

VOLUME I

Research Component

Experience of Family Members Living with a Child Diagnosed with Autism Spectrum Disorder: Important Psychological Factors for Intervention

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A thesis submitted in Partial Fulfilment of the Regulations for the degree of

Doctor of Clinical Psychology (CLIN.PSY.D)

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OVERVIEW

This thesis is submitted in partial fulfilment to the requirements for the degree of Doctor of Clinical Psychology (Clin.Psy.D) at the University of Birmingham. It is divided into two volumes.

Volume I of the thesis represents the research component; this is presented in the form of three papers which are related to the life in a family where there is a child with a diagnosis of Autism Spectrum Disorder (ASD). The first paper is a review of the literature critically examining interventions, delivered in a group format, for parents of children with ASD. It explores parent, child and parenting outcomes that result from parents' participation in a parent training or support groups. The second paper is an empirical paper exploring the experience of living in a family with a child with a diagnosis of ASD from a parent and sibling perspective. These papers have been prepared according to the requirements of the Journal of Autism and Developmental Disorders. The third paper is a public domain briefing paper which outlines the findings from both the literature review and empirical paper. This is intended for dissemination to a wider audience including those who took part in the research.

Appendices are then provided giving details of the interviews and some of the analysis used within the empirical paper.

Volume II of the thesis represents the assessment of the clinical component of training for the Clin.Psy.D; it contains five clinical practice reports; reflecting the work completed on placements. These include; CPR1 is a behavioural and systemic formulation of Carl who is an 11 year old boy with difficulty sleeping. CPR2 is a service evaluation of

the ability to deliver Cognitive Behavioural Therapy (CBT) within the Choice and Partnership Approach (CAPA) model. CPR3 is a case study of a 79 year old woman referred for Palliative Care Psychology. CPR4 is a single case experimental design about CBT formulation and intervention for a 33 year old woman with low self esteem and learning disability. An abstract about CPR5, a case study presentation of a 45 year old male in Assertive Outreach, is also included.

DEDICATION

I would like to dedicate this thesis to Lily Grace, Al, Mum and Dad.

ACKNOWLEDGEMENTS

My deepest thanks go to the families that participated in this research, without them it would not have been possible. I feel privileged to have had the opportunity to hear their stories and I hope I have done justice to them. My thanks also extend to Midlands Psychology Service for supporting the research, in spite of other pressures, through identification of participants.

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Paper to be edited for submission to Journal of Autism and Developmental Disorders

What Do We Know About The Effectiveness Of Group Interventions For Parents Of Children With Autism Spectrum Disorder? A Systematic Review

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ABSTRACT

Background:

Parents of children with ASD frequently report difficulties. Parents often deliver interventions for their child within the family home. This can lead to an increase in stress. Interventions can be more successful when parents are less stressed. This study aims to synthesise the literature assessing the effectiveness of training parents about interventions in a group and offering support in a group. Outcomes for parents, children and parenting are reported.

Method:

Databases were searched from 1980-present day; 17 papers met the inclusion criteria for the review. Twelve papers looked at the effects of parent training programmes whilst the other five reported on the outcomes following support groups.

Conclusion:

The studies analysed had a variety of methodological limitations but suggested that parenting groups can have an effect on parent knowledge, and parenting. It is less clear if they have an effect on the child with ASD. Further research would be needed to strengthen these conclusions.

Keywords

Autism Spectrum Disorder, parents groups, intervention, outcomes

INTRODUCTION

Autism spectrum disorder (ASD) is a neuro-developmental disability that includes diagnoses of Autism, high functioning Autism, Asperger's syndrome, and Pervasive Developmental Disorders not otherwise specified. DSM-V has now categorised these diagnoses into one Autism Spectrum Disorder (American Psychiatric Association et al., 2013). ASD is diagnosed in about one in a hundred individuals; there are 133,500 children with a diagnosis of ASD living in the UK (National Autistic Society, 2011).

Children with ASD struggle to understand how to initiate play and to share enjoyment with their peers. They have difficulties in social situations, particularly in conversations, and are likely to find it difficult to read people's intentions by their language and gestures. In addition, they may display repetitive behaviours and interests (Fava et al., 2012). Behaviour problems have also been widely reported in individuals with ASD (Tonge & Einfeld, 2003), with reports of disruptive behaviour occurring in 50-70% of children with ASD (Bearss, et al., 2013).

Low parenting efficacy, high parenting stress, and a high prevalence of mental and physical health problems have been reported in parents of children with ASD (Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005; Karst & Hecke, 2012). Research has focused on the effectiveness of interventions for the child with ASD and the effect on the parent.

Interventions

Management of the difficulties of a child with ASD is often a priority. There are a variety of Behavioural Interventions (i.e., Applied Behavioural Analysis [ABA] (Dunlap,

Kern-Dunlap, Clark, & Robbins, 1991), Intensive behavioural intervention [IBI] and Lovaas (Lovaas, 1987)) for children with ASD and the majority of these include the active involvement of parents in the treatment delivery (Fava et al., 2012). Parents of children with ASD are frequently used in IBI programmes because they have more contact with their children than educators and clinicians, and can continue behavioural interventions outside of clinician intervention hours (Fava et al., 2012). As a result, parent training is a high priority for the care of the child with ASD (Jang et al., 2012)

McConachie and Diggle (2007) systematically reviewed the available literature assessing the effectiveness of parent-implemented interventions for children with ASD. The interventions reviewed were controlled studies where a parent was delivering an intervention to a child with ASD. Parents were supported to deliver this training with individual parental training. They reviewed 12 studies and concluded that some interventions showed improved child communication, increased maternal knowledge about ASD, enhanced parent-child communication and interaction, and reduced maternal depression. Length of intervention varied from 10 weeks to 18 months.

Effects of intervention on the parent

ABA interventions are often recommended for individuals with ASD, but Schwichtenberg and Poehlmann (2007) investigated the effect of the ABA on the family. The results showed that parents of children with ASD involved in ABA experienced elevated symptoms of depression in comparison to parents of children with other disabilities. In addition, they found that, as children got older, mothers reported fewer depressive symptoms. More intervention hours led to mothers reporting fewer depressive symptoms but increased personal strain. More time-intensive interventions have been

linked with better outcomes for the child with ASD (Osborne, McHugh, Saunders, & Reed, 2008).

Shine and Perry (2010) investigated whether there was an association between parenting distress and progress in IBI. They found a significant negative correlation, indicating that higher parental distress was associated with lower adaptive behaviour skills post treatment, however, this correlation was small. Osborne, McHugh, Saunders, and Reed, (2008) found that larger improvements in children's adaptive behaviour post treatment were reported in families where parental stress was lower pre intervention. The changes in adaptive behaviour were reported by parents and therefore may be influenced by their stress levels. However, reducing parent stress levels may improve outcomes in intervention programs (Osborne et al., 2008)

Parent training for parents of children with ASD has been conducted using a variety of techniques, for example; group and individual training, in homes and centres, using manuals, curricular, video training and live instructions (Fava et al., 2012). Group interventions have an important role and are cost effective in the treatment of individuals with learning disabilities (Matson, Mahan, & LoVullo, 2009).

Parents' perceptions of groups were investigated by Clifford and Minnes (2013). They found that parents of children with ASD participating in a support group described positive experiences. Different attitudes were found from parents not currently involved in support groups - those who felt they would be beneficial but had never tried them due to difficulties with attendance, and those who had tried them and found them not to be beneficial. They concluded that focusing on the individual needs of the parents might lead to better support and more efficient use of community resources.

AIMS OF THE REVIEW

Parents of children with ASD have been reported to face a number of challenges, including being involved in delivering treatments for their children. The purpose of this review is to systematically describe and synthesise the evidence in relation to the effect of group interventions for parents of children with ASD. This review will investigate three areas of interest reported in the literature:

- Parent outcomes including
 - Understanding of ASD
 - Mental health
- Child outcomes including
 - Behaviour
 - Communication
- Parenting outcomes including
 - Perception of parenting
 - Ability
 - Parent – child interactions

This review considers the aims of the groups in addition to highlighting the different outcomes reported in the literature. The methodological factors limiting the conclusions are identified.

METHOD

Search Strategy

A literature search was carried out in March 2013 using the following databases: OVID PSYCHINFO, OVID EMBASE, OVID MEDLINE and WEB OF SCIENCE to identify articles reporting on the outcomes of group interventions for parents of children with ASD. The search strategy involved three strands:

- Identifying interventions for parents delivered in a group setting
- Finding interventions that were evaluated for effectiveness
- Ascertaining that the parents had a child with a diagnosis of an ASD

To ensure that all relevant peer reviewed articles were found, electronic databases were searched from 1980-2013. The term * was used to allow for different word ending to be included in the search eg, *autis** would include *Autistic* and *Autism*. The OVID database allows for search terms to be exploded (*exp*) to include other relevant terms and mapped to subject headings, therefore two different searches were performed: one in OVID where *exp* was used (Table 1) and in WEB OF SCIENCE where it was not (Table 2). In addition it should be noted that *adj2* is used to search for a term within two words of another term. The terms were generated by looking at the keywords in relevant articles and refined for inclusion based on how useful they were in generating appropriate articles when included.

Table 1. Search Strategy Used in OVID Databases

Intervention		Outcome		Diagnosis
exp parent AND (exp “group intervention” or exp “family intervention” or exp intervention or “group intervention” or psychoeducation” or “support groups”) OR “parent training” OR [parent* adj2 (program,* or train* or grou* or educati* or counsel* or course*)]	AND	exp “treatment outcomes” OR (outcome* or success* or efficacy* or effective*) OR (evaluation or “course evaluation” or exp “program evaluation” or “treatment effectiveness evaluation”)	AND	exp Autism
The above entered as keywords in abstract, title, table of contents and subject headings		The above entered as keywords in abstract, title, table of contents and subject headings		The above entered as keywords in abstract, title, table of contents and subject headings

Table 2. Search Strategy Used in WEB OF SCIENCE Database

Intervention		Outcome		Diagnosis
Parent* and group and ("intervent*" or "family intervent*" or "counsel*" or "train*" or "psychoeducat*" or "support")	AND	“treatment outcomes” OR outcome* OR success* OR efficacy* OR effective* OR “treatment effectiveness evaluation” OR evaluat* OR “course evaluat*”	AND	Autis* or Asperg* or ASD
The above entered as keywords in topic		The above entered as keywords in topic		The above entered as keywords in title

Inclusion and Exclusion Criteria

All methodological approaches were included in the study. Inclusion and exclusion criteria can be seen in table 3. To ensure that original peer review articles were considered, a number of articles were excluded. These included dissertation abstracts, book chapters and articles not published in English. All other articles were included and the methodological limitations of these will be discussed.

Table 3. Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Studies were selected for inclusion if they carried out a group intervention for a parent of a child with ASD and measured an outcome following this group	Interventions were delivered but outcomes were not reported
Group intervention package was delivered to a parent of a child with ASD and may have included individual sessions as part of the package	Parents and child participated in the same training group for the whole package
A small number of parent and child group sessions may also have been included in the package	Parent group was part of a larger treatment programme
Studies were included if the child was also receiving intervention	Parents of children with ASD were included in groups including other diagnoses and the effects for parents of ASD was not separately analysed.

Abstracts generated from the database searches were screened for appropriateness.

Full-text articles where parent groups were investigated were then scrutinised for eligibility using the above in/exclusion criteria (Figure 1).

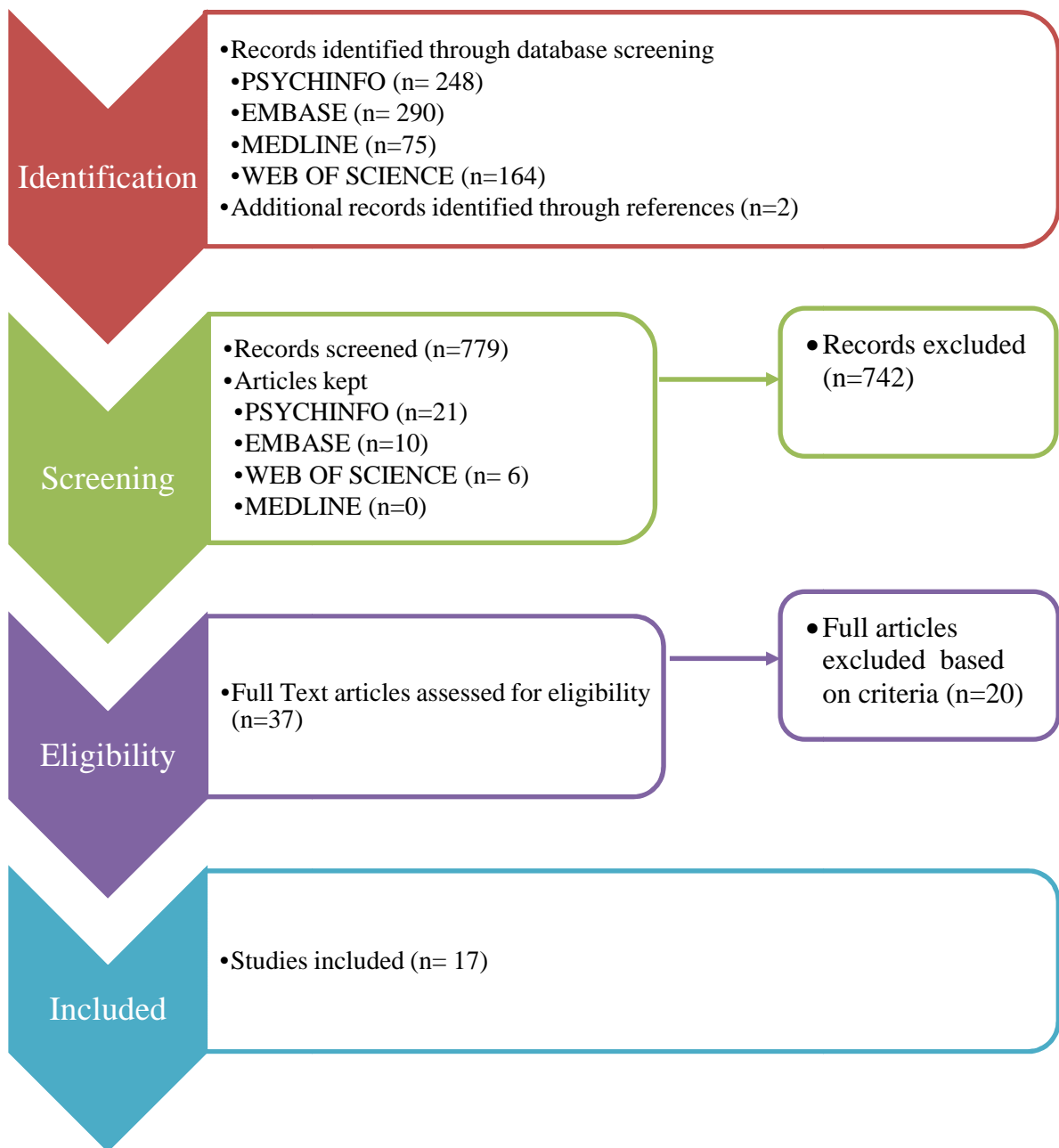


Figure 1. Flow diagram depicting flow of information through the systematic review

Details of papers included in review

Seventeen articles were identified for the systematic review. Full text articles were retrieved through University of Birmingham electronic journals access or by contacting the author directly. There were two types of intervention; parent training groups and support groups. Table 4 contains a summary of the papers detailing country, type of intervention, aims of the study, research design and sample size. More detailed summaries for each paper; including: the sample size, methodology, measures used to assess the outcomes and methodological limitations and an indication of which outcomes are reported can be found in Appendix A.

Table 4. Summary Table of Studies Included in the Review

Author(s) & Year	Country	Type of Group	Aims	Method	Design	Participants
Bitsika & Sharpley (1999)	Australia	Support	Evaluate the effects of an information counselling group for parents of children with ASD	Mixed methods	Case series analysis	n=14
Bitsika & Sharpley (2000)	Australia	Support	Reduce anxiety and depression for parents of children with ASD through delivery of a direct stress management group	Mixed methods	Case series analysis	n=11
Blackledge & Hayes (2006)	Australia	Support	To see whether Acceptance and Commitment Therapy (ACT) might be included as support for parents of children with ASD	Quantitative	Case series analysis	n=20
Farmer & Reupert (2013)	Australia	Support	Increase understanding of child with ASD, increase parenting confidence, decrease feelings of isolation, decrease anxiety	Mixed methods	Retrospective Case series analysis	n=98
Khosroshahi, et. al.(2010)	Iran	Training	Evaluate the Little Bird program against a control group for behavioural change in children with ASD	Quantitative	Randomised Controlled Trial	n=16
McIntyre, (2009)	USA	Training	Is Incredible Years Parent Training (IYPT) more effective than usual care in adapting parenting styles?	Quantitative	Randomised Controlled Trial	n=44
Okuno et al. (2011)	Japan	Training	Evaluation of a shortened parent training programme designed for parents of children with ADHD	Quantitative	Case series analysis	n=13
Pillay, et al. (2011)	UK	Training	Evaluate the Autistic Spectrum Condition Enhancing Nurture and Development Programme (ASCEND)	Quantitative	Case series analysis	n=79

Table 4 Summary Table of Studies Included in the Review - Continued

Author(s) & Year	Country	Type of Group	Aims	Method	Design	Participants
Reed et al. (2009)	USA	Training	Evaluation of a pilot study investigating the impact of a parent group about sleep interventions for insomnia	Quantitative	Case series analysis	n=22
Roberts & Pickering (2010)	UK	Training	Evaluation of the Incredible Years Parenting Programme modified for ASD	Quantitative	Case study	n=8
Roberts et al. (2011)	Australia	Training	Investigate the differences between a home based intervention programme and centre based programme with parent training group in comparison to control group	Quantitative	Randomised Controlled Trial	n=84
Schultz, et al. (2012)	USA	Training	Evaluation of the addition of a social competence intervention for parents in comparison to group for adolescents alone	Quantitative	Case control study	n=16
Stahmer & Gist (2001)	USA	Training	Investigation into the added benefit of a parent support group to Pivotal response training	Quantitative	Case control study	n=22
Tonge et al. (2006)	Australia	Support and Training	Comparison of Parent Education and Behaviour management (PEBM), parent education and counselling (PEC) and control group	Quantitative	Randomised Controlled Trail	n=105

Table 4 Summary Table of Studies Included in the Review – Continued

Author(s) & Year	Country		Aims	Method	Design	Participants
Venker et al. (2012)	USA	Training	Investigate whether parents of a child with ASD can learn to implement verbal responsiveness to facilitate language development	Quantitative	Randomised Controlled Trial	n=14
Wang, (2008)	China	Training	Evaluate the impact on parent interactive skills of a comprehensive parent training programme for teaching children with ASD	Quantitative	Randomised Controlled Trial	n=27
Whittingham, et al. (2008)	Australia	Training	Efficacy of Triple P for parents of children with ASD	Quantitative	Randomised Controlled Trial	n=59

Evidential Quality

To rate the quality of each article, an assessment tool was used to review each study. The “Quality Index” was chosen as it allows a profile of the paper to be developed which alerts the reviewer to methodological strengths and weaknesses (Downs & Black, 1998). This tool consists of 27 items relating to the reporting, validity and power of the study and provides comprehensive coverage of the main domains in a quantitative study. In addition, the NICE (2005) criteria were utilised to rate the type of evidence based on the methodological approach used. There are four levels of evidence ranging from 1 for randomised control trial, through 2 for cohort studies, to level 3 for non-analytic studies (case reports) and finally level 4 expert opinion. Table 5 provides an overview of the Quality Index and NICE Criteria using traffic light coding to highlight strengths and weaknesses. Using the Downs and Black (1998) criteria, papers were critiqued for quality: red indicates problems identified, amber is an indication of minor problems and green indicates good adherence to the criteria. A traffic light system was chosen over an overall score numerical system as this is likely to hide the internal strengths and weaknesses of a paper and skew the perspective of the reader.

