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Mother-Child Relationships and :Maternal Expressed Emotion in Families of Children with Autism

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**Mother-Child Relationships and Maternal
Expressed Emotion in Families of Children with Autism**

Louise M. Hall

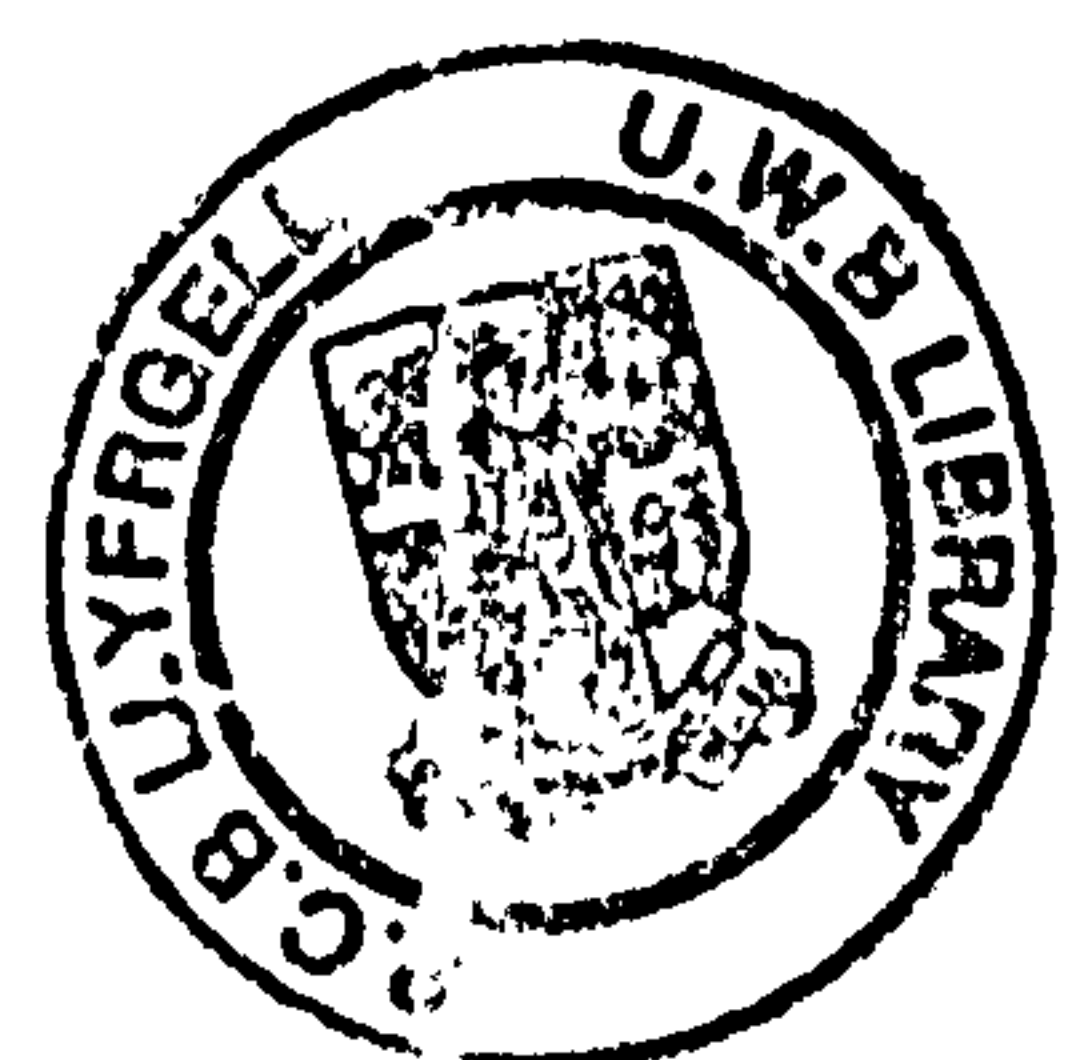
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**Thesis submitted in partial fulfilment of the requirement of the Degree of Doctorate in
Clinical Psychology.**

LARGE SCALE RESEARCH PROJECT



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Additional Information Concerning the Research

Section 4 of this thesis, the empirical research paper, was conducted as part of a larger on-going research project involving families of children with autism. The overall project formed part of a PhD thesis for Mike Petalas on siblings of children with autism, and was supervised by Professor Richard Hastings (Professor of Psychology), Dr. Alan Dowey (Clinical Psychologist) and Dr. Susie Nash (Research Officer). In addition, the project incorporated two DClinPsy theses for Louise Hall and Helen Joannidi, which were supervised by Professor Richard Hastings.

Acknowledgements

I would like to thank all the members of the research group for their inspiration and guidance in the conduct of this study. I am particularly grateful to my supervisor, Richard Hastings, for his expert advice, and to Helen and Mike for their motivation and dedication to the project.

Heartfelt thanks also go to all the mothers who so willingly gave up their time to take part in the study. Without them, this project would not have been possible.

I also wish to extend my thanks to my family and friends for their kindness and support over the last three years. Special thanks go to my sister, Terri, my mum and Stephen for their constant encouragement and belief in me and to Emma, for her invaluable proof reading and warm words.

Finally, I would like to thank my partner, David, whose support has never faltered and whose optimism and sense of humour always helped me to see the light at the end of the tunnel and to enjoy a laugh along the way.

Title: Mother-Child Relationships and Expressed Emotion in Families of Children with Autism

It has been suggested that deficits in emotional and social reciprocity may prevent children with autism from forming secure relationships to their mothers. The limited research available suggests that whilst children with autism can form relationships with the mother, they tend to experience a poorer quality relationship than typically developing children or children with intellectual disabilities.

Expressed emotion (EE) is a measure of the emotional relationship between parent and child. EE can be divided into two constructs; criticism and emotional over-involvement (EOI). In the present study 100 mothers of young children with autism completed questionnaire measures of maternal wellbeing (stress, mental health) and child characteristics (severity of autism, pro-social and problem behaviour). Measures of child adaptive behaviour and maternal EE and warmth were collected during interviews with mothers. In 82 cases mothers also completed problem behaviour, EE and warmth measures for a typically developing sibling to the child with autism. The results indicated that criticism was associated with maternal stress and child behaviour problems. EOI was not significantly related to any maternal wellbeing or child variables. Warmth, however, was associated with the severity of the child's autism. Comparisons between sibling pairs indicated that mothers were more critical towards their child with autism than to the typically developing sibling. A marginally significant difference was also found for warmth, indicating that mothers were less warm towards their children with autism. Children with autism, therefore, appear to experience a poorer quality of mother-child relationship than their typically developing siblings. Implications for reducing EE and improving the relationship are discussed. As this is a relatively under researched area there is a clear need for further research to fully inform interventions.

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SECTION ONE – ETHICS PROPOSAL

1. Title of project

The Autism Families Research Study

2. The potential value of addressing this issue

The goal of the forthcoming cross-sectional investigation is to add to the current literature base reporting on the adjustment of parents of children with autism and parent-child relationships in families of children with autism.

There is a growing literature on the adjustment of families of children with autism. Research indicates that parents of children with autism report high levels of stress and, when compared to other parents, appear to be at increased risk of psychiatric disorder (Duarte, Bordin, Yazigi & Mooney, 2005; Yirmiya & Shaked, 2005). A theoretical understanding of how each parent adjusts to the specific challenges associated with raising a child with autism will help inform support packages. Currently there are few studies that have compared mother and father well-being and explored factors which contribute to the gender differences in adjustment.

Within developmental psychology the mother-child relationship is considered important for a child's social and emotional development (Bowlby, 1969; 1980). Few studies have investigated familial relationships or correlates of relationship quality within families of individuals with autism. Specifically, there is a notable absence of this kind of research involving school-aged children with autism.

The results of the proposed study will add to the research investigating the familial adjustment and relationships in families of children with autism. The longer-term aim is to use these results to inform the development of support interventions

for families of children with autism grounded on a solid theoretical base. This aim is to be achieved through collaboration with the National Autistic Society.

3. Brief background to the study

Parents of Children with Autism

Research with families of children with developmental disabilities has provided evidence for the adverse affects that raising a child with a disability can exert on the parents (Baker et al., 2002). Furthermore, studies comparing parental levels of stress between parents of children with different diagnoses have shown parental distress to vary as a function of the type of the child's disability, with mothers and fathers of children with autism reporting significantly more stress than parents of typically developing children, children with Down syndrome, other developmental disorders, chronic illness, or children from a psychiatric outpatient facility (Donovan, 1988; Dumas, Wolf, Fisman, & Culligan, 1991; Holroyd & McArthur, 1976; Kasari & Sigman, 1997; Koegel et al., 1992; Konstantareas, 1991; Konstantareas, Homatidis, & Plowright, 1992; Sanders & Morgan, 1997; Wolf, Noh, Fisman, & Speechley, 1989).

A study by Hastings et al (2006) looked at stress in mothers of children with autism at two time points, which were two years apart. At the first data collection point, the mean scores of mothers of children with autism on the PSI Parental Distress scale were significantly higher than those of mothers of children with other developmental disorders. This was also the case at the second time point, showing that parents of children with autism may suffer from lasting stress.

There has not been so much research conducted on father's adjustment to having a child with a learning disability or developmental disability. Rodrigue et al

(1992) looked at psychosocial adaptation of fathers of children with autism, Down's syndrome and normal development. The results showed that fathers of children with autism or Down's syndrome used wish-fulfilling fantasy and information seeking as coping strategies more frequently than fathers of normally developing children. Fathers of boys with autism also reported more family cohesion than fathers of girls with autism. Interestingly, a positive result was that no difference between fathers of normally developing children and fathers of children with autism in parenting satisfaction was shown.

A few studies have compared the experiences of mothers and fathers raising children with autism. Hastings & Brown (2002) looked at both mothers and fathers of children with autism, their self-efficacy and mental health. Results showed that self-efficacy mediated the effect of child behaviour problems on mothers' anxiety and depression, but there was no evidence that it functioned as a mediator for fathers. In addition, there was evidence that self-efficacy moderated the effect of child behaviour problems on fathers' anxiety, but not for mothers. A study by Moes et al (1992), looking at stress profiles for mothers and fathers of children with autism showed that mothers reported significantly more stress than fathers, with a pattern suggesting that stress may have been related to the differing responsibility assigned to child rearing for each parent. A qualitative study by Gray (2003) looked at the role of gender and coping amongst parents of high functioning children with autism. The results showed that fathers reported that their child's autism did not impact on them personally, and that there was a more indirect impact through their wives. Fathers also commented that working hard helped to lessen the impact of having a child with autism.

Some of the factors involved in differences in adjustment to having a child with autism have been discussed. However, research has been published into additional factors that may be involved. Factors that have been investigated include: child behaviour problems and their relation to parental mental health (Baker et al, 2003; Hastings, 2003;), support in the form of parenting skills training and its relation to parental mental health, (Tonge et al, 2006), coping styles and techniques (Tunali & Power, 2002; Gray, 2006), self-efficacy (Kuhn & Carter, 2006) and personality factors (Glidden et al, 2006).

Finally, there may be an interaction between family factors and other factors associated with parental adjustment to having a child with autism. Hastings et al (2005) performed a systematic analysis of relationships between child, partner and parent variables associated with parental stress and mental health for parents of pre-school children with autism. Results showed that paternal stress and positive perceptions were predicted by maternal depression. In addition, maternal stress was predicted by their children's behaviour problems and by their partner's depression.

Expressed Emotion and Maternal Warmth

Expressed Emotion (EE) can be conceptualised as a measure of the emotional relationship between parent and child (Hastings et al, 2006). More specifically, it can be used to measure the levels of criticism and emotional over-involvement that one family member expresses in relation to another. In order to better understand EE as a measure of the parent-child relationship, researchers in learning disabilities and autism have focused on investigating the various child and parental factors associated with EE (Dorretor, Nicol, Stretch & Rajikhowa, 1994; Beck, Daley,

Hastings & Stevenson, 2004; Hastings et al, 2006; Orsmond, Seltzer, Greenberg & Wyngaarden Krauss, 2006; Greenberg, Seltzer, Hong & Orsmond, 2006).

