

Psychological needs of neurotypical family members of individuals on the autism spectrum

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Declaration and signature of candidate	
<p>I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.</p> <p>I confirm that the decision to submit this thesis is my own.</p> <p>I confirm that except where explicitly stated, the work has not been submitted for another academic award.</p> <p>I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.</p> <p>Signed: _____ Date: _____</p>	

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Thesis Abstract

Chapter 1 reviews the psychological needs of family members of individuals with Autism Spectrum Disorder (ASD). A systematic search strategy was followed and 12 studies were reviewed which were published since a review by Tint & Weiss in 2015. The synthesis discusses relationships between the difficult experiences and stress, coping mechanisms, and their link to resilience and reduction of stress in parents.

Recommendations from Tint & Weiss' (2015) review which concerned mostly family members of adults with ASD, are reiterated by the presented review which contained research where the family member with ASD was a young person. Further qualitative research needs to be conducted in order to broaden the knowledge base and aim to understand the real life experiences of family members in order to develop the appropriate support to prevent escalation of family members' difficulties.

Chapter 2 addresses the gap in the literature of qualitatively involving siblings in research as previous studies largely gathered quantitative data from parents about siblings as opposed to directly. Photovoice (2016) was used as a photo elicitation method which emphasises participant involvement in both gathering data and analysis. 5 siblings of children with ASD took photographs answering the question 'what is it like having a brother with autism?' before completing an individual interview and group session where participants themselves brought their photographs into overall themes. A thematic analysis revealed main themes of focussing on their brother, difficult times, coping mechanisms, and 'it's not all bad'.

Clinical implications and suggestions for resilience-based interventions are discussed, with reference to supporting previous findings from chapter 1.

Chapter 3 presents two executive summaries, one written to be appropriate for young people, and one appropriate to a parent, carer, or professional reader. These are written with the main aim of disseminating within local CAMHS services.

NB: Papers within this thesis have been written with the intention of submission for publication to Autism: The International Journal of Research and Practice. Extensive author guidelines for manuscript submission can be found in Appendix A, and have been followed as far as is compatible with the purpose of university submission.

Chapter 1

What is known about the psychological impact on family members of individuals with an Autism Spectrum Disorder?

**A review of the recent
literature**

Word count - 6523

Abstract

Autism Spectrum Disorder (ASD) is a widely researched neurodevelopmental disorder which can have a variety of effects on a person's life. This research has largely focussed on the genetic, neurological, and psychological impact of the disorder upon the individual who has been given the diagnosis.

The aim of the review is to explore literature which has a focus upon the psychological impact on their family. Search terms were generated and databases were systematically searched from May to August 2017. The review focusses upon an update of literature published since Tint & Weiss' (2015) literature review, and considers twelve research studies' methodologies, results, and implications for practice which focus on the families of children and young people with ASD as opposed to Tint & Weiss' (2015) review which contained mainly papers relating to families of adults with ASD.

Studies were from across the globe, and few cultural differences were found between papers reviewed. Most studies employed quantitative methods, aside from two qualitative studies, and the majority focussed on parents' responses with the exception of one study which used siblings as participants. Synthesis showed relationships between difficult behaviours, stress, quality of life, and resilience among family members, primarily parents.

Recommendations from the review include increased study populations, potentially by increasing follow up data gathering, as well as the use of qualitative or mixed methodologies. This will facilitate an increase in the knowledge base which thus far indicates significant increases in both parental anxiety and depression, and sibling emotional and prosocial difficulties. These results warrant an increase in awareness among healthcare professionals particularly given the contact these family members will often have, owing to the needs of the individual with ASD.

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterised by social, cognitive, and other impairments which will have a significant impact upon how a person interacts with the world around them. The diagnostic criteria and diagnostic labels given to individuals by mental health professionals were updated in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-V; American Psychiatric Association, 2013). This change was very important for the Autism community, particularly as it denoted the removal of the term 'Asperger's Syndrome' which had previously indicated an ASD without language delay. This term, and the term Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) are now included under the term Autism Spectrum Disorders, and therefore under these guidelines no distinction is necessarily made between previous subtypes. This has received mixed feedback from individuals with ASD and their families, largely affected by the different assumptions the public assign to different labels given, and how this impacts service provision – commonly, Asperger's Syndrome may be viewed as 'higher functioning' than ASD though in functional terms this is not necessarily the case (Ne'emas & Kapp, 2012).

There have been many studies into ASD prevalence with varying results. Matson & Kozlowski (2010) discuss the varying prevalence rates among different studies published across the world from 1997 to 2010. They attributed relatively large discrepancies to differences in diagnosis and awareness. Russell et al. (2014) observed prevalence rates from the Millennium Cohort Study and found that of 14,043 children from the United Kingdom, 1.7% were reported as having been told by a healthcare professional that they have ASD.

Previous publications have varied in terms of the impact ASD is deemed to have on family. Some publications transparently focus on the positive impact and hope (e.g. Bierens, 2009), while others focus on stress and distress among family members, as is largely the case in the current review.

Rationale for the Review

At present, published psychological research predominantly considers the

psychological profiles and needs of individuals with ASD. There are also a wide variety of resources written for the general public which make these findings more available to individuals with ASD and their families. Accessible to those in the United Kingdom and elsewhere, The National Autistic Society (NAS, 2017) website readily acknowledges the psychological impact of ASD on the individual's family, and offers extensive information for parents, partners, children, siblings, and grandparents of individuals with ASD as well as on specific topics such as everyday life.

In practice, the National Institute for Clinical Excellence published guidelines (NICE, 2014) concerning ASD which emphasise the importance of family members and carers being offered post-diagnostic support. Specifically relating to psychological support, the British Psychological Society (BPS, 2006) released a position paper about ASD which included the importance of providing services for families which are responsive to their needs. They also state that an important part of being a practitioner psychologist is providing emotional support to family. In light of this, it is important that families' needs continue to be considered within the development and structure of psychological services. A wide-reaching way of assessing the needs of families and the support they may benefit from is to conduct research and translate what is known into evidence-based practice.

Review Question

The initial search question was as follows -

What is known about the psychological needs of family members of individuals with ASD?

Aim

This review aims to give a summary of the published literature exploring people's experiences of having a family member with an Autism Spectrum Disorder. The included studies have been reviewed critically and summaries presented and synthesised. This will give a direction for future research with the aim of improving the research base to inform services for families of individuals with Autism Spectrum Disorders.

Method

Preliminary Search

The Cochrane Library was initially searched with the term “autism” to identify any systematic reviews which had already taken place in the area. There were reviews published about ASD, including family therapy use in ASD, but none focused on the needs or experiences of family members.

From an initial scoping search, a literature review was found focussing on experience of siblings of children with ASD (Smith & Elder, 2010). This review focussed on parental and sibling characteristics, relationships, and adjustment. This review forms an important contribution to the literature about family members of children with ASD; however, this review has a more direct focus on family members’ psychological needs.

Development of Search Terms

The important components of the review question were family, psychological needs, and ASD. These provided key search terms and care was taken to ensure all variables of terms were included, particularly when considering the recent change in terminology for ASD. Terms are given in figure 1.

Concept	Search terms used
Family	Famil* OR matern* OR mother* OR patern* OR father* OR sibling* OR carer* OR parent* OR brother* OR sister*
Psychological needs	Psychol*
ASD	Autis* OR Asperger* OR “ASD” OR “ASC”

Figure 1: Search terms used.

Following search results, it was concluded that there was no review focussing directly on psychological experiences of family members of individuals with ASD and therefore this review would serve to consolidate information within the field and propose future directions for research.

Inclusion and Exclusion Criteria

Inclusion

- Published in English
- Based on Autism Spectrum Disorders specifically, and solely (that is, without comorbidities which have not been controlled for)
- Focus on family members
- Considers psychological factors
- Published in a peer review journal

Exclusion

- Studies with a genetic basis

Search Strategy

The terms were searched across three databases (AMED, PsychINFO, and CINAHL) on 19th May 2017 using the HDAS databases. This generated 515 results, of which 28 duplicates were removed, leaving 487 unique articles. Web of science was also searched on 17th July 2017 which produced 28 additional unique articles after the removal of 16 which were duplicates from the previous search. An alert was also set up to identify new articles which met the criteria though none were presented prior to the writing of this review.

Screening Process

The researcher carried out a title screening process to remove titles which could be easily stated as not relevant to the present research. These included titles where clear non-relevant terms were given e.g. Down's Syndrome with no mention of ASD. These were verified with the clinical supervisor and any uncertainties were taken to the next stage of the process – abstract level. 306 were removed during the title screen, leaving 209 to be screened at abstract level. 136 were removed at abstract level leaving 73 full text articles to be reviewed. This resulted in 41 articles which met inclusion and exclusion criteria. The full search and screening process is detailed in Figure 2. It is worth noting that there were several dissertations found as part of the search, which were excluded due to the peer review inclusion criteria of this review. These undoubtedly contribute a significant amount of evidence to the knowledge base and will be considered in future original research in this area.

Hand searching took place throughout the process. Authors of relevant papers and linked articles were searched to ensure that the fullest picture possible was found. This produced 6 extra papers.

Due to there being 41 articles remaining for in depth review, which met all of the above inclusion and exclusion criteria, a decision was made to exclude research which took place within the United States of America (USA) due to the significantly different service provision and health services. This resulted in the exclusion of 15 otherwise relevant articles which narrows the remit of this review. Hand searching at this stage brought to light a literature review by Tint & Weiss (2015).

Tint & Weiss' (2015) review considered 86 articles which discussed the wellbeing of family members of individuals with ASD. The majority of the reviewed articles focussed on parents (81 of 86), took place in the United States (40 of 86) and concerned families of adults with ASD (56 of 86). The articles covered a variety of indicators of wellbeing, including mental and physical health, stress, and quality of life. They concluded that many studies used vague concepts which left a lack of synthesis and clarity of results. The authors propose a systemic or social-ecological model of wellbeing in order to consider multiple factors and better represent families' needs. Studies also tended to focus on single caregivers, often mothers, and use single dimensional measures; there is a need for the views of other family members and for increased variables to be considered to give a broader view. Further reviews were encouraged by the authors in order to continue to highlight gaps in knowledge and guide future research.

Considering the high number of articles with a similar focus in Tint & Weiss' (2015) review, the current review will only consider literature published since this date. The final sample therefore of non-USA research, published since 2015, comprised 12 articles.

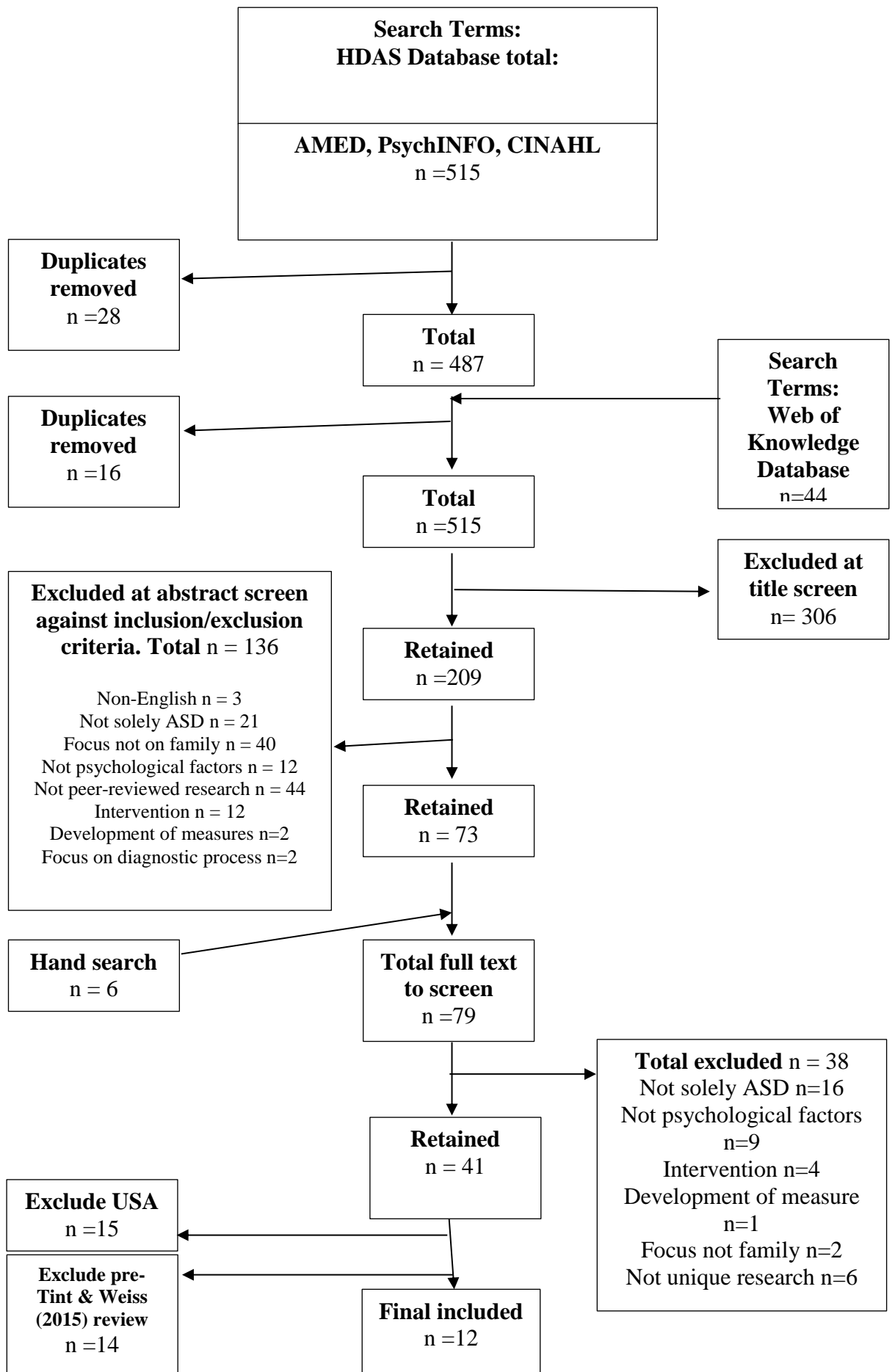


Figure 2: Flowchart of article screening and selection process

Results

Quality Assessment

Twelve papers were critically reviewed for this article, of which ten used quantitative methodology and two used qualitative analysis. Although all papers have been published in peer-reviewed journals, it is important to consider their quality. Jesson et al. (2011) discuss the importance of critically assessing the quality of original sources when completing a literature review, even where a full systematic review methodology has not been completed. The CASP tools for qualitative research (CASP, 2017a) and cohort studies (CASP, 2017b) were chosen as they give a concise way of structuring a critical review of a paper (Nadelson & Nadelson, 2014), as well as giving different tools focussed on different methodologies. This was particularly important as this review has not excluded any articles based on methodology. It is helpful to be able to review different methodologies with similar questions to allow for synthesis of results and themes in order to summarise the results. The CASP also prompts assessment of areas both positively and negatively, forming a critical appraisal as opposed to a purely negative focus – the importance of this is emphasised by Jesson et al. (2011). The CASP analyses are in Appendix B. All studies had clear aims and largely recruited acceptably (exceptions are discussed in more detail below). Most of the quantitative studies did not fully account for confounding variables, with some articles – Ahmad & Dardas (2015) and Yu et al. (2015) not identifying confounding variables at all. In the quantitative studies, the results were of varying precision, accounting for either moderate variance or lower. Neither of the two qualitative studies discussed the impact of the researcher/participant relationship on the outcomes. None of the studies included any follow up though outcomes did largely fit with the other available evidence.

The target family members for the reviewed articles were in two distinct categories – parents or siblings. This review will therefore consider the articles within these two categories, as opposed to separating by methodology which was largely quantitative. Having used review tools both from the same source, both qualitative and quantitative studies have been

appraised against similar standards which will enable an easier, though indirect, comparison. Studies will be discussed in chronological order to support understanding of individual papers, before summaries, synthesis, and discussion of overall themes.

Table 1 gives a condensed overview of each paper discussed.

	Sample	Recruitment strategy	Type of Study	Study Aim	Main findings	Strengths	Limitations
<i>Bitsika et al. (2015)</i>	75 siblings (8-18yrs) of individuals with ASD (3-23yrs) Even gender and older/younger split Australia	Electronic and paper adverts with state's autism service and sport/recreation service	Quantitative - SEARS - CASI	To explore effects of the sibling relationship, including 'child' and 'family' factors.	Higher instances of DSM-V diagnosable anxiety (38.7%) and depression (28%) than previous studies.	Use of validated measures Siblings completed measures for themselves	Little demographic information on participants to allow to judgement of representativeness.
<i>Rayan & Ahmad (2017)</i>	104 parents of children with ASD (31 fathers) 71% had medical insurance covering speech therapy and behavioural therapy Jordan	Through 10 community centres with ASD services across Jordan	Quantitative - DASS-21 - PRC subscale of CERQ	To explore links between positive stress reappraisal coping and distress in parents.	PRC scores significantly predicted stress, anxiety and depression, after controlling for parental age and gender.	Use of validated measures	Low proportion (31/104) of fathers compared to mothers.