Table 5. Quality of the Evidence (Support interventions)

NICE rating	3	3	3	3	2	1
Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	●	●	●	●	●	●
Were losses of patients to follow-up taken into account?	●	●	●	●	●	●
Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	●	●	●	●	●	●
Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	●	●	●	●	●	●
Were study subjects randomised to intervention groups?	●	●	●	●	●	●
Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	●	●	●	●	●	●
Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	●	●	●	●	●	●
Were the main outcome measures used accurate (valid and reliable)?	●	●	●	●	●	●
Was compliance with the intervention/s reliable?	●	●	●	●	●	●
Were the statistical tests used to assess the main outcomes appropriate?	●	●	●	●	●	●
In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls ?	●	●	●	●	●	●
If any of the results of the study were based on “data dredging”, was this made clear?	●	●	●	●	●	●
Was an attempt made to blind those measuring the main outcomes of the intervention?	●	●	●	●	●	●
Was an attempt made to blind study subjects to the intervention they have received ?	●	●	●	●	●	●
Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	●	●	●	●	●	●
Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	●	●	●	●	●	●
Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	●	●	●	●	●	●
Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	●	●	●	●	●	●
Have the characteristics of patients lost to follow-up been described?	●	●	●	●	●	●
Have all important adverse events that may be a consequence of the intervention been reported?	●	●	●	●	●	●
Does the study provide estimates of the random variability in the data for the main outcomes?	●	●	●	●	●	●
Are the main findings of the study clearly described?	●	●	●	●	●	●
Are the distributions of principal confounders in each group of subjects to be compared clearly described?	●	●	●	●	●	●
Are the interventions of interest clearly described?	●	●	●	●	●	●
Are the characteristics of the patients included in the study clearly described?	●	●	●	●	●	●
Are the main outcomes to be measured clearly described in the Introduction or Methods sections?	●	●	●	●	●	●
Is the hypothesis/aim/objective of the study clearly described?	●	●	●	●	●	●
	Bitsika & Sharpley, (1999)	Bitsika & Sharpley, (2000)	Blackledge & Hayes (2006)	Farmer & Reupert (2013)	Stahmer & Gist (2001)	Tonge et al. (2006)

Table 5 continued Quality of the Evidence (Training interventions)

NICE rating	3	3	3	3	2
Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	●	●	●	●	●
Were losses of patients to follow-up taken into account?	●	●	●	●	●
Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	●	●	●	●	●
Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	●	●	●	●	●
Were study subjects randomised to intervention groups?	●	●	●	●	●
Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	●	●	●	●	●
Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	●	●	●	●	●
Were the main outcome measures used accurate (valid and reliable)?	●	●	●	●	●
Was compliance with the intervention/s reliable?	●	●	●	●	●
Were the statistical tests used to assess the main outcomes appropriate?	●	●	●	●	●
In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls ?	●	●	●	●	●
If any of the results of the study were based on “data dredging”, was this made clear?	●	●	●	●	●
Was an attempt made to blind those measuring the main outcomes of the intervention?	●	●	●	●	●
Was an attempt made to blind study subjects to the intervention they have received ?	●	●	●	●	●
Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	●	●	●	●	●
Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	●	●	●	●	●
Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	●	●	●	●	●
Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	●	●	●	●	●
Have the characteristics of patients lost to follow-up been described?	●	●	●	●	●
Have all important adverse events that may be a consequence of the intervention been reported?	●	●	●	●	●
Does the study provide estimates of the random variability in the data for the main outcomes?	●	●	●	●	●
Are the main findings of the study clearly described?	●	●	●	●	●
Are the distributions of principal confounders in each group of subjects to be compared clearly described?	●	●	●	●	●
Are the interventions of interest clearly described?	●	●	●	●	●
Are the characteristics of the patients included in the study clearly described?	●	●	●	●	●
Are the main outcomes to be measured clearly described in the Introduction or Methods sections?	●	●	●	●	●
Is the hypothesis/aim/objective of the study clearly described?	●	●	●	●	●
	Okuno et al. (2011)	Pillay, et al. (2011)	Reed et al. (2009)	Roberts & Pickering (2010)	Schultz, et al. (2012)

Table 5 continued Quality of the Evidence (Training Interventions RCT)

NICE rating	1	1	1	1	1	1
Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?	●	●	●	●	●	●
Were losses of patients to follow-up taken into account?	●	●	●	●	●	●
Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?	●	●	●	●	●	●
Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?	●	●	●	●	●	●
Were study subjects randomised to intervention groups?	●	●	●	●	●	●
Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?	●	●	●	●	●	●
Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?	●	●	●	●	●	●
Were the main outcome measures used accurate (valid and reliable)?	●	●	●	●	●	●
Was compliance with the intervention/s reliable?	●	●	●	●	●	●
Were the statistical tests used to assess the main outcomes appropriate?	●	●	●	●	●	●
In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls ?	●	●	●	●	●	●
If any of the results of the study were based on “data dredging”, was this made clear?	●	●	●	●	●	●
Was an attempt made to blind those measuring the main outcomes of the intervention?	●	●	●	●	●	●
Was an attempt made to blind study subjects to the intervention they have received ?	●	●	●	●	●	●
Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?	●	●	●	●	●	●
Were those subjects who were prepared to participate representative of the entire population from which they were recruited?	●	●	●	●	●	●
Were the subjects asked to participate in the study representative of the entire population from which they were recruited?	●	●	●	●	●	●
Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	●	●	●	●	●	●
Have the characteristics of patients lost to follow-up been described?	●	●	●	●	●	●
Have all important adverse events that may be a consequence of the intervention been reported?	●	●	●	●	●	●
Does the study provide estimates of the random variability in the data for the main outcomes?	●	●	●	●	●	●
Are the main findings of the study clearly described?	●	●	●	●	●	●
Are the distributions of principal confounders in each group of subjects to be compared clearly described?	●	●	●	●	●	●
Are the interventions of interest clearly described?	●	●	●	●	●	●
Are the characteristics of the patients included in the study clearly described?	●	●	●	●	●	●
Are the main outcomes to be measured clearly described in the Introduction or Methods sections?	●	●	●	●	●	●
Is the hypothesis/aim/objective of the study clearly described?	●	●	●	●	●	●
	Khosroshahi, et. al., (2010)	McIntyre, (2009)	Roberts et al. (2011)	Venker et al. (2012)	Wang, (2008)	Whittingham, et al. (2008)

METHODOLOGICAL REVIEW

As part of the critical appraisal, methodological limitations were considered for all studies included in the review. These methodological issues will be outlined here prior to presenting the findings for each of the areas of interest in the following chapter.

Methodology

The majority of the studies reviewed used a quantitative methodology in order to assess the effects of a parent group intervention (n=14). The other three papers utilised mixed methods designs, with two of these using quantitative data to report the effect of the group and qualitative data for evaluation. Seven used randomised controlled trials (RCT) to investigate the effectiveness of a parent group intervention in relation to another intervention or a control group or both (Khosroshahi et al., 2010; McIntyre, 2009; Roberts et al., 2011; Tonge et al., 2006; Venker et al., 2012; Wang, 2008; Whittingham et al., 2008). Seven studies employed a case series analysis to investigate the effects of a number of groups over time (Bitsika & Sharpley, 1999; 2000; Blackledge & Hayes, 2006; Farmer & Reupert, 2013; Okuno et al., 2011; Pillay et al., 2011; Reed et al., 2009) with one of these using retrospective case file data (Farmer & Reupert, 2013). Two studies utilised case control designs (Schultz et al., 2012; Stahmer & Gist, 2001) and one was a case study design evaluating the effect of one group (Roberts & Pickering, 2010).

Interventions

Twelve of the studies investigate the impact of a parent behavioural training programme (Khosroshahi et al., 2010; McIntyre, 2009; Okuno et al., 2011; Pillay et al.,

2011; Reed et al., 2009; Roberts & Pickering, 2010; Roberts et al., 2011; Schultz et al., 2012; Tonge et al., 2006; Venker et al., 2012; Wang, 2008; Whittingham et al., 2008); two of these used the Incredible Years training programme (McIntyre, 2009; Roberts & Pickering, 2010). The other five studies investigated the effect of support, information or therapeutic groups which will be referred to throughout as support groups as their aim was not to provide specific training (Bitsika & Sharpley, 1999; 2000; Blackledge & Hayes, 2006; Farmer & Reupert, 2013; Stahmer & Gist, 2001).

Recruitment

Methods used to recruit participants varied between the randomised controlled trials. Some of the RCTs employed rigorous randomisation procedures which included using a computer algorithm run by a statistician in order to blind experimenter to intervention (Roberts et al., 2011). Others used less random designs: one study randomly allocated to the group but matched control group participants (Khosroshahi et al., 2010) and another matched families prepared to participate to each other, before allocating alternately to group by randomly drawing names out of a hat (Whittingham et al., 2008).

Recruitment methods also varied, with three studies recruiting through special schools (Bitsika & Sharpley, 1999; 2000; Schultz et al., 2012). In five studies participants had been referred for treatment (Farmer & Reupert, 2013; Khosroshahi et al., 2010; Roberts et al., 2011; Roberts & Pickering, 2010; Tonge et al., 2006) and a further two recruited via clinics (Okuno et al., 2011; Stahmer & Gist, 2001). Another method of recruitment was targeting families of children with ASD by letter (Blackledge & Hayes, 2006) or through early intervention providers (McIntyre, 2009). Multiple methods were used in three studies; medical centre, clinic and community (Reed et al., 2009),

advertisement in media and research website (Wang, 2008), adverts, support associations and school newsletter (Whittingham et al., 2008). The final recruitment method was through participation in another study (Venker et al., 2012).

The duration of the recruitment process also varied between studies; with some studies it was clear that they had recruited all their participants over the same time frame, these are evaluated in green in table 5 “Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case control studies) recruited over the same period of time?”. When the studies involved recruitment via referral or multiple deliveries of the same intervention, the duration of recruitment is often not specified in the paper (indicated in table 5 by the colour amber, as caution should be used when evaluating the quality of the recruitment method used). Two studies made it clear that recruitment took place over a number of years (Farmer & Reupert, 2013; Roberts et al., 2011), whilst one study retrospectively analysed data from the files of previous attendees in a clinic group therefore the process of inclusion involved the availability of the information to the author (Pillay et al., 2011).

Fidelity to treatment

Another potential methodological limitation was fidelity to the treatment intervention; this took two forms, adherence to the parent group training package and attendance of participants in the groups. Of the twelve studies that investigated the effect of a parent training group, five controlled for adherence to the programme. This involved randomly selecting parts of the programme and using an unbiased interpreter to test for fidelity (McIntyre, 2009; Okuno et al., 2011; Roberts et al., 2011; Schultz et al., 2012; Tonge et al., 2006). Another way delivery was kept faithful to the programme was through

the use of a manualised package; three further studies used this approach (Khosroshahi et al., 2010; Roberts & Pickering, 2010; Wang, 2008). One study deviated from the manualised plan in order to add extra individual sessions to achieve parental competence in the treatment (Whittingham et al., 2008). In the other study, the programme was changed between sessions following feedback from participants and was delivered by different facilitators (Pillay et al., 2011). One study described using a fidelity assessment and reported good fidelity to the treatment whilst also reporting to adapt treatment as per the group's request (Venker et al., 2012). The final study did not test for fidelity and tailored treatment programmes to the individual needs of the child with ASD (Reed et al., 2009).

Attendance was another risk to fidelity of the training as parents would not have received the full training package if they missed sessions. Rates of participant attendance were not reported in nine of the papers investigating the effect of a training group (Khosroshahi et al., 2010; McIntyre, 2009; Pillay et al., 2011; Reed et al., 2009; Roberts & Pickering, 2010; Tonge et al., 2006; Venker et al., 2012; Wang, 2008; Whittingham et al., 2008). Attendance was also not reported in one of the five papers investigating the effect of a support group (Stahmer & Gist, 2001). In papers reporting attendance rates, these varied from an average of 62% - 94%, with one paper reporting participation as low as 25% for one attendee in a training programme (Bitsika & Sharpley, 1999; 2000; Blackledge & Hayes, 2006; Farmer & Reupert, 2013; Okuno et al., 2011; Schultz et al., 2012).

Group format

Delivery of the groups was variable between studies; four of the studies ran interventions in a partial group format which included one to one interventions as part of the intervention (Khosroshahi et al., 2010; Tonge et al., 2006; Venker et al., 2012; Wang,

2008), and one also included small group sessions which included the child with ASD (Tonge et al., 2006). A further three studies included a separate intervention for the children with ASD and compared the addition of a group to treatment of the children alone (Roberts et al., 2011; Schultz et al., 2012; Stahmer & Gist, 2001). The rest of the studies only delivered training or support in a full group format, although two reported providing additional support outside the group (Bitsika & Sharpley, 1999; 2000). Size of group also varied between studies but they tended to be small groups with the largest group being for 16 parents.

Measures

There were three papers which reported using only valid and reliable measures to investigate the effectiveness of the group (Khosroshahi et al., 2010; McIntyre, 2009; Schultz et al., 2012). Another two papers did use author constructed measures (Bitsika & Sharpley, 1999; Farmer & Reupert, 2013), whilst the other twelve papers either used a mixture of validated measures and author constructed measures, some did not report on the reliability of the measures they were using (Bitsika & Sharpley, 2000; Blackledge & Hayes, 2006; Okuno et al., 2011; Pillay et al., 2011; Reed et al., 2009; Roberts & Pickering, 2010; Roberts et al., 2011; Schultz et al., 2012; Stahmer & Gist, 2001; Tonge et al., 2006; Venker et al., 2012; Wang, 2008; Whittingham et al., 2008). The majority of the studies also utilised parent self-report measures; the risk of this is that parents are reporting a perceived change as a result of the group rather than an actual change. Only five of the studies reduced this risk of bias by using measures that did not rely on parent report, such as observations of the parent and child or researcher administration of tests (McIntyre, 2009; Reed et al., 2009; Stahmer & Gist, 2001; Venker et al., 2012; Wang, 2008)

Sample size

The majority of the studies used a small sample size; only six of the studies used a sample of more than 30 participants (Farmer & Reupert, 2013; McIntyre, 2009; Pillay et al., 2011; Roberts et al., 2011; Tonge et al., 2006; Whittingham et al., 2008) and of these studies only three calculated power before analysing the data (Pillay et al., 2011; Roberts et al., 2011; Whittingham et al., 2008). Therefore, the majority of studies were likely to be underpowered increasing the chance of reporting a type 2 error and making it difficult to assess the intervention effects in the studies.

Statistical analysis

The majority of the studies used appropriate statistical tests to analyse the results, although one test reported only descriptive data (Bitsika & Sharpley, 2000) and only two of the papers allowed for drop-out in the analysis (Venker et al., 2012; Whittingham et al., 2008). Three papers reported no attrition (Bitsika & Sharpley, 1999, 2000; Okuno et al., 2011). Dropout rate was not reported in another seven studies (Blackledge & Hayes, 2006; Khosroshahi et al., 2010; Farmer & Reupert, 2013; McIntyre, 2009; Reed et al., 2009; Roberts et al., 2011; Tonge et al., 2006) whilst a further study recruited 26 people and analysed data for only 16 (Schultz et al., 2012). A further threat to analysis occurred when both mothers and fathers were asked to complete the same measures following treatment and both were analysed as separate individuals although they were unlikely to be independent; four studies did this (Blackledge & Hayes, 2006; Farmer & Reupert, 2013; Pillay et al., 2011; Tonge et al., 2006). Only two studies made adequate adjustment for confounding variables (Schultz et al., 2012; Whittingham et al., 2008). Only three of the studies reported effect sizes (McIntyre, 2009; Wang, 2008; Whittingham et al., 2008)

Qualitative methodologies

Three studies utilised a mixed methods design; the qualitative methodology in two of these studies was used to evaluate the group and did not generate results useful for answering the topics of interest in this review (Bitsika & Sharpley, 1999, 2000). The third study used thematic analysis to investigate the feeling of parents about their understanding of autism; although did not detail the epistemology, philosophy nor provide a reflexive statement about potential bias in the analysis (Farmer et al., 2012). Thus, this part of the study has poor methodological quality.

Participants

Across the studies there was no consistent reporting of the demographics of the participants. There is a limitation in not knowing the ages of the children with ASD, specific diagnoses, which parent participated, ages of the parents, number of children in the family or sociodemographics of the families.

Methodological Limitations: Summary

The studies included have a variety of methodological limitations outlined above, and also highlighted in table 5. NICE ratings show the quality of the overall methodological approach chosen and the traffic light system provides more detail about how rigorously the study was completed. All of the studies have strengths and weaknesses in their methodological approach, these factors influence their reliability. The methodological differences between the studies make it difficult to make direct comparisons between the studies; further details of studies will be synthesised in the following chapters addressing the areas of interest.

SYNTHESIS

In synthesising the papers there is some overlap between areas of interest; as some papers investigate outcomes in more than one domain. As a result the papers will only be described the first time they are reported. The relevant findings and methodological limitations will be presented under the heading to which they apply. In addition to this, papers with poor methodological quality will not be described in detail.

What are the outcomes for parents?

Eight of the studies reported on parent outcomes following attendance in a group; these investigated increased understanding of ASD and mental health implications for the parents. Four of the studies were support groups (Bitsika & Sharpley, 1999, 2000; Blackledge & Hayes, 2006; Farmer & Reupert, 2013), three parent training (Pillay et al., 2011; Roberts et al., 2011; Schultz et al., 2012) and one a comparison between parent support and training package (Tonge et al., 2006).

Understanding about ASD: Training groups

Three studies assessed parental understanding about ASD; one used a mixed methods design to evaluate a parent education programme in Australia (Farmer & Reupert, 2013), another used a quantitative design to evaluate a parent training programme in Japan (Okuno et al., 2011). The third study evaluated a third parent training programme in the UK (Pillay et al., 2011).

Farmer and Reupert's (2013) parent education study aimed to evaluate the delivery of a six session programme delivered in a full group. This large study found that parental

responses on a Likert scale exploring understanding of ASD, significantly improved between pre- and post-test results. A difference was also found in the pre-intervention to post-intervention qualitative responses; feelings of being overwhelmed by the impact of ASD, having little knowledge and not enough information changed to understanding ASD and my child in addition to understanding sensory difficulties.

Both the papers investigating parent training also used pre and post measures. Okuno et al., (2011) adapted a training programme for parents of children with ADHD; significant positive differences were found in mothers' understanding of ASD pre-post test and their reported ability to cope, but no change was found for fathers. Pillay et al., (2011) evaluated the ASCEND programme which has a group format consisting of 11 two-hour sessions. Data were analysed for the parents of 35 children; with significant increases in confidence and awareness for parents (Pillay et al., 2011).

Methodological limitation in these studies include lack of control groups to control for maturation in the sample, unvalidated measures, no measure for stability at baseline and only one study requested that participants did not change any medication or enrol in another study (Okuno et al., 2011).

Understanding about ASD: Summary

Overall, these three studies all indicate that parents are reporting having learnt more about ASD following both parent training and information groups, although the age ranges, diagnoses and method of group delivery varied between the groups. However, this is based on three case series analysis, each having some major methodological limitations, thus it is not possible to draw definitive conclusions from the data.

Mental Health

Eight studies explored the effects of a group on parental mental health, including measures of parental stress, anxiety, distress, depression and general health. Four of these studies used support groups (Bitsika & Sharpley, 1999, 2000; Blackledge & Hayes, 2006; Farmer & Reupert, 2013); whilst the other five delivered parent training packages (Reed et al., 2009; Roberts & Pickering, 2010; Roberts et al., 2011; Schultz et al., 2012; Tonge et al., 2006).

The effect on anxiety, depression and distress was only reported in the four papers where support groups had been delivered. Parental stress was a reported outcome in seven studies; three parent training (Bitsika & Sharpley, 1999, 2000; Blackledge & Hayes, 2006) and four parent support groups (Reed et al., 2009; Roberts et al., 2011; Schultz et al., 2012; Tonge et al., 2006). General health was an outcome in two papers; one parent support (Blackledge & Hayes, 2006) and one parent training (Roberts & Pickering, 2010). As some of the studies measure more than one aspect of parent mental health, each study will be reviewed separately for all of the relevant findings before conclusions are drawn on each of the areas investigated.

Mental Health: Support groups

The effect of an information counselling group was reported in one Australian study (Bitsika & Sharpley, 1999). The measures were developed by the author and had not been standardised; they were administered at the beginning and end of each session. Descriptive statistics indicated that distress reduced each session.

Bitsika and Sharpley (2000) aimed to reduce anxiety and depression using direct stress management techniques; they delivered 2 programmes of 8 x 75 minute sessions.

They used education, progressive muscle relaxation deep breathing and bio feedback to support parents. The measures they used were parent report and not validated measures were administered before and after each group session and were analysed with parametric statistics. Reductions in anxiety and stress were not significant.

General health, depression and distress were investigated by Blackledge and Hayes (2006). Acceptance and Commitment therapy was delivered to 4 groups through a 2-day workshop totalling 14 hours. Twenty parents of children diagnosed with autism participated, with a drop out of five. Pre to post measure improvements were significant for depression and distress but not general health. However, pre-follow up (3 months after) measures were significant in all areas, with larger reduction in scores reported when pre-scores were in the clinical range.

The final study evaluating the effect of a support group was Farmer & Reupert, (2013) which is described in the previous section. In addition to improving parental knowledge they reported a significant reduction in anxiety but do not report the effect size.

Mental Health: Training groups

The effects of parent training were reported in quantitative studies. Reed et al., (2009) investigated the effect of a sleep-based parent training programme, which was delivered in three sessions of 2 hours each. Although not the focus of the intervention, parental stress was measured and no significant change was found pre to post treatment. The 12-week manualised Incredible Years Parenting Programme (IYPP) (Webster-Stratton, 2001), investigated parents general health using pre-post measures and reported a significant improvement in scores on the General Health Questionnaire following the intervention (Roberts & Pickering, 2010).

