

**VOLUME I**

**RESEARCH COMPONENT**

**Living with a Child with Autism Spectrum Disorder: Sibling and Parental  
Experiences**

**BY**

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**A thesis submitted to**

**The University of Birmingham**

**for the degree of**

**DOCTORATE IN CLINICAL PSYCHOLOGY**

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The University of Birmingham

May 2014

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## **Overview**

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. The thesis consists of two volumes.

### **Volume I**

This volume comprises three chapters. The first chapter is a systematic literature review which synthesises and evaluates research exploring the experiences of and impact on family members where a child with Autism Spectrum Disorder (ASD) in the family is undergoing an Intensive Behavioural Intervention (IBI). The second chapter is a qualitative empirical paper investigating sibling and parental experiences of living with a child with ASD. The third chapter is a public domain briefing document, providing an accessible summary of the literature review and empirical paper. These reports have been written in accordance with the guidelines for submission to the Journal of Autism and Developmental Disorders (Appendix A).

## **Volume II**

This volume comprises five Clinical Practice Reports (CPRs). The first report details the case of a ten year old boy who presented with symptoms of anxiety and a fear of being sick. The paper presents this case formulated from a cognitive-behavioural (CBT) and a psychodynamic perspective. The second report presents a small-scale service-related research project, exploring the expectations and experiences of mentoring from the perspective of facilitators who deliver a parenting group. The third report details a case-study of a 35 year old woman with symptoms of depression, formulation from a CBT approach. The fourth report is a single-case experimental design evaluating the effectiveness of a behavioural formulation and intervention for challenging behaviour for a 7 year old girl with a learning disability. The fifth report presents the abstract of an orally presented case study about the use of Acceptance and Commitment Therapy (ACT) for a 29 year old lady in recovery from an acute episode of psychosis following the birth of her child.

## **Acknowledgements**

I would like to thank my Research Supervisor, Gary Law, for his help and guidance over the three years and in particular for giving me a much needed push when I needed it. To Hannah Blanchard, who provided the idea for this study. Thank you also to my Clinical Supervisor, Lisa Summerhill for her help and advice along the way. To the Solihull CAMHS team for helping me to recruit participants, in particular, Baiju Thomas and Nisha Balan.

Very special thanks to the individuals who participated in this study. Without all of you giving your time to share your stories this would not have been possible.

Thank you to my family - Mum, Dad and brother Stephen. You gave me the support, motivation and encouragement when I needed it the most. Also to my friends and fellow trainees who have given me support and words of encouragement along the way.

To my wonderful housemates, Cecily and Ella, for their continued support over the three years for which I could not have done without.

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## **Chapter One**

# **The Experiences and Outcomes for Parents and Siblings When a Child with Autism Spectrum Disorder in the Family is Receiving an Intensive Behavioural Intervention (IBI): A Systematic Review**

## Abstract

**Background:** Living with a child with Autism Spectrum Disorder (ASD) presents unique challenges for parents and siblings. Parents are more at risk of mental health problems and siblings may be more likely to display adjustment difficulties. Many families take up Intensive Behavioural Intervention (IBI), an effective treatment aimed to improve the social, behavioural, adaptive and emotional functioning of children with ASD. This intervention is time intensive and is often carried out within the family home. This study aims to synthesise the literature concerned with the effect on parents and siblings when the child in the family is undergoing an IBI program.

**Method:** Six databases were searched; 16 articles were chosen for review. Each article was assessed on quality and two articles were excluded due to poor quality of reporting their evidence.

**Results:** Four themes emerged from the papers: *parental emotional impact, sibling adjustment, impact on family relationships and practical and social impacts.*

**Conclusion:** The studies varied in quality, however, all papers had methodological limitations and weaknesses. From these studies, parental stress and depression was found to be no greater for parents whose child is undergoing an IBI program compared to other parents who have a child with ASD. From only two papers, it was found that siblings were no more likely to present with adjustment difficulties compared to other children who have a brother or sister with ASD. Parents and siblings experienced a variety of positive and negative impacts as a result of the program. Further research is required in this area, particularly in relation to sibling experience. Caution should be taken when drawing conclusions from these studies due to the low number of papers included and the overall poor quality of the studies.

## **Introduction**

Autistic Spectrum Disorder (ASD) is a neurodevelopmental disability characterised by a marked impairment in social communication, social interaction, and flexibility of thought (American Psychiatric Association, 2000). Falling under the umbrella term of ASD are Asperger Syndrome, Autism, and Pervasive Developmental Disorder not otherwise specified (PDD NOS). Alongside these primary deficits in social communication, interaction and flexibility of thought, individuals with ASD commonly have problems in other areas, including: difficulties with sensory processing, sleeping, feeding, self-care, anxiety and behavioural problems (i.e. aggression towards self and/or others).

### *Living with a child with ASD*

Due to the unique characteristics of ASD, living with a child with this diagnosis is likely to be different to living with a child who does not. Parents of children with ASD may, according to recent findings, be more at risk of developing mental health difficulties. A meta-analysis demonstrated heightened levels of depression for parents of children with neurodevelopmental disabilities compared to mothers of typically developing children (Singer & Floyd, 2006). In addition, it is suggested that mothers of children with ASD experience significantly higher levels of stress compared to mothers of children who have typically developing children (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009; Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney, 2009; Quintero & McIntyre, 2010). It has been suggested that many factors contribute to parental stress, such as the child's difficulties with behaviour, social skills, emotion regulation, eating and sleeping (Davis & Carter, 2008; Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2008; Hastings, 2002). Recently there has been an increasing interest in sibling experience, however, this body of research is small and

the findings are inconsistent. Some studies show that siblings of children with ASD have social, emotional and behavioural adjustment difficulties, while other studies report no adjustment differences (Meadan, Stoner & Angell, 2010).

### *Intensive Behavioural Intervention (IBI)*

Intensive Behavioural Intervention (IBI) has been shown to be an effective intervention which aims to improve the social, behavioural, adaptive and emotional functioning of children with ASD. IBI is also referred to in the literature as Applied Behaviour Analysis (ABA), Early Intensive Behavioural Intervention (EIBI) and sometimes 'Lovaas Therapy' (Cebula, 2012; Reichow, 2012). It is scientifically developed from the principles of Applied Behavioural Analysis, based on aspects of learning theory, such as operant conditioning. The intervention aims to teach children with ASD a comprehensive range of skills such as language development, play skills, self-care, communication and academic tasks through the systematic application of a method called *Discrete Trial Teaching* (DTT; Leaf & McEachin, 1999). This method involves breaking down a skill into small parts, teaching one part at a time, providing prompting and fading procedures and using reinforcement. IBI programs are typically carried out one-to-one with the child and within the family home.

Research into IBI has grown over the years, with its foundations lying with the work carried out by Lovaas, Koegel, Simmons and Long (1973). In this study, children were involved in IBI for 14 months and made significant developments in appropriate behaviours (e.g., speech and play), Intelligence Quotient (IQ), spontaneous social interactions and decreased inappropriate behaviours (e.g., self-stimulatory behaviour). Follow-up studies, recruiting children who had been out of therapy for 12 years or less, showed that those

children receiving over 40 hours of one-to-one therapy per week had significantly better outcomes compared to the less intensive (<10 hours) control group (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993).

Since Lovaas' earlier work, there has been a vast amount of research into the effectiveness of IBI. Most recently, an overview of five meta-analyses concluded that four of the five papers demonstrated IBI to be a powerful and effective treatment showing significant gains in IQ and adaptive functioning for children with ASD during and following treatment (Reichow, 2012). A further meta-analysis indicated that IBI programs were more effective than less intensive behavioural programmes, eclectic treatments and treatment as usual (TAU) groups (Strauss, Mancini & Fava, 2013).

Alongside the intense nature of the intervention, with 30 hours or more being preferred in applied settings (Leaf & McEachin, 1999), other factors have been found to contribute to optimal outcomes with this approach, such as age at intervention onset (e.g., children receiving intervention at a younger age tend to have better outcomes). Further research demonstrates that intellectual and adaptive behaviour improvements in children undergoing the program are positively influenced by family involvement, whereby parents who are trained in behavioural methods can act as tutors or apply behavioural principles outside of therapy hours in order to generalise taught skills into everyday situations (Strauss, Mancini & Fava, 2013).

Conversely, other influences, such as parental stress, can counteract and reduce the effectiveness of teaching programs, particularly in high intensity programs where parents are greatly involved in their child's treatment (Osbourne, McHugh, Saunders & Reed, 2008). Due to the acknowledgement of family factors it is generally recommended that parents attend training, contribute to their child's programme through attending team meetings, help to

generalise skills during evenings and weekends, and organise materials. Additionally, parents may also be expected to set up an appropriate IBI programme for their child by discovering services, finding tutors and sometimes funding the programme.

### *Aims of the review*

There is a vast amount of evidence surrounding the effectiveness of IBI programs on outcomes for children with ASD, therefore families may be increasingly likely to choose this intervention. It is therefore important to understand the experiences of families undergoing this unique and time-intensive intervention, particularly as parents and siblings of children with ASD appear to be at risk of increased mental health and/or adjustment difficulties. Understanding family experiences will help to know more about how to better support those around the child with ASD and also to help facilitate program effectiveness.

There is emerging research into the effect on parents and siblings who are undergoing an IBI program. This is either within research exploring the effectiveness of IBI for the child with ASD (e.g. Birmbrauer & Leach, 1993) or as an area of research in its own right (e.g. Hastings & Johnson, 2001). This report aims to review all of the literature that is concerned with the effects on parents and siblings whilst a child with ASD in the family is undergoing an IBI program. Specifically, this review aims to address the following questions:

- 1) What are the experiences of parents and siblings where a child with the family is undergoing an IBI program?
- 2) What are the social, emotional, behavioural and practical outcomes for parents and siblings whilst a child within the family is undergoing an IBI program?

## Method

### *Search Strategy*

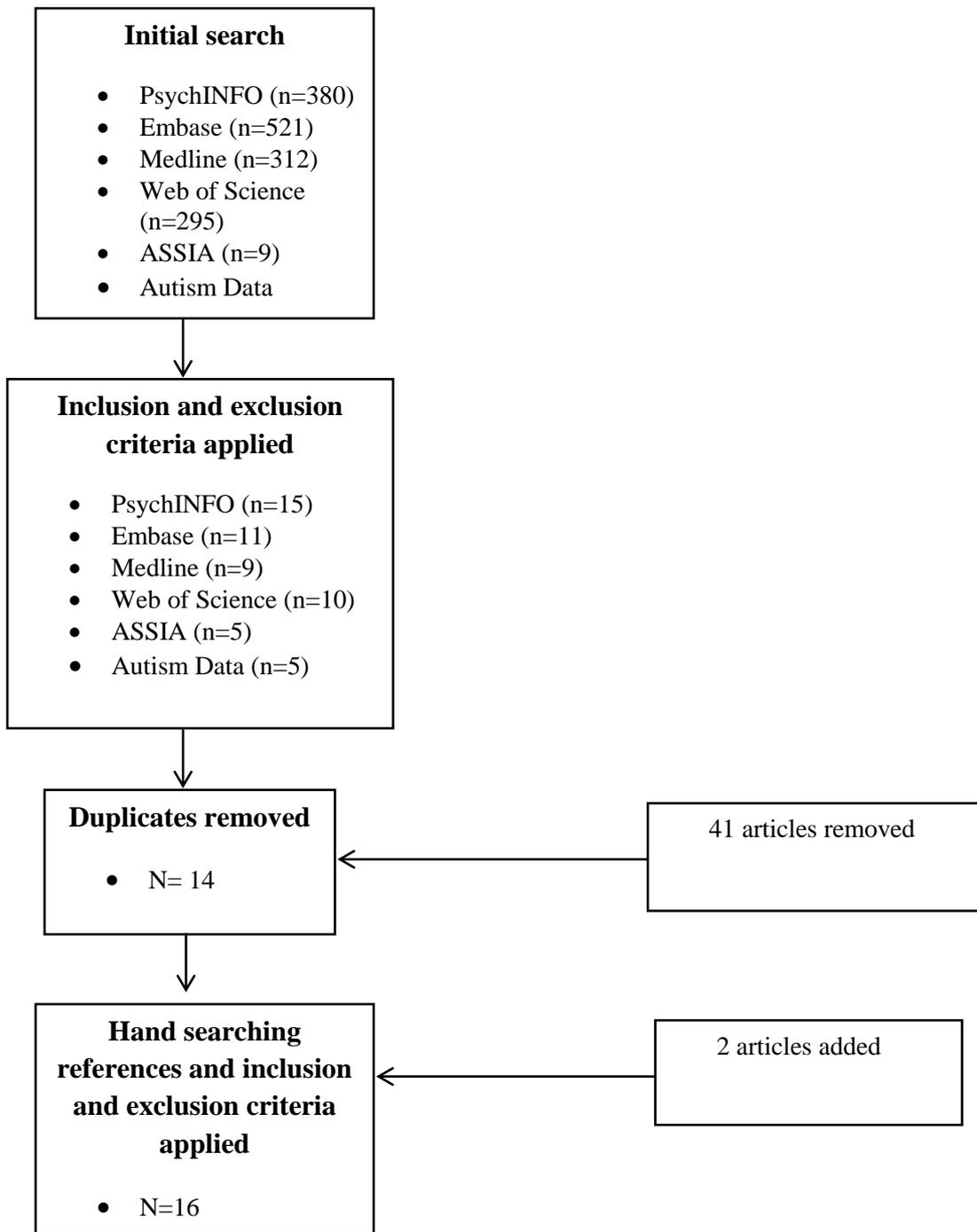
Articles were identified by 1) searching electronic databases and 2) backward searching. A flow chart of the identification of articles is presented in Figure 1.

#### 1) Electronic databases:

A search was carried out (see Table 1) using the following databases: Ovid PsycINFO (1806 to March Week 3 2014), Ovid MEDLINE (R; 1946 to March Week 2 2014), Ovid Embase (1980 to 2014 Week 11), Web of Science (1900 to 2014), ASSIA (1987-March week 3 2014) and Autism Data. A key word search was conducted for all electronic databases for terms related to diagnosis (ASD), intervention (Intensive Behavioural Intervention) and participant group (family).

**Table 1:** Search strategy

Diagnosis		Intervention		Participant group
<p><b>Key word search for all databases:</b> ASD or autis* or PDD* or "pervasiv* develop* disord*" or Asperger*</p> <p><b>MeSH:</b></p> <p><b>PsycINFO and Embase:</b> Autism</p> <p><b>Medline:</b> Asperger Syndrome Autistic Disorder</p>	AND	<p><b>Key word search for all databases:</b> ABA or IBI " or "intensiv* behav* therap*" or "applied behav*" or "intensive* behav* interven*" or lovaas*</p>	AND	<p><b>Key word search for all databases:</b> famil* or parent* or brother* or sibling* or sister* or mother* or father* or carer*</p> <p><b>MeSH:</b></p> <p><b>PsychINFO:</b> Mother; Sisters; Brothers; Fathers; Family; Caregivers</p> <p><b>Embase:</b> Family; Parent; Siblings; Caregiver</p> <p><b>Medline:</b> Family; Parent, Mothers; Fathers; siblings; Caregivers</p>



*Figure 1:* Identification of articles

Terms were developed by using key words presented in other similar articles and by identifying related terms. Search terms were also mapped onto the relevant Medical Subject Headings (MeSH) and all terms were exploded in the Ovid databases for diagnosis and participant group. A MeSH search was not carried out for intervention.

Following the search of the various databases, inclusion and exclusion criteria were applied (Table 2) to the articles emerging from the initial search. To do this, the title and abstract of each article was studied. If it was unclear if an article met the inclusion or exclusion criteria then the whole article was retrieved and read.

**Table 2:** Inclusion and exclusion criteria

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Empirical, peer reviewed studies. Qualitative and quantitative papers to be included.	Non-empirical papers (i.e., opinion papers, book chapters, seminar summaries, dissertation abstracts, article commentaries or literature reviews).
Interventions based on an intensive behavioural approach, an applied behavioural approach or the “Lovaas method”.	Studies that did not explicitly state that the intervention was based on an intensive behavioural approach, an applied behavioural approach or the “Lovaas method”. For example, only stating that it is a ‘behavioural approach’.
Studies that explore the experience of parents and siblings of a child undergoing an IBI intervention (e.g. thoughts, views, feelings).	Studies that only focus on factors relating to outcomes for the child with ASD (e.g. papers that explore how parental factors contribute to child outcome).
Studies that explore the social, emotional, behavioural and practical impact on parents and siblings.	Studies that only describe the practical nature of the intervention and family involvement and which do not explore on the views, experiences, perceptions and impact of the intervention on them.
Studies where children were undergoing the intervention at that time or directly following the end of the intervention.	Follow up studies or papers that only explore anticipatory opinions of family members about the intervention before it began.
The intervention was carried out with children who had a primary diagnosis of ASD (including those with a diagnosis of autism, Asperger syndrome and pervasive developmental disorder).	The intervention was carried out with children who did not have a primary diagnosis of ASD.
Articles written in the English language.	Non-English language articles.

2) Hand searching:

The reference lists from articles meeting the inclusion and exclusion criteria were then searched by hand to identify any further potentially relevant articles. Potential articles were then screened according to the inclusion and exclusion criteria for the review.

A total of sixteen articles (quantitative and qualitative) were identified for inclusion within the review. Table 3 provides a summary of these papers.

**Table 3:** Summary of included articles (articles categorised by method and then presented chronologically)

<b>Authors and year</b>	<b>Country</b>	<b>Impact on</b>	<b>Main data extracted</b>	<b>Method</b>	<b>Design</b>	<b>Participants</b>
<b>Birmbrauer &amp; Leach (1993)</b>	Australia	Parents	Compared parental stress levels pre and post IBI	Quantitative	Non-randomised controlled trial	N=17
<b>Smith, Buch &amp; Gamby (2000a)</b>	USA	Mothers	Measure parental stress at 3 months into parent-directed IBI and at 2-3 years.	Quantitative	Case series	N=6
<b>Smith, Groen &amp; Wynn (2000b)</b>	USA	Parents	Explored impact of IBI on the family, parental stress and perceived quality of treatment	Quantitative	Randomised controlled trial	N=15
<b>Hastings &amp; Johnson (2001)</b>	UK	Parents	Explored factors related to parental stress during IBI and compared stress levels to other populations	Quantitative	Cross-sectional Between subjects comparisons with other samples.	N=141
<b>Hastings (2003)</b>	UK	Siblings	This paper explores sibling adjustment in comparison to a normative sample, the effect of autism severity on adjustment and the role of social support	Quantitative	Cross-sectional Between subject comparison to normative sample	N=78
<b>Remington, Hastings, Korshoff, degli Espinosa, Jahr, Brown, Alford, Lemaic &amp; Ward (2007)</b>	UK	Parents	Compared parental well-being pre, mid and post IBI and treatment as usual groups	Quantitative	Non-randomised control trial	N=44
<b>Schwichtenber &amp; Poehlmann (2007)</b>	USA	Mothers	Explored the relationship between intervention intensity and maternal mental health. Also compared mental health to that of other populations	Quantitative	Cross sectional Between subject comparisons with other populations	N=41
<b>Cebula (2012)</b>	UK	Primarily sibling but includes parental data	Explored sibling experience during IBI and compared psychosocial adjustment with a matched control group. Explored interrelating factors relating to sibling outcome	Quantitative	Cross-sectional Case control	N=90

<b>Strauss, Vicari, Valeri, D'Elia, Arima &amp; Fava (2012)</b>	Italy	Parents	Reports on levels of stress during IBI and comparison group (eclectic treatment)	Quantitative	Non-randomised control trial	N= 44
<b>Webster, Feiler, Webster &amp; Lovwill (2004)</b>	UK	Parents	Parental experiences of ABA and eclectic treatments	Qualitative	Cross-sectional	N=15
<b>Trudgeon &amp; Carr (2007)</b>	UK	Families	The impacts of IBI on families	Qualitative	Cross-sectional	N=16
<b>Grindle, Kovshoff, Hastings &amp; Remington (2009)</b>	UK	Parents	Explored parent experiences of IBI.	Qualitative	Cross-sectional	N=53
<b>Granger, des Rivieres-Pigeon, Sabourin &amp; Forget (2012)</b>	USA	Mothers	Explored emotional impact of maternal involvement in an EIBI program	Qualitative	Cross-sectional	N=13
<b>McPhilemy &amp; Dillenburger (2013)</b>	UK and Italy	Families	Parental experiences of ABA	Qualitative	Cross-sectional	N=17
<b>Dillenburger, Keenan, Gallagher &amp; McElhinney (2004)</b>	UK	Families	Explores parent's perceptions of impact of parent led ABA on family life	Mixed method	Cross-sectional	N=22
<b>Dillenburger, Keenan, Doherty, Byrne &amp; Gallagher (2012)</b>	UK	Families	Parents experiences of school and home ABA	Mixed method	Cross-sectional	N=95

More detail on what data were extracted from the papers is provided in Table 4. Information is presented on: author, title and year of publication, methodology, participant and child information, program information, data extracted, results, and themes and limitations.