Dorretor, Nicol, Stretch and Rajikhowa (1994) found that high levels of maternal EE were more evident in families of children with intellectual disabilities when the child has more pronounced behavioural difficulties. Furthermore, they also found that less severe functional impairment in the child was associated with high levels of criticism whereas emotional over-involvement was associated with more severe functional impairment. In terms of parental factors, high EE was associated with poorer maternal psychological well-being, poorer quality of the marital relationship and less social support. A more recent study found that EE (criticism only) was cross-sectionally, but not longitudinally, related to maternal stress and child behaviour problems (Hastings et al, 2006).

Beck et al (2004) sought to investigate the relationship between EE and child and parental factors further by exploring maternal EE towards two children; a child with learning disabilities and their typically developing sibling. They suggested that a difference in maternal EE towards the child with learning disabilities and their sibling would suggest EE was determined primarily by child factors. No difference would suggest EE was more of a maternal characteristic. Findings indicated that mothers displayed higher EE towards the disabled child, supporting the suggestion that EE is primarily influenced by child factors.

Researchers in autism have recently begun to investigate the relationship between maternal EE and symptoms of autism and behaviour problems in adolescent and adult offspring (Greenberg et al, 2006). Greenberg et al (2006) found that high levels of EE were related to increased severity of child behaviour problems and an

intensification of autistic symptoms (i.e. impairments in reciprocal social interaction) in individuals with autism over time. However, in their study of maternal EE towards children with learning disabilities (some of whom also had autism), Hastings et al (2006) failed to find longitudinal evidence to suggest that EE predicted behaviour problems over time.

Other researchers have investigated levels and correlates of maternal warmth in families of adolescents and adults with autism. Maternal warmth is a positive measure of mother-child relationship quality. It is judged to be high or low based on the mother's tone of voice, spontaneity of speech and the amount of concern demonstrated when talking about her child. In the only published study to investigate maternal warmth in this population, Orsmond et al (2006) found that low warmth was related to higher rates of child behaviour problems and more maternal stress.

4. The hypotheses

Aims of the research/Predictions

The first aim of this study is to explore correlates of parental adjustment outcomes. Variables that will be investigated in relation to parental adjustment will include; family demographics, satisfaction with the marital relationship, parent psychological well-being and stress, parental positive perceptions of raising a child with autism, severity of the child's autism, behaviour problems and level of adaptive skills.

A further aim of the proposed study was to investigate the nature of the emotional relationship between parents and their children with autism, by examining levels of parental EE and warmth and exploring associations between parental EE

and warmth and various child and parent variables. Parental variables addressed by the study will include; family demographics, parent's psychological well-being and stress. Child variables will include severity of the child's autism and behaviour problems and level of adaptive skills. Comparisons between parental EE towards the child with autism with maternal EE towards the typically developing sibling will be made to determine whether EE is primarily influenced by child or parental factors.

Due to the mixed findings from studies, we make no specific predictions on the direction of effects in this part of the study.

5. Participants: recruitment methods, age, gender, exclusion/inclusion criteria

The proposed study is being conducted in collaboration with National Autistic Society (NAS). Participants for the proposed study will be recruited with the help of the NAS. This research will be carried out in conjunction with two projects from the North Wales Clinical Psychology Programme with a specific focus on parental adjustment. Louise Hall is a Trainee Clinical Psychologist; the aim of her research is to compare parents' EE for their child with autism with their EE for their child without autism. Parental and child factors associated with EE will also be investigated. Helen Joannidi is a Trainee Clinical Psychologist; the aim of her research is to investigate the adjustment of parents/carers raising a child with autism.

Information about the study, invitations to participate and contact detail forms will be prepared by the research team and given to the NAS to distribute amongst families registered on their Help¹ database (currently approx. 1000 families). The inclusion criteria for families in the study will be: families must have a child with a formal diagnosis of an Autistic Spectrum Disorder (ASD) aged 3 – 17

¹ Help is a NAS family support programme

years, at least one parent or guardian (i.e. primary caregiver, typically females /mothers) and, where available, secondary care-givers (i.e. males/fathers) and a typically developing child (sibling to the child with autism) aged 3 – 17 years. In families with more than one typically developing child, the sibling data will be collected from the sibling nearest in age to the child with autism.

Those families who fit the inclusion criteria and are interested in participating will then be asked to complete and return contact details and a consent form for the researcher to contact them by phone, to the School of Psychology, University of Wales, Bangor. Following this, families will be sent a questionnaire, an information pack and consent forms. Those that have consented to the telephone interview will be contacted by a member of the research team for an interview, lasting approximately 45 minutes. Our aim will be to recruit 200-300 families of children with autism. We aim to send invitations to approximately 1000 families. From these, a response rate of approximately 40% is expected based on previous similar studies (400 families). From the 400 families who are estimated to agree to take part in the study, it is expected that 70% of these will actually return questionnaires (280 families). It is expected that fewer secondary caregivers (typically the fathers) will participate than primary caregivers.

Written consent for telephone contact will be sought when parents receive the initial invite. Oral consent to conduct and record the telephone interview will be obtained at the start of each interview. Once parents have returned the initial consent and contact form stating that they are willing to participate in the research, written consent will be sought a second time (when families will be asked to give their consent for us to use the information they provide for research) for the

questionnaires and for recording the telephone interview. Written consent will be obtained from all participants completing measures.

6. Research design

A cross-sectional postal survey design will be used. Questionnaires containing the various measures and forms described below will be mailed to the families for completion by primary caregivers and secondary caregivers. The measures are designed to access various aspects of parental adjustment as well as gaining demographic details about the family and information about the child with autism (i.e. formal diagnosis, autistic symptoms, level of disability/adaptive skills and behavioural problems). Parents will also be invited to participate in a telephone interview to complete a measure of adaptive behaviour for the child with autism and a speech sample for the child with autism and the typically developing sibling (for coding EE).

Following participant recruitment as described above, participating families will be sent questionnaire and information packs consisting of a range of measures to be completed by primary care-givers and secondary care-givers (see Measures section below). The measures are designed to access various aspects of parental adjustment as well as gaining demographic details about the family and information about the child with autism (i.e. formal diagnosis, autistic symptoms, level of disability/adaptive skills and behavioural problems).

Primary caregivers will be asked to provide information in the following areas:

- The child with autism – behavioural and emotional adjustment, diagnosis, adaptive behaviour and autistic symptoms

- The primary caregivers own mental health, marital relationship (dyadic adjustment), stress and positive experiences of their child with ASD.
- And speech samples for coding EE toward their typically developing child and their child with ASD.

Secondary caregivers will be asked to provide information on:

- Marital relationship (dyadic adjustment)
- Mental health
- Stress
- Positive experiences of their child with ASD.
- Behavioural problems of their child with autism

7. Procedures employed

Initially all families identified through the NAS will be sent information on the aims and objectives of the project and an invitation to participate in the research (see appendix 1). A contact form (see appendices 1 & 2) will be included where families will be asked to fill in their contact details and consent to being contacted by the research team.

Once contact forms have been returned, participating families will be sent questionnaires for primary carers to complete (see appendix 3). If there is a secondary carer in the family they will receive an identical set of questionnaires. Questionnaires will be posted to families, accompanied by an information form and consent forms for participants to complete (see appendix 4). Families will be asked to complete questionnaires and forms and return them by a specified date, to the researchers at the School of Psychology, University of Wales, Bangor, using the

enclosed stamped addressed envelope.

Once questionnaires and consent forms have been returned the researchers will then contact participating families for stage two of the research study. This involves telephoning families and interviewing with the primary caregiver (probably the mother). During this interview the primary care-giver will be asked to give two Five Minute Speech Samples (FMSS), one for their child with autism and one for their typically developing child. The FMSS's will involve participants speaking about their relationship for five minutes for each child, and will be recorded using a digital recorder, for which families will have given written and oral consent. Following this they will complete the Vineland Adaptive Behaviour Scale - 2nd Version (VABS II) (Sparrow et al, 2005) in relation to their child with autism.

Any families who fail to return the participant packs by the specified date will receive a letter prompting them to return the questionnaires (see appendix 5). Any families that need to be followed up for missing or unclear information that they may have provided, will also be informed that they will receive a telephone call (provided the families have consented to being contacted in this manner via the contact sheet) to clarify their responses in certain areas.

Once data analysis has been completed these families will receive a summary report of the findings of the study.

8. Measures employed

Demographics Questionnaire

All families will be asked to complete a questionnaire to obtain basic demographic information including: age and gender of caregivers and children, marital status of caregivers, number of adults and children in household, educational

level of caregivers, occupational status of caregivers, diagnosis of child with ASD, additional impairments and diagnoses of child with ASD, placement of child with ASD, socio-economic status of family, ethnicity of family, and schools attended by both children (see appendix 3).

Measures for primary caregiver to complete:

Social Communication Questionnaire

The Social Communication Questionnaire (Berument, Rutter, Lord, Pickles, & Bailey, 1999) is an autism screening instrument, which was previously known as the Autism Screening Questionnaire (ASQ) (see appendix 6). It was developed in response to the need for a reliable and valid screening instrument that is based on the current diagnostic criteria for autism and which can be used with all age groups. It is a 40-item questionnaire based on the original Autism Diagnostic Interview - Revised (ADI-R) algorithm used for ICD-10 and DSM-IV diagnosis of autism. The ASQ has good discriminative validity with respect to the separation of PDD from non-PDD diagnoses at all IQ levels, with a cut-off of 15 proving most effective.

Strengths and Difficulties Questionnaire (SDQ)

The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) will be used as a measure of children's' behavioural and emotional adjustment (both for the child with autism as well as the typically developing sibling) (see appendix 3). This questionnaire measures 4 problem domains (emotional problems, conduct problems, hyperactivity, and peer problems) as well as prosocial behaviour. Dimensional scores on each of the SDQ domains can be obtained by adding up the scores on items on each domain (a total difficulties score can be derived by summing the

scores of the four problem domains). In addition, cut-off scores that suggest clinical levels of symptoms across the five domains are available.

The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was constructed to allow a quick measure of depression and generalised anxiety in hospital settings, but it has been widely used in outpatient and community research (see appendix 3). It has also been used specifically to measure anxiety and depression in parents of children with autism (Rydebrandt, 1991; Hastings, 2003). The HADS contains 14, four-point items, with seven assessing depression and seven assessing anxiety. The anxiety and depression sub-scales have been shown to be internally consistent (Mykletun et al, 2001). The scale was chosen for the study due to its previous usage in associated autism research, its acceptance as a valid and reliable measure, and because of its relative brevity to administer.

The Dyadic Adjustment Scale – Short Form (DAS-7)

The DAS (Spanier, 1976) is a 32-item measure in a variety of response formats developed to measure dyadic adjustment (see appendix 3). The measure has four subscales: Dyadic Consensus, Dyadic Satisfaction, Dyadic Cohesion and Affectional Expression. Graham et al (2006) found that the Dyadic Cohesion, Consensus, and Satisfaction subscales had scores of acceptable internal consistency, but that the Affective Expression subscale was found to produce scores with poorer Cronbach's alpha across studies. The DAS is possibly the most widely used measure of relationship quality in social and behavioural sciences research. Spanier (1985)

noted that the DAS had been used in more than 1,000 studies. The Abbreviated version of the Scale (DAS-7) has seven items and has been shown to have good construct validity (Hunsley et al, 2001). The DAS-7 was chosen for the study due to the small number of items and the validity of the scale.