More rigorous methodology was used in a randomised controlled trial comparing a home based intervention to a centre-based programme in comparison to a control group (Roberts et al., 2011). The centre based programme included a 40-week two-hour a week group; however children also received an intervention separately. Thus the individual benefit from attending the group is not clear. The findings showed that the centre based programme and the waiting list groups both reported lower stress at follow up, indicating that the effects of the centre based programme are no improvement on no 'treatment'. The addition of a parent training programme to an adolescent skills programme was the focus of another study (Schultz et al., 2012). The group ran for one hour a session, two sessions a week for 10 weeks. Results from a validated measure suggested that parent stress was significantly reduced with the addition of the parent training group.

The final study, investigating the parent outcomes of general health and stress, compared a parent training group (Parent education and behaviour management: PEBM) to a parent support group (Parent education and counselling: PEC) and to a waiting list control group using a randomised controlled trial (Tonge et al., 2006). Both groups received 10 group sessions of 90 minutes, which alternated with individual sessions as part of the programme. Both PEBM and PEC groups showed improvements on the General Health Questionnaire at follow-up (6 months). Both interventions were significantly better than no intervention however, there was no significant difference between the groups.

Mental Health: Summary

None of these studies reported effect sizes, however, significant reductions on distress were shown following support group interventions. General health also showed significant reductions following training groups and 3 months post support group.

Depression significantly reduced in one study whilst the reduction did not reach significance in another. No other statistically significant changes were reported.

Stress was shown to reduce in six of the studies where it was measured although no change was reported in one study. Following support groups, stress was reduced, but this was not the case after training interventions. There were a number of methodological issues that need to be considered when drawing conclusions based on these results. In both of the randomised controlled trials the individual effect of the group cannot be interpreted as one used 1:1 treatment and the other ran a parallel group for children. The majority of papers providing evidence in this area reported on evaluations of case-series studies where the effects of external factors were not controlled.

Overall there is some evidence to show that mental health can improve for parents, however this is not to a statistically significant finding in all studies. In addition to this, there are methodological limitations which are likely to influence the outcomes of the studies.

What are the outcomes for children with ASD?

Eleven of the studies reported on child outcomes; these investigated behaviour changes including specific behaviours of sleep and social skills and communication changes. One of these used a support group intervention (Stahmer & Gist, 2001), whilst the other 10 reported on parent training (Khosroshahi et al., 2010; McIntyre, 2009; Okuno et al., 2011; Pillay et al., 2011; Reed et al., 2009; Roberts & Pickering, 2010; Roberts et al., 2011; Schultz et al., 2012; Venker et al., 2012; Whittingham et al., 2008). The majority of these studies report behavioural changes, with only three reporting communication outcomes (Roberts et al., 2011; Stahmer & Gist, 2001; Venker et al., 2012)

Behaviour

The effect of a training group on behaviour was reported in eight of the papers (Khosroshahi et al., 2010; McIntyre, 2009; Okuno et al., 2011; Pillay et al., 2011; Reed et al., 2009; Roberts & Pickering, 2010; Roberts et al., 2011; Whittingham et al., 2008). One of the studies investigated the effect of a support group specifically on children's social skills (Schultz et al., 2012).

Behaviour: Support group

Schultz et al., (2012) as described above, investigated the added benefit of a support group to a social skills group. No significant change in social behaviour was found as a result of the treatment.

Behaviour: Parent training

In Iran, the Little Bird programme which runs in a partial group manualised format was investigated in a RCT. There was no difference between groups pre treatment but a significant difference post treatment, indicating that the reduction in stereotyped behaviour was a result of treatment rather than an external event. Okuno et al. (2011) reported on child outcomes in addition to the parent outcomes described above. No significant change following parent training was reported on the Child Behaviour Checklist (CBCL) (Achenbach & Edelbrock, 1983).

In the British study described above (Pillay et al., 2011), behaviour was investigated using the Developmental Behaviour Checklist (Einfeld & Tonge, 1994) a valid parent report measure. There was a significant reduction in challenging behaviour. Both parent-reported child anxiety and self absorption reduced, but not significantly. Roberts and Pickering (2010) investigated the early years parenting programme modified for ASD. Child outcomes were measured using Eyberg Behaviour inventory (Eyberg & Ross, 1978). Following intervention intensity of behaviour scores reduced, this change was not significant and scores were still higher than the clinical cut off for the measure.

In America, McIntyre (2009) delivered the Incredible Years Parent Training (IYPT) programme to pre-school children with a variety of diagnoses; 50% of the sample had a diagnosis of ASD. This RCT added a group treatment consisting of 12, 2.5 hour sessions to usual care and compared it with usual care alone. Analysis revealed that children with ASD displayed more inappropriate behaviours at baseline than other children in the sample, but showed the same level of inappropriate behaviours post intervention (effect size 0.37). These data were coded by observers rather than being rated by parents. Another RCT (previously described) found no significant differences in behaviour in either

the home-based, centre-based or control groups (Roberts et al., 2011). A third RCT evaluating the effect of parent training in addition to interventions for adolescents on behaviour also found no significant difference (Schultz et al., 2012).

A fourth RCT compared the efficacy of the Stepping Stones Triple P nine week programme for parents of a child with ASD (Whittingham et al., 2008). This intervention was in partial group format with extra planned individual sessions added, to allow parents to achieve mastery in the training. Training was in addition to treatment as usual and was compared to a waiting list control group. The valid Eyberg Behaviour Inventory was used to investigate effects on behaviour for the 59 participating families. MANOVA showed that challenging behaviour in the intervention group significantly reduced in intensity (effect size 0.26). One third of the treatment group also experienced a reliable and clinically meaningful change.

Sleep management was investigated in one American study (described above) (Reed et al., 2009). Significant improvements were found in sleep habits and time taken to fall asleep following training. Waking at night was not affected by the intervention. As a secondary investigation, general behaviour was measured; significant improvements were reported by parents in hyperactivity, self-stimulatory behaviour and sleep disturbance. Although there was a significant behavioural change, parents only 'improved' in 4 of the 22 areas advised in the training. Despite the authors connecting improved sleep to better parent reported behaviour, it may be that a parent factor would explain the perceived change in behaviours.

Behaviour: Summary

Overall, these results highlight inconsistency in the effect that parent groups have on child behavioural outcomes. The majority of case series analyses show a reduction in problem behaviour although this is frequently not a significant change. The RCTs also showed a reduction in the problem behaviours being reported by parents, with two studies reporting small- medium effect sizes. Studies of parent intervention for children's sleep difficulties have also shown that problem behaviours can be significantly reduced following a group. Conclusions should be cautious due to the many methodological limitations in these studies including the RCTs as in two of these studies it was not possible to draw conclusions about the unique benefit of the group. Two RCTs investigated the individual effect of groups; these results suggest that meaningful and significant behaviour change is possible.

Communication: Support group

The only study to investigate the effect of a parent support group on communication comes from America (Stahmer & Gist, 2001). This paper reported on the addition of a parent support group to pivotal response training (PRT), a programme designed to improve language and other characteristics of ASD (Koegel, O'Dell, & Koegel, 1987). Eleven parents participated in the support group 1 hour a week for 12 weeks in addition to the 12 week PRT programme. This case-control study compared PRT to PRT plus parent support to a control group. Only parents who met the criteria for mastery of PRT were analysed; children of these parents produced more words. The production of words was taken to mean that the children communicated more often; however it was not clear that the words were directed at people and used to communicate more meaningfully.

All but one of the parents in the support group condition achieved ‘mastery’, the addition of the support group improved mastery of the techniques therefore children of these parents produced more words.

Communication: Parent training

Communication was measured using the Vineland Adaptive Behaviour (Sparrow, Balla, & Cicchetti, 2005) scale in the RCT by Roberts et al. (2011), The centre-based programme was significantly better at improving communication than the home-based treatment however there was a significant improvement in all groups. Again the limitation of this study is the unique effect of the support group cannot be assessed as it was delivered in parallel to a programme for the children not used in the other treatment groups.

Another RCT investigated whether parents of children with ASD can learn to implement verbal responsiveness to facilitate language development (Venker et al., 2012). A treatment group was compared to a delayed treatment group for 14 parents. The treatment package consisted of five parent education sessions lasting 2 hours as well as two 45 minute individual coaching sessions and 14 small group sessions with the child. Analysis of pre-post measures showed significant increase in non verbal communication in the treatment condition, increase in prompted communication and spontaneous communication acts were also found although these were not significant.

Communication: Summary

These three studies all have major methodological difficulties when drawing conclusions about the effect of parent groups on communication. Two of the studies were

run in partial group format; it is therefore not clear whether the effects they are measuring are due to the group part of the package or the other delivery methods. Conclusions should therefore, not be drawn about the effects of parent training. The other study only analysed data for parents who achieved a high level of competence in the model; at this point in the analysis data were collapsed so the child outcomes reported were not attributable to the support group condition.

What are the effects on parenting?

Nine of the studies reported parenting outcomes; these investigated perceptions of parenting, ability and parent child interactions. Four of the studies reported on the effects of a support group (Bitsika & Sharpley, 1999, 2000; Farmer & Reupert, 2013; Stahmer & Gist, 2001) whilst the other five reported on parent training groups (McIntyre, 2009; Pillay et al., 2011; Schultz et al., 2012; Wang, 2008; Whittingham et al., 2008). The majority of these studies report on perceptions of parenting with one reporting on ability (Stahmer & Gist, 2001) and two on parent child outcomes (McIntyre, 2009; Wang, 2008)

Perception of parenting: Support group

All of the studies which report on perception of parenting have been described previously. One study found that parent self-concept increased over time through delivery of the support group and self-efficacy increased and then decreased as the group progressed (Bitsika & Sharpley, 1999); the same authors also found that confidence of parents varied between sessions (Bitsika & Sharpley, 2000). The final study found that confidence increased as a result of the group (Farmer & Reupert, 2013).

Perception of parenting: Parent training

Increased confidence and awareness were also found following participation in a training package (Pillay et al., 2011). Schultz et al. (2012) using case control methodology found that parents reported significantly less “parenting incompetence” with the inclusion of a parent training group. Whilst a significant change with small effect size in overactivity (0.22) and verbosity (0.25) and increase in satisfaction of being a parent (0.21) were reported in the RCT (Whittingham et al., 2008)

Ability: Support group

Parenting technique was improved with the addition of a parent support group in the Pivotal Response Training (PRT) package. The support group was significantly better than PRT alone in use of PRT techniques (Stahmer & Gist, 2001).

Parent-child interactions: Parent training

Observations of parents following IYPT showed a significant reduction in inappropriate negative behaviours. In addition to this more praise was noticed although this did not achieve a level needed for significance (McIntyre, 2009). An RCT investigated the effect of a training programme on parent interactive skills with their child (Wang, 2008). The treatment group package consisted of 16 hours of group training as well as 4 home visits. Findings included significant increase in maternal responsiveness (effect size 0.91) to the child in the treatment group and a change in free play activities chosen by the parents, with less reliance on physical activities. These results were found through repeated analysis of the same measure.

The effects on parenting: Summary

Parents tended to report a variety of improvements in their perception of parenting as a result of attending groups. The majority of these studies were case series analysis which did not control for a stable baseline in their designs, so conclusions cannot be made as the effects of confounding variables were not controlled for. Better methodology was utilised by the case control study and the RCT, however treatment fidelity was not reported.

Only one study reported on improved parenting technique following the group intervention and two studies on parent-child interactions. Although the research suggests that parent groups can be effective in improving parenting technique and parent child interactions this conclusion is based on a limited number of papers reporting these outcomes. In addition, there are methodological limitations in all the studies reported which need to be kept in mind when evaluating findings.

DISCUSSION

The aim was to systematically review the available literature and present a synthesis of the research exploring the effects of groups for parents of children with ASD on a range of outcome variables, including: parent, child and parent-child interaction outcomes. The results show that both parent support group and parent training groups can have an effect on all three outcomes.

The types of parenting group varied; only two studies evaluated the same package (IYPT) and these measured different outcomes. Therefore, it is difficult to assess any the unique programme influences the outcomes. It would seem that support groups can increase knowledge about ASD and improve mental health. The factors were targeted by these groups through the use of parent information, therapy and support. It is less clear whether the effect of training groups are beneficial for parents.

The effect of interventions for children was less clear; there appeared to be a trend in the reduction of behavioural difficulties following the groups. Frequently however, this did not reach statistical significance. Moreover, as the majority of the studies did not control for confounding variables, any changes found may not have been due to the interventions. Parenting effects have not been widely investigated in the literature; the majority of studies report that parents' perception of their parenting can be changed through support groups.

The large variety in reported outcomes and measures used to investigate outcome created a difficulty for this review. A further difficulty was in assessing the intervention groups as they used different programmes which varied in duration and outcome measures. This makes it difficult to synthesise the studies by similar programmes or specific

outcomes. Synthesising the effects of delivery methods (i.e. didactic teaching, videos or modelling) has not been possible as a result of few papers detailing these.

There is a further difficulty in generalising the results due to the idiosyncratic samples used in the studies. Studies were included from around the world where referral criteria to services and cultural understanding of ASD is different from in the UK. Further differences include the varying ages, age ranges and diagnoses in the papers making the characteristics of the sample in each study uniquely different. Therefore this review leaves many questions unanswered that may be of interest to researchers, clinicians and service developers. It is hoped that this review has highlighted some of the strengths and limitations in this field which can be addressed by future research.

Quality of evidence

A feature of this review is the limits of the evidence it presents. There were seven RCTs included and one case controlled study. Although these methodologies improved on the limitations of case series and case studies, they frequently did not investigate the unique contribution of the parent group. It is therefore important to be cautious in considering the findings reported in these papers. Limitations should be kept in mind when reading the conclusions of each outcome area.

Many of the studies utilised parent report to assess the outcomes of a group. There was no rationale presented for why these measures should be used and bias was not controlled for in any of the papers. Use of independent observations strengthened the design (e.g. Reed et al., 2009). A good description of a randomisation procedure was provided by Roberts et al. (2011) this reduced the bias in the methodology and strengthened the likelihood of finding significance. Unfortunately, this study, like the

majority of the RCTs included 1:1 intervention with the group. The lack of good quality papers measuring the unique effect of a parent group does not allow for conclusions to be confidently reported.

Clinical Implications

This review suggests that parenting groups can have an effect on many areas of family life. Mental health was shown to improve for parents; participation in a group may therefore improve the wellbeing of parents who have a child with ASD. The experience of parenting can also improve for parents as they can feel more in control. As parents of children with ASD frequently report more stress, support groups in particular could be utilised to reduce this stress and create a more pleasant parenting experience. This would have implications for parents' ability to deliver interventions for the child with ASD, in addition to how they are able to manage family life.

Behaviours of the child with ASD were also influenced by a group. As groups are a cost effective way to deliver an intervention, service developers should be aware of the potential positive outcomes for both parents and children. As parental stress is linked to child behaviour this would be another way of enhancing family life.

Families of children with ASD may benefit from parents attending a group; however, it has not been possible to assess which aspects of the groups were important for parents. Factors such as having the opportunity to meet other parents and talk about their families were not measured in these papers. It may be important to investigate what parents want in order to best meet their needs in a group intervention.

Future research

There are many potential areas for future research, some of which will be presented here. These weaknesses are highlighted in table 5. Future research should attempt to remove these methodological limitations in order to increase confidence in the results. A randomised controlled trial would be the strongest methodological design.

Further studies are needed to evaluate the effectiveness of parenting groups in comparison to control groups or other interventions. The unique effect of a group in addition to other treatments should be addressed. This can then inform packages of care where groups are included as to the added benefit of the group. Adherence to treatment for both the delivery of the treatment and the attendance rates should be considered. Measures used should not rely solely on parent report as this may lead to bias since parents' perceptions are likely to have been effected by the group. Power analyses should be conducted in order to reduce the chances of a difference not being reported as significant due to sample size. In addition, analysis should take participants lost to drop out into account and report whether changes are clinically relevant.

Due to methodological limitations in all of the currently published studies further research could add validity to the conclusions in this review. These might be from groups delivered as part of clinical services such as cohort and case control studies or from research trials.

Limitations of the review

Publication bias is a limiting factor of this review; the studies included were the result of a literature search of peer review journals. Peer review publications were included as it was thought that these would produce the papers with the strongest methodologies. The file drawer problem (Rosenthal, 1979) is likely to be a difficulty in this review as papers with null findings are less likely to be published than papers with statistically significant results. Although some of the papers reported findings that were not significant, further caution should still be used in drawing conclusions from the review.

By following the inclusion and exclusion criteria and a quality assessment framework, researcher bias has been reduced, however this may still factor in the interpretation of the results. Another limitation is that keywords were used to search for articles; as a result studies may have been missed if the particular keywords chosen had not been used by the authors. Chances of this were reduced by using the papers found to generate additional keywords.

Conclusions

A limited amount of research was available to explore the areas of interest, in addition to this there were many methodological biases in the research. With these in mind the research suggests that parenting groups have an effect on reducing parental mental health factors and increasing parent understanding of ASD. It is less easy to interpret the effect that the parent groups have on children with ASD as the findings vary, but it appears that behaviour and communication may be positively effected as a result. Despite the limited evidence, all of the papers suggest that perception of parenting, ability of parents and parent child interactions can be positively influenced by participation in a group. This

review has demonstrated methodological limitations in the papers reviewed. Further research is needed to strengthen the conclusions and develop this evidence base.

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

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ABSTRACT

Background:

Increased parental stress has been reported by parents of children with Autism Spectrum Disorder (ASD). Parents are also concerned about the impact of ASD on a sibling. Investigation into effects on siblings has been contradictory with both positive and negative outcomes being reported. No qualitative studies to date have investigated the combined experiences of a parent and a sibling, with a child with ASD in the family.

Method:

Interpretative Phenomenological Analysis was used to investigate the experiences of parents and siblings in 6 families.

Analysis:

Four super-ordinate themes emerged from the analysis. 'Life revolving around ASD' 'What's ASD – what's not?' 'ASD changing family roles' and 'Equality'. These were either unique to sibling or parent, or shared experience.

Conclusion:

The findings from the present study again show the difficulties of living in a family with a child with ASD. The results can be utilised by professionals working with these children and their families to highlight potentially different experiences and assumptions held by family members.

Keywords:

Autism Spectrum Disorder, parents, siblings, family, experiences

INTRODUCTION

Autism spectrum disorder (ASD) is characterised by a different way of understanding the world, including difficulties in communication, social interaction, imagination and often repetitive or unusual behaviours (American Psychiatric Association, 2000). A child with ASD can have an impact on all members of the family unit as the family may have to adapt their lives as they attempt to understand and accommodate the needs of the child. Although there is research about how to support a child with ASD in the family home (for a review of the literature see Howlin, Magiati, & Charman, 2009), little is known about the experiences and understanding the other family members have of living with a child on the autism spectrum.

Currently, ASD includes diagnoses of Autism, high functioning autism, Asperger's syndrome and pervasive developmental disorder not otherwise specified (PDD-NOS). DSM-V has now categorised these diagnoses into one Autism Spectrum Disorder (American Psychiatric Association et al., 2013).. ASD is diagnosed in about one in a hundred individuals; there are 133,500 children (aged under 18) with a diagnosis of ASD living in the UK (National Autistic Society, 2011). The difficulties associated with ASD impact on everyday activities and daily life. Research has shown that when a family experiences stressors or strains they are balanced throughout the family system. The effect these stressors have is mediated through the meaning that the family members place on what is happening to them (Patterson, 1988). As different members of families have different stories about their experiences it is necessary to understand the 'impact' of ASD on all the family members and the interactions between them so that effective services can be offered which support the family (Meadan, Stoner, & Angell, 2010).

There are three streams of evidence which allow for investigation into the effect that a child with ASD has on family life; they utilise quantitative and qualitative methodologies. The first stream presents research into the effect on parents; the second stream explores the effects on siblings, whilst the final stream describes the research on combined experiences of parent and sibling.

Effects on parents

The majority of research, investigating the experience of living with a child with ASD has focused on the parental experience. Research indicates that parents of children with ASD experience elevated levels of stress compared to all other parents. (Estes et al., 2009; Montes & Halterman, 2007; Rao & Beidel, 2009). Lecavalier, Leone, & Wiltz, (2006) report increased stress when there are more behaviour problems as reported by parents and teachers. Less parental stress is reported when there are more positive parental experiences with the child with ASD (Kayfitz, Gragg, & Orr, 2010).

Gray (1997) found that parents saw their families as more 'normal' when they experienced emotional intimacy, and 'not normal' when they experienced conflict and rejection in interactions with immediate family members. Routines and restrictions to social activities led to conflict between family members. Differences between parents have been reported with fathers perceiving family life as more 'normal' (Gray, 1997) and mothers expressing more stress (Brobst, Clopton, & Hendrick, 2008).

The interaction between parents' stress has also been investigated; Kayfitz et al., (2010) found as fathers reported more positive experiences, mothers stress reduced. In contrast, Hastings et al. (2005) concluded that fathers experience more stress as the mother

experiences more depression. This suggests that other family members influence individual experiences and perspectives.