**Table 4:** Data extraction table (articles categorised by method and then presented chronologically)

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
Authors & year Article title Country of origin		Parent/Carer/ Sibling/ Number (N) Age (A) Gender (G)	Number (N) Age (A) Gender (G)	Hours p/w (H) Parent hours (PH) Duration (D) Location (L) Implemented by (I)		
Birmbrauer & Leach (1993). The Murdoch Early Intervention Program after 2 years Australia	Quantitative Questionnaire completed biannually over 2 years Intervention and control group (matched samples)	Parents (N): NR (A): NR (G): NR	(N): 14 <b>IBI:</b> (N): 9 (A): 32-47 months (Mean=39 months) (G): 5 boys, 4 girls <b>Control:</b> (N): 5 (A): 22-47 (33) (G): 5 boys	(H): 8.7-24.6 (Average=18.72) (PH): NR (D): 2 years (L): Home based (I): Author, program coordinator, parents, volunteers	PSI	Before program, all mothers had stress levels that exceeded the top of the normal range (mean score=95). After 2 years on the program the mean score for intervention group dropped to 82. Control group decreased 1.8. No statistical analysis presented.

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
Smith, Buch & Gamby (2000a). Parent-directed intensive early intervention for children with pervasive developmental disorder USA	Quantitative Case series.	Parent (N): 6 (A): NR (G): 6 female	(N): 6 (A): 31-45 months (mean = 36) (G): 6 boys	(H): 23-35 (mean=26.2) (PH): NR (D): Varied for each child (1 year +) (L): Home-based with transition to school (I): Parent and therapists	PSI	At three months into therapy mothers fell into the 90 <sup>th</sup> percentile (child domain=90 <sup>th</sup> percentile and parent domain=80 <sup>th</sup> percentile) authors report that this is normal levels of stress.  At 2-3 year follow up, mothers fell in the 30 <sup>th</sup> , 35 <sup>th</sup> and 25 <sup>th</sup> percentile for total, child and parent domains respectively (based on 4 anonymous responses)
Smith, Groen & Wynn (2000b) Randomized trial of intensive early intervention for children with pervasive developmental disorder USA	Quantitative RCT: Children randomly assigned to intervention group or parent training group.	Parents (N): NR (A): NR (G): NR	<b>IBI:</b> (N): 15 (A): 36.07 months (mean) (G): 12 boys 3 girls <b>Parent Training:</b> (N): 13 (A): 35.77 months (mean) (G): 11 boys 2 girls	<b>IBI:</b> (H): 18.4-30.79 hours (for 14 children, mean=24.52) (H): 10-15 (for 1 child) (PH): NR (D): 18-63 months (mean = 33.44) (L): Home-based and then transition to school over time. (I): Student therapists with supervision, caregivers (5 hours per week)  <b>Parent Training:</b> <b>(Goals guided by</b>	FSQ	No significant difference between groups on parent workload (“just right”), stress (no effect) and perceived (“just right”) quality of treatment (positive feedback on all areas).  One parent in the intensive intervention group reported that the treatment was stressful for her.

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
				families) (H): 5 (PH): NR (D): NR (L): Home (I): Novice therapist with supervision		
Hastings & Johnson (2001) Stress in UK families conducting intensive home-based behavioural intervention for their young child with autism. UK	Quantitative Posted surveys to families 31% response rate Compared results with samples from another published and unpublished study and their own sample.	Parents (N): 141 (A): 26 to 53 years (mean=37.41) (G): 130 female, 11 male	(N): 141 (A): Mean = 4.98 years/ mean= 46.38 months when started the programme) (G): 89.4% boys 9.9% girls	(H): NR (PH): Mean=6.47 and 4.15 hours per week (respondent hours and partner hours) (D): Mean= 13.47 months (L): Home-based (I): Parents	ABC Beliefs about efficacy of the Lovaas Method: (9 items on a 7-point scale) QRS (3 subscales used: depression; Pessimism; parent and family problems scale) FSS F- COPES	Parent stress was not different to other parents of children with autism (older children) but higher than parent with other developmental disabilities. Length of time on program was negatively correlated with depression scores (effect size: 0.18). More stress if program began later in childhood. Lower levels of stress were associated with adaptive coping strategies such as acquiring social support (effect size= -0.23 for depression ratings), reframing (effect size=-0.20 for depression ratings and -0.23 for parent and family problems) and beliefs about efficacy of intervention

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
						(effect size= -0.24 for Pessimism).
Hastings 2003	Quantitative  Compared sibling adjustment to normative data from 10,298 children from a large scale study.	Mothers  (N): 75  (A): NR  (G): 75 female	(N): 75  (A): 5.04 years (mean)  (G): 88.5% boys 11.5% girls	(H): NR  (PH): 6.88 maternal hours (mean based on 69.2% of mothers who act as therapists)  3.94 partner hours (mean based on 23.1% of partners who act as therapists)  (D): 13.53 months  (L): Home-based  (I): Parents	ABC  FSS  SDQ	Mothers reported fewer adjustment problems in conduct (effect size= .36), hyperactivity (effect size= .30), peer difficulties (effect size=.33) and overall SDQ score (effect size= .33) compared to normative data.  Siblings whose fathers acted as therapists rated fewer pro-social behaviours.  No evidence that social support acted as a mediator or compensatory factor.
Remington, Hastings, Korshoff, degli Espinosa, Jahr, Brown, Alsford, Lemaic & Ward (2007)	Quantitative  Between group: Intervention group and treatment as usual.  Completed measures at pre, mid (12 months) and post (24 months) intervention	Parents  <b>IBI:</b> (N):39  (A): 26-42 (mean=35.7: mothers); 31-50 (mean=38.7: fathers)  (G): 23 females, 16 males  <b>Control:</b> (N): 36	(N): 44  <b>IBI:</b> (N): 23  (A): Mean= 35.7 months (G): NR  <b>Control:</b> (N): 21  (A): Mean= 38.4 months (G): NR	(H): 18.4-34 hours per week (Average 25.6)  (PH): NR  (D): 2 years  (L): Home-based  (I): Trained tutors and parents	HADS  QRS (Family subscale)  KIPP (Positive Contributions subscale)	Fathers in the intervention group reported more symptoms of depression at 12 months and 24 months.  No other significant differences for maternal or paternal well-being between groups.

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
UK		(A): 26-41 (mean=33.6: mothers); 30-53 (mean=37.5: fathers)  (G): 21 females, 15 males				
Schwichtenber & Poehlmann (2007)  Applied behaviour analysis: does intervention intensity relate to family stressors and maternal well-being?  USA	Quantitative  ABA service providers sent research packets (including 5 questionnaires) to families with ASD.  21% response rate.  Compared overall maternal depression findings to samples from three other studies	Mothers  (N):41  (A): 24-49 years (mean=37.4)  (G): All females	(N): 41  (A): 3-14 years (mean= 6.9)  (G): 88% male	(H): 6 - 50 hours per week (mean=22.8)  (PH): 0-30 hours (mean=3.1 – maternal hours)  (D): More than 6 months (between 288 and 11470 hours in total, mean = 3665)  (L): Home-based  (I): ABA service providers	ABC  FNS  CES-D  IFS (personal strain and mastery subscales)  ABA intensity:  Therapy questionnaire (ABA programme information: hours per week/hours from start of programme; and maternal ABA hours)	Maternal depressive symptoms were not statistically different to the three ASD comparison groups.  Mothers reported fewer depressive symptoms when child with ASD was older (effect size=-0.29) and participated in more ABA hours (effect size=-0.36).  More maternal involvement in the programme correlated with more personal strain (effect size=0.36).
Cebula (2012)  Applied behaviour analysis for autism: sibling psychosocial	Quantitative  Between group: Intervention group and matched control group  Within group:	<b>IBI:</b>  Parents:  (N): 45  (A): NR  (G): NR	<b>IBI:</b>  (N):45  (A): Mean = 7.25 years  (G): 39 male, 6	<b>IBI:</b>  (H): 5-40 hours per week (median = 18)  (PH): 1.5-40 maternal hours (median=3; calculated from 42% of mothers who act as	<b>Parents, siblings and teachers completed:</b>  SDQ  <b>Parents and siblings completed:</b>	No significant differences in behavioural adjustment, self concept, or quality of relationship with sibling compared with control group.  Treatment group only:

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
adjustment during and following intervention use UK	treatment outcome compared to “no change” score on likert scale)	Siblings: (N): 45 (A): Mean=9.08 years (G): 21 male, 24 female <b>Control:</b> Parents: (N): 45 (A): NR (G): NR Siblings: (N): 45 (A): Mean=9.25 years (G): 18 male, 27 female	female <b>Control group:</b> (N): 45 (A): Mean=7.67 years (G): 38 male, 7 female	therapists) 1.5-10 Paternal hours (median=3 calculated from 18% of fathers who act as therapists) (D): 2-96 months (Mean=36) (L): Home-based (I): Tutors and 42% of parents <b>Control group:</b> NR	SIB Intervention Impact Questionnaire <b>Parent completed:</b> GARS PSI FSS <b>Sibling completed:</b> Piers-Harris Children's Self Concept Scale Social Support Scale for children	Parents reported significant decreases in time spent available for sibling, significant increase in positive interactions between siblings (as also reported by siblings) and significant decrease in finances available to spend on the family.  No significant difference in parental stress between control group and ABA group. Parental stress levels were associated with perceived intervention efficacy.  Autism severity associated with stress (only in ABA group not control)
Strauss, Vicari, Valeri, D’Elia, Arima & Fava (2012) Parental Inclusion in Early Intensive Behavioural	Quantitative IBI and control (Eclectic intervention) Measures taken during treatment intake and at six months into	Parents (N) : NR (A) : NR (G) : NR	<b>IBI:</b> (N): 24 (A): 26-81 months (mean=55.67) (G): 22 male, 2 female	<b>IBI:</b> (H): 35 hours or more (PH): NR (D): At least 6 months (L): Centre-based and home-based	PSI	During the first 6 months of intervention parenting stress did not significantly change for the IBI group but did significantly decrease for the control group (due to a decrease in the clinical significant perception of a

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
Intervention: The influence of parental stress, parent treatment fidelity and parent- medicated generalization of behaviour targets on child outcomes  Italy	treatment		<b>Eclectic group</b> (N): 20 (A): 27-67 months (mean=41.94) (G): 19 males, 1 female	(I): Staff and parents  <b>Eclectic group</b> (H): NR (PH): NR (D): 6 months or more (L): Home-based		difficult child).  After 6 months, parents in the IBI group and who are involved in the child's treatment reported higher scores across all parenting stress domains compared to the comparison group.
Webster, Feiler, Webster & Lovell (2004)  Parental perspectives of early intensive intervention for children diagnosed with autism spectrum disorder.  UK	Qualitative  Semi-structured interviews, questionnaires and a focus group.  Analysed for "core themes".	<b>Both IBI and eclectic treatments:</b>  Mothers and fathers  (N): NR  (A): NR  (G): NR	<b>IBI:</b> (N): 6 (A): 4-6years (G): NR  <b>Eclectic treatment:</b> (N): 9 (A): 2-4 year (G): NR	<b>IBI:</b> (H): 15-40 (PH): NR (D): NR (L): Home and school (I): Tutors  <b>Eclectic treatment:</b> (H): 2-16.5 (PH): NR (D): NR (L): NR (I):Tutors	Experiences of services, impact of having a child with ASD, views on the intervention.	Unable to conclude as authors did not separate the eclectic and ABA groups in the results section. It is also unclear whether parental views on aspects such as impact of having a child with ASD was affected by treatment or not.

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
Trudgeon & Carr (2007) The impact of home-based early behavioural intervention programmes on families of children with autism UK	Qualitative Semi-structured interviews Grounded theory Inter-rater reliability: first two transcripts were coded by two independent coders.	Parents (N): 16 (A): 31-45 years (G): 9 mothers, 7 fathers	(N): 9 (A): 4-9yrs. (G): 8 male, 1 female	(H): 14-35 (mean=32) (PH): NR (D): 6 months – 4 years (mean=2 years) (L): Home-based (I): Therapists and parents	Perceptions and experiences of parents four themes: setting up, effects on family life, perceived benefits and disadvantages, facilitators and barriers	Impacts: Environmental; funding; social; family relationships; life choices; psychological impacts; tutors; programme demands; disappointments and challenges; benefits.
Grindle, Kovshoff, Hastings & Remington (2009) Parent's experience of home-based applied behaviour analysis program for young children with autism UK	Qualitative Semi-structured telephone interviews Content analysis carried out on transcripts Inter-rater reliability (87%) – another researcher coded 13 interviews Matched groups	Parents (N): 53 (A): NR (G): 32 mothers 21 fathers (from the same family)	(N): 32 (A): 54 and 77 months (mean=65.8 months) (G): 29 boys, 3 girls	(H): NR (PH): NR (D): 25 months (average) (L): Home-based (I): Therapists	Topics: 1) perceptions of practical issues 2) impact on family life and support 3) parents involvement 4) practical management	Practical benefits and difficulties for themselves and siblings. Impact on family relationships were reported e.g. 100% said parent-child relationship improved. Reported emotional impact. Reported overall evaluation of the program.

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
Granger, des Rivieres-Pigeon, Sabourin & Forget (2012)	Qualitative Semi-structured interviews Thematic analysis	Mothers (N): 13 (A): NR (G): 13 female	(N): 13 (A): 4-6 years (G): NR	(H): 7-35 (mean=20) (PH): NR (D): 1-3 years (L): Home-based, rehabilitation centre and kindergarten (I): Therapists	Topics: Role and participation in intervention; opinions about this; training; thoughts of others.	Emotional difficulty; thoughts about child-parent relationship as parent educator; thoughts about impact on other siblings.
Mothers' reports on their involvement in early intensive behavioural intervention.						
CA						
McPhilemy & Dillengurger (2013)	Qualitative Questionnaires Content analysis and thematic analysis	Families (N): NR (A): NR (G): NR	(N): 17 (10 still undergoing and 5 had commenced treatment) (A): 24 months – 20 years (G): 15 boys, 2 girls	(H): NR (PH): NR (D): Mean=42 months (L): NR (I): NR	Impact on family life	Impact on family life (improvement, lower levels of stress, financial burden, worry for sibling, brought family together)
Parents' experiences of applied behaviour analysis (ABA)-based interventions for children diagnosed with autistic spectrum disorder.						
UK						

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
Dillenburger, Keenan, Gallagher & McElhinney (2004)	Quantitative and qualitative Questionnaires Sample divided into short-term group and short-term group.	Families (N): 22  <b>Short term group</b> (N): 10 (A): 32-43 (mean=36.6) (G): 7 mothers, 3 fathers  <b>Long-term group</b> (N): 12 (A): 31-52 (mean=41) (G): 5 fathers, 7 mothers	<b>Short-term group</b> (N): 10 (A): Mean=52 months (G): NR  <b>Long-term group</b> (N): 12 (A): Mean=125 months (G): NR (I): Parents and supervision for both groups	<b>Short-term group</b> (H): NR (PH): NR (D): 2-12 months (mean=6.1) (L): NR (I): NR  <b>Long-term group</b> (H): NR (PH): NR (D): 18-72 months (mean=35.5) (L): NR (I): NR	Impact on family life	General effect on family life (easier, approaching normal family life, manageable); effect on family cohesion (Brought the family closer together); work load (increase/ decrease); structure (more structure, focus; time and energy); finance (financially stressful) and freedom (can go out more).  Effect on parent: general impact (positive); confidence (improved); coping (improved); Stress (less/more); self-esteem (increased, empowered).

Article	Methodology	Participants	Child information	Program Information	Outcome Data	Results/Themes
Dillenburger, Keenan, Doherty, Byrne & Gallagher (2012)	Mixed methods: quantitative and qualitative	Parents and professionals <b>Parents</b> (N): 95 (A): Average: 40 (G): 87 mothers, 8 fathers <b>Professionals</b> (N): 67 (A): NR (G): 88% female	(N): 100 (A): Mean= 8 years (G): 4:1 (boys: girls)	(H): NR (PH): NR (D): NR (L): ABA based School (25%) or mainstream/eclectic special school with home-based ABA (75%) (I): Staff and parents (52%)	FAN-Q PAN-Q Focus group (10 parents)	Focus group: ABA has had a positive impact, change to family life due to understanding child; feelings when professionals visit the home (negative)  No information from FAN-Q or PAN-Q reported regarding parental experiences/impact on family life.
ABA-based programs for children diagnosed with autism spectrum disorder: parental and professional experiences at school and at home						
UK						

**Note:** NR=Not Reported. *Outcome Measures:*

ABC=Autism Behaviour Checklist (Krug, Arick & Almond, 1980), CES-D=Centre for Epidemiological Studies- Depression Scale (Radloff, 1977), FAN-Q=The Family Autism Needs Questionnaire (Keenan, Dillenburger, Doherty, Bryne & Gallagher, 2007), F-COPES=Family Crisis Orientated Personal Evaluation Scales (McCubbin, Olson & Larsen, 1991), FNS= Family Needs Survey (Bailey & Simeonsson, 1988), FSS=Family Support Scale (Dunst, Jenkins & Trivette, 1984), FSQ=Family Satisfaction Questionnaire (Smith, 1990), GARS=Gilliam Autism Rating Scale (Gilliam, 1995), HADS=Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), IFS=Impact on Family Scale (Stein & Riessman, 1980), KIPP=The Kansas Inventory of Parental Perceptions (Behr, Murphy & Summers, 1992), PAN-Q=The Professional Autism Needs Questionnaire (Keenan et al., 2007), Piers-Harris Children's Self Concept Scale 2<sup>nd</sup> ed. (Piers and Herzberg, 2002), PSI=Parenting Stress Index (Abidin, 1990), QRS=Questionnaire on Resources and Stress (Friedrich, Greenberg & Crnic, 1983), SDQ=Strengths and Difficulties Questionnaire (Goodman, 1997; Goodman, Meltzer, & Bailey, 1998), SIB=Sibling Inventory of Behaviour (Schaefer & Edgerton, 1981, unpublished manuscript), Social Support Scale for children (Harter, 1985).

### *Summary of papers*

The 16 articles are now summarised based on the data that has been extracted and presented in Table 4. They are summarised under the headings: Article demographics, methodology, participants, IBI treatment information and outcome measures.

#### *Article demographics*

Of the 16 articles, the majority were researched within the UK (9 papers), and others included Australia (1 paper), USA (4 papers) and Italy (1 paper) and within both the UK and Italy (1 paper). Most of the articles had been published between 2000 and 2013, with one exception that was published in 1993. Of these articles many included the same author or research group. For example three studies included Dillenburger and four studies included Hastings as authors.

#### *Methodology*

Information regarding the design of the articles is presented in Table 3. Of the five qualitative papers, data were analysed using Content Analysis (2 papers), Grounded Theory (1 paper) and Thematic Analysis (1 paper). One paper described the analysis as developing “core themes” and two papers did not report how data were analysed. Of the quantitative papers, five studies recruited a control group within their study and three of these identified children in the control group as receiving treatment as usual (1 paper), parent training (1 paper) and an eclectic intervention (1 paper). Three studies used normative data and other samples from published or unpublished data to act as a control group.

### *Participants*

Parents were recruited as participants in almost all of the articles (15 papers). In some papers only mothers participated (4 papers) and in others both mothers and fathers participated (5 papers). Some articles reported that parents participated, but did not provide details on gender (6 papers). There was a large variation between studies with respect to number of participants, with one paper recruiting only 6 parents and another paper recruiting 162 (including control group participants) within the quantitative literature. Numbers of participants ranged from 13 to 53 within the qualitative research. Siblings participated in one paper, and teachers participated in one paper. Totalling participants across all the studies where it was reported, were 437 mothers, 78 fathers, 45 'parents', 90 siblings (from one study) and 67 teachers (from one study).

Papers reported on families of between 6 and 141 children with ASD. Out of those receiving IBI, many children were of a young age, with six papers aimed at 3-4 year olds, and most papers where the children had a mean age of below 10. One study however, reported on children in a larger age range of between 2-20 years. Out of the seven papers that reported the exact number of boys and girls, males significantly exceeded girls (86% male).

### *IBI treatment information*

Ten papers reported the number of IBI hours per week that the children received whilst six papers did not. Out of these 10, eight reported both range and average IBI hours. One paper only reported the range of IBI hours and one paper reported that children received 35 hours or more. The average number of IBI hours that children received (based on eight papers reporting data) averaged at 23.5 hours. Viewing the ranges across the papers that reported this, the lowest number of IBI hours that any individual child received was five and

highest number of hours was 50. One study had a very large IBI hour range - between six and 50 hours (Schwichtenber & Poehlmann, 2007).

The majority of papers did not report on parental hours of IBI (9 papers). However, across the papers where it was reported, each parent, on average, contributed between 3 hours and 7 hours per week. Again there was extensive variability in the data reported, with one study showing a range between 1.5 hours and 40 hours per week (maternal hours). Children had been engaging in IBI between 6 months and 42 months according to 13 papers that reported this. However, one study reported a large range between 2-96 months. Three studies did not report program duration.

The child with ASD mostly received home-based IBI (14 papers) with some receiving additional intervention at school (4 papers) or at a centre (2 papers). Two studies did not report where the child was receiving the intervention. Therapists/tutors/volunteers (12 papers) implemented the intervention as well as parents (8 papers). Four papers did not report who implemented the program. Additionally it may have been the case that more parents acted as therapists but this was not reported.