The Questionnaire on Resources and Stress (QRS – F) – Parent & Family Problems Subscale (Short Form)

The Questionnaire on Resources and Stress for Families with Chronically Ill or Handicapped Members (QRS) (Holroyd, 1974) was designed to assess families' coping and adaptational responses to a disabled family member (see appendix 3). The original QRS consists of 285 self-administered, true-false items. Reliability reported in the manual is limited to Kuder-Richardson 20 estimates for internal consistency. The KR-20 reliability correlation was .96 for the full-length QRS. Norms for special populations of families with members with different handicapping conditions have been established for four major classifications: developmental disabilities, psychiatric problems, chronic medical illness, and neuromuscular disease. The short form (QRS-F) (Friedrich, 1983) consists of 31 items and the Parent & Family Problems Subscale consists of 15 items. Analysis of a total stress score on the QRS-F for parents of children with autism was explored by Honey et al (2005). Analyses revealed evidence of good reliability, and expected associations with social support, coping and autism severity. The QRS-F was therefore chosen due to its brevity to administer as well as accepted psychometric properties.

Positive Gains Scale (PGS)

This measure consists of seven items taken from a modified version of the

Parenting Stress Index-Short Form that has been used in research with parents of children with spina bifida and hydrocephalus (PSI-SF43; Pit-ten Cate, 2003) (see appendix 3). These seven items relate to positive experiences associated with raising a child with a disability. Five items relate to the parents pleasant experiences of raising a child with a disability and two items relate to how the family has gained from the experience of having a child with a disability within the family system. Preliminary research findings indicate that the PGS has face and content validity and a Cronbach's Alpha reliability coefficient of 0.79 (Pit-ten Cate, 2003).

Measures for Secondary Care-givers to complete:

Details on all measures can be found in the section above.

- The Hospital Anxiety and Depression Scale (HADS)
- The Dyadic Adjustment Scale - Short Form (DAS-7)
- The Questionnaire on Resources and Stress - Parent and Family Problems Subscale (QRS-F)
- Positive Gains Scale (PGS)
- Strength and Difficulties Questionnaire (SDQ) (to be completed for the child with autism and the sibling)

Telephone Interviews with Primary Caregiver: Measures

Vineland Adaptive Behaviour Scale -2nd Version (VABS II) (Sparrow et al, 2005)

This instrument will be used as a measure of adaptive behaviour for the child with autism (see appendix 7). It will be used in the form of a semi-structured interview conducted with the primary care-giver (probably the mother) of the child with autism over the telephone. It is composed of items arranged in developmental

sequence that measure adaptive behaviour across four domains: socialization, communication, daily living skills, and motor skills. An overall composite score can be derived with reference to respective age in children that are typically developing and can perform the task items.

Expressed Emotion Speech Samples will be coded using:

Five Minute Speech Sample (FMSS)

The Five Minute Speech Samples will be used to measure parental EE towards children with autism and their typically developing siblings (Magna et al, 1986). Parents will be instructed give two speech samples, one for each child (see appendix 8). During the speech sample they will be asked to talk, uninterrupted for five minutes about their relationship with that child. The order of the two speech samples will be counter-balanced across the whole study. Samples will be recorded and later coded for EE. The FMSS manual provides guidelines for coding EE in terms of two dichotomous variables; parental criticism and emotional over-involvement.

The FMSS is widely used in studies of EE. Research performed on the reliability of the FMSS, and the degree of correspondence between the FMSS and the Camberwell Family Interview (CFI, a semi-structured interview and the ‘gold standard’ of EE measurement), indicates good reliability, concurrent validity and inter-rater reliability across measures (Moore & Kuipers, 1999). In addition, compared to the CFI, the FMSS is less time consuming to administer and code, making it more practical for clinical research. Research into EE in parents of children with learning disabilities indicates that the FMSS maintains good code-recode, four week test-

retest and inter-rater reliability (Beck et al, 2004). Furthermore, there good agreement between EE coded from telephone interviews and face to face interviews (Beck et al, 2004).

The Preschool Five Minute Speech Sample (PFMSS)

The Preschool Five Minute Speech Sample (Daley, 2001) is a revised version of the FMSS. The PFMSS is specially adapted to measure parental EE towards pre-school aged children. Unlike the FMSS manual, the PFMSS manual provides additional criteria for rating maternal warmth. The FMSS and the PFMSS use identical methods for gathering speech samples (see appendix 8). Maternal warmth will therefore be coded from the same five minute speech samples collected during the telephone interviews, using the criteria set out in the PFMSS manual. The PFMSS warmth construct has shown moderate to good levels of code-recode, inter-rater and test-retest reliability (Daley, Sonuga-Barke & Thompson, 2003).

9. Qualifications of the investigators to use measures

All members of the research team will be appropriately trained to use the FMSS/ PFMSS and VABS II for research purposes. Michael, Helen and Louise will all receive extensive training for administering the FMSS/PFMSS and the VABS II, by Tracey Lloyd. Tracey has considerable experience using the FMSS/PFMSS. She has been trained in coding by the author of the PFMSS (Dr. Dave Daley) and has provided training in the administration and coding of FMSS/PFMSS the past. She is currently writing up her doctoral thesis, which included work on the validity and reliability of EE as a coding measure for use with mothers of children with an intellectual disability. As part of work towards her MSc thesis Tracey was asked to

administer and code the FMSS by a trained coder. This included reliability checks with other trained coders. Tracey has recently worked on a review paper on the utility of EE entitled: *Expressed Emotion in Families of Children and Adults with Learning Disabilities*. (Hastings & Lloyd, under submission). In addition all members of the research team conducting interviews will be supervised by Dr. Alan Dowey who is an NHS Clinical Psychologist based in Wrexham.

10. Venue for investigation

N/A

11. Estimated start date and duration of the study

We propose to begin data collection in mid-late September 2007, and it is expected that the data collection will stop by April 2008 (or earlier if 300+ families are recruited before this date). Analysis and writing up of data from the study is likely to take up to a further 3 months. Below is an indicative timetable of the research stages from the submission of the ethics application to the final submission of the project.

Timetable:

July 2007

Ethics Proposal submitted to the School of Psychology

September 2007

Ethics approval is anticipated to have been received. Invitations & contact forms sent out by NAS. Families asked to respond by October 2007.

October 2007 - November 2007

Questionnaire packs sent to families directly by research group. Families are asked

to return questionnaires within one month.

December 2007

If questionnaires have not been returned, follow-up letters prompting families to return completed forms sent. (Training in the coding of EE by a member of the School of Psychology to be completed by October 2007).

January 2008

Questionnaires to have been returned.

October 2007 - February 2008

Telephone interviews to have been conducted.

February 2008

Data input and analysis, (FMSS will be coded by Louise and inter-reliability checks will be completed by someone in research group).

March 2008

Data input and analysis continued.

April 2008

Proposed study to be written up and draft reports to be given to supervisors.

May 2008

Any amendments to be made.

June 2008

Final submission of DClinPsy theses to University.

12. Data analysis

Upon return of the questionnaires all data will be entered into SPSS. Data analysis will be carried out on two levels; first inter-group analysis will be carried out. The second step will consist of intra-group analysis where factors associated with and predicting parental adjustment will be explored through multiple regression analysis. This analysis will also involve testing for mediator/moderator relationships between variables.

T tests (or a non-parametric equivalent) will be used to compare mothers and fathers on parental adjustment variables (mental health, stress, coping, positive experiences). A multiple and/or stepwise regression model will be used to assess what factors are associated with parental adjustment.

Speech samples will be recorded during the telephone interview and later coded for EE. Louise Hall is to receive training in the coding of EE from a member of the School of Psychology (Tracey Lloyd). A member of the School of Psychology, University of Wales, Bangor, will conduct inter-rater reliability checks for EE coding.

EE will be analysed quantitatively and two main scores will be used, a dichotomous score for emotional over-involvement (high verses low emotional over-involvement) and a similarly dichotomous score for criticism. To compare parental EE towards children with autism to EE towards siblings, McNemar's tests will be used. A logistic regression will be used to examine the demographic, child and parent variables (from the questionnaires) that predict EE towards the child with autism. A dichotomous score for maternal warmth (high verses low warmth) will be created and analysed in the same manner.

13. Potential offence/distress to participants

There is no risk of potential serious offence/distress to participants that can result as a consequence of participating in this research. However, there is a small possibility that a participant may become upset during the telephone interview when talking about their child/children. In this case the researcher will make a brief assessment of immediate stress (see Appendix 11 - evaluation protocol) and follow the appropriate risk assessment procedure (see appendix 9 - Risk Assessment 1). In the event of severe distress to the participant, the interviewer will seek permission to pass on the contact details of the affected participant to the supervising Clinical Psychologist who will make a follow-up telephone call to offer advice on suitable support services. There is also a possibility that a participant may score in the clinical range for psychological problems (e.g. on the HADS). However, this does not constitute a diagnostic assessment so it would be inappropriate to feedback this specific information. There is also a remote possibility of participant making a disclosure of child abuse, threat of harm to self or others or a terrorist threat. Under such extreme circumstances the researchers will act accordingly (see appendix 10 - Risk Assessment 2)

14. Procedures to ensure confidentiality

To protect the identity of respondents any documents that will contain personal or identifiable information of the respondents (e.g. demographic questionnaire, measures etc), will be treated as confidential information and kept locked in a secure filing cabinet within the school of psychology. Personally identifiable information will be kept separate from the information that participants provide on the questionnaires in line with the procedures of confidentiality and data protection of the School of Psychology, University of Wales, Bangor. The

confidential information of respondents will be used to keep the participants and their families informed about the study. Recordings from telephone interviews will be stored under participant numbers and in secure files on a computer in a locked office at the School of Psychology, University of Wales, Bangor.

15. How consent is to be obtained

Written consent will be obtained to contact parents for telephone interviews and from all parents completing measures. Consent forms will be available in both Welsh and English (see appendix 2). Parents will give written consent to the recording of the telephone interviews when they return the questionnaires. Oral consent to conduct and record the interview will be obtained from the participant again before each interview commences.

16. Information for participants

All families identified as meeting the study criteria that will have replied to our invitation will have read the information sheet (see appendix 1) explaining the aims and purpose of the study. Once the data have been analysed, a summary of the study's results will be sent out to all the families that participated in the research.

17. Approval of relevant professionals

N/A

18. Payment to participants, investigators, departments, institutions

N/A

19. Equipment required and its availability

Digital telephone recording equipment for telephone interviews will be needed. Appropriate devices are already available in the research team, or are on order.

20. Arrangements for participant feedback

All participants and their families will receive a summary of the study's results.

21. Project conformity to BPS guidelines on Ethical Standards in research

This research project will be carried out in accordance with the guidelines laid down by the British Psychological Society and the procedures and ethical guidelines determined by the School of Psychology, University of Wales, Bangor.

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Appendices for Ethics Proposal

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|--------------------|---|
| Appendix 1 | Initial invite to participants and initial family contact and consent form |
| Appendix 2 | Welsh translations of the initial invite to participants and initial family contact and consent form |
| Appendix 3 | Questionnaires for primary and secondary carers. Consisting of: Demographics Questionnaire (primary and secondary carer versions; English and Welsh translations), The Strengths and Difficulties Questionnaire (for child with autism version and typically developing child) (Goodman, 1997),* The Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), ** The Questionnaire on Resources and Stress (QRS; (Holroyd, 1974) *** The Dyadic Adjustment Scale – Short Form (DAS-7; Spanier, 1976), *** Positive Gains Scale (PGS; Pit-ten Cate, 2003) **** |
| Appendix 4 | Information sheets for families, instructions for completing and returning questionnaires and consent forms for completing questionnaires and recording telephone interviews. English and Welsh translations. |
| Appendix 5 | Letter to remind families to return the questionnaires |
| Appendix 6 | The Social Communication Questionnaire (Rutter, Bailey & Lord, 2003) ***** |
| Appendix 7 | Vineland Adaptive Behaviour Scale -2nd Version (VABS II; Sparrow et al, 2005) ***** |
| Appendix 8 | Instructions for administering the Five Minute Speech Sample (FMSS; Magana et al, 1986) *** |
| Appendix 9 | Risk Assessment 1 |
| Appendix 10 | Risk Assessment 2 |
| Appendix 11 | Evaluation Protocol |
| Appendix 12 | Confirmation of ethical approval |

* This measure is available online free of charge.

** The copyright for this measure was obtained from a battery of Health Psychology assessments purchased by the university.

