a study should include an appraisal of whether the chosen methodology allowed for the research questions to be sufficiently addressed and answered. As is outlined in the discussion section, there was a wealth of data produced and available for analysis, which generated rich and detailed responses to the research questions. This is summarised in Table 13:

Table 13

Research questions	Super-ordinate themes present			
	'enduring loss'	'the family versus the system'	'heightened parenting'	'the relief of residence'
1. What are the experiences of a parent of a child with autism who attends a residential school?	√	√	√	√
2. How is the current situation with regard to provision, placement and support from professionals perceived by these parents?		√	√	
3. How is the construct of inclusion understood by these parents?		√	√	√
4. What are the effective features of a residential placement from a parent's perspective?				√

Distribution of super-ordinate themes across the research questions

The research questions were selected from recurring themes in the extant literature and were judged to be pertinent to the chosen area. The interview questions were derived from these original questions. However, on reflection, the original research questions may appear prosaic, focusing as they do on operational and measurable aspects, in comparison with the richness and tone of the subsequent data that emerged from the interviews. Moreover, initially it appeared as if the resultant data would be difficult to analyse, as it did not fit neatly into the categories defined by the original questions. This was because the themes concerned with these were obliquely addressed via the interviews and the responses interpreted by the researcher. This was a deliberate process, designed to elicit maximum information about complex and sensitive subjects from the parents, by encouraging reflection upon their

experiences, that is, to become phenomenological. Open questions carry a risk as the researcher cedes control to the interviewee, allowing them to narrate their experiences in their own way and therefore requires there to be confidence in the methodology. In this instance, IPA proved to be a very appropriate tool for eliciting, analysis, interpretation and reflection, by providing a rigorous model within which to position this complex body of data.

Indeed, the analysis stage, following the guidelines of Smith et al, encouraging as it does, detailed attention to the descriptive, linguistic and conceptual comments of the parents, elicited a wealth of interesting data. The linguistic element could have been pursued further and produced a valuable study in its own right. However, the aim of this study was not to conduct a discourse analysis and therefore this aspect was not considered further.

IPA relies on the ability of the interviewees to be articulate and willing to share their personal experiences. All of the parents in this study fulfilled this requirement. However, if the parents had not had these qualities, then it is possible that the resultant 'rich picture' would not have been obtained. Some were more open in their narratives than others, which could have reflected their own personalities, their perception of the interview situation and their wish to tell their story in their own way. However, this contributed to the twin facets of IPA, that of the idiographic and the general. The focus of this study has been on the themes that have emerged across the cases, as this best suited the original research aims, however, the findings that were related to the individual parents' cases are also addressed, but to a lesser extent. If the decision had been taken to analyse the data from a casework perspective, then a different, but equally valid study would have resulted, such was the complexity of the parents' accounts. A casework methodology could have considered each family in turn, as 'holistic' as Yin would identify it (Yin, 2009). This could entail collecting additional objective data,

including more detailed biographical information, as well as perspectives from the other key agents namely the professionals within the 'system' and the residential school, to triangulate the findings.

IPA is not designed to produce generalisations and this is acknowledged within the discussion in Chapter 3 (Methodology) in the present study. Specifically, one of the key findings was that the parental experience was so closely associated with the particular school and therefore it would not be appropriate to extrapolate this to other situations. However, what IPA allowed, was for the reasons for the parental satisfaction with *this* school to surface. It is acknowledged that a different group of parents involved with a different school, is likely to produce a different set of data.

Similarly, another factor to consider is that the parents in the study were self-selected. In this respect they may have had a particular reason for sharing their story, other than simply of re-telling it to a sympathetic listener. Several of the parents did express feelings of empowerment, post residence and all of them wanted to relate their dissatisfaction with the system, as they had experienced it. This may have been their motivation for taking part. The invitation to the study was open to all parents in the school and it is not known why some did not respond nor what the study would have revealed if such a different group of parents had been recruited. Nevertheless, although the final group of participants may not have been fully representative of those in the school, it did provide a sufficient range (particularly as it included mothers and fathers) to allow for a thorough exploratory study, valid in its own right.

6.2.2 Critique of the Methods and Procedures

As the interviews took place, it became clear that an omission from the preparation had been to systematically clarify the main interviewee prior to all of the visits. Due to the complexities of the families, this resulted in some interviews, which had been anticipated as individual carers, changing into joint carers. This subsequently resulted in a mix of single and couple interviewees, mothers, fathers and in one case a step-mother. This unexpected but welcomed arrangement provided valuable multiple perspectives on the experiences, but may have suggested potential difficulties in separating out any specific findings to specific groups. However, through the analysis, it emerged strongly that certainly in the case of gender, there were no clear differences between the reported experiences of mothers and fathers. The experiences of step-parents were not specifically explored in this study, nor that of absent parents. The status of the carer also emerged as significant with relation to levels of stress,

As the data were analysed, it became clear that additional information would have been useful to provide background and context to the findings. This primarily revolved around factual information. All of the parents had completed an initial biographical questionnaire, but it was not until the interviews began that the importance of knowing other information became apparent. This included more details about the steps to the residential placement, including the tribunal procedure; the pattern of residence and the reasons for this; and details regarding early family compositions and care arrangements. The patterns of residence in particular, which were not uniform, may have had an impact on the parental experiences, possibly reflecting the needs of the child and/or the parent as well as the values and belief system of the parents, regarding residence.

In addition, all of the data were, by definition, from the parental experience. The study did not attempt to identify the perspectives of the other key participants in these narratives, namely the professionals and the child. With regard to the former, the data did not provide any insight into the role of the professionals and this would be very interesting to gain, in order to balance the different viewpoints and to consider points of agreement and of divergence. It is not possible to judge, without this information, whether the parents were able to fully engage with any support or provision prior to residence, or whether the chronic needs of their child had already led them to isolation or disaffection, due to their perceived failure of the system to provide adequate support.

Obtaining information regarding the views of the child proves more problematic, although this should not be a reason for omission. With children and young people with severe communication issues, alternative means need to be employed. Often this is via observation and interpretation of their actions, by those who know them well, rather than through their verbal contributions. Their views would enable a triangulation of the experience for future studies, but were specifically excluded on this occasion.

However, to reiterate, the stated aim of this study (and of IPA in general), was to explore and value in their own rights, the interpreted experiences of these parents, and to this extent, there is sufficient evidence from the findings, to say that these have been fully met.

6.3 Suggestions for Future Research

The present study revealed several areas that would be worthy of future research. This can be divided into three strands: further work into the specific area of autism and residential schools; work that allows for triangulation of data; and increased use of IPA in exploratory studies.

6.3.1 Autism-Specific Residential Research

To recap, ascertaining the experiences of parents of children with autism in residential schools is an under-researched area. The findings of the present study indicate this to be a valuable area for future work. This is also validated by the call from researchers and from national bodies for the increased involvement of both parents/carers and children, in decision-making and by the fact that the numbers of children with autism and challenging behaviour are growing (Wittermeyer et al, 2011, DfE, 2012, NICE, 2012,). Increasing the research quantitatively, by extending this to more parents and to a wider range of residential schools, would add to the body of data. This would be particularly useful in identifying any general features of schools that are valued, that could then be replicated in other settings. This is important, as this study supported the view that there is scant information to satisfactorily answer the apparently simple, yet deceptively complex, question, ‘What is it that residential schools do?’ Clarifying at least one area, that of whether this needs to be autism-specific provision, or a more generic, holistic approach remains an outstanding task. A useful alternative approach to help illuminate this area could be a Realistic Evaluation, as the present study has disclosed that the experience of residence is highly personal (Pawson and Tilley, 1997).

Moreover, as was evident in the present study, parents have a prevailing concern about transition from children to adult services. Following Wittermeyer et al's findings, parents want key pathways for transitions, that reflect the individual needs of their own child and provide opportunities for autonomy to be exercised, by themselves, but also for their child (Wittermeyer et al, 2011). It will be interesting to monitor the progress of the new legislation, planned to replace the existing system. From 2014, as part of the Children and Families Bill, it is planned to replace statements of special educational needs and to extend the duty of care for Local Authorities towards those with additional needs, until the age of 25, and of allowing parents the right to buy in their own specialist care for their children (DfE, 2012). However this change may manifest, it seems inescapable that more adult facilities will be required from now and into the future, to ensure that the needs of this complex group of vulnerable adults are satisfactorily met. Research that identifies good practice obtained from the key stakeholders – schools, parents, professionals and the individuals themselves - can be used to guide the establishment of such settings in the most effective ways. As has been previously mentioned in section 6.2.2 (Critique of Methods and Procedures) obtaining the views of this group is of paramount importance, yet particularly challenging. Sensitive and inventive research to facilitate this should continue to be an aim of future research.

6.3.2 Triangulation of Data

Studies to promote the triangulation of data will be very important, as the present study deliberately did not seek the views and opinions of any stakeholders but the parents. The role of professionals has been highlighted here and elsewhere (Abbott et al, 2000) as a key area that requires careful exploration, not least to clarify whether the frustration expressed by

parents is justified. Moreover, given the recent major change within LAs to the multi-agency Children's Services, further research of the efficacy of this new system, in relation to the target group, will be welcome.

6.3.3 Increased use of IPA

To date, most IPA has been carried out by health professionals with 'patients', rather than with their parents or carers (Rollinson and Wright, 2012). The use of IPA, it has been argued in the present study and elsewhere, is an appropriate tool for exploring meaningful lived experiences, such as those of the parents in the present study (Brocki and Weardon, 2006, Smith et al, 2009). A phenomenological approach illuminates the complexities of their lives and allows an outsider a glimpse of their daily experience, which not only provides validation for this, but also presents it to the wider research community as a contribution to the body of knowledge. Thus, it would seem relevant to call for further studies, using IPA, with other, similar parents, to add to this restricted field.

However, IPA is not suitable as a methodology for all parents nor for all purposes, as it makes stringent requirements on the part of the participants (not least an ability and willingness to articulate their personal experiences), it does not seek to make any generalisations and it is recommended to be limited to small sample studies. Therefore, complimentary, alternative approaches need to be considered, whereby a fuller range of views, across a wider demographic spectrum, can be obtained. This might include less intrusive methods such as focus groups or postal questionnaires. Although this may not reflect the depth of reflection nor enable the interpretative approach that IPA facilitates, it would nevertheless be an equally valuable, additional contribution.

6.4 Implications for Practice

The findings from the present study suggest several implications for practitioners. These will be considered on three levels: epistemological, ideological and operational.

6.4.1 The Epistemological Level

Conducting the research for the present study, using IPA methodology, has challenged the notion of what constitutes valid information and knowledge surrounding families of children with autism. This is because it requires a detailed consideration of parental values and beliefs as well as the consideration of more tangible, quantifiable experiences. However, this phenomenological hermeneutic approach is not one usually adopted by practitioner EPs during the assessment process in their daily role. Then, they are more typically constrained by the demands of regulations and ‘technologies’ of assessment (Billington, 2000 p60). Nevertheless, the findings from the present study supported this earlier call, for practitioners to reflect upon the accepted epistemology of their profession and to consider what might be gained by adopting a more flexible, holistic style of assessment (Billington, 2000).

Knowledge accumulated from spending time gaining the trust of families, recognising the unique characteristics and needs of their children, seeking and respecting their world-views and of validating their experiences, demands an appreciation of children as individuals and not as part of an homogenous ‘autistic’ group. It also reveals parents to be valuable resources and ‘experts’ of their own children and is in keeping with the general ethos of autism as a social construct. The widespread dissatisfaction with professionals, expressed by the parents

in the present study and in the extant literature, is grounds for at least a continued professional debate around how best to support these most complex children and their families.

6.4.2 The ideological level

Perhaps a not unexpected finding of the present study was that the parents were unconcerned with the professional discussion regarding the construct of inclusion for children with complex needs. Rather they were pre-occupied with procuring the most appropriate and effective provision for the individual needs of their own unique child. However, one possibly unexpected finding was the unanimous wish that residence had occurred at a much younger age, despite the conflict of emotion that this decision brought. Thus, a challenge for practitioners may be to reconsider their own construct of inclusion in the light of these, and of earlier, corroborative findings. If as a professional body they are predominantly ‘anti’ residence, on ideological grounds, then they are more likely to have difficulty in ‘hearing’ and understanding the wishes of parents for residence, and may not give their lived experience the credence and validation it requires. Moreover, if the ‘system’ is predominantly ‘anti’ residence on both ideological and also pragmatic grounds, then a much greater shift of emphasis may be required from practitioners. Billington (2000) again has a helpful contribution to make to this discussion. He reminds practitioners of their fundamental role as psychologists, concerned with human experiences. However, just as he observed over ten years ago, practitioners today still may too frequently feel constrained by regulations and statutory guidance and may find themselves caught within a professional dilemma around inclusion (Billington, 2000). The parents in the present study valued professionals — almost without exception wholly located within the residential school - that respected the unique needs of their children. These professionals were perceived to support them in valuing their

first principles of safety, acceptance and self-esteem for their children, rather than striving towards an ideological aim of 'inclusion'. Unfortunately, the practitioners within the field, were apparently unable, under the current structure, also to meet this need. Therefore a call is made from the present study, echoing those of others, for a consideration of a change to the system, which allows a more flexible approach, for the most complex children and families (Jones et al, 2008). This appears, on first reading, to be in line with the proposed legislation in the new Children and Families Bill (DfE, 2013). It will be a challenge for all those involved, to implement the resultant legislation in the most effective ways for the most vulnerable children and families.

6.4.3 The Operational Level

Some changes at the operational level would lead naturally from a consideration of changes at the epistemological and ideological level, as discussed in section 6.4.2, allowing practitioners more flexibility and autonomy in their work with complex families. Specifically, this would require attention from policy makers within Children's Services. However, this study also suggested other more practical implications for practitioners, addressing specific areas of concern.

Parents in this and previous studies repeatedly called for more support from professionals in:

- highly individualised programmes
- transitions, especially into adult services
- on-going involvement once their child was in residence
- more effective forward planning

- individual and creative respite packages
- sharing expertise in autism through training and informal support, including support around diagnosis and other points of decision
- disseminating information about autism to professionals and to society

Each of these are areas in which EPs are skilled and experienced at delivering, and indeed represent work with which many are already involved. However, the particular call from the present study is for practitioners to recognise the specific, individual needs of children with autism and challenging behaviour, and of the consequent needs of their parents. The expertise of these same parents should be utilised in effective family-centred support and personalised learning.

6.5 Conclusion

In summary, the parental experiences in the present study were found to be profound, life-changing and multi-faceted. IPA allowed for these experiences to be illuminated and analysed in a robust way. The impact of autism, as a pervasive, life-long condition was found to be central to the experience. The parents' contact with the system was defined as almost wholly negative, prior to residence. The findings in these areas had many points of similarity with the extant research, particularly with feelings of isolation and frustration over provision and decision-making, but this study was able to position these more specifically to the experiences of parents of autistic children in residence – a group not previously identified as a focus. Nowhere in the parental transcripts was the word 'inclusion' used, yet much of the content resonated with this construct. During this time, the parents were acknowledged as changing their belief systems, as they moved to a position of seeking an approach that

valued the fundamental, individual needs of the child, over any previously held pedagogical or ideological belief. This frequently led to a perceived conflict with the system. Finally, there was an almost palpable change of tone in all of the narratives from the pre-residence to post-residence period – from trauma to relief. However, isolating the precise features of the residential placement that may have contributed to this transformation, revealed that these were more often connected with the ethos of the school than with any tangible operational or pedagogical features. The theme of identifying the school as ‘family’ defined the residence experience, as was a very strong association of the success of the placement with the *specific* school. The need for an effective procedure for evaluating residential schools in general, was also highlighted, as was a call, in line with current proposed legislation, for more family oriented, person-centred assessment.

REFERENCES

Abbott, D., Morris, J. and Ward, L. (2000). *Disabled children and residential schools: A study of Local Authority policy and practice*. Bristol: Norah Fry Research Centre.

Abbott, D., Morris, J. and Ward (2001). *The best place to be? Policy, practice and the experiences of residential school placements for disabled children*. York: Joseph Rowntree Foundation.

American Psychiatric Association (2013). *Diagnostic and Statistical Manual of Mental Disorders: DSM V*. APA, Arlington: VA.

Anderson, A., Moore, D.W., Godfrey, R. and Fletcher-Flinn, C.M. (2004). Social skills assessment of children with autism in free-play situations. *Autism*, 8 (4), 369-385.

Anthony, L.G., Anthony, B.J., Glanville, D.N., Naiman, D. Q., Waanders, C. and Schaffer, S. (2005). The relationship between parenting stress, parenting behaviour and pre-schoolers' social competence and behaviour problems in the classroom. *Infant and Child Development*, 14 (2), 133-154.

Ariel, C.N. and Naseef, R.A. (2006). *Voices from the Spectrum*. London: Jessica Kingsley.

Asperger, H. (1994). 'Die "autistischen Psychopathen" im Kindesalter,' *Archiv fur Psychiatrie und Nervenkrankheiten*, 117, 76-136. English Translation in Frith, U. (ed) 1991.

Atkinson, P. and Delmont, S. (2006). Rescuing narrative from qualitative research. *Narrative Inquiry*, 16, 164-72.

Audit Commission (2007) *Out of authority placements for special educational needs*. www.audit-commission.gov.uk. Accessed 10 July 2011.

Bailey, A., Le Couteur, A., Gottesman, I., Bolton P., Simonoff, E., Yuzda, E. and Rutter, M (1995). Autism as a Strongly Genetic Disorder: Evidence from a British Twin Study. *Psychological Medicine*, (25), 63-77.

Baird, G., Simonoff, E., Pickles, A., Chanler, S., Loucas, T., Meldrum, D. and Charman, T. (2006). Prevalence of disorders of the autistic spectrum in a population cohort of children in South Thames. The Special Needs and Autism Project (SNAP). *The Lancet*, (15), 210-215.

Barnard, J., Harvey, V., Prior, A. and Potter, D. (2000). *Inclusion and Autism: Is it Working?* National Autistic Society: London.

Baron-Cohen, S. (1993). 'Are children with autism acultural?' *Behavioural and Brain Sciences*, 16, 512-3.

Baron-Cohen, S. (1995). *Mindblindness: an Essay on Autism and Theory of Mind*. London: MIT Press.

Barson, C. (1998). *Autism – supporting the family*. Nottingham: The National Autistic Society.

Beresford, B.A., (1994). Resources and Strategies: how parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 15 (1), 171-209.

Berridge, D. Biehal, N. and Henry, L. (2012). *Living in Children's Residential Homes*. Department for Education Research Brief. DFE: London.

Billington, T. (1996). 'Pathologising children: psychology in education and acts of government' in E. Burman et al. *Psychology discourse practice: from regulation to resistance*. London: Taylor and Francis, p 37-54.

Billington, T., McNally, B. and McNally, C. (2000). Autism: Working with parents, and discourses in experience, expertise and learning. *Educational Psychology In Practice*, 16 (1) 59-68.

Billington, T. (2006) Working with autistic children and young people: sense, experience and the challenges for services, policies and practices. *Disability and Society*, 21 (1) 1-13.

Blacher, J. and McIntyre, L.L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disabilities: cultural differences in family impact. *Journal of Intellectual Disability*, 50, 184-198.

Blakemore, S-J. and Choudhury, S. (2006). Development of the adolescent brain: implications for executive functioning and social cognition. *Journal of Child Psychology and Psychiatry*, 47, 3-4, 296-312.

Bluma, S.M., Shearer, J., Frohman, A.H. and Hilliard, J.M. (1976). *The Portage Project: Portage Guide to Early Education Manual (Rev.ed)*: Portage USA, WI Cooperative Education Services Agency.

Bondy, A. and Frost, L. (1994). The Delaware autistic program, in Harris, S. L. and Handleman, J.S. (eds), *Preschool programs for children with autism*. Austin: Pro-Ed.

Bouma, R. and Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46 (6), 722-30.

Brocki, J.M. and Weardon, A.J. (2006). A critical evaluation of the use of IPA in Health Psychology. *Psychology and Health*, 21 (1), 87-108.

Broffnenbrenner, U. (1979). *The Ecology of Human Development*. Cambridge MA: Harvard University Press.

Bromley, J., Hare, D.J., Davison, K. and Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: Social support, mental health status and satisfaction with services. *Autism*, 8 (4), 409-423.

Cameron, R.J. (2006). Educational Psychology: The distinctive contribution. *Educational Psychology in Practice* 22 (4), 289-304.

Carpenter, B. (2000). Sustaining the family: meeting the needs of families of children with disabilities. *British Journal of Special Education*, 27 (3), 135-144.

Carpenter, B., Chatwin, I. and Egerton, J. (2001). An evaluation of SIECCA: an intensive programme of education and care for students with profound autistic spectrum disorders. *Good Autism Practice* 2 (1), 52-66.

Catford, L. and Ray, M. (1991). *The Path of the Everyday Hero*. Forestville CA; Creative Quest Publishing.

Chatwin, I. and Harley, V. (2007). Implementing TEACCH in Support of a 24-Hour Curriculum, in Carpenter, B. and Egerton, J. (eds) in *New Horizons in Special Education: Evidence-Based Practice in Action*, Stourbridge: Sunfield Publications.

Christie, P., Newson, E., Newson, J. and Prevezer, W. (1992). An interactive approach to language and communication for non-speaking children, in Lane, D.A. and Miller, A. (eds), *Child and Adolescent Therapy: A Handbook*. Buckingham: Open University Press.

Clough, R. Bullock, R. Ward, A. (2006) *What Works in Residential Child Care – A Review of research evidence and the practical considerations*. National Children's Bureau.

Cresswell, J.W. (2007). *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*. Thousand Oaks, CA: Sage.

Crowley, C., Hallam, S., Harre, R. and Lunt, I. (2001). Study support for young people with same-sex attraction: views and experiences from a pioneering peer support initiative in the north of England. *Educational and Child Psychology*, 18 (1), 108-124.

Dale, E., Jahoda, A and Knott, E (2006) Mothers' attributions following their child's diagnosis of autistic spectrum disorder: exploring links with maternal levels of stress, depression and expectations about their child's future. *Autism* 10 (5) 463-479).

Davies, J.D. (2002). *Review of the Impact of Special Educational Residential Provision in the UK*. Kent County Council.

Department for Children Schools and Families (DCFS) (2009). *The Lamb Inquiry – Special Educational Needs and Parental Confidence*. DCFS: Nottingham.

Department for Children, Schools and Families (DCFS) and Department of Health (DH) (2009) *Aiming High for Disabled Children* DCFS: Nottingham.

Department for Education (DfE) (2011) Green paper: *Support and Aspiration: A new approach to special educational needs and disability*. Crown Copyright.

Department for Education (DfE) (2011) *Residential Special Schools: National Minimum Standards* <http://www.education.gov.uk> accessed 10 January 2012.

Department for Education (DfE) (2012) *The Children and Families Bill*. Crown Copyright.

Department for Education and Science (DES) (1978) *Special Educational Needs (The Warnock Report)*. London: HMSO.

Department for Education and Science (DES) (1970). *Education (Handicapped Children) Act*. London: HMSO.

Department for Education and Science (DES) (1981). *Education Act*. London: HMSO.

Department for Education and Families (DEF) (1993). *Education Act*. London: HMSO.

Department for Education and Skills (DfES) (2004). *Every Child Matters: Change for Children*. London: HMSO.

Department for Education and Skills (DfES)/Department of Health (DH) (2006) *Transitions: getting it right for young people*, DH: London.

Department for Education and Skills (DfES)/Department of Health (DH) (2002). *Autistic Spectrum Disorder Good Practice Guidance*. Nottingham: DfES.

Department of Health (DH) (2003) *The Victoria Climbié Inquiry: report of an Inquiry by Lord Laming*. Crown Copyright.

Department of Health (DH) (2009) *Valuing people now: a new three-year strategy for people with learning disabilities*
<http://www.valuingpeoplenow.dh.gov.uk> accessed 20 August 2011.

Department of Health (DH) (2012). *Transforming care: a national response to Winterbourne View Hospital*. London: Crown Copyright.

Eatough, V. and Smith, J.A. (2008). Interpretative Phenomenological Analysis. In C. Willig and W. Stainton Rogers (eds), *The SAGE Handbook of Qualitative Research in Psychology*. London: Sage.

Fallon, K., Woods, K. and Rooney, S. (2010). A discussion of the developing role of educational psychologists within children's services. *Educational Psychology in Practice* 26 (1), 1-23.

Farrell, P., Woods, K., Lewis, S. Rooney, S. and O'Connor, M. (2006) . *A Review of the Functions and Contribution of Educational Psychologists in England and Wales in Light of 'Every Child Matters: Change for Children'*. London: DfES Publications.

Fleischmann, A. (2005). The hero's story and autism: grounded theory study of websites for parents of children with autism. *Autism*: Sage.

Frederickson, N., Simmonds, E. Evans, L. and Soulsby, C. (2007). Assessing social and affective outcomes of inclusion. *British Journal of Special Education*, 34 (2), 105-15.

Frith, U. (1989a). *Autism: Explaining the Enigma*. Oxford: Blackwell Science.

Frith, U. et al. (1993). 'Research into the earliest detectable signs of autism: what parents say', *Communication*, 27, 17-8.

Frith, U. and Happe, F.G.E. (1994). Autism: beyond theory of mind, *Cognition*, 50, 115-32.

Fox, D. Prilleltensky, I., Austin, S. (eds.) (2009). *Critical Psychology: An introduction*. London: Sage. (1st edition published as Fox, D. and Prilleltensky, I. in 1997).

Frederickson, N., Simmonds, E., Evans, L. and Soulsby, C. (2007). Assessing Social and Affective Outcomes of Inclusion. *British Journal of Special Education* 34 (2) 105-115.

Gershon, P. (2004). *The Gershon Efficiency Review: Releasing resources to the front line. Independent review of public sector efficiency*. HM Treasury.

Gillum, J. (2013). Educational Psychologists and the DSM-5: Promoting critical reflection. *Debate*, 149, 13-17.

Glaser, B. and Strauss, A. (1967). *The Discovery of Grounded Theory*. Chicago, IL: Aldine.

Goodley, D.A. and Runswick-Cole, K.A. (2012). Reading Rosie: the post-modern disabled child. *Educational and Child Psychology*, 29 (2), 53-66.

Gray, C. (1994). *The social story book*, Arlington, TX: Future Horizons.

Gray, D.E. (2002) Ten years on: a longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*, 27 (3) 215-222.

Gray, D.E. (2006). Coping Over Time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50 (12), 970-976.

Hefferon, K. and Gil-Rodriguez, E. (2011). Interpretative Phenomenological Analysis. *The Psychologist*, 24 (10), 756-759.

Heidegger, M. (1962/1927) *Being and Time*. Oxford: Blackwell.

Hobson, R.P. (1990a). 'On acquiring knowledge about people and the capacity to pretend: A response to Leslie', *Psychological Review*, 97, 114-21.

Hobson, R.P. (1991). 'Against the theory of "theory of mind"', *British Journal of Developmental Psychology*, 9, 33-51.

Hobson, R.P. (2002). *The Cradle of Thought: Exploring the Origins of Thinking*. London: Macmillan.

Hodge, L. Times Newspaper (2008). Daily Life With No Limits. *Times Educational Supplement*, Times Newspapers: London.

Hoffman, C.D., Sweeney, D.P., Hodge, D., Lopez-Wagner, M.C. and Looney, L. (2009). Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disorders*
<http://foa.sagepub.com/content/124/3/173>. Accessed on 17 August 2011.

Holloway, W. and Jefferson, T. (2000). *Doing Qualitative Research Differently: Free Association, Narrative and the Interview Method*. London: Sage.

Howlin, P. and Moore, A. (1997). Diagnosis in Autism. *Autism*, 1, (135-162).

Humphrey, N. and Lewis, S. (2008). What does 'inclusion' mean for pupils on the autistic spectrum in mainstream schools? *Journal of Research in Special Educational Needs*, 8 (3), 132-140.

Husserl, E. (1970). *The crisis of European Sciences and Transcendental Phenomenology* (D. Carr, Trans.). Evanston: Northwestern University Press.

Hutton, A.M. and Caron, S.L. (2005). Experiences of Families with Children with Autism in Rural New England. *Focus on Autism and other Developmental Disabilities* 20, 180
<http://foa.sagepub.com/content20/3/180>. Accessed on 17 August 2011.

Jardine, K., M. (2008). *What meaning does raising a child with autism have for parents? A qualitative study*. Unpublished doctoral thesis for the University of Edinburgh,
<http://nal.handle.net/1842/247>. Accessed 1 August 2011.

Jones, G., English, A., Guldberg, K., Jordan, R., Richardson, P., and Waltz, M. (2005). *Educational provision for children and young people with Autism Spectrum Disorder living in England; a review of current practice, issues and challenges*. Autism Education Trust.

Jordan, R. and Powell, S. (1995). *Understanding and Teaching Children with Autism*. Chichester: Wiley.

Jordan, R. (1999). *Autistic Spectrum Disorders: An Introductory Handbook for Practitioners*. London: David Fulton.

Jordan, R., Jones, G. and Murray, D. *Educational Interventions for Children with Autism: A literature Review of Recent and Current Research*. Research Report No 77. DfEE: Crown Copyright

Kanner, L. (1943) Autistic Disturbance of affective contact *Nervous Child*, 2, 217-250.

Kaufman, B.N. (1994). *Son rise: the miracle continues*. California: H J Kramer.

King, G.A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P. and Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism and Down Syndrome. *Child: Care, Health and Development*, 32 (3). 353-369.

Kitahara, K. (1984). *Daily Life Therapy: a method of educating autistic children*. Volumes, 1, 2 and 3, Boston, MA: Nimrod Press.

Laming (2009) *The Protection of Children in England: A Progress Report*. HMSO.

Little, L. (2002). Middle-class mothers' perceptions of peer and sibling victimisation among children with Asperger's Syndrome and non-verbal learning disorders. *Issues in Comprehensive Pediatric Nursing*, 25, 43-57.

Lord, C. and Schopler, E. (1994). TEACCH services for preschool children. In Harris, S. L, and Handelman, J. S. (eds), *Preschool programs for children with autism*. Austin: Pro-Ed.

Lovaas, O.I. (1987). Behavioural treatment and normal intellectual and educational functioning in autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.

Loynes, F. (2000). *The impact of autism: a report compiled for the All Party Parliamentary Group on Autism*. London: APPGA.

Maslow, A. (1943). *A theory of human motivation*. *Psychological Review*, 50 (4), 370-96.

Massachusetts Department of Education (MDE) (2003). *Private Special Educational School Program Review – Report of Findings on the Boston Higashi School*. Boston, MA: MDE.

McGill, P., Tennyson, A. and Cooper, V. (2006). Parents Whose Children with Learning Disabilities and Challenging Behaviour Attend 52 Week Residential Schools: Their Perceptions of Services Received and Expectations of the Future. *British Journal of Social Work*, 36, 597-616.

Mesibov, G. Shea, V. and Schopler, E. (2005). *The TEACCH Approach to Autism Spectrum Disorders*. New York: Plenum.

Miles, M. B. and Huberman, A.B. (1994) *Qualitative Data Analysis: an expanded source book*. London: Sage

Mills, R. (1999). Q and A: SPELL. *Communication*, p27-28, London: National Autistic Society.

Moore, C. (2004). *George and Sam*. London: Penguin.

Moran, H. (2010). Clinical observations of the differences between children on the autism spectrum and those with attachment problems: the Coventry Grid. *Good Autism Practice*, 11(2), 44-57.

National Autistic Society (NAS) (2003). *National Autism Plan for Children*. NAS: London.

National Institute for Health and Clinical Excellence (NICE) (2011). *Autism: Recognition, referral and diagnosis of children and young people on the autistic spectrum*. www.nice.org/uk/guidance/CG123, accessed 17 January 2012.

Nelson, G and Prilleltensky, I. (2005). *Community Psychology: In Pursuit of Liberation and Well-being*. Basingstoke: Palgrave Macmillan.

Nind, M. (1999). Intensive Interaction and Autism: a useful approach? *British Journal of Special Education*, 26 (2), 96-102.

Nissenbaum, M.S., Tollefson, N. and Reese, R.M. (2002). The Interpretative Conference: Sharing a Diagnosis of Autism with Families. *Focus on Autism and Other Developmental Disabilities*, 17 (30)
<http://foa.sage.pub.com/content/17/1/30>. Accessed 10 September 2011.

Orford, J. (1992). *Community Psychology: theory and practice*. Chichester: John Wiley and Sons.

Osborne, L.A. and Reed, P. (2008). Parents' perceptions of communications with professionals during diagnosis of autism. *Autism* London: SAGE/National Autistic Society.

Osborne, L.A. and Reed, L. (2009). The relationship between parental stress and behaviour problems of children with autistic spectrum disorder. *Exceptional Children*, 76, 54-73.

Ozonoff, S. (1995). Executive functions in autism,' in Schopler, E. and Mesibov, G.B. (eds) *Learning and Cognition in Autism*. New York: Plenum Press.

Pagliano, P. (1999). Designing the multi-sensory environment. *PMLD-Link*, 12 (2), 2-6.

Parsons, S., Guldberg, K., Macleod, A., Jones, G., Prunty, A., and Balfe, T. (2011). International review of the evidence on best practice in educational provision for children on the autism spectrum, 26 (1), *European Journal of Special Needs Education*, p47-63.

Pawson, R. and Tilley, N. (1997). *Realistic Evaluation*. London: Sage

Pinney, A. (2005) *Disabled Children in Residential Placements* – Report commissioned by the Department for Education and Skills (DfES). Nottingham: DfES

Piper, E. and Howlin, P. (1992). Assessing and diagnosing developmental disorders that are not evident at birth: parental evaluations of intake procedures. *Child: Care, Health and Development*, 18, 35-55.

Preece, D. (2002). Consultation with children with autistic spectrum disorder about their experience of short-term residential care. *British Journal of Learning Disability*, 30 (3), 97-104.

Prizant, B. Wetherby, A.M., and Rydell, P.J. (2000). Communication Intervention Issues for Young Children with Autism Spectrum Disorders. In Wetherby, A. M. and Prizant, B. (eds), *Autism Spectrum Disorders: A Transactional Developmental Perspective* (p193-225). Baltimore, MD: Paul H. Brookes.

Quill, K. (1989). Daily Life Therapy: a Japanese model for educating children with autism. *Journal of Autism and Developmental Disorders*, 19 (4), 625-634.

Quine, L. and Pahl, J. (1987) First diagnosis of severed handicap: A study of parents' reactions. *Developmental Medicine and Child Neurology*, 29, 232-242.

Ray, L. (2002). Parenting and Childhood Chronicity: Making visible the invisible work. *Journal of Paediatric Nursing* 17 (6), 424-438.

Rempel, G. and Harrison, M. (2007). Safeguarding precarious survival: Parenting children who have life-threatening heart disease. 17, 824-837.

Reid, G. and Batten, A. (2006). B is for Bullies: experiences of children with autism and their families. <http://autism.org.uk/bullyingengland>, accessed 10 May 2011.

Reid, K., Flowers, P. and Larkin, M. (2005) Exploring lived experience: An Introduction to Interpretative Phenomenological Analysis. *The Psychologist*. 18 (1) 20-23.

Robson, C. (2011). *Real World Research (Third Edition)*. Chichester: John Wiley and Sons.

Rogers, S. and Bennetto, L. (2000). Intersubjectivity in autism: The roles of imitation and executive function. In Wetherby, A. and Prizant, B. (eds), *Autism Spectrum Disorders: A Transactional Developmental Perspective*, (p79-107). Baltimore, MD: Paul H Brookes.

Rollisson, L. and Wright, C. (2012). The Cost of Caregiving. *The Psychologist* 25 (4), 294-296.

Rosenbaum, P., King, S., Law, M., King, G. and Evans J. (1998). Family-centred service: a conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics*, 18, 1-20.

Schuntermann, P. (2007). The Sibling Experience: Growing up with a child who has pervasive developmental disorder or mental retardation. *Harvard Review of Psychiatry*, 15 (3), 93-108.

Shields, J. (2001). The NAS EarlyBird Programme: partnership with parents in early intervention. *Autism* 5 (1), 49-56.

Smart, M. (2004) Transition planning and the needs of young people and their carers – the alumni project. *The British Journal of Special Education*, 31 (3) 128-137.

Smith, B., Chung, M.C. and Vostanis, P. (1994) The path to care in autism: is it better now? *Journal of Autism and Developmental Disorder*, 24, 551-564.

Smith, J.A. (2010) *Evaluating the contribution of Interpretative Phenomenological Analysis to Health Psychology*. Keynote address presented at the British Psychological Society Health Psychology Annual Conference, Aston, UK.

Smith, J.A., Flowers, F. and Larkin, M. (2009) *Interpretative Phenomenological Analysis*. London: Sage.

Storr, A. (1993). Foreword in Heal, M. and Wigrams, T. (Eds) *Music Therapy in Health and Education*. London: Jessica Kingsley.

Sussman, F. (2012). *More Than Words: A Parent's Guide to Building Interaction and Language Skills in Children With Autism Spectrum Disorder or Social Communication Difficulties*. Toronto: The Hanen Centre.

Tams, R. (2001). Parents' Perceptions of Autism – A Qualitative Study, in *Autism – The Search for Coherence*. Richer, J. and Coates, S. (eds). Jessica Kingsley: London.

Tilstone, C., Florian, L. and Rose, R. (1998). *Promoting Inclusive Practice*. London: Routledge.

Traxson, D. (2010). The medicalisation of normal healthy childhood. *Debate*, 136, 12-17.

Webster-Stratton, C. (1990). Stress - a potential disruptor of parent perceptions and family interactions. *Journal of Clinical Child Psychology*, 19 (4). 302-312.

Whitaker, P. Barrat, P., Joy, H., Potter, M. and Thomas, G. (1998) Children with autism and peer group support: using circles of friends. *British Journal of Special Education*, 25 (2) 60-64.

Whitaker, P. (2002). Supporting Families of Preschool Children with Autism – What parents want and what helps. *Autism*, 6 (4), 411-426.