### *Outcome measures*

Articles reported that data were collected through already established psychometric questionnaires (10 papers), own developed questionnaires (4 papers), semi-structured interviews (4 papers) and focus groups (1 paper). The majority of papers (7 papers) explored emotional outcomes for parents. Two papers looked at the impact on sibling adjustment. The qualitative and mixed method articles explored family experiences of undergoing an IBI program (7 papers). Table 5 presents the psychometric measures used for each concept measured.

**Table 5:** Psychometric measures used <sup>1</sup>

<b>Concept measured</b>	<b>Psychometric measure</b>	<b>Number of articles</b>
<b>Stress</b>	Parenting Stress Index (PSI)	4
	Questionnaire on Resources and Stress (QRS)	2
<b>Depression</b>	Centre for Epidemiological Studies- Depression Scale (CES-D)	1
	The Hospital and Anxiety and Depression Scale (HADS)	1
<b>Personal strain and mastery</b>	Impact on Family Scale (IFS)	1
<b>Sibling adjustment</b>	Strengths and Difficulties Questionnaire (SDQ)	2
	Sibling Inventory of Behaviour (SIB)	1
	Piers Harris Self Concept Scale	1
<b>Autism severity</b>	Autism Behaviour Checklist (ABC)	3
	Gilliam Autism Rating Scale (GARS)	1
<b>Family needs</b>	Family Needs Survey (FNS)	1
	Family Support Scale (FSS)	1
	Social Support Scale for Children	3
	Family Crisis Orientated Personal Evaluation Scales (F-COPES)	1

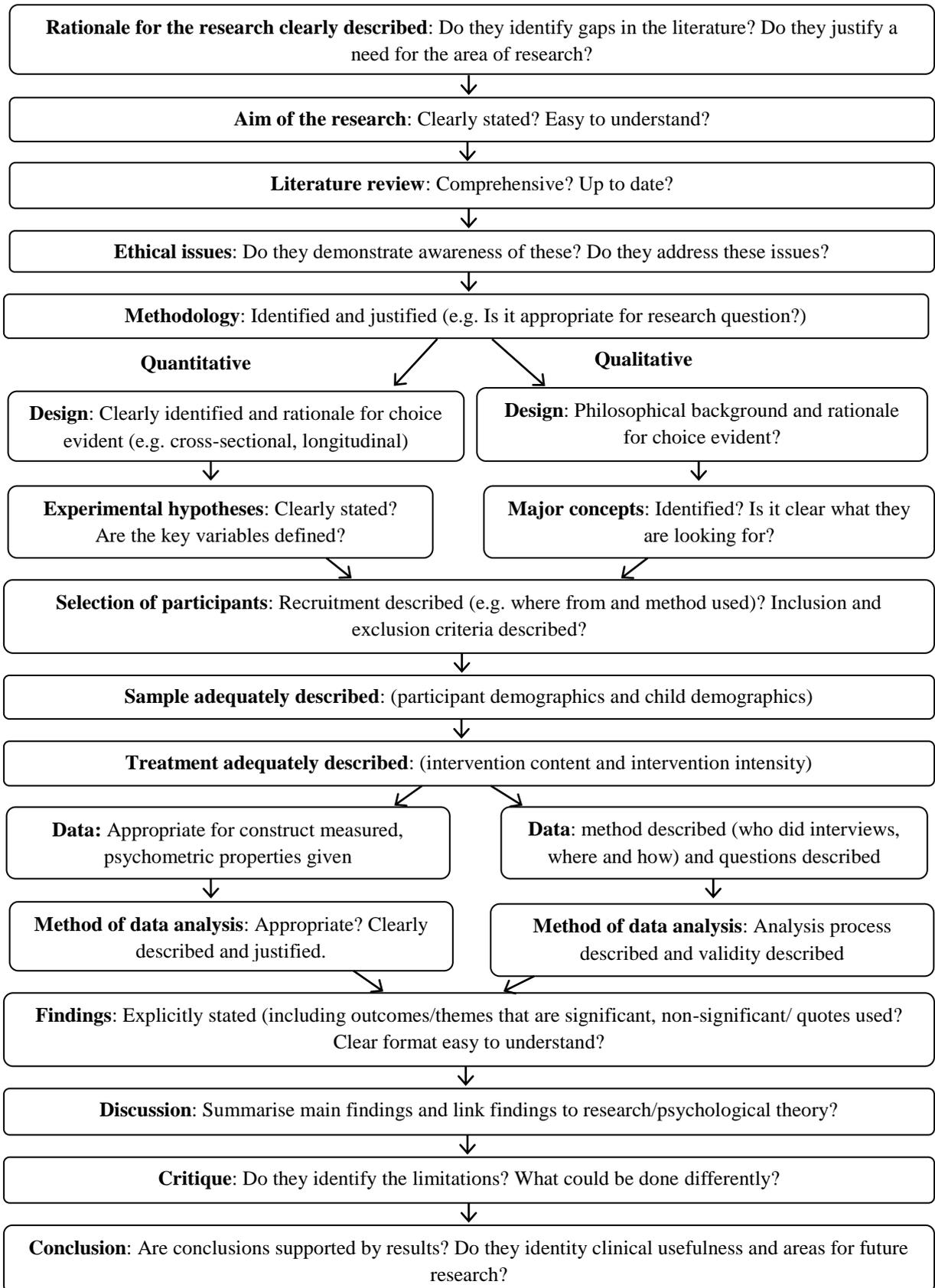
<sup>1</sup> The measures employed by each paper are referred to in Table 4.

### *Critical Appraisal of Articles*

Caldwell, Henshaw and Taylor's (2005) framework for critiquing health research was adopted to evaluate the standard of evidence underlying the data that have been extracted from each article. Other frameworks were explored (i.e. Downs & Black, 1998; Mays & Pope, 2000; Murphy, Dingwell, Greatbatch, Parker, Watson, 1998), however it was felt that Caldwell et al.'s (2005) framework was the most appropriate as it targets both qualitative and quantitative research methodology.

Two areas were removed from the framework, these were 1) 'does the title reflect the content', and 2) 'does the abstract summarize the key components'. The rationale for this exclusion was because many included articles do not primarily focus on parent and sibling outcome. For example they may be firstly interested in child outcome but measure family outcomes as a secondary interest. Therefore this may not be included in the title or abstract and keeping these items in would risk undermining those papers inappropriately. A further criterion was removed ('are the authors credible') and replaced with: 'did the authors critique their research'.

In order to operationalise the framework, each concept was divided into two key questions and a scoring system was utilised (Figure 2). A paper would gain two points if they met both criteria, one point if they met one criterion and zero points if they did not meet any of the criterion. The maximum total score that a paper could achieve was 32; higher scores indicative of better quality.



**Figure 2:** Caldwell, Henshaw and Taylor's (2005) adapted quality framework

**Table 5:** Quality assessment of studies (presented from highest to lowest quality score)

Article	Rationale	Literature	Aim	Ethics	Methodology	Design	Hypoth/Con	Selection	Sample	Treatment	Data Collect	Analysis	Findings	Discussion	Critique	Conclusion	Total
Cebula (2012)	2	2	2	1	2	1	2	2	2	1	2	2	2	2	2	2	29
Hastings (2003)	2	2	2	0	2	1	2	2	2	1	2	2	2	2	2	2	28
Grindle et al. (2009)	2	2	2	0	2	1	2	1	2	0	2	2	2	2	1	2	25
Granger et al. (2012)	1	2	2	0	1	1	1	2	2	1	2	2	2	2	2	2	25
Hastings & Johnson (2001)	2	2	2	0	2	1	2	1	2	0	2	2	2	2	1	2	25
Schwichtenberg & Poehlmann (2007)	2	2	2	0	1	1	1	1	2	1	2	2	2	2	2	2	25
Trudgeon & Carr (2007)	2	2	2	1	2	1	2	2	2	1	0	2	2	2	1	1	25
Strauss et al. (2012)	1	1	1	0	2	1	1	2	1	2	1	2	2	1	1	1	20
Remington et al. (2007)	0	0	1	0	1	2	1	2	2	2	2	1	2	1	1	1	19
Brinbrauer & Leach (1993)	1	0	1	1	1	1	0	2	1	2	1	1	1	1	0	1	15
Smith, Bush & Gamby (2000a)	1	1	1	0	1	1	0	2	1	1	1	0	1	1	1	0	13
Dillenburg et al. (2004)	0	0	0	2	1	1	0	1	2	0	0	0	2	1	0	1	12
Smith, Greon & Wynn (2000b)	0	0	1	0	1	1	0	2	1	2	1	1	1	0	1	0	12
Dillenburg et al. (2012)	1	0	1	1	1	1	1	1	2	1	1	0	0	0	0	0	11
McPhilemy & Dillengurger (2013)	0	0	0	1	1	1	0	1	1	0	1	1	2	1	0	1	11
Webster et al. (2004)	0	1	1	0	1	0	0	1	1	2	0	1	0	0	0	0	8

### *Summary of critical appraisal*

The total scores across the papers varied between 8 and 29 points. There appeared to be a clear cohort of seven papers that scored higher than the others whereby they gained a score of two points on at least 10 of the 16 criteria. The rest of the papers (9) scored a total of two points on six or less of the 16 criteria.

What appeared to be the trend for papers that scored higher was that the reporting of their evidence tended to be of better quality. For example, these papers excelled in identifying gaps in the literature, giving a solid rationale for the need for the research, providing detailed information on the methodology, sample used and how they collected data. Additionally it was made apparent how the data were analysed, findings were clearly reported and then summarised and concluded in relation to the existing literature.

The nine papers that scored lower (< 20) were those in which the reporting of the evidence was of lower quality. These papers were unlikely to give a clear, straightforward rationale for exploring effect on family members, therefore did not clearly identify aims and create a well-designed study around them. Due to these limitations, these papers scored lower on reporting clear findings and linking them back to literature. When viewing the overall content of these papers, the effect of IBI on parents was not the primary focus for four of the articles (Dillenburger et al., 1993, Smith et al., 2000a; Smith et al., 2000b; Strauss et al., 2012), which could explain why these papers scored lower. However, the other five papers state that they were interested in the impact or experiences of families as one of the primary foci, however, they were limited in the quality of reporting their claims.

Caldwell et al.'s (2005) framework appears to be sensitive to how well each paper reported the findings and thus gives a good indicator of quality of reliability. However, it is deemed necessary to further explore the validity of the papers in more depth.

### *Further exploration of the validity of papers*

Seven papers scored higher on the quality framework (>20). Out of these papers there are no randomised controlled trials (RCTs) indicating that the articles, despite scoring highly on the quality framework, are not of exceptional quality. Each quantitative study presented data in comparison to a control group, however it was only Cebula (2012) who recruited their own matched control group. Overall the sample size was small across these studies, with only three recruiting over 50 participants and out of those only one study recruited over 100. There were large variations in IBI hours within and between the papers. Only two papers here explored sibling outcome and it was only one that used sibling self-report.

For those papers scoring lower on the quality framework, one study (Smith et al., 2000b) adopted a randomised controlled design and two studies used a non-randomised control design (Birmbrauer & Leach, 1993; Strauss et al., 2012). However, four studies, which primarily focused on the experience of families, reported a very poor design (Dillenburger et al., 2004; Dillenburger et al. 2012; McPhilemy & Dillenburger, 2013; Webster et al., 2004). For all of the lower quality papers, the design and justification for the research was unclear. As with the higher quality studies, the overall sample size across all of these studies was small with none recruiting more than 50 participants. None of these studies reported on parental involvement in therapy. In some papers there is a large variation in age of child with ASD. For example, McPhilemy & Dillenburger (2013) explore the experiences of families who are currently or have in the past engaged in IBI, thus the ages of the children range from two to 20 years. This is a flaw in the design not only due to large age range, but also that reported experiences will differ for those families currently engaged in IBI and those that have finished. In Dillenburger et al.'s (2012) paper, information on parental experience

only emerges from data within a focus group incorporating 10 parents. This then does not appear to have been qualitatively analysed.

In summary, when incorporating further analysis of the validity of included papers more limitations were seen across all of the papers including the articles that scored higher. Additionally, three studies scored lower on the quality framework, but showed strength with the adoption of a randomised or non-randomised controlled design (Birmbrauer & Leach, 1993; Smith, Greon & Wynn, 2000; Strauss et al., 2012). Two studies were not used in the review due to such poor reporting, design and quality of findings (Dillenburger et al., 2012; Webster et al., 2004).

## Results

The fourteen remaining papers were reviewed for themes related to effect on siblings and parents when a child within the family is receiving an IBI program. Themes were generated through a number of phases. Firstly, every finding that related to the experience or the social, emotional, behavioural or practical impact on parents and siblings were extracted from each article. Secondly, each finding was given a descriptive label. Thirdly, those findings with similar descriptive labels were grouped together to form overall concepts. Lastly, concepts were grouped under core themes. These themes were: *parental emotional impact, sibling adjustment, impact on family relationships, and practical and social impacts.*

### *Parental emotional impact*

A large proportion of papers explored the emotional impact on parents whose child is undergoing an IBI program. Seven papers investigated stress levels for parents whilst undergoing an IBI program. The majority of these papers concluded that stress was similar for these parents compared to others who have a child with ASD (Cebula, 2012; Hastings & Johnson, 2001; Remington et al., 2007; Smith, Greon & Wynn, 2000b). Hastings and Johnson (2001) reported no significant differences in stress between parents whose child was undergoing an IBI program compared to a general sample of parents who have a child ASD. However, parents reported significantly higher levels of stress compared to parents with children with other developmental disabilities. Remington et al. (2007) similarly found no significant differences between stress levels of parents engaged in IBI and parents in Treatment as Usual (TAU) from baseline, 12 months and 24 months into intervention. Smith, Greon and Wynn (2000b) and Cebula (2012) additionally found no significant differences in

stress compared to mothers and fathers who were receiving a parenting training intervention and a matched control group respectively.

Strauss et al.'s (2012) findings differed slightly from the outcome of the above articles. They randomly assigned children with ASD to receive IBI or an eclectic intervention and measured parental stress prior to and six months into treatment. They found that parenting stress did not change during treatment for parents within the IBI group, but lowered significantly for parents whose children were receiving the eclectic intervention.

One paper found that parental stress decreased in the IBI group compared to a control group (Brinbrauer and Leach, 1993). It was unclear if this finding was statistically significant as analysis was not reported. There should be caution when interpreting the findings from this study as authors chose to only report maternal outcomes despite the availability of paternal stress data.

Smith, Buch and Gamby (2000a) examined a parent-directed IBI program for children with ASD and within this explored maternal stress three months into treatment and then again 2-3 years from treatment onset. It was found that mothers fell into the 90<sup>th</sup> percentile on the PSI, which the authors describe as normal levels, however, this score exceeds the normal range indicating higher levels of stress. Furthermore, Smith et al. (2000) go on to report that scores fall to the 30<sup>th</sup> percentile two to three years following onset of treatment for four parents. It cannot be concluded that stress for parents reduced over the course of the program because the respondents were anonymous and authors could not say that all these children were still carrying out the IBI program.

From viewing these seven papers it appears that parental stress does not increase for families who engage in an IBI program. The papers described above vary in terms of quality with Cebula (2012) and Hastings and Johnson (2001) scoring the highest according to the

quality framework. Despite this, there are limitations across all of the papers in relation to small sample size and a large variation in intervention hours between and within studies. It should be noted also that authors use different measures to assess stress (PSI, different domains on the QRS and the FSQ) and therefore each study could be exploring different concepts.

Emotional outcomes for parents, other than stress, were explored by two papers. Remington et al. (2007) found that parental depression, as measured by the HADS, was no different in the IBI and TAU group. Fathers reported significantly more depression within the IBI group over time (at 12 and 24 months), but it was noted that these fathers had fewer symptoms at baseline compared to the TAU group. Schwichtenber & Poehlmann (2007) found that when compared to an ASD sample, maternal depressive symptoms were not significantly different. They found higher rates of depression compared to samples of parents with children with other developmental disabilities.

The two studies described above indicate that depression is no different for parents who have a child engaged in an IBI program compared to those whose child is not. Parental emotional outcome is explored in more depth in the following papers, looking at factors which contribute to differing emotional outcomes for parents.

Cebula (2012) found that parents who perceived IBI to be more effective reported lower levels of parental stress. Similarly, Strauss et al. (2012) found that the significant decrease in stress for the group receiving the eclectic treatment was as a result of decreased perception of a difficult child. Some papers explored ASD severity as a factor affecting stress levels. In Cebula's (2012) paper they found that ASD severity was associated with parental stress in the IBI group but not in the control group. Hastings & Johnson (2001) also found that

the higher the ASD severity the higher the levels of parental stress. However, they found that passive appraisal coping and beliefs in the intervention moderated this effect.

Hastings and Johnson (2001) found that lower levels of stress were associated with adaptive coping such as acquiring social support, reframing and beliefs about the efficacy of the intervention. They also noted that stress levels were higher when the program started when the child with ASD was older. On the other hand, Schwichtenber and Poehlmann (2007) found that mothers reported fewer depressive symptoms when the child with ASD was older and, additionally, when the child participated in more IBI hours. However, they also reported that the greater maternal hours in the program related to higher levels of personal strain. Hastings and Johnson (2001) found that length of time on the program was negatively correlated with depression scores.

The above papers report several factors associated with increased or decreased levels of stress and depression. The majority of the above studies were of good quality according to the quality framework.

Parental experiences related to stress emerged from the qualitative papers. Some reported that the IBI program resulted in lower levels of stress (Dillenburger et al., 2004; McPhilemy and Dillenburger, 2013) and less worry (Dillenburger et al., 2004). Others reported an increase in stress particularly in relation to having to access funding for the program, having to financially fund the program themselves and/or carry out more therapy hours (Trudgeon & Carr, 2007) and finding the program emotionally difficult and tiring (Granger et al., 2012). It was reported that stress initially increased at the start of the program and decreased the more familiar the parents were with it (Dillenburger et al., 2004; Grindle et al., 2009) and when a parent took on less of a therapeutic role (Granger et al., 2012).

Findings reported other positive emotional impacts when on the program such as experiencing feelings of empowerment (Dillenburger et al., 2004; Trudgeon & Carr, 2007), feeling emotionally stronger, better able to cope (Trudgeon & Carr, 2007), feeling more in control and capable of helping their child. Improvements in confidence and self-esteem were also noted (Dillenburger et al., 2004) and reports of a better quality of life and more hope for the future (Dillenburger et al., 2004; McPhilemy and Dillenburger, 2013).

The above papers outline important feelings and experiences of parents whilst their child is undergoing an IBI program. Two of these papers (Grindle et al., 2009; Trudgeon & Carr, 2007) scored highly on the quality framework, however, two articles (Dillenburger et al., 2004; McPhilemy and Dillenburger, 2013) did not and have further design limitations.

### *Sibling Adjustment*

Two papers explored the relationship between IBI and sibling adjustment (Hastings, 2003; Cebula, 2012). Hastings (2003) found no significant differences in adjustment with regard to overall SDQ score, with mothers of children whose siblings were undergoing IBI reporting fewer difficulties in the subdomains of conduct, hyperactivity and peer difficulties compared to a data on sibling adjustment within normative data. Adding to this, Cebula (2012) found no significant differences between the psychosocial adjustment of siblings within this population and of those siblings who have a brother or sister with ASD who were not undergoing an IBI program. They found that both groups were in the “abnormal range” in which they demonstrated strengths in self-concept.

Both papers explored factors that related to differences in adjustment for siblings. Hastings (2003) found some evidence that social support acted as a moderator for sibling behavioural adjustment difficulties for only those siblings who had a brother or sister with

less severe autism. Apart from that, they found no evidence that social support acted as a mediator or compensatory factor within this context. Cebula (2012), on the other hand, found that higher social support reported by siblings related to higher levels of self-concept. This was also found in the ASD control group. Additionally, some aspects of parental social support related to less adjustment difficulties. In particular, perceived helpfulness of informal support reported by parents related to fewer difficulties on the unkindness domain of the SIB (as reported by siblings). Aside from social support, Hastings (2003) found that older siblings reported more prosocial behaviour and it was found that siblings whose fathers acted as therapists displayed fewer prosocial behaviours. Additionally, autism severity was an independent predictor of sibling adjustment, with the higher the ASD severity, the more sibling adjustment difficulties.

In this section both papers report that siblings of children undergoing an IBI program are not more likely to experience adjustment difficulties in comparison to other siblings where their brother or sister has an ASD. There were differences between these papers on what factors contribute to sibling adjustment. Both the papers that were discussed in this section acquired the highest quality score out of all the papers that were reviewed.

#### *Impact on family relationships*

A further theme that emerged was that of relationships within the family. Starting with sibling relationships, parents reported a decrease in time available for siblings to spend together, however, sibling reports showed a significant increase in time for them to spend with their sibling (Cebula, 2012). In the same study, a significant increase in positive interactions was reported by siblings and parents. There was a significant decrease in negative interactions between siblings based on parental reports. In other studies, some parents

reported an increase of play between siblings (Trudgeon & Carr, 2007) and many parents spoke of improvements in the sibling relationship (Grindle et al., 2009).