*** These measures are available from published journal articles/manuals.

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***** Original copies of these measures were purchased for the study.

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SECTION TWO – REFLECTIVE PAPER

Reflections on the Research Process

At the beginning of the second year when we, as a cohort, were urged to think about potential research questions for our LSRP, my initial reaction went from denial and procrastination to panic. The prospect of embarking on such an enormous task seemed overwhelming and hundreds of questions raced through my mind (“What if I can’t think of a project or find a supervisor?”, “What if I don’t get any participants and have nothing to write up?”, “What if I just can’t do it or I fail?” and so on and so forth). On reflection, I now recognise that much of the anxiety I was feeling at this time stemmed from other unrelated stressors and, as things became more settled in my personal life, my anxiety about the LSRP began to subside (momentarily at any rate!).

In terms of study design, I was keen to conduct a project that involved direct contact with the participants, feeling strongly that there was a lot that I could learn from this client group. Prior to starting this project I had limited experience of working with families of children with autism, as an assistant psychologist and during my core CAMHS placement. One theme I did pick up, however, was the difficulties these families faced in accessing services. This was a theme that was replicated time and time again during the data collection stage. Mothers often struggled to contain their feelings in relation to this and would drift into talking about inadequate service provision during the telephone interview. As an employee of the NHS, I sometimes felt as if I was part of the wider system that was failing to meet the needs of this population. As a researcher, I listened, empathised and then gently redirected mothers back to the topic at hand. Given that these mothers had taken time out of their busy lives to complete the interview it seemed only fair to listen whilst they expressed some of these issues.

The recruitment stage was relatively straightforward and I was genuinely surprised by how motivated the mothers were to participate. Conducting the Vineland Adaptive Behaviour Scale over the phone and collecting EE samples meant that the telephone interviews lasted anything from 1 to 2 hours and this was in addition to completing a substantial postal questionnaire. Mothers were also incredibly open during the interviews, which made this project particularly rewarding. On several occasions I was moved by what I heard. Particular examples included feeling quite emotional after hearing a mother become distressed talking about how her child was physically beaten and verbally bullied by children at two separate schools and feeling 'proud by proxy' as another mother gushed about how hard her daughter had worked to overcome her deficits in recent months and spoke with obvious pride about how much her child had achieved. At other times I was in awe of the sheer determination many of these mothers showed in 'taking on the system' (as one mother termed it) in order to access funding for support for their children and could not help wondering how I would have coped in their situation.

Although enjoyable, this project was also incredibly tiring and at times it felt as if the research time intruded into my personal life. Telephone interviews were conducted at all times of the day. Many mothers requested weekend interviews, as this gave them the opportunity to talk freely whilst their partner watched over the children. However, this often meant being incredibly flexible with my own plans and occasionally the lines between the research time and my time became blurred, leaving me feeling a little overwhelmed at times. To manage this I made an effort to 'take time back' to do something enjoyable and completely separate to the research project, although the

sheer amount of work involved in this project made this tricky. In addition to conducting the telephone interviews, weeks were spent coding over 200 EE samples and scoring VABS, before data input could even begin.

Being part of a research team was a great source of support. Being able to talk about the research process, my anxieties and the impact the project was having on me with the other researchers helped to validate and normalise my experience. However, there were practical difficulties related to being part of a group that was based in Bangor when I lived in Wrexham. Hours were spent commuting to Bangor and due to our busy diaries meetings often had to be arranged at weekends. Each member of the research group had their own working style, motivations and priorities. My way of coping with the demands of the project was to break tasks down and set myself mini deadlines and I sometimes found the more laid back approach of other group members anxiety provoking. Each person had competing demands for their time, which meant that tasks were not always completed by the agreed time. Although I found this frustrating and, at times felt let down, I had to remember that, on occasion, I too had sometimes needed extra time. Clinical research does not always run to schedule, no matter how close it is to the thesis deadline! In the end we pulled together as a group, putting in the extra hours when needed.

Throughout the research I was very aware of the changing job market for clinical psychologists and was plagued with thoughts such as “What’s the point in doing the LSRP? It’ll all be for nothing because there are no jobs to go to”. The job situation did sometimes impact on my motivation for the LSRP, especially at the write-up stage.

In general, the write-up was an arduous task, throughout which I was racked with self-doubt and my original anxieties about failing returned. Three things got me through this part of the research process; constructive feedback from my supervisor, a favourite saying of one of the other research group members (“We’ll get through it because we have to!”) and the support of my boyfriend.

On reflection, this was an ambitious project that was made achievable through lots of hard work and late nights, the guidance of my supervisors and the support of the other researchers, my family and friends. If I could change one thing about the experience it would be to give myself more time to enjoy the process, as it often felt like trying to fit a 3-year PhD into half that time!

SECTION THREE – LITERATURE REVIEW

Running head: MOTHER-CHILD RELATIONSHIPS IN AUTISM

Mother-Child Relationships when the Child has Autism:
A Review of the Literature

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Keywords: Autism, Mother, Relationship, Attachment, Expressed Emotion

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Abstract

Background: Early theories hypothesised that autism occurred as a consequence of a disturbed mother-child relationship. Although parenting is no longer seen as a cause of autism, there is lack of detailed research into mother-child relationships in families of children with autism.

Method: Literature searches were conducted using PsychInfo and Web of Science databases for peer-reviewed journal articles that focused directly on the mother-child relationship when the child has autism.

Results: Twenty-two articles covering attachment, attachment security and mother-child relationship quality were identified. Findings indicate that young and older children with autism can and do form good quality relationships with their mothers. However, young children with autism appear less likely to form secure attachment relationships and, mothers of older children with autism report a lower quality relationship with their child than mothers of children with other disabilities.

Conclusions: Whilst the current evidence base is small and subject to a number of limitations, the available research suggests that younger and older children with autism may experience a poorer quality of mother-child relationship, which may influence mother and child outcomes. Implications for clinical practice and future research are discussed.

Mother-Child Relationships when the Child has Autism: A Review of the Literature

Research suggests that parenting a child with autism may be experienced differently to parenting typically developing children or children with other disabilities. Within families of children with autism, mothers often assume the primary caregiving role (Konstantareas & Homatidis, 1992), therefore the majority of studies have focused on the mother's experiences. Mothers of children with autism report higher levels of parenting stress and poorer psychological wellbeing compared to mothers of children without disabilities (Duarte, Bordin, Yazigi & Mooney, 2005; Koegel et al., 1992; Rodrigue, Morgan & Geffken, 1990) and mothers of children with other disabilities (Konstantareas, Homatidis & Plowright, 1992).

Interestingly, although a number of studies have investigated mothers' experiences of parenting stresses when raising a child with autism, relatively few studies have directly examined the mother-child relationship. Clinically and theoretically the mother-child relationship is considered to be very influential in the social and emotional development of the child (Bowlby, 1969; 1980). Early theories hypothesised that autism developed as a consequence of a disturbed mother-child relationship (Cox, Rutter, Newman & Bartek, 1975). Although parenting is no longer seen as the cause of autism, the legacy of these theories meant that exploring the mother-child relationship became a sensitive and contentious issue for many years, resulting in a paucity of research in the area (Yirmiya & Sigman, 2001).

This paper will initially present a brief overview of early theories about disturbance and difficulty within the mother-child relationship when a child has autism.

Following this, the literature on the mother-child relationship will be reviewed. The review will address two main questions. First, what is the evidence to show that mother and child are able to successfully form a relationship when a child has autism? Second, when a relationship is formed, what is the quality of this relationship and what factors are associated with relationship quality? Implications for clinical practice and future research will also be discussed.

Theories of Disturbance and Difficulties within the Mother-Child Relationship

Kanner (1943) noted that children with autism appeared to have an innate disturbance of affective contact. He also reported that the parents of these children displayed unusual personality traits and lacked emotional warmth. The predominance of the psychodynamic model led many of Kanner's contemporaries to assume that autism was a consequence of a disturbed mother-child relationship. Psychodynamic theories postulated that autism was a response to the cold, rejecting attitude of the 'refrigerator' parent (Bettelheim, 1967; Kanner, 1943), or caused by the mother's failure to form a nurturing relationship with her child due to her own psychological problems (Rank, 1949). Emotional deprivation of this kind was said to cause the child to withdraw into themselves, thus affecting their emotional and social development (Rank, 1949). Other writers saw autism as primarily occurring due to inappropriate amounts of stimulation. Mothers were seen as being either unresponsive and insensitive, thereby providing an under-stimulating environment, or as over-possessive and 'smothering' the child (Bettelheim, 1967; Starr, 1954). Both situations were believed to result in the child's social withdrawal and development of autistic behaviours (Fraknoi & Rutter, 1971).

Support for these early theories was drawn from projective tests and early family observations (Meyers & Goldfarb, 1961; Ogdon, Bass, Thomas & Lordi, 1966). However, such studies had a number of methodological limitations including; measures of questionable reliability and validity, a lack of adequate control groups, poorly defined samples and a failure to distinguish autism from psychosis (Cantwell, Baker & Rutter, 1979; Cox et al., 1975). Later studies that attempted to address these limitations failed to find support for the early theories. Studies comparing parents of children with autism with parents of children with dysphasia found no significant between-group differences for emotional warmth, obsessiveness, personality traits (i.e. extroversion, neuroticism), and the amount or type of maternal interactions and communications (Cantwell et al., 1979; Cox et al., 1975). Similar findings were reported by others (Cantwell, Baker & Rutter, 1977; DeMeyer et al., 1972).

In light of the empirical evidence, autism is no longer seen as a consequence of a disturbed mother-child relationship. The current scientific consensus is that autism is a complex neurological disorder characterised by specific impairments in social interaction (APA, 2000). Studies of social interactions between mothers and their children with autism indicate that children with autism are less likely to initiate interactions than typically developing children (Sigman, Mundy, Sherman & Ungerer, 1986; Warreyn, Roeyers & De Groote, 2005) and children with intellectual disabilities (Sigman et al., 1986). Children with autism are also less likely to accept or respond to social bids from the mother compared to typically developing children (Adamson, McArthur, Markov, Dunbar & Bakeman, 2001). Social interaction is an important element in the formation of the early mother-child relationships (Schaffer, 1996). Some

have suggested that the deficits in social relatedness typically seen in autism may affect the mother and child's ability to relate to one another and hamper their chances of forming a cohesive relationship (Cohen, Paul & Volkmar, 1987; Travis & Sigman, 1998). In this paper we will review literature on the mother-child relationship in order to determine whether mother and child can successfully form a relationship when a child has autism and the quality of the relationship that may be achieved.

Method

Literature searches were conducted using the PSYCHINFO and Web of Science search engines. Searches were run from the earliest dates held in these databases to the present day and were limited to articles from English language peer-reviewed journals. To identify any articles related to the mother-child relationship when a child has autism the following search terms were set as keyword and title searches: MOTHER*, PARENT*, MATERNAL, CARE-GIVER*, FAMIL*, CARER*, CAREGIVER, ASD, AUTIS*, ASPERGER*, PDD, PERVASIVE. This produced over 500 articles. The electronic records and abstracts of these articles were searched by hand for relevance. Any articles that focused on mother-child relationships and/or interactions were initially selected. This selection procedure produced 80 articles. Of these 16 were observational studies measuring specific social skills displayed by children with autism during interactions with their parents, 15 studies focused on parental communication and interaction style, 20 studies evaluated parent-implemented interventions for children with autism, 7 papers concerned educational or therapeutic interventions for families of children with autism, 6 studies investigated patterns of care in families of children with

autism, 4 studies measured mother-child relationship quality and 12 studies concerned attachment relationships. Only those articles that directly investigated the mother-child relationship and/or provided a measure of relationship quality were selected for the current review. This included the 12 attachment studies and the 4 studies addressing mother-child relationship quality. Searching the reference lists and completing citation searches of these articles led to the identification of an additional 6 articles; 1 measuring relationship quality, 4 attachment studies and a meta-analysis of attachment studies in families of children with autism.