Willig, C. (2001) *Introducing Qualitative Research in Psychology: Adventures in Theory*. Buckingham: Open University Press.

Wing, L. (1981a). Language, social and cognitive impairments in autism and severe mental retardation. *Journal of Autism and Developmental Disorders*, 11, 31-44.

Wing, L. (1996). *The Autistic Spectrum*. London: Constable.

Wing, L. and Gould, J. (1979). Severe impairments of social interactions and associated abnormalities in children: epidemiology and classification. *Journal of Autism and Childhood Schizophrenia*, 9, 11-29.

Wing, L. and Potter, D (2002) The epidemiology of autistic spectrum disorders – is the prevalence rising? *Mental Retardation Developmental Disability Review* 8, (3) 151-161

Wittemeyer, K., Charman, T., Cusack, J., Guldberg, K., Hastings, R., Howlin, P., Macnab, N., Parsons, S., Pellicano, L. and Slonims, V. (2011). *Educational Provision and outcomes for people on the autism spectrum*. London: Autism Education Trust.

Wolfendale, S. (1998). *Empowering Parents and Teachers*. London: Bloomsbury.

Woodgate, R.L., Ateah, C. and Secco, L. (2008). Living in a World of Our Own: The Experiences of Parents Who Have a Child With Autism. *Qualitative Health Research* 18 (8), Sage. <http://online.sagepub.com>. Accessed 10 October 2011.

World Health Organisation (WHO) (1990) *ICD-10 Diagnostic Criteria for F84- Childhood Autism*.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.

Yin, R., K. (2009) *Case Study Research*. London: Sage

APPENDICES

- 1 DSM-V – Diagnostic Criteria for Autistic Spectrum Disorder
- 2 Application for Ethical Review – University of Birmingham
- 3 Introductory letter to parents
- 4 Script for telephone conversation with potential participants
- 5 Follow-up letter to participants and information sheet
- 6 Consent letter for participants
- 7 Demographic questionnaire – Background Information
- 8 Interview schedule for parents
- 9 Contemporaneous notes – ‘Brian’
- 10 Transcripts of all interviews. Jo (1), Julie (2), Lesley (3), Sue (4), Paul (5), Brian (6)
- 11 Super-ordinate themes - Brian
- 12 Summary of ‘Brian’s’ interview in narrative form
- 13 Full transcript of ‘Brian’s’ interview, showing exploratory comments and emergent themes

Appendix 3: Introductory letter to parents

Dear Parent/Carer

I am an Educational Psychologist with over 20 years experience of working with children and young people and with a particular expertise within the field of autism.

I am employed by an independent psychology service, based in Leicestershire, having worked there since 1998. I was previously employed by Leicestershire Educational Psychology Service, from 1990 until 1998.

I am currently engaged in research as part of my doctorate study into educational psychology at The University of Birmingham, looking at the experiences of parents with children with autism who attend a residential school.

I have worked with staff at (the school) supporting youngsters from (name of) Local Authority, from 2007-2010 and I have discussed my research ideas with the, Director of Care and Education, who is supportive of them.

I am writing to ask if you would be willing to take part in my research project, which will involve an interview, with myself and possibly also completing a questionnaire about your experiences of having a child with autism attend a residential school. There is very little research available on this subject and given its importance, your responses would be very valuable.

The information you provide would be confidential and only used within the research, where any names or identifying factors would be removed. You can be assured therefore that your responses would be totally anonymous.

My contact details are found at the bottom of this letter and I am very happy to answer any queries you may have, regarding my research.

If you are willing to be part of this research, I would be grateful if you could return the enclosed form, in the stamped addressed envelope provided. The interviews are likely to take place in the autumn term, 2011 and can be arranged at a time and place that is most convenient to you.

Thank you very much for your time.

Appendix 4: Script for telephone conversation with potential participants:

Thankyou again for agreeing to take part in my research at school.

I am calling now to give you more details of the research, what it will entail and the consent procedure.

My research question is: 'What are the experiences of families of children with autistic spectrum disorder who attend a residential school?'

In order to find this out I would like to carry out a detailed interview with you, which will last between one to one and half hours. This can be carried out at a venue to suit, either at your home or at the school, if you prefer.

The interview will be searching and in-depth and will have a focus on exploring your experiences and your feelings. I would be sensitive to your feelings in the interview session and will conduct the interview in a professional manner, drawing upon my experience and expertise as a psychologist. I will be recoding the interview so that I can study it in detail.

The results will be published in my thesis, although you as participants, as well as your child, will not be identified. I will also be seeking background information from the school which may involve discussions with teachers. I would like to ask for permission to read appropriate reports on your child, held by the school, as a means of obtaining relevant background information.

I will provide you with feedback from the research. You will be able to comment upon my write-up of your interview, which will be a summary of the interview rather than the full transcript. I will arrange to visit you in order to do this in person. Following the completion of my study, I will post out to you a brief summary.

I will send you a detailed consent letter, for you to sign and return to me, which will also have information about your rights to withdraw from the study, should you wish to do so. I intend to carry out the interviews during the autumn term 2011 and you will have the right to withdraw up until the 31 December 2011. If you choose to withdraw I will reassure you that there will be no further collection of additional data, no further analysis of data collected and the removal of any existing data from the records. There will be no consequences for withdrawal.

All of the data I collect will be securely stored, in line with the requirements of the University of Birmingham Ethical Review Procedures.

I am available to answer any questions or queries throughout the research period.

Thank you very much for your time

Appendix 5: Follow up letter to participants and information sheet

Name of researcher: Jayne Tansley

Title of research: What are the experiences of families of children with autistic spectrum disorder who attend a residential school?’

The research is part of my of my doctorate study into educational psychology at Birmingham University, as part of my EdPsychD course.

The aim of the study is to contribute to the limited existing body of knowledge in this area and to provide benefits in extending knowledge and understanding of the experiences of families in these situations. Additional benefits may be in furthering knowledge within the areas of good practice to improve outcomes for children with autistic spectrum disorder in residential schools, particular at transition to adult services.

As a participant you will agree to a detailed face to face interview with the researcher, which will be audio recorded. There may be a possibility that the questions may provoke difficult emotions, but the risk of this will be minimised as the interview will be conducted sensitively and in a professional manner, with appropriate opportunities to discuss any concerns. You will not be required to answer every question, if you choose not to.

Information disclosed within the interview will be confidential, but you must be aware that any information disclosed that may indicate risk of harm to your child, or relating to any illegal act, will not remain confidential and will be passed onto the relevant authority.

I will also be seeking background information from the school which may involve discussions with teachers. I would like to ask for permission to read appropriate reports on your child, held by the school as a means of obtaining relevant background information.

The data will be analysed using a method called Interpretative Phenomenological Analysis. This is a method concerned with the examination of how people make sense of their life experiences. It is becoming commonly used within psychological research.

The results will be published in my thesis, although neither you, your child nor the school will be identified by name and any other identifying material will be removed.

You will be able to comment upon a summary of your interview during a later face to face session. At the end of the research period, you will have a summary of the whole study.

Participation in the project is voluntary and participants are free to withdraw by informing the researcher by telephone or letter and /or withdraw any data and/or

withdraw any data supplied before December 31st, 2011. If you choose to withdraw there will be no further collection of additional data, no further analysis of data collected and the removal of any existing data from the records. There will be no consequences for withdrawal.

All of the data I collect will be securely stored, in line with the requirements of the University of Birmingham Ethical Review procedures. This will mean that all data, including the original transcripts from the interviews and questionnaires will be stored securely. The University's Code of Practice for Research states that data should normally be preserved and accessible for ten years. Following this time it will be disposed of by shredding. Any information stored electronically, including on memory sticks will be password protected, stored and when required, transported, securely. Only myself will have access to the data and this can be made available to my research supervisor if requested.

The whole of the research study is in line with the requirements of the University of Birmingham Ethical Review Procedures and has been approved by that body.

My contact details are:

Supervisor Contact Details:

Support agencies:

National Autistic Society

- Autism Helpline 0808 800 4104
- Parent-to-Parent Service 0808 800 4106

National Parent Partnership Network

To find your local service go to: www.parentpartnership.org.uk

Appendix: 6 Consent letter for participants:

Name of researcher:

Title of research: What are the experiences of families of children with autistic spectrum disorder who attend a residential school?’

The research is part of my of my doctorate study into educational psychology at Birmingham University, as part of my EdPsychD course.

The aim of the study is to contribute to the limited existing body of knowledge in this area and to provide benefits in extending knowledge and understanding of the experiences of families in these situations. Additional benefits may be in furthering knowledge within the areas of good practice to improve outcomes for children with autistic spectrum disorder in residential schools, particular at transition to adult services.

As a participant you will agree to a detailed face to face interview with the researcher, which will be audio recorded. There may be a possibility that the questions may provoke difficult emotions, but the risk of this will be minimised as the interview will be conducted sensitively and in a professional manner, with appropriate opportunities to discuss any concerns.

The data will be analysed using a method called Interpretative Phenomenological Analysis. This is a method concerned with the examination of how people make sense of their life experiences. It is becoming commonly used within psychological research.

The results will be published in my thesis, although neither you, your child nor the school will be identified by name and any other identifying material will be removed.

You will be able to comment upon a summary of your interview during a later face to face session. At the end of the research period, you will have a summary of the whole study.

Participation in the project is voluntary and participants are free to withdraw and/or withdraw any data supplied, up to 31 December 2011. If you choose to withdraw there will be no further collection of additional data, no further analysis of data collected and the removal of any existing data from the records. There will be no consequences for withdrawal.

All of the data I collect will be securely stored, in line with the requirements of the University of Birmingham Ethical Review procedures. This will mean that the original transcripts from the interviews and questionnaires will be stored securely in my home and disposed of by shredding after my thesis is deposited in the university library. Any other written material will be stored securely in my home. Any information stored electronically, including on memory sticks will be password protected, stored

and when required, transported, securely. Only myself will have access to the data and this can be made available to my research supervisor if requested.

The whole of the research study is in line with the requirements of the University of Birmingham Ethical Review Procedures.

My contact details are:

Consent:

I consent to being a participant in the research study as described above and agree to the conditions.

Name:

Signature:

Date

Appendix 7: Background Information

1. Age(s) of parent(s): _____

2. Child's name and age: _____

3. Age at time of diagnosis: _____

4. Has your child been diagnosed with any additional learning disabilities?
Yes/No

If yes, please give details

5. Does your child have any brothers or sisters? Yes /No

If Yes, what age(s) are they? _____

6. Who lives in the family home?

(i.e. Mum, Dad, child & sister)

7. Are you the main caregiver? Yes /No

If no, who is? _____

8. Do you work? Yes/No

Part-time or full-time? P/T F/T

9. How long does it take you to reach the school?

Thank you

Appendix 8: Interview Schedule for Parents

(Prompts in brackets)

1. Tell me about (your child)

2. When did you first have concerns about (your child)?
(was it them, a family member, friend, professional emotions/response)

3. Tell me about the time you had the diagnosis of autism for (your child)
(when, where, how, by whom, emotions/response),

4. Tell me about (your child) experiences of school, before (the school)
(mainstream/special, support available)

5. Tell me about your experiences with the assessment process (including statutory assessment and probe for LA procedure/inclusion debate)

6. How did (your child) arrive at (the school)?

(the process, whose decision for residential school, positive or negative decision, support from professionals)

7. Did you have any particular concerns over how you and he would cope with the separation?

8. Tell me about the early days of (your child) being at (the school)
(emotions – grief, guilt, relief, contentment, worry, peace...)

9. How do you feel about your decision now? Is there anything you would change about the situation? What?

10. What changes, if any, has (your child) being at (the school) brought to your own life/family life?

11. What changes, if any have you noticed, if any, in (your child) since being at (the school)?

(positive/negative)

12. What have you gained/lost as a result of (your child) being at (the school)? What about the family?

13. What do you think (your child) has gained/lost since being at (the school)?
14. What do you like about how (the school) works?
15. Is there anything they could do differently?
16. How are you as parents kept in touch with how (your child) is getting on?
(day to day things, formal reviews of progress, visits, special events etc)
17. How would you describe your relationship with (your child) now?
18. What are your hopes for (your child) future?

Thankyou

Appendix 9: Contemporaneous thoughts: 'Brian'

At first I felt a little bit uncomfortable as I wasn't sure he was keen to be interviewed separately but once he got started he had loads to say. He was very emotional and very honest about his initial relationship with Becky but then how it had developed.

I felt he really opened up and shared.

He had some useful insights into his relationship with Becky and the decision for Ash House

A determined man but still vulnerable and hurting over the decision.

Felt he had the 'loss' of daughter feeling more than mum, but may be wrong.

I think because the diagnosis was so early they didn't have such a long time to think of Becky as 'normal' – maybe?

Very intense description of the 'tension' prior to the outbursts – linked with his experiences in the Gulf - unexpected

Appendix 10: Original Transcripts

1. – Jo

(Key: I-Interviewer, J-Jo)

1. I - Just tell me a little bit about Taylor
2. J - Right Ok– Taylor, erm, Taylor needs a waking hour curriculum, but he's very very set in routines, he doesn't like any amount of change whatsoever that could be just going from a different car somewhere or taking a different street somewhere, a different route that he's used to, erm, he can be aggressive, likes his own space, doesn't like anybody in that space, erm, that's about it really
3. I - Strengths? Any strengths that you 'd identify?
4. J - Strengths? I don'tThat's a hard one really
5. I - I know
6. J - His strengths tend to focus on his obsessions, if he's obsessed with something he'll learn about everything to do with that, just talk about that thing constantly, erm,, he's got limited language skills anyway, he seems to think, he'll just comes out with random, just say something totally off his head, and that isn't associated with anything that's around him, or anything that he's actually seen that day, so he'll say something like, 'Cat has got green hair', when you say, well where, which cat, where did you see this cat, and you just don't know, when you 're supposed to remember that, yeah,.... one of his strengths, one strength he's got this strength, it's like a photographic memory, or like a good long term memory that comes out now. At the time he can't tell you what's happened, but years later he's recalling things, when he's three or four three, four , and I've forgotten all about them things and he reminds me
7. I - he's stored them
8. J - Yeah, he's stored them, and he's quite loving when he wants to be.....I don't really know what else to say really...
9. I – well, there'll be plenty of more opportunities to fill in...
10. J - Yeah...
11. I – when did you first have concerns about Taylor?
12. J - When he was probably about, coming up for two. Yeah, if you speak to people now they'll say yeah well if you remember he was a bit too good as a baby and if you remember he did this and he did that, so yeah, there were earlier indications that we think there might have been a problem, but he was my first baby and I wasn't sure about babies I'd never seen babies before, only at work, but you only get a snapshot again about how they're supposed to be, so I wasn't really sure and that he would progress like all the other children were, so I think I brought it to light, to a health visitor at his two year check
13. I - Right
14. J - And she was trying to do all these little things with him, she had a horse and she was trying to get him to do the horse
15. I - Yes, yes,
16. And he was having none of it cos he wanted to do what he wanted to do and she was getting quite angry with him cos he wouldn't do what she wanted and I said look, stop, I said I think I've got some

concerns and I told her what he was doing and how he was being and she referred me on to the paediatrician and things and that's when I thought??

17. I - And how were you feeling at that time?
18. J - Really, I don't know cos I suppose a bit disillusioned, because I had all these, because I'm a nursery nurse, well, I still am, I had all these plans and all these ideas in my head about how we were going to do things, and we were going to read together and we were going to do this activity, and none of that was happening, so I was really really you know, severely disappointed, totally upset and I still am now. I have not coped with losing that baby that I had (tearful)
19. I - Ok, yes, so what happened after that, you said you had the paediatrician, referral....
20. J - Erm, he was, he said autism more or less straightaway when he met Taylor, it didn't take him long to say yes, definitely autism, so but then we still had to wait until he was nearly four before a statement was actually put in place, this was like nearly 11 years ago and it's a lot quicker than that now, but it was still like, he was nearly four and he was attending a mainstream nursery, and every morning they'd ring me, he'd only been there about half an hour and I'd get a phone call saying, 'he's wrecking this, he's doing this, can you come and get him?'
21. I - Yeah
22. J - It wasn't until the actual statement was put in place that he got 1-1 support at his, nursery but then I'd already made my mind up then he was going to a special school, because there was no way he would have coped in a mainstream at all
23. I - Right, ok. Can you think back to when you actually had the diagnosis of autism, was it one single interview?
24. J - Yes it was, it was more or less one interview, I think, an educational Psychologist had gone into his nursery I think his name was Tom something, he'd gone in and he'd sat with Taylor, I mean, the paediatrician, now it's the team around the child thing and everybody puts their bit in, and I went in to the meeting with my best friend and he said, he'd just met him for about 10 minutes and he said, I think it's autism....he said I'd put money on it he said but wait til we get everybody else's opinions in and he said we'll do it and then it was just the Ed Psych, the school, the Ed Psych and me that put in a report forward and then a formal diagnosis was made, but it was a long time ago (quiet voice and tearful)
25. I - Yes, can you remember how you felt at that time?
26. J - Yeah, now again, I was just relieved because I knew that I wasn't imagining things but just really really disappointed about it and really angry and stuff, thinking, why have I had an autistic child, was it something I did, was it this, was it that, so, erm yeah, I just felt really like down about it, still do to be honest (small laugh)
27. I - Yeah, well, it's a big thing...
28. J - It's a huge thing (tearful)
29. I - Was there any difference, between, I know that you're not with Taylor's dad now, but was there any difference in how you both reacted
30. J - Yeah I'm with my second husband, he's here now (walks in house)
31. I - Oh, sorry
32. J - Yeah It's only been about 3 and half years
33. I - (hello, hi, are we alright to carry on?)

34. J- Yes, course we are)

I- I wondered if there was any difference between how you felt about things and how his dad felt about things?

35. J - Well, that's why were not together cos he's never really accepted...., well, he has in his world, he's accepted, cos his dad's very straight down the line, very into his routines as well, doesn't like anything that's not to do with him, doesn't think anybody outside the house should know about him either, so , erm, I don't know, I did it all on my own. I was the one who was attending all of the meetings, I was the one that was like coming to terms with the diagnosis, I was the one who visited schools, I was, it was all about me and he didn't really say anything

36. I - Right, ok, So, if you could tell me a little bit more about his early experiences of school, before he went to Ash House

37. J - It was horrendous, until he got that one to one support, it was awful, I mean I was.., Like I said, I got regular phone calls, luckily I only work 2 minutes away so I could walk to the school and come and get him, because we had a preschool at the time, and I worked at the preschool, and that's where Taylor was attending there, with us, until he got a place at school,

38. I - Right

39. J - and that, yeah, every day they were ringing me and saying he's done this, he's done that, he's cleared tables and so I went in and I was really quite cross with the teacher, but I think at the time, this was just when they'd started introducing SENCos

40. I - Oh right yes

41. J - As well, and I think it was just all new to them and I don't think they knew exactly what they were doing, cos the teacher who was actually teaching Taylor at the time, had a child with Asperger's herself and I was really cross with her so I said look, you know what it's like, you know how I'm being treated and yet you're not standing my corner and I met her years later and she said she was so sorry and said she was going with what the head wanted

42. I - Right

43. J - So it wasn't a good thing, so then I mean when he got the support, then he could stay at the school then, cos he had 1-1 support and that lady was following him round all the time but they actually invited me into the school to see if he reacted any different to me and for me to spend a morning with him, to see how it is, well, a normal, typically developed child would have been bored by what they were doing) I mean, they came in, they had to sit down and write their name, which took about 5 minutes, then they had to all come and sit down after that, onto the carpet and wait for everybody to have sat down, before the teacher then began register, and then register lasted, because it was like, "good morning everybody" and everybody had to say, 'good morning' and then there was like the ticking of the register and that took 45 minutes and I thought well they were wriggling so how the hell they expected an autistic child to cope with sitting down, but that was mainly, the school thing, mainly the hard thing, but then when he actually went to Downs Road (a special school) then , which was his infant and junior school, then things got better but I still wasn't as knowledgeable then as I am now and looking back, I think he didn't learn a lot at school, it was more of a babysitting service (laugh) and somewhere for him to actually go and be placated by what they were doing and not actually learning anything, erm...

44. I - So you had feelings there of....

45. J - Yeah, I mean it was ...I don't know, they were lovely and the staff were brilliant and they loved him cos even now, recently, I still have contact with some of the teachers through someone who works at my place and they say, "I really miss him cos he was in my face for 5 years (laughing) and he was here

(gesturing to face) constantly and I miss him, she says' and I'd love to see him and I say, well, when he's at home, I'll bring him, and he actually went and I took him round the school and he knew everything had changed

46. I - Ahh

47. J - He'd say, 'that's not there anymore is it mummy' and I'd say, no, it's not that's changed, and there'd be like a screw moved up from the door he saw it, but I mean nothing, he didn't progress, I mean his writing didn't get any better, his reading didn't get any better, erm, he was just there, and existing at the school

48. I - And kept safe?

49. J - Yeah, and whereas now, I mean at Ash House, he's like, he's not excelling, cos I mean Taylor is so far behind in how he is, but he has made progress, whereas at the school he was the same going in as he was going out

50. I - Yeah, really

51. and I know Ash House have read the records while he was at school, and they were quite shocked that there wasn't this in place, and this in place, and they were quite shocked by it, but I mean he liked going, it was routine, he didn't like to miss out if things was going on, and he knew exactly what was going on so if say we had an appointment with a padiatrician he'd go , but I'm missing PE or I'm missing this ...and then the whole day would blow up you see so he liked it for that kind of security. And routine, but I don't know, apart from that, there's not much else (laughs) education wise until he got to Ash House.

52. I - So, yes, when did you start considering a residential place for him?

53. J - As he got bigger. It was towards the last, last two years of Downs Road really that I thought, things weren't right between me and his dad and like I say, he never went to any appointments, he never went to the school, if there was an IEP meeting or an annual review, nothing like that, he never wenthe didn't admit to his work that he had a disabled child and so they wouldn't let him have time off anyway I suppose, if he was just going for a child's review at school

54. I - Yes

55. J - I think he went to the school, once a year, for a Christmas play, but that's if I insisted that he had to be there and you could tell he didn't want to be there

56. I - Right

57. J - and that's when the cracks started to show really

58. I - right, and you were still together at that time, so it wasn't as if he was living away...

59. J - no, and that's when I decided, right I can't cope with it cos his behaviour was just getting and I actually filmed, I filmed on an old phone, I felt that, when I decided, I felt I was going to keep a record of how he was and he's at the top of the stairs and he's swearing and he's hitting himself. Kyle was only tiny at the time and he used to go for him as well, so I was worried about his safety cos at that time I didn't know that Kyle was autistic, because he wasn't showing the exact same traits as Taylor, as a baby, erm there was an oddness about him about him, but not too noticeable, not, really different from the other babies at work, but he was being aggressive towards him and he was getting aggressive towards me, he was getting quite destructive at home, and it was the slightest change, I mean even if something like just going into town or to go to a supermarket, which some people could do quite easily, it wasn't easy anymore

60. I - Right

61. J - It was different when he was little cos I mean there's an 8 year age gap between Taylor and Kyle and I mean you've got this like toddler throwing himself down and having a fit or pulling something off the shelves he's a naughty little toddler, but when you've got this like 9 year old, that's doing exactly the same and I mean you're getting all the tuts and you know people are looking

62. I - Yes, yes,

63. J - And he was getting stronger and he was getting more physical and I thought this world is kind of damaging to Taylor he can't cope with it and I haven't got the expertise because I was considering life on my own with 2 children

64. I - Right, yes

65. J - And I was thinking, well, you know, he needs 1-1 care but I can't give him 1-1 care because I've got this little baby to look after, as well and I'm thinking he needs just experts around him, so I looked around and I considered it but I just thought we'd have no hope in hell's chance of getting him in anywhere because I knew what the fight was like to try and get him to have a 1-1 worker at school and to try and fight to get him into Downs Road school you know, so I thought it's going to be horrendous trying to get him into any residential placement but I thought well I'll go and have a look around and I went over to , what's it called, there's one at Langley, I went there but that wasn't residential that was specifically for autistic children

66. I - John Sutcliffe?

67. J - No, not John Sutcliffe, no, I didn't know about John Sutcliffe at the time, but I went to visit that later and there was no way in this world that it would have been able to cope with Taylor, it wasn't specific enough, there is one autism specific,Johnson

68. I - Johnson Park?

69. J - Yes, it was there but the thing is, I'd still have the same problems, he'd still be coming home at night times, and I don't know, I just thought, well residential, that's it

70. How were you feeling when you thought about residential?

71. Guilty

72. Yes?

73. Oh, Terribly guilty, I still do now some days and I still feel that we have to do things (for him even though we know it's not going to go well, so it was his birthday and I asked him where he wanted to go and we'd all go, but we decided after this year that we're never doing it again. If we take Taylor out, we take Taylor out alone (emphasised) and if we go on holiday and Taylor needs a holiday we will take him alone and try to find something for the other two to do, or one of us goes, because its just too much, too much stress, (embarrassed laugh?)

74. I - Yes

75. J - Yes, really stressful and it's not fair on the other two as well, to be honest

76. I - I think you have probably have said about getting the statement and you have already said that that took a long time but you got that in the end, so erm, in terms of getting to Ash House, how, did you have an annual review, was it.....did everyone agree?

77. J - Oh, to be honest, yeah, they did kinda agree, but they didn't want to because Ash House is a private school
78. I - Yes
79. J - and it costs a lot of money to go to so the headmistress kind of, of Downs Road, said to me, I feel he needs that kind of placement but my hands are tied because who you're fighting against, is my boss and its, the county council, the city council, so they couldn't be seen to be rocking the boat too much, they could put in 'Taylor would benefit from a waking day curriculum', but they couldn't really say
80. I - The school?
81. J - How that was going to be, how it should really be administered
- I- Yes.
82. J - So, yes, it was the school that actually fought on our behalf, to get him into that school
83. I - So was it straightforward in the end or did you have to go to tribunal?
84. J - No it still went to tribunal, I think it went to tribunal in the end, I can't remember the ins and outs. I know the county weren't happy because we were in the city, and the city started it off, but then I left their dad
85. I - Ah right, so you were living in the city at the time?
86. J - Yes, living in the city, left their dad, met Dave, and we had to move out here (the county) so then it all went to county so the county got it and they were adamant that he didn't need a residential placement, they kept throwing all these different schools at me) and I went to visit all of them and, as lovely as they were, they just weren't Ash House. They weren't geared up enough for him, and I thought, he could clear this classroom with one sweep if he wanted to and you haven't even got the right amount of staff to deal with him. Taylor needs 1-1, even at Downs Road he wasn't getting 1-1, he was getting 1-3 so, they found him very difficult. And even Ash House will tell you now if you ask them, Taylor is one of their most difficult pupils to deal with
87. I - Because he's so challenging?
88. J - Its because he's vocal as well, but he's not really, I've told you that what comes out of his mouth is complete gobbledygook, No, but I mean the school all fought on our behalf and they got a person for me, who was a legal person for me and she actually fought everyone's corner and said, why he needed this, why they were failing him. She even went through the statement and said, well that's not right this needs adding and we had expert opinions. We had a private Ed Psych look at him, a private occupational therapist look at him as well, I can't remember and we had to travel quite a way with him to see somebody, can't remember who that was.
89. I - So quite a lot of effort then
90. J - Yes, it wasn't straightforward, it wasn't 'yes we've read his paper work and we can see, no we had to have other reports to make sure that he got in there and luckily, I think it would have cost them more for him to...for the court battle, than for them to just agree and they agreed, and they agreed to pay the education would pay the education time and the social services that pay for the rest of the year, and I have to have him home 4 weeks of the year, and it's still proving very difficult. Every weekend and then four weeks throughout the year so two weeks at Christmas and 2 weeks in the summer which we share between me and his father.
91. I - So he's home every weekend?

92. J - Not this weekend because I asked if they'd keep him, cos I'm going somewhere and his dad sprung on me last week that he can't have them so it wouldn't be fair to leave all three of them with Dave, cos it would be too difficult, so erm, they said, 'we'll keep him', they're good like that
93. I - How did you think you and Taylor would cope with the change?
94. J - I was, well, it was heartbreaking for me, cos I'm thinking O my god, I'm sending him away, I'm sending him away, then I spoke to friends and they said, you're doing what's best for him and you've got to take you out the equation completely, cos you do feel guilty cos you're sending him away, in a way, you get used to it, cos he started as a day pupil first, cos while we were fighting to get him into residential, I think education said that he could go as a day pupil so he used to travel there every day in a car and come home at night time, so he was slowly introduced into the school and the they kinda said you know, one day, 'would you like to stay over Taylor?' And they started it started slowly and he's never batted an eyelid and we were really worried about this huge, huge change
95. I - Yes
96. J - And he's been absolutely fine, he loves it. He doesn't like it if he doesn't know what's happening though. When I have him back here, cos he knows that he goes to see his dad on a Saturday and he does this and he knows he does that, but if that changes, we have to pre warn him
97. I - Yes. And so were they the things that you were worried about, the change, the change aspects?
98. J - Yeah I was because I just didn't know how he was going to react, you know, because, as much as we know with Taylor that he likes his routines, and stuff like that, he'll surprise you sometimes, like that, and not be bothered by it, or, everything that you put in place will be working up to a certain time) then everything will change completely and you have to come up with a load of new ideas and so that's what it was, it was going quite well, that was it, I was worried about how he was going to deal with it, how I was going to deal with the fact that he wasn't coming home and he was also having to deal with the fact that he wasn't living with his dad anymore, cos we'd moved here but it wasn't him who was bothered, it bothered Kyle more no, but Taylor took to it...
99. I - So, I was going to ask you about the early days of Taylor being there, is there anything else you'd like to add to how you felt? About him staying away
100. J - I was just upset, really really upset, anxious...how it's going to be, I was thinking, what if education decide (it's not the place for him,got to keep fighting , it was just the constant not knowing because it seemed to go on for months and months, yes, not
101. knowing, whether or not he was going to get to go there or would he have to be with us and if he was with us, what would that mean? For both of us here cos like, Dave is self employed, would he have to change his hours to help out with the children and you know, it's just all things like that
102. I - Yes, so it's about not knowing, that's as hard as....
103. J - Yes, it is and I don't understand as well why it's so long drawn out why it can't be a quick process or why there is a time limit , you know, it just seems to drag on and no-one seems to want to give you any information you know, at the end of the day its your child that they're discussing and you should be at the forefront of everything but you don't seem to be
104. I - So, how do you feel about your decision now?
105. J - Really happy about it
106. I - Yes?
107. J - Like I say, I do still have twinges of guilt, but he rings me every week from school and he'll talk me through what he's done that week

108.I - Right

109.J - And he'll tell me about the trip, cos they go on a trip every week and he'll tell me and he's allowed pocket money as well and he's allowed to spend, and I know he's happy

110.I - Yes, so is there anything you'd change about it?

111.J - No, not at all, no, not at all

112.I - So, what changes if any has Taylor being at Ash House brought to your own life, to your family life?

113.J - It's made it a lot easier cos like I've said, when Taylor's not here, we can have a sense of normality and even though Kyle is quite complex, as well, in his own little way, we can kind of, one of us can deal with him, while the other one has the baby, erm, so its 1-1, but when Taylor's there, he kind of triggers Kyle off and Kyle triggers him off, cos, Taylor's quite up for anything so if we're going out, he likes the idea of that, but Kyle probably won't like the idea of that, so Kyle'll say no, that winds Taylor up Taylor will get mad, gets aggressive, starts hitting himself, or hit Kyle or hit whoever's nearest, swearing, blah, blah blah, but it's just him not being here, we can do a bit more easier life, a normal sort of life, I should say

114.I - Yes, so were you with Dave at the time that he went?

115.J - Yes

116.I - So, your relationship, has it had any effect on that?

117.J - I don't know, you'll have to ask him (laughing) I mean , I don't know, I don't feel as if it has, I suppose we don't have to think about who's going to look after him now cos he's 14 as well, there's only one person if we went out we could really leave him with, because she's trained with children and she's got a special needs brother herself, but she's not always available, so, but in the week we're ok because we know that we've got people who can look after the two little ones if we wanted to go and have some 'us' time but if Taylor was here it would be a bit more difficult.

118.I - Yes, yes,

119.J - What about, has it made any difference to how you've been able to get involved in the community, or just round about?

120.I don't know cos we don't really get involved in the community (laugh) cos there's not a lot that Kyle would want to do and the baby goes off and does his own thing with his dad anyway while I go off and take the boys to see their dad...where I would take him to there and do something and do some shopping or whatever, so I don't know about the community as such

121.I - That's fine, so anything that you'd like to say about yourself, say your self perception?

122.J - Yeah, I suppose I feel a bit better about me, a bit more 'me' time, not just thinking that I'm Taylor's mum, that I've got an autistic child to deal with...it's just less stressful, if you'd seen me before I was on anti-depressants, leading up to him going to school

123.I - So do you feel that you've got your identity back

124.J - Yeah, plus with having a more supportive partner, cos Dave is involved in anything and he came to all the , you know, any meetings with solicitors with me, erm, to get Taylor to the school, erm to the paediatricians and whatever, Dave was there, but his dad was invited to turn up, and he still is, even to this day, anything that happens to Taylor, at school or the doctor's coming or whatever, he's invited to everything, but it would be usually Dave who would go (but Dave doesn't come down cos he has to be in for Kyle when he comes home from school cos Kyle's also at a special school as well and the taxi comes and that comes at 3 but if I have to be at Ash House at 2 then there's no way I'm getting back

here for 3 so Taylor tends to stay here now for Kyle, but he'd be there if he could be and dad never comes

125.I - What changes, if any, have you noticed in Taylor since he's been at Ash House? things that he's gained or...

126.J - Like I say, he's writing better now, he's reading better, behaviour hasn't changed a lot, he was a lot calmer at one time, but he's just going through, we think, we think, we've spoken about it, at the school and Dr Carling about it, we think that it might be the onset of puberty, plus everything else

127.I - Yes

128.J - That's making him a bit more aggressive at the minute. He doesn't like, like I say, Taylor doesn't like change and if he's had a break, from school, it can take him a whole term, to get back into the swing of things and they're usually geared up for that around about September, cos that's when new pupils come, staff have left and they get new staff, he doesn't like new pupils and he doesn't like new staff

129.I - Right

130.J - Like I say, when he first meets them, it takes like a whole term to get used to that, I mean, I don't know, changes like, I don't know, not really, I mean he's a lot more...

131.I - But you describe him as if he's made some progress...

132.J - Yes, he's definitely educationally, he's made progress, but he tends to be more insular now, cos when he comes home he'll say 'hi mummy' and then he'll go to his room, he doesn't mix with us, whereas before he'd be like floating around the place, not really mixing but he'd still be around, but now he tends to like his own space whether that's to do with maybe at school I suppose he has got his own space he is with the other pupils, which he doesn't always like, he prefers to be on his own with adult company

133.I - So when he's taking himself off, do you have any feelings about that?

134.J - No, I go up there and have a quick chat with him ,but he'd rather not, I wasn't there he goes upstairs and watch his telly and he did have a computer but he's dismantled that, ...he tends to want to have his own space, doesn't like anybody going in , whether it be a younger brother or a cat, he doesn't like anybody in the room, you know

135.I - Yes

136.J - Apart from, he'll just about bear me if I have to go in to put his ironing away, and he'll be like, have you finished yet mummy?' Have you finished?' and I'll be, 'In a minute I've just got to....'

137.I - Have you noticed any difference in his well being? Is he happier or....?

138.J - It's really difficult with Taylor to know, like I say, he's got his anxieties and it's hard to know with Taylor what he's feeling, it really is, cos I suppose he's that severe

139.I - Yes,

140.J - If Kyle was happy I'd know, because he's not so severe, but with Taylor, and he comes across happy, it seems if things are going his way but...

141.I - Is he ok going Monday morning, does he go Monday morning or Sunday night?

142.J - He's fine, he goes first thing Monday morning, he goes home Monday morning in a taxi

143.I - Did you mean to say go home or back to school?

144.J - Oh, yes, back to school, (laughs) he comes home Friday night and he goes back to school Monday morning

145.Yes

146.I - And does he go ok?

147.J - He comes in fine, they usually tell me if they've had an outburst on the way home, but no, he's generally quite happy with what goes on

148.I - Yes

149.J - But as soon as he comes in the door, he tends to go, I'm going to my dad's tomorrow aren't I? I think to be honest he'd like to go to his dad's all the time to be honest, and live there he prefers to be with his dad cos his dad's more like he is and his dad's got a bigger room at his dad's and he can just make as much mess as he wants at his dad's, but, that's not gonna happen (laughs), it's not gonna happen, so

150.I - What do you like about how Ash House works?

151.J - It's just, what I like about Ash House is nothing is too much trouble for them, they're very understanding, and I like the fact that he's got a carer and a teacher and he's got this team around him, that can cater to him, for everything, you know, I know that's not what life is all about, we can't get what we want, but the fact, because of Taylor being like he is, he needs that, he needs someone who's gonna be there all day and tell him exactly what's happening, whereas I can't predict what's happening in an hours time, or whatever, here, you just can't, I mean even going down to the shops, things could change, and at the school, it doesn't, it's all the same, and he loves that security

152.I -Yes

153.J - So, I like that about it, I mean if we are ever in trouble, we had an incident a few months ago, we had a phone call here, on Friday, when he was on his way home, the school rang me about 3 o'clock to say they'd had an incident at school, Taylor had gone to hit another child and a member of staff had gone to stop him but as she'd gone to do that, she'd fell and pulled him down with her and caught his arm so they rang me to tell me he had a bruise on his arm, which is fair enough because I know I've been like that at nursery when I've gone like that with my arm, I've gestured and, cos they're all at this level, it's easy done and I know that these things happen, but then when the taxi came Taylor decided to go into what ever mode, 'I hate taxis the taxis trying to kill me, my dad's trying to kill me and my dad hits me round the head when I'm naughty' and of course school have got this duty of care and so they had to ring social services.