In terms of the parent-sibling relationship, one study reported no significant changes in time spent together reported by parents and siblings (Cebula, 2012). In Grindle et al.'s (2009) study, many parents reported improvements in their relationship, and few reported deterioration. McPhillemy and Dillenburger (2013) reported some feelings of guilt from parents who lacked the time to give to siblings (Granger et al., 2012), but despite this reported that the intervention brought the family closer together as siblings were included in the program. Similarly, Dillenburger et al. (2004) reported improvements in family life such as improved family closeness and that life felt more normal. Again, Trudgeon and Carr (2007) reported that families do more together, however that there was less time available for the typically developing sibling.

In terms of the parental relationship, some reported deterioration (Grindle et al., 2009; Trudgeon & Carr, 2007), but others said that IBI contributed to strengthening their relationship (Trudgeon & Carr, 2007). Grindle et al. (2009) found that all parents reported improvements in the parent-child relationship as a result of the ABA program. Granger et al. (2012) reported parents spoke of a change of role from parent to educator and that parents felt relieved when they ended the therapist role.

The papers above summarise the impact that IBI can have on relationships within the family. There were similarities between findings (e.g. strengthening of the sibling relationship) but mainly differences within and between studies regarding the impact on other relationships in the family. The quality of the papers vary here with some being of higher quality (e.g. Trudgeon & Carr, 2007) and some papers being of very low quality (McPhillemy & Dillenburger, 2013).

### *Practical and social impacts*

A number of practical and social impacts emerged when reviewing the studies. Benefits for the family are reported in Grindle et al.'s (2009) study such as gaining more support at home, acquiring more free time and socialisation opportunities. Cebula (2012) found that the IBI group had significantly more sources of formal support compared to the ASD control group. Dillenburger et al. (2004) stated that parents reported more structure and that being on the program made life easier.

Negative impacts are also reported such as problems with therapists (e.g. recruitment, unreliability, turnover, presence in home) and difficulties with the Local Education Authorities when attempting to access funding (Grindle et al., 2009). Further concerns were around perceived negative impact on siblings, for instance, siblings gaining less attention, that there was less time to go on family trips and also that it was sometimes necessary for siblings to stay out of the way when therapy was taking place within the home (Grindle et al., 2009). Trudgeon and Carr (2007) reported an impact on the home such as having to make adaptations and changes to the living environment and having to get used to having therapists in the house. The same authors also found that some parents reported a reduction of social life when the ABA program started. Some parents found it a strain to organise sessions and that a lot of time and energy is used to implement the program (Dillenburger et al., 2004). Outcomes also revealed a significant decrease in finances available to spend on family as reported by parents (Cebula, 2012). It was reported by Cebula (2012) that there were no differences in areas such as amount of space in house for sibling, family outings, sibling involvement in housework and sibling time with friends between the IBI sample and the ASD sample.

The above section reveals a number of positive and negative impacts of having a child with ASD engaged with an IBI program and it appears that families often have different experiences. Again, the papers that have been presented here vary in terms of quality.

## Discussion

A systematic review of the literature exploring the effects on parents and siblings when a child in the family is undergoing an IBI program was conducted. Sixteen articles were selected, assessed for quality and then fourteen studies were selected for further review. Four themes emerged from the literature.

The first theme was *parental emotional impact*. The overall finding across the papers is that parental stress and depression is not higher for those engaged in an IBI program compared to other samples from families where there is a child with ASD, however, it is higher than other samples of children without ASD. These findings fit with current literature about stress and depression in families being significantly higher for those who have a child with ASD (Estes, Munson, Dawson, Koehler, Zhou, & Abbott, 2009; Hoffman, Sweeney, Hodge, Lopez-Wagner & Looney, 2009; Singer & Floyd, 2006; Quintero & McIntyre, 2010). Despite this, one paper found that depression in fathers significantly increased during the program. Additionally, one paper found that although stress levels did not change throughout treatment for families engaged in IBI, they did decrease for parents whose children received an eclectic intervention (Strauss et al., 2012). It was reported that this change in stress was as the result of a change in perception of their child, viewing their child as less difficult.

There were elements throughout the papers in the review that refer to the perceptions of parents and how these can be helpful in terms of moderating stress levels. For instance, thinking positively about the child with ASD and about the effectiveness of the intervention was related to lower levels of stress. In some cases, IBI helped parents perceive family life differently such as seeing more hope for the future and for their child with ASD. It is important to note that this is only a correlation and it could be that for those families with

children with ASD who have higher levels of difficulties and where the particular program is not as effective may lead to higher levels of stress.

Some literature did find that ASD severity was a factor contributing to stress levels. This fits with existing research suggesting emotional difficulties for parents could be a consequence of ASD related attributes (Davis & Carter, 2008). It was found that greater parental IBI hours were related to increased stress. Another area of stress is regarding access to funding, and the consequences of not, such as financial pressures and greater parental hours of therapy. One finding was that time on the program was negatively correlated with depression. It could be hypothesised that due to the difficulty in accessing funding and the likelihood that parents have to contribute time and effort into the program at the beginning could lead to heightened levels of stress at the start. This would also fit with the finding that stress levels decrease over time the more parents get used to the program.

The second theme was *sibling adjustment*. Two papers from the review found that siblings whose brother or sister with ASD were undergoing an IBI program were no more likely to experience social, emotional or behavioural adjustment difficulties compared to other siblings of a child with ASD. One paper reported that both groups (ASD sample and IBI sample) actually demonstrated strengths in adjustment, in particular, higher self-concept. There were differences between the papers as to what factors influence levels of adjustment, such as social support. Reviews of sibling adjustment in general for children with a brother or sister with ASD (Meadan, Stoner & Angell, 2010) reflect these inconsistent findings.

The third theme was *impact on family relationships*. Papers reported an overall improvement in the sibling relationship for those families undergoing an IBI program. In terms of the sibling-parental relationship, some reported an improvement, others reported deterioration. Similarly, there were mixed findings regarding the implications of IBI on the

parental relationship, again with some reporting deterioration and other reporting improvements.

The fourth theme was *practical and social impacts*. A number of positive practical and social impacts emerged for the families, such as having more free time and being able to go out more. Despite this, a greater number of negative practical impacts were reported surrounding problems with the implementation of the program, funding difficulties, decreased finances and reports of there being less time available for the typically developing sibling.

### *Clinical implications*

This review suggests that a number of factors contribute to emotional outcomes for parents. It is important for the professionals working with these parents to think about promoting and increasing positive beliefs about the child with ASD, the program and the parents' own abilities and confidence. It may be that individual support could be given to parents around coping strategies such as cognitive reframing.

There should be an awareness of the unique impacts that this type of program has on family life, and the changes and adaptations that families have to make in order to accommodate the program, for instance, having therapists within the home. This literature suggests that the IBI affects each family differently, and it is not clear which elements are perceived as helpful or unhelpful at this point. Due to this, it may be useful for the IBI team to monitor the impact on members of the family and to discuss ways of decreasing negative impacts and increasing positive impacts.

It appears that the start of the program could be the most stressful time for families. Professionals need to think about this critical period and how to provide more support during this time.

### *Further research*

It has been found that parents are more at risk of developing emotional difficulties as a result of having a child with ASD, and the overall finding from this review is that parents do not display an additional significant risk (namely regarding stress) when undergoing an IBI program. Despite this, what emerged from the literature is that family life is negatively or positively impacted on as result of being on the program with relation to relationships within the family, practical and social impacts. Therefore, an area of future research development should be for researchers to consider the factors that have emerged and use them as predictors for differences in emotional outcome.

There were some discrepancies within both the quantitative and qualitative findings with regard to the effect on relationships between members of the family. Therefore further research is needed to understand more about why some relationships strengthen during the program and why some weaken.

Unfortunately there was a lack of sibling self-reported data, with only one study exploring sibling experience. This is an important area for future research, not only in terms of adding to sibling adjustment research, but also in understanding how siblings experience family life in general when their brother or sister is engaged in an IBI program. Similar to this, research needs to find a way of recruiting more father participants in order to get a better understanding of family life and the emotional impacts for them, such as depression.

What appeared problematic from the review of the literature was the large variation in IBI hours within and between the research articles. It is imperative for authors, when designing future research in this area, to take this important factor into account. It could be recommended that authors group together families whose child is engaging in high levels of

IBI hours (i.e. over 25 hours per week) and those whose child is engaging in low levels of IBI hours (i.e. less than 25 hours per week).

### *Quality of papers*

The reviewed papers varied with regards to the quality of the evidence that they were presenting, with some papers scoring highly on the quality framework and some scoring very low. There were further limitations across all of the studies which included a lack of randomised controlled trials and small participant sample sizes. One of the greatest limitations within and across the papers is the large variation in intervention hours that the child with ASD received. It would be assumed that a family's experience when their child receives five hours of intervention would be qualitatively different to a family whose child was receiving 50 hours of intervention. This begs the question also as to what constitutes an intensive intervention. As most of the papers are cross sectional studies where the researchers gain information from families who are already on a program, it may be that when the intervention is applied naturally many families do not receive the recommended number of treatment hours.

### *Evaluation of the review*

An effort was made to equally assess the quality of each paper by adopting and adapting a critical framework and then further assessing the design strengths and limitations. Despite this, a limitation within this quality framework (and that of other frameworks) is that each criterion is equally weighted, but it could be argued that some areas should be more important, such as methodology and design. A further limitation of this review is that there is

no inter-rater reliability to report as the studies were not rated again independently by a second reviewer.

### *Conclusion*

The effect on families where a child with ASD is undergoing an IBI program is a new and developing area of research. Currently there are a small amount of papers that explore this area, all with methodological weaknesses. The majority of these papers focus on emotional outcome for parents and suggest that parents do not experience emotional difficulties over and above other parents who have a child with ASD. It is clear from the studies that there are unique impacts on parents and families whilst undergoing IBI, however, more research needs to be carried out to understand how individual members experience IBI and what factors relate to positive or negative outcomes.

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## **Chapter Two**

### **The Experience of Having a Child with Autism Spectrum Disorder (ASD) in the Family: Sibling and Parental Perspectives**

## Abstract

**Background:** Parents who have a child with Autism Spectrum Disorder (ASD) are more at risk of mental health difficulties compared to parents who do not have a child with ASD. There could also be an impact on the typically developing sibling, in terms of social, emotional and behavioural adjustment. This study addresses a gap in the literature whereby the experiences of parents and siblings from the same family where there is a child with ASD were explored.

**Method:** Five families were interviewed about living in a family where there is a child with ASD. Data from the interviews were then analysed using Interpretative Phenomenological Analysis (IPA).

**Findings:** Three super-ordinate themes emerged from the analysis: '*concept of sibling connection as fragile*', '*trying to keep the peace*' and '*acceptance*'. It was found that some experiences were similar between sibling and parents, however, the way in which they made sense of these experiences tended to differ.

**Conclusion:** Parents and siblings found it helpful to have an understanding of ASD. An area of need emerged for siblings regarding coping with their own emotions. Further research is needed into the coping strategies used by siblings who have a brother or sister with ASD.

**Key words:** Autism Spectrum Disorder, parents, siblings, family, experiences.

## Introduction

Autistic Spectrum Disorder (ASD) is a neurodevelopmental disability characterised by deficits in social communication, social interaction, flexibility of thought and often repetitive movements and behaviours (American Psychiatric Association, 2000). Falling under the umbrella term of ASD are Asperger Syndrome, Autism, and Pervasive Developmental Disorder not otherwise specified (PDD NOS). ASD is a lifelong condition, with symptom onset typically displaying between the ages of 18 and 24 months, and is currently known to affect 1 in 100 people (Baird, Simonoff, Pickles, Chandler, Loucas, Meldrum & Charman, 2006; Baron-Cohen, Scott, Allison, Williams, Bolton, Matthews & Brayne, 2009).

Due to the unique characteristics of ASD, living with a child with this diagnosis is likely to be different to living with a typically developing child. A growing body of research has developed which explores how having a child with ASD effects the family. Two areas of research have emerged: *Parental experience* and *sibling experience*. These two areas will be described below.

### *Parental experience*

There is a large amount of research that explores the effects upon parents who have a child with ASD (Bekhet, Johnson & Zauszniewski, 2012; Stoner & Angell, 2006). Within this, a focus has been on parental emotional outcome (Hayes & Watson, 2013; Singer & Floyd, 2006).

There is substantial research evidence indicating that parents of children with ASD report significantly greater levels of stress compared to mothers of typically developing children. This was demonstrated in a recent meta-analysis by Hayes and Watson (2013). This review also reported higher levels of stress even when compared to families where the child

had other disabilities. Parents of children with ASD are also more likely to be at risk of depression according to a meta-analysis demonstrating heightened levels of depression compared to mothers of typically developing children (Singer & Floyd, 2006).

Several factors have emerged as predictors for higher levels of stress and depression for parents of children with ASD. Hastings (2002) concluded that the presence of behavioural problems in children with ASD is strongly predicative of parenting stress levels. These behaviours are often very difficult to manage (Karst & Vaughan Van Hecke, 2012) and consequently families sometimes restrict what activities they partake in (Gray, 2012). Additional stress arises for parents as children with ASD do not appear physically different to a child without ASD and, therefore, parents are concerned about the perceptions of others (Marcus, Kunce & Schopler, 2005). Other primary characteristics of ASD that are identified as stressful for parents include sensory difficulties (Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2008) and differences in social interaction (Davis & Carter, 2008).

Qualitative research on parental experiences report that having a child with ASD impacts on the whole family. For example, Myers, Mackintosh & Goin-Kochel (2009) conducted an online questionnaire asking 493 mothers how their child with ASD has affected their life and their family's life. Fifteen negative themes and nine positive themes emerged from the responses which were categorised into five thematic clusters: *stress, child's behaviour, parent's personal well-being, work and marital relationship, impact on the whole family and social isolation*. Other qualitative research involving parental perspectives confirm that parents feel that ASD affects the whole family (Cassidy, McConkey, Truesdale-Kennedy & Slevin 2008; Meirsschaut, Roeyers & Warreyn, 2010).

Parents report both positive and negative impacts on the typically developing sibling in relation to having a child with ASD in the family. For example, some parents believe that

the siblings will grow up to have higher levels of sensitivity (Myers et al., 2009) due to having a brother or sister with difficulties. However, other parents are concerned that by having to adopt different parenting styles for each child, and the likelihood that they have to provide more attention for the child with ASD, may mean that the siblings are negatively impacted (Meirsschaut, Roeyers & Warreyn, 2010).

### *Sibling experience*

Research exploring siblings' experiences has tended to focus on the social, emotional and behavioural adjustment of siblings who have a brother or sister with ASD (Hodapp, Glidden & Kaiser, 2005; Stoneman, 2005). However, the outcomes from this research have been varied and inconsistent (Meaden, Stoner & Angell, 2010).

Some studies have reported that siblings who grow up with a brother or sister with ASD do not show difficulties in areas of adjustment (Kaminsky & Dewey, 2002; Pilowsky, Yimiya, Dippelt, Gross-Tsur & Shalev, 2004). For example, some research shows that these children did not display the presence of internalising problems (e.g. anxiety and depression) or externalising problems (e.g. hyperactivity and aggression) compared to a normative sample (Dempsey, Llorens, Brewton, Mulchandi & Goin-Kochel, 2012). On the other hand, some studies reported increases in anxiety, depression and behavioural difficulties (Dew, Balandin & Llewellyn, 2009; Hastings, 2003) for siblings who grow up with a child with ASD in the family compared to those who do not. Some findings report positive effects such as enhanced self-concept, self-competence and prosocial skills compared with other peers who do not have siblings with ASD (Macks & Reeve, 2007; Rao & Beidel, 2009).

Some studies suggest that sibling adjustment is related to ASD severity whereby higher symptoms of ASD negatively affect sibling adjustment (Benson & Karlof, 2008;

Hastings, 2003; Pilowsky et al., 2004). On reviewing sibling adjustment research, Meaden et al. (2010) suggested that the inconsistencies in the findings can be explained by the differences in methodologies between the studies and/or threats to the validity or reliability within them. There are differences between studies in terms of control groups, sampling and measurements that are used.

Alongside the quantitative studies mentioned researchers have also adopted qualitative methodology to explore the experiences of siblings who live with a child with ASD. Most recently, Angell, Meadan, and Stoner (2012) conducted interviews with 12 typically developing children who had a brother or a sister with ASD. Authors report that siblings of children with ASD have a heightened sense of responsibility and role within the family which is of a nurturing nature where there is an awareness of their sibling's needs. It was found that siblings had mixed feelings toward their brother or sister in which they would describe positive interactions at times but also experience feelings of embarrassment due to their brothers or sisters behaviour. They identified ways of adapting and coping with having a sibling with ASD in the family by employing problem focussed and emotional focussed coping strategies (i.e. withdrawing from difficult situations, seeking support from others and using calming techniques of managing their sibling's behaviour).

Further qualitative research with siblings reported the positive aspects of having a brother or sister with ASD, such as spending time and having fun together (Mascha & Boucher, 2006; Petalas, Hastings, Nash, Dowey & Reilly, 2009). However, research also highlights the difficulties of living with a child with ASD, such as aggressive behaviour and feelings of embarrassment (Mascha & Boucher, 2006). Although this was not a qualitative study, Ross and Cuskelly (2006) also found that aggressive behaviour from the child with ASD was most stressful for the sibling and consequently impacted on their sibling

relationship. Siblings tended to adopt particular coping strategies such as regulating their own emotions in response to the difficult situations.

### *Family experience*

It is suggested that in order to understand family life and experience and thus to know how best to support families with children with ASD it is important to focus research on dynamics within the family (Angell et al., 2012; Cridland, Jones, Magee & Caputi, 2014). Some research has already started to do this and identified important psychological and systemic factors that influence sibling experience. For instance, Meyer, Ingersoll and Hambrick (2011) found that the severity of ASD symptoms in the child with ASD positively predicted maternal depressive symptoms which in turn impacted on sibling adjustment. This is supported by other studies that show that adjustment can be affected by relationships within the family and parental well-being (Benson & Karlof, 2008; Quintero & McIntyre, 2010; Rivers & Stoneman, 2003). Benson and Karlof (2008) found that a better quality of family climate (i.e., family connectedness and parental agreement) resulted in greater prosocial behaviour in children with a sibling with ASD.

The majority of research, however, focuses on outcomes on individuals within the family and overlooks the complexities of the family system. Authors recommend that more research exploring the functioning of family subsystems where there is a child with ASD needs to be carried out (Angell et al., 2012; Meyer et al., 2011). There is currently no qualitative research that explores and compares the experiences of two members within the same family where there is a child with ASD.

This current study aims to address this gap in the research by qualitatively exploring and comparing sibling and parental experiences and perceptions of living in a family with a

child with ASD. Through interviewing a child and parent separately, the aim is to collect in-depth and detailed information about experiences within the family from two perspectives which will provide greater insight into how families make meaning of living with a child with ASD, coping strategies and areas of support and needs.

## **Method**

### *Methodological approach*

Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) was chosen as an appropriate methodological approach for this research. It is 'phenomenological' as it is interested in the personal meaning an individual gives to their experience (Larkin & Thompson, 2011). It is 'interpretative' as the researcher tries to understand and make sense of the individual's experience. As part of IPA a 'double hermeneutic' process occurs whereby the researcher attempts to make sense of an individual's experience, who is making sense of their own experience during the interview. Due to this, it is recognised that outcomes from the IPA analysis are a joint result of the participant and researcher. A researcher's prior experience, assumptions and preconceptions are therefore likely to influence the findings. It is important that the researcher reflects on this throughout the process by attempting to engage fully with the participant during interview and analysis in order to explore the personal meaning of the participant's experience.

IPA has been used for this study to enable siblings and parents to share experiences of family life where there is a child with ASD. IPA will be used to make sense of the experiences of parents and siblings individually whilst also comparing experiences across the two groups, to explore if experiences are shared or if they differ. The author reflected on her own preconceptions prior to commencing the research in order to be aware of these possible influences throughout the research (Figure 3)

IPA studies require small sample sizes (5-8 participants) in order for in-depth analyses to be developed (Larkin & Thompson, 2011). For the same reason, IPA requires a sample to be somewhat homogenous in their characteristics (Smith et al., 2009).

Reflexive statement

My interest in the experiences of families who live with a child with ASD developed as a result of working clinically with children with ASD and their parents. My role here included carrying out an intensive behavioural intervention with children with ASD. I remember at the time being struck by the emotional impact that a child with ASD has on parents, and I remember feeling amazed by how resilient these families were. I reflected on how I remember very little about the brothers and sisters of the children I was working with even though I had been working in their home environment. I wonder now what experiences they may have had as a result of having a sibling who required so much support and attention. Throughout my clinical psychology training I have developed a strong interest in supporting children and families and favour behavioural and psychodynamic approaches. I am aware that my past experiences and reflections on these are likely to influence the research both during the interview and whilst carrying out the analysis.

**Figure 3:** Author's reflexive statement

*Data Collection*

Participants were recruited through a Child and Adolescent Mental Health Service, a social enterprise specialising in ASD assessment and through lead members of support groups within the West Midlands area. Ethical approval was gained through the NHS research ethics committee (Appendix B), Research and Development Team (Appendix C), the ethics committee responsible for a social enterprise (Appendix D) and through sponsorship with the University of Birmingham (Appendix E).