Review Results

In total 22 studies were deemed relevant and included in the review. Five studies explored whether children with autism were able to form attachment relationships, whilst a further 11 studies and a meta-analysis focused on assessing the quality of the attachment relationships formed between mother and child (see Table 1). The remaining 5 studies assessed the quality of the mother-child relationship, using self-report and interview data gathered from mothers of adolescent and adult children with autism (see Table 2).

---- Insert Tables 1 and 2 about here ----

The following review focuses on whether mother-child dyads are able to form relationships when the child has autism and, if so, the quality of the relationship that is achieved. In order to do this, the review will be divided into three sections; literature demonstrating the ability of children with autism to form attachment relationships,

literature addressing the quality of attachment relationships, and literature focusing on the quality of the mother-child relationship in older children with autism.

Attachment Relationships

The attachment relationship can be defined as the affectional bond that the child forms with the mother (Ainsworth, Blehar, Waters & Wall, 1978). Systematic research into the attachment relationships of children with autism began a little over two decades ago. Prior to this it was generally assumed that deficits in social and emotional reciprocity prevented children with autism from forming preferential relationships with their caregivers (Cohen et al., 1987). Such assumptions have since been contradicted by the empirical evidence (Dissanayake & Crossley, 1997; Pisula, 2004; Sigman and Mundy, 1989; Sigman & Ungerer, 1984).

The Strange Situation Procedure (SSP; Ainsworth et al., 1978) has frequently been used to assess attachment in young children. The procedure involves a sequence of separations from, and reunions with, the mother. Attachment is demonstrated when a child shows a clear preference for the mother on reunion and displays behaviours designed to maintain contact and proximity with the mother. The SSP has been modified for use for children with autism so that it involves only one separation from the mother, essentially because these children typically have difficulties with disruptions in routine (Van Berckelaer-Onnes, 1983) and may find multiple unexpected separations particularly distressing (Rutgers, Bakermans-Kranenburg, van Ijzendoorn & van Berckelaer-Onnes, 2004).

Sigman and Ungerer (1984) were the first to systematically study attachment in children with autism using a modified SSP. Fourteen children with autism, aged 4 to 6 years were compared to 14 mental-aged matched typically developing children aged 1 to 2 years. The children were observed during separations and reunions with the mother and the experimenter. In-keeping with the attachment behaviours of their typically developing counterparts, the autism group demonstrated a clear preference for the mother by directing more social and proximity seeking behaviours towards the mother than to the experimenter upon reunion. Although, overall the autism group displayed fewer attachment behaviours than the comparison group, these findings indicate that children with autism are capable of forming attachment relationships.

Other studies using a modified SSP have replicated these findings. Children with autism have been shown to display similar patterns of attachment behaviours to children with intellectual disabilities (Sigman & Mundy, 1989), typically developing children and children with Down syndrome (Dissanayake and Crossley, 1996; Pisula, 2004). In terms of the amount of attachment behaviour, research indicates that children with autism show the same amount of attachment behaviours as children with intellectual disabilities, although this is significantly less than typically developing children (Sigman & Mundy, 1989).

A major criticism of these studies refers to the ecological validity of the modified SSP. The SSP is a laboratory-based assessment and as such ought to be supported by observations of a child's attachment behaviour in more naturalistic settings. Home videos provide one method of observing attachment behaviour in the child's natural environment. Although the current literature searches did not identify any

studies where the SSP had been combined with such observations, a study by Bernabei et al. (1998) found evidence of attachment behaviour in an analysis of home videos of children aged 0 to 2 years old who were later diagnosed with autism. This finding supports the conclusion drawn from the SSP studies. Thus, despite their deficits, young children with autism can and do form relationships with their mothers.

With the exception of Bernabei et al. (1998) the majority of attachment studies in children with autism have focused on children aged 3 years and over (Naber et al., 2007a). This presents two problems. First, the SSP was developed to measure attachment in children aged 12 to 21 months and its application to older children may be questionable (Rutgers et al., 2004). Second, little is known about the attachment relationship between mother and child under this age. However, recently three studies (see below) have used the SSP to determine attachment security in younger children with autism (Naber et al., 2007a; Naber et al., 2007b; van Ijzendoorn et al., 2007).

Relationship Quality: Attachment Security

Attachment security is a measure of the quality of the mother-child attachment relationship (Ainsworth et al., 1978). Perhaps the most frequently used measure of attachment security involves coding children as securely or insecurely attached based on the type of attachment behaviours they display during the SSP (Ainsworth et al., 1978).

A recent meta-analysis examined 10 studies in which children with autism were compared to children without autism on attachment security (Rutgers et al., 2004). These studies used a combination of measures to determine attachment security including; the original and an adapted version of Ainsworth et al.'s (1978) coding

system, a continuous rating scale for security, and an attachment Q-Sort. Rutgers et al. (2004) found a combined effect size of $r = 0.24$ (C.I. 0.04-0.43) for the influence of autism on attachment security. Although such an effect would normally be considered small (Cohen, 1988), they interpreted this as a moderate effect size and concluded that children with autism are significantly less likely to be securely attached than children without autism.

Interestingly, the meta-analysis included published and unpublished studies and only the three unpublished studies found substantial differences in attachment security between children with and without autism (Rutgers et al., 2004). Examination of the results from the seven published studies indicates that one study reported higher levels of attachment security in children with autism when compared to children with intellectual disabilities or language delay (Shapiro, Sherman, Calamari & Koch, 1987). Three studies found no difference between the attachment security of children with autism and children in comparison groups (Dissanayake & Crossley, 1997; Rogers, Ozonoff & Maslin-Cole, 1991; Willemsen-Swinkels, Bakermans-Kranenburg, Buitelaar, van Ijzendoorn & van Engeland, 2000) and some signs of attachment security were seen in the children with autism in the other three studies (Capps, Sigman & Mundy, 1994; Rogers & DiLalla, 1990; Rogers, Ozonoff & Maslin-Cole, 1993). Furthermore, for the three studies that used Ainsworth et al.'s (1978) original coding system to measure attachment security (Capps et al., 1994; Shapiro et al., 1987; Willemsen-Swinkels et al., 2000) rates of security in children with autism ranged from 40% to 60% with an average of 52%. Although this average is lower than the 67% security rate that has been reported for children in non-clinical samples (van Ijzendoorn, Goldberg, Kroonenberg & Frenkl,

1992), it does demonstrate that a substantial proportion of children with autism achieve attachment security despite their social and emotional deficits.

Results from the meta-analysis by Rutgers et al. (2004) also indicated that children with more strictly defined autism (i.e. autistic disorder, infantile autism, childhood autism rather than pervasive developmental disorder) were less securely attached. This suggests that the more severe the disorder, the less likely the child is to be securely attached. This is consistent with studies that have found that severity of autistic symptoms was negatively related to attachment security (Naber et al., 2007a; van Ijzendoorn et al., 2007), although other studies have found no such relationship (Rogers et al., 1991; 1993; Shapiro et al., 1987).

Findings from several studies have suggested that attachment security in children with autism is associated with developmental level. Rogers and colleagues (Rogers et al., 1991; 1993) found that less developmentally delayed children were rated as more secure. Other researchers have failed to find an effect for developmental level on attachment security (Capps et al., 1994; Naber et al., 2007a; Shapiro et al., 1987). In the meta-analysis by Rutgers et al. (2004) developmental level was a moderator of attachment security. Only children with autism with lower levels of developmental ability were significantly less secure than children in the comparison groups.

It has also been suggested that children with autism may develop attachment security later than typically developing children (Rogers et al., 1993). Rogers et al. (1993) found a significant positive relationship between chronological age and attachment security in children with autism. However, Capps et al. (1994) and Willemsen-Swinkels et al. (2000) found no difference in chronological age between

those children who were securely attached and those who were insecurely attached. The meta-analysis by Rutgers et al. (2004) also failed to find a significant effect for chronological age.

In terms of chronological age, studies of attachment security in autism have tended to involve children aged 3 years and over, due to difficulties in diagnosing autism below this age. Only three published studies (Naber et al., 2007a; Naber et al., 2007b; van IJzendoorn et al., 2007) have investigated attachment security in children with autism under 3 years of age. These studies used the unmodified SSP and Ainsworth et al.'s (1978) original coding system with 2 year olds who were later diagnosed with autism or Pervasive Developmental Disorder (PDD). Rates of attachment security in these studies ranged from 38% (Naber et al., 2007a) to 48% (van IJzendoorn et al., 2007), with a mean of 44%. These figures are similar to those reported in some studies of older children with autism (e.g. Capps et al., 1994; Shapiro et al., 1987), but lower than those found in normative samples (van IJzendoorn et al., 1992).

Several investigators have looked at disorganised attachments in children with autism (Capps et al., 1994; Naber et al., 2007a; van IJzendoorn et al., 2007; Willemsen-Swinkels et al., 2000). Stereotyped, asymmetrical and mistimed behaviours are indicative of a disorganised attachment (Main & Soloman, 1990). However, such behaviours are also characteristic of autism (APA, 2000). Using a modified SSP, Capps et al. (1994) found that all 15 children with autism in their study were initially categorised as having disorganised attachments. However, 6 children (40%) were subcategorised as securely attached and, of the remaining 9 children who were insecurely attached, only three children displayed 'true disorganised attachments'. These

findings highlight the importance of distinguishing between disorganised behaviours that occurs as a function of autism and those indicating a disorganised attachment. Four subsequent studies have shown that children with autism or PDD display more attachment disorganisation than comparison children (Naber et al., 2007a, 2007b; van Ijzendoorn et al., 2007; Willemsen-Swinkels et al., 2000). Naber et al. (2007a) found that developmental level rather than severity of autistic symptoms was associated with having a disorganised attachment, suggesting that the increased prevalence of disorganised attachments may be better accounted for by a co-morbid intellectual disability rather than autism or PDD per se.

Whilst a number of studies have looked at child factors that may be associated with the quality of the mother-child attachment relationship when a child has autism, few studies have looked at maternal factors associated with attachment security. Van Ijzendoorn et al. (2007) investigated attachment security and parental sensitivity in families where children were either typically developing or had a diagnosis of autism/PDD, language delay or intellectual disabilities. Attachment security was determined via the SSP and parental sensitivity was assessed during 10 minutes of free play. The majority of parents who participated were mothers. Parents of children with autism/PDD were no less sensitive than parents of children in the comparison groups. For children with autism/PDD parental sensitivity was not associated with more secure attachments, whereas the reverse was true for children in the comparison groups. In contrast, Capps et al. (1994) found that mothers of securely attached children with autism were more sensitive than mothers of insecurely attached children.

Using open-ended interviews and a purpose designed questionnaire with mothers of school-aged children with autism and Down syndrome, Hoppes and Harris (1990) found that maternal gratification was positively related to the mother's perception of the quality of her child's attachment to her. Mothers in the autism group reported significantly lower levels of perceived child attachment and maternal gratification. However, no psychometric information is provided for the questionnaire, therefore, these findings may be of questionable reliability and validity.

Overall, findings from the literature suggest that although children with autism can develop secure attachments, they tend to be less securely attached than children without autism (Rutgers et al., 2004). This effect, however, may be related more to an associated developmental delay than the disorder itself (Rutgers et al., 2004). Children with autism or PDD also appear more likely to have disorganised attachments than those without these disabilities, although this may also be due to having a co-morbid intellectual disability (van Ijzendoorn et al., 2007; Willemsen-Swinkels et al., 2000). Findings related to the influence of parental sensitivity remain contradictory and warrant further investigation (van Ijzendoorn et al., 2007; Capps et al., 1994).

Although the attachment literature shows that children with autism are able to form secure relationships with the mother, it tells us nothing of the development of these relationships as the child ages or of the child's perception of the quality of the relationship. Furthermore, only one study has measured the mother's perception of the attachment relationship (Hoppes & Harris, 1990). The attachment literature, therefore, provides a useful but limited view of the quality of the mother-child relationship in autism. Other methodologies are needed to assess relationship more thoroughly and at

different stages across the lifespan. Recently, however, researchers have begun to investigate the quality of the mother-child relationship in families with adolescents and adults with autism.