154.I - Yes,

155. So by then it's going up to 4 o'clock, social services decided to ring me at a quarter to five to tell me that this is what has happened, cos we have got a social worker for Taylor and she rang me up and said, 'look Taylor's said that his dad hits him round the head, he's not to go to dad's this weekend', well, that's the thing he lives for. He wants to come home, he likes having, sometimes we have chips on Friday, or whatever but then dad time is dad time and that is what he looks forward to every weekend, so she said you've got to promise me that if I don't get to speak to his dad, then he's not to go to his dads and Taylor's on his way home. And so I say, 'have you tried to ring him?' and she said, 'I'm going to try to ring him now'. So it's quarter to five, he's still at work. He's not allowed his mobile phone on at work and he won't be at home because he's either leaving work to go home or whatever so I knew she weren't going to get him, so she rang me at just gone 5 and said, 'I've not got hold of him so you're not allowed to let him go to his dad's this weekend.' and by then he's just walked through the door and so I said, 'did you say that daddy hit you round the head?' and he said, 'yes', and I said, 'well, does your daddy hit you round the head?' he said, 'no' and started laughing, and I said, 'well because

you said that now the lady on the phone said you can't go to daddy's this weekend' Well, all hell broke loose, he's screaming he's in his bedroom, he's banging windows, throwing everything around in his bedroom, so I rang the school back and I said, 'look I know you've had to say this, but listen to him' and they could hear him screaming and stuff and they said, 'look give us an hour and we'll be there, we'll support you with a member of staff.' So they were on the way to come and be with him and calm him down cos it was the first Friday in 3 years that Dave had ever decided to go somewhere and I'm stuck here with all 3 kids (laughing) and I thought, 'we'll never do that again either'. So, I'm on my own with 3 kids and the babies hadn't had their tea yet and I hadn't got them ready for bed or anything yet, so they said they'd come and support me, while I did this, cos nothing's too much trouble, they always say if he kicks off big time and you need that support, they'll come and get him, but luckily then I managed to speak to his dad and he said it was totally and utterly ridiculous, but because we couldn't get social services, cos they've have gone home then at 5 o'clock, I rang the duty desk and the duty desk sorted it out enough for us, he said, 'look, he can go to his dad's that's fine,' so luckily everything was calm so I could ring the school back and say, don't worry about coming now

156.I - They were willing to come out?

157.J - Yes, they were willing to come out, and that's what I like as well, it's like having that, that extended family, that extended support, cos me and Dave don't have any support this end, his mum, well they're not her grandkids, but she couldn't cope, my mum is terrified of him because she doesn't know how to calm him down and she's never been one for having the grandkids anyway, so that's it, I mean we've both got brothers but they've all got big families, they've all got their own children so they're not going to be able to come over here and support us

158.I - It's asking a lot...

159.J - Yes, it is, it's not like it's just looking out...., I mean, they'll have Louis cos he's this tiny baby and he's easy to look after, well he's not tiny, he's two, but he's easy to look after and Kyle at a push would be, but with Taylor it's a different story so with Taylor we don't have the support and the fact that if we really needed it and the school are good for advice so 'I'll ring them and say I've got this thing happening, what do you think? And they'll say, well we'll have a think about it and we'll ring you back, they're good and they get back to us straightaway and it's nice having that extra support which we couldn't do with a normal state school

160.I - No, no

161.J - Cos you're lucky if you get to see the head cos they're just too busy or the resources are that stretched that

162.I - Yes, so that flexibility you talked about and like going the extra mile

163.J - It is, and I suppose because it's private and they don't have to adhere to the rules as such that other schools have to, they

164. Yes, they can make their decisions

165.J - Yes, and it's just so nice, cos, we'd got some tickets, this was before cos we'd decided to take the children to Butlins, all 5 of us went and it was horrendous, and it OK but in the end I said to Dave you take the little ones to the chalet and I'm taking Taylor and we'll do something with Taylor just on his own and that was the only time he was calm cos one triggered the other and it was all hell broke loose and we said on that day we will not take them anywhere again altogether. And I had these tickets that were given to us for Legoland form Merlin's Magic Wand charity and I

166.said, 'we're not taking Taylor', I said, 'we can't do it', I said, 'we'll take the little ones cos it's more geared up for them' and I said, 'we'll take Taylor another time' and I rang school to see if they'd keep him and they said, 'well what about if we sent some workers to support him at Legoland, would you be able to take him then?' And we said well, 'yes, if there's the extra support', so that's what they did, they rang up Legoland to secure two carer's passes so they didn't have to pay and they brought Taylor all the way to Legoland and spent the day with us

167.I - Well that's good, it's quite amazing

168.J - Yes, you wouldn't get that from anywhere else

169.I - And that meant that you could go as a family

170.J - Yes, that's it and it was so much less stressful, they even watched the little ones for us while we went on rides with him and things like that. Yes, it was so much better

171.I - Yes, is there anything that you think they could do differently?

172.J - No, not really, not at all

173.I - I'll just suggest a few things, any different programmes, learning programmes or facilities

174.J - No, well the thing is, because as Taylor is as vocal as he is, cos as you know a lot of the children at Ash House, they're not very vocal, but Taylor is, so since he's been there they've had to change their way of learning so they've got him like a reading programme to go on, and he's learning they're on about teaching him piano and things like that cos he's actually very musical

175.I - Oh, ok

176.J - So again, they've gone out of their way to accommodate Taylor completely, so they've not kind of just lumped him in with all the others, which was what was happening at Downs Road, they were all being lumped together, out of their way to accommodate Taylor completely, so they've not kind of just lumped him in with all the others, he gets to have lots of computer time, they've even come up with reward systems for him, because he's got that slight more understanding he understand a reward thing, so he thinks well I've got so many of these books, cos it's books they use, then I get a prize at the end of it, so he understands, he's motivated by chocolate

177.I - Yes, so they've put that into place for him

178.J - So I mean nothings too much trouble

179.I - I'll just mention a few other things, professional support? Communication?

180.J - Yeah, they're brilliant, we have a home school diary and they write down everything he's done every day plus like I say he rings home every week but they always ring first to see if I'm here, so that if he rings up and we're not here it doesn't have the disappointment because he knows the number off by heart and he could ring himself

181.I - Yes

182.J - But yes it's just like keeping his anxiety down as much as possible

183.I - And so the day to day things that they might do for him, are you happy with all of that?

184.J - Yes, yes

185.I - And the formal reviews of his progress?

186.J - Yes, fantastic, I mean they're really good, everybody sits round the table and everyone has an input whereas at other schools, you get a letter home, I mean Kyle gets a letter home

187.I - And visits? Do you go there to see him?

188.J - I don't, no, because he comes home weekends but we go over for the Christmas play and if anyone, I mean if the doctor wants to see me then I go over, also every six months social services need to see me at the school and him at the school, so I go for that, I don't miss any of them

189.I - No, ok, how would you describe your relationship with Taylor now?

190.J - It's better, I can deal with him J - better now, whereas before I couldn't cos it was constant, he was there all the time going on, I was always dealing with him, I couldn't cope but now, I feel like I can cope with him better, I'm more geared up cos I get that break, but by Sunday I'm pulling my hair out even though I've not had him Saturday evening, I've still had him Sunday, and we've had him Friday evening, so we've had him 2 evenings, and that can be a difficult time because he doesn't like showering, he doesn't like cleaning his teeth, he doesn't like getting ready for bed, he doesn't like any of those things so by the time he's ready for the school I'm ready for him to go back I'm like, 'for god's sake, just take him' (laughing)

191.I - But overall? Do you think your relationship is better?

192.J - Better, yeah, better

193.I - And what are your hopes for Taylor's future?

194.J - God only knows? We try not to think about that. The good thing about the fact is now that the company that's took over Ash House, does post 19

195.I - Oh yes

196.J - It goes beyond so we're hoping that he'll be able to continue to stay there, but the way government cuts are going and blah blah blah, we don't know what the future holds, but it looks a little bit brighter now cos they do keep them til way into their old age now I think it's going to be, they've got post 19 and they're building another section

197.I - So are you saying that you could never envisage him coming home, living?

198.J - Never, because the fact is, if I were a stay at home mum and we didn't need my money and blah blah blah, and it was just Taylor here, then the possibility would yes I could have him home, but its not all about Taylor, I've got two other children as well

199.I - It sounds like you think he needs a full time carer, whoever that was

200.J - Yes, he does, he'll never ever be independent. Kyle will be, the way he is he will be, but Taylor will never be independent and the fact that I mean like I say he's 14 now and he's not doing what 14 year olds are supposed to do

201.I - No

202.J - He doesn't know how to wash himself, he can't even eat with a knife and fork, it doesn't matter how much school have encouraged him to, he doesn't, you know, he'd rather eat with his fingers, yeah, I don't know, like I say, it's looking brighter because of the fact that he can stay there until later and he will have that support but that, apart from that, I don't think there would be a very bright future

203.I - I probably should have asked before, but have you still retained full parental responsibility for him cos I know...

204.J - Yeah, we both have, we both have equal rights with him

205.I - Oh yes, but what I mean is, you probably don't know that some of the pupils there, social services have more of a care role with them, but...

206.J - No, it's us, no social services don't have much of a say, he wasn't put in there because he...

207.I - No, no, I see that he's not one of the student's that stay there 52 weeks a year and who only goes home very rarely..., that would be a different arrangement. How've you found the experience of talking with me today?

208.J - Quite enlightening really, I suppose, you kind of lock it up and you don't think about it so I suppose it's been nice to talk about it, and if it can help then...

209.I - And is there anything else that you think is important that we haven't talked about?

210.J -No, not really no, I don't think so

211.I - ok

Appendix 10: Original Transcript

2. Julie and Stuart

(Key: J-Julie, S-Stuart, I-Interviewer)

1. J - Generally he's a very happy, a very strong, a very active young man, with quite a few difficulties I would say, things can get quite, very difficult I would say
2. I - Why, what would they be – behaviour?
3. J - Behaviour-wise, since he's been at Ash House they think he may have some form of epilepsy, we didn't know at the time what was causing the...his behaviour's always been difficult at times, but when he went to Ash House they thought it might be some sort of epilepsy, which I didn't realise and then he goes completely berserk and then he attacks people attacks me, attacks anybody who's near him, people, staff, us.
4. And then he'll gradually come down from them, I mean he goes absolutely mad at times, but he'll gradually calm down, but it usually involves taking his clothes off and biting himself, as well as everything else, and then he'll calm down and he's our Nick again, cos he isn't Nick while he's in one of those things, he isn't Nick at all
5. I - Right, so what do you think of as the real Nick then?
6. J - The real Nick is a very, very happy child, difficult, he's obsessed with videos, I think most of them with autism are, obsessed with like Disney videos and things and whilst things are going Nick's way, and he can more or less do what he wants to do, he's the happiest child, he's gorgeous, he's lovely, he's...
7. I - That's good to hear, now I know we touched a little on this earlier, but when did you first have concerns about him?
8. J - Well, I think it was probably about 18 months. He seemed fine, he seemed like a normal child, and I don't know but it was around the time of the MMR
9. I - Oh yes,
10. J - And I've often wondered if... it worries me
11. I - So you often think about that do you?
12. J - I do, I wonder, maybe, maybe...we took him to the doctors and they didn't really want to say anything, but they did tests on him and things and it became clear, though they said he was on the autistic spectrum, or that he maybe, you know, and I didn't, I thought, oh, autistic tendencies, that's not very much
13. I - Not the full...?
14. J - But at that stage he wasn't doing anything, he wouldn't go near us, and we couldn't do a thing with him.
15. I - And you've got older children? As some people say they can't compare if they've not had children before.
16. J - No, he seemed fine, for his first year or so, he seemed just to be doing the normal things, then, I can't say it was over night, but it was certainly over a short space of time, the things he had been doing, just disappeared. I think he was just starting to say 'mum' and 'dad' and things like that
17. I - Yes

18. J - We couldn't pick him up, we couldn't go near him, he was just...
19. I - so how was that for you?
20. J -Horrendous, absolutely horrendous, I mean you just don't know what's hit you, and then people were coming in and throwing balls to him and he wasn't bothering to catch them, and at that stage he had no eye contact hardly at all, that had all gone
21. I - So there was a loss of skills?
22. J - Yeah, a loss of, a complete loss of...he didn't want anyone near him at all, it was just murder trying to change his nappies or anything, yeah, it just went completely, it was a horrendous time that, probably the worst time, because after that they started trying to get him into some sort of placements and things and people used to come round and see him and try and play with him, which was, impossible (laughs)
23. I - So, did he go into a nursery?
24. J - He went into little, little day things at the Centre, but he just cried to himself until I came and picked him up, so that was just horrendous and so I didn't take him there and then he went to Oak Copse school here, which is just a special needs school, for all sorts of children
25. I - No, it's not just autism is it?
26. J - They did a really, really good job with him to start with, I think he was about 3 years old when he went in there, part time. I'd leave him for an hour and then gradually they eased him into school, and they really did well with him, until later life, I think, I think things gradually got worse with him at school, he didn't want to go, he used to scream and smash the house up if the bus came and things, he didn't want to be there eventually, that was a really tough time. And then he got to the stage where he didn't want to go to school, and when he did go to school he'd be smashing the place up and there were a lot of children there with wheelchairs and with feeding tubes, all sorts, so he was too much, he got excluded from school, all sorts (ironic laugh)
27. I - So, what sorts of feelings were you going through at that time?
28. J - I got to the stage where I didn't even want him to go to school because I knew either there'd be chaos here before he went, because the bus came to pick him up he'd go ballistic as soon as you mentioned the word 'bus' he'd go mad, so I was quite relieved in a way, I mean I felt awful that he'd been excluded 'cos it just sounds so terrible
29. I - Well, I know
30. J - But probably that was the best thing that happened in the end, so I had him here on my own all day and all night, and he was starting to get these fits, I don't know whether you'd call them fits, what you'd call them, fits?
31. I - Like rages?
32. J - Yes, like rages I mean he wouldn't be Nick at all he'd be like a wild animal. And he'd just go into these and you didn't know when, there didn't seem to be a trigger for them or anything and then he'd just smash the whole house up and if you tried to go near him then he would attack me
33. I - That must have been frightening
34. J -It was really, really frightening, it was awful, I mean the house would be in tatters and I'd call social services 'cos I didn't have a social worker at this stage, or didn't know who they were anyway and then they started coming onto the scene and I'd phone them up when he'd had these 'nutties' and they couldn't come out or whatever or it was the wrong time of day or night or something and they told me I

had to call the police, which I had to, because I was here on my own a lot of the time and I couldn't handle it and the police would come, and of course they had no idea what they were dealing with, how they were going to handle it, they were almost ready to give him an ASBO and cart him off, you know

35. I - So that must have been a different sort of feeling that you had then, involving the police?
36. J - Well, I didn't know what else to do, I ...my husband was on a building site twenty miles away and I couldn't get hold of him and even if I had he couldn't get back in time to do anything, there was just nothing else I could do and social services had said if you can't get hold of anybody then call the police which was really a bit stupid and then they'd call the school and the school would exclude him so that moved it on a bit
37. I - It brought it to a head?
38. J - Yes, which was just, it was probably the best thing that happened in the end although it was horrible at the time
39. I - Yes, yes, a sort of a means to an end. Now, we were talking earlier, and you said you couldn't think of a precise time when you had a diagnosis given to him....
40. J - No, I mean everybody always talked about him as if he was autistic, but nobody actually
41. I - Right (laughing)
42. J - Would actually say it, that he had a diagnosis of autism
43. I -So when you had letter from the paediatrician or whatever, would they describe Nick as autistic, but you never had a letter which said, 'I have seen Nick in the clinic today and
44. J - he was diagnosed? No, 'autistic spectrum or autistic tendencies'
45. I - I see, but, in your own mind did you...
46. J - Oh I knew, I mean I didn't want to believe it for years, I mean when he was tiny, I thought, 'oh it's autistic tendencies, it's only a little bit' although I suppose I should have known that it was more than a little bit (ironic laugh)
47. I - Yes
48. J - But I had no idea what autism was at that stage and ...
49. I - Right
50. J - I'm sort of baffled with it, I still am
51. I - And when you found out a bit more about it, how were you feeling then?
52. J - Well I think you just gradually come to the stage when you know that this is quite bad this is, you know, there's no way of knowing what they want or what they need or...
53. I - Is he verbal at all?
54. J - Erm, only in so much that he can say a word like 'drink' and I think he can probably say a lot more, but he doesn't
55. I - Yes
56. J - He can make himself understood to a point, but you could no way hold a conversation with him

57. I - No
58. J - And he says loads of words from Disney videos, he could recite them back to front
59. I - But not in a meaningful conversation?
60. J - No, you couldn't hold a conversation with him, no, no (fading)
61. I - Erm, was there any difference between you and your husband in coming to terms with understanding Nick's difficulties?
62. J - I don't think so, I think we just sort of bungled along as best as we could with it all and he was smaller then and you could remove him from a situation, he was, as he got bigger you just couldn't physically do anything. Things were quite difficult, I mean you'd get good days and bad days, I mean you'd get some days when he was a complete little angel and then another day when it wasn't one of these complete nutty fits, I don't know what to call them, it'd would just be, he wouldn't go into a certain shop or he wouldn't go into a certain road, or... , and you never ever knew why and you'd talk for hours and hours about did we do something wrong, should we have done that (**guilt, confusion**), did he do this, what brought it on we never ever came to any conclusion, never, it was always just...
63. I. Random?
64. J - You'd think you'd upset him by not giving him an ice cream or not letting him watch his videos or there didn't seem to be any real triggers, although he could get in tempers about things, he could, which would be like pretty normal tempers
65. I - So that would be different from...
66. J - Yes, I mean he could get in rages and throw the television across the room and things but these, these later things were, something different
67. I - Did they emerge? Did they just gradually emerge or was it sudden?
68. J - When he got to about 14, just before he got excluded from school, they got worse, he'd go and hide himself in a cupboard in school if he'd had to go and rip all the posters off the wall and things like that, but I'd say when he got to about 14 it really got quite...quite desperate
69. I - Right, and so was that the time you had him at home, did you have him at home for quite a ...
70. J - Yes, I had him at home, for about a year altogether
71. I - Quite a long time
72. J - Yes, and we never ever thought about him going into care, never ever, and it was becoming more and more obvious that we were not coping with him, I mean he was upstairs and the windows would start smashing and you know there'd be glass on the floor and he's smashed the light and he'd be all in the bed and we weren't really coping with it at all we didn't know, because if you'd go in the room then you'd be attacked
73. I - Right
74. J - Until he came out of these, whatever they were
75. I - So, was it you that first thought about the residential thing, in the light of what you've talked about?
76. J - I think somebody had mentioned it but I said, Oh, no no no no, my son's not, we're not, I mean we're his parents he'll be here with us, but I think the thought had been put in my mind that we're really not coping with him. I mean I used to sit here at night and if there was a bang on the ceiling and you'd think he was going to go...

77. I – Yes
78. J - You'd sit here and like shake and think, 'do I go up there?' but if I go up there and speak to him he's going to get worse, 'cos any sort of contact, he wants to be on his own, erm
79. I - Can you remember how you used to feel?
80. J - Yes cos we had one last weekend
81. I - Oh, I see
82. J - And that brought it, it brings it all back, I remember my legs going to jelly and sitting at the top of the stairs, frightened to open the door, well in fact we couldn't open the door because he'd thrown a television in the doorway and we had to sort of push the telly out to get the room open
83. I - Yes
84. J - In case we had to go in there, you know, luckily there were two of us here then but when you're on your own...
85. I - What you're describing is extreme behaviour
86. J - Yes, yes, but not all the time
87. I - No, no
88. J - You never knew when this was going to come on and for what reason, because he was here, he came here Friday, he was coming for the weekend, we usually have him every third weekend
89. I - Oh yes
90. J - And erm he'd been fine coming home from Ash House and he was singing his nursery rhymes, his Disney things. Got home, had his tea and was, he sits in the dining room watching videos and all of a sudden I heard this crash and it sounded like he'd kicked the radiator, it was that sort of hollow noise.
91. I - Yes
92. J - And I just looked through the dining room door and he was stark naked, which is another one of his traits when he's upset or anything, he tends to take his clothes off and I just went to get a pair of pants and a t shirt off the settee and he run straight past me went up the stairs to his bedroom and that's when the television went flying and things got pretty hairy, you know the curtain poles were all bent and down, you know, but luckily we didn't, we decided that unless he was not harming himself or there was glass, we weren't going to go in there, so...
93. I - Yes
94. J - So we didn't get attacked but the time before my husband did actually get attacked (little laugh), so...
95. I - So, you must be, frightened?
96. J - But that hadn't happened for a long time, the last 2 visits, but that's since he's changed into adult services, whether it's, they say he's coped remarkably well
97. I - There?
98. J - There, but whether that's to do with that...

99. 'Cos you're always questioning in your mind, did something happen? Well there were, there was something different, both times we'd been up for a meeting and brought him home ourselves,

100.I - Oh right

101.J - whereas they usually bring him so both those times we'd been and brought him home, but I don't think that was the problem, because he came home quite happily, but, it could possibly have been, or it could have been the transition....and coming back here, I don't know

102.I - So I suppose you're talking about a lot of uncertainty and unpredictability and that must be...quite stressful I imagine

103.J - For Nick?

104.I -Well for you as well, I was thinking about your experience of not quite knowing...

105.J - 'Cos he had been pretty good coming home at weekends, we hadn't had any major outbursts for a long time, well he'd come home, made a mess, been quite happy, watched his video, eats all the time, we had to lock the kitchen doors because he just eats all the time (laughing) and I thought we'd had some really, really good visits with him

106.I - Yeah

107.J - But the last two times were awful, but the last two times we had brought him home, so whether that's....

108.I - Autism is so complex that you don't really know...what little things...

109.J - Although he'd got into the car quite happily both times, We'd brought him home because we'd had meetings both times...

110.I - cos you were up there anyway?...yes, so just thinking about the assessment process, the statutory assessment, can you just tell me a little bit about that, the statement...just taking a few steps back. Do you remember that?

111.J - I do remember him getting a statement but I can't actually remember how it happened, I'm sorry

112.I - It's alright

113.J - Sorry

114.I - It's alright, so do you remember whether it felt like...whether it was easy...to achieve, did everyone help you to do it...

115.J - Yes it was easy, everyone could see he needed it

116.I - It was clear cut?

117.J ..the statement..I do remember vaguely having people come round to see us but I can't remember I don't think it was very stressful time

118.I - You didn't have to fight for him to get into a particular school, they weren't offering a school...?

119.J - No, there wasn't much choice to be quite honest, I mean, I do remember thinking he'd go to a normal school, which was crazy now thinking about it (laugh), but I didn't know...

120.I - What was out there....?

121.J - Well, I was just given by social workers or somebody a list of all the schools in the city and told to go and look for one and I'd gone to sort of normal schools

122.I - Yes, like the local ones. Did you live here then, I mean were you looking at the local ones?

123.J - Yes, I did, yes, there was one not that far away which seemed like quite a nice school but they both sort of looked at him and you know *(laughed)* ... and even one that dealt with autism, they said they couldn't cope with him 'cos he wasn't out of nappies, and he was only little then, *(laugh)*

124.I - Oh

125.J - And he's still in nappies now, virtually

126.I - So how were you feeling then when you were going to these schools and...

127.J - I was just, I didn't know what I was doing and then somebody said then, 'well try Oak Copse, well that was much more comfortable because it dealt with special needs children at least, even if they weren't autistic

128.I - So they wouldn't be fazed by Nick?

129.J - Well, not as fazed as the other schools, you know what I mean, that would have been pretty horrendous

130.I - Yes

131.J - And I kept saying to Stuart (father), 'how can he go to a normal school, he's just going to cause mayhem and they're not going to take very kindly to him either, you know, it's just going to be...' but I think I went to see a couple of schools and I realised there was no way he was just going to fit in or they'd want him or anything, and I don't know how Oak Copse, somebody mentioned Oak Copse and they seemed to want him *(laughing)*, they were lovely people at that time they were really nice

132.(Stuart joins)

133.I - Please feel free to join in if you have things to say

134.J - Please do as I'm really struggling

135.I - No, you're not, you're doing really well, but obviously both of you have been through it...

136.S - In my opinion, the council, the social workers or what ever didn't know what they were doing

137.I - When he was very young?

138.S - Yes. Just, just, what can I say?

139.J - just pulled us from one crisis to another really

140.S - people didn't know what they was doing basically, so....

141.I - So you didn't feel supported? Or that people had a plan?

142.S - well...

143.J - I think they did do Portage or something, that seems to ring a bell

144.S - Yeah, when he was little,

145.J - - So someone would come, when he was very tiny someone used to come round, she was very nice but you couldn't...

146.S- but at Oak Copse when the headmaster, to start with, everything wasn't too bad and...

147.J- school was lovely to start with wasn't it? But it just got worse and worse and worse

148.S- and then there was this, he left didn't he? he wasn't there all the time and then there was this woman came and she wasn't for the likes of Nick

149.J - I think all the autistic children were gradually disappearing, they were causing too much chaos

150.I - Right

151.J - They were just too difficult

152.S -2 or 3 of the kiddies they couldn't control

153.I - Yes, yes. Can you remember how you felt when you could see that things were changing at Oak Copse?

154.J - it was just one crisis to the next wasn't

155.it...it was frightening

156.S - well, it was just er...he said he wouldn't go, and there's one thing with Nick, if you try to force him, then there's only one winner and that will be Nick

157.I - Yes

158.S- and which is the way they deal with him at Ash House, I mean all of them

159.J - they'll just ask Nick and if Nick doesn't want to do it then they'll, if they can, leave it, they won't push him

160.I - Yes, 'cos there's not that many things you need to do

161.J- we came to realise you don't push Nick you just, if Nick is adamant that he's not going to do something or go somewhere, if you try and push him then there's just going to be chaos, there's going to be broken noses and smashed everything, you know?

162.I - Ok, so thinking back then to when you were thinking about Ash House and a residential placement, can you remember how you perhaps thought or if you had any worries about... how Nick might cope with it or how you might cope?

163.J - oh we were terrified, we couldn't, I couldn't imagine that he could go anywhere and anyone could love him like his parents

164.I - Yes

165.J- how can he be, he might be looked after but nobody was going to love Nick the way that I loved him or the way we loved him, we were in a terrible state weren't we, we were....

166.I -Right

167.J - we knew he had to go, we had to fight for him to go, because we knew we weren't coping, we really weren't coping. I mean it was at the stage when he wouldn't have his hair cut, but that's not the end of

the world. His teeth were having to come out because he couldn't clean them, we couldn't cut his finger nails, we couldn't get near him to do any of the practical things that you needed to do

168.I - Yes

169.L – Apart from the outbursts and everything we weren't really being able to teach him anything or do anything with him you know He was just watching videos all the time and if we tried to take that away then...

170.I - You'd have an outburst?

171.J - There'd be even more chaos so it was horrendous but we no way wanted him to go into care did we?

172.S – no, but, you know

173.J– but we knew that we weren't coping with it and when he did go into care well it was the worst day of my life, I mean I just...

174.I - Can you still remember it?

175.J - Nick was fairly happy I remember, Nick seemed to want to go there, he seemed to know. We'd seen another school but we didn't think it was right, it was too regimented, too organised

176.L - When we saw Ash House we thought it seems like a home, you know it seems like home, they're a homely people, you know, they seemed to adore him and he seemed to know. He wanted to go there, he didn't want to come out there. So that was...thank goodness,...that seemed quite nice but when he went I just sobbed all day

I- Yes

177.J - I mean the first time we went to visit him we went up there and just sat in a room with him and he sort of looked at us a bit gingerly and he eventually he did come to sit on my lap and then they said it was his time for tea and we went home and we just sat in a lay by and just bawled our eyes out, didn't we, we went hysterical didn't we the pair of us, just stopped in a lay by and just cried and cried

178.I -And was that because you felt...

179.J – you feel guilty, you feel like, I felt like I'd betrayed him, he was never going to go away, but.....as time went on, it was 6 months or so, and then we started having him home and we realised that he really was in the best place. We couldn't give him anywhere near the outings the ...

180.I - They take them out a lot don't they?

181.J - – taking him out was quite terrifying, you never knew what to expect, but they've got such a lot of staff, for me, to take him out, even to the shops on my own you never knew, you could have had a wonderful day, you could have had an absolutely horrendous time, you know?

182.I - Yes

183.J - You just didn't know. So we did realise, after he'd been there for a while, that he was in the best place and they, in their own way, they do seem to love him

184.I - Yes

185.J – they do, I think they're almost like a family there

186.I -Did you worry at all if, whether he'd remember you? Were they things you worried about or perhaps you didn't?

187.J – No, I don't think.

188.S – if he hadn't gone to the home, then we'd have been in a mad house

189.J- well I would have been, you would have as well, it wasn't just me

190.S – it wasn't so bad for me cos I went to work but Julie had him all day and when I got in...

191.J – he never knew what to expect when he came in from work – the house could have been completely trashed, doors could have been kicked in, walls, curtains down, bowls smashed everywhere

192.I - Yes

193.J – you never knew, cos as I say I could never really get hold of him cos he was on a building site too far away anyway cos they'd calmed down by the time anyone got round here, basically, but it was very traumatic, sending him anywhere would have been horrendous, it *was* horrendous, I just felt like I'd betrayed him, you know . Though I think he was probably better than I was, he was, he seemed to adapt to it

194.I -He took to it?

195.J - Very well

196.I - Yes, and the actual process of getting him a place at Ash House, was that easy or did you have to fight...

197.J – that was a nightmare, that was absolutely horrendous wasn't it? 'Cos social services

198.S - social services...

199.I - To get the local authority to get social services to agree?

200.S – – well we just kept getting told 'well we won't be able to put him into care you know" (*imitating a professionals voice in a mocking way*) by social services 'cos they'd started coming round quite regularly once things started to go completely mad, you know, and we couldn't deal with it and I had said to them, you know, 'we're really not coping and although we don't want to we think he's going to have to go into care'. 'Oh no, he can't go into care, do you know how much it costs?' (*mocking professional tone*) I didn't give a damn at that time

201.I - Yes, and I suppose for you to actually admit that...was very hard

202.J – we didn't want him to go, but we knew we had to

203.I - And to have it thrown back at you

204.J - and to have to fight for something you didn't really want was horrendous..

205.S – we went to a meeting, where was it, at the hospital, from the respite, the psychiatrist from the hospital

206.J – they had the whole lot in the end, they had the educational psychologist

207.S – from Oak Copse, they had their reports, you know

208.J - it was just horrendous I mean it made us feel awful

209.I - What, about how he actually was?

210.J – I mean this is my child and this is what he's done and it's written down, and respite care, at school and here and there

211.I - I suppose they had to do that in order to...

212.J - It was all true...the trouble was it was all true and we're sitting there and we're thinking, but it's worse when you're actually sitting there and have to read it in front of people

213.I -I know

214.S – the place that we took him to at the hospital

215.J – Oh, god (shuddering with remembrance)

216.S – it was horrendous

217.I - Yes

218.J – to have teeth out (laughs)

219.I - Oh dear

220.J – a nightmare

221.S – and we saw, we'd pre-warned them, if we could have gone straight into the hospital and then straight to the ward, but oh no, 'sit him on the bench'

222.I - In the waiting room?

223.J– Nick doesn't do waiting (laugh)

224.S – so we were sitting on the bench, all the glasses went

225.J – chaos, chaos (laughing)

226.S – there's no way we're gonna let him do that, you know, trying to keep him quiet and he's walking about and people are gawping and looking at us, and this went on for about a couple of hours and we finally got him up to the theatre to put him out and then there's two of us wrestling with him to hold him down and then they decided, the two doctors and the anaesthetist or whatever to have a chin wag and I had to say to them, 'please can you get on with it?'

227.J – cos it's just putting more stress on him

228.I - Yes

229.S – and he's kicking and fighting and they're saying, well they don't know

230.J – 'cos he's terrified of being held down or anything being done to him anyway 'cos he doesn't know so we just thought that the quicker they get the needle into him he'll be out and then.....

231.I - Yes

232.S - But then there are other times that we always remember that have been

233.I - Lovely times?

234.S - Yes, that we'll always remember

235.J – oh yes, we've had laughs

236.S – we've had laughs, we've had to laugh at some of the things, my mates always said if he burns the house down, it's only Nick

237.I -So you're accepting, 'cos that's him isn't it?

238.S – yes. I always remember this old boy down at the football club, 'cos I used to take Nick down some times and he always wanted to buy a bag of nuts

239.I - Oh yes

240.S – and he'd push one of the nuts over to Nick, and Nick would push it back and this would go on all dinner time, and it did keep him quiet, and then he'd eat one, Nick, and then he'd push another one to him, and we'd laugh at him, but you know ...(laughs)

241.J – and we used to go on the beach with him, because he loves the sea, he's got a way of walking along the shore, but he only likes going one way. They've just found that out at Ash House I think (laughing)

242.I - Walking to Skegness! (laughing)

243.J - He won't turn round and you want to try and get him off but for some reason he wants to go the same way, he wants to keep going and going and there's always one of us running and one with the other kids and oh ...

244.I - Like you say, good memories as well

245.J -oh yes, we've had laughs, it was quite funny at the time

246.I - So, I think you have said a little about the early days when Nick was at Ash House, is there anything more that you can remember about that, you've said about when you first dropped him off but were there days when it seemed different?

247.S - ...so peaceful, and you could live a normal life

248.J – but I think she's talking about when Nick first went away

249.I - Yes, but when he first went away 'cos it might be different now, you've probably got a bit more used to it now

250.J – well I remember when we went to the beach on our own, I think we'd been to see Nick and we went to the beach on our own and we sat on the beach and we said, 'this isn't right' it's just because it was just the two of us and we didn't have to hair around we just felt completely and totally lost, didn't we?

251.S – I mean you'd see that taking him on holiday wasn't really a holiday with three young kids

252.J – and Nick as well

253.S – and Nick as well, it was just all systems go...we couldn't do it now because of our age, we could not do what we used to do I mean when he went to sleep everyone went to sleep, to catch up with him, 'he's recharging, quick'

254.J – which is normal with children but that went on for a long, long time, (laughing)

- 255.I -Yes, yes, and how do you feel about your decision now – for him to go to Ash House? Maybe I should clarify, did you put him into care and social services take some responsibility for him or did you maintain full responsibility for him?
- 256.S – he had a social worker
- 257.I -Yes, but were you still fully responsible for him?
- 258.J– yeah, obviously the care belongs to them, but
- 259.I-Yes, because I know some of the families have a different arrangement. Yes, parental responsibility and all of that
- 260.J – yes, we still ...and go to all of the meetings
- 261.I - Sure, so how do you feel about your decision to say yes for him to go there and to fight for him to go there?
- 262.J – we're so glad he went there aren't we?
- 263.S - yes
- 264.J – 'cos I don't think he could have gone anywhere better. We really think Ash House have done a fantastic job with him
- 265.S – You had a feeling about Ash House
- 266.J – I had a feeling about Ash House but then I had a feeling that Nick liked it so that was part of the...
- 267.S – I mean....there's another home in (south west) but we didn't really bother to go it, we didn't want him to go to (south west) 'cos how could you get to (south west) and back in a day?
- 268.I - Yes, for a visit or if there was an emergency I suppose
- 269.S – I mean he'd have just got left and as the years gone by...and nobody seeing him, and it's a horrible thought that we've got now, that when we're gone I don't know who'll go
- 270.J - we don't want to put the responsibility onto the kids you know
- 271.S – I don't think they'll go, but, you never know, Ruth might force Thomas (Nick's siblings) to go once every 6 months or whatever... but I don't know
- 272.I - Right
- 273.S – but then Nick, erm..., will he realise?
- 274.J – that's another thing, we're not going to be around for ever anyway, so I suppose it's better that we did it that time, well it was forced on us at that time really, but we knew we couldn't look after him for ever, you know, we're going to be too old, I was forty when I had Nick so, we're not young parents and obviously Nick, under normal circumstances, is going to outlive us by a long way so he was going to have to go into somewhere eventually, so I suppose it's better when he's younger and I suppose they've done a lot more with him there than I could ever have done at home
- 275.I - So what changes have you noticed since he's been there?
- 276.J - He does do bits for himself, he tries to do bits for himself, he seems to have a bit more understanding, and they manage to cut his hair and cut his toenails and he shaves himself and, which he

didn't need to do before he went, but he does now, he shaves himself and he cleans his teeth and I think they have to help him with all of that

277.I -Yes, yes,

278.J - But he seems more content, he seemed a lot more content, after he's been there for a while. I think the first two or three months were a bit dodgy, weren't they? We had quite a lot of wreckage and things

279.S - But they're prepared for that aren't they, that's the thing

280.J - Yes, but once he'd settled down he seemed a lot calmer in himself and ...yeah

281.S – but then again he'd always have his tantrum or whatever you wanna call it and kick off

282.J- don't know what to call em do you?

283.S – and it...last two visits when he, but we've brought him home so that could be

284.J – I was explaining...

285.I - Yeah

286.J - We'll never know

287.I - No

288.J - We'll never know a lot of things (*laughs*)

289.S – hopefully the next time they'll bring him down and then we'll see what happens

290.I - Yes

291.S – it might be that he can't come anymore, you know, I mean...

292.I - Is that something you think about?