	Sample	Recruitment strategy	Type of Study	Study Aim	Main findings	Strengths	Limitations
Yu et al. (2016)	121 mothers of preschool children diagnosed with ASD. China	All first appointment mothers attending an ASD clinic	Quantitative - DBC-P - CWCQ - Affiliate Stigma Scale	To evaluate prevalence of affective disorders among mothers, and identify associated factors.	DBC scores significantly ($p < 0.001$) higher in children of mother with an affective disorder. Multiple mother/environment variables significantly associated with affective disorder prevalence.	Considered characteristics of those who declined to participate Use of validated measures	Underplayed involvement of previous psychiatric history – it is mentioned but inclusion of such cases is not justified. Cross-sectional design with no follow up
Keenan et al. (2016)	24 ASD children (7-14yrs) and 24 TD children (7-12yrs), with each child's primary caregiver (including parents, grandparents and step parents) Australia	N=11 recruited from other research study Online noticeboards Community groups Schools	Quantitative - Security Scale - CSQ - K-10 - PSI-SF - ECR-R	To explore relationships between child attachment style and parental distress/stress/romantic attachment style.	Higher psychological distress, parenting stress, and attachment-related anxiety in ASD parents than TD. No significant difference between TD and ASD children's reports of security of attachment.	TD comparison used Use of validated measures Measures given to ASD child	11 ps from 'existing research study' not explained. Siblings – parents asked to report on 'parenting stress in relation to each child'. Is this easily distinguishable?

	Sample	Recruitment strategy	Type of Study	Study Aim	Main findings	Strengths	Limitations
<i>Di Biasi et al. (2016)</i>	<p>26 TD Siblings (age 4-12yrs) of children with ASD.</p> <p>14vs12 gender split and older/younger split</p> <p>Italy</p>	Psychiatrist contacted eligible families from child psychiatry centres.	<p>Quantitative</p> <p>All completed by parent (for sibling)</p> <ul style="list-style-type: none"> - SRS - CBCL (for parent) - PSI-SF 	To explore variables affecting siblings of children with ASD.	<p>Parental distress was higher when siblings were older than the child with ASD.</p> <p>Maladaptive symptoms positively correlated with sibling's age.</p>	Use of validated measures	<p>88% of families high/medium socioeconomic status – not representative</p> <p>Parents completing measures on behalf of siblings</p> <p>Small sample size</p>
<i>Lai et al. (2015)</i>	<p>136 parents – 54% with a child with ASD and 46% without.</p> <p>80.9% mothers</p> <p>81.6% Chinese</p> <p>Singapore</p>	<p>ASD – Neurobehavioural Clinic attendees sent invite letters</p> <p>Control – Student Health Centre advertising posters</p>	<p>Quantitative</p> <ul style="list-style-type: none"> - PSI-SF - DASS-21 - Brief COPE 	To ascertain if parents of ASD children use more adaptive or maladaptive coping strategies than parents of TD children.	Parents of ASD children experience more stress and depression, and use more maladaptive coping strategies than TD children's parents.	Use of validated measures	Only captures parents of children with ASD who have sought specific professional support.

	Sample	Recruitment strategy	Type of Study	Study Aim	Main findings	Strengths	Limitations
<i>Whitehead et al. (2015)</i>	438 female primary caregivers (biological/foster/step/grandparents) Australia	Contacted 45 autism services after a search. 11 agreed to publicise and recruit both online and offline.	Quantitative - DASS-21 - CD-RISC-35 - DBC-P24 - LCB - Brief COPE - SSI - SOS	To explore psychological distress and resilience in families of children with ASD.	Predictors explored account for 47% of variance in DASS-21 and CD-RISC scores.	Use of validated measures	Sample not representative – mostly Caucasian. Fathers' data excluded without rationale given.
<i>Gong et al. (2015)</i>	196 parents of children with ASD (23-144months) 113 control parents of TD children (23-143months) China		Quantitative - PSI - ABC - CARS - SDS - SAS	To explore stress, distress, and relationship with depressive/anxiety symptoms in parents of children with ASD.	Parents of children with ASD reported significantly higher stress on all scales of PSI measure. Total ABC score, maternal anxiety symptom and child's age accounted for 54.9% of variance of parenting stress scores.	Use of validated measures	Lack of detail about recruitment and sample characteristics .

	Sample	Recruitment strategy	Type of Study	Study Aim	Main findings	Strengths	Limitations
Gona et al. (2016)	<p>103 ps</p> <p>Parents of children with ASD.</p> <p>Professionals in regular contact with parents of children with ASD.</p> <p>Kenya</p>	<p>Parents</p> <ul style="list-style-type: none"> - Neuro-assessment centre (rural) - Educational assessment centre and resource centre (urban) <p>Professionals</p> <ul style="list-style-type: none"> - Special Units - Schools - Hospitals - Social Services 	<p>Qualitative</p> <ul style="list-style-type: none"> - 37ps completed individual interviews - 66ps took part in focus groups <p>Content analysis</p>	To explore challenges and coping among parents of children with ASD.	Important themes including support needed, both physically and emotionally. Also, coping strategies including diet and religion.	Includes varying locations, and parents as well as professionals	<p>Transcripts translated from Swahili to English prior to analysis – may lose some richness of data, and meaning?</p> <p>Unclear parent/ professional split on interviews compared to focus groups.</p> <p>Questions negatively weighted – ‘what challenges...?’</p>

	Sample	Recruitment strategy	Type of Study	Study Aim	Main findings	Strengths	Limitations
Ahmad & Dardas (2015)	101 fathers of children with ASD Jordan	Licensed special education centres	Quantitative - PSI-SF - WHOQOL-BREF	To find predictors of fathers' quality of life	Model accounted for 28% of variance - including quality of life, parental distress, level of education, child's gender, and difficult child subscale most predictive (in order highest to lowest).	Use of validated measures	
Derguy et al. (2015)	162 mothers and fathers (from 50 families of children with ASD and 56 control families) France	ASD - Diagnosis centres - parent associations - Care centres - Schools Control - Schools Total of 21 recruiting centres	Qualitative Content Analysis	To explore the needs of parents with children with ASD in a French sample	6 levels of need - Information - Emotional support - Material - Daily management - Parental Guidance - Relational support	Multiple recruitment sites aiming to be spread geographically to gain representative sample. Rigorous and detailed explanation of analysis method.	Recordings not used – data set is reports written by interviewers after interviews.

	Sample	Recruitment strategy	Type of Study	Study Aim	Main findings	Strengths	Limitations
Garcia-Lopez et al. (2016)	76 sets of biological parents of children with ASD (age 3-18yrs) Spain	Learning Disabilities unit Autism school Spanish professional association of autism	Quantitative - CARS - BPI - PSOC - KIPP-PC - PSI - HADS	To explore the impact of actor-partner influence on parental psychological adaptation.	Higher parental efficacy, and controllability predicts decreased anxiety, stress, and depression, and increased wellbeing among mothers and fathers. Increased happiness and fulfilment predicted decreased stress.	Multiple recruitment sites Inclusion of positive measure Use of validated measures	Lack of clarity for variance accounted for

Table 1: Summary of reviewed articles.

ABC – Autism Behaviour Checklist; ASD – Autism Spectrum Disorder; BPI – Behaviour Problems Inventory; CARS - Childhood Autism Rating Scale; CASI – Child and Adolescent Symptom Inventory; CBCL – Child Behaviour Checklist; CD-RISC-25 – Connor Davidson Resilience Scale; CERQ - Cognitive Emotion Regulation Questionnaire; CSQ – Coping Strategies Questionnaire; CWCQ – Chinese Ways of Coping Questionnaire; DASS-21 – Depression Anxiety Stress Scales-21; DBC(-P) – Developmental Behaviour Checklist (Primary carer version); ECR-R – Experiences in Close Relationships-Revised; HADS – Hospital Anxiety and Depression Scale; K-10 – Kessler Psychological Distress Scale; KIPP-PC – Kansas Inventory of Parental Perceptions Positive Contributions scale; LCB – Locus of Control of Behaviour Scale; PRC– Positive Reappraisal Coping; PSI-SF – Parenting Stress Index Short Form; PSOC – Parent Sense of Competence Scale; SAS – Self-rating Anxiety Scale; SDS -Self-Rating Depressive Scale; SEARS- Social Emotional Assets and Resilience Scales; SOS – Service Obstacles Scale; SRS – Social Responsiveness Scale; TD – Typically Developing; SSI – Social Support Index; WHOQOL-BREF – World Health Organisation Quality of Life Assessment – Brief Self-Administered Instrument

There was a large variation in study location and therefore papers will initially be considered in terms of continent to make clear any cultural differences which are present in studies.

Studies from Asia

Ahmad & Dardas (2015) explored the quality of life of fathers with children with ASD in Jordan, using 2 validated outcome measures. Their resulting model accounted for 28% of variance of fathers' quality of life, of which parental distress was the greatest predictor. The authors call for more qualitative research to improve understanding.

Lai et al. (2015) compared use of adaptive and maladaptive coping mechanisms between parents of children with and without ASD in Singapore. They used 3 validated measures and found that parents of children with ASD used significantly more maladaptive coping mechanisms, and experience of more stress and depression symptoms than parents without an autistic child. The recruitment strategy only targeted parents who were accessing a specific neuro-behavioural support centre which, the authors acknowledge, may not be representative of the general population of Singapore.

Gong et al. (2015) explored the relationship between stress and distress, and depression/anxiety symptoms by comparing parents of children with ASD to control parents. They used 5 validated measures considering both parent and child variables and created a model where total ABC score, maternal anxiety symptoms and child's age accounted for 54.9% of variance predicting parental stress. The key area missing from the paper is detail about recruitment and sample characteristics – the authors acknowledge that they did not measure mothers' and fathers' stress separately but do not elaborate on the proportions of each gender.

Yu et al. (2016) explored the prevalence of affective disorders among mothers of preschool children with ASD in China. They used 3 validated measures and considered the characteristics of mothers who declined to take part, which was not the case for any of the other reviewed studies. They did, though, include participants with mental health difficulties which predated the birth of their child with ASD, the rationale for which was not convincingly argued. They found a large number of variables which were significantly associated with maternal affective disorders including having a

lower income, lack of confidantes, family history of mental illness, and mothers' scores on the stigma scale and CWCQ-resigned distancing subscale. The only child factor which was significantly associated was DBC scores.

Rayan & Ahmad (2017) considered the relationship between positive stress appraisal and psychological distress among parents of children with ASD in Jordan. They used multiple recruitment sites and 2 validated measures. Only 31/104 participants were fathers, a similar sample difficulty to other studies (e.g. Lai et al. 2015). The results showed PRC scores significantly predicted parental stress, anxiety and depression once age and gender had been controlled for.

The Asian studies reviewed were all quantitative exploring parental factors and largely lacked male family members' inputs. It is interesting that Ahmad & Dardas (2015) noted this gap in the literature and chose to solely focus on fathers' quality of life. Their aim and results was slightly different to other studies looking at both parents, with distress being a key predictor of poor quality of life, where other studies looked at predictors of such distress, prior to considering the impact of this distress upon the individual's life.

Studies from Africa

Gona et al. (2016) conducted the only reviewed study which took place in Africa. They used a qualitative methodology to explore the challenges faced by parents of children with ASD as there is little known about the subject in African culture. They used individual interviews and focus groups, covering an urban and a rural county and both parents and professionals. The authors appear to have spent a lot of time considering triangulations and how to make the outcomes representative of the Kenyan population which is a key strength of the paper. The resulting themes were like the other studies, including stigma and care-giver burden, though other themes such as religious influences and diet have not been highlighted in other papers, possibly due to constraints of pre-validated questionnaires. This paper gives evidence that impact upon families may have similarities across cultures, but further qualitative papers will broaden the knowledge of this as inevitably themes will arise which were not initially expected when participants are given the chance to speak freely in an interview.

Studies from Oceania

Bitsika et al. (2015) recruited 75 siblings of children with ASD and explored a large number of variables using 2 validated self-report measures exploring resilience and anxiety/depression symptoms - siblings responded themselves, which is a strength of the paper. The results showed more siblings reporting clinically diagnosable symptoms of anxiety (38.7%) and depression (28%) than previous studies, indicating a more serious issue being present for siblings than was previously thought. The authors acknowledge that the inclusion of siblings with other psychiatric diagnoses does confound results, being significantly associated with increased anxiety, but significantly linked to increased depression.

Whitehead et al (2015) explored psychological distress and resilience among family members of children with ASD. They also recruited using multiple sites across the state and both online and offline promotion to increase the representativeness of the sample. Seven validated measures were analysed from 438 female participants, the largest sample of the review, though the authors do not appear to account for their removal of male participants despite them being a small percentage of the respondents (5%), their data was never analysed. A low number of male participants is a continued theme across research presented, and therefore it is more of a shame that data was collected but never used. The model produced accounts for 47% of variance for distress and resilience scores and factors were consistent with other models presented from other countries' research.

Keenan et al. (2016) explored child attachment, and caregiver factors including distress, stress, and romantic attachment. The authors included step, foster, biological, and grand-parents in the study similar to Whitehead et al. (2016) and these are the only two studies to do so. Five validated measures were used, including a measure for the child with ASD to complete. Results were similar to previous findings both in Australia and beyond; parents of children with ASD reported higher distress, parenting stress, and attachment-related anxiety compared to parents of typically developing (TD) children.

Overall, the findings from the studies in Oceania are similar to those previously and from other countries, with some plausible additions e.g.

attachment-related anxiety. The strength of these 3 Australian studies is within the recruitment, and samples used which is noticeably more inclusive than others discussed thus far. Including other informants, including the child's view of their relationship with their parents, adds further evidence to findings.

Studies from Europe

Derguy et al. (2015) used semi-structured interviews to explore the needs of French parents with children with ASD. The authors recruited for a year across multiple sites, and used a control group for comparison. A major flaw in the analysis is the use of interviewer reports as opposed to recordings which brings into question the validity of the raw data, though the authors do give a detailed account of the analysis process. The authors acknowledge this as a limitation though they do not appear to explore the significance of the impact of this as a methodology. The themes do echo previous findings, which adds to the knowledge base significantly due to the limited amount of qualitative research in the area.

Di Biasi et al. (2016) explored variables affecting siblings of children with ASD in Italy, the only paper to consider siblings in this review other than Bitsika et al. (2015) in Australia. They used 3 validated measures which were compared by parents about siblings, and the authors acknowledged they needed more participants to gain power, though they do present the article as a pilot study. The results contrast with the other sibling study in the review, as Di Biasi et al. (2016) claim that 'ASD-siblings are not exposed to a higher risk... of psychosocial maladjustment'. This may be due to the sample being biased towards a high socioeconomic background and therefore were not representative. Indeed, Derguy et al.'s (2015) study in France found a significant effect of employment levels, which is linked to socioeconomic status.

Garcia-Lopez et al. (2016) studied parent dyads in Spain using 6 validated measures including a positive measure (KIPP-PC). They found that an increase in parental efficacy and controllability predicted decreased anxiety, stress, and depression, as well as increased wellbeing among both mothers and fathers. They also found that increased happiness and fulfilment

predicted lower stress levels – the only reviewed study to directly consider benefits from having a child with ASD.

Overall there were no obvious differences between outcomes regardless of the location of the sample. This may be more evident in qualitative research where participants can speak more freely as opposed to being constrained by questionnaires. This is something which would be helpful to explore in future to identify culturally specific needs which have not yet been researched. Whilst the above studies using validated measures is a clear strength, it can be assumed that questionnaires will only be validated and chosen for use if there is existing evidence for a particular phenomenon. Many studies also used similar validated measures such as the PSI (Haskett et al., 2006). It is a strength of the studies that they all used validated measures which allowed for comparison against the general population statistics. However, the bulk of research evidence being based upon the same measure may mean results are partly due to biases in the measure as opposed to being a complete and true picture of family members' wellbeing. Studies largely had a strong recruitment strategy including multiple sources of participants, though the participants themselves were not always representative of the local community. In particular, male family members were lacking in all but Ahmad & Dardas' (2015) research which made fathers the focus of their research for this reason. Many of the studies discuss the need for longitudinal research as impact on individuals may change over time, and this is clear in Appendix A where none of the studies include a follow up. This may be particularly pertinent given findings (Di Biasi et al., 2016) that maladaptive symptoms increased with siblings' ages. Following up the same participants would increase the validity of findings for any of the above studies.

Much of the research reviewed was quantitative and completed by parents, even in cases where they were not the primary research focus. Asking individuals affected be they siblings, individuals with ASD, or outside parties, will triangulate data as some of the reviewed studies did, to increase the reliability of results.