Qualitative methodologies have shown that parents report difficulties including; problems with the child's language, play, relating to other people, stresses, strains and restrictions placed on themselves and other family members. They also express a broad range of concerns about the impact on themselves and their families (Cassidy, McConkey, Truesdale-Kennedy, & Slevin 2008). Five further themes emerged from Meirsschaut, Roeyers, and Warreyn's (2010) study, including: 'affecting our whole life', 'lack of understanding outside of the family', 'lack of access to services', 'learning to cope', and 'concerns and questions'.

Appraisals of the perceived effect of the child with ASD on the family have been expressed as both positive and negative by parents (Bayat, 2007; Myers, Mackintosh, & Goin-Kochel, 2009). Myers et al. (2009) asked parents to write a response to an online question "how has your child with autism spectrum affected your life and your family's life?". Negative subthemes included; sibling neglect, financial strain, the child with ASD being the centre of family life which changes everything, and strained relationships with extended family. Positive themes included adjustment and support from the family, and positive impact on the sibling (e.g., more sensitive, compassionate, humble and tolerant) (Myers et al., 2009). The positive aspects of raising a child with ASD were reported to outweigh the negatives when investigating the resilience of parents (Bayat, 2007). Important positive factors included becoming advocates for the child and feelings of pride and honour in having a child with a disability.

Mothers have expressed concerns about the influence of the child with ASD on their sibling, such as jealousy and resentment because more time is spent with the child

with ASD. In addition they expressed fear and sadness for the sibling (Hutton & Caron, 2005). Mothers are also conscious of differences in their parenting of their two children and expressed guilt over not being able to 'do enough' for their typically developing child (Meirsschaut et al., 2010).

Effects on the Sibling

Sibling relationships are important for children with ASD as siblings are a source of social contact and play (El-Ghoroury & Romanczyk, 1999). Yet, in contrast, it may be difficult for typically developing siblings to form relationships with a brother or sister with ASD (Beyer, 2009).

The quantitative results using parent report are contradictory with some studies concluding that there is no greater risk of negative outcomes or maladjustment for the sibling (Benson & Karlof, 2008; Hastings, 2006; Tomeny, Barry, & Bader, 2012), while others report negative outcomes such as fewer pro-social behaviours (Hastings, 2003).

Quantitative investigations using sibling report also produce inconsistent results. Some studies reported that siblings were well adjusted and had low levels of loneliness (Kaminsky & Dewey, 2002) and, in some cases, more positive self-concept (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Verte, Roeyers, & Buysse, 2003). In contrast, others conclude that siblings have peer and behavioural problems (Bågenholm & Gillberg, 1991; Kaminsky & Dewey, 2002; Verte et al., 2003), higher levels of depression (Gold, 1993) and are 'disturbed' by their siblings (Rivers & Stoneman, 2003). There are a number of differences in methodology, sampling and measures that are likely to have influenced these outcomes.

A comparison of the siblings' self-perception and the perception of their parent has been investigated in one study (Macks & Reeve, 2006). This quantitative study demonstrated that siblings rated themselves as having a better self-concept than their peers without ASD in the family, whereas their parents rated their emotional adjustment more negatively. Orsmond and Seltzer (2007) commented that having a child in the family with ASD impacts on the relationship between the parent and the other siblings.

Qualitative methodology has rarely been utilised to assess siblings' perceptions of their brother or sister with ASD. Petalas et al. (2009) used Interpretative Phenomenological Analysis to investigate the experience of eight siblings (aged 9-12) and reported positive themes; these included having fun and feeling proud of their siblings' achievements (Petalas et al., 2009). In contrast, a study using content analysis revealed negative accounts related to the children with ASD displaying aggressive behaviour and the embarrassment caused by such behaviour (Mascha & Boucher, 2006), and some siblings have expressed feelings of loneliness (Benderix & Sivberg 2007). Siblings have also expressed that they feel their parent has a preference for the child with ASD (McHale, Sloan, & Simeonsson, 1986).

Most recently, the impact and experience of siblings of a child with ASD was explored using grounded theory. Both positive and negative experiences were reported: high levels of empathy and patience as well as contrasting feelings of being unsafe and anxiety over aggressive behaviour (Angell, Meadan, & Stoner, 2012).

Parent-sibling combined experience

There are fewer investigations into the combined experiences of parents and siblings and, to date, no studies have used qualitative methodologies to investigate this.

Quintero and McIntyre (2010) concluded that maternal stress was more likely to be due to the presence of a child with ASD rather than due to the sibling. Rao and Beidel (2009) also reported that behaviour problems of the child with ASD directly related to parental stress; however there was no difference in siblings' self-concept scores in comparison to their peers.

Overall, the majority of studies examining the potential effects of children with ASD report on, separately, either the parents' or siblings' perspectives. Many of the studies have called for research to include other family members (Angell et al., 2012; Bayat, 2007; Macks & Reeve, 2006). Most of the emphasis has been placed on emotional regulation and impact on individuals, with little research focusing on relationships within the family, family roles and shared understanding. There has been little investigation into the shared experience of two members of the same family. Through giving a voice to the parents and siblings in the family and exploring their points of view, different and shared experiences of two family members can be understood. The current study begins to address a gap in this field by investigating, using qualitative methods, the experience of living in a family where there is a child with ASD, but from the perspective of both parents and siblings.

METHOD

Methodological Approach

The experiences and understanding of parents and siblings of children with ASD will be explored using Interpretative Phenomenological Analysis (IPA). IPA is used to make sense of how people experience and understand their world (Smith, 2007), where the participant is the expert in their experience (Petalas et al., 2009). Experiences and meaning are captured through conversation, and through detailed examination of the accounts of individuals themes emerge; these themes are analysed for shared experience and variation (Smith, Flowers, & Larkin, 2009). The aim of the researcher is to interpret the social and psychological phenomenon without drawing conclusions based on assumptions or previous theories (Smith et al., 2009). Instead, the researcher engages in a 'double hermeneutic' where interpretations are created through their own interpretative and conceptual position (Smith, 2007). The use of a reflexive diary is encouraged to enable the researcher to reflect on their own experiences, values and interests in order to ensure the accessibility and clarity of IPA (Brocki & Wearden, 2006). A reflexive diary (Appendix C) was kept throughout the research and was utilised during the analytic process.

This study uses IPA to communicate the experiences of a sibling and a parent in the family of a child with ASD. Shared experiences and variations are used to describe siblings' perceptions and parental experiences separately, in addition to dyadic experiences of two individuals within the same family.

For IPA, sample sizes are usually small (6-8 participants), but homogeneous so that the research question is meaningful (Smith et al., 2009). This allows for in-depth examination of participants' accounts of their experience (Brocki & Wearden, 2006). As a

result of needing a homogeneous sample the inclusion and exclusion criteria were necessarily specific (see table 6 & 7).

Table 6. Inclusion Criteria

Inclusion Criteria	
Parent	<ul style="list-style-type: none"> • Must live in the family home with the child with ASD and the participating sibling and have parental responsibility for the children. • No restriction on age or gender of the participating parent. • Must be at least two adults within the family home. • Must be able to communicate in English. • Must be able to provide informed consent.
Sibling	<ul style="list-style-type: none"> • Must live in the family home with a sibling with ASD and the participating parent. • Must not have a diagnosis of any mental health disorder • No restriction on gender. • Sibling between the ages of 11 and 16 years old • The participating sibling can be older or younger than the child with a diagnosis ASD. • Must be able to communicate in English. • Must be able to provide informed assent.
Family	<ul style="list-style-type: none"> • The family must include a child with ASD without significant learning difficulty living within the family home. The presence of a learning difficulty (requiring attendance at a special school) is likely to mean the child requires additional support and the experience of family members would not, therefore, be the result of ASD alone. Children attending a mainstream school will be assumed to have no significant learning difficulty. • The child with ASD must not have a diagnosis of psychosis or be under investigation for psychotic symptoms. Due to the high prevalence of comorbid conditions in children with ASD, children with other comorbid diagnoses will be included. • The child with ASD should be no older than 16. It is likely that a child over the age of 16 would be given more responsibility and therefore would not be at the same developmental level as the participating sibling. • There should be no more than three children (including the child with ASD) living in the family home. • There can only be one child with a diagnosis of ASD in the family. • Diagnosis of ASD made by a health professional less than two years prior to inclusion in the research.

Table 7. Exclusion Criteria

Exclusion Criteria	
Parent	<ul style="list-style-type: none"> • Parents who do not live in the family home or do not have parental responsibility will be excluded. • Parents who are unable to communicate in English will not be able to take part in the interviews. • If a parent, in the judgement of the recruiting clinician, is assessed as being unable to make informed consent they will not take part in the study. • Single parents will not be invited to participate. • If the clinician deems, during clinical interview, that a parent has a current mental health difficulty that is likely to be affecting family life then they will be excluded from the study. However, if parents express depression or stress that is related to the pressures of family life then they will not be excluded.
Sibling	<ul style="list-style-type: none"> • Siblings over 16 years old or under 11 will not be included. • More than five years older or younger than the child with a diagnosis of ASD. • Siblings who have not grown up in the family home will not be included. • Siblings who have a mental health diagnosis will be excluded • Siblings who are not able to communicate in English will not take part. • Siblings who are unable to demonstrate to the researcher that they understand the research and can consent to take part will not be included.
Family	<ul style="list-style-type: none"> • If the child with a diagnosis of ASD is younger than 8 or older than 16 they will not be included. • Families with more than two siblings to the child with ASD will be excluded as the impact is likely to be diffused between the siblings. • Families will be excluded where the diagnosis of ASD is not formal i.e. has not been made by a health professional. • If the child with ASD lives outside the family home the family cannot take part. • Families not known to clinicians working with children will not be included. • A family will be excluded if the diagnosis of ASD was made more than two years before inclusion.

Context

Qualitative data were collected through recruitment by a social enterprise specialising in ASD assessment. This third sector supplier to the NHS provides services to a county in the Midlands and accepts referrals only from General Practitioners or Child and Adolescent Mental Health Services. It was selected as a point of recruitment because it offers a specific service for ASD and has been offering diagnostic services for the past two years, positioning it as a service likely to be knowledgeable of families meeting inclusion for the study.

Data Collection

Ethical approval was obtained through the NHS research ethics committee (Appendix D), and the ethics team responsible for research governance in the social enterprise (Appendix E). Participants were sampled purposefully in order to meet the strict criteria necessary for the study. Families were identified by clinicians who knew the family or identified them through their database of children with a formal diagnosis of ASD. Clinicians within the service approached the families and consent was given for their details to be passed onto the lead researcher, where appropriate. Information about the study was provided through information sheets for parents and siblings (Appendix F & G), given to the families by the recruiting clinician with written consent obtained from the parents (and assent from the siblings) involved in the research (Appendix H & I).

The researcher conducted individual interviews, separately for parents and siblings. Each interview lasted for an average of one hour (range 35-79 minutes). All interviews took place in the family home. Each interview was recorded and transcribed verbatim. For presentation of the findings, sibling interviews are indicated in italics and parent interviews

in ordinary text. To keep the identities of the participants confidential, and to meet the requirements of the study's ethical approval, all names have been changed.

Materials

An in depth semi-structured interview is a flexible approach where the researcher can pose questions based on the interview. It is the preferred format for interview as it enables rapport to be built with the participants; this happens as participants are seen as experts and are given the opportunity to tell their story in the way they would like. Questions are used as prompts to elicit improved understanding rather than for seeking a specific answer.

The semi-structured interviews for siblings and parents (Appendix J & K) were developed through discussion with the research team and in liaison with a family of a child with ASD known to the researcher. The interview schedule involved a warm up activity of drawing a picture of the important people in the family (i.e., 'could you tell me who is in your family?'); this was included to put the participant at ease and to help create conversations about the family, as advised by Smith et al. (2009). Topics of conversation then covered four areas: life in the family, experiences of parenting or having a sibling with ASD, the meaning of having ASD in the family, and advice to other parents. Families chose which order participants were interviewed in. All but one parent went first. Although the researcher attempted to reduce any bias caused by order of interviews, there is a possibility that this influenced the conversation because it set the context around family life.

Ethical Considerations

Participants gave informed consent before interviews commenced. The purpose of the interview was communicated via the information sheets and participants were told that excerpts from the interview would be quoted in the final report. They were aware that the data would be anonymised during transcription, therefore only the researcher would see the data in an unedited form. Participants were informed that the conversations could be reported: as themes or as quotes. They were informed that there was a possibility that the other participating family member would be able to identify them from their combined comments. As a safeguard, following the interview participants were given the opportunity to highlight any parts of the conversation that they did not want to be used. Participants were happy for all aspects of their interviews to be used in quotes.

As this study is investigating the experience of living in a family with a child with ASD, participants frequently expressed opinions about non-participating family members (e.g., child with ASD, other parent or wider family). Due to the small sample size and differing demographics of the families (i.e., one girl with ASD, one Dad), non-participating family members may also be able to identify comments that relate to them. To maintain anonymity, and in accordance with the recommendations of the ethical committee, following the format of previous dyadic IPA publications (Larkin, Clifton, & de Visser, 2009), detailed descriptions of the families will not be used in this report. As a further safeguard, when quotations are presented, care will be taken to maintain anonymity by removing some names and changing genders.

Participants

Participants were 6 families known to the service who had a child with a formal diagnosis of ASD; sibling participants were aware of the diagnosis. Two children with ASD were receiving individual intervention at the time of the recruitment. Genders and ages of family members are shown in table 8.

Table 8. Descriptions of Family Members

	Gender	Age range (years)	Other information
Participating parent	1 father, 5 mothers	35-58	
Participating sibling	4 brothers, 2 sisters	11-15	1 dyslexia, 1 dyspraxia
Non-participating parent	5 fathers, 1 mother	37-60	
Child with ASD	5 males, 1 female	9-14	3 Asperger's, 3 ASD Diagnosed between 5 and 24 months
Non-participating siblings	1 male	7	Only one family had 3 children

For the participating siblings, four were older brothers (i.e., older than the identified child with ASD), one was an older sister, and one was a younger sister. All participating families had two working parents (mothers worked part time and fathers full time) living in the family home. All of the children with ASD were in mainstream educational settings. Parents and siblings did not report any current mental health diagnoses.

Data Analysis

The anonymised transcripts were analysed systematically using IPA. This iterative and inductive cycle (Smith, 2007) follows a process of six non linear stages. Figure 2

shows the stages described follow the process set out in Smith et al. (2009) (Appendices L, M & N show this process).

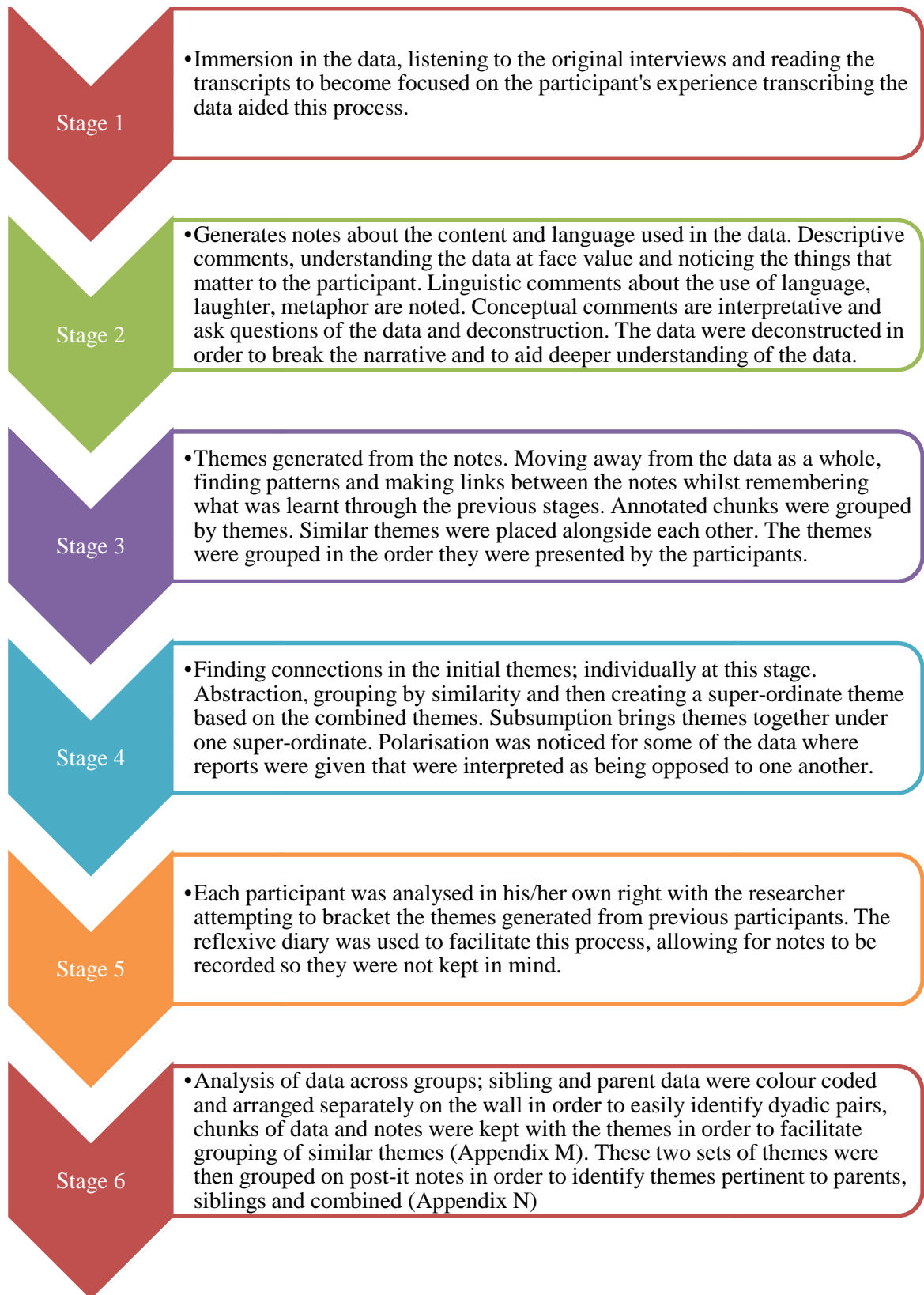


Figure 2. Process diagram of IPA analysis.

Throughout the process, support was received from academic and clinical supervisors and through peer discussion with other trainees familiar with IPA methodology in order to maintain credibility and reflexivity.

The nature of IPA allows for personal reflection from the researcher as a function of the interpretative process of the analysis (author's reflexive statement is presented in figure 3). Rather than this being seen as a bias, it is thought of as inevitable in the process of making sense of other people's experiences (Smith et al., 2009).

Reflexive statement

I became interested in the experiences of living with a child with ASD as a result of my clinical experience, which has allowed me to provide support to families. I also know siblings of children with ASD personally. Knowing that there was little literature about their experience and even less literature about shared experiences I was keen to facilitate their stories and give a voice to those often unheard behind the diagnosis of a child with ASD. I am interested in how families possibly make sense of their experience. I am the third child of four and the only female sibling, there is a large age gap between myself and my older siblings and I grew up hearing stories about myself that I did not remember or understand. Since becoming a mother, I have noticed my perceptions about parenting change. My experiences are likely to have influenced the research in conscious and subconscious ways; both during the interviews and throughout the analysis. I thought it was important throughout the research to use a reflexive diary and supervision to try to balance my interpretations.

Figure 3. Author's reflexive statement

ANALYSIS

Four major themes emerged from the analysis: across these, 12 subthemes emerged (see table 9). Themes were chosen for their prevalence and their perceived importance to the participants. There were similarities and differences in the themes generated by the analysis; as a result, these themes are representative of the majority.

The experiences shared during the interviews were complex and variable; as a result it is likely that the themes will overlap despite their presentation as separate entities.

Table 9. Super-ordinate and Sub-ordinate Themes

Super-ordinate	Sub-ordinate
1. Life revolving around ASD	
Combined	Constant-ness Walking on thin ice Restrictions
Parent	Finding a balance
2. What's ASD - what's not?	
Sibling	Comparison to normal
Parent	What's normal?
Combined	Understanding
3. ASD changing family roles	
Sibling	Loss of relationship
Parent	Cycle of reactions
Combined	Protecting each other
4. Equality	
Sibling	How I understand inequality
Parent	ASD as an explanation

Theme 1: Life revolving around ASD

The theme 'Life revolving around ASD' explores how family life is affected by having a child with ASD. The day to day 'constant-ness' and variable nature of ASD meant that parents and siblings find it difficult to predict what will happen and how they felt unable to get a break from ASD. Parents and siblings also described 'walking on thin ice' where they are conscious about the effect of their own behaviour and are fearful of the consequential reactions of the child with ASD. 'Restrictions' were seen to be placed on family life by the child with ASD and the family's desire to minimise distress and unwanted behaviours. Parents expressed a struggle with 'finding a balance' between their ideas about parenting with adjustments they feel are needed to parent a child with ASD.