293.S – well, we're open to suggestions, you know, and the best plan of attack

294.J – well we were saying weren't we, can't.....twice it had happened and twice it was horrendous and we were saying well perhaps we'll have to go and visit him

295.I - Yes

296.J - But then that's going to be different for Nick and that could be a total disaster...'cos when he sees us he just expects to come home and he just sees the next thing, and the last time we spoke to the social worker she said maybe we should try having him home again but that they'd bring him home, which was the case,

297.S - the social worker we've got is brilliant

298.I - Oh that's good

299.S – she really knows her stuff and she's helping us with some forms and this that and the other and you can't knock her, very professional, and a nice woman, but the one before, and that was the girl who was saying to me, he can't go into the home

300.J – he can't go into the home or anything

- 301.S – ‘cos she’d been told that by her superiors
- 302.J – it all came down to money in the end but in the end there were so many people who were saying that we couldn’t cope with him, I mean we just couldn’t cope with him
- 303.S – I mean my mate, and sort of people we know, turned round and said, ‘how you cope with that, I don’t know?’
- 304.I - I know
- 305.S - my brother in law said, ‘Stuart, how you...’
- 306.I** - So you knew...you knew you weren’t giving in, giving in easily?
- 307.S –(laughing) no we had a fair stab at it....
- 308.I - Yes, it sounds like it. Just thinking about Ash House, what particular things do you like about it, I know you’ve already said somethings....
- 309.S – family atmosphere, as soon as you come in you’re taken in and everyone speaks to you
- 310.J – yeah, family, they look after us as well as looking after Nick when we go there. I couldn’t say that there’s one person there who you couldn’t say isn’t a part of your family, so they give us that feeling and the way they talk about Nick, is, they all adore him
- 311.I - Right
- 312.J - And I think they all adore all of them, you know
- 313.I - Yes
- 314.J – they all miss him now he’s gone into a different section of Ash House, they say, ‘ah we miss Nick we try and look through the fence for him,’ and they absolutely seem to miss him and adore him, you know, even the ones who don’t see him very often
- 315.I - Yes, so how does that make you feel then?
- 316.J – oh, it’s such a relief, to feel that he’s loved almost as much...
- 317.I - Cos you were saying that you didn’t think anyone would love him like you
- 318.J – Well, I do think that they do love him in their own way
- 319.I - Yes
- 320.J – well it may be a bit different from a mother’s love, but they do seem to adore him and do the very best they can for him
- 321.I - Yes, Is there anything else you’d want to comment on, say the learning programmes they have...
- 322.J – well we never really see the learning, we don’t go into the...
- 323.I - Well I suppose at the review you hear a bit about it...
- 324.J – yes and they say he’s doing really well and they got a fantastic Ofsted report when he was in the school, but now he’s not in the school as such (in the post 19 area)
- 325.I - Yes, do they still do life skills?

326.J - Yes, they do life skills, they take them out and he does cooking and cleaning

327.S – he's supposed to be going horse riding, which he did when he was at Oak Copse, and apparently, this coloured lad, well he's left now, his mum took him out, which I think is a great shame

328.I - Oh right, I might know who you mean

329.S – and she's regretting that now

330.J – well we don't know that

331.S – we've heard, according to the carers

I- Oh right

332.J – but they got on really well

333.I - But you're relieved that you've kept him there?

334.S/J - oh yes

335.J – I don't think we could have him back now

336.S – we have him, we have him for a weekend, on Sunday when he goes out the door

337.J – we're exhausted

338.S – he gets in the van and we both look at each other

339.I - Yes

340.S – and the house is like a

341.J – like a bomb site

342.S – and we say, let's leave it until Monday

343.I - Yes, what about things like communication with Ash House? Are you happy with how that works?

344.J – we don't hear a lot from them unless something serious happens

345.I - Ok

346.J – but when we do see them they always have a lot...and when they bring him here to drop him off and that we always have a good chat and that

347.I - Ok

348.J – they usually have us in fits about something, strange things that he's said,

349.I - Yes

350.J – he doesn't really even speak hardly but he does come out with some things that seem to be quite sort of (laughs) normal, evidently he was, one of the other boys kicked off and they were all running round trying to sort him out and Nick put his hands on his hips and said, ' I think we need Sheila (the head)'

I- (Laughs), oh

351.J – and for a child that hardly speaks, he can speak I'm sure of it, but he just doesn't, you know, but he just comes out with these weird phrases every now and then and they always have us in fits don't they? These bits and pieces

352.S - ...he doesn't need to do it

353.J – if he doesn't need to speak he won't

354.S – I mean he'll get toast, drink, water, sausage roll

355.J – that he'll demand

356.S – yeah and then he'll bring that in and he'll bark something else and I'll go ok Nick I'll go and get that. So it's just all one word

357.I - For things that he needs? Yes, so, how would you describe your relationship with Nick now? Has it changed at all?

358.J - I adore Nick, I've always adored him, Nick, I mean I think the other two got left out quite a lot to be quite honest, Nick always needed me more.

359.I -Yes

360.L – I do think they lost out on quite a lot really when they were young, but I absolutely adore Nick and I don't really know how else to say it

361.I -Well, that's it

362.L – he is the most beautiful, he has got the most beautiful nature under normal circumstances, and he's happy isn't he?

363.I -What about yourself (to Stuart) do you think...?

364.S – well, apart from the last couple of weeks and the trouble we've had with him

365.J – well, you see...he seems to let me do more, although I can't ...but he seems to let me get nearer to him than Stuart can, when he's in one of his moods

366.I -Right

367.S – he'll come and sit on me, roll about and he'll want to be tickled and this and that, you know, but the last couple of weeks, it's taught me he's changed

368.I - Right

369.S – you know, it'd got to the stage where we'd say we're going and we'd say, Nick go to the toilet and he'd go into the toilet, sit on the toilet, take his trousers down and sometimes it was a success and this that and the other, er, you know, flush the toilet, come out and well

370.J – he hit you on the head in the toilet didn't he?

371.S- well, three weeks ago, he just growled at me and I got a cuff across the back of the head, and when he starts to growl....

372.J – I think I can keep my voice, even when I'm upset, I can keep my voice fairly level

373.I -Yes,

374.J- and I think Stuart's got quite a loud voice

375.I - Yes

376.J - well I don't know, does that mean, but I seem to be able to get a bit nearer to him although you don't get too near to Nick when he's going into a rage

377.I - Do you think it's as close, do you pick up where you left off?

378.J – yeah, he's just exactly the same when he comes here as when he went

379.I - Yes

380.J – well in fact he almost goes backwards when he's compared with what Ash House have taught him, not completely but he just reverts back to how he was when he was here

381.which doesn't bother me too much 'cos I know it's only a weekend 'cos he just sits solidly watching videos which I know they wouldn't allow, 'cos I know they only let him do so much

382.I - Yes

383.J - but he just reverts back to how he was here doesn't here, basically? He's just the same. Nick only wants you when he wants you anyway. I mean, if Nick thinks he wants to have a cuddle he'll come and have a cuddle I mean he still thinks he's a tiny baby I mean he just lands on you and tickle, tickle, tickle and baby I think he thinks he's a baby even though he's huge, I mean he's not tall, but he's big, you know, erm

384.I - Yes

385.J - But then when Nick has finished with that Nick'll go back to do what Nick wants, you don't instigate things with Nick

386.I – No

387.J - Cos if I go and sit in there (indicating other room) he'll go and push me out 'cos he always did. Everything is always on Nick's terms, which you get to accept over the years (laughs)

388.I - Yes, so in terms of the future, what are your hopes for him? I know you've mentioned about your fears...

389.S – well, we've always thought that we'll go to sleep one day and he'll wake up normal (tearful) haven't we...(out of the blue)

390.J – yes, I think we hope that he'll stay where he is 'cos we can't imagine anywhere better for him

391.S – yeah

392.J – and we're hoping the children will keep an eye on him

393.S – yes

394.J - 'cos it's a big responsibility isn't it?

395.I - Yes

396.S – I think in the summer they go for days out to the beach, quite regular you know, I mean the whole home gets into the van and off they go

397.I - Yes, I've been surprised at how often they take them off site

398.J – yes and some days Nick just refuses to go, for some reason, 'cos he loves the beach. But some days he just won't get in the van, and nobody knows why, but he'll go one day and won't go the next

399.S – and they take time to get them an ice cream or something

400.J- but if Nick decides he's not doing something then

401.I - I don't suppose they push him then

402.J – no, they don't push him

403.S – they say, and they're quite right, they say there's only going to be one winner, and that's Nick, and they're quite right, when he first went and they had to get him up the stairs, into the rooms, have you been to the...

404.I - Yes, yes, I know it

405.S – it was difficult

406.J- he used to take all his clothes off at the bottom of the stairs 'cos he know they couldn't take him up. He's got his own little sort of strategies

407.I - Yes

408.J – he's not silly

409.I - Not silly in that respect

410.J – no, he's not, he's quite cute actually, in his own way

411.S – Once you get to know Nick, a lot of people say he's not stupid

412.J – I know

413.S – and as Julie's pointed out, he only does what he has to do

414.I - And keeps the rest in really

415.S – yes, and he doesn't want to sort of learn or whatever I mean it's not that he's a.... he just doesn't understand

416.I - No, I suppose what he's doing is trying to keep his world as secure as possible for him by managing the things he does

417.J –yes

418.S – you'd think it could be a good point, it could not, we just do not know and I don't think anyone knows what autism is, or what causes it, do they? (a direct question) I mean are they any nearer knowing from when Nick was born or from kids before?

419.I - Well, they're finding out little bits more, I mean obviously I'm doing loads of research into it but there's still lots of Nick's coming forward and having lots of difficulties

420.J – One useful bit of information for me, was when I realized that for Nick, out of sight is out of mind if he can't see it,'cos I mean if a toy was broken and you'd try and mend it but you couldn't and he'd go

into a complete, oh, he'd go completely mad, but if I could manage to hide it, it was never ever thought about again

421.I - Yes I do think that that is one thing that they think, that everything is about the here and now

422.J - if you can't see it...

423.I - So you can't think ahead as to what might happen

424.J - but I did find out that if I hid things that didn't work there was nothing to worry about but that took a long time to work that out as well

425.I - Is there anything that we haven't talked about that you think is important that you want to tell me, or ask or...

426.J- I don't really know what you want to know

427.I - No, well you've told me lots and lots, so don't think that....

428.J - well, he can be very funny, but then probably not to him but to us, I mean the things that he'll come out with when he hardly speaks and you don't know whether it's something that he's just heard or something that seems to be the right thing for the right time (laughs), I just don't know

429.I - Ok

430.L - He's just the happiest child, basically, he's happier than the other two, isn't he, I suppose he hasn't got the responsibilities of the other two

431.S – and when things are going well for him at Ash House and he's happy, he's got the life of old riley, hasn't he

432.I - Yes

433.S- there's no doubt about that I mean you think to yourself, I wouldn't mind that (Laughs)

434.J– I do worry that the education stops I know as you say he's still doing life skills, but these kids, they really need to continue

435.I - They need a lot longer to learn don't they?

436.J – Yes they need more than a normal kid, they need to keep at it all the time

437.I - Yes, that's a good point and I guess that's to do with funding in education when they suddenly say...that's it,

438.J - but Nick isn't 19, not mentally

439.I - No, no, so they could look at that. And just, how have you found the interview, you can be honest

440.J – just like a good chat really (laughing)

441.I - Well, that's what I was hoping it to be, but has it been ok talking about things

442.J – oh, I'd rather talk about things that worry me, anything that worries me, I'd rather talk about it anyway, 'cos I don't think you always get the opportunity to talk 'cos when you've started to talk...

443.I - Well, you've done well. You've done my hour which is what I needed

444.J - I just feel sorry for people (laughs)

445. After formal interview had finished, and the tape was switched off, they began to talk again. The following is as close to what I can remember, written immediately after the interview – but it is not verbatim.

446.J – we didn't know if he would miss us when he went – he didn't seem to miss us

447.S - we try to accept it – we haven't really yet – we never will. We still go to bed and hope that we'll wake up in the morning and he'll be alright – but we know it will never happen,

448. We still beat ourselves up over it, blame ourselves, could we have done anything different – but nobody knows with autism do they?

449. Some comments about the broad spectrum of autism

450.S – we never knew Nick was severe, not for years. We get annoyed when we see things like Rainman, they think they're all like that , but Nick isn't.

Appendix 10: Original Transcript

3 - Lesley

(Key: I-Interviewer, L-Lesley)

1. I - I'm interested in finding out more about your experiences of having a child, children, with autism at a residential school. So, tell me a little bit about both of your sons.
2. L - Well, they're identical, they were born with medical problems. Sam was born with volvulus, you know, a twisted gut, so it was actually gangrenous. They were both premature and Sam had an operation the morning he was born, he wouldn't have survived otherwise. Ben had a bowel blockage as well but they managed to dislodge that, it wasn't as advanced as Sam's so they managed to dislodge it before it got to that point because he'd been born so they could do something about it, whereas with Sam, they couldn't, although it was identified before he was born, there wasn't much they could actually do until he was actually born and of course all of this took place at (specialist hospital 60 miles away), so when the boys were born, they were born by caesarean section because that was the safest way to deliver them, because of their difficulties and they took them away straight away, both of them went down to (specialist hospital) and I didn't see them and I didn't feel as if I'd had a baby
3. I - Oh right, so were you living here?
4. L - (laughs) yes, (description of hospital location)
5. I - So, you had them there, and then they were taken away. Had you seen them?
6. L - Briefly, but it was in a haze of pethidine so I don't really (laughing) remember them that morning because I was really sort of out of it. I remember a leg and a hand, that I touched, I think, but that's it. But of course they took polaroids so that I'd have them, to see them and look at them, to reassure myself that I'd had them
7. I - So was it a while before you were well enough to go and see them?
8. L - I went down at the end of the week, to see them, straight down to (the hospital) they were down for 2 weeks they were, so we were down there for 2 weeks before we came back up here, to, do they call it neonatal? They were there for 3 weeks and eventually we all came home, so it was nice to be home
9. I - Right and at that time were you just aware of the medical....obviously they were very young
10. L - Oh yes, I started to get uneasy when it got to the point about 15 months, I started to feel uneasy because I wasn't hearing, I was hearing sounds, that sounded like words, but no words at all. They actually passed their 18 month check, the health visitor passed them which I was amazed as I thought they needed a fair few words but she said, 'well they're premature, they're boys, they're twins, they'll be slow', but I mean I thought...
11. I - But you were starting to be concerned?
12. L - I felt that there was something wrong, you know, but anyway, I brushed it aside, but oddly enough it was only when my sister said, she said, 'they don't look at you any more', and then I knew, I knew straight away it was autism
13. I - Did you, what, why did you think that?
14. L - No eye contact, there was no eye contact anymore, and they were fairly quiet, withdrawn, and I knew, no speech, no eye contact, withdrawn, I just knew it was autism.

15. I - When your sister said they don't look at you anymore, had they looked at you before?
16. L - Oh yes, they used to follow me around the room
17. I - So it was a kind of regression?
18. L - Oh yes
19. I - How old were they then?
20. L - About 2
21. I - Can you remember that time, and how you were feeling?
22. L - Distraught I think (laughing) cos although I knew, Martin (husband) knew as well I think, although we both tried to sort of erm, put it aside sort of thing, until a professional rubber stamps it, you've always got hope haven't you, that you're wrong, but we both knew that we were right, but we had to wait until they were 3 to be diagnosed
23. I - Even though that's what you were saying?
24. L - I know (laughing) I couldn't believe it
25. I - That's because different professionals had to see them together?
26. L - Well they had to be diagnosed at the CDC (Child Development Centre) and that's not what the system is now, but then you had to wait for an appointment, you had to have an appointment at the child development centre and it was the doctors there, the paediatricians there that actually diagnosed autism, but we didn't wait that long, we knew it was autism so we employed a private speech therapist to come in and work with them cos to wait a year, that's a long time in a child's life, so that's what we did and when they were actually diagnosed we actually got a bit of help then cos the NHS speech therapist would come, not very often, but at least she was involved
27. I - Right, so you had that support then?
28. L - Yes, and that's the only support we had (laughs ironically)
29. I - Was it?
30. L - Yes, (laughs) nothing else and then the NHS speech therapy dwindled, to practically to nothing
31. I - Did they go into a nursery or a school?
32. L - No. I took them along to a nursery, the university there, it used to be the college and they used to have a crèche there and I took them along there, it was mainly for students but they took outsiders and it was ideal cos they had 2 classrooms, with about 8 children in each, and if I took them on particular days, I think they went twice a week, 2 mornings a week, there would only be about 4 children in each room, which was good, because I noticed then they didn't like to be with a lot of people, they didn't like a lot of noise, you know a lot of stuff going on around them, you know that would upset them, I mean I remember one incident, in fact two, one of them, we put them to bed, and we thought, 'that's it now, they're asleep', cos my sister and my husband came round, and they came down and they suddenly saw this room full of people and they just freaked. They were so distressed they vomited everywhere, absolutely everywhere, I just couldn't believe it and they did the same sort of thing when my sister was having a sort of party at their house, just for family, nobody else, just family and we went there and it was the same thing, walked into a room, a crowded room, lots of people talking, lots of people moving around and they just...

33. I - Right

34. L - So we stopped going out at that point, we felt, for the sake of them, cos it was actually causing them a lot of anxiety

35. I - So it would have put quite an impact on your social life?

36. L - Yes, it actually makes you quite isolated

37. I - Yes, if you feel you can't go out places

38. L - Yes because we didn't attend any other family functions, I didn't go to one of my sister's weddings

I- Didn't you?

39. L -No, I couldn't go, I just couldn't go, I couldn't leave them with a member of the family cos they were all at the wedding, so we just didn't go, I mean at the end of the day they came first which they still do of course, but at that point any thing, decisions that we made it was, 'how's it going to affect the boys?' erm, and that's just what we did and in the end we just ended up staying here (laughing) not going anywhere, occasionally people would drop around but you had to say, not too many, not all at once. Christmas is a terrible time, Christmas is always a terrible time, I hate Christmas cos you can't have decorations up or anything cos they tear them all down. We used to have a Christmas tree and they'd just pull it down

40. I - Because it's not what they expect?

41. L - Yes, and they don't like all the, all the variety that goes on at that time of year, they just can't cope with it. So I have to say to people, 'don't all come at once, stagger it, don't stay for very long', you know, all that kind of thing, which you know, cuts all the joy out of it you know

42. I - Yes, it's a big impact isn't it

43. L - Yes, you know, they don't do very well at Christmas, but can't avoid it (laughs)

44. I - Was there any difference in those early days in how you felt about things and how your husband felt about things, as far as you know?

45. L - No, we worked quite well together actually, you know we always discussed everything, before we actually did anything. We thought the most important thing for em, even then, we felt the most important thing for them was to stick to the same thing, so what ever we were doing, we were doing the same, you know, to be consistent, you know because we saw that at that early stage, that seemed to pacify them you know so we had to do everything the same all the time, I mean you couldn't vary anything

46. I - So quite a lot of accommodation?

47. L - Oh yes, we arranged all the furniture so it was all around the room and nothing in the middle so they didn't have to negotiate anything and we changed all the décor, so all the walls were plain cos we used to have floral paper (laughs) I can't believe it but we changed all that cos we thought the least amount you know the less busy the environment, visually, the better it was for them, cos I read Donna Williams book, and she actually says things like that in it so we thought, 'well we'll put that to use' and it helps

48. I - Seems to...

49. L - It helps

50. I - You've told me a little bit, but could you tell me a bit more about the experiences they had in their schools, before they went to Ash House
51. L - Well, the first year they were there, at Noah's Ark, they started there when they were five, they actually did quite well, it was a very small school then, they only had about 40 children, their class consisted of 6, they had a very good teacher, a very good teacher. Course it all changed the following year, the school suddenly doubled in size, the teacher left to become deputy head somewhere so she wasn't in the classroom, so there was a lot of change, the size of the school, more children in the class, and it kind of threw them, they totally, totally regressed, it took a couple of years for them to come up again, and then they hit puberty, started to hit puberty, err, sort of thing and it regressed again (laugh), so it was just a disaster really. They didn't get much support in school, there was no speech therapist, you was lucky if you got a speech therapist in once every couple of months. What they would tend to do is they would come in, work with the staff, who would then work with the children, so you were sort of getting speech therapy but through a third party, the teacher, rather than the speech therapist, which I mean as hard working as the staff were, working with the children, and they were quite committed to the children, they're not speech therapists, they can't pick up on little things and push them a bit if they spot something, they were learning support assistants, which you know...
52. I - Yes, so you didn't feel very satisfied? Or confident?
53. L - No, I could see it wasn't working, it wasn't working at all. They were having no OT whatsoever, you know, Occupational Therapists won't work with autistic children in this county, certainly not in special schools, I don't know whether they work with autistic children in mainstream schools, that might be different because I've noticed that autistic children in mainstream schools get more speech therapy than they do in special schools, so no OT, next to nothing speech and language therapy, no clinical psychology input and that was the state of affairs
54. I - Right, right
55. L - it was pretty poor
56. I - Difficult. So when did you start thinking about a residential placement, or were you thinking about it during that time?
57. L - No I wasn't. I was never thinking ... I never thought that, because I always thought that the boys could stay at home, you know, for as long as possible and that we'd get the help we needed, but it was never coming, you know, no matter how many letters we wrote or
58. I - Did you feel you needed help at home as well as school?
59. L - Well we didn't get any respite, there was no respite cos I mean to begin with there was no respite for, at that time, for children under 8, with autism and after that, I don't know whether you've heard of them, the Thomsons that live on the road. They had a triple garage that they converted into a 2 bed bungalow and that was it, that was all they had, respite, and of course my boys never went there cos it wasn't the right environment. It was all open plan, there was no structure, it just wouldn't work, and I thought, 'no', cos to me, and to Martin, we always felt respite should work both ways, they should gain something from it, as well as giving us a break, erm, but it wasn't they were just like posted in front of the television or whatever, to watch dvds but they could do that at home, I don't need to put them there to do that.
60. I - So, what did make you consider residential?
61. L - When they hit puberty their behaviour deteriorated to such a degree, there was a lot more self-harming, there was a lot more physical aggression towards us around them, lots of destruction within the house, and we just felt, 'what is going to happen to these boys?' We're not getting any help, the school was in the middle of Ofsted, it had a terrible Ofsted, which then the authority decided to close it, so they were trying to find places for all these children that were there, in other

schools, and they couldn't find anywhere for Sam and Ben to go and they were the only two boys left in their class, so they were in a class with just each other, that was it, and I thought there was no social development whatsoever. How could there be? They weren't going out into the community anymore because of the behaviour so they were actually just confined to the school, occasionally they'd go on a bus ride around the town, and I thought, 'I don't want this, I want them to have an education, I want them to experience, you know, things in the community, be part of it, I don't want to send them somewhere just to be contained', sort of thing, so we looked around and fortunately a head that came there, she was only there a short time, a year probably, she left before Ofsted came in, she actually set up Ash House, and she told me about it so we thought well ok, but even then I didn't want them to go residential, you know, I wanted them to commute, but then we thought about it and we thought no, they're not going to cope with that, going backwards and forwards everyday, they just wouldn't, they need a 24 hour curriculum and that's when we got in touch with people, approached the authorities and said that's what we want to do and we asked for a reassessment of their needs, cos they'd changed, obviously, and the last assessment they had had was when they were 3

62. I - Oh right, and were they about 14 now?
63. L - 12, so it was a long time and they said no straightaway, we can't do that, so we went right ok, so went to a solicitor and we went from there
64. I - So you had to do a lot of it yourself?
65. L - The tribunal yes, we had 2 tribunals to get them in there. The first tribunal we had erm, and this is very rare, they never do this, they decided there and then, that day
66. I - Right, against you, you mean?
67. L - No no
68. I - Oh for you
69. L - And they advised the representative from the authority to issue the other twin, the other one, because you couldn't have a dual tribunal Ben had his first and she advised that Sam's statement should name Ash House as well and they said yes, ok, but they didn't and they forced us to go to another tribunal
70. I - Oh, I didn't know they could do that
71. L - Yes, so we had to do that. It was a terrible time.
72. I - So, can you remember the feelings you had at that time then?
73. L - Despair I think, whatever
74. I - Did it stretch over a period of time?
75. L - Yes, they had to wait 4 months and during that time also things go through your mind, 'Will we succeed? What will happen if we don't succeed? Do we have to end up going to the high court? How are we going to fund that?' you know, all those sorts of things and in the meantime the boys are suffering, it's all time, their time, they only have one chance and you know you've got to give em the best that you can.
76. I - Yes. So did you think about the emotional separation of them going?
77. L - Yes, but we thought we'll cross that bridge when we come to it, let's get this out of the way first, let's get them in first and we'll think about that afterwards you kind of stop yourself feeling that, I mean it's always there at the back of your mind, but it actually took priority, actually getting

them there, getting through this legal minefield and getting them in there and once we'd done that it kind of like hits you and then I didn't want them to go anymore

78. I -Right

79. L - (laughing) it was awful and my husband was saying 'don't be ridiculous' but I didn't want them to go, it was awful, especially the last week coming up to when they were due to go, it was a horrible time for me, I just wept and wept and when I left them at Ash House I wept, but it didn't last long, it was funny because I only felt like that for about 2 weeks, but then I could quickly see how happy they were and how different they were, just in the couple of weeks they'd been there

80. I -So how different were they? What did you see that made you think they'd changed?

81. L -There was a sparkle, they were actually enjoying being there, which was never before because they never had anything for them to do. But at Ash House they have an ethos of, they take them out all the time, don't they, and obviously that's what they needed. The staff are obviously very good with them, they give them lots of support. I remember the first day they started there, the speech therapist and the educational psychologist were in the classroom that morning, they were ready to receive them and to start working with them, and I thought that was brilliant

82. I - So I expect you felt more confidence, and confidence in what they were doing?

83. L -Yes

84. I -And do they come home.....? What's their pattern of coming home?

85. L - They come home every weekend

86. I - And that's always been the pattern has it?

87. L -Yes, I think that's their clock, they know when it's the end of the week

88. I - And how do they cope with that change then ?

89. L - It's a bit difficult to start with. The Friday evening's always a bit difficult cos of the transition, same as it is when they get back on the Sunday night I should think, it must be difficult there as well cos there's one thing I know for certain about the boys and I'd bet the house on it they're not the type of children who'd behave in one way in one environment and in another way in another. They're the same, so if they're badly behaved here, because of the thing, whatever is causing it, it will be the same wherever they are, they're exactly the same, their behaviour is the same cos I know some parents say, 'oh he doesn't do that here' or 'he doesn't do that there', they do, it's the same. I don't know whether that's a good thing or a bad thing, if it means they're comfortable doing it (laugh)

90. I - Did you worry at all about how they'd cope with the change?

91. L - Yes

92. I - Yes, what sorts of things were you....

93. L - I just thought, 'my god if they're not happy there, if they're so terribly unhappy there and distressed, what are we going to do?' Cos there was no school for them here, it had closed down. They'd been at home from Christmas until May, when they started at Ash House and I thought, 'I don't want to go through that again'. It was awful I mean I love em to bits but I was stuck in the house 24 hours a day with them, no respite, no school for them to go to, I was just at the end of my tether, I really was I mean I love em to bits but I thought, 'this is killing me'

94. I - Yes

95. L - I mean, the house went to pot, I couldn't tidy it or do anything in it, it was a real mess, in fact that was the first thing I did, that's how I actually dealt with them being away, I redecorated the whole house
96. I - Did you, like a focus?
97. L - Yes, the entire house, I felt like I had to distract myself
98. I - Well yes, if you'd had them with you 24/7 and then you hadn't it would have been....
99. L - It felt like a loss actually, I don't know whether that's the right thing to say
- 100.I - Yes, people have said they experience it like that. So how old were they when they did go to Ash House?
- 101.L - 14, they were 14, so it was 2 years to get them in there
- 102.I - Right so how do you feel about the decision now, would you change it or do anything different?
- 103.L- No. I wish I'd have done it earlier
- 104.I - Right
- 105.L - I wish I'd done it earlier, I'd always been, I'd always resisted anything residential, because I'd always worried, 'would they be happy, would they be safe?' But now I've seen the progress they've made and I thought well if they'd had em earlier, could they have made more progress? You do wonder don't you?
- 106.I - Well yes you do, but it's unknown I suppose. I think you've alluded to this already, but you might want to add something, about what affect the boys being at Ash House has had on you personally or on your family life.
- 107.L - Well, I've read a lot
- 108.I - Have you?
- 109.L** - I never had, well, I read a Donna Williams book, but I never had much time for reading or for doing anything because I had two boys with severe difficulties, you know. Even when they were at school I was getting things ready at home for them, I mean that sort of thing, so I never had time to actually read or do anything like that so one of the things we did once I'd got the house sorted out was started attending conferences about autism
- 110.I - Oh yes, to try to find out?
- 111.L - Yes, I decided it wasn't going to happen again, I wasn't going to listen to people who thought they knew it but actually didn't. I was going to empower myself, if you like, with knowledge about autism and how that affected my boys, because I felt that, they're all different aren't they? Every single one of them is different
- 112.I - Yes
- 113.L** - And I felt that because they knew one or two of them they felt that they were an authority on all of them, but they're not. You can't treat them all the same
- 114.I - When you're saying 'they' who are you meaning?

115.L -Local authorities, even the staff at the school, they treated them all the same. I mean we had a.... when the boys were at Noah's Ark because the speech wasn't coming and because they had no means of, no functional means of communication, they were trying to sign with them or use Rebus or Makaton symbols, which weren't working, you know, but we'd been using them, or trying to use them for about 3 years by that point and they had never worked and we thought if they were going to work they would have worked by now, but I mean signing is linguistic isn't it and it's for people who can....and they're not they're concrete learners and they're very literal so you can't do that with them and we had this argument with the school and we said. 'you'll have to find something else' and in the end we looked at PECS and we read up about it and we thought let's try it for now and the school wouldn't let em do it. The school, said, 'no, we're not going to use that, this is what we use here.' but I said, 'yes but it's not working so you've got to try something else'. And we had to fight them and in the end we had to bring the authority in and they had to like force them to try it and then it was like odd cos by the end of the 6 months the whole school was using it and like, you know, a lot of the time we felt like we were fighting other people's battles, not just our kind of ones, you know

116.I - And then you started going to conferences?

117.L -Yes, cos I thought we're just gonna, we're gonna read up about it, find out as much as we can about it, and we're gonna see how it affects the boys and any means we go to and then any people we come across who say this is what he does and this is what he should be doing, we can say whether we agree with it or not, and we'll know, but before, we, you put your faith in em, you believe in them

118.I -Well yes, they're the experts, or that's what you're led to believe (laugh)

119.L - But they're not always right, they're not always right and this is the thing, and a lot of the time they don't like to be criticised, which is understandable cos if I was a professional I'd think, well I wouldn't like that either, probably, but on the other hand you should have an open mind when it comes to these children because they are quite complex. It's not like a child with like, dyslexia, where it's cut and dry, or whatever, the autism is made up of so many different things

120.I - And with your boys they've got additional difficulties as well

121.L - Yes, I think that that's what autism is, I think it's a mixture of all these things, thrown together and the reason that they're all so different is cos they've got different things in the pot, if you like. I think Donna Williams describes it as a fruit salad and you have to identify each piece of fruit and work on each piece of fruit and I think she's absolutely right there cos they are all so different.

122.I - Yes, so do you feel more empowered now?

123.L -Yes

124.I - Because of the knowledge that you've gained?

125.L - Yes, yes, I think that's their problem, and it's probably true of the majority of them, is sensory based, everything, I mean if you look at the triad, I always wondered, even behaviours, you diagnose by behaviours

126.I - You observe

127.L - You don't get a blood test or anything, but behaviours are functional, and what causes them? If you look further down and I've looked at some of the research that Markman has done in Switzerland and it makes so much sense to me, the problems that they have and it affects and cuts across communication and it cuts across the social, the behaviours they have to do to cope with what's going on

128.I - And that makes sense?

129.L - It all makes so much sense and I know that Sam and Ben have a terrible problem with noise and vision and tactile and clothes. I know they're quite sensitive to taste, and although they're hyper in the other ones, they're actually hypo in taste because they have pica

130.I - Ok, so they'll eat anything and you have to watch that all the time?

131.L - Yes

I- So, you were telling me what changes them being at Ash House had brought to your own life, as you've had more time, by the sounds of it and perhaps had the energy and the motivation to find out more and has it had any impact on your involvement with the community or your social life, has it given you time to ...or perhaps you've not wanted to...

132.L -Yes, I mean you go out a bit more, see your family a bit more, I've got quite a lot of family so I'm able to see them a lot more than I used to, and some friends we used to have, there's a quiz night down the road we go to once a month and we couldn't do any of those things, so we've been able to have a social life again. So obviously you don't do anything at the weekend cos of the boys, but anything that we want to do we do in the week, the weekends belong to the boys

133.I - Do they come home for the main holidays, for Christmas?

134.L - Yes, they come home for Christmas

135.I - You said a little bit about the changes, what changes you noticed in the boys as soon as they went to Ash House, have you noticed any changes in them over the years? Is it mainly the progress....

136.L - Mainly the progress, but there's been a little bit, a tiny bit of regression, because of the transition into the adult facility, but that's what we expected anyway, cos you can't do anything like that without being put back a little bit

137.I - No

138.L - But hopefully that will...

139.I - That will settle?

140.L - That will settle, it's only been this summer hasn't it and it does take them a long time to...I mean initially everything went perfectly, but that was the honeymoon, we called that the honeymoon period

141.I - But now they know it's everyday...

142.L - I call it the shell shock period (laughing) cos it's like, it's all gone in but they haven't processed anything yet and once they've done that...

143.I - I mean, haven't they tried to keep some of the same staff?

144.L - They have but its different, the timetable is different

145.I - Cos there's no education?

146.L - The timetable is different, the living accommodation is different

147.I - So, what do you like about how Ash House works?

148.L - I like their attitude that these children can do anything if you give them the chance. I like the fact that they have high expectations of them, which I felt where they were before, they didn't, I like the fact that they take them out places, which is what they need, otherwise, how do they become confident going out into the community. I think the staff are lovely, they're really committed to the children, they care about them, I don't know if that's because it's a small school or whether they would be anyway, whether you'd get that in a bigger residential place like (another provision), for instance, I don't know. It's like a family, which is nice, the boys are always clean, you know, I can't fault their care of the boys, you know, the boys can have virtually anything they want, so I think it's that combination of going out a lot, high expectations, not too high cos of course you don't want to overdo it, cos it would be just too challenging, but the fact they keep trying, you can take them somewhere and they might not like it the first time, or they might not know that they like it, so you have to take them 2 or 3 times, and if you get the same reaction 2 or 3 times you know they don't wanna do it but you have to give them that opportunity and if they're not going to like it, then it all filters through and they think, 'I enjoyed that'

149.I - And you feel that Ash House gives that opportunity?

150.L - Yes, yes, I mean they ride in the mini bus, go bowling I think that's going to start again soon, I hope, all those sorts of things.

151.I - Is there anything that you think they could do differently? Or any different types of programmes or facilities?

152.L - Work experience I think, which they haven't got at the moment. They had it when they were in school, but not at them moment, which is a shame because they could do with a vocation, going somewhere to do something, actually going somewhere to do something, rather than doing it on the premises, that sort of thing. I think that's something they're looking into

153.I - What about communication - how do you find that?

154.L - Funny you should say that, because I didn't realise that this was going to happen, but when they actually moved into the cottage, they removed the visual structures, so all the visual structures they had in school, didn't get crossed over and I think the speech therapist was at fault there, there was no, because they have no speech, they have no way of knowing what's now or next and they can't communicate and there was nothing on the walls, no schedules or anything

155.I - Would they use a schedule if there'd been one?

156.L - A very, very simple one with 2 or 3 things on it, they'd not even understand that. They use tokens, the cut outs, so they would use those to request and they'd put those on the folders, but there was none of that, erm and I don't know whether the managers felt that cos they were adults now....and I had this out with them, and I had to say about it, cos it had started affecting their behaviour because they want predictability and routine, mostly they want predictability, they want to know what's happening, that's what makes them anxious, not knowing, and I didn't think that that was there and I said, 'where are all the symbols?' And I had to ask 2 or 3 times and the speech therapist hadn't done nothing. It got to the point where one of the boys was starting to be affected by it and I had to say at that point, I thought I'd left it long enough, given them a chance to put it right, so now they're doing that, so, I mean they do need that, they do

157.I - Yes, yes, so how do you get to know about things?

158.L - It's just what I observe when I go in

159.I - But if you wanted to get in touch with Ash House, is that easy enough?

160.L - Oh yes I can ring or they ring me

161.I - So that sides ok is it

162.L - Oh yes, no problem

163.I - And the reviews that they have?

164.L - Just had one, last week. You have to have a 12 week review after a change of placement, this is the authorities review, about the placement, to see how it's going and these issues were discussed, so we'll have another one in 6 months time, and depending upon how well it's going, a bit like a statement,

165.I - Oh, yes, but I suppose it social care that have got...

166.L - Yes, if it's working alright then they just come every 12 months

167.I - Yes, so you're happy with that regime?

168.L - Oh yes

169.I - So, how would you describe your relationship now with the boys? Has it changed?

170.L - It's never changed, they're still my little boys, I always refer to them as my boys, but I mean they're adults now, only in law, but they're really children in an adult's body, just little boys in an adults body and they'll always be my babies, whatever age they are, and I just miss em, I miss them during the week, sometimes, don't laugh, sometimes I'm sitting here right, and I'm feeling, I'm really, really missing em and I just have to hold my breath

171.I -Because the feelings so strong?

172.L -- Yes, especially when they ring up and they tell you that one of them hasn't been very happy or been distressed or whatever, and I just wanna, I just wanna hold them, but I wouldn't be able to hold them even if they were here because they don't want me to do that, I mean you can't do that although sometimes you do try cos sometimes it's what they need is a good strong hug, a tight hug, but I just want to be able to do that but I can't because they're over there and I'm over here (becoming upset)

173.I - Yes, do you feel that there's any difference in how they perceive you, or their dad?

174.L - No, cos everytime we go, they've only got to see us there on school premises and they...

175.I - It's as if ...

176.L - Yes, they think that's the cue to go home, so when we go to these meetings we have to be careful to make sure that the boys aren't around, we have to sneak into the back or whatever cos if they see you they think, they take that as, they always have done, ever since they were little, they see you and it's time to go home

177.I - And if you try to delay that I guess they become agitated. So do they go back on Sunday nights? Do you take them back?

178.L - We take them back

179.L - Do they understand that they're going back?

180.Yes, I always tell em, cos their understanding of verbal language is miles better than their actual expressive language and communication and you can say, as long as you keep to simple words, concrete words and 3 or 4 at the most, then give 'em time to process the instruction, then they'll actually, you know, do as you say. Sometimes you only need one word and they know exactly what you want, like for instance I'll say, 'bath' and...

181.I - They know...

182.L - You don't need to say 'upstairs for bathtime', they just know by the one word

183.I - So if you say, 'Ash House' or 'car' or 'school'...