Discussion

This review was completed with the aim of bringing together the literature which has a focus on the psychological needs of family members of individuals with ASD. Summarising the outcomes, the above literature strongly argues negative effects on family members of a child with ASD. Gong et al. (2015) and Keenan et al. (2016) found results showing higher parental stress in parents of children with ASD as opposed to typically developing children. Yu et al. (2016) found that an increase in the child with ASD's difficult behaviours was linked with increased affective disorders among mothers. Whitehead et al. (2015) and Ahmad & Dardas (2015) also linked behavioural disturbance with increased parental distress. Ahmad & Dardas' (2015) focus on fathers also found that distress predicted quality of life, and therefore it may be assumed that other parents or carers of individuals with ASD may experience poorer quality of life than families who do not experience the same levels of difficult behaviour in the home. Focussing on families' mental wellness, multiple studies showed increased anxiety and depression levels in both parents and siblings of individuals with ASD (Gong et al., 2015, Bitsika et al., 2015, Keenan et al., 2016; Di Biasi et al., 2016). Derguy et al. (2016) found qualitatively that emotional needs were important to parents, in support of Whitehead et al. (2015) who found that social support was a predictor of reduced distress and increased resilience. Garcia-Lopez et al. (2016) further support Whitehead et al. (2015)'s findings that an internal locus of control predicts reduced distress, as Garcia-Lopez and colleagues found a relationship between increased parental efficacy and decreased stress, anxiety and depression. As a natural progression from the above described difficulties, some studies focussed more on how family members managed their distress. Lai et al (2015) found that maladaptive coping mechanisms were linked with higher parental stress. Conversely, Gona et al. (2016), Whitehead et al. (2015) and Rayan & Ahmad (2017) found that adaptive coping mechanisms predicted lower stress levels and parental distress, and higher resilience. Positively, as well as being linked to a decrease in parental distress (Whitehead et al.,

2015), Bitsika et al. (2015) found that resilience was linked to decreased anxiety though this was only the case in child siblings under 12years old. The qualitative studies (Gona et al., 2016 & Derguy et al., 2016) considered many other areas which were otherwise not directly researched. These included stigma experienced by parents, a lack of appropriate support, and daily, material, and financial needs.

Overall, there is a narrative of family members of individuals with ASD experiencing difficulties which significantly affect their wellbeing, and mental health. This then leads to the development of coping mechanisms which may be either adaptive or maladaptive – the variables which result in which strategies are developed appears to remain unclear. Those who do develop helpful coping mechanisms are likely to report an improvement in both their distress and resilience compared to those who have not.

This serves to update Tint & Weiss' (2015) synthesis to continue to keep an up-to-date understanding of research, informing the support of family members. Building on Tint & Weiss' (2015) review, the findings of this review confirm the ongoing need for an increase in qualitative and exploratory research as there are many factors which are lacking investigation and therefore understanding, due to the targeted nature of quantitative studies which use focussed measures.

Clinical Implications

Due to the nature of ASD assessments and potential ongoing support, it is highly likely that family members will be in contact with mental health professionals more so than families without children with similar difficulties. As such, it is important for mental health professionals to be aware that although family members may not be attending appointments, clinics, or schools for their own support, they are likely to have psychological needs which would benefit from consideration. It is also likely that the psychological needs of family members may affect both the likelihood of attendance at mental health services, and the perception of the child's behaviour and how this is presented to mental health professionals.

The synthesised findings of increased parental distress and the impact of development of coping mechanisms and resilience, give important insights into how professionals can better support individuals proactively prior to

difficulties potentially reach clinical significance as was the case for some of the participants detailed above (e.g. Yu et al., 2016).

Review Limitations

The main limitations of the review were exclusion of studies which were otherwise relevant due to inclusion criteria as described during the screening process. The major source of this was non-peer reviewed papers including dissertations. This means the papers reviewed may be subject to publication bias and important findings either from research which will never be, or has yet to be published in a scientific journal, has not been included in the synthesis.

The review gives a picture of the research breadth from diverse cultures and contexts, but does not present a depth of research from similar cultures which would allow for comparison and triangulation of findings. As culture is inevitably an important variable in the findings, it will be important for research to continue within individual countries to build depth and further evidence to confirm findings with different participants and settings of the same culture.

It is worth noting that research reviewed spanned children with ASD from 23months to 23years. Focussing on children and young people was not a criterion of the literature search though it is interesting given Tint & Weiss' (2015) review unintentionally including a majority of adult individuals. In this manner, this review has added to the current summary of knowledge by focussing more on families of children with ASD.

The review was completed by an independent researcher, and so the screening process and adherence to inclusion/exclusion criteria may be down to interpretation. The stages of screening have been described in a transparent way and decisions clarified in order to improve readers' understanding of this.

Future Research

Considering the worldwide population of people with ASD, the sample populations used in many of the above studies are low. Follow up data would increase the data set available, particularly for quantitative comparisons. Tint & Weiss (2015) recommended an increase in qualitative research and this remains an area which lacks full investigation given the low proportion of

explorative studies in this review. Initially it would be helpful to explore the needs of families more widely, in order to ascertain areas which may have been missed, as was demonstrated by multiple themes from this review's two qualitative studies. Mixed methods studies could then enable a link between quantitative evidence of such topics, and qualitative views on how individuals would like to be supported.

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Appendix

Appendix A - Journal Submission Guidelines

Autism is a major, peer-reviewed, international journal, published 8 times a year, providing research of direct and practical relevance to help improve the quality of life for individuals with autism or autism-related disorders. It is interdisciplinary in nature, focusing on evaluative research in all areas, including: intervention; diagnosis; training; education; neuroscience; psychological processes; evaluation of particular therapies; quality of life issues; family issues and family services; medical and genetic issues; epidemiological research.

Autism provides a major international forum for peer-reviewed research of direct and practical relevance to improving the quality of life for individuals with autism or autism-related disorders. The journal's success and popularity reflect the recent worldwide growth in the research and understanding of autistic spectrum disorders, and the consequent impact on the provision of treatment and care.

Autism is interdisciplinary in nature, focusing on evaluative research in all areas, including:

- intervention
- diagnosis
- training
- education
- neuroscience
- psychological processes
- evaluation of particular therapies
- quality of life issues
- family issues and family services
- medical and genetic issues
- epidemiological research

1. What do we publish?

1.1 Aims & Scope

Before submitting your manuscript to *Autism*, please ensure you have read the Aims & Scope.

1.2 Article Types

The Journal considers the following kinds of article for publication:

Research Reports. Full papers describing new empirical findings;

Review Articles

- (a) general reviews that provide a synthesis of an area of autism research;
- (b) critiques - focused and provocative reviews that may be followed by a number of invited commentaries, with a concluding reply from the main author.

Both full Research Reports and Review Articles are generally restricted to a maximum of 6,000 words, including all elements (title page, abstract, notes, tables, text), but excluding references. Editors may ask authors to make certain cuts before sending the article out for review.

Short Reports. Brief papers restricted to a maximum of 2,000 words with no more than two tables and 15 references. Short reports could include other approaches like discussions, new or controversial ideas, comments, perspectives, critiques, or preliminary findings. The title should begin with 'Short Report'.

Letters to the Editors. Readers' letters should address issues raised by published articles. The decision to publish is made by the Editors, in order to ensure a timely appearance in print. Letters should be no more than 800 words, with no tables and a maximum of 5 references.

1.3 Writing your paper

The SAGE Author Gateway has some general advice and on how to get published, plus links to further resources.

1.3.1 Make your article discoverable

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: [How to Help Readers Find Your Article Online](#).

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2. Editorial policies

2.1 Peer review policy

Autism operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and, the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each new submission is carefully read by one of the Editors to decide whether it has a reasonable chance of getting published. If the Editor thinks it does not have this chance, at least one other Editor will be consulted before finally deciding whether or not to send the manuscript out for review. Autism strives to do this within two weeks after submission, so that authors do not have to wait long for a rejection.

Feedback is also provided on how to improve the manuscript, or what other journal would be more suitable. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within (e.g.) 6-8 weeks of submission. As part of the submission process, you will be asked to provide the names of 2 peers who could be called upon to review your manuscript. Recommended reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Please be aware of any conflicts of interest when recommending reviewers. Examples of conflicts of interest include (but are not limited to) the below:

The reviewer should have no prior knowledge of your submission

The reviewer should not have recently collaborated with any of the authors
Reviewer nominees from the same institution as any of the authors are not permitted

Please note that the Editors are not obliged to invite/reject any recommended/opposed reviewers to assess your manuscript.

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.4 Funding

Autism requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the Funding Acknowledgements page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Important note: If you have any concerns that the provision of this information may compromise your anonymity, you should withhold this information until you submit your final accepted manuscript.

2.4.1 National Institutes of Health (NIH) funded articles

If you have received NIH funding for your research, please state this in your submission and if your paper is accepted by Autism an electronic version of the paper will automatically be sent to be indexed with the National Library of Medicine's PubMed Central as stipulated in the NIH policy.

2.5 Declaration of conflicting interests

Autism encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the SAGE Journal Author Gateway.

2.6 Research ethics and patient consent

Medical research involving human subjects must be conducted according to the World Medical Association Declaration of Helsinki

Submitted manuscripts should conform to the ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals, and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the ICMJE Recommendations for the Protection of Research Participants

2.7 Clinical trials

Autism conforms to the ICMJE requirement that clinical trials are registered in a WHO-approved public trials registry at or before the time of first patient enrolment as a condition of consideration for publication. The trial registry name and URL, and registration number must be included at the end of the abstract.

2.8 Reporting guidelines

The relevant EQUATOR Network reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed CONSORT flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed PRISMA flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The EQUATOR wizard can help you identify the appropriate guideline.

Other resources can be found at NLM's Research Reporting Guidelines and Initiatives

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3. Publishing Policies

3.1 Publication ethics

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Autism and SAGE take issues of copyright infringement, plagiarism or other breaches of best practice in publication very seriously. We seek to protect the rights of our authors and we always investigate claims of plagiarism or misuse of published articles. Equally, we seek to protect the reputation of the journal against malpractice. Submitted articles may be checked with duplication-checking software. Where an article, for example, is found to have plagiarised other work or included third-party copyright material without permission or with insufficient acknowledgement, or where the authorship of the article is contested, we reserve the right to take action including, but not limited to: publishing an erratum or corrigendum (correction); retracting the article; taking up the matter with the head of department or dean of the author's institution and/or relevant academic bodies or societies; or taking appropriate legal action.

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4. Preparing your manuscript for submission

4.1 Formatting

Autism asks that authors use the APA style for formatting. The APA Guide for New Authors can be found on the APA website, as can more general advice for authors.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines. Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Terminology

Autism has researched and compiled their own Terminology Guidelines which all authors should follow.

4.5 Reference style

Autism adheres to the APA reference style. View the APA guidelines to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

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5. Submitting your manuscript

Autism is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit <http://mc.manuscriptcentral.com/autism> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored

for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a persistent digital identifier that distinguishes researchers from every other researcher and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities ensuring that their work is recognised.

We encourage all authors to add their ORCIDs to their SAGE Track accounts and include their ORCIDs as part of the submission process. If you don't already have one you can create one here.

5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

5.3 Permissions

Please also ensure that you have obtained any necessary permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please see the Copyright and Permissions page on the SAGE Author Gateway

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6. On acceptance and publication

6.1 Lay Abstracts

Upon acceptance of your article you will be required to submit a lay abstract of your article to the Social Media Editor, Laura Crane (journalautism@gmail.com). Lay abstracts are brief (max 250 words) descriptions of the paper that are easily understandable. These abstracts will be made available to researchers and clinicians, as well as the general public (including individuals with autism spectrum disorders and their families). These abstracts should avoid both technical terminology and the reporting of statistics. Examples of lay abstracts are provided in recent issues of the journal.

6.2 SAGE Production

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

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From <https://uk.sagepub.com/en-gb/eur/journal/autism#submission-guidelines>

Appendix B - CASP Analyses
Quantitative papers

	1/ Clearly focussed issue?	2/ Recruitment acceptable?	3/ Exposure accurately measured?	4/ Outcomes minimise bias?	5a/ Identified confounders? 5b/ taken into account?	6a/ follow up complete? 6b/follow up long enough?	8/How precise?	9/Believe results?	10/Local population?	11/ Fit with other evidence?
<i>Yu et al. (2016)</i>	Yes	Partial	N/A	Yes	5a - Yes 5b - Partial	6a – No 6b – N/A	X	Partial	Yes	Yes
<i>Rayan & Ahmad (2017)</i>	Yes	Yes	N/A	Yes	5a - Partial 5b - X	6a – No 6b – N/A	X	Yes	X	X
<i>Ahmad & Dardas (2015)</i>	Yes	Partial	N/A	Yes	5a - X 5b - X	6a – No 6b – N/A	Model accounts for small variance	Yes	Yes	X
<i>Lai et al. (2015)</i>	Yes	Partial	N/A	Yes	5a - Partial 5b - X	6a – No 6b – N/A	X	X	Partial	Yes
<i>Yu et al. (2015)</i>	Yes	Yes	N/A	Yes	5a - X 5b - X	6a –No 6b – N/A	Model accounts for moderate variance	X	Yes	Yes
<i>Bitsika et al. (2015)</i>	Yes	Yes	N/A	Yes	5a - Partial 5b - Partial	6a – No 6b – N/A	Outliers accounted for	Yes	Can't tell	Yes

	1/ Clearly focussed issue?	2/ Recruitment acceptable?	3/ Exposure accurately measured?	4/ Outcomes minimise bias?	5a/ Identified confounders? 5b/ taken into account?	6a/ follow up complete? 6b/follow up long enough?	8/How precise?	9/Believe results?	10/Local population?	11/ Fit with other evidence?
Whitehead et al. (2015)	Yes	Yes	N/A	Yes	5a - 5b -	6a –No 6b – N/A	Model accounts for moderate variance	Yes	Partial	Yes
Keenan et al. (2016)	Yes	Yes	N/A	Yes	5a - Partial 5b - Partial	6a –No 6b – N/A	X	Yes	Can't tell	Yes
Di Biasi et al. (2016)	Yes	Yes	N/A	Yes	5a - Yes 5b - Partial	6a – No 6b – N/A	Low power due to participant numbers	Partial	No	Partial
Garcia-Lopex et al. (2016)	Yes	Yes	N/A	Yes	5a - Yes 5b - Partial	6a – No 6b – N/A	X	Yes	Yes	Yes

Qualitative papers

	1/ Clear aims	2/ Appropriate methodology	3/ Design appropriate	4/ Recruitment acceptable?	5/ Data addressed research issue?	6/ Relationship between researcher and participants	7/Ethical consideration?	8/ Analysis rigorous?	9/Clear statement of findings?	10/ Valuable research?
Gona et al. (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	New research in Africa. Contribute to support.
Derguy et al. (2015)	Yes	Yes	Partial	Yes	Partial	No	Yes	Yes	Yes	Confirms previous findings plus additional themes. Data collection not transcripts therefore of questionable value

Chapter 2

**‘At times peaceful,
sometimes not’**

**A Photovoice exploration of
the psychological needs of
neurotypical siblings of
children on the autism
spectrum**

Word count - 7953

Abstract

Neurotypical siblings of children with ASD are in a position which largely lacks the support structures which are in place for other individuals such as parents and professionals. Often these siblings will spend more time with a child with ASD than anyone else yet there is minimal research which has sought siblings directly as participants for research, particularly younger children. The aim of this study was to develop an understanding of the siblings' psychological needs from their perspectives, as previous research has focussed on quantitative and/or parent reports. Using Photovoice as a participatory methodology, five children aged between seven and eleven years old took photographs under the title 'what is it like having a sibling on the autism spectrum?' Participants then completed an individual interview to discuss their photos, and came together as a group to theme their own photographs. The results are presented in four superordinate themes: 'focus on the sibling with ASD', 'conflict and struggles in daily life', 'coping mechanisms', and 'it's not all bad' which are supported by both quotes from participants, use of their photographs, and the themes which they devised as a participant group. Strengths and limitations of the study are considered, as well as the implications of the outcomes on future support services for siblings which would need to take into account the distressing nature of some of the experiences which are likely to be part of the daily life of siblings of children with ASD, as well as acknowledging the positive and fun experiences which having such a sibling can bring to a family. Finally, the significance of promoting resilience and development of positive coping mechanisms is discussed, with its importance derived from the sometimes adverse situations which the participants explored both in their interviews and photographs and also drawing on findings from previous research. Further directions for research are also proposed.

Key words: Autism Spectrum Disorder (ASD); siblings; photovoice

Introduction

The National Autistic Society (2017) defines autism as 'a lifelong developmental disability that affects how people perceive the world and interact with others'. Baron-Cohen et al. (2009) estimated that among the school population in the United Kingdom there are around 157 children with autism per 10000, including children who do not have a formal diagnosis. According to the Office for National Statistics in 2016, 55% of families in the UK had more than one child. It can therefore be reasonably assumed that there are a large number of school children who have a sibling on the autism spectrum, and the nature of autism as stated suggests that there will be some difference in the experience of having a sibling with autism as opposed to a sibling who is neurotypical (without neurological differences).

