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### **Mothers and fathers of children with autism spectrum disorders : comparisons and predictors of well-being**

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**Mothers and Fathers of Children with Autism Spectrum  
Disorders: Comparisons and Predictors of Well-Being**

Helen Joannidi

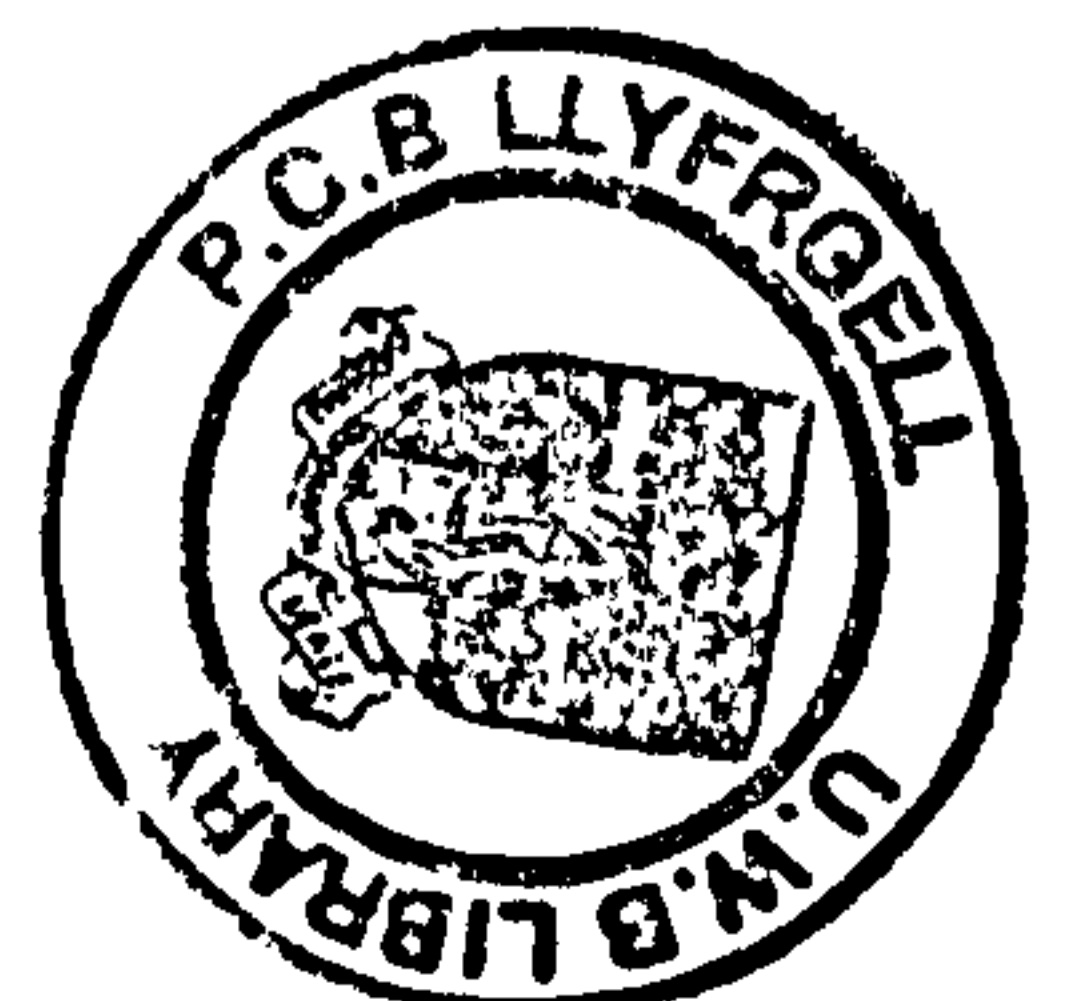
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## **Abstract**

Mothers of children with autism generally report lower well-being than fathers. This thesis compares the well-being of mothers and fathers of children with autism spectrum disorders (ASDs) and what factors contribute to reported differences in mother/father well-being. A literature review showed that the most robust evidence is for differences in mother/father depression, and that mothers are more affected by child behaviour problems than fathers. A likely factor in mother-father differences include the fact that mothers are more likely to spend more time with their child, although this has not been well researched. In addition, partner mental health and coping may be important factors. An empirical study carried out on 100 mothers and 81 fathers of children with autism investigated which variables were related to mother and father well-being, as well as which variables predicted well-being. The results showed that mothers reported higher levels of anxiety, depression and stress than fathers, and that fathers reported higher levels of positive perceptions about their child than mothers. Regression analysis showed that maternal stress was predicted by child behaviour problems and employment status. Father stress was predicted by mothers' depression. Future research needs to explore what other variables may be more predictive of both maternal and paternal well-being, and also by what mechanisms mothers and fathers become stressed. Services may have to support mothers and fathers differently in their different roles, and this needs to be born in mind by professionals. Overall, there is still much to be found out about the reasons why mothers of children with ASDs have lower levels of well-being than fathers and what else services can do to support mothers and fathers differently and effectively. Future interventions will be more effective if targeted in a way that will make the greatest difference for mothers and fathers' well-being. Implications of the study, including the contribution of systemic factors and employment are discussed.