Relationship Quality: Adolescents and Adults

Using sub-samples from a longitudinal four-wave study, Greenberg and colleagues (Abbeduto et al., 2004; Greenberg, Seltzer, Krauss, Chou & Hong, 2004; Greenberg, Seltzer, Hong & Orsmond, 2006; Lounds, Seltzer, Greenberg & Shattuck, 2007; Orsmond, Seltzer, Greenberg & Krauss, 2006) have published five papers investigating the quality of mother-child relationships in families of adolescents and adults with autism. All adolescents and adults were independently diagnosed with an autistic spectrum disorder (i.e. autistic disorder, PDD, Aspergers syndrome) prior to the study and demonstrated a profile consistent with autism on the Autism Diagnostic Interview-Revised (Lord, Rutter & Le Couter, 1994).

Across the five papers three different measures were used to assess mother-child relationship quality. The Positive Affect Scale (Bengtson & Schader, 1982) is a self-report measure on which the mother rates her feelings of positive affect towards her child and the extent to which she perceives her child to reciprocate these feelings. The Five Minute Speech Sample (Magna et al., 1986) involves the mother speaking for five minutes about her relationship with her child. This speech sample is then coded for maternal Expressed Emotion (EE). EE is a measure of the emotional relationship between parent and child (Hastings, Daley, Burns & Beck, 2006) and can be divided into two constructs, criticism and emotional over-involvement (EOI). Levels of overall

EE, criticism and EOI are rated as 'high' or 'low'. Warmth demonstrated by the mother towards the child is also coded from the speech sample.

Four of the five studies used the Positive Affects Scale to measure the quality of the mother-child relationship in families of adolescents and adults with autism (Abbeduto et al., 2004; Greenberg et al., 2004; Lounds et al., 2007; Orsmond et al., 2006). All four studies found relatively high levels of positive affect (mean scores of 43.8, 47.5, 44, 45.9 out of a possible score of 60). These studies focused on examining the complex patterns of associations between various maternal and child variables and levels of positive affect.

Greenberg et al. (2004) found that mothers of adults with autism reported higher levels of positive affect than mothers of adults with schizophrenia but significantly lower levels than mothers of adults with Down syndrome. Positive affect in the autism group was related to increases in maternal wellbeing and optimism and decreases in depression. Maternal optimism partially mediated the relationship between positive affect and maternal depression, and fully mediated the relationship between positive affect and maternal psychological wellbeing, suggesting that a better quality of relationship (i.e. higher positive affect) contributes to feelings of optimism, which then impacts positively on maternal wellbeing.

Abbeduto et al. (2004) found that mothers of adolescents with Down syndrome and fragile X reported higher levels of positive affect than mothers of adolescents with autism. However, across all three groups, lower rates of child behaviour problems and higher levels of problem-focused coping were related to increased positive affect.

In a longitudinal study, Lounds et al. (2007) found that maternal reports of positive affect were relatively stable over time. Furthermore, when change did occur the dominant pattern was of increased positive affect. Interestingly, changes in the child's autistic symptoms, behaviour problems, physical health and use of psychotropic medications were not predictive of changes in positive affect over time. In contrast, mothers of adult children who had left secondary school during the study, were female and had good physical health reported increases in levels of positive affect over time.

Orsmond et al. (2006) investigated the quality of mother-child relationships in families of adolescents and adults with autism by examining levels of positive affect, maternal EE and warmth. In line with the relatively high levels of positive affect reported, ratings of maternal warmth and EE also suggested a relatively positive relationship between the majority of mothers and their children. Eighty-six percent of mothers demonstrated high or moderate levels of warmth and only 28.7%, 19.3% and 10.9% presented with high overall EE, criticism and EOI respectively. Maternal pessimism and child behaviour problems were consistent predictors of relationship quality with lower levels of pessimism and behaviour problems being associated with greater positive affect, lower levels of criticism and increased maternal warmth. Greater caregiving gains were associated with higher levels of maternal warmth and more positive affect towards the child, whereas increased caregiving strains (i.e. stress) were related to high criticism and less positive affect towards and from the child.

Similar levels of high EE were found by Greenberg et al. (2006) in an 18-month longitudinal study. Levels of EE showed considerable stability over the duration of the study. A cross-legged analysis indicated that high overall EE was related to increased

levels of behaviour problems and social impairment in the child with autism over time. High criticism was longitudinally related to increased levels of child behaviour problems and repetitive behaviours. EOI was not significantly related to any changes in autistic symptoms or child behaviour problems over time. These findings suggest that the quality of the mother-child relationship, as measured by EE, can influence the severity of a child's behaviour problems and autistic symptoms. There was also evidence to suggest that a child's behaviour problems may influence relationship quality over time, although this evidence was weaker.

Findings from these five studies suggest that most mothers of adolescents and adults with autism enjoy a relatively good relationship with their child. This can be deduced from the relatively high levels of positive affect reported across studies (Abbeduto et al., 2004; Greenberg et al., 2004; Lounds et al., 2007; Orsmond et al., 2006), and the high percentage of mothers who displayed moderate or high levels of warmth towards their child (Orsmond et al., 2006). The relatively low levels of high EE reported are also suggestive of positive relationships in many cases (Greenberg et al., 2006; Orsmond et al., 2006).

A number of mother and child variables appear to be related to the quality of the relationship including; maternal wellbeing, optimism, depression, coping strategies, pessimism, caregiving gains/strains and child behaviour problems, autistic symptoms, gender, health and educational status. Three studies considered the possible impact of a co-morbid intellectual disability on relationship quality (Greenberg et al., 2006; Lounds et al., 2007; Orsmond et al., 2006). Two studies found that the presence of a co-morbid intellectual disability was not associated with relationship quality (Lounds et al., 2007;

Orsmond et al., 2006), whilst one found that mothers of children with a co-morbid intellectual disability were more likely to be coded as low for EOI.

With the exception of Greenberg et al. (2006) and Lounds et al. (2007), these studies have adopted a cross-sectional design meaning the temporal ordering of variables could not be determined. However, in their longitudinal study Lounds et al. (2007) found that changes in child characteristics were not predictive of later changes in relationship quality. In addition, Greenberg et al. (2006) found strongest evidence for the suggestion that the direction of influence may flow from the mother to the child, in that high levels of maternal EE were related to increasing severity of child behaviour problems and autistic symptoms over time. Such findings highlight the potential role of the quality of the mother-child relationship in shaping the behavioural presentation of young people with autism.

These studies are, however, subject to a number of limitations. First, all five studies drew sub-samples from a larger study. Therefore, replication of these findings from an independent source is imperative. Second, the generalisability of these findings may be limited. With exception of Greenberg et al. (2004), the majority of participants lived with their parents. It is possible that these participants still lived at home because they enjoyed a better relationship with their mothers than those who had left home. A further limitation relates to the reliability and validity of the measures for use with families of children with autism. With the exception of some studies with mothers of children with intellectual disabilities and mixed aetiologies (e.g. Beck et al., 2004; Hastings et al., 2006), no other published studies have used the five minute speech

sample with families of children with autism. There is also a lack of published evidence to support the use of the Positive Affects Scale for this population.

Discussion

The purpose of this paper was to attempt to answer two questions. The first question asked whether mothers and their children can successfully form a relationship when the child has autism. The attachment literature suggests that young children with autism can and do form relationships with their mother, although the amount of attachment behaviour they display may be less than typically developing children (Sigman & Mundy, 1989). The second question referred to the quality of the mother-child relationship and the factors associated with relationship quality. The answer to this question is less clear. Whilst studies using Ainsworth et al's (1978) original coding system show that between 38% (Naber et al., 2007a) and 63% (Willemsen-Swinkels et al., 2000) of children with autism display secure attachments, the meta-analysis by Rutgers et al. (2004) suggests that young children with autism are generally less likely to form secure attachment relationships than typically developing children.

In studies of families of adolescent and adult children with autism, high levels of maternal positive affect and warmth combined with low levels of EE (Abbeduto et al., 2004; Greenberg et al., 2004; Greenberg et al., 2006; Lounds, et al., 2007; Orsmond et al., 2006), not only suggest that most mothers enjoy a relatively positive relationship with their child, but also clearly contradict early theories that claimed mothers of children with autism were cold and rejecting (e.g. Bettelheim, 1967). However, the lack of typically developing comparison groups in these studies make it impossible to

ascertain whether the levels of maternal positive affect, warmth and EE reported differ from what might be expected in a normative sample. When compared with other *clinical* groups, mothers in the autism group reported higher levels of positive affect than mothers of individuals with schizophrenia (Greenberg et al., 2004) but lower levels than mothers of individuals with fragile X and Down syndrome (Abbeduto et al., 2004; Greenberg et al., 2004). Further research involving comparison groups is necessary to explore the effect of autism on the quality of the mother-child relationship in families of older children.

A number of variables have been found to be associated with relationship quality in the literature reviewed. Rutgers et al. (2004) concluded that severity of autism and the child's developmental level were important moderators of attachment security. However, findings are inconsistent and, whilst some studies have found associations between the severity of autistic symptoms (Naber et al., 2007a; van Ijzendoorn et al., 2007), developmental level (Rogers et al., 1991; 1993) and the quality of the attachment relationship, other studies have failed to replicate such findings (Capps et al., 1994; Shapiro et al., 1987; Willemsen-Swinkels et al., 2000). Furthermore, the investigation of other potentially influential variables such as maternal depression, which has been found to be associated with attachment security in typically developing children (Martins & Gaffan, 2000), has been neglected. Clearly, more research is needed to determine which variables are consistently associated with the quality of attachment relationships of children with autism.

In families of adolescents and adults with autism, relationship quality (as measured by positive affect, EE or warmth) was associated with maternal wellbeing,

optimism, depression, coping strategies, pessimism, and caregiving gains and strains (Abbeduto et al., 2004; Greenberg et al., 2004, Orsmond et al., 2006). Child behaviour problems, autistic symptoms and the gender and health status of the child were also associated with relationship quality (Abbeduto et al., 2004; Greenberg et al., 2006; Lounds et al., 2007).

Findings regarding the effect of an individual's level of functioning on relationship quality in children with autism remain unclear. Whilst developmental delay was associated with poorer relationship quality (i.e. attachment insecurity) for younger children (Rutgers et al., 2004), in studies involving adolescent and adult children with autism, the presence of a co-morbid intellectual disability was either not associated with relationship quality (Lounds et al., 2007; Orsmond et al., 2006), or related to low EE (EOI) (Greenberg et al., 2006). The influence of level of functioning on relationship quality, therefore, requires further investigation.

Greenberg et al. (2006) found that high levels of EE (overall EE and criticism) predicted increasing severity of child behaviour problems and autistic symptoms over time. However, when considering the implications of these findings for the mother-child relationship and the effect this relationship may have on the behaviour of children with autism, two things must be held in mind. First, it must be remembered that the majority of parents in this study appeared to enjoy a relatively good relationship with their child, with only a relatively small percentage of mother's being rated as high on overall EE (27.5 %), criticism (18.1%) or EOI (10.1%). Second, these findings are preliminary and warrant further investigation. In a similar study examining EE in mothers of 56 children with intellectual disabilities (20 of whom also had autism), Hastings et al. (2006) failed

to find evidence that EE predicted child behaviour problems over time. Furthermore, current conceptualisations suggest that EE is best understood as an interaction between mother and child characteristics, whereby the certain characteristics of the mother may incline them to become critical when faced with particular behaviours of the child (Hooley & Gotlib, 2000). This interaction is thought to be bi-directional. Greenberg et al. (2006) did find some weak evidence of bi-directionality in that child behaviour also influenced EE over time. More longitudinal research is needed to investigate this further.

There are a number of methodological limitations within the research reviewed. In particular, most studies relied on parental reports of their child's diagnoses and not all studies were able to have these diagnoses verified by a suitably qualified professional. Furthermore, the diagnostic criteria used for autism varied across studies and some studies combined children with PDD, Aspergers syndrome and autism, to form one group. The lack of consistency around diagnoses could challenge the validity of comparisons made both within studies (i.e. autism group verses other groups) and between studies (i.e. autism group verses autism group).