Much of the research involving neurotypical siblings of children with ASD focusses on predicting rates of diagnosis in siblings (e.g. Yoder et al., 2009) or sibling rates of other linked impairments including social functioning deficits (e.g. Cornew et al., 2012) and language problems (e.g. Drumm et al., 2015). There has also been investigation into siblings' roles within interventions for individuals with ASD; Shivers & Plavnick (2015) completed a review of such interventions. They report siblings playing a fundamental role in intervention, including acting as a role model, and promoting social skills. Siblings are a constant and present member of the child with ASD's support network; therefore it is important to consider their needs. This may be in a similar way to how professionals receive supervision and parents can attend parent support groups offered routinely post-diagnosis (e.g. the Earlybird programme run by the National Autistic Society). Indeed, Shivers & Plavnick (2015) acknowledge that further research should consider the impact upon siblings potentially involved in interventions, in order to improve outcomes for all children involved.

Smith & Elder (2010) reviewed twelve studies which all focussed on parents and siblings of individuals with ASD. The nine sibling studies considered

sibling behaviours, sibling relationships, and sibling adaptation. Particularly related to the present research, Benderix & Sivberg (2007) interviewed siblings of children with ASD who lived in a group home; they presented themes including feeling a sense of responsibility, and exposure to difficult behaviour related to their sibling's diagnosis. Smith & Elder (2010) summarise that there is a variation in findings between the studies they reviewed which Orsmond & Seltzer (2007) posed was due to the variation in methods used within the studies.

Since the Smith & Elder (2010) review, Tsao et al. (2012) have considered the question 'what is it like to grow up as a sibling of a child with autism?'; they reviewed potential sources of support for siblings, including parenting strategies and support groups. They recommended that further work focusses on siblings, particularly considering differences due to life stage. Tsao et al. (2012) did not involve siblings' views directly within their paper; as such the current body of literature which discusses siblings' needs lacks a direct sibling voice.

Hastings (2013) reviewed the needs of siblings with ASD in collaboration with the charity Sibs who support siblings of people with a disability. His review identified multiple gaps in research completed, including the need to gain a better understanding of the effect of both positive and negative impacts having a sibling with ASD can have on a child. Hastings also recommends further research into sibling support packages in order to produce robust programmes to offer appropriate support. Using a method which meets this need may serve to bring together previous research and theories. At the time of writing, a robust evidence base for sibling support and groups continues to be lacking and therefore it is posed that the need to research how siblings can be best supported and how effective current support packages are in addressing this area of need, is increasingly important both for the wellbeing of siblings, and for the appropriate use of resources.

The current study therefore had the aim of exploring this area using a different and participatory method (Photovoice; Photovoice, 2016) in order to

contribute to the literature with a view to developing more tailored support for siblings of young people with ASD. This piece of research focussed on giving siblings a voice such that their perspective could formally contribute to the literature in this area and in some way triangulate the findings of previous research. By involving young people so actively, and using a methodology which is tailored to facilitating participants being able to speak out and communicate (Photovoice, 2016), it is hoped that the results will make a strong contribution to the current literature which can be combined in the future to form an evidence-based support package for siblings of individuals with ASD.

Research question

What are the psychological needs of neurotypical children, specific to having a sibling with a diagnosis of autism spectrum disorder?

Method

Photovoice is a participatory action research methodology which is growing in popularity for allowing vulnerable and marginalised groups to have a voice and communicate where they would not otherwise have a forum to do so. Its most key components are bringing together a group, and giving them camera equipment to take photographs which communicate their view/perspective. The resulting photographs and verbal/written data can be used in a variety of different ways; the specifics of this study will be detailed further below. Wang & Pies (2004) used the Photovoice method to explore maternal and child health by engaging community members and using this information to support the development of services, similar to the current research. Fortin et al. (2015) found that involving a homeless population in their analysis resulted in a meaningful and accurate contribution to the literature. The current research aims of contributing to the evidence base for psychological support of siblings are similar to these two previous studies indicating its suitability. The inclusive nature of Photovoice, highlighted as a strength in the above authors' articles, allows vulnerable members of the community to contribute to academic research in a non-threatening and empowering way

which is also a key element of how the current research will aim to fill a gap in the literature of allowing siblings' voices to be directly heard.

Recruitment and Participants

The Child and Adolescent Mental Health Service (CAMHS) where the researcher was employed was the setting for the research, and links were built with the ASD service during the proposal stage of research development. The service runs short term post-diagnosis groups for parents of children with ASD. These groups are co-facilitated by the clinical supervisor as part of their existing job role, and four of these groups were attended by the lead researcher. The purpose of this was to promote the project, such that any parent who felt their children may be interested in participating could approach the researcher at the end of the group to receive participant information sheets for both themselves and their child.

Participating children were required to be aged seven to eleven years old, and have a sibling with a formal ASD diagnosis which the participating child was aware of. Unfortunately due to lack of funding for translation services, non-english speakers were unable to participate. Participants were also excluded if they themselves had a formal ASD diagnosis, or were on the waiting list for an ASD assessment due to this not meeting the aims of the research question. This was the only practicable way of screening that participants themselves did not have ASD. The stated age range was chosen due to Tsao et al. (2012) recommending that life stage is taken into account when furthering research in this area. Focussing on a specific age range also gives a more homogenous group which promotes a more in depth understanding of the impact upon this life stage. Restricting the age in this way places the children within a similar stage (e.g. all in key stage 2 in primary school) in relation to their abilities, meaning the group was more cohesive in order to allow consideration, post-analysis, of the needs which specifically related to having a sibling with autism, as opposed to variation occurring due to other factors.

Hergenrather et al (2009) completed a qualitative review of Photovoice studies. Of 31 studies included, the minimum participant number was 4, the maximum was 122, with a modal score of 5. It is worth noting that the subsections ‘living with disabilities’ and ‘improving quality of life’ which are most in keeping with this study, had the lowest participant numbers with 4 out of 9 studies having 5 participants or less. As such, the recruitment aim was 5-7 participants.

Recruitment posters (see Appendix D) were also displayed in CAMHS waiting rooms though no participants were recruited via this method. From the post-diagnosis groups, fourteen parents (who represented sixteen children) approached the researcher. Of these, two children were too young for the study’s criteria, and eight parents did not contact the researcher. This resulted in five children from four families who wanted to participate after they had been given written information - see Appendix E for child participant information and Appendix F for parent participant information. The 5 participants and parents all discussed involvement verbally with the lead researcher at the service location prior to signing assent and consent forms (see Appendix G and H) and participating. During this time, the lead researcher reviewed the participant information sheets with young people and their parents, and answered any questions. All young people who met the researcher in person decided to participate in the research.

The children chose their own pseudonyms as part of promoting their involvement in the research, and the participants are described in Table 1. All participating children were male, living full time with their siblings with ASD who were also male.

Name	Age	Older/younger than sibling with ASD
Andrez	10	Younger
Voltboy	11	Younger
Steve	8	Younger
CJtheDJ	7	Older (NB: also sibling of Bigmac)
Bigmac	10	Older (NB: also sibling of CJtheDJ)

Table 1: Participant characteristics

Research design

Using the Photovoice methodology, the research process was designed to involve the participants as often and as authentically as possible, to allow them to take ownership and control of the project whenever it was practicable and did not undermine the scientific element of the research. As such, the lead researcher and supervising clinician were present at the group theming session as facilitators as opposed to being in an expert position. The philosophy of adapting the methodology around the participants is one which underpins Photovoice projects (Photovoice, 2009), in order that vulnerable groups are still able to have a voice and participate fully.

With the researcher present in case of questions, the young people read and signed assent forms designed to be age appropriate in terms of simplified language and content (see Appendix G) and their parent also signed a consent form at the same time (see Appendix H). After giving consent to participate, participants were invited to a group where they were taught to use a digital camera and the aims of the research were discussed. They were each given a camera to take away with them, to take photographs which they felt answered the question 'what is it like having a brother with autism?'. Participants then took photos in their own time for a period of three weeks which spanned both school holiday and term time. Participants returned the camera to the researcher prior to the interview taking place, so that photographs could be printed and laid out on the table during the interview. This allowed the young people to see all photos at the same time and choose without bias which photo they wanted to talk about. Qualitative semi-structured interviews then took place with each of the participants at the CAMHS building where the research was based. They were given the choice of whether they wanted to have their parent present or wait outside the interview room – 3 young people chose to have their parent present, and 2 chose to have their interview alone. It was emphasised to present parents that the focus was on their child's views and parents should refrain from interrupting where possible. On occasion, parents did interrupt and facilitate their child sharing more information about their experience which was helpful – only the young people's words were included in the analysis as opposed to

any comments from parents. Participants chose one photo to discuss, before choosing the next one up to a total of 5. No guidance was given on how to select which photograph to talk about; this was up to the young person. Without prompting, several of the young people chose multiple photographs to talk about at once and so discussed 5 'groups' of photos in their interviews. Interviews lasted between 14 minutes 9 seconds and 40 minutes 36 seconds. The mean interview length was 29minutes 47 seconds. The PHOTO method of questioning was used as follows -

- Describe your **P**icture?
- What is **H**appening in your picture?
- Why did you take a picture **O**f this?
- What does this picture **T**ell us about your life?
- How can this picture provide **O**pportunities for us to improve your life?

This method has been used by multiple researchers as a recognised method of triggering discussion (Hergenrather et al., 2009). Focussing on its relevance for the current research, as well as being clear for the age of participants, the questions are worded in such a way as to elicit information which helped meet the aims of the study – to find out the psychological needs of the children. The full interview schedule can be seen in Appendix I and this details the discussion with young people prior to the interview taking place which reiterates that the research or researcher would not be able to directly improve the participants' lives or experiences. It was deemed important to ask the final question as part of the PHOTO method of questioning due to one of the key aims of the research being to inform sibling support. Directly asking young people this question helped to elicit these responses. Some young people went on to tell their parents about their ideas, but there was no indication that any of the young people felt their suggestions could or would be implemented by the research team.

Once all interviews were completed, all children were invited back for the theming group where the 4 attending children discussed their photos and grouped them into themes which they named themselves. Unfortunately the 5th child was unable to attend, though no reason was given for this. This

group was also audio recorded and this, along with the interviews were then analysed using thematic analysis. The addition of recording this group was an amendment put in by the researcher (see Appendix J for ethical approval documents and Appendix K and L for additional consent forms) due to the content and value of discussion in the consent meetings with participants which included multiple examples of experiences with their sibling and how they felt about this. The group theming between participants was valuable in prompting broad discussion between young people about things in their life which had not necessarily happened in the three week period during which they took their photos. These themes were then triangulated with the themes from the participants' group session. At the end of the process once the above was complete, families were invited to a celebration event as described in the ethical considerations section below.

Ethical issues

The study received ethical approval from Staffordshire University Peer Review panel, as well as through North of Scotland REC Panel and HRA (see Appendix C for all documentation). Photovoice as an organisation has also created a Statement of Ethics (Photovoice, 2009), which outlines Core Principles and Key Areas of Ethical Concern which were factored into the design and adhered to within the current research. The main ethical issues requiring consideration were around the nature of photography, impact upon the child with ASD, and consent from the families involved. It was agreed that assent would be sought from participants, with consent from their parent, though it was felt obtaining sibling consent may be a barrier to participation for some children who had valuable experiences to contribute to the study; it was therefore accepted that the child with ASD would not be formally involved in the consent or research process. During the initial group where participants were taught to use their cameras, discretion and anonymity were discussed in terms of being respectful to their sibling and others. Participants agreed to only take photographs of people with their verbal consent and practised how to take photographs which did not include identifiable features of a person. Only these non-identifiable photographs have been used in this report and all other dissemination of the findings. The group also included

discussion around how images can be used symbolically for example to record an event after it has happened, or if a person does not wish to be in a photograph. Safety such as being aware of surroundings before stopping to take a photograph was also covered.

Finally, there was a celebration event held at the end of the project which all participating and non-participating family members were invited to attend where participants were thanked for their involvement, given copies of their own pictures, and this also served as a more informal social event for the participants and families who had worked together and shared experiences as part of the methodology. It is important due to the group nature of the project, that all participants have closure on their participation (Photovoice, 2009).

Researcher's position

The research question was derived from the lead researcher's clinical experience of conducting ASD assessments and working with young people with an ASD diagnosis within mental health services and specialist school settings. Largely working with young people in various settings, a preference for systemic practice and curiosity is the professional position of the lead researcher. This will undoubtedly have an impact upon the presented study in terms of a tendency to consider the impact of relationships and systems upon individuals and should therefore be borne in mind when interpreting the results. The lead researcher does, though, hold a position of naïve observer, seeking to understand a position which will never be held by oneself – despite an interest and curiosity, the position of being a child with a sibling with additional needs is one which has not been experienced by any of the research team. Pillow (2003) emphasises the importance of doing research “with” participants and this is a key element of the methodology chosen by the research team. Using this, and particularly triangulating themes with those the participants themselves developed, it is hoped that the inevitable impact and bias of the small research team, is minimised, and the presented results are an authentic representation of the young people's experiences.

Data analysis

All interviews were both conducted and transcribed by the lead researcher which promoted immersion in the data and being able to synthesise similarities and differences between participants. This process was also supported by the photographs and participants coming to multiple sessions, meaning the analysing researcher had a broader sense of the participants which enabled people to be held in mind as opposed to solely being based upon a written record of their words.

The group theming session for the participants was facilitated by two of the research team, however this took place prior to the thematic analysis of the transcripts therefore minimising the likelihood of influencing the themes, as these had not been produced. 4 of the 5 Participants, and 3 parents (due to 2 participants being siblings) attended the theming group. They were asked to match pictures together which they felt were similar, and then to write a title which represented all of the pictures in that group – see Appendix M for an example of a resulting group of photographs. Participants were observed to complete this task with discussion with one another as opposed to direction from the researchers, with the researchers there to ensure themes were kept together correctly and answer any practical questions which arose. There was potential for attending parents to contribute to the theming of photographs and override the siblings' views; however, this was not observed to be the case, and the participants refused and disagreed openly where they did not agree with something.

Thematic Analysis

Thematic analysis is a widely used method of analysis when using qualitative data which involves finding patterns or 'themes' which occur across the data. This lends itself to the Photovoice method of collecting data as it enables different media to combine to form a single analysis and set of themes. Braun & Clarke (2006) discuss the importance of refining this method in

order to increase scientific rigour and detail a multi-step method which was followed in this research and are described as follows –

Engaging with the literature

As discussed above, the group theming session took place prior to the full analysis in order to minimise potential influence however due to the small research team, ethical and proposal processes which took place prior to the research, a literature review was conducted and therefore the analysing researcher is likely to have taken an approach which was theoretical in nature. Tuckett (2005) argue that this engagement with current research can enhance the thematic analysis by increasing awareness of the subtleties of data.

Familiarising with the data and transcription of interviews

All interviews, the theming group, and transcription were carried out by the researcher in order to promote familiarity with the data. This enabled repeated listening to, and reading of the interviews as well as regularly looking at the content of the photographs – photograph codes were embedded in the transcripts to allow the researcher to reference which photos the child was discussing. Meeting the participants multiple times and their involvement also promoted this as the researcher was able to build a contextual view of the participants' experiences as told through the different sets of data.

Generating initial codes

Once familiar with the data, the researcher began to note on the transcripts features of the participants' experiences, using different colours to denote similarities (codes) between and within the data. See Appendix O for an example page with coloured codes from this stage. Within the young people's interviews, without prompting, they often chose more than one photograph to discuss and in this way created 'themes' naturally which increased the data-driven nature of the analysis.

Searching for themes

Once the transcripts were coded, this was considered with the themes from the group session. All codes were written into a Table with quotes and photographs, and then superordinate themes were created which brought together multiple codes. See Appendix P for the final Table created.

Refining the themes

Once created, it was important to reconsider the superordinate themes and if they were representative of the data which was coded under that title. Sometimes themes included contrary views on a similar topic, as is particularly the case for example including both positive and difficult elements of the siblings' relationships. Once the themes were refined, it was important to consider that they represent the data as a whole and fit together.

Defining, naming, and reporting themes

Describing the themes was important as it allowed the researcher to present the essence of what is important about the codes within the theme. This process was supported by the young people both grouping their photographs in their interviews and also completing the group theming session. Titles were created with the aim of being representative of all subordinate themes (from codes). When reporting, as below, the themes have been presented in the order in which they flow and most coherently represent the data, where one theme follows on from the previous. Quotes and photographs have been selected based upon both what most clearly represents the theme, and also from the group's photograph themes which share similarities with the superordinate themes created by the researcher.

Results

Photographs

The five participants took a total of 123 photographs; each young person took between 11 and 39 photos with a mean of 25 photos. Most of the 123 photographs were discussed during the individual interviews and all of the four attending participants' photographs were used in the group theming

sessions – see Appendix N which shows the distribution of photographs in each group theme.

NB: titles of themes devised by the participant group have been highlighted in bold for emphasis, both in Table 2 below and in the description of themes which follows. A full theme Table with more extensive quotations can be seen in Appendix P.