Families were identified by individuals running support groups or working clinically with families of children with ASD. Respective professionals provided families with a brief written summary of the research, including participant inclusion and exclusion criteria (Appendix F) and full participant information leaflets for parents and siblings (Appendices G and H for sibling and parent leaflets, respectively). Families either contacted the researcher directly to enquire further about participating or gave their consent for their contact details to

be passed onto the researcher. In the case of the latter, the researcher contacted the families no less than 48 hours after the information was given to families. During the first contact with the family, the researcher clarified that they fitted the inclusion criteria for participation, and confirmed their willingness to participate. Participants confirmed their consent by completing a consent form (Appendix I and J).

Interviews were carried out individually with each participant. They took place either within the participants' homes, the child's school or the University. The duration of interviews ranged from 35 to 40 minutes for siblings and 55 minutes to 84 minutes for parents. Interviews were recorded and then later transcribed verbatim.

#### *Ethical considerations*

Participants were informed that their transcripts would be anonymised to ensure confidentiality. They were made aware that they would be quoted in the final paper and that these quotes may be identified by other members of the family. Therefore, participants had the opportunity to state if they would not like particular quotes to be used in the study. This was checked with them after each interview and also after having been given the opportunity to read through their transcripts.

#### *Participants*

Thorough inclusion and exclusion criteria were developed (Table 7). This was guided by the recommendation that IPA requires a homogeneous sample (Smith et al., 2009).

**Table 7:** Participant inclusion and exclusion criteria

	<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Participating parent	<ul style="list-style-type: none"> <li>English speaking</li> <li>Must live with the child with ASD and the participating sibling</li> </ul>	<ul style="list-style-type: none"> <li>Current mental health difficulty that would affect experience of family life. This would be unrelated to difficulties of family life with a child with ASD. This will be assessed during the interview</li> </ul>
Participating sibling	<ul style="list-style-type: none"> <li>Aged between 11 and 16</li> <li>English speaking</li> <li>Be able to give informed consent</li> <li>Does not have a diagnosis of ASD</li> </ul>	<ul style="list-style-type: none"> <li>Siblings who have not grown up in the home</li> </ul>
Child with ASD	<ul style="list-style-type: none"> <li>Aged between 8 and 16</li> <li>Diagnosed five years of more ago</li> <li>Lives within the family home</li> <li>Comorbid diagnosis other than psychosis</li> </ul>	<ul style="list-style-type: none"> <li>Has a diagnosis of psychosis</li> <li>Has a diagnosis of a learning disability excluded by having an IQ of under 70 or not attending a mainstream school</li> </ul>
Family	<ul style="list-style-type: none"> <li>Only one child with a diagnosis of ASD within the family</li> <li>Two adults within the family home</li> </ul>	<ul style="list-style-type: none"> <li>Any more than three children within the family home</li> </ul>

Five families participated in the research. A summary of the participants is displayed in Table 8. The five parents participating were of similar ages ranging from 37 to 44 and four were mothers and one was a father. All families had two parents within the home. All mothers had adopted a primary caregiving role in the family since the birth of their first child in which they had adapted work by either discontinuing with their occupations or adapted work to fit in with parenting (e.g. less hours or less demanding job role). The father was qualitatively different because he had switched parenting roles with his wife within the last year, and had adopted a primary caregiving role. Sibling participants were three males and two females

**Table 8:** Summary of Participants

Family	Participants		Child with ASD	
	Parent (Pseudonym, age)	Sibling (Pseudonym, age)	Pseudonym, age	Other information
1	Becky, 39	Sarah, 13	Tom, 15	Diagnosed aged 10
2	Lynda, 37	Andrew, 11	Sam, 13	Diagnosed aged 7
3	Beverly, 42	Gemma, 14	Reece, 16	Diagnosed aged 10 Additionally diagnosed with Tourette's Syndrome
4	Nicky, 41	Simon, 12	Hugo, 15	Diagnosed aged 3
5	Frank, 44	Matthew, 14	Adam, 16	Diagnosed aged 3

ranging between the ages of 11 and 14. The children with ASD in the family were all male ranging in age between 13 and 16. There was a large range regarding the age at which the child was diagnosed with ASD (range: 3-10 years). Three children with ASD attended mainstream schooling. Two children with ASD attended schools with specialist ASD provision but were completing GCSE's. Four families had three children in the family including the child with ASD. Only one family had only two children in the home.

### *Materials*

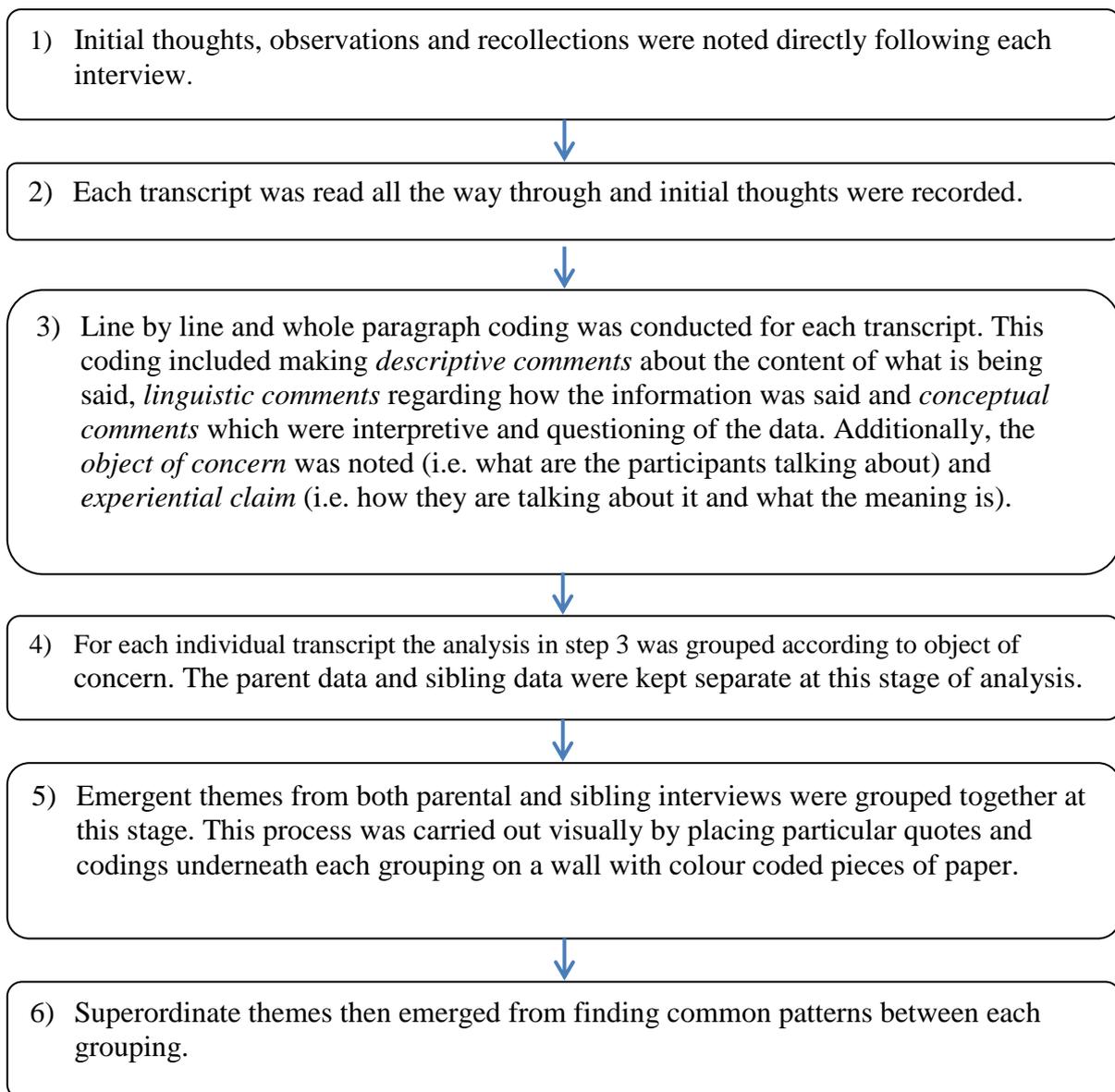
Two semi-structured interview guides were developed for parental and sibling interviews (Appendix K and L, respectively). The development of these was guided by IPA recommendations for constructing an interview schedule (Smith et al., 2009). Both interview guides were designed to elicit detailed information about the experiences of family life and what it is like living with a child with ASD. For example, all the questions are open-ended and are broad enough for participants to share what is important to them. The schedules were also designed to build rapport between researcher and participant in order for the participant

to feel most at ease and able to talk about their experiences. The schedules acted as a guide as opposed to a fixed interview that one could not deviate from. For example, further prompts and probes were used to elicit more information about a person's experiences (i.e. "can you tell me more about that?"; "what was that like for you?").

### *Data Analysis*

In IPA there is not one single method of analysing the data (Smith et al., 2009). The analysis was therefore guided by recommendations from Smith et al. (2009) and Larkin and Thompson (2011), and focussed on analysing from an individual level primarily then to looking at what is shared between participants and what the common personal meanings are for this group of individuals. Stages of the IPA analysis used in this study are depicted in Figure 3. Examples of the stages of this process can be found in Appendix M, N and O. Parental and sibling data were initially analysed separately and then combined in stage 5 of the analysis (see Figure 3). Credibility was assessed throughout the IPA analytic process by meeting regularly with an IPA peer group where emergent themes were discussed and checked.

When carrying out IPA, researchers are required to be aware of and reflect on their own role and assumptions during the interviews and how they affect interpretations of the data. To aid reflexivity the author kept a reflective journal throughout the process, from designing the study to interviewing, data collection and the analysis stage. The author made comments about thoughts that emerged from the process, reflected on own biases and personal experiences and views in relation to the content of the interviews.



**Figure 3:** Stages of IPA analysis as guided by Smith et al. (2009) and Smith & Thompson, (2011)

## Results

Three super-ordinate themes emerged from participant data. The first theme that will be discussed is the *'concept of sibling connection as fragile'*. The second theme *'trying to keep the peace'* includes three sub-ordinate themes: *'for the greater good'*, *'intuitive versus acquired understanding'* and *'containment of emotions'*. The final theme that will be discussed is *'acceptance'*. This theme included two sub-ordinate themes: *'concept of normal'* and *'positive growth'*. When presenting these findings, the participants name will be provided after each quote along with the line number from the interview and a letter 'S' or 'P' which tells the reader if the quote is from a sibling or a parent, respectively. Within the quote the letter "I" indicates the interviewer's comment and the letter "P" indicates the participant comment. Further quotes to support the emergent themes are displayed in appendix P.

### *Concept of sibling connection as fragile*

Overall, the sibling and parent participants spoke about the sibling relationship as being fragile. This concept emerged throughout each interview and was in relation to changes in relationships over time or frequent changes in the present moment:

I: "... when are the times when you get on better with them?"

P: "Probably, probably when we're like out together or on holiday"

I: "And are there times when you don't get on so well with your brother or sister?"

P: "Yeh. Like Hugo's, like, gets in a mood sometimes cause something's happened at school and he's just like funny with everyone" (S: Simon, lines 26-30)

This quote from Simon reflects other participants thoughts about the influence that the child with ASD has on the nature of the sibling relationship. It appears from Simon's quote, and throughout the rest of his interview, that this perception only occurs in relation to his

sibling with ASD as he does not have the same experience with his typically developing sibling. Simon's quote also reflects the need for siblings to understand and make sense of why these changes in dynamics occur, and how they can be due to underlying difficulties for the child with ASD. In this example, Simon talks about his brother's mood change as a result of particular situations and triggers. There is a sense from the majority of participants that this explanation enables them to empathise with their sibling during these unpredictable changes in relationships. It also gives them an explanation of why their relationship changes and that the cause is the child with ASD.

Some siblings spoke about more rapid and unpredictable changes in the mood of their sibling with ASD that leads to immediate changes in the relationship:

*"... he can be like really fun sometimes but then if he gets, if he has too much fun then he gets over the top and hyper and then he'll hurt me like badly"* (S: Sarah, lines 160-162)

*"Sometimes, well, quite a bit of the time, erm, we're like good friends and that but it's like sometimes it's where there can be a few slip ups and [long pause] and then it'll be like bad"* (S: Andrew, line 72).

Both Sarah and Andrew talk about a fine line between a positive and negative experience. Again there is a sense that the relationship and feelings experienced by the siblings are of a consequence of their brother or sister's change in mood and/or behaviour. It was often the case that sibling connection was determined by the child with ASD and their interests. This is exemplified in quotes from both a parent and a sibling from the same family:

*“...when he's got something that he's excited about he'll come and tell you about it, but when you've got something that you want to tell him he doesn't seem to care at all...that's not too bad most of the time” (S: Gemma, lines 104-105 and line 115).*

*“...and it is a shame that they haven't got that close bond... Gemma I would say she's missing the closeness with Reece. You can see that sometimes she tries to talk about games he's into even though she's not really interested in them and the only thing I can presume is that she wants to be close with him again” (P: Beverly, lines 38-39 and lines 43-45).*

These quotes from Gemma and Beverley reflect other participants awareness of the nature of the sibling relationship as being largely dependent upon the child with ASD and their interests. What is interesting is that this experience differed between parents and siblings. As can be seen in Gemma's quote, siblings often recognised and allowed the conditional nature of their relationship with their brother with ASD. Parents, however, tended to experience this dynamic as a lack of closeness within the sibling relationship and that this, in some way, felt like a loss for the typically developing sibling. Parents were likely to feel that siblings change and adapt their behaviour in order to maintain closeness with their brother as was also exemplified in Beverley's quote. Parents tended to be aware of a difference in the sibling relationship and had a perception of what an ideal relationship should be like:

*“...they're not, like erm, pals, they don't like not get on but they do get on, sometimes they'll play like, running about kind of boyish kind of games together and they will play on like the PS3 and things together and things like that [mmm] so they have moments when they play together and moments where they don't” (P: Nicky, lines 255-262)*

In the above quote, Nicky appears to question what it means to get on well with a brother or sister and considers that although Simon and Hugo play together occasionally this

does not make them ‘pals’. Here, Nicky is reflecting the views of the majority of other parents, whereby the fragility and the changing nature of the sibling relationship is experienced as a lack of a deep and meaningful relationship. There is a sense that parents are placing their own preconceptions of what a close relationship should be like and this is likely a reflection on their relationships with other family members, for example, their own sibling relationships:

*“Well, I think it’s a shame for Matthew, in a way, ‘cause when Matthew was little it probably affected him more, they just go their own way now, they don’t really... I think it’s sad that they’re not, ‘cause me and me brother are, you, like, brothers and sisters do have fights and that, don’t they, me and me brother would argue, you know and have fights but we still, we went about together, you know and played football and cricket together and go for a, down the pub when we got older and everything like that but the, you know, you, you’re sort of, they’re separate really, they don’t associate with each other at all” (P: Frank, lines 511-526).*

Overall this theme reflects a sense from both parents and siblings that the sibling relationship can be fragile and influenced by the child with ASD. It appears that the child with ASD’s mood difficulties and restricted interests can influence the relationship with their sibling. Perceptions of the quality of the sibling relationship differed between sibling and parental reports, with parents in some way feeling a sense of loss that siblings do not have what they perceive, to be a typical, meaningful and close relationship.

### ***Trying to keep the peace***

Overall, the content of the interviews suggested a lot of thought and effort was put into achieving balance and harmony within the family from both siblings and parents. The first sub-ordinate theme ‘*for the greater good*’ refers to the notion that it is for every family

member's best interests if adaptations are made around the child with ASD. Linked to this emerges the second sub-ordinate theme '*intuitive versus acquired understanding*'. The third sub-ordinate theme '*emotional containment*' refers to the process of family members needing to control their own emotions in order to keep the peace.

*For the greater good*

It emerged for the majority of parents (Becky, Lynda and Nicky) that decisions which incorporated the child with ASD in the centre were for the best interests of the whole family:

P: "...sometimes I think if somebody isn't happy [coughs] I can't always change it but whatever I do I try and do for the greater good so to speak I think"

I: "What's the greater good?"

P: "Peace and harmony [laughs] no one fighting [laughs]. And I think if it's decisions about going out somewhere that people get enjoyment out of it, I think to be fair the whole family is focused on Sam and meeting his needs, probably more than the others which in a way is really bad because you're not then putting the other two as the centre of attention but if things aren't right for Sam it makes everybody else's life a misery sometimes" (P: Lynda, lines 651-660)

This quote from Lynda reflects the thoughts of the other two mothers (Becky and Nicky). It appears that there is an idealistic family life which includes 'peace and harmony', however, there is a sense from Lynda's tone (i.e. laughing) and content in the quote that this is unlikely, improbable and difficult to achieve. It is difficult for the mothers to know that one child is being put first, however, it appears to be helpful to rationalise this difficult decision-making as Lynda does in the above quote by saying it will benefit the whole family, and that if they don't others will be miserable. This form of rationalisation can also be seen in a quote from Becky:

*“I’ve always tried to think of the both of them. Erm, tried to develop strategies that would sort of help the pair of them really and then I could concentrate on Tom and get him to school in a less anxious state”* (P: Becky, lines 148-153).

Again she is justifying her decisions to put Tom first. It is not always easy to rationalise, and feelings of guilt emerge from some:

*“So I did spend, have to spend more time with Simon, and Hugo didn't really moan you know, but I think he did feel left out, I think it affected him a lot.”* (P: Nicky, line 191)

The above parents talk about making decisions and planning in order for there to be as much peace as possible in the family. Both parents and siblings also spoke about the nature of their own behaviour in shaping the outcome for the child with ASD in the moment:

*“I hate going on holiday with him. Like just, if you just step out of line, like argue something, like a tiny bit wrong, he goes on massive tantrums and gets angry”* (S: Sarah, line 179)

Some siblings perceive their own behaviours and responses as influencing the mood and behaviour of their brother. The use of language in Sarah’s quote, “step out of line”, which is similar to language used by other siblings, implies that they have to be careful about how they behave around the child with ASD, and that by responding slightly incorrectly or accidentally can lead to large consequences such as tantrums. Family three and family five differ here in that the child with ASD does not react with extreme behaviour in response to other family members. Although these children react differently, their behaviour is still perceived as unusual and can evoke reactions from family members. For example, in the

quote below Beverly is describing a situation where she had to stick up for her son with ASD (Reece) due to his lack of reaction:

*“he will never argue with you, never ever argue Reece won't you know despite anything...I Just feel sorry for Reece because he looks like little boy lost you know he just, he just looks like so meek and quiet and confused by it all and ok I'll go but this is why I perhaps stick up for him a bit more than I would for [younger sibling] you know” (P: Beverly, lines 509-510 and 515-517).*

#### *Intuitive versus acquired understanding*

What appears striking from all sibling interviews where the child with ASD does display behavioural difficulties is the sophisticated and in-depth understanding that the siblings have about their brother. The data are peppered with examples of behaviour from the child with ASD which is reflected on in terms of understanding and explanation:

*“...when he's like anxious or erm in a bad mood he, like, ignores everyone even people he's friends with and he just, like, runs off from anything, he gets, like, oversensitive when he's happy and unhappy” (S: Simon, lines 75-77)*

As can be seen from this quote, Simon is describing a particular behaviour, and it is understood by a mature understanding of his brother's underlying difficulties with emotions such as anxiety and sensitivity. This extract from Simon's interview is one of many examples where understanding is embedded within descriptions of behaviour. It appears that it could be helpful for siblings to be able to make sense of their brother's behaviour in order to cope with and think differently about situations which may impact on how they respond.

Most parents discussed explicitly the importance of understanding ASD in terms of underlying difficulties when they talk about the child with ASD's behaviour:

*"I would just say that, you know, the best thing to do is to join a support group and try and do as much research about autism as you can because I think knowledge is power and more you can find out about it the better it is, the more educated you are, the easier it is for you to deal with situations because you can, I don't think you can ever read what's going to happen because some days they'll act as a normal autistic child and other times they don't"* (P: Lynda, lines 460-465).

Lynda experiences knowledge and understanding as a way of gaining control and power in the light of unpredictability and uncertainty. Lynda's experience reflects the views of other parents that understanding ASD is helpful. What appears different between sibling and parental reports regarding understanding of behaviour is that siblings tended to have developed an intuitive understanding of their siblings difficulties whereas many parents have purposefully researched and attempted to understand ASD.

Family five differed slightly to the other families in understanding the child with ASD's behaviour. Frank speaks of gaining external help:

*"So I learnt this on an autism course thing that I went on, but it was what I was doing anyway, I was like trying to push the boundaries a bit* (P: lines 121-125)"

What was missing from his interview compared to others, was a deeper understanding of the reasons behind the behaviour. Frank's son, Matthew, differed from other siblings in that he appeared to have purposefully and consciously learned about his brother's behaviour and how to respond, through an external family member and through trial and error:

*“...whatever they do, they’re usually trying to be friendly... my aunty actually said this to me as well, if there’s someone being like really grumpy or trying to annoy you, and you’re just really happy, eventually they’ll start being the same with you ... when he was about 12, I started to say like nice things to him...”* (S: Matthew, lines 537-538, lines 547-548 and lines 565-569).