Life Revolving Around ASD: Constant-ness [combined]

This sub-ordinate theme describes the need for parents to be constantly thinking about ASD and the isolation that comes from other people not understanding the day to day effects. Parents and siblings described the child with ASD as being unpredictable in their responses to people and the need to be flexible in order to manage these changes. The experience of 'constant-ness' frequently involved preparing the child for things they have to do and parents' experience of it becoming a natural process.

Parents frequently described changes in the behaviour of their child. Liz described these changes and how the constant-ness of ASD led to all aspects of her life revolving around it:

P: Hard 'cause I've had to drop my hours at work, erm which caused a lot of trouble at work which ended up me moving to another ward for a while, 'cause I work at the hospital, which was a lot of stress. I was off for three months last year

because of the stress which was just awful cause [child with ASD] was in a really bad place where he wasn't eating, sleeping, aggressive at the time. I think I even called the police at one point cause he came at me and [sibling] with a stick and I just didn't know what to do. He still can be a little bit aggressive. We just found, well, we out I'm pregnant 12 weeks, when I was about 8 weeks pregnant he attacked me at the school and it took 2 male teachers to get him off me, so he still has it nowhere near as bad as it was last year, he's a lot better but yeah tough times

As Liz reflects on the changes in behaviour she is reminded about the difficult times that have been faced. She expresses a sense of relief that things are not as bad and that she has less worry, but this seems to be contrasted with remembering how things were and a concern that things could be worse again. Liz notices a change over time that is shared with other parents.

Siblings also notice that behaviours change; however, they do not share a sense of optimism that things are improving. They make attempts to justify not noticing the change, perhaps feeling as though their parents' perception is more important than their own;

S: Mum and dad keep saying Tom's getting better but I'm not sure I can't notice it much, I guess it's a bit like growing you don't notice it as much but it happens. Or like watching 10 past go to 20 past on the clock, unless it's a digital clock in which case

There were also a number of changes that families were managing on a daily basis. Inconsistencies in the behaviour of the children with ASD were frequent within parents' narratives; these posed difficulties for managing them from a parenting point of view.

Parents felt that they needed to manage or control the behaviour of the child in order to keep the peace within the family. This task posed difficulties as what would work one day would not work the next. Parents appeared to spend a lot of time guessing how to parent and adapting their methods after reflecting on their relative success or failure; they seemed motivated by a need to maintain calmness. Again, parents expressed a hope that they were learning the 'best' way to deal with ASD.

P: We're managing it better than we used to (laughs)

I: In what way?

P: Just strategies really we just tend to leave him where before we'd say come on calm down, and not on at him but you'd keep going. But now we say right you know what to do go to your room or we just totally ignore it. Which most of the time does work but not always, the door incident, but yeah. But [sibling] does go through it a bit as well

I: How did you find out what works and what doesn't work?

P: Just by trial and error really, just try different things

In this excerpt the parent is describing how they have modified their parenting in order to minimise the behavioural impact of the child with ASD. Parents were not always successful in managing ASD the way they wanted to. There were times when stresses from outside the home affected their ability to maintain balance. Parents seemed to be judging themselves for not managing better, continuing to think about things after the event in order to learn from them. Edith described how the whole family is affected when stress gets in the way of feeling in control, and how the stress is also dependent on the child with ASD behaving appropriately:

P: We might not like each other all the time, erm, I think as parents it depends what's going on at work and it depends largely on how [child with ASD]'s getting on at school as to how stressed us parents are I have to say. Erm

I: How does that stress knock on then?

P: Well I think it reduces your tolerance levels doesn't it? Makes you less patience, less patient. And whilst we know probably what we should be doing, when we're feeling stressed, we don't. We deal with it and we react, we overreact and we react incredibly and then afterwards when you do a post-mortem like me and my husband do at the end of every day, it was "that hasn't gone very well has it." When I did that I shouldn't have done that should I? Because that then made him do this erm, and as, as, Mum and Dad we watch each other do the wrong thing sometimes

Edith appears to be criticising herself for creating distress in her children. It appears that it is important for her to be able to manage her emotions at all times and contain her own stress when dealing with her children; when she is unable to do this then there is a consequence from ASD for which she feels responsible. Parents seemed to place minimising the distress of ASD at the centre of their thinking. This takes preparation, thought and flexibility in the way that things are approached in order to communicate effectively with the child. This parent spoke about always being one step ahead:

I: Is that about being flexible do you think?

P: Yeah, absolutely. Yeah, you have to be flexible with a capital F.

I: (laughter) It sounds like erm,

P: We haven't got it sorted trust me.

I: I was gonna say it sounds like it takes a lot from you to try and think about how

to go about doing things.

P: I'm constantly on the next bit because when I said to [Dad] about going up to College and he said "Ah well he doesn't even leave until next year" and I say "I know" but I says "we need, we need to get our head round it so we can talk to Alistair about it and so he can get his round it"

Parents felt that during a break they could not rest due to thinking about the things they needed to do or things that had happened. Sheila described the constant-ness as quite isolating and as a result she struggled to communicate the effects of it. She felt that other people could not understand:

I: How much do you think I've got an understanding of what it's like?

P: Erm, I'm afraid to say that unless you have a personal member of your family with Autism or Asperger's, I'm sorry but I don't think you understand it at all but I also think that erm, it's the same with the dyslexia and it's the same with [niece] having CF (cystic fibrosis). I think unless you live with that person then I don't think you can appreciate what it's like. I think you've probably got a good idea

I: Yeah

P: But I think you have to be there, you have to be in it

I: Is that about it being every day or is that about

P: Yes, yes I would say so. Yeah, because there's no day off is there. And I think even, as we said I don't have a lot of time away from the family, but we choose, that's our choice. We could go away but erm, even if you did have a weekend away you still, you can't, you can't switch off from it. He will always concern me in that respect.

The constant thought that parents put in to life was common to all parents. Yet despite the planning and reflecting on their own behaviour and lack of respite from the situation, parents find that as they become more experienced in having a child with ASD it becomes natural to think about them constantly. They appear to adapt to their family life in order to compensate for ASD.

P: Erm, I will pre-warn Alistair at the earliest opportunity. It's definitely easier now than it probably was 5 years ago.

I: Mmhmm

P: Erm, because he would've dug his heels in and said "No, I don't want to" so he's definitely better but you see, we wouldn't decide at ten to four we were going out for a meal tonight. We just wouldn't do that, we would decide at the beginning of the week "ooh what would you think about..." and you just you do it automatically after a bit

I: Yeah

P: Because you know that he's going to dig his heels in and like I say you don't look for trouble, you don't want to make life difficult for yourself and after a while you get very much used to thinking like that and erm, I start thinking about the weekend on the Wednesday deliberately to think "Well what are we going to do, eat, say go" and give, give myself time to warn Alistair that that's what's going to happen. We're having a haircut tomorrow and I told him on Wednesday, I told him yesterday "Don't forget we're having a haircut on Saturday" cause, so he, he knows what's going on and he knows it's going to happen and there's no room for whatever (laughter)

Siblings appear to share this understanding of planning although they do not share the same sense of ‘constant-ness’ as the parents. Parents tended to take on the role of planning and structuring for the child with ASD, their constant thinking means that the siblings do not need to take on this role. As a result siblings are aware that planning is needed but it is not a constant part of their lives in the same way as for their parents. Siblings seem to be providing support to their parents by being aware of the necessary planning:

S: It was a lovely evening but John came to accept it whilst we were there but before that he was saying “no I don’t want to go” and was having a tantrum. It’s got to be fixed in his mind and you have to give him at least a few days notice.

These descriptions highlight the perceived need to minimise difficult behaviour through preparation, routine and a restriction on family activities.

Life Revolving Around ASD: Walking on thin ice [combined]

Both the siblings and parents of children with ASD modify life in order to minimise unpredictability. They hope to reduce the number of behaviours that are seen as uncontained and difficult to regain control over. The children with ASD displayed a number of behaviours when they were upset including crying, suicidal comments, violent comments, verbal and physical aggression directed at themselves, their families or their homes. The result of these behaviours ranged from damage to property which had financial implications, hurt of siblings, parents or self and emotional distress of the whole family. An example of the impact of these behaviours was provided by one of the parents:

P: For a while there was an impact it's not bad now but for a while you know, I'd roll up my sleeves and I'd have 4 or 5 bites on each arm erm, or different bruises from different a day ago, 2 days ago and 4 days ago and all that so erm there's that but erm, yeah.

Understandably, these were behaviours that families strived to avoid. It was difficult for them to understand the behaviour of the child with ASD posed a challenge in controlling and containing it. Chris described how he attempts to provide support his brother:

S: He'll say no to everything he'll just cut off his nose to spite his face. Which I find kind of strange, you don't really you've got to try to understand why you've annoyed him and how and what you've got to try and do is to fix that and you've got to do it in a sensitive way so it won't set him off even worse. If you don't comfort him in a certain way, so you say a few things that he thinks you're faking and you're just doing it for him he'll say "no go away" and he'll say that just to get you away from him so that he can calm down or sulk.

I: Does that work if you go away from him does that calm him down?

S: It takes a while but it does usually work but the ice gets thinner so you have to do your best to try to cope with him

Chris describes how his actions can create further instability. He suggests that although his brother is able to calm down with space he is likely to respond more quickly or more aggressively to any further upset. There was a sense that families were 'walking on thin ice' regarding their own behaviour. Siblings expressed a concern that it was not

good for the child with ASD to be distressed; they appeared to be concerned for their wellbeing in addition to behaviour. One sibling who noticed that the feelings of the child with ASD had implications for other members of the family:

S: Tom can't feel good being grumpy because he likes being grumpy and then it's bad for the 3 of us

I: What happens when it's bad, do people get along, do people not get along?

S: On a bad day I'll talk to Tom and mum and dad are "no you shouldn't do that he's having a bad day"

This further highlights the idea that life in the family is difficult if the feelings and behaviours of the child with ASD are not contained. The sibling is asked to modify his interactions by his parents in order to reduce the risk of saying the wrong thing to the child with ASD. This is explored further in the 'restrictions' sub-ordinate theme. There was a sense from the siblings and parents of not wanting to 'rock the boat' so when things were settled they left the child with ASD alone:

S: Don't interfere in anything that he's doing, if he's on his own in his room and he's playing or he's in his room on his own then leave him alone cause he's peaceful.

By not interrupting or making the child with ASD do things that they did not want to, unwanted behaviours were avoided. The expectation of a fight or negative response led to families prioritising joint activities. Others adapted by providing ways for the child with ASD not to take part in activities and did things with the sibling without them. The families who chose this second option seemed to be more conscious of not 'rocking the

boat'; it did not follow however, that these were the families where the more violent behaviours were experienced. Each family appeared to have a different level of tolerance to the distress of the child with ASD. Michelle gives advice to another family with a child with ASD in this excerpt which highlights how in her family they prioritise activities:

P: Yes and to really pick your battles and you know and to only force the issue if it really matters. You know and if they want to do something some way well let them because if it doesn't affect anybody else, is it really a problem and they've really got to they've really gotta decide what's important and what's not.

She expresses the difficulty she would have as a parent in enforcing a plan on the child with ASD: there are times when she will not do this; when it's not worth 'rocking the boat'. Parents' concerns about maintaining stability are likely to come from a lack of confidence in being able to manage any resultant unwanted behaviour and some parents expressed feeling like a failure as a result of this. Liz explained how she needed someone to blame in order to explain the behaviours of her child with ASD. She felt that it is normal for parents to blame themselves when things go wrong in the family rather than balancing her feelings with the knowledge that her child has a diagnosis of ASD.

P: And I don't know whether we blamed it, I think we blamed each other some of the time because we just thought, and I blamed myself cause I thought I must be a terrible parent, I've got a child that I can't control, I must be terrible you know so I just thought oh it's my fault, which I think you do about most things in parenting, oh it's my fault so yeah

This judgement made by Liz shows that parents think they should be able to

contain behaviours and minimise the likelihood of them occurring. Further to the judgements that parents place on themselves they perceive judgement from society when challenging behaviours occur outside of the home. One parent expressed how their partner worries about what other people will think:

P: Erm but [partner] worries that people think that we're just neurotic parents; we're not parenting very well. Or also or alternatively thinking that other people will think we're neurotic parents, er sorry or that we're bad at parenting. so there's this crossover between him being compliant with others and non compliant with us and people see that and [partner] worries that people are thinking, commenting things on that and we do worry that other people will think we're er, that he doesn't really have Asperger's and why are we making all this fuss.

The hidden disability of ASD can make parents fearful that others will not understand and/or make allowances for behaviour; as a result parents fear they will be blamed.

Life Revolving Around ASD: Restrictions [Combined]

ASD places restrictions on family activities as a result of the behaviours that may occur whilst outside of the home. To avoid judgement from others, families may avoid situations where behaviours are seen, instead preferring to confine ASD to the family home. Siblings expressed a sense of frustration and not understanding the behaviour of the child with ASD. Paul described how the restriction affects every day family life:

S: *Erm, sometimes ordinary things that we do on days, he, he, he just decides that he doesn't want to do those things.*

The inconsistency of ASD, in addition to the inflexibility, can lead to feelings of sibling and parental isolation from peers and society. Parents shared siblings' frustrations and appeared to have a desire to be free of the limitations and restraints. There was a sense of having to make allowances rather than wanting to make them. Frustration that children with ASD would not do unplanned things and further frustration came from refusal to engage in previously agreed activities for which they had been prepared. One mother described her frustration about the inflexibility linked to ASD:

P: I wish we didn't have the, I wish I could get round this inability to erm, say "come on then John, you've agreed we're gonna do this, we do it". I wish, I'd get, I wish I could get rid of that bit saying "No I'm not"

Avoiding unwanted behaviours leads parents to choose an easier parenting option; changing the sibling's behaviour rather than risking unmanageable behaviours. One sibling described how his brother is involved in making decision about what he is allowed to do:

S: Oh yeah and there was this yeah, debate cause like you had to be 10 to go to go ape and I've never been to it and I really want to go and Tom was like no you're not going until I can and I was like why.

I: Sounds really frustrating

P: It is that particular incident was.

The sibling's life is, at times, felt to be controlled by the child with ASD. The resulting frustration of the sibling was likely to be easier to manage than the challenging behaviour associated with ASD would have been.

Life Revolving Around ASD: Finding a balance [Parent]

'Finding a balance' relates to parents balancing the needs of the child with the needs of the family, as well as with their own expectations of parenting and being judged as failures by others. Parents expressed the importance of keeping the child with ASD calm; protecting them from distress that would be caused by instability. Parents' and family lives appeared to be controlled by controlling this; one of the parents expressed feeling pleased due to having a happy child:

P: Stephen takes up a lot of my time and a lot of my effort.

I: Mmm

P: He's the one that demands the most just to keep things stable for him really. I think we do a really good job of it. He's you know, generally happy and calm and erm, and our family sort of revolves around that really I suppose.

Despite a need to maintain stability and calmness for the child with ASD, there was an acknowledgement of the effect on and feelings of other children in the home. This disparity between life being controlled by ASD and keeping control can be seen in a contrasting quote from the same parent:

P: I think you've gotta be consistent and you know, it, Stephen could easily rule the roost if allowed, erm, and you'd have to make sure that his behaviours is appropriate and isn't seen to be too different from the others, you have to make sure that they stick by the same rules.

A struggle exists between parental expectations of maintaining a balance between the needs of the child with ASD and the feelings of the other children in the family. They

also experienced difficulty in balancing advice about how to manage ASD with their own values about how to parent. Values included the importance of bringing children up to be responsible adults who displayed socially appropriate behaviours. At times it appeared that parents were describing a tension between their own ideas and their understanding about the needs of ASD. Ian described this struggle:

P: Cause the paediatrician when we last saw the paediatrician cause we've seen paediatricians before in [place] and then here and the one here said essentially what he wants you have to give him and not fight it at all and not try to change it. But you can't live life like that and there are things that have to be done. But there's a kind of. Cause part of you says good parenting is trying to guide a child through and encourage them to grow up and take responsibility, and all that so you're trying to get this balance between letting him do what he wants and not get angry with him at all and guiding him through whatever it is that he has to do. And it's difficult, sometimes, I mean sometimes, I mean he'll have a bust up, if he's had his bust up he's released whatever it was that was inside him and he's calm again. Erm, so there's quite a lot of if you give him space at the right moments and taking space yourself...but the debate that goes through your mind is well should you get him to understand that it's not right to be telling lies like that or do you say we've been advised just to let him calmly go about his business so there's a bit of me that wants to keep on going at him no that's not the right thing to do

Parents attempted to maintain calmness in the family home and balanced staying in control of ASD with ASD being in control. This was difficult when in order to stay in control of ASD ideas about parenting had to be modified.

Whilst most of the siblings mentioned restrictions to their lives they did not portray a sense of balancing life with ASD to values they held. This may well be due to the different perspectives held by parents and siblings. The struggle for parents was to manage their own perceptions and advice and to balance these with the constant tasks that ASD posed.

Theme 2: What's ASD –What's not?

This super-ordinate theme explores the difficulty for parents in knowing which of the behaviours displayed by the child are the result of ASD. Siblings struggled with knowing what was 'normal' and managing the perspectives of their peers. Parents also struggled with maintaining a perspective and were concerned with 'what's normal?'. This appeared to be important for parents to 'understand' their child. The 'normal' distinction was used to evaluate the behaviours of the child, and to decide how much control the child had over their behaviours. Families' understanding of ASD also affected their explanations and responses to it.

What's ASD - What's not?: Comparison to normal [Siblings]

Siblings found it difficult to explain what it was like to have someone with ASD in the family. They noticed that they had no frame of reference in order to make a comparison and therefore are less likely to be aware of the extra difficulties in the family. As a result they may consider the restrictions and behaviours that occur as being a normal part of family life. Chris reflected on not knowing any difference.

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

S: It's hard to say because I don't know what it's like living with a normal, someone who's not autistic. So it's just I'm guessing you have to treat them slightly differently. You can't really give them a big telling off because that will knock his confidence quite majorly really and you just have to be supporting and give him something, give a shoulder to cry on or someone to lean on. You've just got to be as kind as possible really. You've got to try to be nice you can joke with him. Life seems normal because I don't know what it is living with someone who's not autistic. It's just something I'm used to.

Chris struggles with his language about 'normal' suggesting that he is aware that things would be different if there was not a child with ASD in the family. He demonstrates an awareness that you have to treat the child with ASD differently, but seems unsure. His use of the word "guess" implies that he does not fully understand the situation. Elaine demonstrated this struggle to understand and lack of awareness of what was 'normal' when her peers asked her about life in the family:

S: Cause everybody, well my friends always asks me what's it like having an autism brother and I just say it's just normal to me but they don't think so cause they don't have an autism brother

I: What's that like for you having to explain that to them?

S: Erm quite easy because I normally explain them why it is he's like that and stuff cause whenever they come round he's like that and they always say well why is he like that and I always say it's because he's got autism, well I just call it anger issues

I: Oh ok so is that what they'd see? They'd see anger?

S: He hasn't got really angry issues he's just got, well I don't know what he's got really

I: Is it hard to explain it?

S: Yeah, cause I just call it anger issues cause I don't know what it actually is.

Communicating the effects of ASD is difficult when you do not have a frame of reference. Elaine has difficulty explaining to her peers and although the child with ASD would not come across as angry she finds this an easier explanation of his behaviour than

describing autism. This suggests that for siblings difficult behaviours, restrictions and social isolation may be 'normal'. Siblings' 'understanding' is described in more detail later in this theme.

What's ASD – What's not?: What's normal? [Parents]

Parents had a different perspective from the siblings of children with ASD. They expressed what life might be like without ASD and how stress may be reduced or that they would be less socially isolated. Edith gave an example of how she wonders about the difference ASD makes to her life:

P: I do sometimes sit and think what it would be like, I quite often think that...Not totally stress free, cause I think when you've got kids it never is, especially when you've got teenage [children], but definitely less stress and less worry definitely cause [it] is a worry.

Edith balanced her perception of the reduction in stress due to ASD with an idea about what it is like to have teenage children. When parents spoke about ASD they struggled to separate it from their child; this difficulty externalising seemed to make it difficult for parents to express their opinions about ASD. There was a sense that parents were unable to be critical about ASD as this meant they were being negative about their child. In addition to this parents struggled in understanding what was ASD and what was 'normal', with parents' perspectives seeming dependent on the birth order of their children. Sheila expressed a difficulty in knowing what a typical developmental trajectory was and when behaviours were as a result of ASD:

P: because [he]'s my first child, sometimes it's hard to know what's typical teenager and what isn't. ...It's difficult to separate it out, his personality is his personality

Sheila's struggle is similar to that of the siblings in that she has no frame of reference as to the way a child without ASD could be developing. The struggle that parents faced in deciding whether behaviours were ASD or were 'normal' added to the difficulty in balancing their parenting. The following sub-ordinate theme explores how parents and siblings understanding of ASD influences their behavioural attributions.