184.L - I always say 'school' because I think I'll confuse them if I say...

185.I - If you give it a name?

186.L - Yes, because it's the same place really for them, so I just say, 'school' and they know where it is they're going, sort of thing

187.I - And when they get there do they change over to that mode?

188.L - Yes, they go straight in and do whatever it is they're doing. You know, Ben sort of wanders around outside for a bit, cos he needs to do that before he can go in. Sam will go in and sit down on the sofa or whatever 'cos Sam, have you met them?

189.I - Not formally, but of course I've been at Ash House and I've seen them

190.L - Sam doesn't move around as much as Ben, Sam has an immature gait, so he finds it more difficult, because of his dyspraxia, finds it more difficult to engage his mind I suppose, what he has to do, it's too much of an effort for him and he has more severe Tourette's than Ben. Sam does a lot of phonic motor tics.....tics so he finds it difficult to move around a lot, whereas Ben has a few motor tics, mostly facial tics than he... vocal tics and but he jumps around a lot, Ben does, he's on the move a lot, he's very rarely sat down, he moves around a lot, that's the difference between them, but yes, they just go with their own things.

191.I - And what are your hopes for their future?

192.L - I never think that far ahead really

193.I - Oh right

194.L - For the moment I'm just hoping that this is gonna work out

195.I - Yes, its early days

196.L - Yes, and that's why any hint of a crack appearing, needs to be sorted, pounced on immediately and dealt with immediately, because if you leave it.....and if you leave it for other people to sort out then it doesn't get done, it's left you have to push for it, they're big lads now, we've wasted enough time I think

197.I - So just to ask how you've found the experience of talking with me today?

198.L - Ok, yeah, fine

199.I - Have you talked about it a lot to various people?

200.L - No, we didn't...that was one thing we probably should have done, we knew they were probably autistic from about 2, but we never discussed it with the family or anything, we never discussed it, we never said, 'cos one of the reasons was because we didn't know anything about it, we didn't know much, we knew it was autism, but we thought, 'well, what is autism?' And we thought, we're not prepared for all the questions, 'cos we don't know anything ourselves so we can't tell anybody else so we thought we'd leave it and we kept it amongst ourselves, everybody knew there was something wrong, it was obvious, but we didn't say what it actually was and it wasn't until

they got to school and they were actually 5 that we said, cos we could ask the school questions at the start, kind of thing and they were able to tell us kind of the basics

201.I - Did you not look into it, were you hesitant to look into it...?

202.L - We looked into it, we started looking into it afterwards, yes, because I was worried about their future, I wanted to know what would happen when they left school. I know it was far ahead but I wanted to find out 'cos I wanted to know what to work towards

203.I - Yes, I can see that

204.L - You know, what did we have to gear ourselves towards, and I wanted to see what other children were like as well and they started to go to school and I started talking to other mums whatever I found out, how different it was for each child, I mean when they went to Ash House we went to conferences. I went to the Lorna Wing one...

205.I - Oh did you?

206.L - Donna Williams, all that sort of people, and I thought, that's the best way to get knowledge people that really know about it and people that have children themselves, 'cos Lorna Wing has a daughter that's quite severe doesn't she? And she has two children with it, one of them's quite severe, the boy and the girl has Asperger's – both ends of the spectrum, so she knows what she's talking about really, so it was good to go to these, and Donna Williams who has it herself, so it was good to listen to these people who actually experienced it, you know, whether it was as a parent or as the individual themselves, or even as a professional, Donna Williams writes books and does research herself

207.I - So had you started talking to your family by then?

208.L - Oh yes

209.I - But initially you kept it...

210.L - Initially we couldn't because they were our own only children, and I felt we'd done something wrong, I felt like that to begin with, 'cos I thought was it something we'd done cos I didn't know what autism actually was, I knew it was poor eye contact, poor speech and ... but that's as far as I knew, but I wanted to know more and I felt, 'had we done something wrong?' you know, so we were feeling really sort of low and devastated at the time, 'cos you have expectations don't you when children are born don't you and then suddenly all those expectations change, they're no longer like the normal ones, leave school, go to uni, get married or whatever, that's never going to be the case, so all your hopes had sort of tumbled down around your ears, so all you could hope for now was that they had all the help that they needed, that they would be happy, safe, you know and actually have some purpose. I thought about this, that other people think the same way cos I thought at first that I was being horrible, thinking that I shouldn't be thinking like this, they're alive they're healthy, apart from....

211.I - And you thought you had lost the children...

212.L - I started feeling guilty, but later on I read that other parents felt the same

213.I - It's very common

214.L - It's the loss of the child that you thought you had, that you haven't got any more, kind of thing. Jim Sinclair (an author with Aspergers), have you read his...

215.I - Oh yes

216.L - Brilliant yes, that gave me some inspiration after I read that, god bless the bloke, that's one of my favourite writers

217.I - Yes and sometimes you can just connect with somebody and it helps

218.L - Yes

219.I -But what you're saying is common to lots of people I'm interviewing, so it's a common experience. So finally, is there anything important that you want to talk about, something that you thought I might ask you or that you want to tell me?

220.L -I just feel that the authorities don't have the best interests of the children in mind, I think that the only thing that they worry about is the budget and the funding. They don't, you have to fight for your child all the time when they were diagnosed I never in a million years thought I would have to fight as hard as that and all the time for every little thing for them, I mean it's their right, they have these difficulties and they have a right to be helped after all we're a compassionate society, but it doesn't feel like that and they don't make you feel like that, you know I think they should do more about the child and think more about the child and oddly enough children get a lot of support in comparison to adults

221.I - Yes, now you've seen the difference

222.L - Nothing, they get nothing, absolutely nothing which I think is a disgrace and I think they should do more. I think if children need a 24 hour curriculum, they should have one

223.I - From earlier than....

224.L - Yes, in fact there's no residential school in this county, at all

225.I - So you'd be an advocate of this would you, if it's right?

226.L - Yes I would because I've seen how it benefits them, they need it, it's as simple as that, I mean that was one of the things I had to overcome, my needs as opposed to their needs

227.I - Ok yes

228.I mean you just have to forget about your needs

229.I - That you'd miss them and you'd want them at home?

230.L - Yes, you have to think about what's best for them, Now I have a friend, and she has a son and he's 23 years old he's still at home and he has terrible, terrible problems and he's very severe, very complex, doesn't eat, hardly, sometimes doesn't drink for days, so they have to sort of have him in somewhere and he self-harms 'cos he's quite aggressive at times and she won't let him go to residential, whereas I think it would probably help him if you've got a load of people working around him together, consistently

231.I - And does she know about the experience you've had with your boys?

232.L - Yes, yes, but she won't do it because she says, 'how can I send him away, what would people say?' and I said, 'well, it doesn't matter what they say'

233.I - Is that something you worried about?

234.L - I thought that to begin with but you get to a pitch where it doesn't matter any more. It's like somebody dying of cancer, you get to the point where the pain is so bad you just wanna die. It's the same sort of thing, you get to a point right and you just can't do it any more and they're

suffering most of all and you have to do something about it, you know, I think 24 hour curriculums are essential for children with severe autism and they need that throughout the day.

235.I - Ok thank you

Appendix 10: Original Transcript

4. Paul

(Key: P – Paul, I – Interviewer)

1. P - He's 19 now, but autistic with severe learning difficulties,..... no communication, and up until recently, doubly incontinent, never harmed a fly, but harms himself
2. I - Right
3. P - Good looking boy, every body likes him
4. I - Is there a photo of him?
5. P - Yes, there
6. I - Oh yes
7. P - Very loving, loves contact, loves being around people....but doesn't know what to do when he's around them...you can see the frustration on his face. Yeah, he's not had the support he deserves, not from day one
8. I - Right
9. P - All the time he's lived with me, up until 3 years ago
10. I - Right
11. P - He just got too big to manage, I struggled, I could manage him, although it was disappointing with the diagnosis it devastates you, you never understand why, you're always looking for that answer, 'why'. In the beginning, he only hurt himself mildly, you could manage it, but when he approached puberty he went nuts, it must have been the hormones, or something
12. I - Yes
13. P - And he was just intent on hurting himself all the time, and that's when the medication started, and now it's just one endless battle to control his moods, to stop himself hurting himself
14. I - Right, ok, ok, well I'll ask you a few more questions as we go through, and feel free to join in (partner joined) don't feel excluded at all (to partner who has joined us)) . So when did you first have concerns about him, I know that's probably thinking back...
15. P - Well, his mum had them, I'm not with his mum now, I split up with his mum, when Connor was 10, but it would be around the 9-10 month age, cos he wouldn't play with toys properly, everything went to mouth and he had to lick everything, that was the first concern
16. I - Was he your first child because I know others say that they had nothing to compare with?
17. P - My first, but she had others. So he was in the system, very early, so although he was statemented at 3 years old, he had to wait until his third birthday to receive his statement
18. I - Right
19. P - The diagnosis had occurred long before
20. I - Ok, so you'd had a diagnosis of autism before then?
21. P - Long before then but they wouldn't officially say it was autism until his 3rd birthday

22. I - Ok, so was it you who first spotted these difficulties when he was little, or was it a health visitor...
23. P - No, it was her, my ex-wife, his mother
24. I - And then did you take it on to professionals, was it a health visitor?
25. P - No it was a consultant psychiatrist down at the hospital and over a period of months he had lots of tests to do with his hearing
26. Partner – didn't he have some dexterity tests?
27. P - He would, but he was young and he wouldn't know what to do, they observed him
28. I - Like pegs and things?
29. P - Yes he did but he was too young
30. I - Yes, ok, can you remember how you felt at that time?
31. P - Gutted, absolutely gutted, I knew something was wrong because he wouldn't say, the consultant wouldn't say
32. I -Right
33. P - They never said, they'd never say, 'don't worry, it'll be something he'll grow out of, it was always a case of, 'you'll have to come him back for more tests'
34. I - Oh, so that left you sort of not knowing? How were you feeling?
35. P - Devastated, more so than anybody
36. I - Why do you say that?
37. P - First born wasn't it? (distressed)
38. I - So that disappointment?
39. P -Mmmm, Yes
40. I -Now, you have mentioned about the diagnosis being given but is there anything else you want to say about that? Did you ever have it formally said?
41. P - When he was 3 years old. When he was 3... So he got a full statement and that statement opened up all the services, you know the services that deal with the spectrum
42. I - - Yes
43. P - The schools, play groups support groups and things like that
44. I - Oh yes
45. P - I was never interested in support groups or anything, but after we got his statement and he went to his first nursery at 4, which was Melrose House
46. I - Oh yes, I used to work there a long time ago, or go in there a long time ago, at least used to go in there regularly
47. P - He was abandoned there

48. I - Oh
49. P - Never had a social worker, never had nothing any of the contact with any professionals was driven by me or his mum
50. I - Was it? So things like annual reviews, did they occur?
51. P - They did occur, every year, yeah, annual review of the statement at the school and I attended every single one of them
52. I - Ok
53. P - And every single one of them, for the first 6 years, every single one of them, they said, the statement still applies and no changes
54. I - So did you feel that there wasn't any progress made, is that what you mean?
55. P - There was no progress made at all. The support.... The things that Connor needed, that he's getting or he's had for the last three years he needed from a very early age
56. I - Yes
57. P - And I think they should be offered rather than being pursued
58. I - Right
59. P - And that is the most frustrating thing about anything to do with autism, is the fact that you're abandoned and left to fight for yourself, rather than have access to these places, cos it's the intensive that they need and it has to follow a 24 hour clock, and be rigidly applied
60. I - And have that consistency?
61. P - Yes, and there's nothing there
62. I - I don't know whether it's awkward for me to ask you this now, but was there any difference between how you felt about things and how his mother felt about things?
63. P - I don't know, I didn't really know, I didn't really speak to her closely about how she felt
64. I - Ok The next question is to ask you about school before Ash House. You've told me about Melrose House, but that was just a nursery, did he go onto....
65. P - He went to Melrose when he was young and he enjoyed it and school was all the more bearable as well because he was picked up and transported from school and brought home
66. I - Then presumably he was at a special school was he?
67. P - Yes, from Melrose House he went onto Pendleton
68. I - Oh yes, yes
69. P - He was at Pendleton for a long time. From the age of 7 up to the age of 16, when he went to Ash House
70. Partner - yes, it was just before..
71. P - yes, the day before his 16th birthday, the schools, I always thought...

72. Partner– did the best that they could do
73. P - but they weren't specific to the autism, especially Pendleton, that had a, had a ...various degrees of disability, there was mild, moderate and severe in there
74. I - oh right
75. P - Connor was there for a long time before they even set up a specific autism unit
76. I - Oh right
77. P - He was probably, 12, was 12 by that time
78. Partner - That still weren't enough, Connor had learned to hit himself to get into the spa bath
79. P - yes he was...
80. Partner - the spa bath, so everyday he hit himself so that he could have that, cos he liked the water didn't he, he learned, didn't he?
81. P - All to do with Connor's schooling I felt it was to give him something to do with his day rather than to tackle his difficulties. I've always felt that
82. I - Sort of occupy him and keep him safe but not... move him on?
83. P - Yes, to give the parents a break, that sort of thing
84. I - Did you ever take advantage of the respite that they offered, the overnights, at Pendleton?
85. P - At Pendleton he had the occasional....
86. Partner– didn't he...once a month?
87. P - Once every 6 weeks he had time at the hostel there
88. I - Yes
89. Partner– Monday, Tuesday he used to stay there
90. P - Yes, something like that. Monday, Tuesday every six weeks, and then later on, when I got social services involved myself, they organized some respite where he went to RASP (a respite facility) for a week at a time
91. I - Oh yes
92. P - For a week every other week wasn't it?
93. Partner– yes
94. P - And that lasted about 6 months
95. I - So, tell me about that then, having to get social services back involved
96. P - It was just despair, it was just not knowing what to do next. With Connor it was, the personal experience that we had with Connor at that time was, he was doubly incontinent, he wasn't on any medication so his mood swings were high and low and flitting between the two quite quickly, and he was double incontinent which means, he made a lot of mess

97. I - Yes

98. P - The house was the proverbial... (laughs)

99. I - Yes

100.P - It was one Saturday morning, after the third time I'd been up to clean his room, after he'd...smeared

101.I - Mmm

102.P - It was 4 o'clock in the morning and I just said, 'I can't do this'

103.I -No

104.P - I rang social services up, but there was only an answer phone

105.I - Right

106.P - Saying a different number to call and then I just got on with it again but...pursued it, a few days later, initially it was to do with wanting some more respite, and then they sent a trainee social worker out so that's how we first got involved, with social services

107.I - So did they then help with the respite, was that their main thing was it?

108.P - No, (laughing) cos they tried to give us direct payments for us to sort out our own respite

109.I - Oh I see

110.Partner— she (**quite aggressive**) said that we had respite when he went to school –

111.P - Yes, that's what she said

112.Partner - which we didn't really want to hear...

113.I - No,

114.Partner - ...When you've been up all night and one thing and another

115.I - No

116.Partner - So then it got passed to the disabled children's team, didn't it?

117.P - After a couple of months

118.I - Cos you'd got your other family as well?

119.P - Everybody was suffering, these (indicating his daughters who had temporarily joined the couple on the sofa) couldn't have friends round, or have a proper nights sleep, everything was fractured

120.Partner – we were not functioning very well were we ?

121.P - No, sometimes, it varies, cos amongst all this he'd be happy as Larry, we'd all be like... (gesturing despair) and he'd be laughing his head off and having a great time

122.I - Yes, what sorts of things did he enjoy doing then?

123.P - Music, yes, he loves music,

124.Sibling – likes driving in the car

125.P - loves transport and water, they're his three main things, he loves water, so his baths, showers and swimming, he absolutely loves it

126.I - Right

127.Partner - you have to be careful though if you go out and about

128.I - In case he sees water?

129.Partner- if he sees water he will go to it

130.P - Tries to, anything to do with music, videos, bands, radio, TV, anything to do with music

131.Partner– he's always liked music

132.P - Rough and tumble, he likes rough and tumble patting, strokes, all that

133.I - Yes, ok

134.P -And you can see then that he enjoys it?

I- Oh yes, he taps you to do it again

135.Partner - we know if he wants to do something he takes your hand

136.I - So, when did you consider a residential placement as more of a full time occurrence?

137.P - When he was 15, when the hormones kicked in and all he was interested in was hitting himself

138.I - Right

139.P - He had two black eyes, a yellow bruised face, and every time we let him go he just tried to hit himself

140.I - Right

141.Partner– that was terrible, awful wasn't it – that was the worst bit wasn't it

142.P –Yes, (beginning to cry)

143.Partner - And the doctor gave him something, made him calmer

144.P - And that's when social services started taking us seriously, when he started doing that

145.I - Yes, yes, he'd be a threat to himself wouldn't he? So can you remember how you felt when you were sort of thinking about residential, when you were coming to that decision?

146.P - Yes, enough's enough is what I felt, as much as I loved himerm I started thinking of the others now

147.Partner - yes, you felt guilty, to a degree

148.P - Erm?...I was more matter of fact about having to do that than I'd ever been

149.I -As if it was...

150.P - Necessary now

151.I – Necessary...?

152.P - for him

153.I - Right

154.P - Erm I don't know why, obviously handing him over was difficult of course but I had no trouble over 'why'

155.I - You were convinced, maybe?

156.P - Yes

157.I - Did you think that you had any other alternative?

158.P - No, I always felt that he needed that,that everybody pulling in the same direction (crying)

159.I - Yes

160.P - I always felt, he needed, he deserved that chance

161.I - Yes

162.Partner– specialists

163.P - He was 15, all that stuff ended at 19, so I wanted him, to get some...to get....

164.I - Ok, stepping back a bit and thinking about the statutory assessment and how you took the steps to get to Ash House, because he would still have a statement would he at 16? So he would have to go through education. Tell me a little bit about that experience

165.P - It was ait was a battle

166.I - Ok

167.P - When I said, when I approached Pendleton and I spoke to the head master, Neil Brookes, he er..I bounced ideas off of him and he agreed and I didn't know how to approach it where to go, what to look at. I can't remember, who did I speak to? what was the first meeting? (referring back to partner for confirmation)

168.Partner – it was the CAMHS team

169.P - I stumbled across Ash House

170.I - Oh right

171.P - From the CAMHS team at Park Road because we were at crisis here

172.I - Dr Carling gets involved there

173.P - Yes, and they come into the house to set up some routines so that we could tackle some of his behaviours. They just weren't specific enough. It was just impossible, we couldn't apply it 24 hours...who did I approach at the council?

174.Partner – it was....

- 175.P - Mark North, Mark North, that was it, social worker, I said to Mark North, 'come on , I want this now, he pointed me in a few directions.... He was very good Mark North. He was the best social worker Connor ever had. So I started looking, I went to Ash House, straightaway I thought, 'this is good, I wouldn't mind him being here' and everything else they said...I just blocked, cos I wanted him to go Ash House
- 176.Partner– they wanted him to go somewhere near Durham didn't they?
- 177.P - They wanted him to go somewhere near Lancaster – what was it? I can't remember what it was called
- 178.I - I'm not sure
- 179.P – there were a couple of places and they were all a long way off. There was no way he was going. Ash House was perfect, cracking place, good care, I was convinced by the teaching side of it as well
- 180.I - Yes
- 181.P - And it was nearby, within an hour, it's only a 50 minute drive
- 182.I - Yes
- 183.P - And the council said, 'no, too dear', straightaway, 'too dear', and they wanted to send him to look at places, there was one in Lincolnshire and one in Lancashire. We didn't get any further than that cos I wanted him to go Ash House, but they said no, all along the line so we ended up going to tribunal and they relented at the last minute
- 184.I - Right, so did you actually go to tribunal, or was everything prepared...
- 185.P - No, the solicitors were employed, cases were filed
- 186.Partner - cos they'd broken the law on numerous occasions and they didn't want it to go to court, basically
- 187.I - Right, so what your feelings during that process, leading up to the tribunal?
- 188.Partner: that it's wrong that you have to do all this to get some body in care, cos Connor's got such complex needs and to get somebody to do the care...
- 189.P - I feel, I genuinely feel that the authorities, I could swear (getting angry) they don't give a monkeys
- 190.Partner – I know there's only so much money and there's pots of money, but people with the highest level of needs, like Connor
- 191.P - They should use that money
- 192.Partner - It's not a tickbox
- 193.P - My conscience was clear, cos throughout all this, when they were explaining about the money, cos for all them years they never spent a penny on him, cos he'd been at home, so all that time, he needs this, it's his last chance
- 194.I - Yes, did you feel that it was the money?
- 195.P - Yes, yes, it was the money, everything's money
- 196.Partner - it's the bottom line innit?

197.I - Right

198.P - -- unfortunately, it's not quality of life

199.I - Mmmm

200.P - There's families out there that haven't found out what we've found out you know they're not aware of places like Ash House, there not aware of what they're entitled to from social services

201.Partner - they're not aware of the allowances

202.P - They don't make you aware, that's the thing

203.Partner - No they don't

204.P- They're just sat in a corner waiting for someone to contact them, and then asking. They don't say, don't you know about this... It's a load of...(laughing)

205.Partner - not it's not...for people who don't know the law and don't know your rights it'syou've had it really

206.P - You're just left out to dry – just get on with it

207.Partner - cos I mean there's been kids that did attend Connor's schools that got took out cos their local authority has just gone, right

208.I - At Ash House?

209.Partner - There's been...

210.I - Just withdrawn the funding you mean?

211.P - Yeah, I've seen young people at Pendleton get a lot *more* care and respite than we ever had

212.I - So does that affect how you feel about Connors's place there? Do you feel insecure about it?

213.Partner – yes, definitely at the minute cos he's post 19

214.P - Well, cos he's got another thing going on now, now he's post 19, the education funding's finished but I want him to continue cos he's got post 19 provision now, up until 20's at least

215.I - Yes and they're looking to extend it...

216.P - Yes, and you'll laugh at this...we've had no contact with social services, whatsoever

217.I - Oh, you mean he's just there and...

218.P - I've had to preempt the next stage, I mean he's 19, 'what you doing?' 'Oh, I don't know?' I mean literally, so we've had to grant a 3 month stay of execution for Connor, while they sort it out

219.I - So it's not clear that he would stay do you mean?

220.P - It's still not clear

221.Partner – but in the meantime they have broken the law cos if they'd wanted him to move they should have put in a transition stage

222.P - There's no transition stage, there's no reviews nothing and no contact... and no contact with me, no input from me, nothing

223.I - Right

224.P - Anything that's happened I've rang them, I've rang them twice now but I'm at the stage where I'm not going to push them any further – I shouldn't be doing this

225.I – So..?

226.P - I can't , I'll wait to see what they come back with

227.I - A frustrating time?

228.P - ...I'll take them to court again they haven't got a leg to stand on

229.Partner - no they haven't

230.I - Mmm, difficult Just thinking now about Connor actually going to Ash House, did you have any particular thoughts about how he'd cope actually being away from you for that length of time

231.(pause)

232.I - Cos some people would think that young people with autism wouldn't...

233.P - (unclear) cos he can't communicate his feelings – you don't know how he'd be, I wondered if they'd look after him properly

234.I - yes

235.Partner - you were worried that he wouldn't know who you were, weren't you?

236.P - Mmmm

237.I - Ok

238.Partner– but that's never happened has it?

239.P - No, no, no

240.I - So when you see him he knows you straight away does he?

241.Partner - laughing

242.P - Oh yeah he didn't bounce off the ceiling or anything (laughing)

243.(Difficult following conversation with 2 people speaking at once)

244.Partner - when he comes home apparently he gets all excited, doesn't he, as he realises where he is?

245.I - Oh, as he's driving back?

246.Partner - yes

247.P - A few miles away he'll start making noises

248.I - Yes

249.P - That's when you know Connor is...

250.I - Getting excited?

251.P - And they're convinced that... he seems to recognize some of the route back

252.I - So you'd got your worries about whether or not he'd remember home and things and how he'd be at the school itself whether he'd be settled. Is that what you're saying – have I understood that? Or what ..?

253.hesitation

254.I - It's difficult

255.P - Mmmm

256.P- OK, but what I'm hearing I think is that he's settled and he's happy

257.P - He's fine now

258.I - Yeah, yeah, good... I know, big, big things aren't they, and I know, I mean, I haven't met Connor, well I may have cos when I've been recently I haven't known who they all are, but they're big strapping lads but they're still your....

259.Partner - He's your own....

260.I - But they're still your little ones aren't they

261.Partner– yeah

262.I - I know. Can you remember back...(is it alright for me to carry on)? Yeah? Can you remember back to the first days maybe, when he went? How you felt? Were you....?

263.P - Lost

264.I - Lost, yeah Did it seem empty perhaps here

265.P – (nodded)

266.I - yeah , yeah, mmm

267.Partner - worried, worried about how he was being looked after

268.I - Yeah

269.P - Constant ringing em up

270.I - Yes

271.Partner - just that he was being alright, being treated well, that was my main concern cos if he couldn't tell us

272.I - No, and I know it is what parents worry about

273.Partner– it is, because...it is what you worry about

274.I - Yes, you here a few stories

275.Partner - What you see on the tele...

276.I - Yes

277.Partner-,we got over that, the reason we got over that was cos, if Connor, if he didn't like something he'd..

278.P - He'd kick off

279.Partner –he'd protest– that's what I used to think, he'd come home, when the carers come ...if he didn't like them or they were being nasty to him

280.P - Nasty – there's ways to treat him weren't there? He didn't like being pulled anywhere did he?

281.Partner - no

282.P - He wants to go in his own time

283.I - Yeah

284.P - And if he didn't like the way they were doing things, he'd be able to express it, but yes, I was ringing them up all the time

285.I - Yeah

286.P - But they said, if necessary....he wore pads at home

287.I - Ok

288.P - And eventually at night, to make things a bit easier, towards those final few months we got these 'Fledglings', I don't know whether you've heard of them?

289.I - No

290.P - They make specific things for kids with problems and we got these like vests and shorts that zipped up the back so they couldn't get them off so he couldn't get his nappies off in the night

291.I - Oh

292.P - So it made our life....., bearable

293.I - Oh right

294.P - Cos I wasn't having to go in every night and clear his smearing

295.I - Right

296.P - So the last few months before he went, it was actually a bit....more tolerable at night

297.I - Yes, yes

298.P - Anyway, from day 1 at Ash House he didn't wear them and they wouldn't let him wear a pad and they said, 'If necessary we'll follow him round with a mop and bucket,' which I thought was hilarious

299.I - they were trying to get him trained?

300.P - Toilet trained yeah

301.I - Oh, ok

302.P - But initially it was how was he settling in, how's he taking to the staff, and I think he had a few...on the whole he was fine, but he had a few testers, does he like his new room, how's he going to cope with the new routine, cos I insisted it was strict

I- Right

303.P - And no way should he ever be allowed not to do something was on the 24 hour routine, I wanted them to apply it rigidly

304.I - Ok right

305.P – Last chance saloon really, so yeah, it was hard to begin with but soon, soon got into it

306.I - Yes, so now, it's been three years since he's been going?

307.P - He actually started at Ash House on his 16th birthday

308.I - Oh right

309.Partner - Well, the day after

310.P - The day after, he had his 16th birthday here and then he went. It's been 3 years

311.I - So, how do you feel about your decision now?

312.P - Wish I'd done it ages before

313.I - Right

314.P - Not for the fact that he's not at home, but the fact that they do good work with him

315.Partner - the intensive work that they've done with him

316.P - They've applied the 24 hour routine that he needs. He goes toilet now – and that's something I never thought I'd see in my life time

317.I - Right

318.Partner - he takes himself to the toilet

319.I - So is that perhaps a frustration cos you feel that he missed out on what he could have done earlier?

320.P - It is yes, the intensity of work that these kids need, it should happen, from as soon as they're stated I think you just don't know and what they're capable of, but you feel gutted that you don't try

321.I - Yeah

322.P - Until you try you don't know and I think they all deserve

323.I - That opportunity?

324.P - That amount of support

325.I - Yes. So what changes, if any, has Connor being at Ash House brought to your own family life?

326.P - You name it, you name it

327.I -So, it's completely different?

328.P - Yeah

329.Partner– it's more relaxed, more relaxed

330.I - So, a Saturday morning wouldn't have been like this...

331.P - It's a normal family atmosphere now, whereas before, it was a battlefield, and erm...er and despite how much you love someone, the frustration is within, and its to do with that stuff, cleaning up, walking on egg shells, trying not to upset him, they were deprived of stuff like normal Tv programmes, having friends round, cos he quite often (upset again)

332.Partner - and just being able to go out, all of us, all going out together, cos before you had to stay in with Connor

333.P - Every aspect of it, I looked after Connor, these lot did their own thing

334.I - So, you were like a carer for him and in terms of your relationship and the relationship with your children, its different now?

335.P - Oh it's a lot different now

336.Partner - it was Paul looked after Connor and I looked after the girls, really wasn't it

337.P – (too upset to answer) Mmm

338.(hesitation)

339.It was the only way we could do it though wasn't it ? Looking back, you just evolve into it, it's not a conscious decision, it's just the way it happened he's got to be looked after so someone's got to do it

340.I - So you just made, found your way through it?

341.P - Yes

342.I - Has Connor being at Ash House affected your working life at all?

343.P - Well yeah cos I've been able to retrain cos I mean I had to give up work to care for him

344.I - Did you?

345.P - Yes, cos when I split up with his mum, I mean I was working shifts

346.I - Right

347.P - I was a computer operator and at the time my mum helped me out

348.I - Right

349.P - But she was approaching retirement age and she was working full time at that point, so for example if I was on nights and I had to leave here at 6 o'clock, cos I worked in (neighbouring town). She'd be working til 5, get a bus here, look after these while I went off to work, then I'd come back in the morning and she'd go off to work. And I could see it taking a big toll on her she was getting tired and not doing stuff which she always did and I thought, 'that's enough' so I gave up work

350.I - Well that was a big decision then?

351.P - Well, I had to, to be honest

352.I - Yeah

353.P - And when Connor went off to Ash House, my job weren't there no more, the IT industry had moved on so everything I did was mainly automated, they didn't need any skills, they just needed people to ring somebody really...so I had to retrain so I've been college the last three years

354.I - Oh

355.P - So I'm a painter and decorator now

356.I - So a big life change then?

357.P - Plus I needed flexibility so you never know when that phones going to ring

I- And you can just drop everything and you can go?

358.P - Yes

359.I - And what changes, if any have you noticed in Connor since he's been at Ash House?

360.(hesitation)

361.I - you've said a bit about his physical progress...self help...

362.P - his main change is his ability to use the toilet, that's the main change, and I think

363.Partner- there's more eye contact

364.P - even post 19 now, and his routine's not as rigid as it was, the education's stopped. I think he's learned to recognise that he's more comfortable sitting there when you're dry than it is ..., so he goes to the toilet and that's the number one thing

365.I - And that's made a difference to how you see him as well, that he's not so dependent on....

366.P - It's doubly frustrating cos he's learned to do that and what else could he have learned to do? And what more could he have learned if he'd had that from the age of 3, that input? Oh, frustrating! I wouldn't say that I had particularly noticed many changes in him. I'm convinced that the changes in Connor are to do with his medication

367.I - And he's been on that since...?

368.P- Since 15

369.I - Is that medication for ADHD?

370.P - It's mood controlling, he's on (not clear) with a bit of diazapan to help him sleep. And then stuff to help him move his bowels. And then stuff for hayfever – it's a bit of a cocktail, but I've said I don't want him to be on anything unless he has to be on it No

371.P - When we go to visit, he's ever so cool, calm, and collected and I tell you something that I've not seen in a long long, long, long, long time, is an outburst

372.I -Oh

373.P - Normally you'd think you'd see one or two over the week, cos he used to have one every single week without fail, but I've not seen one for donkey's years

374.I - And they've not...I'm sure they'd tell you if there was one

375.P - There's a procedure laid down that if there's anything prolonged, then I have to be notified

376.I - So that must be a change if you think about it

377.P - Now, I'm perfectly at ease and comfortable with how they care for him. I know all the staff, we talk to them and they're approachable and I'm 100% confident that if there's anything that happens to Connor, I'll know about it, so I don't have to worry and I don't worry, now, I don't

378.I - That must be a relief after all this.

379.P - (unclear)...and Connor's happy, you can see that. They do far more there than they would do anywhere else, with regards giving them something to do in the day...swimming one day, gardening another day, trip over to the seaside another day, shopping, they do things, they're not just sitting down in front of the telly all the time. Changes?

380.I - Well you've told me lots

381.P - He's well fed so he's a bit bigger, so his physical appearance, probably for his age, a little overweight. His injuries are clearing. He's always going to have scar tissue from... he'll always have scar tissue but he'll sit calmly for longer, and I've noticed he takes a lot more interest in what he's looking at rather than it being fleeting

382.I - Ok

383.P - So like the eye contact that he'll give you will be a bit more than what it would have been years before

384.I - So it's as if he's a bit more settled and comfortable with things?

385.P - Yes, but we don't know whether that's his medication, his hormones settling down, whether it's his environment, whether he's away from here, you're never gonna know and that's another of the frustrations

386.I - No, no yes, but what you're describing are positive changes rather than anything....

387.P - If he wasn't happy, and if he wasn't happy after a year at that place, then he'd have been out and back here, but he's happy

388.I - Yes

389.P - If he's happy, I'm happy and if he's happy with the care staff, the education staff...if I'm not happy, then they'll know about it

390.I - You've said quite a few things but is there anything more you'd like to say about what you like about Ash House and what it does?

391.Hesitation...

392.I - I know you've mentioned quite a few things

393.P - What I like about Ash House, is that every single one of them, to a man, is approachable I said from day one, I don't want any...I don't want them to dress anything up. I want to know how it is – if it's bad – tell me, if it's good tell me, but don't feed me any bull and that's the number one thing I like about Ash House, straight down the line, tell it like it is

394.Partner - and they said, 'he's your son and you can see him whenever you want'.

395.P - I can turn up 4 o'clock in the morning, and nothing to hide

396.Partner- nothing to hide.

397.P - It's an open house, but that's the one, they're all approachable, I want to get something for Connor, they'd do it, if I said I want to do something for Connor, they'd do it for Connor, no questions asked and the other thing I noticed, they care about the kids, they do, (unclear) that's good

398.I - That's good right, so you trust them, by what you're saying

399.P - Yes

400.I - Is there anything that you think they could do differently?

401.P - What, Ash House? Erm (hesitation)

402.I - I guess no-where's perfect?

403.P - To do with Connor, to do with Connor (hesitation) where does this go, if I say it?

404.I - Oh, it's between us

405.(what followed is removed from the transcript to respect confidentiality. However, it does not contain anything controversial or pertinent to the focus of the research)

406.(continuation of transcript)

407.Is there anything else you want to say about your relationship with Connor now, I mean how do you feel about it....

408.P - Part time dad now innit, - towards him

409.I - Ok

410.P - There's been a few realizations now since he's been away for a while, I mean he'll never be back at home again, so I'm looking into that sort of thing now

411.I - Right, so coming to terms with some things

412.P - Yes

413.I - You say 'part time dad' - what do you mean? When he's here?

414.P- Yes

415.Partner - you say that but you're not - he's always in your thoughts

416.I - He's just not physically here

417.Partner - he's just not physically here and, you know, you've always maintained a relationship with him so you're not a part time dad (supporting him)

418.I - So, I'll just ask you this question what hopes have you got for him, for the future?

419.Partner - (Paul unable to answer) - that he's happy, that he's looked after, with the best

420.P - You can see they're caring

421.Partner - that he doesn't regress, the point is that he's got to with the toilet

422.P - You can't, if they had their way, he'd be sitting here

423.I - No

424.P - It's not to do with how I feel about things, it's what's suitable for him my priority is that people respect him and give him...So, more of the same for that..., yeah.

425.I - Well thanks for that, that's the last question. I'm sorry it's been...., but I do appreciate you sharing this and as you know I'm seeing quite a few parents and they...

426.Partner – so what is it you're actually doing then?

427.I - I'm doing research into the experiences of families, because there's hardly any research about asking families, what the journey's been like and what I hope to find out at the end, things that are similar, and there are things that are similar and each family's very different and they've come to their decision for different reasons, but also...

428.P - I just find it hard to talk about it, I'm quite happy saying what I've got to say

429.I - Yes, ok

430.P - it's just, it's just, it provokes feeling

431.I - Of course

432.P - I'm quite... But, it doesn't bother me, but I've never spoke about stuff, before, but I'm quite willing
433....

434.I - Yes, and other families have shared similar things

435.P - How many opinions will you be canvassing?

436.I - Several of the families

437.P - Is it just Ash House? I've always thought as well, Alton Place, (an alternative local residential provision) I'm convinced that if the parents of the kids there knew about Ash House, they'd want them to go to Ash House

438.I - Oh, right

439.P - Do most families have to fight for it, it's not offered is it, when you're fighting for someone like Connor, you're fighting from a personal point of view, you're talking to people who are controlling money, and you're speaking from the heart, but they're not bothered

440.Partner- It's the difficulties of social care isn't it?

441.Paul - I've always said to anyone working with Connor, come and see him, when they've seen him for five minutes they know, all except the top one in education, Warren Brown, he's always said 'no, too dear'. It's what you could do without – this battle.