Matthew is the only sibling who talks about having to deliberately gain help from others outside the family home in terms of understanding the child with ASD’s behaviour. It might be suggested that this is linked to the possible lack of in depth understanding from his father.

The sense of maturity from siblings around the understanding and responding to behaviour, tended to result in a possible heightened sense of responsibility and an adoption of a parental role:

*“...because anything I try and do, it doesn't really help... I've like tried to, like, ask him if he can calm down sometimes and, like, mum has and dad has and had talks to him about stuff but erm, it doesn't really work. It's like something that you can't change ...”* (S: Andrew, line 308 and line 310)

In this quote, Andrew is summarising a feeling of many siblings. There appears to be a sense of longing to help, to make things better either with the child with autism or within the family home, but there is a feeling of helplessness and powerlessness to create change. For Andrew in particular, there was a strong sense of sadness whilst he was discussing these issues. There is a similar sense for parents also when situations feel uncontained and out of control:

*“...it almost makes you feel like you're a failure I think sometimes. Because you can't step in and make things right straight away. But because I've done a lot of research on autism myself I can rationalise things in my mind that I've got to let things progress and I can see the pattern that happens with it” (P: Lynda, line 51).*

Although the parent and sibling quotes appear similar in that it is difficult when there is no easy strategy in situations, there are qualitative differences in the way they are spoken about. Lynda acknowledges that she may feel like a failure, however, she uses coping strategies to handle this feeling such as cognitive rationalisation and thinking about the behaviour long-term. It was felt that her son, Andrew, may not have developed this way of thinking and there was instead a feeling of helplessness.

#### *Containment of emotions*

Emotional containment emerged throughout most parent and sibling interviews. As mentioned above, many families speak of the difficulties of the child with autism to contain their own emotions and behaviour and the effect this then has on the family as a whole. There appears to be possible pressure on some siblings to have to contain their own feelings:

*“...and on a daily basis Sam is really going off on him about eating with his mouth open. And I think he feels like Sam is on at him all the time and some days he is, he really is ... I think it's that that gets to Andrew and that's why it is hard work because he feels constant pressure from Sam ...” (P: Lynda, line 425 and 438)*

*“I think they just find him really unpredictable and I, yeh, sometimes they walk on egg shells, but then other times they just don't. If they did that all the time that would be great [laughs]. But then I wouldn't really expect them to, to be fair” (P: Lynda, lines 536)*

These two extracts from Lynda's interview sum up the feelings of other participants of having to 'walk on egg shells' and is interpreted as having to contain one's emotions and behaviours. She talks about it being 'hard work' and 'constant pressure' and is seen to be emotionally difficult for Andrew to experience on a daily basis and that he could be having to, at times, contain his own feelings of frustration and stress. As Lynda says, although this is not expected, it would help in order to maintain balance and peace in the house.

Trying to inhibit emotions or responding to behaviour that would then cause disharmony in the family was implicit or explicit during sibling interviews. During Matthew's interview he spoke about feeling very angry when he was younger towards his brother, but also toward family and peers. He explains that he learned ways of controlling these feelings:

*"Um, it was fairly hard because naturally when someone did something annoying I would, I would get very annoyed easily...and I just keep it all, all my anger, keep it down without releasing it or going, lashing out at anyone..."* (S: Matthew, lines 593 and 815)

Matthew speaks of feeling angry in situations thus has learned ways of controlling this which feels unnatural and difficult to do. Just reading this extract evokes a feeling of pressure, and difficulty to stop natural feelings occurring where the only way he has of managing is to push the feelings down. For Sarah, her anger was displaced onto her mother:

*"And then because I got really angry I used to hurt her, so once I pushed her over I felt so bad after that I wished I'd never of done it. That's because Tom got me so angry inside that I took it out on her. Because I know that I can't beat Tom but then I just took it out on her. And then we weren't talking and then, I felt really bad"* (S: Sarah, lines 378-382).

This passage demonstrates the pressures of living with a child with ASD and not knowing entirely what to do with the feelings of anger that may naturally be evoked. In

Sarah's case she does not hold the emotion in but releases it on her mother. However, this then creates feelings of guilt for Sarah. From participants there is a sense of a frustrating situation where there is no easy resolution of how to handle emotions.

This theme explores participants striving for peace and harmony in the family and how this is difficult to achieve. Parents are trying to do the best they can for the whole family and often this means putting the child with ASD first. Both parents and siblings notice that the child with ASD does not react typically to the behaviour of others, either through difficult behaviour or not at all. This then evokes feelings in others of having to tiptoe around or protect the child with ASD. Through understanding the child with ASD and their difficulties, participants are able to adapt their own responses. There was an embedded and sophisticated understanding for most siblings, however, parents consciously needed to learn about ASD. There was a heightened sense of responsibility which led to feelings of hopelessness at times for siblings. The desire for there to be peace within the house, and also needing to, at times, be conscious about the impact that one has in relation to this, came with the feeling of having to contain their own emotions. This comes with difficulties as it is hard to know, particularly for siblings, how to control difficult emotions.

### *Acceptance*

Acceptance emerged as a third super-ordinate theme for all participants. Within this theme, two sub-ordinate themes emerged: 'concept of normal' and 'positive growth'.

### *Concept of normal*

All participants, when speaking about family life, reflected on the concept of ‘normal’; what is ‘normal’ and what is not. This tended to be explicit in parental interviews and implicit in sibling interviews. For example when talking about family life:

*“...it's just a normal everyday life, they have their hobbies, you have your dinner, erm, we try and do things on a weekend [yeh], no, it's just a normal everyday life. But erm, it, it just, it can get a bit stressful, erm, I just think, I just think we're used to the way things are. But it's just a normal family really”* (P: Nicky, lines 9-15)

Nicky’s quote is representative of other parental interviews whereby it is explicitly stated that family life is “normal”. It is striking from Nicky’s interview that she repeats this three times, giving a sense of trying to convince and persuade. Nicky does hint that life could be different to others (i.e. stressful) but that this has been adapted to, accepted and is now normal. This is evident in other interviews where parents speak of normal family life however there are areas throughout the interview that indicate that family life is a bit different, for example: *“And I'm not just talking about general kids fighting this is, sort of, when we're getting melt down situations”* (P: Lynda, lines 60-61). Siblings concept of normal was embedded in their descriptions of family life:

*“Well erm, I normally go downstairs and get my breakfast in the morning with erm, Sam... there as well and sometimes there's a bit of a fight at the table because Sam's like ‘Oh don't eat with your mouth open’ and like other stuff like that ‘stop looking at me’”* (S: Andrew, lines 3-6)

The extract above from Andrew is typical of the way siblings speak about family life where normality is manifested in the descriptions of living with a brother with ASD. There is

a sense that siblings do not know any different and have grown up with the characteristics of ASD and the child's sensitivities. It was seen that difference becomes more apparent to siblings when they are affected by the perceptions of others:

*I: What's it like having a brother with autism?*

*P: Erm, I don't, erm, [pause] can't think of anything to say really. I don't know, it's kind of normal, because 14 years erm, yeh he doesn't do things at school. He won't, he doesn't like playing rugby or football or anything at school...Erm, so sometimes he was walking past classrooms and I was getting asked why is he doing that and it's a bit weird and stuff like that (S: Gemma, lines 63-65 and lines 70-71).*

Gemma's quote represents other siblings views about their brother and the normality and unquestionable acceptance of ASD, until the views of others come in to play. Similarly, sibling's talk about ASD as an exaggeration of their sibling's personality:

*"And I tell me friends, they're just like "oh is it difficult?" and I'm like "it's just any normal person it's just they get a bit angry and over the top and don't know when to stop sometimes". Because everybody always thinks it's a bad thing when actually it's not...And I reassure my friends that it's not a bad thing that he's got it. And that's why I don't like bringing my friends back because I'm scared of what they'll think of my family" (S: Sarah, lines 301-304 and 311-313)*

Sarah's understanding of her brother's ASD is similar to that of other siblings whereby the ASD is not separate to the child but more of an extension of the person, for example, here she says that someone with ASD is normal but that they may go a bit "over the top". Interestingly, it is only perceived as a problem and a difference when the perceptions of other people are taken into account.

Parents' thoughts about ASD differed to siblings in that they were more likely to externalise ASD as being separate from the child and were aware that the child is different to others. This can be seen within these quotes from Nicky, Beverly and Becky and what is also noted is differing levels of acceptance of ASD:

*“Erm, it's erm, to be honest it's, if I'm totally honest, erm, sometimes I absolutely hate it, I hate that he's got autism, erm, I wish he hadn't got it because, not because of us, because of him [accentuates "him"]. You know, because of, I feel he's missing out on so much...you know, and then other times I feel incredibly proud and feel incredibly privileged to have a child with autism in the family, so it's, it's hard really ...”* (P: Nicky, lines 291-295 & lines 308-311)

*“I would, just would thoroughly recommend having a child with autism because they are such lovely children”* (P: Beverly, lines 621-622)

*“I wouldn't swap my child for a child who's not on the spectrum (laughs), because he's so loving you know, he's always been extremely loving”* (P: Becky, lines 364-365)

Firstly, within these quotes is an underlying notion that the ASD is either separate from the child (i.e. “I wish he hadn't got it”) or by having it makes him different to other children (i.e. “they are such lovely children”), and something you could choose to have or not have (“I wouldn't swap my child”). This is different to views of siblings where acceptance is unquestionable. Secondly, there is acknowledgement of the unique and positive qualities that come with having a child with autism. It appears to be difficult for Nicky to think about her son's ASD in this respect as there are aspects of ASD that she does not like, but without it she would not feel so proud and privileged. Beverly instead appears to disregard any difficulties with ASD and displays a somewhat radical acceptance stance. Frank differs from the other

parents in his interview in that his views align more with how the siblings see the child with ASD:

*“but I say, you know, he, you’ve got to sort of count your blessings and that really you’ve got three healthy children and things and they, they’ll push you to the limit, you know and, [laughs], keep you on your toes. But you see kids who are, you know, you know, very ill, when they’re little and in wheelchairs and all the rest of it and that and you think how lucky you are really”* (P: Frank, lines 161-171)

Here Frank’s acceptance is demonstrated by grouping the family together and, like the siblings do, not seeing the child with ASD as being separate or different in anyway. He uses positivity, possibly as a method of acceptance and coping, by comparing family life to others which, in his opinion, are less fortunate.

#### *Positive growth*

Throughout all of the interviews with the mothers, they made references to difficulties within the past in order to explain how family life is like now:

*“I mean, going back to the exclusion, that took probably 6 months damn hard work. And a lot of research. It was really difficult at the time to go through but now, especially with running the support group, I’ve been able to turn it into positive. So at the time it was hell and there was nothing worse that I’d been through but now I’ve managed to help another 2, 3 people go through the same thing by offering advice..”* (Lynda, lines 326-331).

Lynda’s example is representative of the manner in which all mothers speak about life now, positive change and growth. Parents thought about difficulties in the past in order to

appreciate the present and the good things that have occurred as a result of those past difficulties. A further example is when parent, Becky, talks about how her son is now:

*“We used to live in fear of Tom....so things are absolutely brilliant now really, he comes home he’s happy at school, he’s, he still comes home incredibly loud, we know he’s home ...”*  
(P: Becky, lines 17-18).

It appears that going through adversity can lead to an appreciation and acceptance of the here and now. For Becky, she states that Tom still comes home loud, but this is better than things used to be. There is also a sense that past difficulties can also create positive changes for individual members of the family, for instance, Lynda, above, was talking about being able to help others, and in this example Nicky talks about how having a child with ASD is positive for her other children:

*“I’ll say autism, a child with autism erm, but it’s, it just opens you up to a whole new world and I think where it’s helped us, it, it’ll make Simon and [other sibling] into better people, they’re more tolerant, they’re more understanding, you know, they’re, you know, they they stick up for people and people’s differences and erm, it’s opened us up to a whole new world really”* (P: Nicky, lines 320-328).

Frank is the only parent who does not make references to the past to think about how things are in the present. It could be hypothesised that he was less likely to make comparisons with the past as he was not always the primary care giver. Alternatively, there may be a gender difference in how situations are made sense of or how they are spoken about.

In summary, as part of a process of acceptance, the concept of what is ‘normal’ emerged from all participant interviews. Parents tended to talk about normal family life and spoke about differing levels of acceptance of ASD. Siblings acceptance in relation to family

life and their brother tended to be unquestionable, and one in which they did not see their brother and the ASD as separate. Positive growth emerged as a sub-ordinate theme for participant mothers in which they would consider difficulties in the past in order to appreciate the present.

## Discussion

This research enabled siblings and parents from the same family to share their experiences of living with a child with ASD. What emerged was that some experiences were similar between sibling and parents, however, the way in which they made sense of these experiences tended to differ.

The first theme to emerge was perception of fragility within the sibling relationship. It was perceived that the sibling connection changed over time or from moment to moment, and that the change was due to the characteristics of ASD, such as their restricted interests or emotional difficulties. This finding links partially to other qualitative research whereby siblings reported positives aspects of having a brother or sister with ASD (Mascha & Boucher, 2006; Petalas, Hastings, Nash, Dowey & Reilly, 2009) but also negative aspects, such as aggressive behaviour (Mascha & Boucher, 2006). In this study, siblings tended to be accepting of the contingent nature of their relationship whereas parents struggled and perceived a lack of depth and meaning to the sibling relationship. Parents often had an ideal image of what the relationship should be like. As most siblings in this study had more than one sibling, it could be hypothesised that they were able to form reciprocal relationships with their typically developing sibling, and therefore could be accepting of experiencing a different relationship with their brother with ASD. This could support a finding by Kaminsky & Dewey (2002) that siblings had higher levels of adjustment when there were more children in the family home.

Parents noted that siblings often changed their own behaviour in order to keep a connection with the child with ASD. This leads on to the second theme which was the need for both siblings and parents to adapt around the child with ASD. Decisions were made centred around the child with ASD in order to keep the peace within the home. This finding

may support previous qualitative research where having a child with ASD impacts on the whole family (Cassidy, McConkey, Truesdale-Kennedy & Slevin 2008; Meirsschaut, Roeyers & Warreyn, 2010; Myers, Mackintosh & Goin-Kochel, 2009). In the current study this decision making often evoked feelings of guilt in parents, as was found in other literature (Meirsschaut, Roeyers & Warreyn, 2010). Despite this, it was found that parents were able to reframe and rationalise decisions.

In order to adapt around the child with ASD, parents and siblings were able to make sense of the child's behaviour. Siblings tended to have an intuitive and mature understanding where they would consider the underlying emotional difficulties. Parents, on the other hand, researched and acquired knowledge of ASD in order to manage and feel in control. Other literature shows that when parents of children with ASD establish an understanding and coherence of situations it can be helpful in order to adapt and cope with adversity (Pisula & Kossakowska, 2010). There appeared to be heightened responsibility on the part of the siblings and this led to feelings of disappointment and failure when they could not help their brother with ASD. Although parents also experienced this, they, as before, were able to internally rationalise these feelings. The finding that having a brother or sister with ASD can lead to a higher sense of role and responsibility in the family was also displayed in Angell, Meaden and Stoner's (2012) qualitative research with siblings.

The concept of emotional containment emerged as a further area of interest from participant interviews. It appeared difficult, particularly for siblings, to contain difficult emotions around the child with ASD and adopted ways of managing their emotions. This supports existing research from Ross and Cuskelly (2006) whereby siblings often felt angry as a result of the behaviour from the child with ASD but would adopt emotion regulation strategies to manage these feelings.

The third theme to emerge from the interviews was that of acceptance. Parents tended to adapt to family life with ASD and talk about it being normal, with the awareness that things are different for them. The normality of family life for siblings, however, was not questioned until the views of others, such as peers, emerge. This, however, did not tend to be in the form of embarrassment as was found in another study (Mascha & Boucher, 2006). Siblings' unquestionable acceptance was evidenced through their perception of ASD as being an extension of their brother's personality. Parents, however, tended to perceive ASD as something separate to the child. Parents also spoke about the good aspects that emerged from having a child with ASD and would consider difficulties in the past to appreciate the positives in the present.

One participating family differed somewhat over the two themes: *'trying to keep the peace'* and *'acceptance'*. The father did not reflect as much as the participating mothers about the emotions and underlying difficulties of the child with ASD. Thus, it was found that the sibling did not show an intuitive understanding but had gained information about his brother's behaviour from external sources. It could be hypothesised that he had not developed this understanding because it was not communicated within the family home. The father in this family also differed in that he did not think about the past to appreciate the present as did the other parents. It's likely that the differences in perceptions were due to this father only having recently adopted the primary caregiving role. Alternatively, it could also be a difference between how mothers and fathers experience family life.

#### *Clinical implications and further research*

Much of the literature indicates that higher symptoms of ASD may negatively affect sibling adjustment (Benson & Karlof, 2008; Pilowsky et al., 2004). It emerged from this study

that many siblings naturally understood the difficulties their brother with ASD had, acknowledged the implications of their own responses, tended to adapt their behaviour around the child and contained their own emotions. It could be hypothesised that this could actually lead to positive outcomes for these siblings as individuals. For instance it could mean that they are more accepting, understanding, and sensitive of others and have a high level of self-concept as is mentioned in other literature (Macks & Reeve, 2007; Myers et al, 2009; Pilowsky et al., 2004). However, these factors could also lead to negative outcomes such as internalising difficulties from having to contain emotions, which has been reported in one study (Ross and Cuskelly, 2006). Additionally, problems with adopting a role of responsibility at a young age may mean that siblings develop beliefs about themselves as not good enough as they are less able to manage as a parent would (Bryn-Hall, 2008).

It is therefore important to note that it may not be merely the siblings' ASD that relates to predictors of adjustment, but moderating factors that accompany them, such as family communication and social support. The parents of those siblings in this study who had a good understanding of their brothers' behaviour were those who had researched and acquired ASD knowledge and most likely communicated it to the siblings in the family.

Further research should explore the coping strategies used by siblings and the influence of parental factors on adjustment problems such as internalising difficulties. In terms of clinical implications, families could benefit from support in helping siblings to learn healthy coping strategies instead of maladaptive strategies such as withholding emotions. Additionally, families, including both parents and siblings, would benefit from support in understanding ASD, as this has shown to be helpful.

Another interesting finding from this study was that of the fragility of the sibling relationship and that siblings tended to make sense of this, adapt to or change their behaviour

in order to keep a connection with their brother or sister. Further research could explore how this experience may impact on siblings' views about themselves and how it may affect their relationships with other people.

### *Evaluation*

The families who took part in this research were those who were evidently willing and keen to share their story. This means that firstly there is sampling bias inherent in the design. Two of the parents in particular lead ASD support groups and took on responsibility for helping other parents with children with ASD. Secondly, many of these mothers were extremely thoughtful and reflective during their interview. This meant that it was, at times, difficult to be as interpretative compared to sibling interviews.

Both parents and siblings were interviewed and the generated data were primarily analysed separately, then combined to produce overall themes. It could be suggested that this method of analysis; looking at common themes between the two groups, may have led to particular themes emerging and others being discarded. For instance, it could be the case that important themes may have been generated that only applied to parents.

Although every care was taken to provide homogeneity within the sample, there were clear differences between some of the families. For instance, the participating father had recently adopted a parental role within the family, and as a result, his experience of family life differed to the other parents. Additionally, there appeared to be distinct differences in the presentation of the child with ASD in the family. Three families spoke of behavioural problems such as verbal and physical aggression from the child with ASD. The other two families did not experience this. This factor is important as it affected how those families experienced and perceived family life.

### *Conclusion*

This research explored views of parents and siblings from the same family where there is a child with ASD, addressing a gap in the current literature. The outcomes highlighted that parents and siblings differ in the way they experience and make sense of family life. This has implications for those working clinically with families and for those wishing to further research this area.

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## Chapter Three

### Public Domain Briefing Document

The research was conducted by Rachel Crowe as part of the Doctorate in Clinical Psychology at the University of Birmingham. The research was supervised by Dr Gary Law, Academic Tutor, at the University of Birmingham and Lisa Summerhill, Clinical Supervisor. There are two parts to the research. The first part is a literature review and the second part is an empirical research paper.

#### **Literature review: The experiences and outcomes for parents and siblings when a child with Autism Spectrum Disorder (ASD) in the family is receiving an Intensive Behavioural Intervention (IBI): A systematic review**

This systematic literature review synthesises the research exploring the effects on parents and siblings when a child with Autism Spectrum Disorder (ASD) in the family is undergoing an Intensive Behavioural Intervention (IBI). IBI is an effective intervention which aims to improve the social, behavioural, adaptive and emotional functioning of children with ASD (Reichow, 2012). After screening six databases, sixteen papers were found to meet the selection criteria. The quality of the articles were evaluated on a defined set of quality criteria and two papers were of such poor quality that they were not included in the review. The fourteen remaining papers varied in quality, with most papers presenting with limitations and thus caution should be taken when interpreting the findings.