What's ASD – What's Not?: Understanding [Combined]

This sub-ordinate theme explores the combined understanding of parents and siblings. It considers the role that having the diagnosis plays in the understanding of behaviours. The consequences of not understanding ASD led to siblings internalising the meaning of behaviours.

Siblings struggled to understand how the child with ASD experienced the world. When the child's behaviour was different from their own, some siblings explained a difficulty in making sense of it. Neil explained his difficulty:

S: I just don't tend to properly understand it...No like erm, it doesn't make sense how that can happen how someone can be in that mind-set and whatever,

I: So you don't understand what the explanation is how that might make [child with ASD] think?

S: More why, why it's the way it is

I: Why it's the way it is, is it ok to not understand that or would you like to understand that?

S: I would like to but, it's just different to how I am

Neil expressed a desire to be able to understand his brother and a struggle with being able to see why his brother behaved differently from him. When siblings didn't understand the effects of ASD they had a tendency to attribute the child with ASD's behaviour as being something to do with them; internalising it. One sibling thought that;

S: He doesn't want to do anything with me cause he doesn't like me

This led to sadness from the sibling who wanted a relationship with their brother but was unable to understand lack of desire to interact was due to his ASD. Left with no other explanation, the sibling believed it was because they were not liked. Understanding led to empathy towards the child with ASD. Ruth described how the diagnosis has allowed her to see past the 'bad' behaviours and is now able to see a nice side to the child with ASD which she had not previously noticed:

S: I've noticed that [child with ASD]'s got a lot, a really nice side to him when he wants to be, like I've never seen it before he was diagnosed, do you know what I mean,

Having the diagnosis led to an increased understanding of the sibling with ASD. Ruth was able to make comparisons to her peer group and developed empathy. She noticed limitations which led to her feeling sorry for the child with ASD:

S: It must be horrible to feel as though you can't go out and stuff and you can't do as much as normal kids do

Understanding ASD seemed to be difficult for all of the siblings who 'understood' ASD from their own perspective. This did not allow for the child with ASD to think

differently from them (i.e. not want to go out). Incorrect interpretation of behaviours led to internalising and sadness; understanding led to empathy and feeling sorry for the child with ASD.

Although parents and siblings demonstrated an empathy for the child with ASD, the child with ASD did not show empathy towards them; this led to a difficulty for parents in 'understanding' the child with ASD. One parent described how the child with ASD misinterprets the effect his own behaviour has on people:

P: Tom doesn't seem to understand how he's verbally hurting people and physically he quite often says, if he's hit someone if he hits me and I go "ouch" or something like that he'll say "you're faking it", and there's something about unless he see blood he doesn't think anyone's ever hurt, cause sometimes he'll see blood and say ohh that's terrible but it's only a small cut and it's not terrible, you know. So and it's quite hard to understand and it's quite a concern and we do worry about at times that he doesn't have a concept about how his behaviour impacting others.

This parent worried about how their child would be perceived by people as a result of lack of empathy. This created a struggle in understanding the child and feeling in control of ASD. This parent does not attribute the behaviours to ASD. Other parents attributed differences in the behaviour of their children as being due to ASD. This parent's comment reflects this:

P: Tim might say sometimes, "I'd like to get the shotgun and shoot Paul's head off" you know, things like that. But he's that's because he's the one with Autism and he's the one who will say things like that you know.

It can be seen here that parents might attribute abusive behaviours from the child with ASD as being due to ASD. As parents struggle to maintain calmness in family life they may balance a feeling that the behaviour is unwanted with their knowledge about ASD. This would allow them to accept the behaviour rather than trying to change it, thus avoiding more difficult behaviours. The need to maintain calmness and stability justifies allowing the behaviour. This explanation avoids self judgement for letting the child with ASD say something abusive to their sibling. Although parents used the diagnosis of ASD to explain difficult behaviours they also noticed that ASD had other effects on their child that were not considered to be negative. Ian gave an example of his child's behaviour:

P: You can say that it's because of autism that he's will take a, if he's got a set, like in the older days when he was still reading Beatrix Potter books, and you get a set of Beatrix Potter books and they've got numbers on the back of them so he'll put number one up the top then 2 3 4 5 in a in a matrix, now so that's autism affecting him because that's the way that he will play but that's not a negative effect but that's how he is

This contrast shows that parents are able to maintain a positive perspective of the effects of ASD. Siblings are able to see past ASD when they understand whereas, parents to use their knowledge about ASD to notice how it affects their child.

A strong connection between the themes suggests that parents integrate their knowledge about ASD and their expectations about parenting to re-evaluate their parenting style once they receive a diagnosis. The new information gained following the diagnosis is assimilated into parents' understanding and new explanations are created which allow for all their knowledge to be used. Before the diagnosis, parents did not have an explanation

for differences in behaviour between the sibling and the child with ASD. The knowledge gained allowed this parent to think about her expectations and her perspective of her parenting was modified. This allowed her to feel that the situation was more 'normal' than she had previously felt:

P: Well they'd be different anyway wouldn't they, even if Tim didn't have his diagnosis and I never thought that that would be the cause, stupidly. I thought, if you had two children and you bring them up the same way, but you don't bring them up the same way because when you, when Tim came, we'd already got [sibling] so we already had less time for Tim erm and then that means we've got less time for [sibling] cause we've got Tim so you don't bring them up the same way and then top of that I'm only just now probably this last 6 months, maybe a year, realising that actually they are individuals and they are individual personalities and that they don't have to do, they don't have to have the same viewpoint on things that I have, they won't have.

This suggests that parents are able to use their knowledge about ASD to guide their parenting style in order to experience life as more 'normal'

Theme 3: ASD changing family roles

This theme explores how roles within the family change as a result of ASD. Siblings expressed a 'loss of relationship' which they fantasised would have been different without ASD. Parents similarly experienced a loss following diagnosis and their 'cycle of reactions' showed a struggle in containing their feelings. A combined sub-ordinate theme emerged where parents and siblings strived to 'protect each other' in the family.

ASD changing family roles: Loss of relationship [Sibling]

Siblings appeared to have an idea about how they would want a relationship with their brother and sister to be; none of the siblings expressed happiness with the relationship they had. The loss of this fantasised relationship led to siblings isolating themselves. One sibling described his relationship:

S: (sighs) Tom's not really like, the person who I like do stuff with.

I: Who is the person that you like to do stuff with?

S: Me, I really should get out more

I: Is that cause you want to or cause you have to?

S: Bit of both

He struggled with not having a relationship with his brother and as a result chose to complete activities on his own. The idea that he had to be 'out' of the house suggests he is isolating himself to meet the needs of his brother. This was further exacerbated when siblings believed that the child with ASD did not want to spend time with them:

S: I'd tell them it really annoys me that I can't erm, that erm, I can't do the things with him that other people do with their brothers, like I can't erm, I can't like erm, I can't take him somewhere on my own in case he gets angry and Mum and Dad aren't there to sort it out. Erm, I wouldn't he doesn't like me as much as other erm, erm, people like their brothers, sometimes he doesn't like me very much, sometimes he don't like me very much

The desire for things to be different is acknowledged by the sibling who wants a relationship with the child with ASD and sees the relationship they have as not 'normal'. When the child with ASD plays with the sibling the sibling appears to find this an enjoyable experience:

S: hair and makeup and nails, I like doing that and I like the fact that she can sit down and talk to me like say if she can't tell mum and dad stuff

In this quote the sibling seems to feel privileged when her sister shares things with her. The transient nature of the positive relationship may also add to sibling's distress and loneliness when it is taken away from them; they are likely to wonder what they have done wrong and struggle to balance attempting to repair the relationship with avoiding rejection.

ASD changing family roles: Cycle of reactions [Parents]

Parents did not describe a loss of a fantasised relationship with the child with ASD but they seemed to respond to a loss of a child following the diagnosis. Parents expressed a desire for things to be different and described a transition to managing the diagnosis. Parents frequently expressed their 'wish' for difference. The feeling of 'wishing' and

remaining hopeful is in contrast to the sadness that parents expressed. One parent expresses her feelings following the diagnosis:

P: I also felt quite sad for a while last year, the end of last year, that I hadn't got perfect children.

Another difficulty is expressed by this parent who generalises not perfect to both her children. Not attributing difficulties to ASD separately leads to the sibling being included as 'not perfect' in this stage of the cycle. Some parents struggled to make agencies listen to them whilst others were frustrated that agencies hadn't noticed the possibility of ASD. Frequently, anger was directed to agencies as can be seen in this quote:

P: Erm, it makes me cross, it makes me feel let down by the school, erm, because they, they must've known something wasn't right. They must've been, they must've had some inkling. You can't spend 38 weeks a year with a child and not think "hmmm". You mean to say they haven't had a child with Asperger's, I'm sorry, I don't believe it. I do feel let down by them but then on the other hand, he's one of 30, you can't expect them to know everything about all of them can you? So, I try not to judge and I try not to let it get too far cause it isn't healthy and it isn't gonna change the situation and it isn't gonna help is it?

This parent does not feel comfortable with her anger, and is striving to keep it under control. She is seeking reassurance that she is doing the right thing suggesting that acceptance does not feel natural for them. As this cycle presents as transient, parents described being at a different stage from their partners; this led to tension and frustration. One mother spoke about her husband's struggle:

P: Craig keeps go, keeps going “Why us? What have we done to deserve this?” oh Craig, it's not about that, just deal with it, you know, stop saying why us, cause it's nothing to do with us, it's all to do with the fact that this is how John is, there's nothing you can do about it, nothing to change it, there's no fault of anybody and erm, we've just gotta deal with it. But he concentrates on why us, rather than actually accepting the situation and dealing with it, so that makes it difficult.

Parents were at different stages in accepting the diagnosis and adapting their parenting of the child. For example, tension is created when a mother is accepting while a father is questioning, and attempting to find something to blame.

ASD changing family roles: Protecting each other [Combined]

This sub-ordinate theme explores how siblings attempt to protect their parents; the result of them trying to help out and parents' response to this. In addition, the perspectives of the parent and sibling on the role of other family members are presented.

Siblings were conscious of how feelings were passed around their family. They were empathic to the stress of their parents and noticed how they also felt upset or depressed as a result of this. Chris describes how his mum's stress led to him needing support from CAMHS:

S: these sessions also taught me how to deal with John just through talking about it and how to deal with mum and dad fighting. Erm that really helped because it was also a stage of depression really I think because mum being stressed meant that I was stressed because I didn't like seeing her stressed and I didn't like seeing her upset it kind of radiated to me and I got really upset sometimes because of this.

When siblings were able to notice the pressure that their parents were under they tended to want to protect them from it. Ruth described how she is able to get support from her wider family and will then decide whether she needs to tell her mum things:

S: I'm normally scared to tell mum all my stuff cause like the way, I'm not sure how she'll react and I don't want to upset her so I'll tell my Nan it and then see what she thinks of it and if she says it's not as important, you know, then don't tell them and if it is important then you're best off telling them

Ruth is attempting to protect her mother from unnecessary stress, suggesting that she feels there is enough stress from living with ASD. Another way that siblings attempt to alleviate the stress on their parents is by acting as a third parent in the family or by 'stepping up' into the parenting role. As siblings feel isolated by the lack of the relationship they have with the child with ASD they may seek to align themselves with parents in order to feel connected to someone in the family. Parents have a mixed response to the attempts of the sibling to help them in this way.

P: Ruth will then jump in and say "leave mum alone" or "don't say that" and then obviously it causes a row between them but Ruth's very protective and if Ruth goes away and stays at a friend's house or something she always worries about leaving me "I'm alright" but she worries, a bit of a worrier Ruth

Although Ruth is not successful in avoiding unwanted behaviour; she diverts it away from her mother onto herself. Her mother perceives this as being protective of her and does not complain about the result. In contrast when the 'stepping up' is not welcomed the parent experiences frustration at the sibling:

P: [sibling] tries to step in to be the third parent and then we get cross with him “Just leave, just let us deal with it, just leave it” and [sibling] can sense sometimes we're getting stressed and he'll try to say to Tim “Oh for goodness sake Tim, will you just do as you're told” when we're trying to get him to do something. Erm, and that doesn't help. You know and but he still tries to do it, no matter how many times we say so I do, I do feel a bit sorry for [sibling] sometimes but equally I do think he brings some things on himself as he can be a bit silly and wind Tim up and Tim isn't tolerant and then they're, and then it all goes pear shaped and then they both end up being shouted at you know and so it can be a bit fraught.

The parent suggests that the sibling is not helpful in their attempts to manage ASD. There is a sense that the ‘help’ of the sibling makes the situation more difficult to contain and the parent struggles with this. Siblings see their attempts to help as protecting their parents and they express a desire to be able to help and an acknowledgement that they get it wrong:

S: I wish I could talk to Tom and like, (sigh) it's I got really annoyed because Tom is in a mood and mum was like, I yeah no, well she was like I think I'm the one who should try to calm Tom down, I was like I can do it and mum was like no you can't and I was like I wish I could

When siblings' attempts are seen as unwanted, they feel a sadness that could be due to the rejection from the parenting position and another disconnection from the family. When siblings' attempts are wanted by the parent and siblings have learnt how to get

things right with the child with ASD, the alliance is seen as supportive. This is described by one parent:

P: he's lovely and erm, and because he is so in tuned into John and the way he works because they've grown up together, there's x years and y months between them. Erm, he is very tuned to him so, he does make allowances, he's very generous from that point of view and erm, you know, it's, it's only sometimes that he gets frustrated and less so now because they're both getting older

In this family, it is apparent that the sibling and the parent share the same understanding of ASD. This was not common: parents and siblings frequently have a different understanding. It was also clear that when other family members did not have the same understanding of ASD, and did not respond in the same way, this led to further tensions. The same mother describes how she and her husband differ in how they modified their behaviour to make allowances for ASD:

P: Daddy comes home and says ooh, let's go out, I'm home early, let's go out for a meal (gesture of frustration)...he just will not understand or I, I don, I ju, I just don't un, I just don't know what it is with Craig, I really do not know whether, he's just like this and forgets or whether he's just so selfish that he couldn't give a damn I just do not know but erm but the two of them together makes it really really difficult cause if he could take on board how you need to treat John and and deal with John I think it would make it a bit easier...but he doesn't, so, so things are fun sometimes.

Another parent attempted to reduce the difference between her understanding and that of her husband by sending him on courses to gain more information. She also expressed that his understanding is not as important as hers:

P: but really he doesn't deal with the day to day battles, I do it all, I do it.

Mothers are protective of fathers, often acknowledging that the father has to work longer hours. As a result they often do not share the responsibility of parenting with them.

Avoiding and containing unwanted behaviours protected the siblings. Siblings were also protected from parents' opinions about them. One parent expressed that she thought the sibling was not always kind to the child with ASD. She made allowances for the sibling, understanding the difficulties of living with a child with ASD. As a result this remained unspoken between them:

P: Probably one thing I don't want him to know about, is I think that he can take out his frustrations on [child with ASD], you know cause he, he is generally frustrated with him.

The siblings did not suggest that they took their frustration out on the child with ASD and they did not seem aware that parents made these allowances.

Theme 4: Equality

This theme demonstrates a difference between equality as the siblings see it ('how I understand inequality') with the parents' perspective of 'ASD as an explanation' of inequality.

Equality: How I understand inequality [Siblings]

This sibling only sub-ordinate theme shows a struggle with noticing different treatment between themselves and the child with ASD. Siblings reported feeling that things were unfair when they perceived the expectations on them to be different from the child with ASD. This could be due to different roles:

S: Well erm, in comparison to my age and his, when I was his age I did more than he does now and I've always been really annoyed about that

different rules

S: Erm, I get annoyed because they don't tell him off and I get annoyed cause sometimes I get into trouble, just me gets into trouble when we've both been doing the same thing.

or different limits

S: Yeah, Tom's bar of being told off is higher than mine, I'm not sure how much higher but

I: You feel that you get told off a lot easier?

S: I'm not sure about a lot, but easier

I: For littler, for smaller things, for different things?

S: I'm not sure about how much smaller but like I said I'm not sure

Siblings also noticed that even when parents punished them in the same way this did not always have the effect of being an equal punishment

S: He prefers to go out and play with his friends and like sometimes when we're banned from electronic stuff for the day he's ok cause he doesn't mind playing with toys but I find that really boring so I have to read or just do nothing

A further annoyance expressed by a sibling was when the child with ASD was rewarded for 'good' behaviour that would have been typical for them.

S: It annoys me that he's getting a reward for something that I do anyway but I can understand why cause if they do reward him for doing it then maybe he might stop being naughty, it doesn't seem to be working

As can be seen in these quotes, siblings feel a sense of frustration and do not fully understand the differences between themselves and the child with ASD. None of these siblings expressed an understanding that they were different from the child with ASD. When siblings understood that ASD was the reason, it still seemed difficult for them to use this knowledge to overcome the feelings of frustration caused by the perceived inequality. This cognitive dissonance was expressed by one sibling:

P: (pause) as in I kind of know why he's doing it, or know what to blame for him doing it but I don't necessarily like it

This difficulty in connecting knowledge to feelings does not allow for the frustration to dissipate. As a consequence, siblings are likely to be frequently in a state of frustration which rapidly returns when inequality is perceived.

Siblings attempted to manage their frustrations on their own; feeling that voicing them to their parents may result in more trouble. There were also times when they felt as though nothing would change as a result of them mentioning things. They then decided that the consequences of saying how they felt would be worse than continuing to have the feeling.

S: Cause I don't like to talk about it and mum and Dad probably, cause they're the ones that make me feel annoyed I wouldn't go and talk to them about the fact that they, I feel annoyed because they might annoy me even more, they might tell me off even more

There was a difference in the feelings of the sibling when they were able to integrate their knowledge about ASD with their feelings. This appeared to create a sense of control which resulted in understanding that there had to be a difference and that things were fair.

S: I'm alright with how I'm treated, I mean like I know if I've done something bad that I'd have to do the time for it, like [child with ASD] doesn't understand it.

For this sibling acknowledgment of ASD as the reason for the difference in treatment fitted with the understanding of deserving the consequences she received.

Equality: ASD as an explanation [Parents]

There was a difference for siblings when they understood that inequality was justified and when they could connect this with their feelings. Parents were aware of the siblings' feelings.

P: Neil certainly at time feels things are unfair

In spite of this acknowledgement, the consequence of needing to control the behaviour linked to ASD, led to parents treating the sibling differently. Again they struggled with ‘balancing’ the needs of the sibling and the needs of the child with ASD.

Parents tried to find reasons and justifications of this difference which tended to place some responsibility on the sibling’s behaviour for making situations worse. One parent reflected on times when the sibling may have been treated in a different way if they did not have a child with ASD in the family:

P: But we sometimes say to Mark no you can’t go on the computer because [child with ASD] will want to and he will never stop, so Mark says “well why should my life be controlled by my brother” “why should I not get” cause otherwise Mark would have been let on it. So there’s, there are things we ask Mark to do in terms of being restrained about things that he might otherwise do because of the impact that it would have on [child with ASD] and erm and he feels that his life is being controlled by his younger brother, erm and to some extent it is, we feel a little bit that Mark brings it on himself because he does, he contribute to it, that’s not all the time, but sometimes he does contribute to [child with ASD’s] behaviour.

This parent seems to feel sad for Mark and for having to treat him more harshly. This was typical when parents made allowances for ASD which affected the sibling. A further explanation of difference was provided by one parent who was unable to find consequence for the child with ASD.

P: John never ended up doing anything like that and he was never really naughty

erm, I kept saying to Chris, “if John's winding you up you come to tell me, so then John will get punished” but he was never really naughty like that whereas Chris was naughty, John was never really naughty, so he never got to the point where you'd send him to his room but again punishment to John, “if you do that I'll take such and such away”, “well take it away then”, he couldn't care

I: mmmhmm

P: at least if he does he's got a jolly good way of not showing it. You know, if you do that we'll we'll take this off you, you can't do that even. Say I didn't want to anyway. He's virtually unpunishable

Although parents are noticing an inequality in the treatment of their children the constrictions from ASD limit what they can do about it. They balance this discrepancy in treatment with the understanding that they have about the needs of children with ASD. This understanding is not shared by the siblings in many cases which leads to a different understanding of ‘equality’

DISCUSSION

This research used IPA to gain an understanding of the experiences of life in a family with ASD; how parents and siblings understanding is shared or differs. Each of the four themes that emerged showed elements of combined experiences and also meanings that were not shared. 'Life revolving around ASD' was the most prevalent theme which was shared in many ways, although parents seemed to be most affected by the constant-ness of ASD and the struggle with balancing expectations. 'What's ASD – what's not?' explored a difference in perceptions and understanding of ASD. As families attempted to adapt, 'ASD changed family roles' where there was a sadness in response to ASD and a need to protect each other from the effects. The final theme 'inequality' showed different views for the siblings and the parent, which resulted from a difference in understanding of the reasons for it.