Appendix 10: Original Transcript

5. Sue

(Key: S- Sue, I-Interviewer)

1. S - Becky is 17. She was diagnosed autistic at 18 months. At first I thought she was deaf because when she was small I used to go into the bedroom to pick her up, she never gave me eye contact, so I thought there was a problem with her hearing, so we had that extensively checked and we put her under general anaesthetic and we checked that and they said, yes that's fine so we, later, we were living in (area) at the time, we moved back to (current location) and we got a referral to see somebody at (hospital) and then they diagnosed Becky as being autistic, which we kind of knew at the back of our minds, but we got the diagnosis which we were quite pleased about because it's very difficult to actually get a diagnosis but if you don't have a diagnosis you can't then get the help, so she went to a special school when she, started school, oh sorry, she had all her goal posts, sitting up, she did that quite late, her walking was spot on 18 months so she was on the cusp of everything, she was quite late in her development. Erm, she went to school erm, in, what's the name of that school...?
2. I - Was it a local school?
3. S - No, she had to get a taxi there. There was a local school, there's one in (local town) but she didn't like it we went to have a look around but she didn't, she wasn't very keen on it at all. Lea Side (*remembered name of school*), and then they said in 2002 that it wasn't the school for her, and to look around for something else that was at the annual review they told us, so that was a bolt out of the blue, it was not the school for her, to look for something else
4. I - Was it a mainstream school?
5. S - No it was a special school and dealing with autism
6. I - Oh right, I see
7. S - So, we did think it would be ok. But I think the children they had were more had speech whereas Becky doesn't
8. I - Right, did you say, she had any additional learning difficulties? Has she got severe learning difficulties as well?
9. S - Yes she does, yes, so then we found a school at (local town) for her, she went to a school at (local town) in 2002 and she was fine there for a couple of years and then 2008 she, her behaviour just deteriorated and she got excluded, from that school which takes some doing really, excluded from a special needs school
10. I - Yes
11. S - But she actually hadn't been taught at all and she obviously caused a lot of disruption but they just realised they couldn't cope with her any more
12. I - How old would she have been about then?
13. S - Erm, she's 17 now, so she'd be about 14, so whether that was to do with puberty or, I don't know but she was a danger to other pupils because they had to basically when the smaller pupils went through they had to lock her in the headmaster's office
14. I - Oh dear
15. S - And she was that mad that she, she bent the frame of the door, she was very, very powerful
16. I - So what were you feeling when you were hearing stories like that ?

17. S - It was just, I knew she could be bad, I was under no illusion, because she would attack me and she would attack Brian (husband) which was, I thought, 'my god', when they said there was like 6 of them to try and restrain her, then you just say, 'um', the taxi people had also said there'd been problems, she'd been attacking them and in the end they had to get a taxi with three rows of seats and put her at the back and not have anybody sitting next to her so that she couldn't reach out and grab, erm, and we had a meeting at Lea Side and we decided that that wasn't the school for her and social services were involved and they suggested we have a look at The Holt (an alternative residential school to Ash House).
18. I - Oh yes
19. S - Not Ash House
20. I - Yes, I know which you mean
21. S - Erm so we went and had a look at that, she didn't like it, she would *not* settle, she wouldn't even have a look at round it, she didn't want to stay at all so I had to have a look at Ash House and, straight in there, liked it, loved it, went off with the staff you know while we had a proper look around and a chat with (the head) and they said they'd pay for 38 weeks so we'd have 14 weeks of cover to great, so they then said that they would put, during the school holidays, obviously we'd then have to be off, now we'd both changed jobs, I used to be a civil servant Brian used to be in the air force we'd both used to get 6 weeks leave but now we get 4 weeks so it was like really difficult and I was part time so what I used to do is I used to build up my flexi and annual leave so when it was the holidays I could stretch it, stretch the holidays out with the flexi so I thought, 'well, how are we going to do this because it was a stretch before', but they said oh, that they'd put these people in the house, we had to be here and it was understood that they would not intervene should she get aggressive or anything, cos this was not their job)
22. I - Were these from social services?
23. S - Yes, they lasted erm Monday Brian was off and he was able to control Becky a little bit better, Tuesday I was off with her, and they lasted until lunchtime and then went
24. I - So that wasn't a solution?
25. S - That wasn't a solution and then after that they just said they'd pay for a 52 week placement at Ash House
26. I - They understood the need then ?
27. S - Yes, but they had to, it was annoying in that we had to do that. They wouldn't listen to us and say, do you know what, if we could have coped with her for weeks at a time, we would have her for weeks at a time, we wouldn't be putting her into residential care.
28. I - No
29. S - It's not something that you do lightly, and then you think, 'is it just down to money', and they were going, 'no it's not', but obviously it is, down to money, you know what I mean.
30. I - It's difficult isn't it Just taking a few steps back that's great I've got a feeling now about how that was. Can we go right back to when you said at sort of 18 months and you thought she was maybe deaf. Can you remember how you were feeling at that time when you had those concerns?
31. S - Obviously I was very worried, like I say I maybe I knew at the back of my mind that it was more than...
32. I - More than deafness?

33. S - Yes, than deafness, because of the delayed development , it's just that, we also had Emma, there's only 22 months between them, and she was like one handful, and because Becky was so quiet and placid I was thinking, 'thank god for that', you know what I mean, because I couldn't cope with two of them like that, but as time went on and I just thought, 'um, no', and then, and then you are really worried because you just think, 'what's going to happen in the future, why, how is she going to get schooling, how are we going to sort this out?' and at first she was fine because she was that much smaller and she was more like good natured and she'd maybe just take herself off and do her own thing and we were able to take holidays with her and things like that
34. I - So was she more passive?
35. S - Yes, very much so
36. I - Did she have any speech?
37. S - No she doesn't have any at all.
38. I - But when she was younger you could manage better?
39. S - Oh yes
40. I - So, you've told me about, can you remember getting the diagnosis. Was it a face to face interview or in a letter afterwards or...
41. S - No, it was face to face. They called us back and it was face to face to say that she was autistic and we basically kind of knew anyway....
42. I - And did you say she was 18 months, because that is very young isn't it?
43. S - When we started the ball rolling
44. I - Oh I see, right
45. S - So she would have been just after 2
46. I -Right, Still it's young but I know in many ways its good to have that diagnosis?
47. S - Yes, like I say, I wanted the diagnosis because I knew it would take a long time to get the ball rolling, to get people involved and I didn't want her starting school, in mainstream school and then them saying, erm, 'there's a problem' ...
48. I - Right, so did she go to any specialist nursery or anything like that?
49. S - No, just local nursery, but then when she was erm, the year before she started school she went to St Mary's (a local nursery) and that had like a special needs section to it, but that was only for the afternoons, a couple of hours in the afternoon so what I used to have to do was drop her off at her other nursery and take a lunch break and then go and swap her over to St Mary's and then pick her up at night
50. I - So how were those experiences for you? Did she manage OK at the nurseries? They weren't ringing you up to say pick her up? She wasn't having tantrums?
51. S - Oh no, at the erm, just the, the what we'd call normal nursery, you know, the one that was open to everybody, they basically just let her do what she wanted to do, erm I don't know as she got much stimulation but it seemed a caring place and that's what I was more interested in as well, erm the other place at St Mary's was more geared up for special needs and they did a lot more with her.

52. I - Oh, ok, and then moving on from there, did she go straight into a special school? Did she have a statement at that time?
53. S - Yes,
54. I - How did you find that experience of getting the statement?
55. S - Erm, I suppose that was a lot easier because she had the diagnosis, to get the statement, because normally it's like you go round in circles, you get the statement, you get the diagnosis so that's why I was so intent on getting the diagnosis because I wanted to be like fully armed and ready, to go.
56. I - So it was fairly straightforward then, the statementing procedure?
57. S - Yes
58. Ok, so you've talked about the change in Becky's behaviour when she was in her teenage years, was it?
59. S Yes
60. I - And that's when you started considering the residential option was it? When she got excluded from Priory school?
61. S- Yes
62. I - Can you tell me any more about how you were feeling at that time when the behaviour was changing?
63. S - Oh it was, I just couldn't believe it, you were tense every time she came home in the taxi, it was like, 'oh god, what kind of mood is she going to be in? and she'd come flying through the door, just take her shoes off, have some snack, go and take herself next door, which was like basically her domain and go and watch her videos and sometimes she'd be alright and sometimes she wasn't and you always had that knot in your stomach, and you were just waiting for the back lash
64. I - Yes
65. S - Erm, when she has outbursts, she'd have them good and proper, and what would happen is that if Brian was at home, then me and Emma would go upstairs and Brian would deal with Becky and try and calm her down, we just got out of the way cos she would just grab anybody in sight, anybody that was passing, anybody, you know, you would get it basically, and if you weren't quick enough she could get you by the hair and she could actually pull you down to the ground, she was very, very strong.
66. I - Is she quite a tall girl?
67. S - Yes, she is, yes she's taller than me
68. I -Oh right
69. S - And weighs more as well, erm...
70. I - So were you thinking about your safety?
71. S - Yes, yes, definitely safety first and as well when she was disruptive at night, cos she used to be disruptive, and we would think. 'well it's not fair for Emma.' cos Emma was still at school herself and doing GCSEs and you just think, you just well 'this can't go on, basically'
72. I - Yes, right

73. S - Erm, we went on holiday to America and she had loads and loads of outbursts. She wasn't very happy at all now whether it was erm, we went into a particular shopping mall and whether it was because it was a big bright space, I don't know but something set her off, and she was.... we just couldn't do anything with her, she was like trying to grab passers by and everything and when we came back and we were at the airport, the flight was delayed for 11 hours
74. I - Oh dear
75. S - Er, and she just went berserk and it was only because there was like an ex policeman that helped restrain her and we managed to like get her into a wheel chair and she was just like grabbing all the time she'd been pulling Brian's ear, she'd gone through it a few times, she'd gone for his ears, and it was all cut at the back and his face was all cut and when he got back to work people thought he'd been in a car accident. It was that bad and we were so worried cos we didn't know whether they'd actually let us on the aeroplane (laughs) and we thought, 'oh god', and we thought, 'well, we'll not, never take her again.'
- 76.
77. I - And previously had you been on flights?
78. S - Oh yes we'd been away cos she'd love the pool so we'd go to, it was usually Mallorca because it was only 2 hours away, and it was before you had to get to the airport 3 hours before, it was before all that so it was quite easy and she liked the aeroplane and she liked, you know the whole, you know, being in the pool at the other end
79. I - Yes ok, so when you were having to think about the residential, what sorts of feelings were you having about that decision?
80. Guilty, you feel very, very guilty, because you just think you've failed as a parent,
81. I - Yes
82. S - you think well this is our child and we shouldn't have to be, you know, putting her away, but as (the Head of Ash House) said, if you had a gifted child, that was offered say a music scholarship, you wouldn't think twice, you would just say, you know, 'there you go'
83. I - No, no
84. S - So, it's just basically the same thing but you just feel a failure as a parent because you feel well I should be able to cope, cos she's our child and why, why have we had to resort to this? (getting upset)
85. I - Yes, a very hard decision, I can see that. Did you have any particular thoughts about how Becky would cope herself with going to residential?
86. S - Yes, I didn't know whether she would take to it. I knew she liked, she liked the place because she made that clear when we actually went to look around so it was a lot, it was more important for us to fight for Ash House, rather than for the other school because she didn't like it, she didn't like it all, she didn't like the vibe of it, she didn't just like the aspect of it, the whole thing, but Ash House, she just, she just seemed to slot in and that was fine erm so we did feel a bit more comfortable but obviously we weren't, you know it wasn't the ideal thing to do because, like I say, you feel such a failure, but we felt that was the best option for her
87. I - Yes, so how did you think she'd cope with the separation from you? Did you worry about that, did you think that she would handle it or...
88. S - I don't know cos it's so very hard to tell, you know, with autistic children. You know, she knows who we are and that this is her house.
89. I - So when you go and collect her she knows she's going home, but when you take her she's.....

90. S - She's happy to go back, yes, she's happy on Monday morning, she's happy to go back and I think she likes that routine, to be honest
91. I - Yes, well it is very structured. Can you remember, the first days when you took her, and left her and came home, how you were feeling about the situation?
92. S - We were distraught, the pair of us (laughing), I was just a wreck, it was awful it was like the worst feeling.
93. I - The days that you dropped her, and she wasn't home, and the days that she wasn't around and ..
94. S - I think that as well it's guilt as well, cos it's kind of a relief
95. I - Yes
96. S - It was, it was...erm...
97. I - A lot of parents say that
98. S - Yes, yes, you think, you know, you don't want to get attacked every two minutes and you don't know cos, she'll be fine one minute and then will just turn like that and grab you
99. I - Unpredictable
- 100.S - Yes
- 101.I - So how do you feel about your decision now? Is there anything you would change?
- 102.S - Oh no, definitely not, because she's in the best place because if she didn't like it or if there was something she wasn't happy with, believe you me we'd know about it
- 103.I - Because her behaviour would change?
- 104.S - Yes
- 105.I - You said it wasn't easy to get her into Ash House, could you tell me a bit more about that procedure.
- 106.S - Every single school that we've gone to we've had to fight with social services and the education authority, everybody erm when she, when she said it, the first school that it wasn't the place for her and we were looking around for other schools and they said she had to go to the one at (local town)
- 107.I - Right
- 108.S - So I took her again, actually I took her on a couple of different occasions and she didn't like it, she just *did not* like it there was something, she just didn't want to be there, she got upset so I thought, 'I'm not sending her there, no way', so we went to have a look at the Priory School and we were told that if she went there we would have to transport her there, we would have to pay for transport, so we thought, 'well, here we go again' so we just said right we're going to appeal against the decision and we'd been told these other places and then they said, 'well, we're considering sending her to a special school in (distant town),' so we both said, 'we don't want that,' so we did a massive, great big report
- 109.I - Did it go to tribunal?
- 110.S - Yes and we won and they said yes she'd be able to go there and yes, we'll pay for the taxi
- 111.I - Right

112.S - But you just think, erm, I'm not being funny but if you didn't have as much about you if you weren't as geared up you would just, you would just think that you'd have to do what they wanted you to do, the education authority and social services, but no you don't cos at the end of the day this is your child and you have to do what you think is best for your child and I knew she didn't like that school and would have trouble if she had gone to the one at (local town). There's something about it, I'd taken her a couple of times and I thought, 'I'm not sending my child there, there's just something she doesn't like about it, she's not going,' erm so like I say, every time I feel that we've had to have a battle, every step of the way and now that she's 18, well 17 actually and we're having to go and look at post 19 and I just said to the social worker at the last meeting, I said, 'I want her to stay here, at Ash House, for post 19 and believe you me we will be fighting, so I'm just giving you warning, we're used to doing it, she will stay where we think she needs to be, where we think she'll get the best care, where we think she wants to be' and she just looked at me like that (amazed look), it was a different social worker and I thought, 'oh well, you might as well know, you don't think you're going to be fobbing us off'.

113.I - It sounds like you're a strong advocate for her

114.S - Yes, definitely, because Emma her sister, I mean she got to choose which High School she went to and I thought, 'well, Emma can do that, why can't Becky, why can't she have the same choice just because she's special needs and she's got very challenging behaviour, why can't she have the same choice?'

115.I - Right, have you seen any changes in Becky since she's been at Ash House?

116.S - Oh yes, definitely, she's a lot calmer, I'm not saying she doesn't have outbursts because she does, you know she can still turn, she can still give you a good, you know a good bout, if she's not happy, you know she changed? but generally she's a lot calmer and she's making fantastic progress at the school, although she doesn't do the same sort of things at home (laughs)

117.I - Oh, so what sorts of things is she doing?

118.S - They've got her own bathing routine and she's brushing her teeth, well, we do give her a toothbrush but then we go in afterwards, same as Ash House does ... and she's doing like household chores, she's Hoovering, helps prepare all the food, well I just said to her, 'come on in the kitchen we'll do this,' and she just laughed and ran away, 'maybe not then!'

119.I - So some independence then?

120.S - Oh yes, but she wouldn't, I mean like you say, if she was at home she wouldn't be doing that, like I say because home's home, school's school and she does keep those things very separate.

121.I - And what about the changes in your own family life, that have resulted?

122.S - Oh much more relaxed, so we're going to meet friends tonight, which we couldn't do because we couldn't have people to the house, we couldn't let Emma have sleepovers here when, you know, when she was younger, so we did feel bad, so we never, so for Emma we always made sure that we were available to take her places, if she was going to meet friends, you know we always made the effort to do that because we thought well, she can't have them here, so she has to ... have to compensate, we thought that was very important because we didn't want her to resent Becky, because to think well I can't do this because of you

123.I - I was going to say, does Emma visit, but I suppose it's more that Becky comes home than you go and visit

124.S - Yes, oh yes

125.I - Ok, what do you like about how Ash House works?

126.S - I like the calibre of the staff, the staff are fantastic, they've obviously been really well trained and they know exactly what they're doing and I feel Becky's safe and secure there, erm, they've just got a good vibe about them and I know there won't be any abuse of Becky which is *always* at the back of my mind, always, erm,

127.I - Is that because she's a girl?

128.S - I think just mainly physical, you know, being rough with her, but they would never do that. They're absolutely brilliant, they're very, very supportive when she was home one time her television wasn't working next door and she just went absolutely berserk and I was out at the supermarket, Emma was at home and she said, 'don't bother coming back' because she was going absolutely mad, she'd pulled the television over and it was a big heavy one so Brian actually called Ash House and they sent like four members of staff, you know, straight down and they stayed I think, Brian went to get a new television for her, so he did that and it was absolutely brilliant, the support is just fantastic

129.I - Yes, yes, is there anything you think they could do differently, I don't know

130.S - No, I think they've got it just about right

131.I - Ok, if I just suggest a few things, just in case you think about any of them, the learning programmes...

132.S - They're working because she's making such good progress

133.I - The facilities that they've got, I know you can always improve on everything....

134.S - I'm happy with them

135.I - What about the communication between you and them...

136.S - Oh it's brilliant you can just pick up the phone if you've got any queries, they phone us if there's any problems cos as I say she has epilepsy so I say if she ever has any fits, we want to know no matter what time of day or night we want to be advised, erm, they come with us all the time she has appointments, which is absolutely brilliant, because it's just great to have that extra pair of hands. We went to Queen's Med to see the neurologist, not this last visit but the visit before and she wasn't happy she wasn't happy at all, there was too much waiting about and she was a bit of a handful and so we were just really glad for an extra pair of hands, to try and calm her down.

137.I - Is that sort of communication, is it different from what you expected when you first thought about residential, did you...?

138.S - Oh yes

139.I - Did you perhaps think that she'd go and you might not hear... (too leading?)

140.S - Oh yes, you'd hear about her progress, but when she comes home she's got a home to school diary so we can see what she's been doing during the week and we fill it out to say what she's been doing at the weekend and whether we've been able to get out or what

141.I - So that's good to share?

142.S - Yes, to share

143.I - How would you describe your relationship with Becky now? Has there been any change since going to residential...is it the same, or better, worse ...?

144.S - I think it's better because I think we're more relaxed so when she does have an outburst we can cope with it more whereas it was 24/7 before and we were just so tired and worn down and we're just waiting

for the next one to come and it's only whereas now, you think, 'well, she's going off on one, but we can cope with it.'

145.I - And do you think that's because, like you say, you know it's not for ever?

146.S - Yes

147.I - So you know you can manage it and you can send for Ash House? And what are your hopes for Becky's future?

148.S - Erm, I don't think she is ever going to be able to live in the community, we're talking about her doing supported living but I don't think that's for her, I think she needs more structure, like she's got now

149.I - Ok

150.S - And I know Ash House....my fear was putting her somewhere where she was going to be put in a corner and they'd drug her up

151.I - Yes

152.S - That, is, that, is, because of her behaviour, that they'd just drug her, you know, and that, and that is just a big no-no for me so Ash House is the absolute perfect place cos I know they've got the ethic and I know, (the Head) said herself, they don't have them sitting around all day doing nothing, they're very active, you know, doing things, I think she will be in residential for the rest of her life, I can't see her, even though she's making progress in leaps and bounds, she hasn't got any awareness of danger say if you were crossing the road or helping cooking, it's fine but she couldn't do it on her own, she couldn't get herself a drink, even at Ash House, she doesn't do that. She wouldn't think, 'oh these clothes are dirty I need some new ones, I need a bath or use that initiative or... But some sort of place where she's cared for and allowed to develop to the extent that she can ..

153.I – Yes. Is there anything else that we haven't talked about that you think is important and would want to say?

154.S - No, I don't think so, just that we're really happy to have found somewhere like Ash House and I used to work with this girl and she went to work for another company and we used to be in the civil service together and we got made redundant and she once said she wanted to do some work, something completely different and I was just chatting to her and I was saying about the problems Becky was having and she said there's a place (in the next town), Ash House, which is residential, for autistic children so I went on the website and had a look and just got some background information about it

155.I - So it was like chance, finding out?

156.S - Yes, yes, we would have done anyway

157.I - You are convenient for it aren't you?

158.S - Yes

159.I - And just finally how have you found the experience of taking about his with me today?

160.S - Yes it's been, it's been a little bit emotional but, yes, ok

Appendix 10 - Original Transcript

6. Brian

(Key: I-Interviewer, B-Brian)

1. I - So, from your point of view, when did you start having concerns about Becky?
2. B - When she was really, really young. When she was, she..... seemed completely unaware of people around her, not so much her surroundings, but of people, and didn't seem to pay any attention, she was, I wouldn't say she was a whingy child, but when she started crying, she didn't take comfort in the same way as you'd expect, at least I didn't think she did which was quite frustrating obviously as
3. . I - You can't do anything...?
4. B -You do all the things, carry her about, and all the rest of it, it didn't seem to make any difference. At first, as Sue (mum) has probably said, we first suspected that she couldn't hear
5. I -Yes, yes
6. B - Because the kind of thing that she would do is if, if you went into her room, she wouldn't sort of look, and I've never known a child not do that, so of course the first thing you think is she simply can't hear us but we had her hearing tested and all the rest of it so I'd say she was probably as young as a year, maybe 18 months...
7. I -When you were wondering about things?...
8. B -There was something not right, but we didn't, I mean we didn't at the time suspect at all that it was autism as I say at first we thought she's got a hearing problem, but after that was tested, well we were up in (air base) at the time I was in the air force and we were stationed up there and it started to be investigated and we told the doctor in the hospital about it and we got posted down to (new county) and she happened to know a doctor in the local hospital and she actually referred her to that doctor, the doctor who gave the diagnosis that she was autistic and she was able to do it at a very young age, she said normally you can't diagnose this until I think she said about 4
9. I -Yes, around then
10. B -But she said, 'I've no doubt she's showing *all* the traits'. She did think that she would probably have speech, but unfortunately she never really had and she said the chances are she'd be a bit eccentric
11. I -Right
12. B - But again, it's been somewhat worse than that
13. I -So can you remember how you felt at that time, when you were hearing that...?
14. B -Well I think to a certain extent we were glad that we now knew what it was, we didn't know what autism was, obviously, we had to do a bit of research on that, but at least we knew, yes, it wasn't just us, that there was something, something there and of course at the time, because the doctor had said, the chances are she will have speech it may be a bit slow in developing but she probably and then she never did...
15. I - So you perhaps had some optimism...
16. B - There was a little bit of optimism, but as time went on I think we fairly quickly realized, I mean she has said the odd thing and I mean one day in here, cos, I think the other thing that helped then was that we started getting help because as the doctor pointed out, the best thing for autism was through education so the education side started coming in then, and, you know, we started, getting people

coming in to see her and of course that led to her, she got a place at a specialist, or more specialized place, at a nursery that had specialized, so you see those sort of things happened

17. I - So some interventions

18. B - so she did one day when, I can't remember now, it's such a long time ago, she just sat there and she just came out with one phrase, which was 'the wheels on the bus', she wanted me to sing it, and it was perfect, and we thought, 'oh, is this the beginning?' never happened again (laughing), strange, but yes, I mean I think yes, there was optimism, then and at least we knew we were starting to get the right help

19. I - Yes, yes, so something was happening. So you've told me about the time of the diagnosis as well there, erm can you tell me a little bit more about, from your point of view, Becky's experiences of school before Ash House, what you can remember about it?

20. B -Erm, I think when she was, ...she was fine at nursery, not a great problem at nursery, she then went to Lea Side school, and at first I think it was alright but as time went on, they said to us, I actually became a governor of the school

21. I - Alright

22. B -The headmaster, I think said, 'look', he said, 'we don't think....'

23. ('sorry but that was Elmtton not Lea Side' - Sue from kitchen)

24. B -ok, it was Elmtton, so, then they then said, really, we, you know, she needs more specialist than what we have cos I don't think any of the children at Elmtton I think there was one of them, but again that child moved in the end, the rest of them all had speech so yes, they did have autistic children but they all had speech. Fairly high functioning and so really it needed another school so at first she was fine, then they're saying, 'really we're not going to be able to do a great deal for her, she needs to go to a school that's more set up for children with her special needs'. We then sent her to Lea Side and fantastic to off start with, can't fault the school and the staff and all the rest of it, and again she was alright, but as time went on and she got closer to puberty she became more and more of a risk and unfortunately the school, in the end, had to take the decision, to, to er, to suspend her for a period because in effect it wasn't so much that she was a danger to the staff, although she was, it was the fact that really she was a danger to the other children

25. I - right

26. B -so, and they were really disappointed, the head teacher was so disappointed that he was having to do this and that's when we started looking, and things were becoming more and more difficult at home

27. I - and so was she at home for a time, while she was out of school?

28. B -oh yes she, she lived at home until she went to Ash House

29. I - oh no, sorry, I mean was she not going to school?

30. B - there was a period, I can't remember exactly how long it was, while she was suspended yes, when she was at home and we were having to take time off, the county put 2 carers in, after half a day they were gone because they went, 'this is well beyond our ...' and at the time then we were looking, obviously, looking very hard for a school and incredibly the first school we went to just seemed perfect, which was Ash House, not that it was the only school we looked at, it was the only school where she seemed happy

31. I - right, yes, so had you thought about residential prior...

32. B - I think....

33. I - Had you looked at those because they were residential or...
34. B - It was only after she's been suspended from Lea Side that we looked at residential schools, before that as far as we were concerned, I mean we knew that at some point she was going to end up in residential care, we were never going to be able to look after her for her entire life, it was just physically impossible for us to do and we knew, but, I think we both had hoped to put that off as long as possible
35. I - Yes, yes
36. B - Certainly til after she'd finished school, but, we'd also come to the realization that we'd get to the point where we could no longer really cope without major intervention,
37. I - Yes, because of her behaviour?
38. B - Yes
39. I - Can you remember how you felt at that time when you were making those decisions about, you know, residential sooner than you'd expected?
40. B - To a certain extent devastated and I mean in many respects I still am, you know, there's an element of guilt there, I think that you know, and to a certain extent a feeling a little bit of a failure, you know you can't look after your own child, now.... I think we'd normalized her condition and normalized what she was doing and we were just saying that this is just the way she is and we've got to cope, but the reality is I mean most of the people I've talked to since, they've said we don't see how you coped as long as you did
41. I - No
42. B - You know, most people would have, that would have been years before...
43. I - But it was what you were used to I guess
44. B - Well yes, plus the fact that you still think to yourself, you still think, this is our child, we brought this child into the world, it is our responsibility, at least until we realized that she was never going to look after herself, but that's kind of the mind set we had, that's how we were brought up, that's what we expected to do
45. I - Yes, yes, can you remember the process of Becky getting to Ash House in terms of her getting a place allocated and ..
46. B - Well, it...yeah (resigned laugh), obviously there was a social worker involved at this point and the decision had more or less been made and we said we think we're gonna have residential, that she needs to go to a residential school and that was agreed at a meeting, the social worker went, they had an agreement for residential care but at first it was going to be term time only and we said, 'well, to be honest we don't think we can cope with that because that's that's....term time is 14 weeks a year we've got to look after her.' and they said, 'well yes, you have to do that if your child is in normal school', but no, because, we do what we can....when she was younger, you know, when people could cope, my wife's mother would look after the children, she'd come and look after the children for a couple of weeks during the summer holidays, we would take time off separately, effectively, that wasn't available as far as Becky was concerned we would need specialist, so, it would mean that effectively one of us couldn't have a proper job and, you know, we said that so the actual getting a place in a residential school was fairly straight forward, looking for a school could have been problematic, as I say we went to two schools, one was in county one was The Holt (another residential school in a neighbouring county) obviously Ash House and there were others that we could have landed up at but having gone to Ash House and seen how settled she was immediately she seemed perfectly happy, she wasn't phased by the place she just wanted to get out of The Holt
47. I - Right ok

48. B - We struggled to look round The Holt to be honest and we said, 'look, we've found somewhere almost instantly, is that acceptable?' they went, 'its out of county but we decided to give a yes to that', but they decided it was only for term time and once we got her in to the school then we had a bit of a fight on our hands to have it as a 52 week placement. I have to say that (the Head at Ash House) was absolutely fantastic, cos she said, 'there's no two ways about it, she is as bad as any of the children that we've got, with her behaviour and her condition, and they're all 52 weeks, usually 52 weeks, I mean you can see her any time you want, you can take her out any time you want as long as...', I can't remember the number of days is, she told us you know, weekends obviously are free, but what we particularly liked about the way that Ash House worked is effectively it's a 52 week year because they go to school 52 weeks a year, whereas the other schools, and that was something that meant in effect, that Ash House couldn't give her a full years education, cos what they do is, where they're supposed to have the 40 weeks, as you're probably well aware, they do Monday Tuesday, Thursday and Friday as school days and every Wednesday
49. I - They go out
50. B- They go out, so overall that means that they're getting the number, I can't remember...
51. I - There's a statutory number of days, yes
52. B - in actual fact, it's slightly higher than that and that's how they can turn round and say, I think its up to 4 weeks a year, they can say, up to 4 weeks a year, is alright, cos they still get their statutory days at school.
53. I - So you had to sort of fight for that, but then they
54. B - Yes, I mean to a certain extent not so much the state schools but every step of the way, was kind of a little bit of a fight, but we do understand why. In a perfect world it would be unlimited, but of course everything costs money and particularly at the moment
55. I - Yes. Yes,
56. B - And everything's being cut back and we do understand and we know that we've got another fight coming up
57. I - With the post 19?
58. B - Cos I've no doubt that they'll try and offer something that we'll think is appropriate and its not because they don't care, it's because they've got financial burdens and so they've got to and we've got to sort of fight the case to get the very best care that we can for Becky
59. I - Did you have any particular thoughts about how you and Becky would cope with her going to residential, so I suppose firstly did you wonder how she'd cope, would she adjust easily and things...?
60. B - We worried about it, we worried that she wouldn't be able to adjust to it and cope with it and that, I mean, it's difficult to say because she can't tell you, that she'd have a feeling of rejection
61. I - Yes
62. B -Because we weren't there all the time, erm,
63. I - So did you think...did you wonder whether that might be so?
64. B -Yes, but we didn't know, erm, as it turned out she settled in, pretty much immediately and now she's in a very good routine, she knows when she's coming home,
65. I - Yes

66. B -She's happy to come home, she's equally happy to go, I think we've only had one occasion when she didn't want to go back to school and we'd had a week's holiday on a narrow boat and we'd had a really lovely time and she'd had a really lovely time and when we took her back to the school, she wanted to be with us
67. I -Oh, right
68. B - And that's the only time that it's happened, I mean we've taken her out since, she's had two holidays since and both times she 's been perfectly happy to go back to the school
69. I - Yes
70. B - Ready to go back, I think she'd had such a lovely time, you know, so relaxed, but the next two times weren't quite as relaxed in fact, there were tensions by the end of it,
71. I -So really, you say, apart from the exception, she's been ...she's always coped with the transition
72. B- - Oh, yes, she knows the routines, she knows....obviously there are certain things the staff must be doing so that she knows that we're coming to collect her
73. I - Yes
74. B - And I normally go and collect her
75. I - So she doesn't come on transport?
76. B -No, no, because it's so close, Ash House have said, 'we'll bring her if you want, we'll transport her if you want , but we've said, 'you know, its only 20 miles up the road', it's not a great burden for us to go and collect her and take her back so it means that we pick her up normally on a Friday afternoon, take her back on a Monday morning, on the way off to work,
77. I - Can you remember yourself how you felt the first few days after you first took her?
78. B - Dreadful,
79. I – Yes?
80. B - I was (beginning to cry), even now.
81. I - Yes,
82. B - It's ...and we've been very lucky, that the school is so fantastic and very understanding, I mean they have coped with all of this before, and yes, when we took her, because we'd taken her the day before and then she came back home cos we took her stuff, got her packed in and then took her the next day
83. I - To stay?
84. B - To drop her off and I just wanted to be off but unfortunately there was paper work to do
85. I - Oh right
86. B - And we had to hang around and I was...I was...in bits really,
87. I - Right
88. B - Not happy at all

89. I - And was it, I presume, its eased, but perhaps, like you say, you still find it difficult?
90. B - I think it was very hard the first couple of weeks until we took her out the first time and that was probably the hardest, the house just seemed so empty, quiet, and of course, it's a bit difficult thinking back to it now, but of course there was no tension....there had always been tension before, because we never knew when she was going to kick off,
91. I - Yes
92. B - Yes, I mean, If I was at work and obviously Becky was here with Sue, I mean I had to carry a phone with me anyway, my work was pretty good if she started, I just said, 'she's off, I gotta go' and they'd say, 'go on then' and people would shut down my computer for me and...so that was pretty good, but...
93. I - And then, you didn't have that I guess...
94. B - It was just gone and then, the best way to describe it, its, its strange but, as I say I was in the airforce and I was in the first Gulf conflict and the airfield I was at was one of the ones that was most heavily targeted with scud missiles and we, the first time the sirens went off, everybody was a bit...but then it changed and you became tense until the sirens went off and once the sirens had gone off, you were calm, you were happy then
95. I - it was the waiting....?
96. B - Yes, when you first went in the shift you knew what was going to happen, pretty much, we found out that we was going to be alright, cos, you know, we were going to be pretty unlucky if anybody was hurt, to be honest, so I guess it worked that way, so it was a little bit the same, the tension, you were waiting all the time, for the outburst, once the outburst came, you could cope with it
97. I - Yes, yes
98. B - And then when she was gone it was like, you're lost, and you are still waiting for that
99. I - Sort of expecting it?
- 100.B - Cos that's what you've come to expect, and that would have taken about 2 weeks, probably not more, after that, I think now, it's a little bit less, because, we've kind of, as time's gone by, again, you normalize things, it's because sometimes you'll think to yourselves, well she's coming home this weekend, God, I haven't thought about her for..
- 101.I - Yes
- 102.B - I haven't given her a second thought, for the past week, the truth of the matter is you probably have, lots of times
- 103.I - Of course
- 104.B - But....
- 105.I - It's not in your face sort of thing?
- 106.B -- Yes, that's dreadful that, I should be thinking about her all the time but of course you don't cos you have to get on with things
- 107.I - I wonder, cos I know your wife said that your other daughter is away at university, I wondered if there was any similarity at all with her going away, I mean there may not be but I was just wondering, that's all?

- 108.B - Erm, there is to a certain extent, despite the fact that she is 19 now, she was 19 when she went, cos she didn't start til...
- 109.I - She took a gap year?
- 110.B - No, no, they have two intakes, she took the second one
- 111.I - Oh, I see
- 112.B - So it was February when she went away, she's been gone since February, I mean I didn't want her to go away and I'd still prefer her to be here, to a certain extent, but the difference was that she was going voluntarily to improve herself, to train, the start of her adult life, her career, all the rest of it, she's done that off her own bat, we pushed Becky, we didn't but we pushed Becky away
- 113.I - It felt like that?
- 114.B - Yes, we haven't you know, the decision to go to London, that was all Emma, if we had had our own way she'd have gone to (the local university)
- 115.I - Yes (laughing)
- 116.B - To be perfectly honest, but she said, 'No I don't want to go there, I want to go a bit further away', so she ended up in London
- 117.I - Ok, I just wondered cos that's like a separation as well, isn't it? But it's interesting how you've described it, one was voluntary, as you see it, one wasn't...
- 118.B - What I was saying to you, when she went, there's a positive end to it maybe, and we can see now that she's you know, she does have a home, and obviously she does feel a bit lonely down there, and that's one of the reasons why we would have preferred her to go to (the local university) we knew that everyone would be spread over a vast area
- 119.I - So how do you feel now about your decision to allow Becky to go to Ash House?
- 120.B - Erm, (hesitation) I think it's probably been the best thing for her, in reality erm, it's been good for us as well, but, for her I think it's been by far the best thing for her, I mean, she still has her moments, she can still flare up, but it's a lot less likely, we know she's in a safe environment which she likes, we know she likes all the activities that they do, and there's loads of them, good grief it's fantastic what she gets to do, so now we feel it's, and now in hindsight we say, 'we should have done it a lot earlier'
- 121.I - Right
- 122.B - It would have, it may have been the difference between, I'm not saying she would have had speech, or anything like that, but, I think she would have been far more settled in herself, she wouldn't have had that...it must have been traumatic for her as well, I mean she didn't know and when she became aggressive it was obvious she didn't know what she was doing and she was lashing out because she was frightened, most of the time, that's the way it felt to us, so she, you know...
- 123.I - So you could have avoided that....
- 124.B - Yes,
- 125.I - How old was she when she went to Ash House?
- 126.B - She was 14
- 127.I - So how much younger would you have thought it might have been better, like you say, if you could choose again?

128.B -Erm (long hesitation) now that's difficult to say, I would have said, probably as young as junior school

129.I - Ok, yes

130.B - Erm, certainly 10 I would have thought, because, that's not when she started becoming aggressive or anything like that, but it was where, I think that was probably the time when it started to get harder and harder and harder, to cope

131.I - Yes, I suppose as she got bigger physically as well, and things like that

132.B - Yes, you know, she is a big girl

133.I - Yes, your wife was saying that she's taller than her, is she

134.B -Oh yes and she's nearly the height of me

135.I - Yes

136.B - And she is losing weight now but she is at the moment heavier than I am

137.I - Right

138.B - Erm, but hopefully that's going to switch because they've got a good regime now for her eating and the weight's coming off fantastically well, to be honest, she's lost about 44 pounds

139.I - Has she?

140.B - Yes, since March, I mean it was essential, cos obviously the weight that she was it was starting to....physical and medical things, diabetes and heart disease and so , I think the changes they made were quite small and then all of a sudden, she...it's not as if they were giving her bad food

141.I - Oh no

142.B - It was just, that just that a little tiny change of behaviour...

143.I - And it's worked. You've talked there about a lot of positive things for Becky at Ash House, are there any other changes that you've noticed in her, since she's been there?