Four areas/themes of interest emerged from the papers: *parental emotional impact*, *sibling adjustment*, *impact on family relationships*, and *practical and social impacts*. It was found that, overall, parents whose child with ASD was undergoing IBI had similar levels of stress compared to other parents whose child with ASD was not having IBI. There were

factors that related to higher or lower levels of stress in parents, for example, the more hours that they acted as therapists the more stress they felt. Two papers explored the outcome on siblings when their brother or sister was undergoing this intervention. It was found that siblings were no more likely to have social, emotional or behavioural difficulties compared to other siblings whose brother or sister was not receiving IBI. There were mixed findings regarding the impact of IBI on relationships within the family and a variety of social and practical impacts emerged for families. The findings from this research indicate that IBI teams working with children with ASD need to be aware that the intervention affects each family differently. Therefore, it is important to monitor these impacts and to discuss with the family how best to increase positive experiences whilst on the program. Further research needs to be conducted within this area, particularly in relation to the experience of siblings.

**Empirical paper: The experience of having a child with Autism Spectrum Disorder (ASD) in the family: Sibling and parental perspectives**

This research project explored the experience of parents and siblings who have a child with ASD in the family. Past research has found that parents who have a child with ASD are more at risk developing mental health problems compared to parents who have children who do not have ASD (Hayes & Watson, 2013). Also, siblings who have a brother or sister with ASD may be at increased risk of social, emotional and behavioural problems (Meadan, Stoner & Angell, 2009). This research aims to understand more about family life from the perspectives of parents and siblings from the same family.

One sibling and one parent from five families were interviewed about family life and living with a child with ASD. The interviews were then analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009), which is a method that

aims to find out how people make sense of life experiences. It was found that parents and siblings spoke about similar aspects of family life but, often, they experienced them in different ways. Three main themes emerged from the interviews: '*sibling connection as fragile*', '*trying to keep the peace*' and '*acceptance*'. Both parents and siblings spoke about the changing nature of the sibling relationship and that it is influenced by the characteristics of ASD. Parents perceived this outcome as a lack of closeness and meaning in the sibling relationship. The second theme refers to the way in which family members alter their own actions, feelings and decisions with the child with ASD in mind. Within the third theme, parents tended to accept family life as being 'normal', with the awareness that it is different from other families. The normality of family life for siblings, however, was not questioned until the views of others, such as peers, came into play. Siblings also viewed ASD as an extension of their brother or sister's personality.

Overall, both parents and siblings found it helpful to have a good understanding of the child with ASD's behaviour. Therefore one area of need for other families could be for both parents and siblings to gain help in understanding ASD. A further area of need, particularly for siblings, is supporting them to cope with having to be highly aware of their own emotional and behavioural responses to the child with ASD. Siblings may require help to find ways of dealing with difficult emotions of their own.

It would be beneficial to understand more about the coping strategies siblings adopt in families where there is a child with ASD. Therefore more research needs to be carried out in this area.

## *References*

- Hayes, S. A. & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43 (3), 629-642.
- Meadan, H., Stoner, J. B., & Angell, M. E. (2009). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 22(1), 83–100.
- Reichow, B. (2012). Overview of meta-analyses on early intensive behavioral intervention for young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 4, 512-520. doi: 10.1007/s10803-011-1218-9.
- Smith, J. A., Flowers, D. P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research (Reprint.)*. Sage Publications Ltd.

## **APPENDIX A: Instructions for authors**

### **Journal of Autism and Developmental Disorders: Instructions for Authors**

**Editor-in-Chief: Fred. R. Volkmar**

#### **REVIEW YOUR MANUSCRIPT FOR THESE ELEMENTS**

##### **1. Order of manuscript pages**

Title Page with all Author Contact Information & Abstract with keywords and the corresponding author e-mail information.

Blinded Manuscript without contact information and blinded Abstract, and References

Appendix

Figure Caption Sheet

Figures

Tables

Author Note

#### **MANUSCRIPT SUBMISSION**

##### **Manuscript Submission**

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

##### **Permissions**

Authors wishing to include figures, tables, or text passages that have already been published elsewhere are required to obtain permission from the copyright owner(s) for both the print and online format and to include evidence that such permission has been granted when submitting their papers. Any material received without such evidence will be assumed to originate from the authors.

##### **Online Submission**

Authors should submit their manuscripts online. Electronic submission substantially reduces the editorial processing and reviewing times and shortens overall publication times. Please follow the hyperlink “Submit online” on the right and upload all of your manuscript files following the instructions given on the screen.

#### **TITLE PAGE**

The title page should include:

- The name(s) of the author(s)
- A concise and informative title
- The affiliation(s) and address(es) of the author(s)
- The e-mail address, telephone and fax numbers of the corresponding author

#### **ABSTRACT**

Please provide an abstract of 120 words or less. The abstract should not contain any undefined abbreviations or unspecified references.

#### **KEYWORDS**

Please provide 4 to 6 keywords which can be used for indexing purposes.

#### **TEXT**

## **Text Formatting**

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

## **Headings**

Please use no more than three levels of displayed headings.

## **Abbreviations**

Abbreviations should be defined at first mention and used consistently thereafter.

## **Footnotes**

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

## **Acknowledgments**

Acknowledgments of people, grants, funds, etc. should be placed in a separate section before the reference list. The names of funding organizations should be written in full.

## **BODY**

- The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:
  - Introduction (The introduction has no label.)
  - Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)
  - Results (Center the heading.)
  - Discussion (Center the heading.)

## **HEADINGS**

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

## **FOOTNOTES**

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables. Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

## **TERMINOLOGY**

Please always use internationally accepted signs and symbols for units (SI units).

## **CITATION**

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott 1991; Barakat et al. 1995; Kelso and Smith 1998; Medvec et al. 1999).

## **REFERENCES**

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

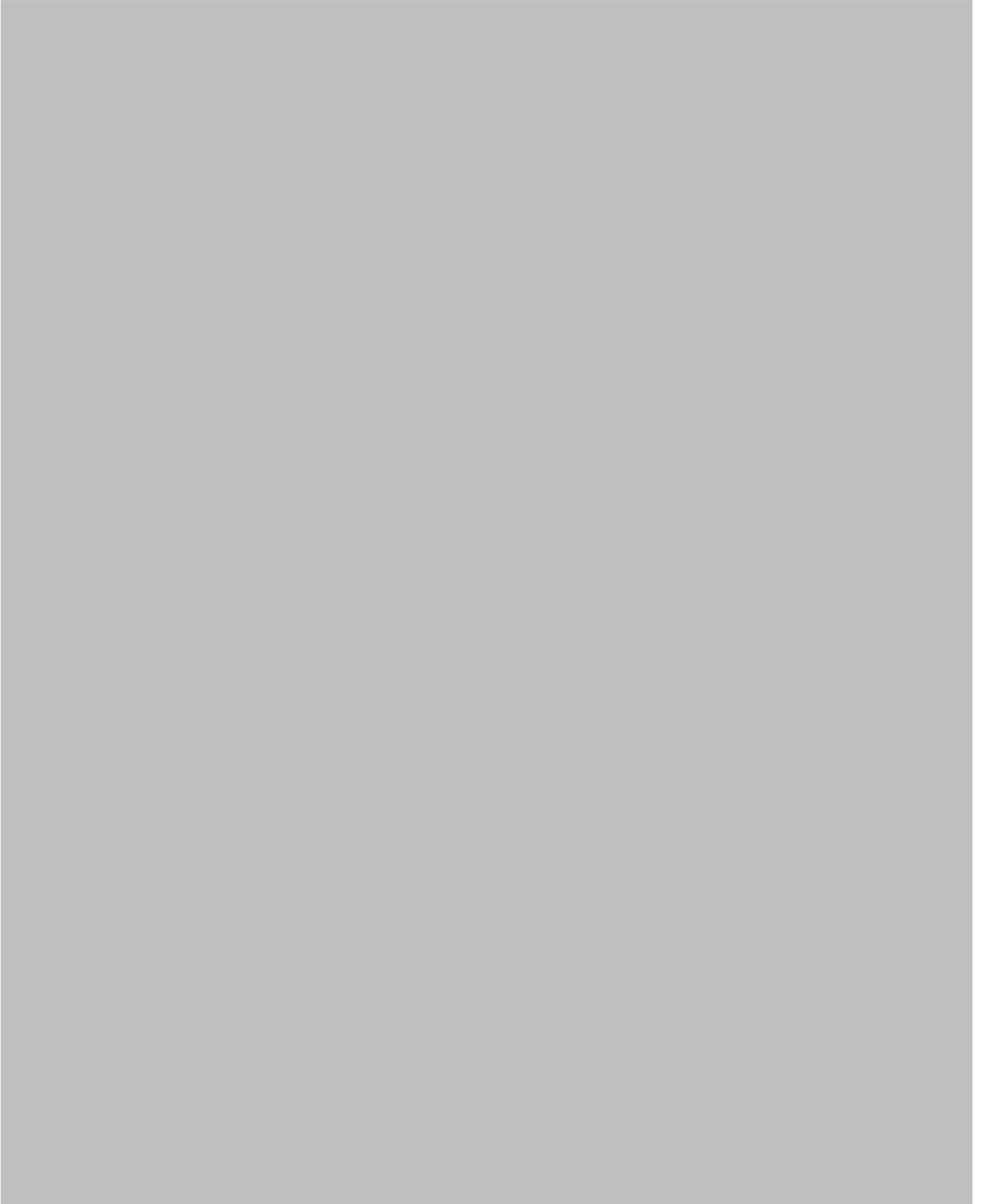
Reference list entries should be alphabetized by the last names of the first author of each work.

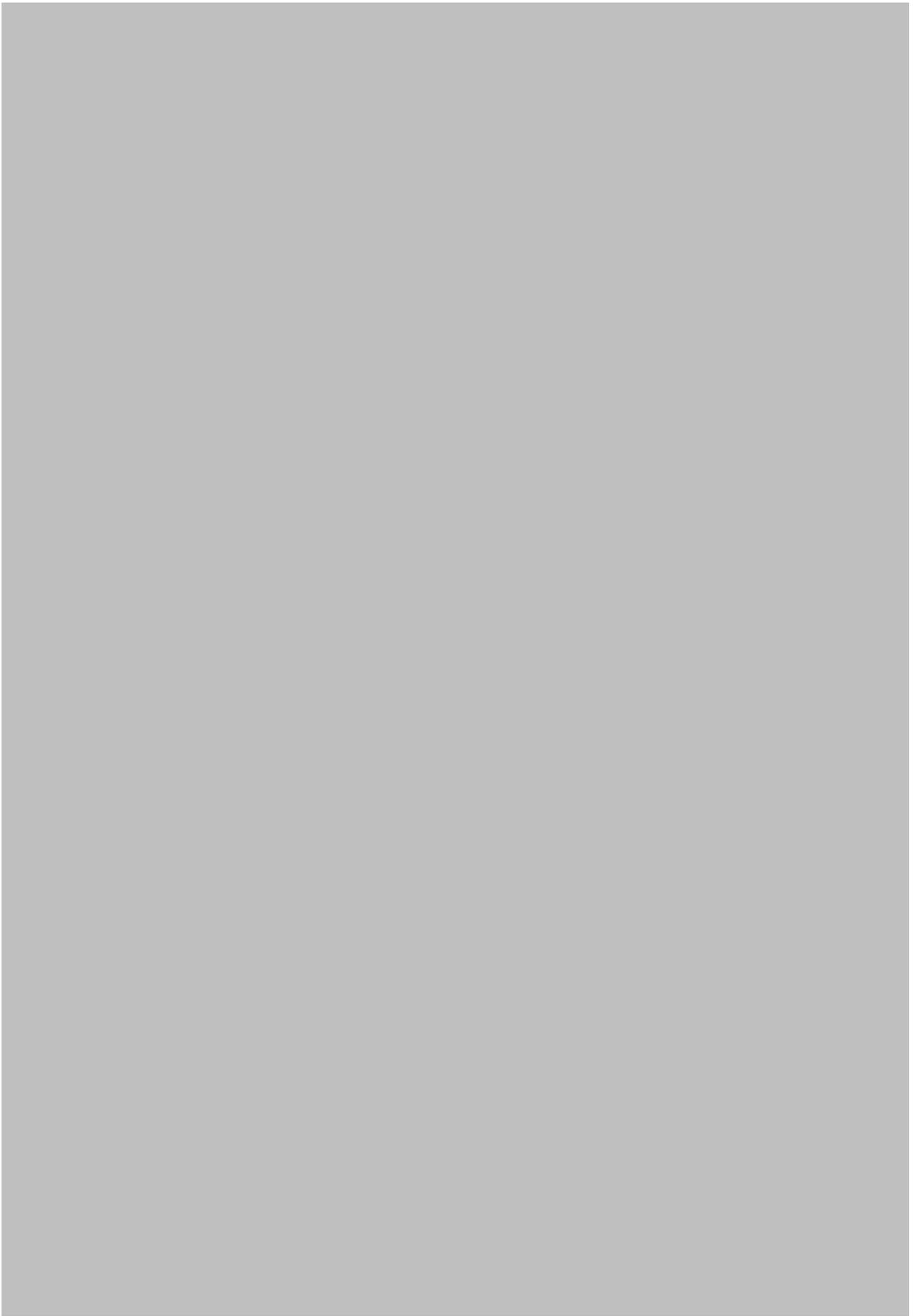
Journal names and book titles should be italicized.

- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

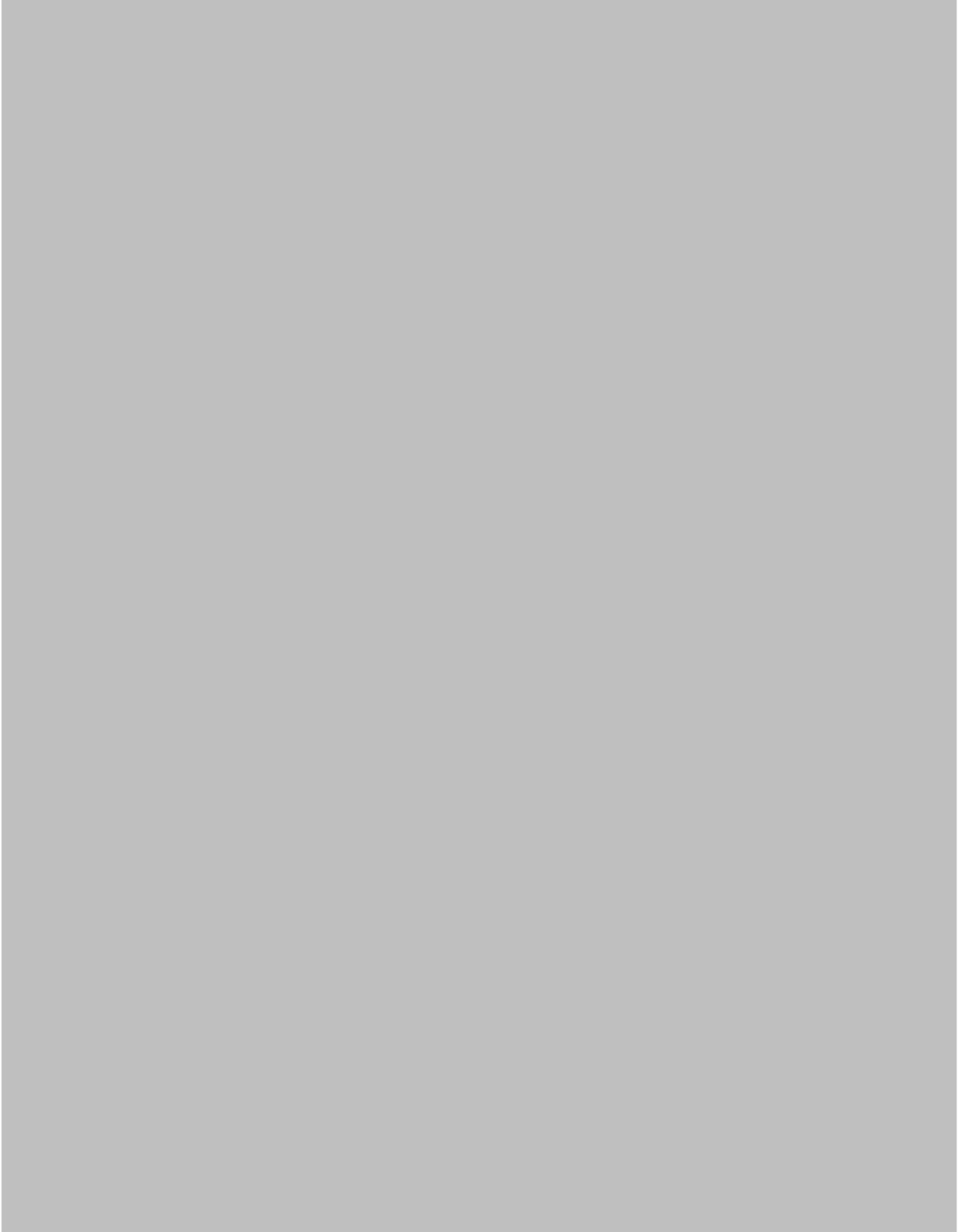
**APPENDIX B: NHS Ethical Approval**







**APPENDIX C: Research and Development Ethical Approval**

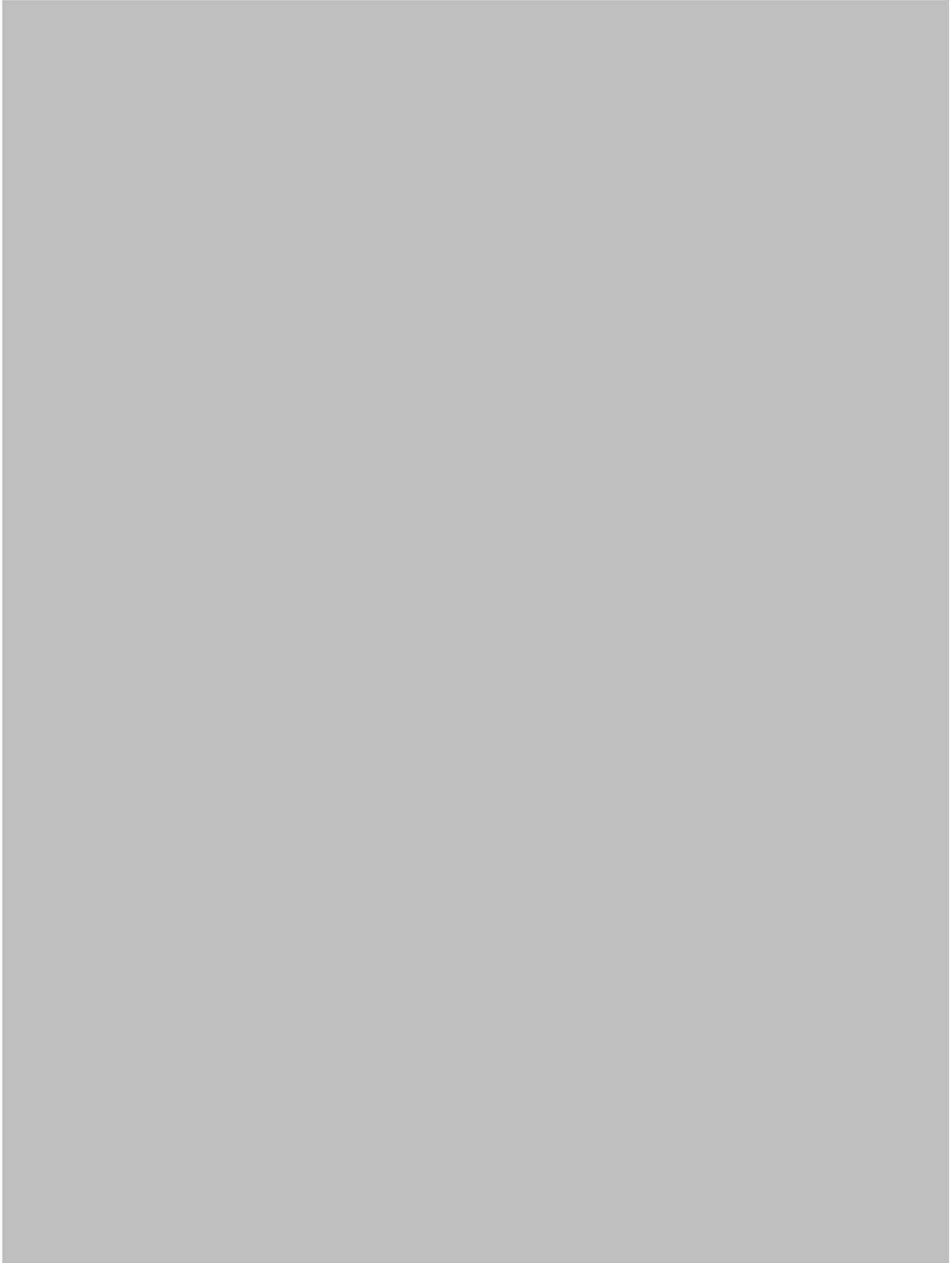




**APPENDIX D: Midlands Psychology Ethical Approval**



**APPENDIX E: University of Birmingham Sponsorship**





## APPENDIX F: Brief Written Summary of the Research

# The Experience of Living in a Family With a Child With Autism Spectrum Disorder (ASD)



**Do you have a child with an Autism Spectrum Disorder (ASD)?  
Are you interested in talking about what family life is like?**

My name is Rachel Crowe and I'm a researcher in the School of Psychology, University of Birmingham, who would like to talk to parents and brothers or sisters of children with ASD about their family life. This research will help improve understanding to those who help and support families where there is a child with ASD.