'Life revolving around ASD' was a particularly strong theme for parent and siblings. They perceived life to be treacherous as a result of the unpredictability of the child with ASD. In contrast, Angell et al's.(2012) siblings did not express feelings of being unsafe or anxiety resulting from these behaviours. This is possibly due to the measures that families took in order to minimise the effects of these behaviours. Although no embarrassment was expressed about behaviours, it had been recorded by siblings in previous research (Mascha & Boucher, 2006) and was a hypothesised explanation for preventing behaviours occurring in public. The theme of constant-ness similarly indicates increases in stressors, strains and restrictions reported by parents (Cassidy et al., 2008).

'What is ASD – what's not?' explores a difficulty in knowing how to attribute behaviours. The difference in frame of reference of the siblings and parents accounted for

some difference in their perspectives. Siblings spoke of life 'being normal to them' in contrast to their parents who make comparisons to peers or the sibling but also struggle when they have no frame of reference. There are subtle differences in the way siblings and parents use their knowledge about ASD. Siblings tend to internalise behaviours that they do not understand, whereas parents struggle to know how developmental trajectories are influencing behaviour.

The understanding displayed by parents and siblings varied, with siblings tending to show more limited understanding. They empathised with difficulties faced by a child with ASD from their own perspective, rather than allowing for differences in the way a child with ASD might experience the world. Parents' understanding of ASD allowed them to not judge themselves when they did not modify abusive behaviours; not sanctioning challenging behaviour protected the family. Both parents and siblings were able to see past the negative to more positive influences that ASD had over their child with the diagnosis. These shared experiences and meaning of behaviours may suggest that experience and perspectives of participants are influenced by other family members (Hastings, 2006).

Family roles were modified when there was a child with ASD in the family. Both parents and siblings showed self reflection in their conversation. Parents reflected upon their parenting ability and siblings tended to reflect on triggering unwanted behaviours. Perspectives had changed following the diagnosis; parents reflected a feeling of loss for a 'normal' child and siblings thought they may have a different relationship with their sibling if they did not have ASD.

Siblings tried to be restrained in their own behaviour and tried to 'step up' in order to help their parents with parenting. Parents tended not to notice this restraint and expressed frustration when they felt that the siblings added to their stress. Siblings tended

to want to support their parent and felt sad when they were unsuccessful. When members of the same family shared experiences, the relationships were seen as more supportive. It is interesting to note that in the family where mother and sibling were united in parenting, the mother had prior knowledge of ASD and had suspected it for many years prior to diagnosis. It is likely that this sibling grew up understanding the reason for the difficulties displayed by his brother. This sibling appeared to have the greatest knowledge of ASD.

Although previous research has found a difference in the way mothers and fathers experience stress, this was not obvious from the sample used in this study (Kayfitz et al., 2010). Although mothers tended to attempt to protect the fathers from the day to day impact of ASD, the participating father was aware of this stress, possibly as a result of working from home.

Difficulties in the parental relationship were noticed by siblings. The two siblings who had received outside support were from the families with the most difficult parent relationships. Parental stress in addition to living with a child with ASD may have been influential for these children requiring professional support. This contradicts Rao and Beidel (2009), who found that parents' stress did not affect siblings. Also of note is that in these two families, the child with ASD demonstrated high levels of aggressive behaviour and the families were very restricted. However, the wider family mechanisms were different for these two siblings, with one having support from grandparents whilst the other one did not access support from the wider family network. Despite the conflict and lack of support in these families, they did not as express their family as less 'normal' as may have been expected from the research of Gray (1997).

'Equalities' shows the differing perspective held by parents and siblings. Siblings expressed frustrations at the difference in treatment which parents were aware of; this is

consistent with Meirsschaut et al., (2010) findings that parents acknowledged differences in parenting their children. Parents were not able to modify their parenting to adapt to this, possibly due to the restraints and difficulties of parenting a child with ASD and a sibling without.

When siblings expressed unfairness they did not report thinking that it was due to favouritism; this finding was contradictory to McHale et al. (1986). Siblings noticed that they may be more likely to be in trouble however, although many recognised that the reason for this was ASD, some of them struggled with a dissonance between integrating their knowledge about ASD with their feelings about their treatment.

Hutton and Caron (2005) reported parents' concerns about jealousy, resentment, sadness and fear for the sibling; none of the parents in this study expressed these concerns. Although they did feel sorry for the siblings as a result of 'life revolving around ASD', parents often found it was easier to discipline the sibling than the child with ASD. A common explanation for this was that ASD requires different treatment.

Clinical implications

Petalas et al., (2009) reported acceptance as a major theme in their study of siblings of children with ASD. It appeared that when siblings were able to use the knowledge they had about ASD to moderate their feelings they were more able to accept differences in treatment. It may help siblings to be supported to make these connections in order to feel less frustrated in the family. The result of this is that siblings may be more able to manage their own emotions and it may facilitate the sense of control over the consequences of ASD.

Two of the siblings in the study had received support from outside agencies. In these families there was increased conflict between the parents. It may be that siblings of children with ASD are at greater risk of developing difficulties when there is additional conflict in the family home. The siblings demonstrated resilience and maturity during the interviews; particularly in the way they were able to express themselves and think about the feelings of other family members.

It would also appear important to manage the different reactions of parents, it may be through increased support and knowledge, they can develop a shared acceptance and understanding which would then facilitate a supportive relationship. This is likely to also have positive implications for the sibling.

The support received by the families in this study varied. Some parents attended courses and found that this helped them to understand their child with ASD, but others felt they understood and could manage their child without these interventions. The support needs of individual families should therefore be assessed so to tailor support to their requirements. None of the siblings had attended support groups or courses and many had a limited understanding of ASD. Some of the children felt that the child with ASD did not like them and felt sad about this. It is possible that a clearer understanding of ASD provided by either parents or outside support could have alleviated this distress and isolation.

The dynamics within these families played a part in the understanding, management and distress. There are many possibilities for family work to be undertaken in order to facilitate conversations, which would allow the unspoken perspectives to be shared. This may relieve some of the pressure parents put on themselves as it could allow them to realise that the sibling's perspective is different from their own.

Methodological approach

The IPA methodology, a strength of this study, allowed for in-depth exploration of the experiences of parents and siblings. Each of the participants' accounts was comprehensively analysed in order to capture the experience of the participant and increase methodological rigour. This study intentionally utilised a broadly homogeneous sample of families in order to make meaning from the experiences. This was utilised in order to meet the idiographic commitment of IPA (Smith et al., 2009). This sample is not intended to represent all families with a child with ASD. Although attempts were made to sample a homogeneous group some variation existed. There were a large number of variables which were not controlled such as parent age, family demographic and family structure. Although the differences need to be considered, the sampling method used allows for some transferability of the results and clinical implications. Some of the decisions that were made about inclusion and exclusion criteria were made on the basis of clinician experience in the absence of supporting literature.

The innovative design using dyadic IPA allowed for the perspectives of two family members to be reported together, allowing direct comparison of perspectives. It has allowed for the exploration of different understandings and meaning makings of the same situation. In addition, the approach overall has allowed parents and siblings to express what they feel is their life is like in a non-directive manner.

A further consideration is the sampling bias. The couples who agreed to take part in this research may have done so as a result of needing to express their stories. Parents spoke about finding the process therapeutic and of feeling that the sibling would benefit from being able to talk to someone.

The final potential bias comes from the interpretations. It was difficult to move the analysis away from the descriptions provided by the participants as these were found to be reflective. There were times when interpretations felt judgemental when they were only guided in part by the actual words of the participants. This created a struggle within the researcher which was managed through discussion.

In sibling interviews there was a need for the conversation to be facilitated by cues from the interviewer. In spite of measures being taken to reduce the bias cues used were likely to have been guided by previous interviews and prior experiences of the interviewer.

Future research

Further research could assess whether there are differences due to developmental stage of the children and relative age of the sibling, time since diagnosis and family demographics (single parent families, more siblings in the family) in addition to the wider family networks. Parents and siblings responded well to the interview methodology in this study and some reported feeling a therapeutic value to having talked about their family.

There is scope for more research to understand the experiences of different family members, this could include mothers and fathers and members; of the wider family. Including both parents in a future study would allow for further investigation into shared and different understanding about ASD, which from this research appeared to create conflict in relationships and add to family stress. The perspective in this study was that the child with ASD was often unaware of the effect of ASD on the other family members. It may be of interest to see how their experience of life in the family compares to other family members.

Conclusion

The findings from the present study show the challenges of living in a family with a child with ASD. Previous researchers have called for support, training and information for parents, siblings and professionals in contact with these families (Petalas et al., 2009). It is important to tailor support to meet the needs of the family. Allowing parents and siblings to describe their experience of living in a family with a child with ASD, allowed them to express not only their own, thoughts but their perceptions of other family members. The difference in parental ideas about the sibling's perspective and their own, may account for some of the discrepancies in previous literature which has utilised parental report for siblings. This study would suggest that this is likely to produce a biased result. The IPA perspective has allowed for stories and the meaning of two individuals in the same family to be interpreted and compared filling a gap in the literature. The results can be utilised by professionals working with children with ASD and families to highlight potentially different experiences and assumptions held by family members.

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Clinical Implications in the Delivery of Service to Families with a Child with Autism Spectrum Disorder

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OVERVIEW

The research detailed below was submitted as partial fulfilment for the degree of Doctorate in Clinical Psychology. The first part represents a literature review, in which the effects of delivering a group to parents of children with ASD were investigated. The second part was research exploring the experiences of a parent and sibling living in a family with a child with ASD. This paper provides the reader with a brief summary of these areas.

Part One: Literature Review

Autism spectrum disorder (ASD) is a neuro-developmental condition. There are 133,500 children with a diagnosis of ASD living in the UK (National Autistic Society, 2011). The majority of these live within the family home. Behaviour problems, such as aggressive behaviour have been reported in individuals with ASD (Tonge & Einfeld, 2003). Research indicates that parents of children with ASD experience elevated levels of stress compared to all other parents (Estes et al., 2009). Parents are frequently trained individually to deliver interventions to their children within the family home; these interventions can increase their stress. There are also times when parents are trained using group interventions or offered support to help them manage.

This study synthesises the research regarding the effectiveness of group interventions for parents of children with ASD.

A systematic review of the literature was conducted in March 2013 to gather research written since 1980. The main outcomes from the literature were effects on parents, effects on the child with ASD and parenting outcomes. 17 studies met the

inclusion criteria for the view. In twelve of the studies a parent training group was delivered whilst a support group was the intervention in the other five.

All the studies had limitations in the methods they chose to investigate the groups. As a result caution is needed when interpreting the results. The review found that support groups appear to be effective in increasing knowledge about ASD and improving mental health. The evidence is less clear as to the benefit to parents of training groups. The effect of groups on children was also mixed although it appeared that behaviour problems were reducing following a group. Following support groups, parents had a more positive view of their ability to parent.

Clinical implications

Parenting support groups could play a role in improving parental stress; this would allow parents to feel more confident in parenting and in delivering training interventions to the child with ASD. Parent training in a group setting may also have benefits for delivering interventions to the child with ASD in a cost effective manner.

Part Two: Research

A child with an Autism Spectrum Disorder (ASD) thinks, communicates and understands social situations in a different way from a typically developing child. Children with ASD often require additional support within the family. Life for the family can be limiting as they are frequently unable to be spontaneous; they often follow rigid routines and schedules in order to accommodate the needs of the child with ASD. Research has identified high levels of stress that can result from such factors, both for parents and

siblings within the family. However, little is known about parental and sibling experiences of life within the family. This qualitative research aims to explore the perspectives on family life from typically developing siblings and parents. What it is like to live in the family and the experience of having ASD in the family was explored through interviews.

Six families, where there was a child with ASD, took part in the research. Parents and siblings were interviewed separately. The twelve interviews were analysed using interpretative phenomenological analysis (IPA). Each of the four themes that emerged showed elements of combined experiences and also meanings that were not shared. 'Life revolving around ASD' was the most prevalent theme which was mostly shared by family members. 'What's ASD – what's not?' showed that families are struggling to understand how ASD affects the child. 'ASD changed family roles' shows that all family members try to help protect each other from the effects of ASD and 'inequality' showed different perspectives of life in the family held by the siblings and the parent.

Clinical recommendations

When there was a shared understanding about ASD in the family, management of ASD appeared to be easier. This suggests that parents and siblings should be included in education programmes to improve understanding about ASD. Siblings tended to feel sad and frustrated when they did not properly understand why a child with ASD was treated differently. Brief support offered to them may overcome their struggle to control their feelings of unfairness.

There was also a distinct difference in how parents perceived the effects of ASD on the sibling to how siblings understood it themselves. Family work could be used to assist

communication so families can have a better understanding of each other. This would reduce the worry that they have and the need to protect one another.

Future research

Research into the different perspectives in a family with different demographics is needed to develop the evidence base. In addition to this more research is needed to explore the experiences of different family members including the child with ASD.

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Appendix A – Summary of Included Articles

<i>Parent Outcomes and Parenting Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Bitsika & Sharpley, (1999)	Effect of informational counselling group.	13 female 1 male parent 28-55 years old	Mixed methods	Parent Support Group Questionnaire (PSGQ) (not validated)	Descriptive statistics used. Not analysed for significance.	Non-standardised and non-validated measures
	3 groups of 8, 75 minute sessions	Recruitment by coffee morning	Quantitative effect of group and qualitative evaluation of the intervention	Parent Evaluation Feedback Questionnaire (PEFQ) (not validated)	Group cohesion and self concept increased over time	Small sample size
	Counselling and problem discussion training program on wellbeing	Children attended the same autism-specific school	Measures administered: Beginning and end of each session and PEFQ 6 weeks after completion		Self efficacy increased and then decreased over time	Variability of responses not presented
	Groups facilitated by an author and a teacher				Distress decreased over time	Adherence to treatment - Different group facilitators, attendance not reported
					Evaluations positive	Other support received

<i>Parent Outcomes and Parenting Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Bitsika & Sharpley, (2000)	<p>Aim: to reduce anxiety and depression for parents of children with ASD through direct stress management.</p> <p>Group format and schedule. 2 groups on the basis of age of the child</p> <p>BIOVIEW monitoring of heart rate, deep abdominal breathing taught</p>	<p>20 parents showed an interest with 11 taking part.</p> <p>Parent age range 29-39 years</p> <p>Recruited from a autism-specific school</p>	<p>Mixed methodology</p> <p>Measures administered: Beginning and end of each session</p>	<p>Parent support group questionnaire version 2 (PSGQ-2) (not validated)</p> <p>Program Evaluation Questionnaire (PEQ) (not validated)</p> <p>Self-rated anxiety scale (reliable)</p> <p>Self-rated depression scale (reliable)</p>	<p>No significant change pre – post.</p> <p>Trends reported:</p> <p>Anxiety reduced</p> <p>Depression reduced except in final session</p> <p>Stress reduced</p> <p>Confidence varied between sessions</p> <p>Evaluation positive</p>	<p>Back-up counselling was offered to some participants</p> <p>Non- validated measures were used</p> <p>Small sample size</p> <p>Adherence to treatment -</p> <p>Different group facilitators, attendance not reported and topics chosen by participants</p>

<i>Parent Outcomes and Parenting Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Blackledge & Hayes (2006)	ACT intervention 4 groups of 7,6,3 & 4 participants 14 hours in 2 days workshop. (10 hours for one group)	20 parents started 2 dropped out 1 attended	Quantitative	Global severity Index (GSI) self report (reliable)	No significant change in coping time 1-2	No control group
		only first day of workshop	Measures – 3 weeks before 1 week before 1 week after last day of group 3months after	Beck Depression Inventories (BDI-II) self report (reliable)	Significant Pre – post test improvement BDI-II & GSI but not on GHQ	Groups of different sizes and lengths
		15 females 5 males				Small sample sizes
		5 couples				
		3 geographical regions represented		General Health Questionnaire (GHQ) self report (reliable)	Small significant changes pre-follow up scores BDI-II GSI & GHQ	2 participants from the same family
		Children diagnosed with autism, only one diagnosed child in the family		Parent locus of control scale (PLOC) self report (reliable)	PLOC dropped from analysis due to low baseline scores	Students assessing for adherence were trained by the author
		Children in the family ranged from 1-6		Acceptance and Action Questionnaire (low reliability)	Analysis of parents scoring in the clinical range shows significant change of scores pre-follow up	Reliability of some measures
		Sample not selected on the basis of clinical levels of distress		Automatic Thoughts Questionnaire		No correction for repeated analysis of statistical tests

<i>Parent Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Farmer & Reupert (2013)	<p>Improving knowledge and understanding of autism, gaining confidence in parenting, decrease feelings of loneliness and anxiety</p> <p>10 groups over 6 years</p> <p>6 2 hour session programme</p> <p>5-16 participants per group</p>	<p>98 parents of children aged between 2 and 6 years old</p> <p>102 people started the group 98 attended 4 sessions or more</p> <p>79 children represented by the parents</p>	<p>Mixed methods</p> <p>Quantitative pre-post measures and Qualitative thematic analysis</p>	<p>Self constructed 15 questions on likert scale and open ended questions exploring understanding of ASD, understanding my child, personal confidence and capacity</p>	<p>t-tests showed significant change on all the questions asked between pre and post</p> <p>Qualitative Pre-intervention included: feeling overwhelmed by impact, having little knowledge, not enough information and feeling lost in the system. Post intervention included: understanding ASD, my child, feeling we are not alone, understanding sensory processing and self confidence</p>	<p>After the first group the planned topics changed</p> <p>Modifications were made between groups</p> <p>Repeated t-tests were used with no correction for increased error</p> <p>No measures for normal distribution of responses</p> <p>No control groups</p> <p>Measures were not validated</p>

<i>Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Khosroshahi, Pouretamad, & Khooshabi (2010)	<p>Evaluate the effect of the Little Bird Programme for children's behaviours</p> <p>Manualised intervention was compared to a matched control group</p> <p>Programme consisted of group sessions which included 1:1 support to learn to understand ASD.</p> <p>3 month programme, both groups received individual ABA treatment in addition to this intervention</p>	<p>16 mothers of autistic children</p> <p>12 randomly allocated to treatment, 8 completed. These were matched by age and gender of the child to control group</p>	<p>Quantitative</p> <p>Measures used</p> <p>One month before the group,</p> <p>At the beginning of the programme,</p> <p>In the middle – one month after starting</p> <p>post- end of the programme</p> <p>Follow up at one month after</p>	<p>Gilliam Autism Rating Scale (GARS) (validated)</p> <p>parents completed the measure</p>	<p>Stereotyped behaviours showed a significant decrease between baseline and post measures</p> <p>No significant differences between control group and treatment group scores pre intervention but significant difference post intervention</p>	<p>Small sample size</p> <p>Limited investigating into the power of the results</p> <p>No exploration about the effect sizes or the clinical implications of any differences found</p> <p>Package was translated for the group</p> <p>Process of random assignment and matching is not clear</p> <p>Adherence to the programme is not clear</p>

<i>Parenting Outcomes & Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
McIntyre (2009)	Incredible Years Parenting Training (IYPT)	Of 57 pre-school children screened 49 met the inclusion criteria	Quantitative	Family Impact Questionnaire (reliable)	Observations: showed significant reduction in inappropriate negative behaviours (effect size 0.37)	Observation measure was piloted for reliability
	Manualised programme with checklist	21 completed treatment group 23 control	Randomized controlled trial	Child Behaviour Checklist (CBCL) (reliable)		Recruitment from 2 schools, was this representative of the population
	12 week group 2.5 hours per session	8-12 parents per group 88.5% attendance	Randomly assigned to group or control	Observation – coded by blind interpreter (inter-rater reliability 97.4-99.2%)	More praise was noticed but not significant change	Groups were not standard in size
	Comparison with usual care alone this included educational and multidisciplinary support	50% diagnosed with ASD Inclusion criteria child aged between 2 and 5 years Vineland Adaptive Behaviour score between 45-85 ambulatory and living with caregiver for at least 6 months	Pre – post intervention measures used 14-16 weeks apart		CBCL: significant reduction in behaviour problems ASD outcomes more negative behaviour pre intervention than other developmental difficulties same post intervention	Drop out was not controlled for in the analysis Only descriptive statistics used in analysis rather than investigations into group effects

<i>Parenting Outcomes & Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Okuno et al. (2011)	<p>Evaluation of a shortened parenting training programme designed for parents of children with ADHD</p> <p>4 small groups of 3 to 4 parents were reviewed</p>	<p>14 mothers of children diagnosed with a pervasive developmental disorder including 4 Asperger's syndrome, 3 autism and 7 PDD-NOS. 5 children also had diagnoses of ADHD</p> <p>Children were 4.2-9.6 years old</p> <p>37.5 years average age of primary caregiver</p> <p>Selected for group in order of application</p>	<p>Quantitative</p> <p>Measures: pre – within one month pre group post within one month after group</p> <p>Mothers and fathers completed measures</p>	<p>Confidence Degree Questionnaire (CDQ) – 5 point non-standardised scale, change in scores analysed</p> <p>Child Behaviour Checklist (CBCL)</p>	<p>Fathers showed no change on their scores pre – post test</p> <p>Significant differences for mothers indicating increased coping and understanding.</p> <p>CBCL no significant changes identified although 10/14 children's scores were lower</p>	<p>No correction of significance level for repeated t-tests (18 completed)</p> <p>Non-standardised measures with unknown reliability</p> <p>Small sample size</p> <p>No control group</p>