Theme	Sub themes
Focus on sibling on the autism spectrum	Focus on sibling Unfair/imbalance between siblings Helping sibling/family
Conflict and struggles in daily life	Constant nature of disruption – troubled times The dark side Late or missing squad
Coping strategies	Thinking of solutions to support the child with Autism Escape the situation and coping for the sibling themselves
It's not all bad	The funny side Autism affecting the sibling relationship Like 'normal' siblings

Table 2: Theme overview Table

Theme 1 - Focus on sibling on the autism spectrum

Focus on sibling

Three participants spoke directly about their brother being a focus within their daily life as well as the participants' narratives being focussed on their brothers' needs as opposed to their own.

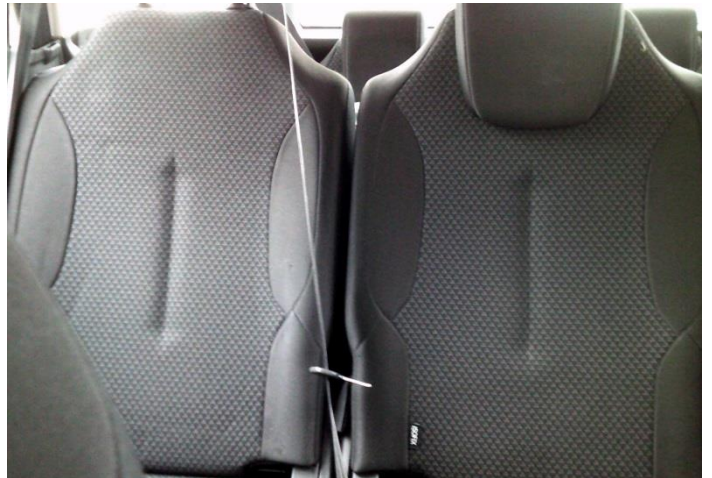
Interestingly, during the group theming session this was not named as a group or anything similar.

'and would that be better for you as well?

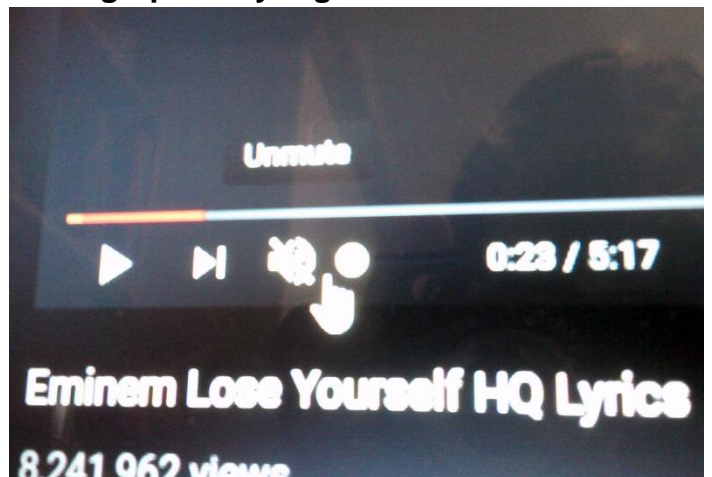
Yeh because then there's be less shouting, less stress, and it would be better for his education' (Voltboy)

'makes me feel a bit sad cos he's missing out' (Bigmac – photograph 1 – empty seat where brother would usually sit)
'I've always got to just think... what [he's] doing' (Andrez - photograph 2 – favourite music muted)

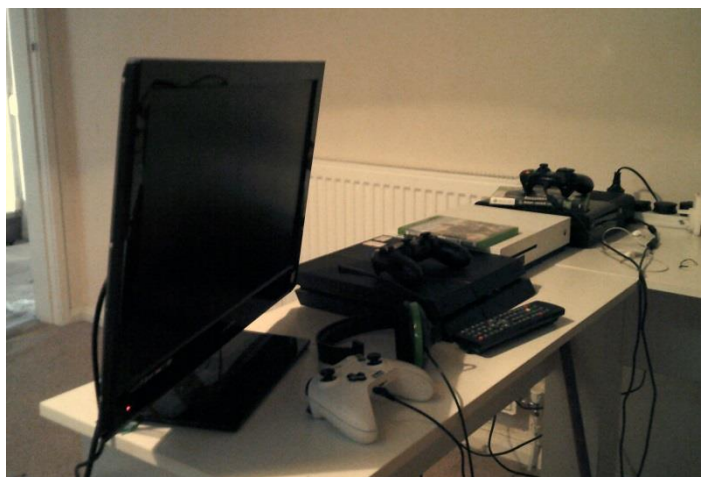
The participants demonstrated an acceptance of the increased needs of their siblings, in a way which affected the usual running of their day to day life. There appears to be a sense that the participants feel better when their brothers are okay, but that this requires an element of effort and



Photograph 1: by Bigmac



Photograph 2: by Andrez



Photograph 1: by Voltboy

vigilance from the family and sibling, as is supported by the two subsequent superordinate themes.

In the photographs this focus on the sibling was apparent as the participants took many pictures directly of their siblings during both positive and difficult events, and one participant's brother took his camera and took a number of photographs of himself.

Unfair/imbalance between siblings

A subordinate theme within the area of focussing on siblings, was of things being unfair, or imbalanced between the two siblings. This was spoken about by the same three participants. In some instances, this was in the context of siblings being treated differently and there being certain accommodations made for their brother due to their autism: *'Unfair that he gets all this in his room and I don't get it (Voltboy – picture 3) and '[mum doesn't] give me a warning so that's even worse' (Voltboy)*. In other instances, participants were accepting of the way things are different, but this acceptance did not mean there was no impact: *'I don't get the game some days... kind of feel a bit jealous' (Bigmac)*. One participant spoke not about material possessions and rules being different, but by the needs of their sibling being prioritised over his which affected the participant's enjoyment of activities or trips: *'sometimes my experiences can be either like ruined or changed... because of [his] autism' (Andrez)*.

Helping sibling/family

Finally within this theme, the participants spoke about directly helping their sibling/family. This was particularly the case for one participant who said *'mum has a time struggling with him... I take the bags for her and help her up' (Bigmac)*. Other participants spoke about indirectly helping situations e.g. *'I let him have them' (Voltboy)*. This indicates a sense of responsibility to help, which was also highlighted by Benderix & Sivberg's (2007) study.

Theme 2 - Conflict and struggles in daily life

Constant nature of disruption – 'troubled times' and 'The dark side'

Four participants spoke about difficulties with their sibling on a regular basis.

In the group theming session the group labelled '**troubled times**' for these



struggles which included photograph 4. The participants spoke at length about the difficulties they had experienced with their brothers and the impact this had on them, which is also similar to the findings of Benderix & Sivberg (2007). '**The dark side**' was also a category of photographs developed by the group, which contained photographs of things which caused arguments.

'he can get angry at that, he'd shout at that'

(Voltboy)

'he's shaking and he goes 'aaarrghhhh''

(Bigmac)

Photograph 4: by Voltboy



There was a constant, regular nature to this, as told by the participants.

'it's not really safe... I still get the shouting... still feel bad... still hear the same amount of noise when you're younger, it still scares you'

(Voltboy)

Photograph 5: by CJtheDJ



'times where he's just...

unbearable' (Andrez)

'you can't really get away from it because it's in your house and it's in your mind' (Voltboy)

'when he is.. not happy I feel a bit sad cos I'm like nooo not again... it happens pretty often' (Bigmac)

'I've got to sit by myself, I've got to

Photograph 6: by Andrez

eat at different times' (Andrez)

This is one of the elements which prompted the design of the current study. The participating siblings all lived with their brother, and largely attended the same school as their sibling. This extended amount of time spent is likely to be longer than either a parent or professional would spend in most circumstances. From the participants' accounts, this intensity of contact is one of the driving factors behind what they struggle with in relation to their sibling.

Late or missing squad

The group theming also generated a category which they named '**late or missing squad** [team]', for which photographs 5 and 6 were key images. The instances described included school, and also missing out on other activities/experiences as a direct result of their brother.

'being late for school when he's having a meltdown' (CJtheDJ – photograph 5)

'I was feeling worried because like we might miss the slot in the tour' (Andrez – photograph 6 – waiting outside Warner Bros. Studios for the Harry Potter tour which has a set start time. Harry Potter was his *'favourite thing'*).

There was only one child who did not have any photographs in this category. Their parent during group theming spoke about separating siblings such that one did not miss out because of the other –

'If something happens then we still make sure [he] does something because it's not fair' (parent - group session).

This in itself presents that there was the opportunity for one sibling to miss out, but effort has been made to stop this happening. The impact of missing out on experiences or being late for school can be difficult for young children to manage, particularly if they receive a consequence for something which was not their doing, for example *'I get in trouble at school if I'm late'* (Bigmac).

Theme 3 - Coping strategies

Thinking of solutions to support the child with Autism

Following on from the above theme of difficult times, there was a strong theme within the interviews and the group theming session of participants having developed ways to cope when these difficulties arise. The group spoke about finding '**solutions**' which were sometimes small things which helped and sometimes major changes for the family.

'he sat through that fine because he had... headphones on' (Andrez)

'we got a dog to help... put up a chart to like rules and that... we had an extension' (Voltboy – the house extension meant the two siblings no longer had to share a room which was causing significant difficulties and conflict for the family)

'Escape the situation' and coping for the sibling themselves

While only one participant explicitly spoke about escaping in their interview, all participants at the theming group contributed to a group which they named '**escape the**



Photograph 7: by Bignac

situation'. These photographs included physical escapes such as picture 4, as spoken about below, but also mental escapes such as technology as seen in photograph 7.

'I used to go in here... so no one could get in so then if [he] was getting angry at me I could go and he couldn't get in' (Voltboy – picture 4).

The need for an escape is increasingly important when considering the recurring nature of a lot of the difficulties, as described in the previous theme.

It is encouraging that the participants have all developed ways of managing difficulties.

Spending time with others in a similar position was mentioned by one participant, who spoke positively about the experience, saying *'being with other people that have got... the same things... To know that you're not the only one'* (Steve).

Part of the positive impact of using a Photovoice methodology which encourages interaction between participants, is the experience of participation being validating for the young people involved, therefore it is positive that this participant found it helpful to spend time with others in a similar position.

Theme 4 - It's not all bad

'The funny side'

Hearteningly, the only theme every participant contributed to was the positive side of having a brother on the autism spectrum. The group theming session produced a theme titled **'the funny side'** which



Photograph 8: by CJtheDJ

contained 23 photographs including photograph 8. All of the other photographs in this category included photos directly of or with their brother - participants were told at the initial group meeting they could take photos of people as long as they gained verbal consent, though these would not be used in any dissemination. These photographs therefore have not been reproduced in this report in order to maintain anonymity. Participants spoke about these photographs in their individual interviews

'there's never like a dull moment... there's the funny things with the bad things' (Andrez)

'he's very fun' (Steve)

'we can have fun' (Bigmac)

'I usually play with him' (CJtheDJ – photograph 8)

Autism affecting the sibling relationship and Like 'normal' siblings

Enjoyment and positive engagement is undoubtedly a key part of a sibling relationship and the balance of positive and difficult times is likely to contribute to the resilience of the participants. And while sometimes participants spoke about the negative impact of their brother's autism on their relationship –

'a brother, they can be annoying, but they can help you. They can help each other... you don't have a proper brother... he doesn't really count as a proper brother' (Voltboy)

- they also spoke about the numerous ways in which their relationships were like any other sibling relationship.

'I think that's just how brothers feel' (Voltboy)

'[he] is my brother and I couldn't do any, much without him' (Steve)

'It's just like having a normal 5 year old pretty much' (Bigmac)

Clearly, the young people did not see their brothers' autism as negatively impacting every situation, as they were still able to rationalise that no sibling relationship is perfect.

Discussion

Tint & Weiss (2015) highlighted the need for further research in family wellbeing to also consider positive elements. This has been possible due to data being derived from participants being asked the open question 'what is it like having a brother with autism?' which did not specify a positive or negative direction. The themes described above demonstrate the participant-led nature of the research, as they flow from everyday life and focussing on their brothers, to difficult times, how the siblings cope, and also the positive side of being with their brother.

The element which seems to be unique to siblings of young people with autism appears to be the impact of autistic traits becoming significantly more profound in different settings/circumstances such as new places or where sensory sensitivities are triggered. This means alternating, sometimes quickly, between positive experiences, and regular challenges which can be very distressing, requiring siblings to rapidly employ their coping mechanisms. It is likely that this changeable experience is less pronounced in other sibling groups e.g. those with a learning disability or chronic medical condition, as these conditions are arguably more stable and predictable in their nature.

Daniel & Wassell (2002) discuss resilience in terms of Bronfenbrenner's (1989) ecological model. They pose that it is important to consider the resources a child has within themselves, their family relationships, and their wider community. As these young people, from the current findings, are living in regularly adverse situations which they can find difficult to manage, these principles are undoubtedly applicable and would be helpful to promote their continued wellbeing. It likely will also have an impact that these young people's family relationships, siblings in particular, can be a source of stress for the household therefore removing potential sources of constant support.

As seen in the themes, the participants linked brothers' difficult behaviours e.g. *'there are other times when he's just unbearable'*, to the impact upon them (*'unbearable'*) which supports previous research with parents finding that higher symptoms and behavioural disturbances resulted in increased stress (Yu et al., 2016 & Whitehead et al., 2015). One young person directly addressed this and expressed his struggle *'and you can't really get away from it because it's in your house and it's in your mind'*. It must be assumed, given the prevalence of autism, that this is not a unique experience and such distress left unaddressed may escalate into significant difficulties for young people who may not be equipped to manage such emotions. There was insufficient data to ascertain whether or not siblings separated their brother from their autism and therefore where they attributed responsibility for these difficult behaviours.

The young people involved in this research have begun to develop coping strategies in the way of escaping mentally or physically; however the remainder of the solutions continued to focus on making things easier for their sibling primarily. Maladaptive coping styles have been linked to increased parent stress (Lai et al., 2015) - the same may be true of siblings and therefore it will be important for siblings be supported in developing a variety of healthy coping mechanisms to manage the difficulties they encounter. Coping style can be predictive of resilience in parents (Whitehead et al., 2015) further evidencing the potential value of this when supporting siblings.

Bitsika et al. (2016) found that resilience was linked to decreased anxiety in child siblings of individuals with ASD and therefore increasing resilience as a preventative measure appears to be a valid proposed intervention to support these young people.

Implications

The aim of the research was to gather evidence supporting the development of a support package for young people in a similar situation to the participants. This would need to balance the responsibility some siblings reported, but also provide a place where their needs are met with unconditional positive regard and acceptance of the difficulty of repeated disruption to their lives.

Gilligan (1997) presents three areas which promote resilience, the ability to manage under adverse circumstances, as a secure base, good self-esteem, and a sense of self-efficacy. A support package based upon these principles would be conducive to building the resources needed – coping strategies have been highlighted repeatedly in both this and previous research and therefore should form an essential component of intervention.

It is often the case that events are run with 'siblings welcome' in addition to children with ASD – this set up should be carefully considered in light of the above findings, and balanced with the likely focus on the child with ASD, but also the benefits of spending time with peers. The limited sibling-specific groups which are run for this client group would benefit from embedding

evidence such as this previous research into their practise in order to best support young people. Evaluations of such interventions continues to be recommended (Hastings, 2013) and would give further insight into how siblings can be supported in order to prevent siblings reaching a level of distress which meets clinical levels (Bitsika et al., 2016).

Strengths and Limitations

As discussed above, the research was with the aim of understanding siblings' psychological needs though it is important to note that the methodology itself did not directly ask this question of participants. The questions the young people were asked about their photographs, and their theming session, enabled themes to be derived which built a picture of what they experienced. Given the age of the young people, it was felt that this would be an effective way of understanding their psychological needs as they could express what was important to them, either difficult or positive. The recommendations, although an interpretation, map closely onto the experiences of the young people, for example needing support to manage under adverse circumstances.

Practically, from the file numbers of the photographs, participants had deleted some images, and young participants also took more photographs than older participants. Neither of these issues were explored directly with the participants but the young children particularly appear to have had more of a voice due to the use of a methodology which was less reliant on verbal communication. It is also worth considering what participants may have omitted in the photographs brought to interview.

One of the compromises of qualitative research, especially which is as involved as Photovoice, is the limited participant number; one participant did not attend after the individual interview, reducing their representation in the analysis. Although a depth of insight is presented, it would have been positive to have a larger sample had time and resources allowed. Similarly, the impact of one main researcher completing the majority of research tasks will have impacted upon the results presented. Considering the researcher's professional and individual position, it is likely that some of these values and

biases were present with the themes. For example, previous experience of working with children with a diagnosis of ASD may have biased results towards the known difficulties an ASD diagnosis is likely to bring – it can be assumed that some level of difficulties are present for all young people with ASD, as if they were not, a diagnosis would be very unlikely to have been pursued or made. Therefore, in hindsight, there was an expectation on the part of the researcher that these difficulties would form part of the research, and indeed discussion of difficult topics was discussed at the ethical proposal stage, and information regarding this is included in participant information documents (Appendices E & F).