### Do you have...

- |   |   |
|---|---|
| a child between the age of 8-16 who was diagnosed with ASD 5 years or more ago, AND | ✓ |
| a child who does not have a diagnoses of ASD and is between the age of 11-16, AND   | ✓ |
| no more than 3 children within the family home, AND                                 | ✓ |
| 2 adults within the family home, ...  | ✓ |
| ...AND your child with ASD does not have a learning disability                      | ✓ |

**If you would like to find out more please read the information leaflet about the study. If you are interested in taking part or would like to ask any questions, then please give me your details and I will call you.**

Name \_\_\_\_\_ Address \_\_\_\_\_

Phone number \_\_\_\_\_ Signature \_\_\_\_\_

If you prefer not to pass on your details here, please telephone the Birmingham Clinical Psychology Office on **0121 4146296** to leave me a message and I'll call you back.



Rachel Crowe, Trainee Clinical Psychologist.  
School of Psychology, Frankland Building, University of  
Birmingham, Edgbaston, Birmingham, B15 2TT



## APPENDIX G: Young Person's Information Sheet

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### What will happen to what I have said?

Your words might be used as quotes when the project is written up. Your name will be changed so nobody will know it was you who said it. It will be anonymous, what you say is confidential.

### Will my parent taking part know what I have said?

It is possible that your parent might recognise something that you have said if they read the final report. This can only happen if I put your words (quotes) together with theirs. We will talk together, you can tell me if you have said anything that you do not want to be recognised by your parents or if you do not want me to quote something you have said at all. I will then not use your words but talk more generally about the topic.

### What will happen to the results of the project?

The project will be written up and bound as part of my studies. It is hoped that the study will be published in a journal so that other people can read what I have found to help them to support families like yours.

### What if I change my mind about taking part?

You can change your mind about taking part at any time without giving a reason until your interview has been written up.

### If you have any questions please contact.

/Rachel Crowe or Gary Law at University of Birmingham Clinical Office on 0121 4147124.



THANK YOU

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### Young Person's Information Leaflet

## The Experience of Living in a Family With a Child With Autism Spectrum Disorder (ASD)



Hello my name is Rachel. I am interested in what it is to live with someone who has a diagnosis of Autism Spectrum Disorder (ASD). I am interested in talking to brothers and sisters and parents of children with ASD about their family life.

Thank you for taking the time to read this leaflet, it will invite you to take part in some important new research. It is important that you read this information leaflet carefully so that you understand what the research is about and so that you understand what you will be asked to do if you take part. You can read this leaflet with an adult if you like and you will get the chance to ask me any questions that you might have about the research

Your family has been invited to take part because you have a brother or sister with a diagnosis of ASD.



### **Who is doing this research?**

I am Rachel Crowe. I am a researcher in the School of Psychology, University of Birmingham. I am completing this research as part of my training in clinical psychology. Dr Gary Law and Dr Lisa Summerhill also work with the University and they are my supervisors. I will be working with them to make sure the research is carried out to the highest standard.

### **Why is this research being done?**

We know that children with ASD can think, feel or behave differently from other children, but we do not know how this might affect other members of the family. We are interested in finding out what family life is like in a family where there is a child with ASD. Particularly what brothers and sisters and their parents think. We hope that this information will help us to better understand families like yours. We want to know this information so we can better support families in the future.



### **What is this research about?**

We want to talk to brothers and sisters of children with ASD and their parents. We are interested in what day to day life is like; for example: What it is like living with your brother or sister? and How you feel about living with them? We might also be asking more specific things such as what it was like finding out about the diagnosis? And how it affects other areas of your life; such as hobbies and friendships. We will meet in private so that no one will hear what you have said. We also want to know what your parent point of view is and we will talk to them separately.

### **What will happen if I want to take part?**

It is up to you whether you decide to take part. You might want to talk to an adult about it. If you decide to take part I will arrange to meet with you and your parent so that you can ask me any questions and sign a form if you agree that you want to take part. We will then sit down privately (on our own) to talk, I will ask you questions about your family. The questions won't be hard and you don't have to answer them if you don't want to. It will be just like a conversation. I will also meet with your parent at a separate time to ask them similar questions. The meeting will be recorded so that I can write down exactly what we say. I will use your words to look for patterns in what people have said to me. I will check out with you that I have understood what you meant.

### **Are there any advantages to taking part in the project?**

You might find that it helps to talk about your family life. You can choose to be entered into a prize draw. Things will not change in your family because you have taken part in the research. It is hoped that this research will help families in the future.

### **Is there potential disadvantage to taking part?**

You only have to talk to me about things that you are comfortable with. If you do become upset I will make sure you have someone to talk to about how you are feeling, this might be your doctor.

### **Will other people know what I have said?**

I will not tell anybody what you have said. If you say something that makes me worried that some harm might come to your family then I would have to discuss this with my supervisor so that we make sure we keep you safe.



## APPENDIX H: Parent information sheet

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### **Will other people know what I have said?**

The interview will be confidential. However, if you say something that makes me worried about the safety of someone in your family I would have to discuss this with my supervisor and possibly follow child protection protocols if this were necessary.

### **Will my child taking part know what I have said?**

There are three ways that the conversation we have can be used in the report. The themes and topics of conversation can be presented, your words can be quoted, or your quotes can be paired with those of your child. If your quotes are paired; then it is possible that your child might recognise something that you have said if they read the final report. We can meet so you can tell me if there is anything that you would not like using in this way. The other ways of reporting the conversation can then be used. You have control over how our conversation is reported. Your child will also be given the same opportunities.

### **What will happen to the results of the project?**

The project will be written up and bound as part of my studies. It is hoped that the study will be published in a journal so that other people can read what I have found to help them to support families like yours. Any quotes that are used in the final report will be anonymous.

### **What if I change my mind about taking part?**

You can change your mind about taking part at any time without giving a reason until your interview has been written up.

### **If you have any questions please contact.**

Rachel Crowe or Gary Law at University of Birmingham Clinical Office on 0121 4147124.

Thank you for taking time to read this leaflet.  
We would really value your involvement in this important research.



Page 4

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Parent's Information Leaflet

## The Experience of Living in a Family With a Child With Autism Spectrum Disorder (ASD)



Hello my name is Rachel I am interested in what it is like to live with someone who has a diagnosis of Autism Spectrum Disorder (ASD). I am interested in talking to parents and brothers and sisters of children with ASD about their family life.

Thank you for taking the time to read this leaflet. We would like to invite you to take part in some important new research. This leaflet gives you more information about the research and the process you will go through if you decide to take part. You will also get the chance to ask me any questions you might have about the research.

Your family has been invited to take part because you have a child with a diagnosis of ASD and another child without a diagnosis. We would like to know what life is like in a family like yours.

Page 1

### **Who is doing this research?**

I am Rachel Crowe, I am a researcher in the School of Psychology, University of Birmingham. I am completing this research as part of my training in clinical psychology. My supervisors at the university are Dr Gary Law and Dr Lisa Summerhill they will be working with me to ensure the research is undertaken to the highest standard.

### **Why is this research being done?**

We know that children with ASD can think, feel and behave differently from other children, but we do not know how this might affect other members of the family. We are interested in finding out about the experiences of parents having a child with ASD and other children without the diagnosis. We are also interested in the experiences of other children in the family. We hope that through gaining a better understanding of people's experiences we will better be able to support families in the future.

### **What is this research about?**

We want to talk to parents and siblings of a child with ASD. We are interested in what day to day life is like; for example: what it is like being a parent when you have a child with an ASD diagnosis? And how you experience family life? We might also be asking more specific things such as what it is like parenting your children? We are also interested in how the experience of other family members is similar or different.

### **What will happen if I want to take part?**

It is up to you and your child (without an ASD diagnosis) whether you decide to take part. I can meet with you to answer any questions you might have before you make up your mind. I will then ask you if you consent to taking part in the research. We will then meet to talk privately, you can choose if you would like this to be at your home or at a clinic or at the university. Our meeting will be a conversation about your family. I will talk to you and your child separately, both interviews will be confidential. Both of the interviews will be recorded so that they can be transcribed verbatim. To analyse the interviews I will look for patterns in what you and your child have said to me. You will be given the opportunity to look at what you said to make sure I have understood you correctly.

### **Are there any advantages to taking part in the project?**

You might find that it helps to talk about your family life. This research will not benefit your family directly. It is hoped that this research will help people working with families with ASD know what it's like living in the family and will help them offer support in the best possible way in the future.

### **Are there potential disadvantages to taking part?**

You only have to talk to me about that you are comfortable with. It is unlikely that there will be disadvantage to taking part. If you or your child become upset by anything that is talked about I will make sure that support is provided to you either by the service supporting your family or by your GP.

## APPENDIX I: Parent consent form

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### Consent Form



*To be completed by the parent*

Participant Name:	Please initial the box if you agree with the statement
I have been given the information sheet	<input type="checkbox"/>
I have read the information sheet	<input type="checkbox"/>
I have been given the chance to ask questions about the project	<input type="checkbox"/>
Hannah has answered all my questions satisfactorily	<input type="checkbox"/>
I understand that I do not have to take part and can stop at any point without giving a reason	<input type="checkbox"/>
I understand that the interview will be recorded and some of what I say might be used in the final report	<input type="checkbox"/>
I understand that there is a small chance that my participating child might recognise something I have said in the final report if my words are reported with theirs. If there is anything that I would not want them to recognise I can indicate this and my words will not be quoted in this way.	<input type="checkbox"/>
I understand that I can ask for things I say not to be quoted in the final report at all	<input type="checkbox"/>
I understand what the project is about	<input type="checkbox"/>
I would like to take part in this project	<input type="checkbox"/>
Please sign here if you have ticked all the boxes and would like to take part in the project	
Name .....	
Signature.....	Date.....



*For the researcher:*

*The participant has been provided with the information sheet, they have had the opportunity to ask questions and have had these answered. I have explained the project to them and they have indicated their consent to participate.*

Name of researcher.....

Signed..... Date.....

## APPENDIX J: Sibling consent form

### Consent Form



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*To be completed by young person*

<p>Name: _____</p> <p>I have been given the information sheet</p> <p>I have read the information sheet</p> <p>I have been given the chance to ask questions about the project</p> <p>Hannah has answered all my questions</p> <p>I understand that I do not have to take part and can stop without giving any reason</p> <p>I understand that the interview will be recorded and some of what I say might be used in the final report</p> <p>I understand that there is a small chance that my parent might recognise something I have said in the final report if my words are reported with theirs. If I say something I do not want them to recognise I can tell Hannah and she will not put my words with theirs in the final report.</p> <p>I understand that I can ask for things I say not to be quoted in the final report at all</p> <p>I understand what the project is about</p> <p>I would like to take part in this project</p> <p>Please sign here if you have ticked all the boxes and would like to take part in the project</p> <p>Name .....</p> <p>Signature..... Date.....</p> <p>I consent for my child ..... (name) to take part in this project</p> <p>Parent signature .....</p>	<p>Please initial the box if you agree with the statement</p> <p><input type="checkbox"/></p> 
--	---

*For the researcher:*

*The participant has been provided with the information sheet, they have had the opportunity to ask questions and have had these answered. I have explained the project to them and they have indicated their consent to participate.*

*Name of researcher..... signed..... date.....*

## APPENDIX K: Interview guide for parents

Settling in question - Could tell me about who is in your family?

- (draw genogram to illustrate family members and relationships)

I would like to ask you about life in your family – Can you tell me what it is like to live in your family?

What is it like parenting your children?

*Prompts*

- *What things go well?*
- *When are things more difficult?*

What is it like having Autism in the family?

*Prompts*

- *Can you tell me what you know about Autism?*
- *How do you feel about Autism?*
- *Does Autism get in the way of you doing things?*
- *How do you think Autism affects each member of your family?*

What would you tell other parents who have a child with autism and a child with no diagnosis?

*Prompts*

## APPENDIX L: Interview guide for sibling

Settling in question - Could tell me about who is in your family?

- (draw genogram with the child to illustrate the family members)

I would like to ask you about life in your family – Can you tell me what it is like to live in your family?

*Prompts*

- *What do you spend your time doing when you are at home?*
- *Who gets on with whom?*
- *What do you do together?*
- *Tell me about the rules in your house?*

What is it like having a brother/sister with ASD?

*Prompts*

- *What are the good things?*
- *What things are more difficult?*

What is it like having Autism in the family?

*Prompts*

- *Can you tell me what you know about Autism?*
- *Does Autism get in the way of you doing things?*
- *What do you tell your friends about Autism?*
- *How do you think Autism affects each member of your family?*

What would you tell other children who have a sibling with autism?

APPENDIX M: Example of stage 3 of the IPA analysis- line by line coding

- description  
- conceptual comment

- linguistic object meaning. Tone

- ADDITIONALLY, INTERVIEWED Parent 43

1 I: So what is it like living in your family home?  
 2 P: It's pretty fine yeh, everything's going alright, the children get on quite well together  
 3 I: Do they  
 4 P: Yeh, erm [redacted] and [redacted] used to be very very very close erm, there's 19 months  
 5 age gap between them, they are one school year apart so they've done everything very  
 6 close together throughout their lives. [yeh] and up until about 2 and half, 3 years ago  
 7 they were practically inseparable, got on so well together, [redacted] was a massive support  
 8 for [redacted] and we always used to wish that she was the eldest really because it's been  
 9 hard for [redacted] transition years you know, moving from preschool to first school then to  
 10 middle school then to high school or college as they call it around here. We always used  
 11 to wish [redacted] was there first because she is such a good support for him [hmm hmm]  
 12 but they sort of drifted apart when she probably got her teenage hormone bits kicking in  
 13 and she got a little bit more feisty and arguey [ok] and he found that hard to sort of live  
 14 with you know because he likes things to run smooth and people to be calm and he  
 15 doesn't like any arguing or anyone kicking off and he, you know, obviously found that  
 16 hard when she, I mean she is a very very good child you know nearly all the time [yeh  
 17 yeh] but odd little bits where you know she did have a bit of a tantrum or a bit of upset.  
 18 He'd find that hard, so they've sort of drifted apart and that's the only thing I can put it  
 19 down to [yeh] and he never used to want anything to do with [redacted] who's almost 4  
 20 years younger, they were both December children so they're almost 4 years between  
 21 them and he's never really wanted much to do with [redacted]. I mean when they were little  
 22 they would play together when [redacted] was sort of you know 5, 6 and [redacted] was 1,2,  
 23 they'd play together then but as they've gone through the years they've not really had  
 24 much to do with each other but now they're both into playing computer games, well x-  
 25 box games, computer games, they're really close and bonded quite well now [right ok]  
 26 even though there's a 4 year age gap [yeh]. So, but they do all get along very well,  
 27 there's not much trouble really between them.  
 28 I: So it sounds as if they all get on well, but the relationships have changed over [yeh]  
 29 the years [yeh] so it used to be [redacted] and [redacted] that were very close and it's altering  
 30 now [yeh] so [redacted] and [redacted] are much closer.  
 31 P: Because they've got their games in common with each other so they sit and discuss  
 32 their games all the time.  
 33 I: OK. What are your thoughts about [redacted] and [redacted] drifting apart?  
 34 P: It's a shame really because she has been such a good support for him, but you know,  
 35 she's pretty calm and steady again, it was obviously just a wobble phase she was  
 36 probably going through [yeh] stuff she was finding hard to handle, friendships and  
 37 things and you know, went through a difficult bit but I mean nothing out of the ordinary

Sibling Age  
[redacted] should be  
eldest! - support  
[redacted] wished she  
was eldest.  
Relationship changed.  
Due to [redacted] changing  
not as close  
Rlship changed due to  
not handling [redacted]  
tantrums  
Relat changing - [redacted]  
used to be support ∴  
they was close. Now  
close to [redacted] duo  
to shared interest.  
Not much trouble  
[redacted] doesn't like  
trouble.  
why is [redacted] support  
now? [redacted] had a  
wobble.  
Back to normal  
now.  
used to be close  
Repetition of "close"  
very close  
Relationship sibling impo  
used to be close  
moving schools / transition  
Hard  
[redacted] should be eldest.  
[redacted] changing.  
[redacted] find hard.  
likes things to run smooth  
people to be calm.  
∴ r/ship (sib) changes due to  
[redacted] / ASD - can't cope w/ change  
sibling r/ship part  
parent - work r/ship with younger  
brother. Did the very young  
sib r/ship now  
- bonded close with [redacted]  
- shared interest.  
- no trouble  
about 4 year age gap. it's not  
about age, it's about shared  
interest?  
Both like games.  
Rlship change is a shame  
Rlship change  
A shame.  
Was good support  
ups + downs are normal  
for teenagers?

calm + steady.  
other people have to be calm  
nothing out of ordinary.

## APPENDIX N: Stage 5 of the IPA analysis



### APPENDIX O: Parent and sibling data extracts

Theme	Quote	Exploratory notes
<p><b>Concept of sibling connection as fragile</b></p>	<p>“they sort of drifted apart when she probably got her teenage hormone bits kicking in and she got a little bit more feisty and arguey [ok] and he found that hard to sort of live with you know because he likes things to run smooth and people to be calm and he doesn't like any arguing or anyone kicking off and he, you know, obviously found that hard when she, I mean she is a very very good child you know nearly all the time [yeh yeh] but odd little bits where you know she did have a bit of a tantrum or a bit of upset. He'd find that hard, so they've sort of drifted apart and that's the only thing I can put it down to” P: Beverley, lines 12-18.</p> <p>I: What about, um, Adam, who does he get on best with? P: Sometimes he will get on with me, like because he has his obsess, obsessions with things, like he doesn't like video games usually, but there was a game I liked, um, called Red Dead Redemption, there was a train in it...</p>	<p>Relationship in the past: used to be close</p> <p>Gemma changing: Reece found this hard (repetition of “he found that hard”)– likes things to run smooth (ASD characteristics)</p> <p>Therefore: Relationship changes due to Reece – as he doesn't like change.</p> <p>Relationship dependent on Adam's interests.</p>
<p><b>Trying to keep the peace</b></p> <p>For the greater good</p>	<p>“Yet I've still had to consider Sam first. Not necessarily first I don't think, it's how it's going to affect him is then the catalyst of how it's going to effect everyone else I think. [yeh]. Yeh and again that comes back to guilt is</p>	<p>Had to, have to – this is necessary/needed Couldn't do anything different</p> <p>Feelings that it affected sibling (guilt?)</p>

	<p>how I feel about that because I, I don't necessarily think it's right to put him first all the time or consider what his needs are when I'm not thinking about, well I am thinking about the others. See this is my stupid rationalisation process going on here [laugh]" P: Nicky, lines 673-678</p>	<p>Parents response: Including Simon and making a fuss, informing him of decisions that are made Simon- "didn't moan"</p>
<p>Intuitive versus acquired understanding</p>	<p>P: I wouldn't say I've always been calm (laughs). Because I'd be lying (laughs). Erm, I suppose just understanding that, I mean, when he was particularly bad, erm, or being aggressive, was erm, what's helped me to stay calm, knowing that he's not, it's not coming from him, it's not a personal thing. Knowing that it's coming from a source of anxiety, that he can't help a lot of it (P: Becky, lines 389-393).</p> <p>P: Because they really will get agitated over anything. And they get anxious. Like I've treated Hugo as a normal 15 year old brother but I still look after him and I know erm that he gets anxious and that's when I treat him like he's got autism like I treat him like he's got autism anyway but I don't treat him like he's younger than he is I just feel like he is, cuz he's got autism. S: Simon, 235-238.</p>	<p>Understanding Tom is helpful. It's not him (it's ASD? Who is it? Where is it coming from? Splitting off loving boy V ASD difficulties. Due to anxiety not personality.</p> <p>Understanding of emotions and adapts strategies (parenting/responsibility?) Treat him differently when he's anxious.</p> <p>Hugo-normal 15 year old brother What's normal? Concept of age and "older brother".</p>
<p>Emotional containment</p>	<p>We spoke to her about how Reece would feel and she was very good about it, planned something else for her birthday instead. She's always been very very grown up...don't really complain about it you know"</p>	<p>Gemma- grown up, "very good" "very very grown up", doesn't complain. (What is Gemma wasn't grown up, how would that effect family decision making and family</p>

	I'm just like eating normally quietly. And he goes "stop making nosies". I'm just like – "you're the one..." and then we just get into arguments and fighting and then crying. S: Sarah, lines 395-398).	dynamics?)  Tom gets annoyed at little things easily, if argue back this escalates the situation.
<b>Acceptance</b> Concept of normal	"he acts like erm, er, like a hyperactive 9 or 10 year old cuz like his personality that's like the way he is" S: Simon, lines 147-148.	Simon: acts younger but this is personality, the way he is. Not different to normal. Not separating out ASD.
Acceptance – positive growth	"I wouldn't change him for another person, I wouldn't change him for another boy, sort of like a normal teenager if you like". P: Becky, lines 18-19	I wouldn't change him (is this an option? How would it be different if he was different? Possibility of change? What is normal?