<i>Parenting Outcomes, Parent Outcomes & Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Pillay, et al. (2011)	<p>Evaluation of ASCEND parent programme</p> <p>11 sessions 2 hours each</p> <p>Evaluation of 7 groups from 2004-2007</p>	<p>79 parents of 58 children</p> <p>51.5% recruitment rate</p> <p>Child age 5-15</p> <p>Groups were matched by diagnosis in 2004 but not after</p> <p>59 parents of 44 children completed pre-post measures</p> <p>Parents included 3 grandparents</p>	<p>Quantitative</p> <p>Pre and post measures used for 5 groups after 2004 and evaluation</p> <p>Pre in first session post returned by post after the group</p>	<p>Developmental Behaviour Checklists (DBC) parent rated (validated)</p> <p>Parent satisfaction questionnaire (from ASCEND manual)</p> <p>A 22 item 10cm visual analogue scale measured parental learning</p>	<p>Increased confidence and awareness</p> <p>DBC n=55</p> <p>Total behaviour problems reduced</p> <p>Disruptive behaviour reduced</p> <p>Challenging behaviour significantly reduced</p> <p>Lower anxiety not significant</p> <p>Lower self absorbing behaviour not significant</p> <p>The majority of parents were satisfied with the group.</p>	<p>Groups were facilitated by different therapists with no assessment for fidelity of delivery</p> <p>Course changed following parent feedback</p> <p>No investigation of stability of baseline pre-intervention</p> <p>No control group</p> <p>Recruited over a long time period</p>

<i>Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Reed et al. (2009)	<p>Pilot study investigating the impact of parent training on teaching children to sleep and to see if behaviour improves as a result</p> <p>3 group sessions 2 hours each</p> <p>5 sessions were run</p>	<p>25 families of children with Autism, PDD-NOS and Asperger's where sleep is a concern</p> <p>Children with sleep apnoea and narcolepsy were excluded</p> <p>Included LD and medication</p> <p>22 families completed the training and 20 returned questionnaires</p>	<p>Quantitative</p> <p>Pre and post measures post within one month of completion</p>	<p>Children sleep habits questionnaire (reliable)</p> <p>Family Inventory of sleep habits 22 item 5 point Likert scale, parent report (not validated)</p> <p>Parental Concerns Questionnaire (PCQ) (validated)</p> <p>Repetitive behaviour scale – revised (RBS) – observer completed</p> <p>Parenting Stress Index – short form – parent rated</p> <p>Actigraphy watch</p>	<p>Significant improvement in sleep habits and 4 of 22 items about sleep habits (routines)</p> <p>Actigraphy n=12 sig improvement in time to get to sleep, night waking did not change</p> <p>PCQ – significant decrease hyperactivity, self stimulation, sleep disturbance</p> <p>RBS – behaviour improvement on restricted behaviour</p>	<p>Analysis used a correlation with an unmentioned measure</p> <p>No adjustment for multiple comparisons</p> <p>Small sample size</p> <p>Drop out not accounted for</p> <p>No control group</p> <p>No investigation into stability of baseline</p> <p>Use of non-validated measures</p>

<i>Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Roberts & Pickering (2010)	Investigation into the incredible years parenting programme modified for ASD 12 week manualised programme	Diagnosis of ASD or ASD under assessment 8 parents of 7 boys	Mixed methods Quantitative Pre measure 1 st session Post measure end of programme Qualitative evaluations	General Health Questionnaire GHQ – self rated (reliable) Eyberg Child Behaviour Inventory (ECBI) Social worries questionnaire The Australian scale of Asperger's syndrome	GHQ: Parental mental health significant ECBI intensity of behaviour score reduced not significant, remained higher than clinical cut odd Social worries and Australian scale no significant	Not all formally diagnosed with ASD Some parents had attended the course before Small sample size No investigation as to behaviour at baseline

<i>Parent and Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Roberts et al. (2011)	RCT investigating the effects of a home based (HB) intervention a small centre based programme(CB) and a non-treatment comparison group (WL)	95 recruited, 84 completed HB - 27 CB -29 WL – 28 Parents of children aged between 2.2-5 years 90.5% male	Quantitative	Pragmatic Profile of Everyday communication – parent completed	VABS –CB significant to other groups	Unknown the unique effect of the parenting group
	HB 2 hours support a fortnight	59 autistic 13 ASD 10 diagnosed but pre assessment		Developmental behaviour checklist (DBC) – parent completed	Beach HB – worse all domains not significant CB- improvement in all domains significant in parenting and total score WL- improved significant parenting	Participants may also have had other interventions WL group used more other interventions
	CB programme included a 40 week two hour a week group children also received intervention separately – 6 groups of 4-6 children	questioned diagnosis HB group higher proportion of children diagnoses autistic		Parenting Stress Index (PSI) – parent completed (standardised)	PSI – HB – increase CB- decrease WL - significant decrease	Children scored below floor cut off of the test
	Parents chose the focus of the group			Beach Family Quality of Life Questionnaire		
				Parent perception Questionnaire (non-standardised) Vineland adaptive Behaviour Scales (VABS) Reynells Developmental Language Scales	Reynells CB>HB significant	

<i>Parenting Outcomes, Parent Outcomes and Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Schultz, et al. (2012)	<p>Evaluation of a social competence Intervention for parents (SCI-P)</p> <p>SCI-P intervention ran in parallel to the SCI-A intervention for adolescents</p> <p>Comparison of SCI-A plus SCI-P to SCI-A alone</p> <p>SCI-A and SCI-P both run in group format for 1 hour twice a week for 10 weeks</p> <p>4 groups evaluated with 6 parents in each</p>	<p>Parents of children who participated in after school SCI-A</p> <p>27 parents participated</p> <p>Children were age 11-14 years</p> <p>Diagnosis Autism, PDD-NOS or Asperger's IQ>75</p> <p>Diagnoses validated</p>	<p>Quantitative</p> <p>Pre-post design</p> <p>Pre 2 weeks before</p> <p>Post 2 weeks after</p>	<p>Stress Index for parents of Adolescents (validated)</p> <p>The parenting sense of competence scale (validated)</p> <p>Youth Social Skills Responsiveness scale (SRC) (validated)</p> <p>Social Validity group experience</p> <p>All parent rated</p>	<p>Stress: significant reduction in stress SCI-P significantly better than SCI-A alone on parenting stress domains and total parenting stress</p> <p>Significantly less parenting incompetence in SCI-P group</p> <p>No significant reduction in competency</p> <p>No significant change in social behaviour</p>	<p>Quasi-experimental methodology</p> <p>Parents only assigned to waiting list when the SCI-P group did not coincide with SCI-A group</p> <p>Only using parent rated scales</p> <p>No measure of fidelity to treatment</p>

<i>Parenting Outcomes and Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Stahmer & Gist (2001)	Investigating the effect of pivotal response training (PRT) plus parent support group in comparison to PRT alone	22 families of children under 5 years old with a diagnosis of ASD for less than 6 months	Quantitative	MacArthur Communicative Developmental Index (CDI)	Support group was significantly better than PRT alone on use of PRT techniques	Other support was received by some of the parents
	Investigating effect on language and other characteristics in ASD	11 in parent information support group		Observations	More parents from support group reached criteria for Mastery in Observation post group, both groups improved technique.	Small sample size
	Half of parents in recruited were enrolled in the parent information group				Parents that met the criteria for PRT understood more words – effect of support group not investigated	The effect of the groups on CDI was not reported
	Parent support group was 1 hour a week for 12 weeks					

<i>Parent Outcomes and Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Tonge et al. (2006)	Investigation into the different outcomes from Parent education and behaviour management (PEMB), Parent education and counselling (PEC) to control for non-therapeutic effects and control group Both PEMB and PEC were delivered in 10 sessions each lasting 90minutes,4-5 families per group, sessions alternated with 10 60-minute individual sessions Control received local services	Parents of children aged 2.5-5 years were recruited via consecutive referrals	Quantitative Pre-measures Post-measure 2 weeks after and 6 month follow up	General Health Questionnaire (GHQ) – self administered (Validated) Parent Stress Thermometer visual analogue of general stress McMaster Family Assessment Device (FAD) (good validity) Developmental Behaviour Checklist (DBC) – parent rated (Validated) DBC- Autism screening algorithm The Psycho-educational Profile - Revised	Behaviour – Follow up both PEMB and PEC better than control group at follow up but no significant difference between PEMB and PEC GHQ – Follow up PEMB and PEC better than control PEBM more improvement on lower initial depression scores PEBM improved stress scores and FAD scores over 1.89 PEC scores improved FAD scores 1.75	Few participants in control scores over the range PEC had effect on FAD Multiple respondents from the same family All measures self report

<i>Parenting Outcomes and Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Venker et al. (2012)	<p>Investigate whether parents of children with ASD learn to implement verbal responsiveness to facilitate language development measured by a change in child communication acts</p> <p>2 groups treatment or delayed treatment</p> <p>Programme included 5 parent education sessions 2 hours each and 2 individual 45 minutes sessions and 14 small group sessions with the child with ASD</p>	<p>14 parent child dyads</p> <p>Children aged between 28-68 months</p>	<p>Quantitative</p> <p>Pre measure 1-2 weeks prior and post measure</p>	<p>Preschool language scale forth edition (PLS-4)</p> <p>Mullern Scales of Early Language (MSEL)</p> <p>McArthur Communicative Development Inventory (CDI) – parent report</p> <p>Autism Diagnostic Observation scale (ADOS) or ADOS toddler version (ADOS-T)</p> <p>10 minute free play</p>	<p>No difference at baseline between groups although delayed treatment group showed more expressive language</p> <p>Parents increased in all 4 target behavioural responses</p> <p>More children in treatment increased prompted communication</p> <p>Non-verbal communication increased significantly in treatment group</p>	<p>Assessors not blind to treatment group</p> <p>Small sample size</p> <p>Differences at baseline measures</p> <p>No stable baseline</p> <p>Different times between administration of baseline measures and start of the group, effects of maturation</p>

<i>Parenting Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Wang, (2008)	<p>Implement and evaluate the effectiveness of a comprehensive parent training programme on parent interactive skills with their child with ASD</p> <p>Utilising principles and strategies from ABA</p> <p>20 hours over 4 weeks 16 hours in 4 groups and 4 hours of home visits</p>	27 parents of children with ASD included 3 grandparents per group. 1 maternal auntie and 2 fathers in control group only	<p>Quantitative</p> <p>Pre and post measures</p>	<p>Childhood Autism Rating Scale (CARS) used to test for ASD and group differences</p> <p>Psycho-educational profile revised</p> <p>5 – 7 minutes observation coded with Maternal Behaviour Rating Scale (MBRS)</p>	<p>No differences pre intervention</p> <p>MBRS post measure significant increases in responsiveness and treatment affect (effect sizes 0.91, & 0.75 respectively)</p> <p>No other significant group differences</p> <p>Change in free play activities chosen by parents</p>	<p>Small sample size</p> <p>Repeated analysis of the same measure</p> <p>Unknown effect of group alone</p> <p>Short observation used to code behaviour</p>

<i>Parenting Outcomes and Child Outcomes</i>						
Author	Summary of research	Sample	Methodology	Measures used	Outcomes	Methodological limitations
Whittingham, et al. (2008)	<p>Efficacy of stepping stones Triple P for parents of children with ASD</p> <p>Hypothesis that SS would have positive impact upon parent reported behaviour problems and dysfunctional behaviour styles and parenting satisfaction and efficacy</p> <p>Comparison to waiting list control group</p> <p>Treatment as usual continued</p>	<p>59 families</p> <p>29 in treatment group and 30 in waiting list group</p> <p>Autism or Asperger's syndrome diagnoses</p>	<p>Quantitative</p> <p>Between – within subjects design</p> <p>Pre post and follow up measures</p>	<p>Family Background Questionnaire pre measure</p> <p>Eyberg Child behaviour Inventory (ECBI) (validated)</p> <p>Parenting Scale (PS) (not validated)</p> <p>Being a parent scale (validated)</p>	<p>ECBI – pre-post significantly lower behaviour in treatment group on intensity and problem scales (effect size 0.26)</p> <p>Pre-follow up significant reduction in intensity and problem scales (effect size 0.16)</p> <p>1/3 of group experienced clinically meaningful change</p> <p>PS - significant change in overreactivity, verbosity and increase in satisfaction of being a parent</p>	<p>Matched then allocated randomly to group</p> <p>WL received intervention before follow up measure completed</p> <p>No parties were blind to the allocation</p>

Who is doing this research?

I am Hannah Blanchard, 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 Liz Shea 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 – Consent Forms - Parents

Appendix IV v.2 (10.9.12)

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Consent Form



To be completed by the parent

<p>Participant 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 satisfactorily</p> <p>I understand that I do not have to take part and can stop at any point without giving a 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 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.</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.....</p>	<p>Please initial the box if you agree with the statement</p> <div style="display: flex; align-items: center; justify-content: center;"> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> </div> <div style="display: flex; align-items: center; justify-content: center;"> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> <div style="width: 20px; height: 20px; border: 1px solid black; margin: 5px;"></div> </div>
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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 I – Assent Form - Child

Appendix V v.2 (10/2/12)

Consent Form



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To be completed by young person

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	<input type="checkbox"/>	
I understand that I do not have to take part and can stop without giving any 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 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.	<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.....		
I consent for my child (name) to take part in this project		
Parent signature		

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– Topic Guide – 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

- *Think back 5 years before got the diagnosis. Is there any advice you would give to another family in that situation?*

APPENDIX K – Topic Guide – Siblings

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 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?

Prompts

- *Think back 5 years before got the diagnosis. Is there any advice you would give to your family knowing what you know now?*

APPENDIX L – Parent and Siblings Data Extracts

1	Restrictions	157	But I get him on the floor, kicking and ref, “I’m not going grrrrr”,	Behaviour
1	Restrictions	132 - 150	Out of the house. Getting him out of the car and into the chapel and er, we went to, we, Chris had his carol service and kicked up a fuss ...first getting him into the car, ... a lot of it is “I don’t want to come”, “why do I have to come” “it’s a waste of time”, “I wanna be at home”. And then getting him out of the car but I think there was an evening I think on this one he actually got out of the car for once, he did get out without too much trouble and came and was brilliant in the chapel, began get to the end saying “how long’s this gonna go on for” you know, “can we go now”. And we managed to get him in to erm, into the hallway, the kit, the canteen, it’s a big hall the canteen’s on the side and cause there were mince pies and er, and of course Chris was with him and we got him in there, loads of people but it was brilliant and er, he had a drink and we were there 10 minutes, “can we go now?” (laugh) we did, it was brilliant. ... he wouldn’t get out of the car erm, I tried to persuade, get Chris to take him ... didn’t get out of the car the whole time, wouldn’t wouldn’t ... again refused to get out of the car ... Chris did actually manage to get him into his house and go and see his room so he did manage to do it once ..., if he’s gonna stay in the car you can’t get him out.	ASD impacting on significant events, examples to support negative predictions and positive outcomes (exception) Struggle, difficult but normal life described as brilliant, Using sibling
1	What’s normal	590	“No I’m not” so I cause it’s not like a normal child saying no I’m	not typical child
1	Response to diagnosis	102 - 103	just a nightmare and Craig won’t understand and then he’ll come along and say ah “John’s a lot better now do you really think he’s still autistic”, erm yeah,	Partner’s understanding different - conflict
1	Hidden disability	174	Erm, I think as again, because John is not a needy disabled child	What does disabled mean? Not needy?
1	Plans constant	276- 278	I knew his feet need to be measured so I thought rather than take two trips to (place, town), lump it with his hair, do the two together and he’s gonna have that, I’ve told them already he’s gonna have to go in the Easter holidays cause his shoes will last him til the spring	Simplifying, planning

1	Constant-ness	557-558	because I can't just, we have to think, I have to think so much in advance of how I know we've gotta do this, how we're gonna get John round it. Erm, you can't just do things like spontaneously,	Constantly thinking
1	Parent and sibling shared understanding	563-570	he's brilliant but he does get frustrated sometimes when John's being a pain in the neck. And he'll say, oh well why can't I just have a normal brother who will interact, interact normally. Erm, and he does, he can get a bit upset, that's the very rare because Chris is very positive, quite a buoyant chap, he's lovely and erm, and because he is so in tuned into John and the way he works because they've grown up together, there's 2 years and 4 months between them. Erm, he is very tuned to him so, he does make allowances, he's very generous from that point of view and erm, you know, it's, it's only sometimes that he gets frustrated and less so now because they're both getting older and erm, and both able to negotiate perhaps a bit more and Chris is alright then John, you do it	Sibling wanting things to be different but has adapted. Good relationship with mum. He makes allowances. Can get frustrated.
1	Hidden disability	177	say "John, autistic, really?" To the wider world he just seems a bit you know he seems normal	Public don't notice his difficulties
1	What's ASD what's normal	306-314	Not because he's setting out to achieve something, like, erm, well now having said that John John's John's erm, not got the ability to be sly I suppose ... but he will sneak into the cupboard and ... when he knows that's the rule 2 a day he will sneak into the cupboard and eat more but then erm, whereas Chris will sneak into the cupboard and if I come into the kitchen he'll hide it, John'll just stand there eating it	Comparing behaviour to sibling. Not negative effect of ASD
1	Life revolving around ASD	273-274	it is is understanding what needs to be done that then trying to find ways of getting done what you know needs to be done.	Planning thinking about ASD
1	Family roles	166-172	he just will not understand or I, I don, I ju, I just don't un, i just don't know what it is with Craig, i really do not know whether, he's just like this and forgets or whether he's just so selfish that he couldn't give a damn I just do not know but erm but the two of them together makes it really really difficult cause if he could take on board how you need to treat John and and deal with John I think it would make it a bit easier ... so things are fun sometimes	Balancing, understanding and blaming Inflexible Sarcasm used to explain difficulty

4	Life revolves around ASD	510 - 511	<i>because just being me sets him off cause like, what he thinks about me is not someone to like spend time with it's more not really but I'd like to be that sort of person</i>	<i>Wanting things to be different</i>
4	Life revolves around ASD	18-21	<i>Tom's the boss, he's not the boss, no one the boss I don't think So he's not really the boss but when you think about him you do think about him being in charge a bit do you? Sometimes</i>	<i>Tom feels like he's in charge sometimes</i>
4	Life revolves around ASD	78-85	<i>Ok that sounds really frustrating; it sounds like you have to really think about what you are doing and not lose your temper with him I don't, yeah, I don't feel like I'm like setting him off because I like do subtle things Because what sorry Because I do subtle things, so it's harder for everyone to realise including me It's hard for you to realise Kind, Sometimes yeah What it's hard for you to realise if you're doing things that are going to set him off?</i>	<i>Not knowing what's going to happen. Being responsible. Changing own behaviour</i>
4	Comparison to Normal	313	<i>(sighs), I haven't had a brother without autism so I'm not sure I'd know</i>	<i>Not good just realising no perspective</i>
4	ASD behaviour	594 - 603	<i>Sometimes like when he's like attacking me I will hold onto his hands and like he's like let go of my hands and I'm like I don't want to let go of your hands So you might try and stop him from doing anything else by keeping hold of him It's awkward trying to keep hold of someone's hands and try to stop them kicking you at the same time And then does it look like you're the one doing something you shouldn't? Looks like we're both being annoying to each like Looks like it's both of you? Like "why can't you shut up Mark and Tom" cause the majority of people on the bus are a lot older than us</i>	<i>Aggressive behaviours. Trying to prevent them occurring in public. Taking the blame with his brother</i>
4	Equality	482 - 487	<i>I guess mum and dad have the job of calming Tom down and I'm like why can't you just get Tom to do what he's supposed to why can't we like tell him he has to go to his room because he's done something wrong, but my dad's like the only way to, the only way to do it is to calm him down so leave him alone for like a few minutes by the time he's done it it's like 10 minutes since he did something now Tom go to your room. By telling him when he's calm it makes him uncalm and when he's uncalm we can't get him to do what he wants and when you tell him to</i>	<i>Not understanding what parents are doing</i>

			<i>do something.</i>	
4	Equality	542 - 543	<i>I think, if I told my mum to shut up she'd be offended but Tom she'd be like not that bad, but like I'm not saying she'd be like that's ok but</i>	<i>Different treatment</i>
4	Equality	547	<i>Yeah, Tom's bar of being told off is higher than mine, I'm not sure how much higher but</i>	<i>Unclear about the different treatment. What he can do</i>

APPENDIX M – Stage 6 of IPA Process; Grouping of Themes



APPENDIX N – Stage 6 of IPA Process; Combined Themes