144.B - Erm...obviously the fact that she's a lot more settled, she seems happier, most of the time, in herself, the outbursts are...she still has outbursts but they're nowhere near as bad as they were and she seems able to cope with them better in herself and seems to have learnt in herself, things that she can do that's going to help her as well and Ash House will tell you this as well, if they say that she'll now take herself, when's she feels this coming on, she'll take herself away and she will go to what she will regard as a safe place

145.I - Right, ok

146.B - And I mean they've got some soft rooms where she can go, I mean they did at Lea Side

147.I - Safe places, yes, and will she take herself there at times now?

148.B - Yes, but in the end at Lea Side, they were concerned that she just saw that as a treat and she was just retreating into those places

149.I - Ok

150.B - I mean she still doesn't really interact with other children, even children that are...although that is slightly better now that she has become older, she has always, a very small child, I don't think she understands,

151.I - They're unpredictable

152.B - And she's very wary and doesn't want them near, she's always gone more for adults. She's always been fairly good with her sister, apart from the time when she stood on her head, which wasn't very clever (laughs)

153.I -Oh dear

154.B - Erm, so she's accepted her sister, who is, broadly speaking, but there's 2 years between them, so she's a little bit bigger but not much and she's accepted other children around her but she hasn't really interacted with them very much

155.I - Right

156.B - Whereas she would be more likely to interact with adults. I think she's now starting to interact more with them, probably because they're all young adults now,

157.I -Yes, well that's true and more familiar too

158.B - So she's interacting with them now more than she used to

159.I - Right, and you may think that you've said all that you want to say, about that, but changes in your own family situation, since Becky has been away? You did say that you had felt more relaxed, so is that the main change, or is there any other?

160.B - Erm, the other advantage of course of her being in residential school, is if she comes home, you know, we see an end to it, we know it's only going to be for the weekend, if she has a particularly bad weekend, we've only once asked Ash House to come and collect her

161.I - Right

162.B - And by the time they'd got here we'd actually managed to turn it round.

163.I - Ok, right

164.B - So she ended up stopping the weekend anyway, but I think from our perspective, we're better able to cope with her now, in that respect although when she does act up it does come as a bit more of a shock

165.I - Yes

166.B -And you have to rewind a little bit but we're better able to cope because of course we know that ...

167.I -It's time limited?

168.B - It's time limited, whereas before, really, without realizing it, when it was 24/7 it was

169.I - Unrelenting?

170.B - Yes....and especially when she got suspended from the school, cos that, even though, while she was at school all we did was go to work

171.I - Yes (laughing)

172.B - That was our respite

173.I - Yes, I see, so when you came home you were on duty, almost?

174.B -Yes, and I mean, you know, when she was younger it didn't matter so much she wasn't particularly bad, but towards the end, yes, it was pretty....

175.I - And again, and I know you've alluded to some of these things, is there anything else you'd want to say about what you like about how Ash House works?

176.B - Erm, I don't think there's anything about Ash House I don't like, the way that they've, certainly the way that they've, and I'm assuming this is because they have good interviews and all the rest of it, all the staff are fantastic, they're all very caring, they've made it as much like a family environment for the children as they possibly can and it, I think the children appreciate that. Particularly for autistic children, the educational method, this two days, a day off, two days, the weekend off, that they use, is by far the best because they don't have, autistic children need routine and they have this routine it is bang bang bang, it is there, and it doesn't have a 4 week break, or a 6 week break over the summer

177.I - No, it's a clever way of doing it

178.B - It really is, it's a superb way of doing it, I mean, I don't know how they do it but obviously most teachers, I know they don't really get this time off, but most teachers they're not at the coal face for 14 weeks of the year, it's a very nice job, I mean I know that teachers do have to do work when they're not at the school, during holiday time

179.I - Yes, I know what you're saying, but it's not the same as being in front of the...

180.B -Exactly

181.I - I guess they can manage it because they're a privately owned...they can make their own conditions for the teachers..

182.B - I'm just assuming that they've just got enough teachers and every so often one of 'em has some time off, otherwise they're... (laughs) working all the time, I mean I know they don't go in for the week of Christmas, but the care staff obviously are and the care staff still take them into the school and still do educational things with them, but without the teacher with them, but the types of things they're able to do

183.I - So, is it open every day of the year? So is it open Christmas day?

184.B - Oh yes, erm, it is.....we believe that we are unusual in the fact that we will always have Becky on Christmas Day

185.I - Ok, right

186.B - And that quite a lot of the children are there on Christmas day

187.I - Yes, cos in fact Christmas Day can be a particularly stressful time can't it for children with autism, so I suppose families make decisions....

188.B - Yes, to my mind, without naming any names, we know why some of the children are there and we think that those families are, it's not that they don't want their children on Christmas Day it's that the extended family can't cope with their children and in my opinion, if the extended family can't cope, that's their problem, that's the way that we feel. I mean luckily for us, our extended family would think there was something wrong with us if we didn't have Becky with us

189.I - Right

190.B - I'm not saying there'll not come a day when we don't, as time goes on

191.I - No, but at the moment that's what you want to do

192.B - Yes and certainly, while she's a child and when she starts getting into proper adult hood, then there may be an occasion when, the case in question would be, potentially, if Emma, not if, *when* Emma gets married, and has a family of her own and it may be that she wants us to go and see her at Christmas, in that case, then obviously we'll have a Christmas with Becky but then we'll go and see Emma. If Emma gets her own way she'll emigrate soon...

193.I - A long holiday then...

194.B- Yes. But, what else about the school? the size, the fact that they've limited themselves to a maximum of 11 residential students – I think they've got one or two ...

195.I - They've got a couple of day students

196.B - ...couple of day students, but they've limited themselves to 11 and the staff ratios are incredible. You don't normally get those kinds of staff ratios and the truth of the matter is, that, on occasions, they say they need, you know, it's all well and good saying, yeah, we know that each child needs 2 carers but they don't need 2 carers all the time, so if we've got 2 children we'll have 2 carers cos that will be enough, if we've got 4 children, we only need 3 carers and that'll still be enough, no, that's not the way Ash House do it, each child, 2 carers, and that way, obviously the carer's have other duties to do as well, as they're other things that have gotta be done, but ...

197.I - They're there if...

198.B- They're there if, yes

199.I - So you feel confident in that side of things then, yes

200.B - Yes

201.I - What about things like communication, do you feel happy that you know what's going on in Becky's life?

202.B -Yes, definitely, if there's any change that has to be made to her medication, in reality, the school almost by default been given the right to do that, now, they ask our permission for every piece of medication, I mean, and its written down what they can do, so for example, paracetamol, we've explained when we would give Becky paracetamol and we've given them permission to give it so they don't ring us up to say, 'can we give her paracetamol'.

203.I - Yes

204.B - That sort of thing, but any of her diagnosed medication, they'll call us and say, 'we've sent you an email can you respond and give your permission for this change?' Any major changes, for example, they changed the epilem and they asked us to approve that, which we've done so, as far as her health's concerned, if 'er, if one of the doctors says, 'yeah, I want this procedure to be done' they say, 'yes, we'll ask the parents for permission', so they come to us over that sort of thing and any thing like they want to do with her, that's new, again, they come to us and say, 'right, we'd like to do this with Becky, is that alright? 'Yes', 'so next time you come in can you sign a consent form?' Some people would say that they're trying to hand over the blame to a certain extent but that's not the reason it's done, it's to keep you in the loop and they most positively say, that, you know....

205.I - She's yours?

206.B - 'We're looking after her for you, you make all the decisions, you make the decisions on her behalf we'll do whatever you ask', unless of course it's against the law, or whatever, it's got to be within the

parameters of the law and all the rest of it. But yes, and other things, you know, they'll call up and say, 'she's had a really good day'

207.I - So you do feel that you know what's happening to her and things?

208.B - Yes, and of course the other thing is and another thing which is a major plus as far as Ash House are concerned, we can go and see her any time, without notice, we're always welcome with open arms and we can collect her whenever we want, I mean, we always give them notice of course, but occasionally it gets missed in the diary and the last time we picked her up, we turned up and they went, 'oh, we weren't expecting you today, but that's not a problem, we'll just get her meds and we'll get her sorted for you', so it's off you go, so there's no problems as far as that's concerned and it's any time of the day or night, erm...

209.I - So it sounds like, all of that, makes you feel very confident and relaxed about where she is

210.B - Oh yes, cos I mean in some places you have to book a visit, and book permission to take em out and if we were to go now and say, 'we're having Becky for the weekend', it wouldn't phase them at all, they'd say, 'oh, yeah, we didn't have it in the diary but it doesn't matter' it doesn't make any difference. The only thing they advise, and it's entirely up to you, you can take her out every single weekend if you want, but what we'd advise is, that you take her out every second or third weekend and we've taken that advice on board and we do take her out, I mean we try to make it every third weekend and occasionally it had to be adjusted cos if there's a meeting at the school we'll inevitably bring her home with us, there's slight adjustments and obviously Christmas times, it obviously doesn't always fall exactly three weeks so there are adjustments there...

211.I - Yeah, so there is that flexibility, that you're describing, the openness...

212.B - Oh yes, extremely and very, very open, there's nothing, well there isn't anything that.... you don't feel as if there's any possibility that it's hidden...

213.I - Right, erm, how would you describe your relationship with Becky now, since she's been there? Has there been any change, is it better or worse than it was before?

214.B - (hesitation) it's not worse, I wouldn't say it was better. Is it better? I didn't connect with Becky when she was young, for a long time

215.I - ok

216.B - probably because...it got better once I knew she was diagnosed

217.I - ok, because you wondered what it was and you couldn't make sense of it?

218.B - Yes, yes, and as time went on, I mean, when she's good, she's fantastic, she's just lovely

219.I - Yes

220.B - And, as time went on, I think as well she got physically stronger, I had to start taking the lead more, simply because physically I could cope with her and so in that respect I think...I'm no more distant from her now, but I, I think I became very, very close to her

221.I - Yes, yes

222.B - From a, from what I would regard now as a very poor start, erm (becoming upset)

223.I - Maybe you were at work and away as well, were you?

224.B - Erm, no....

I- It wasn't that?

225.B - Not, I just somehow, didn't connect until...., I don't know....., maybe the gap between Emma and her turned out, it's a better gap now as it's turned out. But maybe it was a little bit short cos Emma still needed a lot of attention and then of course somebody else comes along and I... my attention for Emma and this ones not responding and...

226.I - So again, maybe it was when you felt you had a role to play later on?

227.B - Quite possibly, but overall, I would say my relationship is...I wouldn't say it was better, it's more relaxed

228.I - Right ok

229.B -it's more relaxed, but I wouldn't say it's better now than when she went to Ash House

I- But it's not worse?

230.B - Certainly not worse

231.I - It's just different by the sounds of it?

232.B -It is different, yes it is, it's different

233.I - Yes, and finally, what are your hopes for Becky's future?

234.B - Well, we know that there's not going to be any independence, erm, as far as we're concerned, we want her to continue at Ash House as long as possible. If it's not Ash House then it has to be something that's run on exactly the same lines.

235.I - Yes, right

236.B - I don't know anywhere else that's built on exactly the same lines as Ash House, erm, I mean we did once consider a residential school before, but the only ones we found were miles and miles away and I mean their methods, I mean some of the schools, two schools were run along the lines of the Higashi schools

237.I - Right

238.B - Which they've had fantastic results, but I think that's a hard regime

239.I - Yes, yes, and you've got to be comfortable with it yourself, I think

240.B - Yes, yes I think that can be a hard regime and I don't know whether it would have benefitted Becky at all so, obviously we've now accepted the fact that she's got to be in residential care for the rest of her life, really and what we want, what our aim would be that it's as close as possible to Ash House, in fact, as far as we're concerned, it needs to be Ash House

241.I - Yes, ok, right, and is there anything else that you think is important that I've not asked you about, that you want to say?

242.B - No, I can't really think of anything else that springs to mind, it's ...

243.I - Ok, that's fine. And just finally I just wanted to ask you how you found the experience of being interviewed about Becky, today

244.B - Alright actually it's quite good in some respects cos obviously we've discussed it amongst ourselves, but it's nice to discuss it with someone else, perhaps on a more professional level and realise

some of the things, that you forget, cos you see you do normalize it and so it just serves as a reminder of what it's like, what it was like,

245.I - Where you've come from...

246.B - To be honest, how lucky we are at the moment, to have her where she is, cos I have to say that if we hadn't found Ash House I think we'd still be struggling a great deal cos

247.I - As a family you mean?

248.B - Well, it would have had to be a residential school and we'd have struggled to find somewhere and I don't know if Becky would have settled as well, well she may have done, but I think it would have been a pretty hard thing. It certainly wouldn't have been The Holt

249.I - Right, yes

250.B - Erm, which means that we'd probably be the school in (the town 150 miles north) which we'd tried to put her name for, which is along the Higashi lines and there's another one in (a town 150 miles south) and they would have been obviouslyif that had been the case our preference would have been (the town 150 miles north), cos we're obviously from that area and have family there and I think we would have preferred that there was some family close at hand, that could, if there had been any emergency, they could perhaps go and see Becky, while, you, know, in the time it took us to get there

251.I - Yes, not like you could just nip up the road

252.B - No, it would have been a three hour drive and then of course seeing her would have been that much more difficult and that much more expensive, I mean let's face it, the cost of fuel now, it's horrendous, I mean, we've been very lucky in that respect.

253.I - Well thank you very much.

Appendix 11

Super-ordinate themes	Emergent themes
enduring loss	lost identity losing identity as parent as expert of their child loss of autonomy loss of expected child calm vs tension confusion enduring nature of the feelings guilt the unknown disappointment loss of expected grandchildren failure as parent impact of change/decision enduring nature of experience impact on family life intense demands of asd
family versus system	abandoned helpless rejection reliance on the system rejection by the system conflict with the system dependent on the system battle against the system frustration
extreme parent	worry regret denial urgency parent intuition protective parent advocate the journey of asd identity as parent normalization of behaviour threat to parenting identity
relief of residence	like a family extended support acceptance coping support loyalty trust individual vs generic needs relief gratitude rescue confidence safe and secure order and stability restoration of confidence restoration transformation

	transparency openness time limited vs enduring adjustment
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Appendix 12 – Summary of ‘Brian’s’ interview

First concerns:

- Brian found Becky confusing as an infant
- he knew there was something wrong, but was not sure what this was
- he tried to make sense of her behaviour
- he found this a difficult time as a parent

Feelings around diagnosis:

- it was a relief to get the diagnosis –to find out there was a reason for Becky’s behaviour – not due to something Brian, as a parent, had done ‘wrong’
- he had some optimism about her progress initially, but this has not been realised, specifically Becky has not developed speech, which is a regret for Brian
- Becky had an early diagnosis – there was no difficulty in receiving this and this was not a source of any additional stress or frustration
- the diagnosis was also a relief as it opened up routes to education and early intervention

School experiences before Ash House

- Becky went to a specialist nursery, as well as a mainstream nursery and then onto special school
- school was manageable when Becky was younger, but things become more difficult as she got stronger and more physical as a teenager
- Brian could see that Becky required more specialist help than the school could offer
- she was becoming more challenging at home and at school
- she was finally excluded from school and spent a period of time at home while Brian and Sue were looking for a more suitable school for her

- this was a very challenging period of time when Becky was at home full time and Brian and Sue had to share the caring for her as well as working and caring for Emma, their older daughter

First thoughts about residential school:

- after Becky was excluded from her local special school, Brian was forced to look for residential schools as these were the only schools that offered the next level of provision
- he had wanted to delay this move for as long as possible, at least until Becky had left school, but as the situation changed and caring for Becky became so challenging, Brian had to look at residential schools to make sure she was safe and secure and receiving appropriate education
- Brian, as a parent, had to do a lot of research himself, as support from professionals was not forthcoming and he was then very clear about what he wanted for Becky
- Brian was very aware of the need to consider the rest of the family, including Emma
- Brian described a feeling of devastation and guilt when he first had to make this decision to place Becky away from the family home and he still has these feelings, several years later
- Brian had strong feelings of failure, as if he should have been able to care for his child, as he cared for Emma and as all parents are expected to care for their children, but he couldn't care for Becky at home, in the same way
- he now realises that he had 'normalised' the situation and considered the daily family life, with Becky, as normal – which then made it harder to accept that what he was doing, in considering a residential placement, was the right thing for Becky and his family.
- friends provided social support and helped Brian to appreciate that he was doing the right thing, by placing it in perspective, when they pointed out that it would be unreasonable to expect anyone to manage and meet Becky's complex needs.

Gaining a place at Ash House:

- Brian quickly identified Ash House as the right place for Becky, but then had a battle with the Local Authority over a 52 week placement
- he needed support from the Head of Ash House for this, and also the way that Ash House organises its school year helped in the negotiations with the Local Authority
- he can appreciate that there are monetary considerations for Local Authorities but is also aware that this makes it very difficult for families like his own, with a child that has such complex needs – this is a dilemma that Brian recognises
- Brian feels he has had to fight for Becky, to be her advocate, to gain the right provision for her.
- he is prepared to continue this fight into post 19, which is the next step in her process, and beyond.

How Brian and Becky would cope with the change:

- Brian worried about how Becky would adjust to the change, particularly because she is not able to communicate her feelings through speech, only through her behaviour
- he held a particular concern that if she felt rejected, from being away from him and the wider family, it would be impossible to explain this to her
- Brian was therefore very relieved that she quickly settled into the routines of Ash House and he was assured of this by the fact that she happy to come home but equally happy to go back to school, following visits
- Brian has complete confidence in Ash House, and he considered it a primary factor in making his choice, that Becky immediately looked comfortable and at ease in the school, from her first visit

The first days at Ash House

- Brian had very strong emotions at this time and this feeling is still present, and able to stir up deep emotions, as evidenced during this interview as he became distressed, recalling the events
- Brian felt reassured that the school had been so welcoming and that Becky had immediately settled, but it was still very hard to leave her and he was very distressed at this time
- it was very difficult for Brian during the first two weeks of Becky's residence as the house was empty and he also realised that there was no longer the tension in the house that had been present while Becky had been with the family. Brian compared it to a constantly stressful situation when he had been serving in the Gulf War and had been on a constant state of alert until the sirens had gone and there was then, paradoxically, a sense of relief– which was how it had felt at home – he had been very stressed, waiting, until Becky had an outburst, then there was almost a sense of relief as he knew then what to do and how to cope with it. It took about two weeks for this feeling to subside.
- Brian sometimes feels guilty now when he realises he has not thought about Becky during the week as he thinks he should be thinking about her all of the time. However, Brian can recognise that he has a different sort of life now – where Becky is not demanding his attention every second of the day.
- Brian is coming to terms with understanding that he has his own life to lead, separate from Becky (as most parents of teenagers/young adults also come to realise)
- Brian can see some parallels between the separation of Emma from the family, to go to university and Becky going to Ash House, but he feels strongly that the difference is that Emma made her own choice to go, that she went voluntarily and that there will be a 'positive' end for her (i.e. a professional qualification). For Becky, he has a feeling that he 'pushed' her away, she didn't make a positive choice, even though he is satisfied that she likes it at Ash House.

Brian's reflections on the decision:

- it was the best decision for Becky and for the family

- Becky has every opportunity, she's safe and secure
- Brian has a regret that he did not make the decision earlier, possibly around age 10, to save Becky the trauma of the challenging behaviour that she showed, prior to starting at Ash House

What changes has Brian seen in Becky?

- she is more settled, happier, fewer outbursts at Ash House and when she comes home
- she has more self awareness as she will take herself to a 'safe place' at Ash House if she feels distressed
- there is possibly more interaction with her peers

Changes in Brian and the family:

- everything is more relaxed
- Brian can cope with any difficulties that might arise at the weekends as it is 'time limited' and there is the knowledge that Becky will be going back to Ash House.
- if Becky does have an outburst, it can take Brian by surprise as he has become accustomed to a calmer life. When they do occur, it is a reminder of how stressful family life had been prior to Ash House

What Brian likes about Ash House:

- Brian is very pleased with how Ash House works and has no suggestions for improvements
- He particularly noted as positive factors: the staffing ratio; the quality of staff; the small size of the school; the 'open door' policy; the general flexibility of it all; their specific arrangement for providing education 52 weeks of the year; and their methods of communication
- Brian has complete trust in the staff at Ash House and is very confident to leave Becky in their care

- Brian particularly values the fact that although Ash House could make decisions on his behalf, regarding Becky, they still respect him as her parent and will always seek permission
- He also particularly likes the openness of Ash House, that he feels he can drop in at any time, without any appointment

Brian's relationship now with Becky:

- Brian felt that he had a difficult time 'connecting' with Becky as a young child, because he found it difficult to understand her. As a result of the autism, Becky did not respond to him as Emma had done and also he felt as if he had to share his attention between Emma and Becky as their age gap was close and both were demanding
- However, Brian's relationship with Becky became closer as she grew up and he assumed a bigger role in her care (through necessity, as she became too strong for her mother to manage at times)
- this was a more functional role, but Brian describes his relationship with Becky as a result of this as 'very close'
- now Brian thinks his relationship with Becky is more relaxed, it is different, not better not worse, but different
- Brian can remember with affection, the very happy times that he had as a family, with Becky - a holiday on a narrow boat in particular. He is able to remember that she is often a lovely girl
- Brian feels strongly that Becky is an integral part of his family and he finds it hard to fully understand how some parents make different decisions regarding, for example, having their child home for Christmas, as including Becky is a fundamental principle for Brian.

Hopes for Becky's future:

- Brian has reluctantly accepted that Becky will never live independently

- He wants the very best for her in terms of provision – he would like her to stay at Ash House for as long as possible, and if she has to move, then it should be to a place on exactly the same lines as Ash House.
- Brian realises that Ash House is probably unique, so there is a sense of worry and uncertainty about what might happen in the future

How did Brian find the interview process?

- he found it useful to discuss the issues with someone outside of the family
- he found it useful to look back over events and this helped him to realise just how difficult it had been at times with Becky, as well as appreciating the happy times
- the interview has helped Brian to confirm his decision to choose a residential placement for Becky as the correct one
- Brian feels fortunate to have found Ash House. This is a strong view, to the extent that Brian has stated that he is not sure what the outcome would have been without finding a school he was happy with, because Becky could not have remained at home. This may have resulted in the need to make a very hard decision about a place that would not have been his first choice.

Exploratory comments	Original transcript	Emergent themes
<p><u>Parent's intuition? Confused narrative – is this as it was confusing when Becky was young?</u> describing a confused and frustrating time</p> <p><u>Confusing time, hard for a parent to not be able to meet the needs of their child?</u></p> <p><u>Confusing time, worrying time</u></p> <p><i>Intuition, 'there was something not right'</i> <u>Running away with the story, did it seem like things were happening fast then?</u> <u>As if they were losing control, handing over to professionals?</u> Becky was diagnosed early – <u>was this due to</u></p>	<p>I - So, from your point of view, when did you start having concerns about Becky?</p> <p>B - When she was really, really young. When she was, she..... seemed completely unaware of people around her, not so much her surroundings, but of people, and didn't seem to pay any attention, she was, I wouldn't say she was a whingy child, but when she started crying, she didn't take comfort in the same way as you'd expect, at least I didn't think she did which was quite frustrating obviously as</p> <p>I - You can't do anything...?</p> <p>B - You do all the things, carry her about, and all the rest of it, it didn't seem to make any difference. At first, as Sue (mum) has probably said, we first suspected that she couldn't hear</p> <p>I - Yes, yes</p> <p>B - Because the kind of thing that she would do is if, if you went into her room, she wouldn't sort of look, and I've never known a child not do that, so of course the first thing you think is she simply can't hear us but we had her hearing tested and all the rest of it so I'd say she was probably as young as a year, maybe 18 months...</p> <p>I - When you were wondering about things?...</p> <p>B - There was something not</p>	<p>Losing identity as parent as expert of child</p> <p>Confusion</p> <p>Frustration</p> <p>Lost identity, Helpless</p> <p>Vigilant parent</p> <p>Parent intuition</p> <p>The journey of asd</p>

<p><u>connections in the air force?</u></p> <p>The diagnosis was not very accurate and may have given Brian false hopes</p> <p>Understated, <i>'it's been somewhat worse than that'</i></p> <p><u>Some relief but didn't understand the impact of the diagnosis, relief at knowing what it was and that it wasn't them being neurotic. Had they been made to feel like this? Should the doctor have been clearer?</u></p> <p><i>Confused and disjointed narrative – is it difficult for him to think this through</i></p> <p><u>The journey of realization of the impact of the asd, 'there was a little bit of optimism, but as time went on...we quickly realized...'</u></p> <p>The diagnosis helped to secure provision for Becky. <u>Brian is focused on the practicalities rather than on his feelings – is this a</u></p>	<p>right, but we didn't, I mean we didn't at the time suspect at all that it was autism as I say at first we thought she's got a hearing problem, but after that was tested, well we were up in (air base) at the time I was in the air force and we were stationed up there and it started to be investigated and we told the doctor in the hospital about it and we got posted down to (new county) and she happened to know a doctor in the local hospital and she actually referred her to that doctor, the doctor who gave the diagnosis that she was autistic and she was able to do it at a very young age, she said normally you can't diagnose this until I think she said about 4</p> <p>I -Yes, around then</p> <p>B -But she said, 'I've no doubt she's showing <i>all</i> the traits'. She did think that she would probably have speech, but unfortunately she never really had and she said the chances are she'd be a bit eccentric</p> <p>I -Right</p> <p>B - But again, it's been somewhat worse than that</p> <p>I -So can you remember how you felt at that time, when you were hearing that...?</p> <p>B -Well I think to a certain extent we were glad that we now knew what it was, we didn't know what autism was, obviously, we had to do a bit of research on that, but at least we knew, yes, it wasn't just us, that there was something,</p>	<p>Loss (of expected child)</p> <p>Loss of expected child</p> <p>Conflict of emotions Vigilant parent</p> <p>Dependent on the system, loss of autonomy</p> <p>Journey of asd</p> <p>Vigilant parents</p> <p>Loss of expected child</p> <p>Relief</p>
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<p><u>deliberate act?</u></p> <p><i>Returning to his point about Becky speaking – very confused and rushed narrative</i></p> <p>Poignant time – Brian remembers this clearly ‘oh, is this the beginning? Never happened again’ the disappointment of the false hope and the realization that Becky would not develop language pleased and relieved to be receiving help</p> <p>Difficult for Brian to recall the detail</p> <p><u>Did he become a governor to have some influence?</u></p> <p><u>Sue clarifying – why does she feel a need to do this?</u></p> <p>Already Becky is challenging the provision and presenting as having more complex needs.</p>	<p>something there and of course at the time, because the doctor had said, the chances are she will have speech it may be a bit slow in developing but she probably and then she never did...</p> <p>I - So you perhaps had some optimism...</p> <p>B - There was a little bit of optimism, but as time went on I think we fairly quickly realized, I mean she has said the odd thing and I mean one day in here, cos, I think the other thing that helped then was that we started getting help because as the doctor pointed out, the best thing for autism was through education so the education side started coming in then, and, you know, we started, getting people coming in to see her and of course that led to her, she got a place at a specialist, or more specialized place, at a nursery that had specialized, so you see those sort of things happened</p> <p>I - So some interventions</p> <p>B - so she did one day when, I can't remember now, it's such a long time ago, she just sat there and she just came out with one phrase, which was 'the wheels on the bus', she wanted me to sing it, and it was perfect, and we thought, 'oh, is this the beginning?' never happened again (laughing) , strange, but yes, I mean I think yes, there was optimism, then and at least we knew we were starting to get the right help</p> <p>I - Yes, yes, so something was</p>	<p>Confusion Reliance on the system</p> <p>Rejection Disappointment</p> <p>Journey</p> <p>Rejection</p>
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<p><i>Brian's narrative is confused again</i></p> <p><u>Rejection? Disappointment</u></p> <p><u>Rejection? Disappointment?</u></p> <p>The turning point is puberty as Becky's behaviour deteriorated and she got physically stronger Becky had to be excluded – why is this the only option? <i>Brian hesitates over saying 'suspend' – does he still find it hard to think about</i></p> <p><u>Was this the case? Does Brian have to believe that Becky was not rejected? The reality was because there was no suitable provision</u></p> <p><i>Repetition of 'disappointment' to emphasise the depth of feeling – this was personal to Becky and not a decision made according to a checklist?</i></p> <p>Becky's behaviour is also affecting homelife</p> <p>A misunderstanding – <u>is Brian sensitive to the fact that she's not living at home now?</u></p> <p>Becky has to stay at home and this puts a strain on the family <i>'this is well beyond our...'</i></p>	<p>happening. So you've told me about the time of the diagnosis as well there, erm can you tell me a little bit more about, from your point of view, Becky's experiences of school before Ash House, what you can remember about it?</p> <p>B -Erm, I think when she was, ...she was fine at nursery, not a great problem at nursery, she then went to Lea Side school, and at first I think it was alright but as time went on, they said to us, I actually became a governor of the school</p> <p>I - Alright</p> <p>B -The headmaster, I think said, 'look', he said, 'we don't think.....'</p> <p>('sorry but that was Elmton not Lea Side' – Sue from kitchen)</p> <p>B -ok, it was Elmton, so, then they then said, really, we, you know, she needs more specialist than what we have cos I don't think any of the children at Elmton I think there was one of them, but again that child moved in the end, the rest of them all had speech so yes, they did have autistic children but they all had speech. Fairly high functioning and so really it needed another school so at first she was fine, then they're saying, 'really we're not going to be able to do a great deal for her, she needs to go to a school that's more set up for children with her special needs'. We then sent her to Lea Side and fantastic to off start with, can't fault the school and the staff and</p>	<p>Battle against the system Individual needs vs generic</p> <p>Advocate</p> <p>Failure as parent denial</p> <p>Coping</p>
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<p><i>the extent of Becky's needs.</i> The carers could not meet Becky's needs –this provision was totally inadequate and illustrates the mismatch between Becky's needs and how the council perceive it – <u>individual vs general</u> Brian thinks its important for Becky's views to be taken into account '<i>it was the only school where she seemed happy</i>' <u>Inclusion argument – is viewing children as individuals and not as a general class more respectful?</u></p> <p>Brian is realistic about the long term for Becky, but it was difficult for him to consider residential while she was still young '<i>but I think we had both hoped to put that off as long as possible</i>' – <u>viewed as a negative move? A final admission of failure as a parent?</u></p> <p>Brian is realistic – the situation is very serious</p>	<p>all the rest of it, and again she was alright, but as time went on and she got closer to puberty she became more and more of a risk and unfortunately the school, in the end, had to take the decision, to, to er, to suspend her for a period because in effect it wasn't so much that she was a danger to the staff, although she was, it was the fact that really she was a danger to the other children</p> <p>I - right</p> <p>B -so, and they were really disappointed, the head teacher was so disappointed that he was having to do this and that's when we started looking, and things were becoming more and more difficult at home</p> <p>I - and so was she at home for a time, while she was out of school?</p> <p>B -oh yes she, she lived at home until she went to Ash House</p> <p>I - oh no, sorry, I mean was she not going to school?</p> <p>B - there was a period, I can't remember exactly how long it was, while she was suspended yes, when she was at home and we were having to take time off, the county put 2 carers in, after half a day they were gone because they went, 'this is well beyond our ...' and at the time then we were looking, obviously, looking very hard for a school and incredibly the first school we went to just seemed perfect, which was Ash House, not that it was the only school we looked at,</p>	<p>Conflict of emotions Failure Guilt Normalization of behaviour Coping Enduring nature of the feelings</p> <p>Identity as parent Loss of expected child Enduring nature of experience</p> <p>Conflict with the system</p> <p>Complexity of asd</p>
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<p>The depths of emotions for this decision Conflict of emotions <i>'devastated' the feeling is still there, 'in many respects I still am'</i> <i>'an element of guilt'</i> <i>'and to a certain extent feeling a little bit of a failure' 'you can't look after your own child'</i> Ruminating on normalizing Becky's behaviour Brian needs the vindication of others to help him cope with the decision</p> <p><u>Brian hesitating over saying, 'residential' – is he ashamed, or still doesn't like to make it real?</u></p> <p>Strong parental responsibility for Becky, <i>'this is our child, we brought this child into the world, it is our responsibility'</i> – is this borne out of guilt? Brian thinks this goes back to his and Sue's own style of upbringing – <u>maybe this is why it has been so hard to accept that she has gone to residential school?</u></p> <p><u>Doesn't seem to have been any dispute over gaining a place at a residential school</u></p>	<p>it was the only school where she seemed happy</p> <p>I - right, yes, so had you thought about residential prior...</p> <p>B - I think....</p> <p>I - Had you looked at those because they were residential or...</p> <p>B - It was only after she's been suspended from Lea Side that we looked at residential schools, before that as far as we were concerned, I mean we knew that at some point she was going to end up in residential care, we were never going to be able to look after her for her entire life, it was just physically impossible for us to do and we knew, but, I think we both had hoped to put that off as long as possible</p> <p>I - Yes, yes</p> <p>B - Certainly til after she'd finished school, but, we'd also come to the realization that we'd get to the point where we could no longer really cope without major intervention,</p> <p>I - Yes, because of her behaviour?</p> <p>B - Yes</p> <p>I - Can you remember how you felt at that time when you were making those decisions about, you know, residential sooner than you'd expected?</p> <p>B - To a certain extent devastated and I mean in many respects I</p>	<p>Impact on family life</p> <p>Individual vs generic</p> <p>Restoration Rescued</p> <p>Battle against the system</p> <p>Openness Support Acceptance</p> <p>Support rescue</p>
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<p>– just the particular one and the hours</p> <p><u>The conflict with the system over care for Becky in the holidays – the dilemma over what you could reasonably expect a parent to do themselves – but also it is the issue of those with asd learning 24/7, not just during the school day or term time –it is a qualitative difference not just time?</u></p> <p><i>Brain is indignant at the suggestion from social worker that they were trying to get away with caring for Becky, ‘but no, because we do what we can...’</i></p> <p>Brian describing the efforts they had gone to to care for Becky at home</p> <p>Impact on family life, ‘<i>it would mean that effectively one of us couldn’t have a proper job</i>’ – <u>should this be considered?</u></p> <p>Taking Becky’s views as the deciding factor, trusting her instincts, even though she could not communicate them conventionally –it is important to Brian that they consider Becky</p> <p>‘<i>a bit of a fight on our hands</i>’ – <i>conflict metaphor to secure the right provision</i></p>	<p>still am, you know, there’s an element of guilt there, I think that you know, and to a certain extent a feeling a little bit of a failure, you know you can’t look after your own child, now.... I think we’d normalized her condition and normalized what she was doing and we were just saying that this is just the way she is and we’ve got to cope, but the reality is I mean most of the people I’ve talked to since, they’ve said we don’t see how you coped as long as you did</p> <p>I - No</p> <p>B - You know, most people would have, that would have been years before...</p> <p>I - But it was what you were used to I guess</p> <p>B - Well yes, plus the fact that you still think to yourself, you still think, this is our child, we brought this child into the world, it is our responsibility, at least until we realized that she was never going to look after herself, but that’s kind of the mind set we had, that’s how we were brought up, that’s what we expected to do</p> <p>I - Yes, yes, can you remember the process of Becky getting to Ash House in terms of her getting a place allocated and ..</p> <p>B- Well, it....yeah (resigned laugh), obviously there was a social worker involved at this point and the decision had more or less been made and we said we think we’re gonna have residential, that she needs to go to</p>	<p>Fight against the system</p> <p>Fight against the system</p> <p>Advocate Vigilant parent Fight against the system</p> <p>Rejection Worry</p>
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<p>Brian appreciates the support of the Head He appreciates the transparency of the provision and the easy access to Becky</p>	<p>a residential school and that was agreed at a meeting, the social worker went, they had an agreement for residential care but at first it was going to be term time only and we said, 'well, to be honest we don't think we can cope with that because that's that's....term time is 14 weeks a year we've got to look after her.' and they said, 'well yes, you have to do that if your child is in normal school', but no, because, we do what we can....when she was younger, you know, when people could cope, my wife's mother would look after the children, she'd come and look after the children for a couple of weeks during the summer holidays, we would take time off separately, effectively, that wasn't available as far as Becky was concerned we would need specialist, so, it would mean that effectively one of us couldn't have a proper job and, you know, we said that so the actual getting a place in a residential school was fairly straight forward, looking for a school could have been problematic, as I say we went to two schools, one was in county one was The Holt (another residential school in a neighbouring county) obviously Ash House and there were others that we could have landed up at but having gone to Ash House and seen how settled she was immediately she seemed perfectly happy, she wasn't phased by the place she just wanted to get out of The Holt</p>	<p>Order and stability</p>
<p>Brian describing the unique way Ash House operates which supports parents in their request for a 52 week placement</p>	<p>that's....term time is 14 weeks a year we've got to look after her.'</p>	<p>Confidence stability</p>
<p>Brian describing the unique way Ash House operates which supports parents in their request for a 52 week placement</p>	<p>and they said, 'well yes, you have to do that if your child is in normal school', but no, because, we do what we can....when she was younger, you know, when people could cope, my wife's mother would look after the children, she'd come and look after the children for a couple of weeks during the summer holidays, we would take time off separately, effectively, that wasn't available as far as Becky was concerned we would need specialist, so, it would mean that effectively one of us couldn't have a proper job and, you know, we said that so the actual getting a place in a residential school was fairly straight forward, looking for a school could have been problematic, as I say we went to two schools, one was in county one was The Holt (another residential school in a neighbouring county) obviously Ash House and there were others that we could have landed up at but having gone to Ash House and seen how settled she was immediately she seemed perfectly happy, she wasn't phased by the place she just wanted to get out of The Holt</p>	<p>Order and stability</p>
<p>This was a bit confusing but to Brian it was the key to securing the 52 week placement Getting a bit lost and tied up in the detail of the placement, but it was important to Brian because it meant that the LA agreed to Becky having a full time placement at Ash House</p>	<p>we do what we can....when she was younger, you know, when people could cope, my wife's mother would look after the children, she'd come and look after the children for a couple of weeks during the summer holidays, we would take time off separately, effectively, that wasn't available as far as Becky was concerned we would need specialist, so, it would mean that effectively one of us couldn't have a proper job and, you know, we said that so the actual getting a place in a residential school was fairly straight forward, looking for a school could have been problematic, as I say we went to two schools, one was in county one was The Holt (another residential school in a neighbouring county) obviously Ash House and there were others that we could have landed up at but having gone to Ash House and seen how settled she was immediately she seemed perfectly happy, she wasn't phased by the place she just wanted to get out of The Holt</p>	<p>Impact on family</p>
<p>This was a bit confusing but to Brian it was the key to securing the 52 week placement Getting a bit lost and tied up in the detail of the placement, but it was important to Brian because it meant that the LA agreed to Becky having a full time placement at Ash House</p>	<p>problematic, as I say we went to two schools, one was in county one was The Holt (another residential school in a neighbouring county) obviously Ash House and there were others that we could have landed up at but having gone to Ash House and seen how settled she was immediately she seemed perfectly happy, she wasn't phased by the place she just wanted to get out of The Holt</p>	<p>Calm, order and stability</p>
<p>Getting a bit lost and tied up in the detail of the placement, but it was important to Brian because it meant that the LA agreed to Becky having a full time placement at Ash House</p>	<p>but having gone to Ash House and seen how settled she was immediately she seemed perfectly happy, she wasn't phased by the place she just wanted to get out of The Holt</p>	<p>Identity as parent</p>
	<p>I - Right ok</p>	<p>Identity as parent</p>
	<p>B - We struggled to look round</p>	