The combination of individual and group themes being kept together as one analysis may be seen as a limitation due to the potential impact of group processes during the group theming session. There were no prominent signs of conformity observed by either of the two researchers present within the session. The titles of the group themes have been clearly marked throughout the analysis and are all supported by themes from individuals' interviews. It is, though, acknowledged group processes may have impacted upon the themes the young people created and added to within the session. It is interesting that the young people in group theming identified 'obsessions and anxiety/brainwashed' as a theme though this was not evident in their individual interviews, despite obsessions and anxiety being common traits of individuals with autism (NAS, 2016). This could have been further explored directly with the participants though it appears as though the participants saw their brothers' interests as a part of who they are as opposed to an 'obsession' which has negative connotations. It was only when they came together as a group and were looking for similarities, that this theme was produced. 'Anxiety' was, though, present in individual interviews and the behaviours associated with this were largely present in the 'troubled times' theme and also referenced in the 'coping strategies' theme.

The spectrum nature of autism means that although individuals will share certain characteristics, they will present so variably that inevitably the experiences of their siblings will also vary significantly. Due to this, it is a challenge to meaningfully quantify how severely affected young people are.

Within the findings, a picture was clearly built of some individuals finding their brother extremely challenging to live with, and others highlighting more positive factors. Using another methodology such as a case study with increased depth in one family, or a mixed methodology incorporating quantitative measures of functioning, may give insight into the link between how different presentations of ASD impact siblings.

The size of sibling groups and birth order varied between the families, with 2 families having two children and 2 families having three (where one had a diagnosis of ASD), and the participants spanned eldest, middle, and youngest child. While there were no obvious impacts of these factors during the thematic analysis, it is likely that these differences would have an influence upon how a child perceives their experience and manages difficulties. Further research may be helpful to explore this, and may seek a more specific participant group, and/or employ a method which allows for a richer depth of understanding such as Interpretative Phenomenological Analysis.

Although this could not have been altered due to the nature of the sampling, all participants were male and all of their siblings were male. It is increasingly discussed within the autism community and literature about how girls on the autism spectrum present and are affected differently, so this is an area which continues to be a gap in the research.

Triangulation is an important factor in creating a scientifically robust study, and the participatory nature of the methodology allowed the young people to explicitly create themes where there were similarities, as opposed to this responsibility being solely with the research team. In future, although not possible in this case, it would be fitting with the methodology for participants to continue to be involved post-analysis. In this example, the final themes and recommendations could have been discussed with participants and the development and evaluation of support packages would also benefit from directly involving service users.

Conclusions

Overall, the Photovoice methodology appears to have been effective in eliciting a rich quality and quantity of information from the participants which has served to fill a gap in the previous literature around authentically representing the views of the siblings.

Highlighting positive and difficult experiences, from struggles in daily life, to coping mechanisms, and focussing on their sibling which arguably has a preventative effect, this gives valuable information as to the psychological needs of the young people.

Recommendations centre on providing siblings with a dedicated space within which to increase their resilience by teaching and facilitating the development of coping mechanisms, increasing self-esteem, and self-efficacy. Both previous research and the presented findings indicate that this intervention would have a positive impact upon the wellbeing and mental health of young people who have a sibling with ASD.

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Appendix

Appendix C - Ethical approval documents



Date: 31/03/2017

To whom it may concern

Application for Independent Peer Review Approval

Researcher: Freyja BANCROFT

Study Title: Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder

I can confirm that Staffordshire University supports this research project proposal being put forward by the above research project applicant, and that the University is willing to act as sponsor of the project if it received LREC approval.

Our support for this project takes account of the outcome of an independent peer review of its scientific merit undertaking within the University.

I can also confirm that the University has generic indemnity/insurance arrangements in place as stated on the attachment to this letter, that arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed, that arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts and that the duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

A handwritten signature in blue ink, appearing to read 'N. Chockalingam'.

Professor Nachi Chockalingam
Chair,
University Academic Ethics Sub-Committee

Miss Freyja Bancroft
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Staffordshire
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Email: hra.approval@nhs.net

22 June 2017

Dear Miss Bancroft,

Letter of HRA Approval

Study title:	Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder
IRAS project ID:	219955
REC reference:	17/NS/0053
Sponsor	Staffordshire University

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *“After Ethical Review – guidance for sponsors and investigators”*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is 219955. Please quote this on all correspondence.

Yours sincerely

Gemma Oakes
Assessor

Email: hra.approval@nhs.net

Copy to: *Dr Helena Priest, Staffordshire University [Academic Supervisor]*
h.m.priest@staffs.ac.uk
Dr Liz Boath, Staffordshire University [Sponsor Contact]
e.boath@staffs.ac.uk
[Redacted] [Lead
NHS R&D Contact]
[Redacted]

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Contract/Study Agreement [Statement of Activities]	1	05 June 2017
Contract/Study Agreement [Schedule of Events]	1	05 June 2017
Copies of advertisement materials for research participants [Recruitment Poster]	1.2	09 April 2017
Covering letter on headed paper		03 May 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Zurich Municipal commenced 01 August 2016]		01 August 2016
IRAS Application Form	219955/1089393/37/740	16 May 2017
IRAS Application Form XML file [IRAS_Form_19052017]		19 May 2017
IRAS Checklist XML		08 June 2017
Letter from sponsor [Professor Nachi Chockalingam]		31 March 2017
Other [REC Provisional Opinion Response Letter]		08 June 2017
Other [Zurich Municipal: Staffordshire University Public Liability]		16 July 2016
Other [Protocol]	1.0	17 May 2017
Other [Full Data Set]		19 May 2017
Participant consent form [- Parents/Guardians]	1.4	08 June 2017
Participant consent form [Assent form]	1.4	08 June 2017
Participant information sheet (PIS) [- Parent]	1.3	17 May 2017
Participant information sheet (PIS) [- Children]	1.3	08 June 2017
Research protocol or project proposal [Peer Review Proposal and Comments]	1.2	15 March 2017
Summary CV for Chief Investigator (CI) [Freyja Bancroft]		03 May 2017
Summary CV for student [Freyja Bancroft]		03 May 2017
Summary CV for supervisor (student research) [Dr Helena Priest]		08 June 2016

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Dr Helena Priest
 Tel: 01782 294 580
 Email: h.m.priest@staffs.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has submitted statement of activities and schedule of events. No other form of agreement is required, or will be used.
4.2	Insurance/indemnity arrangements assessed	Yes	The Chief Investigator has confirmed that she is liable for loss/damage of the cameras during the course of the study. Where applicable, independent contractors (e.g. General Practitioners)

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study.
4.3	Financial arrangements assessed	Yes	External funding has not been obtained to run the study at site.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion was issued on 12 June 2017.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type participating in this study. All research activities are the same at participating NHS sites as detailed in the study protocol and supporting documentation.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research

management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England will be expected to formally confirm their capacity and capability to host this research.

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The HRA expect Principal Investigators to be appointed at participating NHS sites and these have already been identified.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

No arrangements under the HR Good Practice Guidance are expected for this study.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

- The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

IRAS project ID	219955
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- The Chief Investigator will provide the cameras to participants for use in the study.

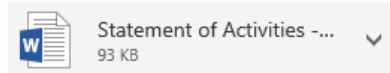
IRAS [219955] Needs of Non-Autistic Siblings of Children with ASD - NHS
Confirmation of Capacity and Capability at [REDACTED]
[REDACTED] NHS Trust



Fri 07/07/2017, 17:13
BANCROFT Freyja; +3 more

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Inbox



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Dear Freyja

NHS Confirmation of Capacity and Capability at [REDACTED] Trust

Short Title:	Needs of non-autistic siblings of children with ASD
IRAS ID.:	219955
Principal Investigator:	Freyja Bancroft

This email confirms that [REDACTED] Trust has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation.

We agree for you to start this study from the date of this confirmation as previously discussed.

NHS Confirmation of Capacity and Capability for the above research has been granted on the basis described in the HRA approval application. The documents received are:

Document	Version	Date
Protocol	1.0	17/05/2017
Participant Information Sheet: Parents/Guardians	1.3	17/05/2017
Participant Information Sheet: Children	1.3	08/06/2017
Assent Form	1.4	08/06/2017
Consent Form: Parents/Guardians	1.4	08/06/2017
Recruitment Poster	1.2	09/04/2017

For further information regarding how to notify us of any amendments to the study please refer to the [Amendments Guidance for Researchers](#).

If you wish to discuss this further, please do not hesitate to contact me.

Kind regards

[REDACTED]




[REDACTED]



Does one of your children have a diagnosis of autism?

We are doing a photo project with **children aged 7-11 who have a sibling with a diagnosis of autism**, to find out what it's like having a brother or sister with autism

The project will take place over the summer holidays, and camera equipment will be supplied

If you think that your child might like to take part, please contact Freyja Bancroft for more information
Freyja.bancroft@ 



Appendix E - Participant information sheet for young people



PARTICIPANT INFORMATION SHEET: CHILDREN

STUDY TITLE: Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder

Are you aged between 7 and 11?
Do you have a brother or sister with autism?
If so, would you like to take part in a photography project?

Who? We are looking for children aged 7-11 years old who have a brother or sister with autism.

What? We want children to take some photos of what it's like to have a brother or sister with autism, and then talk to us about these pictures.

Where? We will ask you to come to CAMHS at [redacted] for a group session with other children to learn about the project. Then you can take a camera away to take pictures at home before coming back to talk to us about your pictures individually for up to an hour. We would also like you to come back for another group session, with the same other children, to look at all your photos together.

When? In the summer holidays.

Why? We want to know what it's like having a brother or sister with autism so we can try and help other children in the future.

What if I have a question, or am worried about something? We want children to be honest with us about what it's like to have a brother or sister with autism. This can be hard if there are things you aren't happy with. If you want any help, you can ask your parent or carer, or any of the staff – we will give your parent or carer our details.

Do I have to take part? You don't have to take part in the project, and you can choose to stop at any time.



Appendix F - Participant information sheet for parents



NHS Trust

PARTICIPANT INFORMATION SHEET: PARENTS/GUARDIANS

Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder

We would like to invite your child to take part in a research study. The study is aimed at children aged 7-11 years who have a sibling diagnosed with an autism spectrum disorder, to participate in a photography project over the summer holidays, where they will be given a camera to take photos expressing what it is like to have a sibling with ASD. It is being carried out as part of a doctoral qualification.

Before deciding whether or not to take part, it is important for you to understand why the research is being done, and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if anything is unclear, or if you would like more information.

What is the purpose of the study?

We are exploring the views of children without an ASD who have a sibling diagnosed with an ASD.

This study will focus on giving siblings a voice so their perspective continues to formally contribute to the research in this area. It is hoped that the results will make a strong contribution to the current literature, which can be used in the future to form an evidence-based support package for siblings of individuals with ASD.

Why has my child been invited?

As your child without ASD, has a sibling with ASD, we believe they have a valuable insight, therefore would like to understand their views.

Do we have to take part?

No, it is up to you to decide, it is completely voluntary. If you do decide to take part, you can contact the principal researcher to discuss the study further and to answer any questions you may have. The researcher's contact details are stated below. You will also be given this information sheet to keep, and be asked to sign a consent form along with your child who will sign an assent form.

You will be free to withdraw from the study at any time, without giving a reason and without it affecting any care your child/children receive from services now or in the future. Any data collected would then be deleted from the study.

What will taking part involve?

The principal researcher will make an initial appointment to meet with you and your child to discuss the study and answer any questions you may have. You will both then be asked if you consent to take part in the study. If so, the researcher will ask you to complete and sign a consent form, and your child to complete and sign an assent form. This meeting will last approximately thirty minutes.

The researcher will then invite you and your child to a group briefing session (for all participants) at [REDACTED] to give out camera equipment, instruction, and state rules for the study. The briefing will last approximately two hours.

Once supplied with the camera, your child will have around three weeks to take photos using a working title of "what it's like to have a brother/sister with ASD". We will leave it up to you to decide how responsible your child should be for their camera. We want to gain your child's full perspective, so would kindly ask that, for the validity of the project, you do not stop your child taking photos, unless they go against the study rules. At the end of the stated period, the researcher will arrange a convenient time to collect the camera.

The researcher will print your child's photos, and arrange an interview with you and your child at [REDACTED] CAMHS, where they will be asked to select five photos to discuss further. The interview will last approximately one hour. At the end of the interview the researcher will ask if you and your child would like to attend a further group session and celebration event.

The researcher will invite you and your child to a final group session (for all participants) at [REDACTED] CAMHS, where all participants, with permission, will be tasked with grouping all photos into themes. The session will last approximately one and a half hours. At the end of the session the researcher will ask if you and your child would like to attend a celebration event.

The researcher will invite you and your family, including your child who has participated and your child with ASD, to a celebration event at [REDACTED] CAMHS, where each child participant will be presented with a photobook containing the photographs they took during the study as a thank you for participating. The event will last approximately one hour.

What are the possible risks of taking part?

We recognise that involving just one sibling within a family may be difficult, particularly to explain to a child with ASD. Please contact us if you require further support.

Your child will be encouraged to voice and express their full and honest views at their study interview, however positive or negative. This may be difficult for you to hear. If you wish to access personal support, then please contact us.

We do not anticipate the research causing any undue distress to your child, but discussing personal feelings about their brother/sister with ASD may evoke distress. If your child does become distressed, we can stop the interview or take a break or be comforted by you. If your child becomes extremely distressed then the clinical supervisor or a trained member of the CAMHS team can be contacted.

What are the possible benefits of taking part?

Although there are no direct benefits of participation, we hope this will be an enjoyable project for your child over the summer holidays. The research does, though, have the aim of informing support for siblings of children with ASD, which may benefit children/other siblings in the future.

What happens to the information we give?

All the information you and your child provide will be treated with the strictest confidence. Upon consent to the study a unique identification number will be allocated to each participant, and will subsequently be referred to in all transcripts and materials to maintain confidentiality.

All paper documents will be stored in a locked filing cabinet, and all electronic information will be stored on an encrypted memory stick until the study is completed. Once the study is completed, all documentation pertaining to this study will be stored securely in an archive room at Staffordshire University for 10 years. After this time, all documents will be destroyed.

Who is organising the research?

The research Sponsor is Staffordshire University.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given approval by the North of Scotland Research Ethics Committee (1). It has also been subject to scientific review by Staffordshire University Faculty of Health Sciences Research Ethics Committee.

What will happen to the results of the study?

The results will be written-up into a thesis to form part of the principal researcher's doctoral qualification. Results will also be submitted for publication in a peer reviewed journal, presented at relevant seminars and conferences, disseminated

through relevant websites e.g. The National Autistic Society, and made available to the services and people who have taken part.

All published information will be anonymised, and participant's identity will remain confidential.

What if I have a complaint?

If you wish to make a complaint about any aspect regarding the way you have been treated during this study, there are a number of means to do so. You are welcome to contact the principal researcher, or alternatively either of the project supervisors, who will do their best to answer your questions and support you with your concerns. We can be contacted using the details below.

If you remain unhappy and would like to make a more formal complaint, then you can follow the NHS complaints procedure by contacting the Patient Advice and Liaison Service on [redacted] (Freephone), or via email [patientexperience@\[redacted\]](mailto:patientexperience@[redacted])

Who can I contact for further information?

If you have any further queries about the study, then please do not hesitate to contact the principal researcher or project supervisors using the contact details below.

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact [redacted] Research Governance Facilitator at [redacted] or phone [redacted]

Principal Researcher: Freyja Bancroft

[Freyja.Bancroft@\[redacted\]](mailto:Freyja.Bancroft@[redacted])

Contact Number: [redacted]

Clinical Supervisor: Dr [redacted]

[\[redacted\]@nhs.uk](mailto:[redacted]@nhs.uk)

Academic Supervisor: Dr Helena Priest

H.M.Priest@staffs.ac.uk

Thank you for taking the time to read this information sheet

Appendix G - Assent form for participants



NHS Trust

Participant Identification Number: _____

ASSENT FORM: CHILDREN

Study Title: Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder

Researcher: Freyja Bancroft

Please initial box, example



Incorrect Correct

1	I have read the information sheet (Version _____, Date _____) about the study, had chance to think about it, ask questions, and had answers I am happy with.	
2	I understand that taking part will not affect the care me, my brother/sister receive from CAMHS.	
3	I will look after the camera as best I can, and follow the rules we are told.	
4	I understand that I can choose if I want to take part, and that I can stop if I want to anytime.	
5	I agree for my interview with the researcher to be sound recorded.	
6	I agree to sharing my photos with other children doing the research, in a group session.	
7	I understand that my information will be kept safe and confidential.	
8	I am happy for my photos to be used in the final study write-up, and that I can choose a different name if I don't want people to know they're my photos.	
9	I know if anything happens to make the researchers worry about mine or anyone else's safety, they might have to contact another organisation to offer support.	
10	I agree to take part in the study.	