A further limitation of the evidence base concerns the ages of the participants with autism. With the exception of Hoppes and Harris (1990), there is a lack of literature investigating the mother-child relationships of older school-aged children with autism. The school years are a period of rapid maturation and development. Future research needs to include school-aged children in order to investigate whether such developmental changes impact on the mother-child relationship.

To date, studies investigating the mother-child relationship in families of children with autism have generally failed to take account of both the mother's and the child's view of the relationship. Perceptions of the relationship may differ between mother and child, and efforts should be made in future research to gather information from both members of the dyad. However, co-morbid intellectual disabilities, poor communication skills and deficits in social and emotional understanding may make it difficult for some individuals with autism to engage in the research process and considerable effort may be needed to establish measures that are reliable and valid for this population.

Clinical Implications

Findings from the current review have a number of clinical implications. First, it would seem that, although autism definitely does not mean relationships cannot be formed, it may be more difficult for mother-child dyads to form secure, good quality relationships when the child has autism (Rutgers et al., 2004). Furthermore, it is possible that the quality of the mother-child relationship could influence mother and child outcomes. For example, a better quality relationship is associated with increased maternal optimism, well-being and care-giving gains, and decreased maternal depression, pessimism and care-giver strains (Abbeduto et al., 2004; Greenberg et al., 2004, Orsmond et al., 2006). In terms of child outcomes, findings from the review suggest that children with autism are less likely to be securely attached than children without autism (Rutgers et al., 2004). Although there is a lack of published follow-up studies for insecurely attached children with autism, insecure attachment in children

without autism is generally considered a risk factor for the subsequent development of emotional and social difficulties (van Ijzendoorn, Juffer & Duyvesteyn, 1995). Given the possible impact of relationship quality on mother and child outcomes, the mother-child relationship would seem an appropriate target for clinical intervention.

Currently the evidence base for relationship-focused interventions for families of children with autism is limited. Two studies show that parents engaging in Massage and Touch Therapy reported feeling emotionally closer to their child following intervention (Cullen-Powell, Barlow & Cushway, 2005; Cullen & Barlow, 2002). In addition, studies evaluating ethologically orientated family therapy and mother-child psychotherapy in families of children with autism reported improvements in child social and cognitive functioning (Kalmanson & Pekarsky, 1987; Zappella, 1990). However, these studies are subject to a number of limitations including small sample sizes and a lack of valid, reliable outcome measures.

If replicated and proven to be a robust effect, Greenberg et al.'s (2006) finding that high levels of EE were related to increasing severity of child behaviour problems and autistic symptoms over time has particular clinical relevance. The influence of EE is well documented in psychosis research, with high familial EE being predictive of relapse in individuals with schizophrenia (Butzlaff & Hooley, 1998). There is some evidence that family interventions can reduce levels of EE in families of individuals with psychosis (Askey, Gamble & Gray, 2007). Such interventions often focus on psycho-education and on enhancing problem solving, coping and communication within the family (Askey et al., 2007). If maternal EE does influence the behavioural presentation of individuals with autism over time, then offering a similar type of

intervention to high EE mothers of children with autism could possibly limit the hypothesised effect of high EE on child behaviour and autistic symptoms. Outcome research from such interventions would help to further clarify questions about the direction of influence between EE and child behaviour and symptoms.

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Table 1: Studies demonstrating attachment behaviour and studies assessing attachment security in children with autism

| Authors | Purpose | Classification of autism | Diagnosis verified ¹ | Participants (mean age in months) | Method | Findings |
|------------------------------|---|------------------------------|---------------------------------|---|---|--|
| Bernabei, et al., 1998 | Investigate early development. | DSM-IV; Autism, PDD, PDD-NOS | Psychiatrists | 10 children with autism/PDD/PDD-NOS (40mths). | Analysis of home movies from 0-2 years of life. | All children showed evidence of attachment behaviours during first two years of life. |
| Dissanayake & Crossley, 1996 | Investigate attachment behaviour. | DSM-III; IA | Psychiatrist | 16 x autism (52mths) | Observed child behaviours to mother and stranger in lab playroom. | Similar attachment behaviours in all groups. Increased behaviours when stranger present. |
| Pisula, 2004 | As above | DSM-IV/ICD-10: Autism. | - | 12 x autism, 11 x DS, 10 x TD. All 4-6 yrs | Modified SSP | Similar patterns of attachment behaviours in all groups. |
| Sigman & Mundy, 1989 | As above | DSM-III; Autism. | Psychiatrists | 14 x autism (52mths) | Modified SSP | No difference between autism and ID but both showed less attachment behaviour than TD. |
| Sigman & Ungerer, 1984 | As above | DSM-III; Autism. | Psychiatrists | 14 x autism (52mths) | Modified SSP | Similar behaviours in both groups but autism group showed less attachment behaviour. |
| Capps et al., 1994 | Investigate attachment security. | DSM-III; Autism. | Psychiatrists | 14 x TD (not reported). 15 x autism (49mths) | Modified SSP | All initially categorised as disorganised but only 20% were 'true disorganised'. 40% sub-categorised as securely attached. |
| Dissanayake & Crossley, 1997 | As above | DSM-III; IA. | Psychiatrist | 16 x autism (52mths) | Modified SSP | No between-group difference for responses to separations/reunions in attachment security. |
| Hoppes & Harris, 1990 | As above and explore maternal gratification | DSM-III; Autism. | - | 16 x DS (55mths) 16 x TD (51mths) 21 x autism (84mths) 17 x DS (108mths) | Purpose designed questionnaires, interview | Lower maternal gratification and perceived attachment in autism group |

| | | | | | | |
|--|---------------------------------------|-----------------------------------|--------------|---|-----------------|---|
| Naber et al., 2007a | Investigate attachment security | DSM-IV; AD, PDD, PDD-NOS | Psychiatrist | 34 x ASD (AD, PDD, PDD-NOS) (30mths) 28 x non-ASD (ID, language delay) (25mths) | SSP | ASD: 38% secure, 38% disorganised attachments non ASD: 60% secure, 12% disorganised. Severity of autism was related to insecurity. Disorganised attachment related to developmental level. |
| Naber et al., 2007b | As above | DSM-IV; AD, PDD, PDD-NOS | Psychiatrist | 20 x ASD (AD, PDD, PDD-NOS) (29mths), 18 x non-ASD (ID, language delay) (26mths) | SSP | ASD: 45% secure, 40% disorganised attachments non ASD: 56% secure, 22% disorganised. |
| Rogers & DiLalla, 1990 | As above | DSM-III; IA, PDD | Psychiatrist | 39 x ASD (IA, PDD) (45mths) | Modified SSP | All children showed some signs of secure attachment. |
| Rogers et al., 1991 | As above | DSM-III, DSM-III-R; IA, PDD | Psychologist | 17 x ASD (IA, PDD) (48mths), 17 x non-ASD (other clinical disorders) (51mths) | Modified SSP | No between group difference for attachment security. Attachment security related to developmental ability in ASD but not non-ASD. |
| Rogers et al., 1993 | As above | DSM-III, DSM-III-R; IA, PDD | Psychologist | 32 x ASD (IA, PDD) (48mths), | Modified SSP | 50% of sample demonstrated secure attachments. Chronological age and developmental ability were related to attachment security. |
| Shapiro et al., 1987 | As above | DSM-III; Autism, PDD | - | 15 x autism (40mths), 10 x PDD (44mths), 8 x language delay (40mths), 3 x ID (50mths) | Modified SSP | Higher proportion of secure attachment in PDD (50%) and autism (53%) groups compared to ID (33%) and language delay (13%). |
| van Ijzendoorn et al., 2007 | As above & parental sensitivity | DSM-IV; AD, PDD- NOS | Psychiatrist | 21 x ASD (AD, PDD), 10 x ID, 9 x language delay, 15 x TD (mean age across groups; 28mths) | SSP | No difference between groups for parental sensitivity. 48% of ASD group were securely attached. Security was related to severity of autism. |
| Willemsen- Swinkels et al., 2000 | As above | DSM-IV; AD, PDD- NOS | Psychiatrist | 32 x PDD (AD, PDD-NOS) (68mths), 19 x language delay (63mths), 1 9 x TD (54mths) | Modified SSP | 60% of ASD group were securely attached. No significant between groups difference for attachment security. Only those with PDD and co- morbid ID had more disorganised attachments. |

¹ States if diagnosis of autism/PDD was verified by a professional for the study.

AD = Autistic disorder, DS = Down syndrome, IA= Infantile autism, PDD = Pervasive developmental disorder, PDD-NOS = Pervasive developmental disorder – Not otherwise specified, ID = Intellectually disabled, TD = Typically developing

Table 2: Studies investigating mother-child relationship quality in adolescents and adults with autism

| Authors | Purpose | Participants' (mean age in months) | Method | Significant Findings |
|------------------------|--|---|--|---|
| Abbeduto et al., 2004 | Investigate the relationship, maternal coping and mental health. | 174 x autism (196mths) 39 x DS (196mths) 22 x FX (194mths) | Positive Affects Scale, coping, mental health and behaviour questionnaires. | DS and FX had higher positive affect. In all groups, child behaviour and maternal problem-focused coping were predictive of levels of positive affect. |
| Greenberg et al., 2004 | Investigate the relationship, maternal optimism and mental health. | 102 x autism (416mths) 292 x S (496mths) 126 x DS (409mths) | Positive Affects Scale, optimism, mental health and behaviour questionnaires. | Autism group had higher positive affect than S group but less than DS. In autism group, positive affect was related to increased optimism and decreased depression. |
| Greenberg et al., 2006 | Investigate the relationship over time. | 149 x autism (239mths) | FMSS for EE, behaviour questionnaire, autism interview | 27.5 %, 18.1% and 10.1% had high overall EE, criticism and EOI. High EE was related to increased behaviour problems and autistic symptoms over time. |
| Lounds, et al., 2007 | As above. | 140 x autism (203mths) | Positive Affects Scale, mental health, pessimism, behaviour, child health/ demographic questionnaires, autism interview, | Positive effect was stable over time. The child leaving secondary school, being female and in good health were related to increases in positive affect over time. |
| Orsmond et al., 2006 | Investigate the relationship, maternal gains/strains. | 202 x autism (238mths) | Positive Affects Scale, FMSS for EE & Warmth, Gains/strains, behaviour & pessimism questionnaires. | 28.7%, 19.3% and 10.9% had high overall EE, criticism and EOI. Pessimism and child behaviour predicted of relationship quality. Positive affect and warmth predicted gains and strains. |

¹ Individuals with autism had a range of diagnoses (i.e. autistic disorder, PDD, Aspergers syndrome). Diagnoses were obtained independently of the studies. The only form of verification of diagnoses involved researchers conducting the Autism Diagnostic Interview-Revised (ADI-R, Lord et al., 1994) with participants. All participants in autism groups had a ADI-R profile that was consistent with an autistic spectrum disorder.
AD = Autistic disorder, DS = Down syndrome, FX = Fragile X, S = Schizophrenia, FMSS = Five minute speech sample, EE = Expressed emotion, EOI = Emotional over-involvement

Appendices for Literature Review

Appendix 1

Notes to contributors

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SECTION FOUR – EMPIRICAL PAPER

Running head: EXPRESSED EMOTION AND AUTISM

**Maternal Expressed Emotion Towards
Children With Autism and Their Siblings**

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Abstract

Background: Expressed Emotion is a measure of the emotional relationship between parent and child. Few studies have investigated expressed emotion in families of children with autism.

Method: One hundred mothers of young children with autism completed questionnaire measures of maternal wellbeing (stress, mental health) and child characteristics (severity of autism, pro-social and problem behaviour). Measures of child adaptive behaviour and maternal expressed emotion (criticism, emotional over-involvement) and warmth were collected during interviews with mothers. In 82 cases mothers also completed problem behaviour, expressed emotion and warmth measures for typically developing siblings.