<p>Brian is understanding of the system, <i>'every step of the way was kind of a little bit of a fight but we do understand why'</i></p> <p>Finance is an important factor and Brian recognizes this <i>'another fight coming up'</i></p> <p><i>'it's not because they don't care'</i> <u>Brian is understanding of the system, but sees it as all to do with money – Brian sees this as an inevitable fight between him and the system to gain the right provision for Becky</u></p> <p><u>Worried about Becky being able to adjust and cope and also that she would feel rejection - from the family I think ?</u></p> <p>Hard for Brian to think back on this – emotional</p> <p>Brian is settled as well as Becky – there is this symbiotic relationship</p>	<p>The Holt to be honest and we said, 'look, we've found somewhere almost instantly, is that acceptable?' they went, 'its out of county but we decided to give a yes to that', but they decided it was only for term time and once we got her in to the school then we had a bit of a fight on our hands to have it as a 52 week placement. I have to say that (the Head at Ash House) was absolutely fantastic, cos she said, 'there's no two ways about it, she is as bad as any of the children that we've got, with her behaviour and her condition, and they're all 52 weeks, usually 52 weeks, I mean you can see her any time you want, you can take her out any time you want as long as...', I can't remember the number of days is, she told us you know, weekends obviously are free, but what we particularly liked about the way that Ash House worked is effectively it's a 52 week year because they go to school 52 weeks a year, whereas the other schools, and that was something that meant in effect, that Ash House couldn't give her a full years education, cos what they do is, where they're supposed to have the 40 weeks, as you're probably well aware, they do Monday Tuesday, Thursday and Friday as school days and every Wednesday</p> <p>I - They go out</p> <p>B- They go out, so overall that means that they're getting the number, I can't remember...</p> <p>I - There's a statutory number of days, yes</p>	<p>Impact of change/decision</p> <p>Enduring and intense impact</p> <p>Acceptance Like a family, extended support</p> <p>Enduring and intensity of the impact of the decision</p> <p>Loss (of identity as parent) Abandoned guilt Chaos vs order Calm vs tension</p>
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<p>This was hard for Brian, but can see it as understandable so this does not bother him and make him question the placement</p>	<p>B - in actual fact, it's slightly higher than that and that's how they can turn round and say, I think it's up to 4 weeks a year, they can say, up to 4 weeks a year, is alright, cos they still get their statutory days at school.</p>	
<p>Sounds a calm and settled arrangement</p>	<p>I - So you had to sort of fight for that, but then they</p> <p>B - Yes, I mean to a certain extent not so much the state schools but every step of the way, was kind of a little bit of a fight, but we do understand why. In a perfect world it would be unlimited, but of course everything costs money and particularly at the moment</p>	<p>Urgency vs calm</p> <p>loss</p> <p>The intensity of the experience</p>
<p>Taking Becky on family holidays recently have not been so easy</p>	<p>I - Yes. Yes,</p> <p>B - And everything's being cut back and we do understand and we know that we've got another fight coming up</p>	<p>Coping</p>
<p>Brian confident in how the staff work</p>	<p>I - With the post 19?</p> <p>B - Cos I've no doubt that they'll try and offer something that we'll think is appropriate and it's not because they don't care, it's because they've got financial burdens and so they've got to and we've got to sort of fight the case to get the very best care that we can for Becky</p>	<p>Adjustment</p> <p>loss</p> <p>Normalization</p> <p>Adjustment</p>
<p><u>Is this a way of Brian maintaining control/his father's role?</u></p> <p>The routine seems to work</p>	<p>I - Did you have any particular thoughts about how you and Becky would cope with her going to residential, so I suppose firstly did you wonder how she'd cope, would she adjust easily and things...?</p>	<p>Normalization</p> <p>guilt</p>

<p><i>'dreadful'</i> – the impact of the change</p> <p>Brian still finds it a very distressing memory</p> <p>Brian appreciates the experience of Ash House in supporting parents in the transition, <i>'I mean, they have coped with all of this before'</i></p> <p><i>'I was in bits really' – a very emotional time</i></p> <p><i>understated, 'not happy at all'</i></p> <p><i>'the house just seemed so</i></p>	<p>B - We worried about it, we worried that she wouldn't be able to adjust to it and cope with it and that, I mean, it's difficult to say because she can't tell you, that she'd have a feeling of rejection</p> <p>I - Yes</p> <p>B -Because we weren't there all the time, erm,</p> <p>I - So did you think...did you wonder whether that might be so?</p> <p>B -Yes, but we didn't know, erm, as it turned out she settled in, pretty much immediately and now she's in a very good routine, she knows when she's coming home,</p> <p>I - Yes</p> <p>B -She's happy to come home, she's equally happy to go, I think we've only had one occasion when she didn't want to go back to school and we'd had a week's holiday on a narrow boat and we'd had a really lovely time and she'd had a really lovely time and when we took her back to the school, she wanted to be with us</p> <p>I -Oh, right</p> <p>B - And that's the only time that it's happened, I mean we've taken her out since, she's had two holidays since and both times she 's been perfectly happy to go back to the school</p> <p>I - Yes</p> <p>B - Ready to go back, I think</p>	<p>Guilt</p> <p>Guilt</p> <p>Acceptance Intensity of decision</p> <p>Guilt Conflict of emotion</p>
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<p><i>empty’ – loss, abandoned, isolation?</i></p> <p><i>‘there was no tension’ – the realization of the tension they had been living under</i></p> <p>Brian was on edge at work the whole time <i>A sense of urgency, ‘she’s off, I gotta go...and people would shut down my computer for me’</i></p> <p><i>‘it was just gone’ – the realisation that the tension had gone from the home</i></p> <p><i>powerful comparison of how tense he had felt in the house – compared with his military experience in a war zone</i></p> <p><i>‘you were waiting all the time for the outburst, once the outburst came, you could cope with it’ – the extent of the tension</i></p>	<p>she’d had such a lovely time, you know, so relaxed, but the next two times weren’t quite as relaxed in fact, there were tensions by the end of it,</p> <p>I -So really, you say, apart from the exception, she’s been ...she’s always coped with the transition</p> <p>B- - Oh, yes, she knows the routines, she knows....obviously there are certain things the staff must be doing so that she knows that we’re coming to collect her</p> <p>I - Yes</p> <p>B - And I normally go and collect her</p> <p>I - So she doesn’t come on transport?</p> <p>B -No, no, because it’s so close, Ash House have said, ‘we’ll bring her if you want, we’ll transport her if you want , but we’ve said, ‘you know, its only 20 miles up the road’, it’s not a great burden for us to go and collect her and take her back so it means that we pick her up normally on a Friday afternoon, take her back on a Monday morning, on the way off to work,</p> <p>I - Can you remember yourself how you felt the first few days after you first took her?</p> <p>B - Dreadful,</p> <p>I – Yes?</p> <p>B - I was (beginning to cry), even now.</p>	<p>Identity as parent</p> <p>Conflict of emotions</p> <p>Safe and secure Relief Regret</p> <p>Regret The unknown Protective parent</p>
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<p><i>'you're lost' – difficult to adjust</i></p> <p><i>adjusted quite quickly, but the feeling is still there</i></p> <p><i>This concern about 'forgetting'</i></p> <p><i>Hesitant</i></p> <p><i>Guilt, 'I should be thinking about her all the time' 'you have to get on with things' – accepting that life must move on, but hard</i></p>	<p>I - Yes,</p> <p>B - It's ...and we've been very lucky, that the school is so fantastic and very understanding, I mean they have coped with all of this before, and yes, when we took her, because we'd taken her the day before and then she came back home cos we took her stuff, got her packed in and then took her the next day</p> <p>I - To stay?</p> <p>B - To drop her off and I just wanted to be off but unfortunately there was paper work to do</p> <p>I - Oh right</p> <p>B - And we had to hang around and I was...I was...in bits really,</p> <p>I - Right</p> <p>B - Not happy at all</p> <p>I - And was it, I presume, its eased, but perhaps, like you say, you still find it difficult?</p> <p>B - I think it was very hard the first couple of weeks until we took her out the first time and that was probably the hardest, the house just seemed so empty, quiet, and of course, it's a bit difficult thinking back to it now, but of course there was no tension....there had always been tension before, because we never knew when she was going to kick off,</p> <p>I - Yes</p>	<p>Coping</p> <p>Threat to parenting identity</p> <p>Loyalty</p>
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<p>Brian finds it hard not to think of 'pushing' Becky away, but he is also conflicted about this, '<i>we pushed Becky, we didn't, but we pushed Becky away</i>' contradiction shows he is reluctant to accept it</p>	<p>B - Yes, I mean, If I was at work and obviously Becky was here with Sue, I mean I had to carry a phone with me anyway, my work was pretty good if she started, I just said, 'she's off, I gotta go' and they'd say, 'go on then' and people would shut down my computer for me and...so that was pretty good, but...</p>	
<p>Brian is protective over both of his daughters</p>	<p>I - And then, you didn't have that I guess...</p>	<p>Order Transformation Restoration</p>
	<p>B - It was just gone and then, the best way to describe it, its, its strange but, as I say I was in the airforce and I was in the first Gulf conflict and the airfield I was at was one of the ones that was most heavily targeted with scud missiles and we, the first time the sirens went off, everybody was a bit...but then it changed and you became tense until the sirens went off and once the sirens had gone off, you were calm, you were happy then</p>	
<p>Brian is considering the difference between Emma's choice and Becky's situation</p>	<p>I - it was the waiting....?</p> <p>B - Yes, when you first went in the shift you knew what was going to happen, pretty much, we found out that we was going to be alright, cos, you know, we were going to be pretty unlucky if anybody was hurt, to be honest, so I guess it worked that way, so it was a little bit the same, the tension, you were waiting all the time, for the outburst, once the outburst came, you could cope with it</p>	<p>Parent as expert</p>
<p><u>Hesitating, perhaps not sure if he wants to say it has been the best thing for them as well?</u></p>	<p>I - Yes, yes</p> <p>B - And then when she was gone</p>	<p>Parent as expert</p>

Brain values the safety and security aspect as well as the opportunities it provides	it was like, you're lost, and you are still waiting for that	
He wishes that they had made the decision (or had the opportunity?) to do it earlier	I - Sort of expecting it?	Loss (of expected child)
<u>There is a sense of regret, as if the not knowing whether it would have made a difference to her progress is still a cause for regret?</u>	B - Cos that's what you've come to expect, and that would have taken about 2 weeks, probably not more, after that, I think now, it's a little bit less, because, we've kind of, as time's gone by, again, you normalize things, it's because sometimes you'll think to yourselves, well she's coming home this weekend, God, I haven't thought about her for..	
<u>Interpreting Becky's behaviour as due to her stress and anxiety and there is a sense of regret that she may have been spared this if she had had different provision</u>	I - Yes	
	B - I haven't given her a second thought, for the past week, the truth of the matter is you probably have, lots of times	
	I - Of course	Time limited vs enduring
	B - But....	Coping
	I - It's not in your face sort of thing?	rescue
	B -- Yes, that's dreadful that, I should be thinking about her all the time but of course you don't cos you have to get on with things	
<u>Is this hesitation because he feels unsure or whether he thinks it might reflect badly on him as a parent if he suggests an earlier age?</u>	I - I wonder, cos I know your wife said that your other daughter is away at university, I wondered if there was any similarity at all with her going away, I mean there may not be but I was just wondering, that's all?	Adjustment
Reflecting on when Becky's behaviour and when it began to become more difficult	B - Erm, there is to a certain extent, despite the fact that she is 19 now, she was 19 when she	Coping

<p>Becky is a physically challenging girl</p> <p><u>Brian is relieved that the school can help with this aspect of Becky's development too?</u></p> <p><u>Quick to defend Ash House and to prevent any criticism</u></p> <p>Becky is more settled and her outbursts have reduced.</p>	<p>went, cos she didn't start til...</p> <p>I - She took a gap year?</p> <p>B - No, no, they have two intakes, she took the second one</p> <p>I - Oh, I see</p> <p>B - So it was February when she went away, she's been gone since February, I mean I didn't want her to go away and I'd still prefer her to be here, to a certain extent, but the difference was that she was going voluntarily to improve herself, to train, the start of her adult life, her career, all the rest of it, she's done that off her own bat, we pushed Becky, we didn't but we pushed Becky away</p> <p>I - It felt like that?</p> <p>B - Yes, we haven't you know, the decision to go to London, that was all Emma, if we had had our own way she'd have gone to (the local university)</p> <p>I - Yes (laughing)</p> <p>B - To be perfectly honest, but she said, 'No I don't want to go there, I want to go a bit further away', so she ended up in London</p> <p>I -Ok, I just wondered cos that's like a separation as well, isn't it? But it's interesting how you've described it, one was voluntary, as you see it, one wasn't...</p> <p>B - What I was saying to you, when she went, there's a positive end to it maybe, and we can see now that she's you know, she</p>	<p>Intense demands of asd Intensive and enduring</p> <p>Impact on family</p> <p>Restoration of confidence</p> <p>Parent as expert</p> <p>Loyalty confidence</p>
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<p>Brian thinks that Becky has learned to manage these better herself, as well as Ash House having an influence</p>	<p>does have a home, and obviously she does feel a bit lonely down there, and that's one of the reasons why we would have preferred her to go to (the local university) we knew that everyone would be spread over a vast area</p>	
	<p>I - So how do you feel now about your decision to allow Becky to go to Ash House?</p>	
	<p>B - Erm, (hesitation) I think it's probably been the best thing for her, in reality erm, it's been good for us as well, but, for her I think it's been by far the best thing for her, I mean, she still has her moments, she can still flare up, but it's a lot less likely, we know she's in a safe environment which she likes, we know she likes all the activities that they do, and there's loads of them, good grief it's fantastic what she gets to do, so now we feel it's, and now in hindsight we say, 'we should have done it a lot earlier'</p>	<p>Confidence Trust</p>
<p>The provision at the previous school was not as successful</p>		
<p><u>Brian has to work hard at keeping things in perspective</u> – Becky still has very significant learning difficulties</p>	<p>I - Right</p>	<p>Identity as parent</p>
	<p>B - It would have, it may have been the difference between, I'm not saying she would have had speech, or anything like that, but, I think she would have been far more settled in herself, she wouldn't have had that...it must have been traumatic for her as well, I mean she didn't know and when she became aggressive it was obvious she didn't know what she was doing and she was lashing out because she was frightened, most of the time, that's the way it felt to us, so she, you know...</p>	
<p>Brian is normalizing extreme behaviour</p>		<p>Identity as parent</p>
<p><u>A disappointment still for Brian?</u> Becky still has extremely limited social</p>		

<p>contact</p> <p>Brian can see this limited progress, but this is encouraging for him</p> <p>The experience with Becky is now time limited and so this is better for them to cope</p> <p>Ash House act as a supportive network</p> <p>Brian can recognize that they are better able to cope with her. They have normalised life without Becky, so it is a shock when they have to readjust</p> <p><i>'but we're better able to</i></p>	<p>I - So you could have avoided that....</p> <p>B - Yes,</p> <p>I - How old was she when she went to Ash House?</p> <p>B - She was 14</p> <p>I - So how much younger would you have thought it might have been better, like you say, if you could choose again?</p> <p>B -Erm (long hesitation) now that's difficult to say, I would have said, probably as young as junior school</p> <p>I - Ok, yes</p> <p>B - Erm, certainly 10 I would have thought, because, that's not when she started becoming aggressive or anything like that, but it was where, I think that was probably the time when it started to get harder and harder and harder, to cope</p> <p>I - Yes, I suppose as she got bigger physically as well, and things like that</p> <p>B - Yes, you know, she is a big girl</p> <p>I - Yes, your wife was saying that she's taller than her, is she</p> <p>B -Oh yes and she's nearly the height of me</p> <p>I - Yes</p> <p>B - And she is losing weight now</p>	<p>Loss of expected child/grandchildren Impact on sibling/family dynamics</p> <p>Confident Order</p>
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<p><i>cope because of course we know that it is...time limited'</i></p>	<p>but she is at the moment heavier than I am</p> <p>I - Right</p> <p>B - Erm, but hopefully that's going to switch because they've got a good regime now for her eating and the weight's coming off fantastically well, to be honest, she's lost about 44 pounds</p>	<p>Identity as parent</p> <p>Autonomy</p> <p>Trust</p> <p>Confidence</p>
<p>The 24/7 demands of autism 'even though while she was at school all we did was go to work, that was our respite'</p>	<p>I - Has she?</p> <p>B - Yes, since March, I mean it was essential, cos obviously the weight that she was it was starting to.....physical and medical things, diabetes and heart disease and so , I think the changes they made were quite small and then all of a sudden, she...it's not as if they were giving her bad food</p>	<p>Transparency</p> <p>transparency</p>
<p>The difficulties increased as Becky became more challenging and physically stronger</p>	<p>I - Oh no</p> <p>B - It was just, that just that a little tiny change of behaviour...</p>	<p>Loyalty</p>
<p>Brian is very positive about the provision, 'I don't think there's anything about Ash House I don't like...'</p> <p>He likes the family atmosphere and the care of the staff</p> <p>He likes the system of continual education</p> <p>Brian understands and is knowledgeable about autism, 'autistic children need routine'</p>	<p>I - And it's worked. You've talked there about a lot of positive things for Becky at Ash House, are there any other changes that you've noticed in her, since she's been there?</p> <p>B - Erm...obviously the fact that she's a lot more settled, she seems happier, most of the time, in herself, the outbursts are...she still has outbursts but they're nowhere near as bad as they were and she seems able to cope with them better in herself and seems to have learnt in herself, things that she can do that's going to help her as well and Ash House</p>	

<p>Brian is supporting the teachers at Ash House</p>	<p>will tell you this as well, if they say that she'll now take herself, when's she feels this coming on, she'll take herself away and she will go to what she will regard as a safe place</p> <p>I - Right, ok</p> <p>B - And I mean they've got some soft rooms where she can go, I mean they did at Lea Side</p> <p>I - Safe places, yes, and will she take herself there at times now?</p> <p>B - Yes, but in the end at Lea Side, they were concerned that she just saw that as a treat and she was just retreating into those places</p> <p>I - Ok</p> <p>B - I mean she still doesn't really interact with other children, even children that are...although that is slightly better now that she has become older, she has always, a very small child, I don't think she understands,</p> <p>I - They're unpredictable</p> <p>B - And she's very wary and doesn't want them near, she's always gone more for adults. She's always been fairly good with her sister, apart from the time when she stood on her head, which wasn't very clever (laughs)</p> <p>I - Oh dear</p> <p>B - Erm, so she's accepted her sister, who is, broadly speaking, but there's 2 years between them, so she's a little bit bigger but not</p>	<p>Family vs system</p> <p>Transparency</p> <p>Transparency</p> <p>adjustment</p> <p>Transparency trust</p> <p>Adjustment Loss of expected child</p>
<p><u>Brian is very happy with the arrangement. He can only see it as being positive</u> <u>Brian is unsure of the precise arrangements but he trusts Ash House and so he is satisfied</u></p> <p><u>Slight implied criticism of those parents who might not have their child home for Christmas. Is Brian wanting to demonstrate that he is determined to do the best for</u></p>		

<p><u>Becky?</u></p> <p>I was trying to defend other parents and their decisions</p> <p>Brian has strong opinions about families and their responsibilities towards their children</p> <p>Brain has an accepting extended family</p> <p>Brian has thought about this. <u>He seems to have plans for Emma – is this because he knows that Becky will not marry and have children? Will Emma have to compensate and marry and have children – does she feel this? Is this why she has moved away and is thinking of emigrating? Does she feel a lot of pressure as the sibling? Or would her parents have been like this anyway?</u></p> <p>Brian likes the small size of the school</p>	<p>much and she's accepted other children around her but she hasn't really interacted with them very much</p> <p>I - Right</p> <p>B - Whereas she would be more likely to interact with adults. I think she's now starting to interact more with them, probably because they're all young adults now,</p> <p>I - Yes, well that's true and more familiar too</p> <p>B - So she's interacting with them now more than she used to</p> <p>I - Right, and you may think that you've said all that you want to say, about that, but changes in your own family situation, since Becky has been away? You did say that you had felt more relaxed, so is that the main change, or is there any other?</p> <p>B - Erm, the other advantage of course of her being in residential school, is if she comes home, you know, we see an end to it, we know it's only going to be for the weekend, if she has a particularly bad weekend, we've only once asked Ash House to come and collect her</p> <p>I - Right</p> <p>B - And by the time they'd got here we'd actually managed to turn it round.</p> <p>I - Ok, right</p> <p>B - So she ended up stopping the</p>	<p>Loss of confidence/identity as parent</p> <p>Identity as parent</p> <p>Adjustment Loss</p> <p>Identity as parent</p> <p>Guilt Impact on family/sibling</p>
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<p>Brian is very impressed with the staff ratio – <u>does this help him to feel reassured and confident?</u></p> <p><i>‘no, that’s not the way Ash House do it...’ – <u>he is proud of them, like a family member?</u> Is this <u>something that parents have to feel, to allow their child to stay there?</u></i></p> <p>Brian is satisfied with the level of parental control he has, he is impressed with the lengths they go to, <i>‘they ask our permission for every piece of medication’</i></p> <p>This is another way in which the school gains the confidence of the parents</p>	<p>weekend anyway, but I think from our perspective, we’re better able to cope with her now, in that respect although when she does act up it does come as a bit more of a shock</p> <p>I - Yes</p> <p>B -And you have to rewind a little bit but we’re better able to cope because of course we know that ...</p> <p>I -It’s time limited?</p> <p>B - It’s time limited, whereas before, really, without realizing it, when it was 24/7 it was</p> <p>I - Unrelenting?</p> <p>B - Yes....and especially when she got suspended from the school, cos that, even though, while she was at school all we did was go to work</p> <p>I - Yes (laughing)</p> <p>B - That was our respite</p> <p>I - Yes, I see, so when you came home you were on duty, almost?</p> <p>B -Yes, and I mean, you know, when she was younger it didn’t matter so much she wasn’t particularly bad, but towards the end, yes, it was pretty....</p> <p>I - And again, and I know you’ve alluded to some of these things, is there anything else you’d want to say about what you like about how Ash House works?</p> <p>B - Erm, I don’t think there’s</p>	<p>Order vs chaos</p> <p>Adjustment</p> <p>Vigilant parent</p> <p>Parent as expert</p> <p>Acceptance Vigilant parent</p>
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Brain is very confident that the staff check with him before they make any changes – and this increases his confidence in them, <i>‘right, we’d like to do this with Becky, is that alright?’</i>	anything about Ash House I don’t like, the way that they’ve, certainly the way that they’ve, and I’m assuming this is because they have good interviews and all the rest of it, all the staff are fantastic, they’re all very caring, they’ve made it as much like a family environment for the children as they possibly can and it, I think the children appreciate that. Particularly for autistic children, the educational method, this two days, a day off, two days, the weekend off, that they use, is by far the best because they don’t have, autistic children need routine and they have this routine it is bang bang bang, it is there, and it doesn’t have a 4 week break, or a 6 week break over the summer	Normalization
Aware of possible criticism and ready to defend them		Gratitude
<i>‘We’re looking after her for you...’ key quote?</i>	I - No, it’s a clever way of doing it	
Pleased with general level of communication also	B - It really is, it’s a superb way of doing it, I mean, I don’t know how they do it but obviously most teachers, I know they don’t really get this time off, but most teachers they’re not at the coal face for 14 weeks of the year, it’s a very nice job, I mean I know that teachers do have to do work when they’re not at the school, during holiday time	Vigilant parent
Brian is pleased with the easy access at Ash House, <i>‘we’re always welcome with open arms’ – like a family?</i>	I - Yes, I know what you’re saying, but it’s not the same as being in front of the...	
Some parents may have interpreted this negatively, but Brian only sees it as a positive in that the school will totally accommodate his wishes	B -Exactly I - I guess they can manage it because they’re a privately owned...they can make their own conditions for the teachers..	

<p>Brian enjoys the flexible approach that Ash House has</p> <p><u>Does this, from Ash House give the parents permission to leave the children there over several weekends? Would it be difficult otherwise?</u></p> <p><i>‘very, very open, there’s nothing...you don’t feel as if there’s any possibility that it’s hidden’ - a resounding endorsement of the care and trust – do parents have to invest this kind of trust in a place?</i></p> <p><u>This has caused Brian to reflect on his relationship with Becky, ‘I didn’t connect with Becky when she was young, for a long time’</u></p>	<p>B - I’m just assuming that they’ve just got enough teachers and every so often one of ‘em has some time off, otherwise they’re... (laughs) working all the time, I mean I know they don’t go in for the week of Christmas, but the care staff obviously are and the care staff still take them into the school and still do educational things with them, but without the teacher with them, but the types of things they’re able to do</p> <p>I - So, is it open every day of the year? So is it open Christmas day?</p> <p>B - Oh yes, erm, it is.....we believe that we are unusual in the fact that we will always have Becky on Christmas Day</p> <p>I - Ok, right</p> <p>B - And that quite a lot of the children are there on Christmas day</p> <p>I - Yes, cos in fact Christmas Day can be a particularly stressful time can’t it for children with autism, so I suppose families make decisions....</p> <p>B - Yes, to my mind, without naming any names, we know why some of the children are there and we think that those families are, it’s not that they don’t want their children on Christmas Day it’s that the extended family can’t cope with their children and in my opinion, if the extended family can’t cope, that’s their problem, that’s the way that we feel. I mean luckily for us, our</p>	
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<p><u>Why was this? – was it then he wasn't blaming himself or wondering if what he was doing was wrong or causing the poor interaction etc</u></p> <p><u>Brian's relationship slowly developed with Becky. He wants to show that she can be a lovely girl – not just a child with challenging behaviour and with asd -</u> <i>'when she's good, she's fantastic, she's just lovely'</i></p> <p><u>In a strange way, Becky's more challenging behaviour provided a role for Brian – was it this role that he lost and missed when she went away?</u></p> <p><u>Brian's view of his relationship with Becky, 'I think I became very, very close to her from a, from what I would regard now as a very poor start' very emotional</u></p> <p>I was trying to help Brian and to put it in perspective, but he knew what the reasons were</p> <p>Brian is still puzzling over his relationship, <i>'No I just somehow didn't connect until...I don't know...'</i> Family life is complicated and Brian is trying to work</p>	<p>extended family would think there was something wrong with us if we didn't have Becky with us</p> <p>I - Right</p> <p>B - I'm not saying there'll not come a day when we don't, as time goes on</p> <p>I - No, but at the moment that's what you want to do</p> <p>B - Yes and certainly, while she's a child and when she starts getting into proper adult hood, then there may be an occasion when, the case in question would be, potentially, if Emma, not if, <i>when</i> Emma gets married, and has a family of her own and it may be that she wants us to go and see her at Christmas, in that case, then obviously we'll have a Christmas with Becky but then we'll go and see Emma. If Emma gets her own way she'll emigrate soon...</p> <p>I - A long holiday then...</p> <p>B- Yes. But, what else about the school? the size, the fact that they've limited themselves to a maximum of 11 residential students – I think they've got one or two ...</p> <p>I - They've got a couple of day students</p> <p>B - ...couple of day students, but they've limited themselves to 11 and the staff ratios are incredible. You don't normally get those kinds of staff ratios and the truth of the matter is, that, on</p>	
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<p>out why he found it difficult to bond with Becky</p> <p><i>'it's more relaxed'</i> – Brian's role before was as 'controller' almost</p> <p>not prepared to accept that it is a better relationship, <i>'it's more relaxed but I wouldn't say it's better now...'</i> did accept the suggestion that the relationship is different</p> <p>An acceptance of Becky's limitation, 'well. We know that there's not going to be any independence...' Brian is determined that Becky will have care alongside the same lines as Ash House – he is not prepared to compromise <i>'if it's not Ash House then it has to be something that's run on exactly the same lines'</i> <u>Brian is informed and knows what he wants for Becky</u></p>	<p>occasions, they say they need, you know, it's all well and good saying, yeah, we know that each child needs 2 carers but they don't need 2 carers all the time, so if we've got 2 children we'll have 2 carers cos that will be enough, if we've got 4 children, we only need 3 carers and that'll still be enough, no, that's not the way Ash House do it, each child, 2 carers, and that way, obviously the carer's have other duties to do as well, as they're other things that have gotta be done, but ...</p> <p>I - They're there if...</p> <p>B- They're there if, yes</p> <p>I - So you feel confident in that side of things then, yes</p> <p>B - Yes</p> <p>I - What about things like communication, do you feel happy that you know what's going on in Becky's life?</p> <p>B -Yes, definitely, if there's any change that has to be made to her medication, in reality, the school almost by default been given the right to do that, now, they ask our permission for every piece of medication, I mean, and its written down what they can do, so for example, paracetamol, we've explained when we would give Becky paracetamol and we've given them permission to give it so they don't ring us up to say, 'can we give her paracetamol'.</p> <p>I - Yes</p>	
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<p>He has considered the different methods and has made his decisions</p> <p>Brian has thought about the options and has made his decision, <i>‘in fact as far as we’re concerned, it needs to be Ash House’</i></p> <p><i>‘because you do normalize it and so it just serves as a reminder of what it’s like , what it was like’</i> – Brian is able to look at the interview as a way of thinking about the experience</p> <p>Brian is aware of how valuable Ash House is to them as a family – <u>what would they have done of they had not found it?</u> – This is what he thinks They are <u>very dependent on it</u></p>	<p>B - That sort of thing, but any of her diagnosed medication, they’ll call us and say, ‘we’ve sent you an email can you respond and give your permission for this change?’ Any major changes, for example, they changed the epilem and they asked us to approve that, which we’ve done so, as far as her health’s concerned, if ‘er, if one of the doctors says, ‘yeah, I want this procedure to be done’ they say, ‘yes, we’ll ask the parents for permission’, so they come to us over that sort of thing and any thing like they want to do with her, that’s new, again, they come to us and say, ‘right, we’d like to do this with Becky, is that alright? ‘Yes’, ‘so next time you come in can you sign a consent form?’ Some people would say that they’re trying to hand over the blame to a certain extent but that’s not the reason it’s done, it’s to keep you in the loop and they most positively say, that, you know....</p> <p>I - She’s yours?</p> <p>B - ‘We’re looking after her for you, you make all the decisions, you make the decisions on her behalf we’ll do whatever you ask’, unless of course it’s against the law, or whatever, it’s got to be within the parameters of the law and all the rest of it. But yes, and other things, you know, they’ll call up and say, ‘she’s had a really good day’</p> <p>I - So you do feel that you know what’s happening to her and things?</p>	
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<p>It would have been a very different scenario if Becky had gone to one of the more distant schools. Is Brian still worrying about what the options might have to be post 19?</p> <p>These are the considerations that need to be made</p> <p><i>‘I mean, we’ve been very lucky, in that respect’ key phrase?</i></p>	<p>B - Yes, and of course the other thing is and another thing which is a major plus as far as Ash House are concerned, we can go and see her any time, without notice, we’re always welcome with open arms and we can collect her whenever we want, I mean, we always give them notice of course, but occasionally it gets missed in the diary and the last time we picked her up, we turned up and they went , ‘oh, we weren’t expecting you today, but that’s not a problem, we’ll just get her meds and we’ll get her sorted for you’, so it’s off you go, so there’s no problems as far as that’s concerned and it’s any time of the day or night, erm...</p> <p>I -So it sounds like, all of that, makes you feel very confident and relaxed about where she is</p> <p>B - Oh yes, cos I mean in some places you have to book a visit, and book permission to take em out and if we were to go now and say, ‘we’re having Becky for the weekend’, it wouldn’t phase them at all, they’d day, ‘oh, yeah, we didn’t have it in the diary but it doesn’t matter’ it doesn’t make any difference. The only thing they advise, and it’s entirely up to you, you can take her out every single weekend if you want, but what we’d advise is, that you take her out every second or third weekend and we’ve taken that advice on board and we do take her out, I mean we try to make it every third weekend and occasionally it had to be adjusted cos if there’s a meeting at the school we’ll inevitably bring her home with us, there’s slight</p>	
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	<p>adjustments and obviously Christmas times, it obviously doesn't always fall exactly three weeks so there are adjustments there...</p> <p>I - Yeah, so there is that flexibility, that you're describing, the openness...</p> <p>B - Oh yes, extremely and very, very open, there's nothing, well there isn't anything that.... you don't feel as if there's any possibility that it's hidden...</p> <p>I -Right, erm, how would you describe your relationship with Becky now, since she's been there? Has there been any change, is it better or worse than it was before?</p> <p>B - (hesitation) it's not worse, I wouldn't say it was better. Is it better? I didn't connect with Becky when she was young, for a long time</p> <p>I - ok</p> <p>B - probably because...it got better once I knew she was diagnosed</p> <p>I - ok, because you wondered what it was and you couldn't make sense of it?</p> <p>B - Yes, yes, and as time went on, I mean, when she's good, she's fantastic, she's just lovely</p> <p>I - Yes</p> <p>B - And, as time went on, I think as well she got physically stronger, I had to start taking the</p>	
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	<p>lead more, simply because physically I could cope with her and so in that respect I think...I'm no more distant from her now, but I, I think I became very, very close to her</p> <p>I - Yes, yes</p> <p>B -From a, from what I would regard now as a very poor start, erm (becoming upset)</p> <p>I - Maybe you were at work and away as well, were you?</p> <p>B - Erm, no....</p> <p>I- It wasn't that?</p> <p>B - Not, I just somehow, didn't connect until...., I don't know....., maybe the gap between Emma and her turned out, it's a better gap now as it's turned out,. But maybe it was a little bit short cos Emma still needed a lot of attention and then of course somebody else comes along and I... my attention for Emma and this ones not responding and...</p> <p>I - So again, maybe it was when you felt you had a role to play later on?</p> <p>B - Quite possibly, but overall, I would say my relationship is...I wouldn't say it was better, it's more relaxed</p> <p>I - Right ok</p> <p>B -it's more relaxed, but I wouldn't say it's better now than when she went to Ash House</p>	
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	<p>I- But it's not worse?</p> <p>B - Certainly not worse</p> <p>I - It's just different by the sounds of it?</p> <p>B -It is different, yes it is, it's different</p> <p>I - Yes, and finally, what are your hopes for Becky's future?</p> <p>B - Well, we know that there's not going to be any independence, erm, as far as we're concerned, we want her to continue at Ash House as long as possible. If it's not Ash House then it has to be something that's run on exactly the same lines.</p> <p>I - Yes, right</p> <p>B - I don't know anywhere else that's built on exactly the same lines as Ash House, erm, I mean we did once consider a residential school before, but the only ones we found were miles and miles away and I mean their methods, I mean some of the schools, two schools were run along the lines of the Higashi schools</p> <p>I - Right</p> <p>B - Which they've had fantastic results, but I think that's a hard regime</p> <p>I - Yes, yes, and you've got to be comfortable with it yourself, I think</p> <p>B - Yes, yes I think that can be a hard regime and I don't know whether it would have benefitted</p>	
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	<p>Becky at all so, obviously we've now accepted the fact that she's got to be in residential care for the rest of her life, really and what we want, what our aim would be that it's as close as possible to Ash House, in fact, as far as we're concerned, it needs to be Ash House</p> <p>I - Yes, ok, right, and is there anything else that you think is important that I've not asked you about, that you want to say?</p> <p>B - No, I can't really think of anything else that springs to mind, it's ...</p> <p>I - Ok, that's fine. And just finally I just wanted to ask you how you found the experience of being interviewed about Becky, today</p> <p>B - Alright actually it's quite good in some respects cos obviously we've discussed it amongst ourselves, but it's nice to discuss it with someone else, perhaps on a more professional level and realise some of the things, that you forget, cos you see you do normalize it and so it just serves as a reminder of what it's like, what it was like,</p> <p>I - Where you've come from...</p> <p>B - To be honest, how lucky we are at the moment, to have her where she is, cos I have to say that if we hadn't found Ash House I think we'd still be struggling a great deal cos</p> <p>I - As a family you mean?</p>	
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	<p>B - Well, it would have had to be a residential school and we'd have struggled to find somewhere and I don't know if Becky would have settled as well, well she may have done, but I think it would have been a pretty hard thing. It certainly wouldn't have been The Holt</p> <p>I - Right, yes</p> <p>B - Erm, which means that we'd probably be the school in (the town 150 miles north) which we'd tried to put her name for, which is along the Higashi lines and there's another one in (a town 150 miles south) and they would have been obviouslyif that had been the case our preference would have been (the town 150 miles north), cos we're obviously from that area and have family there and I think we would have preferred that there was some family close at hand, that could, if there had been any emergency, they could perhaps go and see Becky, while, you, know, in the time it took us to get there</p> <p>I - Yes, not like you could just nip up the road</p> <p>B - No, it would have been a three hour drive and then of course seeing her would have been that much more difficult and that much more expensive, I mean let's face it, the cost of fuel now, it's horrendous, I mean, we've been very lucky in that respect.</p> <p>I - Well thank you very much.</p>	
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