Name of Participant

Signature

Date

Name of Researcher

Signature

Date



1 copy child, 1 copy researcher, 1 copy parent/guardian

Assent Form: Children; Version 1.4; 8/6/2017; IRAS ID 219955

Appendix H - Consent form for participants' parents

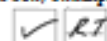


NHS Trust

CONSENT FORM: PARENTS/GUARDIANS

Study title: Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder
 Researcher: Freyja Bancroft

Please initial box, example



Incorrect Correct

I (Name) have been consulted about (Name of my child)'s participation in this study. I confirm that I have read the information sheet (version , date) about this study. I have had the opportunity to consider the information, ask questions, and had these satisfactorily answered.	
I understand that my child's participation is voluntary, and that we are free to withdraw from the study at any time, without giving a reason and without it affecting the care we receive from services now or in the future.	
I understand that data collected during the study may be looked at by individuals from Staffordshire University, the regulatory authorities, or from [REDACTED] where it is relevant to my child taking part in the research. I give permission for these individuals to have access to my child's information.	
I agree to take overall responsibility for the camera equipment whilst in my child's possession, while not unnecessarily censoring the photos they wish to take.	
I understand that the interview between my child and the researcher will be audio-recorded. I give permission for the researcher to audio-record the meeting with my child.	
I understand that my child will be invited to a group photo theming session where my child will share their photos with other participants.	
I understand that information collected from my child and published in the results of the research will be done so anonymously. I give permission for my child's quotes to be published anonymously.	
I am aware that should any risk/safeguarding issues arise or be disclosed, the researchers have a duty to contact the relevant organisations (e.g. police/social care), and that I will be informed of this referral wherever possible beforehand.	
I give my consent for my child to participate in this research study.	

Name of Parent/Guardian

Signature

Date

Name of Researcher

Signature

Date

1 copy parent/guardian, 1 copy researcher

Consent Form; Version 1.4; 8/6/2017; IRAS ID 219955

Appendix I - Interview schedule

Interview Schedule

All photos from the child's camera to be printed before interview, and laid out on the table for the child to see.

- *Re-explain to child interview will be recorded, and gain verbal consent for this, further to main written consent form.
- *Ensure child is aware of purpose of interview, and manage expectations at this point and throughout in relation to possible outcomes from interview. I.E. Remind children we are here to listen and learn about their experience but cannot make big changes in their life. Hopefully the research will result in more support for children like them in future. If appropriate, suggest children may like to speak to parents about any specific things they would like *changing* – interviewer to judge on individual basis.
- *Ask child to choose the 5 photos they would like to discuss, reminding them we may not be able to talk about all of their photos, depending on the time.
- *Remind child they can take a break, postpone or stop the interview at any time.

Child chooses first photo to discuss –

- Describe your Picture?
- What is *Happening* in your picture?
- Why did you take a picture *Of* this?
- What does this picture *Tell* us about your life?
- How can this picture provide *Opportunities* for us to improve your life?

Once complete, ask child to choose the next photo they would like to discuss

Ask child between photos, or if it seems pertinent, if they would like to take a break/stop/reschedule the interview.

Repeat above questions until around 1 hour, 5 photos, or until the child's concentration wains, whichever comes first.

- Is there anything else you want to say before we finish?

End of interview.

Appendix J - Amendment approval

North of Scotland Research Ethics Committee

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558458
Facsimile: 01224 558609
Email: nosres@nhs.net



09 February 2018

Miss Freyja Bancroft
Staffordshire University
School of Psychology, Faculty of Health Sciences, Science Centre
Leak Road, Stoke-on-Trent
Staffordshire
ST4 2DF

Dear Miss Bancroft

Study title: Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder
REC reference: 17/NS/0053
Amendment number: AM01 (REC Ref Only)
Amendment date: 05 February 2018
IRAS project ID: 219955

Thank you for your letter of 05 February 2018, notifying the Committee of the above amendment.

The Committee does not consider this to be a 'substantial amendment' as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Notice of Non Substantial Amendment - Amendment Request	AM01 (REC Ref Only)	05 February 2018
Amendment Approvals Staffordshire University		06 February 2018
IPR Amendment		25 January 2018
Group Audio Assent Form	1.1	05 February 2018
Group Audio Consent Form	1.1	05 February 2018

statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

17/NS/0053:	Please quote this number on all correspondence
-------------	--

Yours sincerely



Karen Gauld
Ethics Administrator

Copy to: Miss [REDACTED] NHS
Trust

RE: IRAS 219955. Confirmation of Amendment Assessment



TOTENHOFER, Ashley (HEALTH RESEARCH AUTHORITY) <ashley.totenhofer@nhs.net>



Reply all | v

Thu 08/03, 15:53

BANCROFT Freyja; PRIEST Helena; BOATH Elizabeth; [REDACTED]@nhs.uk

Inbox

You forwarded this message on 26/03/2018 21:00



Action Items



Dear Miss Bancroft

Further to the below, I am pleased to confirm **HRA Approval** for the referenced amendment.

You should implement this amendment at NHS organisations in England, in line with the conditions outlined in your categorisation email.

Please contact hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Kind regards

Ashley

Ashley Totenhofer
Technical Assurance Officer

Health Research Authority

HRA Centre Manchester | 3rd Floor, Barlow House | 4 Minshull Street, Manchester | M1 3DZ

T. 0207 104 8017

E. ashley.totenhofer@nhs.net

W. www.hra.nhs.uk

Amendment Categorisation and Implementation Information

Dear Miss Bancroft

Thank you for submitting an amendment to your project.

If you have participating NHS/HSC organisations that are affected by this amendment in any other UK nations we will forward the information to the relevant national coordinating function(s).

Please note that you may only implement changes described in the amendment notice.

What Happens Next?

When available, please forward any other regulatory approvals for this amendment to hra.amendments@nhs.net

Information Specific to Participating NHS Organisations in England

1. An assessment against HRA standards will take place.
2. Once the HRA assessment has been successfully completed, you will receive an email confirming that your amendment has HRA Approval.
3. You may implement this amendment **as soon as HRA Approval for the amendment is issued.**
4. You should ensure that participating NHS organisations in England are informed of this amendment. In doing so, you should include the NHS [R&D Office](#), [LCRN](#) (where applicable) as well as the local research team.
5. Participating NHS organisations in England should prepare to implement this amendment, where expected.

IRAS Project ID:	219955
REC Reference:	17/NS/0053
Short Study Title:	Needs of non-autistic siblings of autistic children
Date complete amendment submission received:	16/02/2018
Sponsor Amendment Reference Number:	AM01 (REC Ref Only)
Sponsor Amendment Date:	05 February 2018
Amendment Type	Non Substantial
Outcome of HRA Assessment	HRA Approval for the amendment is pending. The HRA will separately confirm HRA Approval for the amendment by email.
For NHS/HSC R&D Office information	
Amendment Category	C

If you have any questions relating to the wider HRA approval process, please direct these to hra.approval@nhs.net

If you have any questions relating to this amendment in one of the devolved administrations, please direct these to the relevant [national coordinating function](#).

Additional information on the management of amendments can be found in the [IRAS guidance](#).

Please do not hesitate to contact me if you require further information.

Kind regards

Mrs Alka Bhayani

Amendments Coordinator

Health Research Authority

Ground Floor | Skipton House | 80 London Road | London | SE1 6LH

E. hra.amendments@nhs.net

W. www.hra.nhs.uk

Sign up to receive our newsletter [HRA Latest](#).

R&D Approval of Amendment at [REDACTED] NHS Trust

👍 ⤺ Reply all | ▼

Fri 13/04, 15:39

BANCROFT Freyja; Bancroft Freyja [REDACTED]

Inbox

Dear Freyja

R&D ID.:	CHC0140/RS
Study Title / Acronym:	Needs of non-autistic siblings of autistic children
IRAS ID.:	219955
Amendment Number:	AM01
Amendment Date:	05/02/2018

Thank you for notifying us of the recent study amendment as detailed above and below. We have reviewed the amendment, and can confirm that these will not impact on the NHS Confirmation of Capacity and Capability issued for [REDACTED] NHS Trust. The amendment can now be implemented as detailed below.

Documents received, and to be used at site, as part of the amendment are:

Document	Version	Date
Group Audio Assent Form	1.1	05/02/2018
Group Audio Consent Form	1.1	02/02/2018

For Office Use Only	
Amendment Summary:	To audio record the group theming session – planned as part of the original application
Local Implementation Date:	13/04/2018

Please do not hesitate to contact us if you have any further queries.

Kind regards

[REDACTED]



Appendix K - Group recording assent form for participants



NHS Trust

Participant Identification Number: _____

GROUP AUDIO RECORDING ASSENT FORM: **CHILDREN**

Study Title: Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder

Researcher: Freyja Bancroft

Please initial here, example



Researcher Consent

1	I have signed an assent form before (Version 1.4, Date 8/6/2017, signed on _____) to agree to take part in the study, after having chance to think about it, ask questions, and had answers I am happy with.	
2	As well as the things I agreed to before, I also agree for the group session to be audio recorded.	
3	I understand that my information will still be kept safe, confidential, and anonymous.	
4	I understand that I can choose if I want the group session to be audio recorded or not, and even if I agree now, I can change my mind during the session.	
5	I understand that the group session being audio recorded is the only change to what I originally agreed to.	

Name of Participant

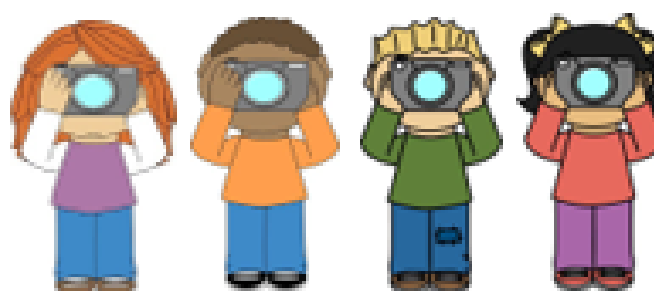
Signature

Date

Name of Researcher

Signature

Date



1 copy child, 1 copy researcher, 1 copy parent/guardian

Appendix L - Group recording consent form for participants' parents



NHS Trust

GROUP AUDIO RECORDING CONSENT FORM: **PARENTS/GUARDIANS**

Study title: Psychological needs of children without an autism spectrum disorder who have a sibling diagnosed with an autism spectrum disorder

Researcher: Freyja Bancroft

Please initial here, example



Incorrect Correct

I (Name) have been consulted about (Name of my child)'s participation in this study. I confirm that I have signed a full consent form previously (version 1.4, date 8/6/17, signed on). I have had the opportunity to consider the information, ask questions, and had these satisfactorily answered.	
In addition to agreements from the previously signed consent form, I give permission for the group theming session including my child, other participating children, and the researcher to be audio-recorded.	
I understand that transcripts from the group session will be treated in the same way as individual interview transcripts in terms of confidentiality, anonymity, right to withdraw, data security, and anonymous use of quotations in reports.	
I understand that the above mentioned amendment is the only alteration to the originally agreed information I was given prior to my child beginning participation in the study.	

Name of Parent/Guardian

Signature

Date

Name of Researcher

Signature

Date

1 copy parent/guardian, 1 copy researcher

[illegible]

Appendix N - Group theming session photo Tables

The resolution/Peace and quiet/Apology time/ The solution

10095	30001	150093	160002
10094	30019	150055	
10048	30025	150083	
10077	30009	150098	
10089	30029	150056	

The troubled times (things leading to incidents)

10086	30029	150004	160020
10054	30042		160003
10050	30009		160015
10037	30028		160023
			160007

Brainwashed/Triggers because of anxiety and controlling methods/Take control/Obsessions and anxiety

10037	30027	150050	160001
10050	30009	150076	160015
10095	30044		160014
10079	30019		
10039	30001		
10017	30025		
10081	30013		

The dark side

10086	30009	150050	160011
10039	30044	150054	160010
10093	30042	150084	160017
10040	30022	150049	160014
		150091	160018
		150089	160016
		150048	160012
		150097	160005

Late or missing squad

10050	NONE	150004	160079
10079		150075	160008
10060		150077	
		150080	
		150078	
		150074	
		150065	
		150066	
		150058	

The funny side

10075	30034	150087	160006
10045		150082	160013
10049		150096	160021
10073		150095	160022
10090		150099	160024
10074			
10091			
10046			
10047			
10044			
10071			
10092			

Escape the situation

10084	30028	150053	16002
10017	30027		
10083	30035		
10082	30013		
10080y	30016		

Appendix O - Transcript extract with coding

Interview transcript - [REDACTED]

There we go, okay. So which is the first picture you'd like to talk about?

This one

Okay

And can you describe for me what's in that picture?

[REDACTED] 008, [REDACTED] 003

It's an empty car seat because {brother} didn't want to come with us some places that he doesn't he can get worked up he sometimes doesn't want to come with us places

difficulties

Okay and what does that picture tell me about how your life is?

It tells you how it is because, kinda tells you, because it can be hard sometimes

Yeh. Hard in what way?

Like he can, if we're trying to go out somewhere he can make us late because like he's set have a meltdown sometimes, stuff like that

late

Okay, so how could this picture give us an opportunity to improve your life?

Give me a bit like, like give him a bit more help like to to like keep his anger down and like can help control it so he can go out and come more places



focus on sibling's needs

So you mean, whose anger do you mean?

{Brother}'s

Okay

Cos {brother} can get worked up really quickly

life is better if sib's anger is less + he can go out.

Yeh, okay, and when {brother}'s angry, and it means he can't come out, how does that make you feel?

Makes me feel a bit, makes me feel a bit sad cos he's missing out basically

Yeh, okay, is there anything else you want to say about that picture?

Mmm..

No, sure?

Sure

Appendix P - Full theme tables detailing quotes and photographic codes

Superordinate	Subordinate	Key photo refs	Quotes	Participant involved (initial)				
				A	V	S	C	B
Focus on sibling with ASD	unfair/imbalance between siblings	30025	he can just go to the park, he can just go with his friends, I cant do that' (3/10) you don't give me a warning so that's even worse (3/11)		x			
		30009	unfair that he gets all that in his room and I don't get it' (3/1) I don't get the game some days... kind of feel a bit jealous (16/7) he sometimes attacks us if when something doesn't go his way (16/8) [he] had my game most of the time (16/12) I was feeling a bit like anxious or nervous that [he] like might ruin my experience (1/12) sometimes my experiences can be either like ruined or changed... because of [his] autism (1/12) 'it doesn't really give me any freedom (1/2) I cant listen to to things I want to listen to (1/2)	x	x			x
	focus on sibling	160004/ 10081	and would that be better for you as well? Yeh because then there'd be less shouting, less stress, and it would be better for his education (3/2) so he can go out and come more places (16/1) makes me feel a bit sad cos hes missing out (16/1) keeping him entertained (16/18) ive always got to just think... what [he's] doing (1/3) he says well if you want to eat something youll have to go out the room (1/5) i had to just sit and wait for him to adjust (1/12)	x	x			x

	helping sibling/family		I let him have them' (3/2) 'we can settle him down (16/11) I say dyou wanna hold llama's hand (16/14) 'mum has a time struggling with him... I take the bags for her and help her up (16/13) I wanted to walk round like showing everybody... mum had to go off with [him] cos he didn't like it (1/7)	x	x			x
Conflict and struggles in daily life	noise, constant nature of disruption	150098	and you cant really get away from it because its in your house and its in your mind (3/4) it's not really safe... I still get the shouting, still feel bad... still hear the same amount of noise when you're younger, it still scares you (3/7) at times peaceful, sometimes not (15/5) it affects me cos... it can be like one moment happy and then... hes like 'aaaaahhh' (16/6) when he is... not happy i feel a bit sad cos im like noooo not again... it happens... pretty often (16/18) ive got to sit by myself, ive got to eat at different times (1/3) ill be stuck back going how I was before so its gonna be the same as it is now. (3/17)	x	x		x	x
	The dark side		you hear shouting, he can get angry at that, he'd shout at that' (3/2) it gets in even more chaos (15/3) hes shaking and he goes 'aaaahhh' (16/15) most of the time he overreacts (16/21) 'the dark side' things that cause arguments (g/9)		x		x	x
		30042	and he'd call me names and that makes me feel uncomfortable or annoyed or sad (3/4) hes attacked him (16/7) shouting at me... come into my room and hit me.. Break my mouse (1/3)	x	x			x
			brainwashed/triggers because of anxiety and controlling methods/take control/obsessions and anxiety (group names)					

			erm annoying a bit scary and uh upsetting that you cant do something (3/6)		x			
	troubled times	30028	it's hard (3/4) it can be hard sometimes (16/1) we get really angry sometimes (16/9) its hard to cope (1/9) there are other times where he's just... unbearable (1/9)	x	x			x
	late or missing squad	150058/160004/10079	us being late for school when hes having a meltdown (15/1) he can make us late (16/1) I get in trouble at school if im late (16/6) why would I want to go out the room cos then ill have to miss out (1/5) I was feeling worried because we might like miss the slot in the tour (1/12)	x			x	x
Coping strategies	thinking of solutions	10095/30019/160002/30001	it could be better if the family does something more outdoors or something more sociable (3/2) we say 'do you wanna play some lego' and hes like yeh yeh yeh (16/5) he sat through that fine because he had... headphones on (1/6) we got a dog to help... put up a chart to like rules and that (g3/12) we had an extension (g3/12) the resolution/peace and quiet/apology time/the solution (g titles)	x	x			x
		30025	well its stopped him doing most things (3/11)		x			
	escape the situation	9002/9003/9004	being with other people that have got... the same things.. To know that youre not the only one (9/6-7)			x		
		30029	it was getting that bad um I slept in mums room, beside her bed, uh this is like a little air mattress (3/8)		x			
		30028/30013	I used to go in here... so no one could get in so then if [brother] was getting angry at me, I could go and he couldn't get in (3/4) I used to hide (3/6) 'it's good to... get away... to take your mind off something (3/3)		x			

<i>It's not all bad</i>	the funny side		my little brother having fun' (15/2) theres some funny things (1/1) theres never like a dull moment... there's the funny things with the bad things (1/8) funny stuff like that's good (g/7)	x		x	x	
		150099/ 9001	I usually play with him (15/2) hes very fun (9) we can have fun (16/4)			x	x	x
	like 'normal' siblings		I think that's just how brothers feel' (3/2) [he] is my brother and I couldn't do any, much without him (9/2) we bond... we're literally doubles of each other (16/4) 'another thing he likes doing with us and other people is sitting there with them and watching TV' (16/5) even though [he's] in the wrong... sometimes i can be in the wrong as well (16/9) its just like having a normal 5 year old pretty much (16/21)		x	x		x
	autism affecting the sibling relationship		a brother is a brother, they can be annoying, but they can help you. They can help each other.... You don't have a proper brother.. He doesn't really count as a proper brother (3/9)		x			

Chapter 3

‘What’s it like having a brother with autism?’