Results: Criticism was associated with maternal stress and child behaviour problems. However, logistic regression analysis indicated that only child behaviour problems had a significant independent effect on maternal criticism. Emotional over-involvement was not significantly related to any maternal wellbeing or child variables. Warmth, however, was associated with the severity of the child's autism. Comparisons between sibling pairs indicated that mothers were more critical towards their child with autism than to the typically developing sibling. A marginally significant difference was also found for warmth, indicating that mothers were less warm towards their children with autism.

Conclusions: Children with autism appear to experience a poorer quality of mother-child relationship (as indicated by higher maternal criticism and lower warmth) than their typically developing siblings. Implications future research and interventions to improve the mother-child relationship in autism are discussed.

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SECTION FIVE – EXTENDED DISCUSSION

Mother-Child Relationships and Maternal Expressed Emotion In
Families of Children with Autism: Extended Discussion

Despite the importance placed on the mother-child relationship in the social and emotional development of children without disabilities (Bowlby, 1969; 1980), this area remains relatively under-researched in autism (Yirmiya & Sigman, 2001). Within the last two decades there has, however, been a small amount of research covering this topic. One of the aims of this thesis was to review this literature.

A review of the existing literature indicated that children with autism were less likely to experience secure, good quality mother-child relationships than typically developing children (Rutgers, Bakermans-Kranenburg, van Ijzendoorn & van Berckelaer-Onnes, 2004) or children with other disabilities (Abbeduto et al., 2004; Greenberg, Seltzer, Krauss, Chou & Hong, 2004). However, the majority of the studies have focused either on very young children (i.e. 5 years and under) or on adolescents and adults with autism. Therefore, a second aim of this thesis was to conduct an empirical investigation into the quality of the mother-child relationship in a sample of predominantly school-aged children with autism and their typically developing siblings, using measures of expressed emotion (EE) and maternal warmth. The purpose of this paper is to discuss the theoretical, research and clinical implications of the findings from the literature review and the empirical study.

Implications for Future Research and Theory Development

Although EE is a well-established measure of familial environment and relationships (Hooley & Parker, 2006), a question remained as to whether maternal EE was determined by child factors or was a general maternal characteristic. The empirical study demonstrated that the children with autism experienced more high EE (criticism) than their siblings. This findings indicates that EE is variable and not, therefore, a general maternal characteristic. The specific reason for the difference between siblings was, however, unclear. Whilst problem behaviour was predictive of criticism in the autism group, the difference in the level of behaviour problems between siblings did not explain the difference in criticism.

To fully determine the effect that autism has on EE, more detailed research involving comparison children is important. In the wider EE literature, self-reported parenting competence (Baker, Heller & Henker, 2000), the availability of social support (Dossetor, Nicol, Stretch & Rajkhowa, 1994) and maternal attributions about the causes of child behaviour problems (Bolton et al., 2003) have been associated with EE. Future research could compare mothers on these variables in relation to a) their child with autism and b) their typically developing child. Regression analyses could then be conducted to determine which variables predict high maternal EE for each child. Such investigations may give a clearer understanding of how and why mother-child relationship quality (i.e. EE) differs between siblings, when one sibling has autism.

The empirical study also found a marginally significant difference between siblings for maternal warmth. It could be advantageous to examine this difference further, by including a measure of warmth in future investigations comparing siblings on

maternal EE. Researchers may, however, wish to revise the warmth measure used here, to increase the sensitivity of the measurement. The empirical study found that the majority of mothers were coded as moderate for warmth, with codes between siblings varying in only 11 cases. The lack of variability in the warmth codings could indicate that the measure was not sensitive enough to pick up on the actual range of maternal warmth studied.

Adaptations may also need to be made to measurements of EE for use with families of young children. The lack of significant findings for emotional over-involvement (EOI) in the empirical study and prior suggestions that EOI may actually tap into normal or positive parenting behaviours when assessed in parents of younger children, question the validity of this measure for use with this age-group (McCarty & Weisz, 2002).

With the exception of the attachment literature, the past and present research has examined the mother-child relationship from the perspective of the mother only. It has been suggested that children with autism generally lack the ability to recognise that others have minds, feelings and thoughts independent of their own, which may make it difficult for them to fully understand interpersonal relationships (Baron-Cohen, 1991). However, high functioning individuals with autism have been able to report on their peer relationships (Bauminger & Kasari, 2000). Bauminger and Kasari (2000) used a self-report measure of friendship quality (consisting of five domains: companionship; security, intimacy and trust; closeness; helpfulness and conflict). To check their understanding of friendship, children were also asked to explain what a friend was. A similar methodology, combining a purpose-designed questionnaire and open-ended

questioning, could be used in future studies to assess the child's perception of the mother-child relationship.

However, approximately 75% of the population of individuals with autism have co-morbid intellectual disabilities (Carr, 2006), therefore to include these individuals in the research process, careful consideration would have to be given to the cognitive load of such measures and certain adaptations may be needed (i.e. simplified language, multiple-choice question formats, visual prompts).

For pre-verbal individuals with autism, researchers may want to use observational methods. Researchers could combine maternal reports of the relationship with observations of mother-child interactions. Free play sessions have frequently been used to investigate the quality of mother-child social interactions in autism (e.g. El-Ghoroury and Romanczyk, 1999; Doussard-Roosevelt, Joe, Bazhenova and Porges, 2003; Watson, 1998). Using free play sessions and a measure of EE, Daley, Sonuga-Barke and Thompson (2003) found that warmth was positively associated with maternal praise and displays of affection, whilst criticism was negatively associated with displays of maternal affection and joint play. Using similar methods in autism research would also help theorists understand how maternal perceptions of the relationship, and abstract attitudinal constructs such as EE, impact on parenting behaviours and parent-child interactions.

The family provides the main developmental context for children with autism (Shields, 2001). Fathers tend to be less involved in the care of children with autism and report less stress than mothers (Holmes & Carr, 1991; Herring et al., 2006). In light of these differences it would be interesting to investigate the quality of the father-child relationship and the factors associated with this. Siblings, however, are important social

agents for children with autism (El-Ghoroury & Romanczyk, 1999) and generally report positive relationships with their brothers or sisters with autism (Rivers & Stoneman, 2003). Future research could adopt a family systems approach by investigating which within-family variables (e.g. maternal, paternal and sibling well-being, marital satisfaction, family coping strategies) influence the quality of each family member's relationship with the child with autism, using measures of EE. Longitudinal research of this kind could investigate the associations between autism, familial adjustment and relationships over time.

Implications for Clinical Practice

One question raised by past and present research, concerns the longitudinal impact of the mother-child relationship on children with autism. Only one study has investigated EE over time in families of individuals with autism (Greenberg, Seltzer, Hong & Orsmond, 2006). The findings indicated that high EE predicted increases in autistic symptoms and child behaviour problems. Outside of the autism literature, EE has been found to be a psychosocial risk factor for poor emotional and behavioural outcomes and psychiatric relapse (Butzlaff and Hooley, 1998; Hooley & Parker, 2006). This evidence, in addition to the associations between EE and behaviour problems in past and present research, suggests two things. First, there is an urgent need for more longitudinal research. Second, high EE may be a risk factor for poorer outcomes in autism and as such could be an appropriate target for intervention.

The empirical study demonstrated that EE was variable and not, therefore, a maternal trait. Furthermore, the associations between stress and EE found in past and

present research, although weaker than those between behaviour and EE, suggest that both maternal and child factors may interact to influence EE. From this interactional perspective, EE, rather than being seen as a maternal trait that is blamed for poor child outcomes, is seen as part of a normative experience of having to deal with demanding, stressful situations (Hastings & Lloyd, 2007). Future research investigating the effect of EE on maternal stress over time would help substantiate this suggestion.

The implications, therefore, of the EE research are that clinical assessments, formulations and interventions need to be holistic, covering the full range of variables that may influence EE. The possibility that EE may influence child outcomes, points to the need for effective early, or even preventative, interventions. Family interventions have been found to decrease rates of high EE in families of individuals with first onset psychosis and can reduce relapse rates (Askey, Gamble & Gray, 2007). Such interventions focus on psycho-education and behavioural strategies to help families cope with the difficulties associated with the disorder. Similar interventions could be offered to families of children with autism following the child's diagnosis.

Psycho-education about autism would be an important part of such interventions. Explaining that aggressive behaviour can be a reaction to the threat children with autism feel when they can not understand or predict social situations, could help parents reattribute the causes of their child's behaviour. The general EE literature suggests that mothers who make 'child blaming' attributions are more likely to be critical (Bolton et al., 2003). Mothers of children with autism who understand that their child's behaviour is heavily influenced by the disorder and the social environment may, therefore, be less critical.

Interventions that teach parents skills to engage in more joint interactions may enhance the quality of the mother-child relationship. For example, imitative play is naturally repetitive and predictable and may therefore be a less threatening form of interaction for those with autism (Dawson & Galpert, 1990). There is some evidence to suggest that such techniques can facilitate mother-child interactions (Dawson & Galpert, 1990).

Social and communication skill deficits in autism can make joint interactions more difficult. Therefore behavioural programmes to teach these skills (e.g. Remington et al., 2007) may help facilitate mother-child interactions. Whilst it does not necessarily follow that improved social and communication skills will lead to improved relationship quality, such skills could be considered the building blocks for interpersonal relationships (Travis & Sigman, 1998). Improving these skills could, therefore, be a vital first step to enhancing relationship quality.

Past research suggests that mothers' dissatisfaction with the quality of the mother-child relationship may be associated with poor social and emotional reciprocity skills in children with autism (Hoppes & Harris, 1990). Interventions to teach children with autism social and emotional understanding have been found to improve social interaction skills and emotion recognition (Bauminger, 2002). Future research could investigate whether such interventions improve the quality of the child's relationships, specifically the mother-child relationship.

Training parents in Mindfulness may improve the mother-child relationship on a number of levels (Singh et al., 2006). First, Mindfulness may reduce maternal criticism because of the focus on practicing non-judgemental acceptance of the self and others.

Second, Mindfulness improves present moment focus and may, therefore, enhance the quality of mother-child interactions. Third, Mindfulness is effective in reducing stress (Chang et al., 2004). Given the associations between maternal stress and EE, it is possible that a reduction in stress could lead to a reduction in high EE, thus improving the mother-child relationship. Mindfulness training with parents of children with autism has been shown not only to increase parents' satisfaction with their own parenting skills and parent-child interactions, but also to reduce child behaviour problems (Singh et al., 2006).

In cases where children are already displaying severe behaviour problems it would be important for interventions to ameliorate these before attempting to improve mother-child relationship quality. In such cases, behavioural interventions based on the principles of Applied Behaviour Analysis (ABA) and a thorough functional assessment would be necessary. Interventions based on ABA have been found to be effective in reducing behaviour problems in autism (Grey & Hastings, 2005).

Conclusion

Although autism does not prevent children from forming good quality relationships with the mother, children with autism appear to experience a poorer quality relationship than typically developing children or children with other disabilities. Child behaviour, and to a lesser extent maternal stress, are associated with relationship quality as measured by EE. Whilst psycho-education about autism, mindful parenting, and behavioural strategies to encourage social interaction and ameliorate behaviour problems may help improve the mother-child relationship, there is a clear need for further research in this area to inform the development of comprehensive interventions. Specifically, this

research should consider the longitudinal effects of the mother-child relationship, the child's perspective of the relationship and the influence of other familial relationships.

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SECTION SIX – WORD COUNT

Word count

| | |
|---------------------------|---------------|
| Summary | 276 |
| Ethics proposal | 4,652 |
| Reflective Paper | 851 |
| Literature Review | 6,358 |
| Empirical Paper | 6,259 |
| Extended Discussion Paper | 1,604 |
| Sub total | 19,999 |

References and Appendices

| | |
|---|---------------|
| Ethics Proposal – references and appendices | 8,891 |
| Literature Review – references and appendices | 5,289 |
| Empirical Paper – references and appendices | 4,100 |
| Extended Discussion Paper – references | 935 |
| Sub total | 19,215 |
| Grand total | 39,214 |