Two executive summaries of the previous empirical paper, prepared for young people, and their parents and professionals.



What's it like having a brother with autism?

For young people

We did some research at {SERVICE NAME} to find out what it was like for young people living with a sibling with autism. Here's what we did and what we found...





What is autism? Autism is a 'spectrum' which means every person who has autism is different. What they all have in common is doing some things differently – they might play differently, find it hard speaking to other people, and have some things they are really interested in or good at.

Autism is something different about a person's brain, so the person and their family might have to work together so the person can do all the things they want to do. Lots of people with autism have jobs and children, and feel their autism is a big strength of theirs.

Why did we do this research?

We know lots about autism, and a bit about children with autism's siblings, but lots of research asks parents questions. We wanted to ask the young people themselves what it's like having a brother or sister with autism.

What did we do? We asked children to take photos for 3 weeks telling us what it's like having a brother with autism. Then we asked them to talk to us about the photos. We also sat together as a group and made 'themes' where more than one child had taken photos of similar things.

Who took part? 5 young people who have a brother with autism took part. They were all between 7 and 11 years old.

What did we find out? There were 4 themes which are on the next 4 pages...





'Unfair that he gets all this in his room and I don't get it (Voltboy)

Focussing on their brother

3 children spent lots of time talking about their brother and not themselves.

'I don't get the game some days... kind of feel a bit jealous' (Bigmac).

'Sometimes my experiences can be either like ruined or changed... because of [his] autism (Andrez).

They spoke about things being unfair or different between brothers.

One young person felt activities or trips were different because of his brother.



'Makes me feel a bit sad cos he's missing out' (Bigmac)

The young people also spoke about helping their family and brother.

'Mum has a time struggling with him... I take the bags for her and help her up' (Bigmac)





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Difficult times

'He can get angry at that, he'd shout at that' (Voltboy)

4 young people took photos which they called 'troubled times'.

'He's shaking and he goes 'aaarrghhhh' (Bignac)

'The dark side' was a group of photos of things which caused arguments.

The group also made a set of photos called 'late or missing squad' which had these photos.



'being late for school when he's having a meltdown' (CJtheDJ)



'I was feeling worried because like we might miss the slot in the tour' (Andrez)

'You can't really get away from it because it's in your house and it's in your mind' (Voltboy)

This is one of the reasons we did this research, because brothers and sisters probably spend more time with each other than anyone else.



'We got a dog to help... put up a chart to like rules and that... we had an extension' (Voltboy)

'He sat through that fine because he had... headphones on' (Andrez)

Coping strategies

The young people had found 'solutions' to help them manage the difficult times.

← The young people made a photo group called 'escape the situation'. These 2 photos were in that group. ↓



'I used to go in here... and he couldn't get in' (Voltboy)



By Bignac

One young person spent time with other similar children and said it was helpful.

'Being with other people that have got... the same things... To know that you're not the only one' (Steve)



It's not all bad

The only 'theme' everyone added to was the good side of having a brother with autism. The group called this 'the funny side' which included this photo.

Young people spoke about these photographs -



I usually play with him' (CJtheDJ)

'There's never like a dull moment... there's the funny things with the bad things' (Andrez)

'he's very fun' (Steve)

'we can have fun' (Bigmac)

Some young people felt their brother's autism changed how they are a brother - *'a brother, they can be annoying, but they can help you. They can help each other... he doesn't really count as a proper brother' (Vultboy)*

But they also spoke about lots of ways they are still 'normal' brothers. *'I think that's just how brothers feel' (Vultboy)*

'[he] is my brother and I couldn't do any, much without him' (Steve)

'It's just like having a normal 5 year old' (Bigmac)



What now?

As autism is something someone will have for their whole life, it is really important that brothers and sisters are supported so we can try and stop the difficult parts from taking over and turning into a big problem for young people.

As well as {service name}, we are going to show this research to charities and other people who support families. Hopefully this will mean they can develop more help for brothers and sisters. At the moment this kind of thing is rare or there is none at all, but it is really important that young people can find coping strategies like the young people in this research, as well as having an escape and some time away.

I want to talk to someone about what I've read.

There is a parent/ carer version of this booklet so it might be helpful to speak to your parent/ carer first if you want to. They will be able to find someone who can help you if they can't.

Thank you for reading about our research,
Freyja Bancroft, Dr [redacted] and Dr Helena Priest
[redacted] NHS Trust and Staffordshire University





What's it like having a brother with autism?

For parents/carers/professionals

Recently, we did some research at CAMHS to find out about young people's experiences of living with a sibling with autism. Here's what we did and what we found...



What is autism? Autism Spectrum Disorder (ASD) or autism, is a neurological difference in how a person interacts with and perceives the world. Although all individuals are affected differently, typically people are impacted in three main domains – social interaction, communication, and imagination.

Why did we do this research? There is extensive research about many aspects of autism, only a small proportion of this considers children with autism's siblings. This research largely asked parents about the young people as opposed to the siblings directly. This research aimed to ask the young people themselves what it's like having a sibling with autism, in order that their views and experiences could contribute to the body of literature which already exists. This will allow their voices to be heard by professionals who otherwise may not hear them, as often these young people are in mainstream schools with no history of mental health service involvement.

Who took part? We had 5 young people taking part who all have a brother with autism. They were all between 7 and 11 years old.

Where did this research take place? The research was sponsored by Staffordshire University and took place at [REDACTED]

Who reviewed this study? All research in the NHS is reviewed by an independent group, called a Research Ethics Committee to protect participants' safety, rights, wellbeing and dignity. This study was given approval by the North of Scotland Research Ethics Committee (1). It was also subject to scientific review by Staffordshire University Faculty of Health Sciences Research Ethics Committee.

What did we do? We asked the children to take photos for 3 weeks telling us what it's like having a brother with ASD; this method is called Photovoice (see www.photovoice.org for more information). This time period spanned both school holidays and term time. Then the young people came in for individual interviews to speak about their photos, what they represented and why this was important to them. The young people then came back together as a group with their parents and created themes where they had taken photos which represented similar things.

The young people's interviews were transcribed and a thematic analysis was conducted, finding common areas which multiple children had spoken about. These themes were then combined with the photographic themes the young people had created.

What did we find out?

There were four overall themes from the young people's photographs and interviews which are described below.

The theme titles the young people devised have all been emphasised in bold.

Focus on sibling on the autism spectrum

Three participants spoke directly about their brother being a focus within their daily life as well as the participants' narratives being focussed on their brothers' needs as opposed to their own. Interestingly, during the group theming session this was not named as a group or anything similar.

'and would that be better for you as well?

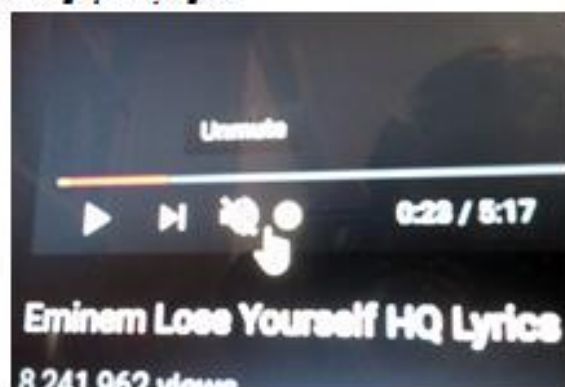
Yeh because then there'd be less shouting, less stress, and it would be better for his education' (Vltboy)

'makes me feel a bit sad cos he's missing out' (Bigmac - photograph 1)

'I've always got to just think... what [he's] doing' (Andrez - photograph 2, of music muted)



Photograph 1: by Bigmac



Photograph 2: by Andrez



Photograph 3: by Vltboy



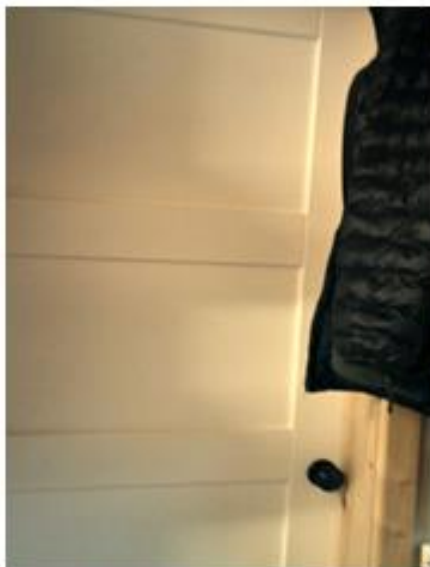
The participants demonstrated an acceptance of the increased needs of their siblings, in a way which affected the usual running of their day to day life. Participants feel better when their brothers are okay, but this requires an element of effort and vigilance from the family and sibling.

A subordinate theme within the area of focussing on siblings, was of things being unfair, or imbalanced between siblings. In some instances, this was in the context of there being certain accommodations made for their brother due to their autism:

'Unfair that he gets all this in his room and I don't get it (Voltboy – picture 3) and '[mum doesn't] give me a warning so that's even worse' (Voltboy).

In other instances, participants were accepting of the way things are different, but this did not mean there was no impact: *'I don't get the game some days... kind of feel a bit jealous' (Bigmac)*

One participant spoke about the needs of their sibling being prioritised which affected the participant's enjoyment of activities or trips: *'my experiences can be either like ruined or changed... because of [his] autism (Andrez).*



Photograph 4: by Voltboy

Finally within this theme, the participants spoke about directly helping their sibling/family. This was particularly the case for one participant who said *'mum has a time struggling with him... I take the bags for her and help her up'* (Bigmac). Other participants spoke about indirectly helping situations e.g. *'I let him have them'* (Voltboy).

Conflict and struggles in daily life



Photograph 5: by CJtheDJ

Four participants spoke about regular difficulties with their sibling. The group session labelled **'troubled times'** for these struggles which included photograph 4. The participants spoke at length about the impact these difficulties had on them. **'The dark side'** was also a category which contained photographs of things which caused arguments.



Photograph 6: by Andre

'He can get angry at that, he'd shout at that' (Voltboy)



'He's shaking and he goes 'aaarrghhhh'' (Bigmac)

There was a constant, regular nature to this -

'it's not really safe... I still get the shouting... still feel bad... still hear the same amount of noise when you're younger, it still scares you' (Voltboy)

'times where he's just... unbearable' (Andrez)

'you can't really get away from it because it's in your house and it's in your mind' (Voltboy)

'when he is.. not happy I feel a bit sad cos I'm like nooo not again... it happens pretty often' (Bigmac)

'I've got to sit by myself, I've got to eat at different times' (Andrez)

This is one of the elements which prompted the design of this research. The participating siblings all lived with their brother, and largely attended or had recently attended the same school as their sibling. From the participants' accounts, this intensity of contact is one of the driving factors behind what they struggle with in relation to their sibling.

The group theming also generated a category which they named '**late or missing squad**', for which photographs 5 and 6 were key images.

'I was feeling worried because like we might miss the slot in the tour' (Andrez - photograph 6).

'being late for school when he's having a meltdown' (CJtheDJ - photograph 5)

The impact of missing out on experiences or being late for school can be difficult for young children to manage particularly if they receive consequences, for example *'I get in trouble at school if I'm late' (Bigmac).*

Coping strategies

Following on from the theme of difficult times, participants had developed a variety of coping strategies. The group spoke about finding '**solutions**' which were sometimes small and sometimes major changes for the family.

'he sat through that fine because he had... headphones on' (Andrez)
'we got a dog to help... put up a chart to like rules and that... we had an extension' (Voltboy)

All participants at the theming group contributed to a group named '**escape the situation**'. These photographs included physical escapes such



Photograph 7: by Bignmac

as picture 4, spoken about below, but also mental escapes such as technology in photograph 7.

'I used to go in here... so no one could get in so then if [he] was getting angry at me I could go and he couldn't get in' (Voltboy – picture 4).

The need for an escape is vital when considering the recurring nature of a lot of the difficulties, as described in the previous theme. It is encouraging that the participants identified positive ways of managing.

Spending time with others in a similar position was mentioned by one participant, saying *'being with other people that have got... the same things... To know that you're not the only one'* (Steve).

Part of the reason for using Photovoice was the experience of participation being validating for the participants, therefore it is positive that this child found it helpful to spend time with others in a similar position.

It's not all bad

Hearteningly, the theme every participant contributed to was the positive side of having a brother with ASD. The group theming session produced a theme titled **'the funny side'** which contained 23



Photograph 8: by CJtheDJ

photographs including

photograph 8. Participants spoke about this in their individual interviews -

'there's the funny things with the bad things' (Andrez)

'he's very fun' (Steve)

'I usually play with him' (CJtheDJ - photograph 8)

Enjoyment and positive engagement is undoubtedly a key part of sibling relationships and the balance of positive and difficult times is likely to contribute to the resilience of the participants. While sometimes participants spoke about the negative impact of their brother's autism on their relationship -

'a brother, they can be annoying, but they can help you. They can help each other... you don't have a proper brother' (Voltboy)

They also spoke about the numerous ways in which their relationships were like any other sibling relationship.

'I think that's just how brothers feel' (Voltboy)

'[he] is my brother and I couldn't do any, much without him' (Steve)

'It's just like having a normal 5 year old' (Bigmac)

Clearly, the young people did not see their brothers' autism as negatively impacting every situation, as they were still able to rationalise that no sibling relationship is perfect.

What now?

Highlighting positive and difficult experiences, from struggles in daily life, to coping mechanisms, and focussing on their sibling which has a preventative effect, these themes gives valuable information as to the psychological needs of the young people.

The aim of the research was to gather information which would support the development of a support package for young people in a similar situation to the participants. This would need to balance the responsibility some of the siblings reported in terms of helping their brother and family, but also provide a place where their needs are met with unconditional positive regard and acceptance of the difficulty of repeated disruption to their lives. The young people themselves had begun to develop coping strategies in the way of escaping mentally or physically,

however the remainder of the solutions continued to be focussed on making things easier for their sibling primarily.

Daniel & Wassell (2002) discuss resilience and pose the importance of considering the resources a child has within themselves, their family relationships, and wider community. As these young people, from the current findings, are living in regularly adverse situations which can be difficult to manage, these principles are undoubtedly applicable and would be helpful to promote their wellbeing. These young people's siblings may be a source of stress for both themselves and their wider families. All of these family members would typically be sources of support for young people but may be less consistent in these cases due to the difficulties previously discussed.

Gilligan (1997) presents three areas which promote resilience, the ability to manage under adverse circumstances. These are a secure base (an individual the child can rely on for support when they need it), good self-esteem, and a sense of self-efficacy. A support package based upon these principles would be supportive to building the resources needed.



I'm worried about my child/a young person I work with

If you have urgent concerns please contact CAMHS Central on {phone number} or attend A&E out of hours.

CAMHS welcome referrals for young people struggling who have a sibling with a diagnosis of ASD, and your child's school may also be able to offer support.

Please contact one of the research team if you have any questions –
Principal Researcher: Freyja Bancroft [Redacted]

Clinical Supervisor: Dr [Redacted]

Academic Supervisor: Dr Helena Priest [Redacted]

References

- Daniel, B., & Wassell, S. (2002). *The early years: assessing and promoting resilience in vulnerable children*. Retrieved from <https://ebookcentral.proquest.com>
- Gilligan, R. (1997) 'Beyond permanence? The importance of resilience in child placement practise and planning' *Adoption and Fostering* 21, 1, 12-20.