## **Additional Information Concerning Conduct of 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 studentship 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.

## Section One: Ethics Proposal

## **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 mother-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 and Mooney, 2005; Yirmiya and 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). 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 younger 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 diagnosis 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 maternal EE and warmth and exploring associations between maternal EE and warmth and various child and parent variables. Maternal variables addressed by the study will include; family demographics, mother'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 TD sibling will be made to determine whether EE is primarily influenced by child or maternal 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 the 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 Help<sup>1</sup> 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 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

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<sup>1</sup> Help is a NAS family support programme

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. 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 assess 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 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 the primary caregiver. 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 oral consent. Following this they will complete the Vineland Adaptive Behaviour Scale - 2<sup>nd</sup> Version (VABS II) (Sparrow et al, 2005) in relation to their autistic child.

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 across the five domains (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 yet agreed 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 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 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 non-autistic 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 and 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 (Moore and Kuipers, 1999). 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 and Lloyd, under submission). In addition all members of the research team conducting interviews will be supervised by 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 8 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 (UWB) 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 UWB. 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 UWB.

#### **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). Oral consent to conduct and record the interview will be obtained from the participant before the interview commences. Parents will also give written consent to recordings when they return the questionnaires.



## **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 UWB.

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## **Approval from School of Psychology Ethics Committee**

Email from the Ethics Committee 19/09/07

Dear Colleagues

**THE AUTISM FAMILIES RESEARCH STUDY PROPOSAL 986**

Your research proposal referred to above has been considered by the School of Psychology Ethics Review Committee and they are satisfied that the research proposed accords with the relevant ethical guidelines, subject to you submitting Welsh translations of your information/consent and debrief forms to me (the Translation Unit is contactable on 382038/translation@bangor.ac.uk).

Data collection should not commence until you have submitted the Welsh translations.

If you wish to make any modifications to the research project, you must speak to your supervisor about it. If your supervisor thinks that the modifications are at all important, you must inform the committee in writing before proceeding. Please also inform the committee as soon as possible if participants experience any unanticipated harm as a result of taking part in your research.

Good luck with your research.

Everil

## **Appendices for Ethics Proposal:**

- 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

\* 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.

\*\*\*\* The author's permission was obtained to use this article from an unpublished thesis.

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

**Appendix 1**

Dear Parent,

Thank you for attending the *help!* Programme; it was a pleasure to meet you. For your information I have included a brief update of new resources that might helpful for you and your family.

On a different note, I am also writing to you to let you know about a piece of research that may be of real interest to you. In light of this gap over the last two years The National Autistic Society has been working with the University of Wales - Bangor to learn more about family experiences. To this aim the research team is embarking on a large scale study of families across the UK. - If you are interested in taking part in the study or would like more information, please complete the interest form enclosed and return this to the Research team in the SAE provided. I realise that you may have already taken part in research studies, and it is entirely up to you if you would like to take part in the study.

It is our sincere hope that the knowledge gained from the study will benefit families of children with autism in a practical way, and will inform our work. We would be very happy to share the results of the study with you, and can assure you that any information you provide will be treated with the utmost respect and confidentiality. It will be subject to the high standards of professional integrity demanded by the University of Wales, and neither you or your family would be identified in any way.

The research is being conducted by Michael Petalas, Louise Hall and Helen Joannidi who are postgraduate students at the University of Wales – Bangor. They will be happy to answer any questions that you may have about the research and what it entails.

Thank you very much for taking the time to read this letter,

Yours Faithfully,

**Andrew Powell**

Head of *help!*

## Information Sheet for Families

### Study Title

The Autism Families Research Study

### Project Team

Michael Petalas, Research Student

Richard Hastings, Professor of Psychology

Alan Dowey, Clinical Psychologist

Susie Nash, Postdoctoral Research Officer

Helen Joannidi, Trainee Clinical Psychologist

Louise Hall, Trainee Clinical Psychologist

The research is a partnership between the University of Wales, Bangor and the National Autistic Society (NAS), who are funding part of the research along with the European Social Fund. We are interested in hearing from any family caring for a child with an ASD (autism spectrum disorder) who is between 3 and 17 years of age.

### What is the purpose of the study?

We are interested in exploring how families of children with autism are affected by the experience of living with a child with ASD (e.g. autism, Asperger's syndrome). In particular, we wish to better understand the perspective of siblings (brothers and sisters) and how parents and carers cope with a child with autism in the family. We would like to get information from a number of families around the UK in order to get a good idea of the different experiences they have. We will be providing a report on the results of our research to the NAS and so hope that the information will be used in future planning of support for families of children with ASD.

### What are the benefits of taking part?

The main benefit of this research is to improve the knowledge that we have about the needs of families of children with autism. By giving families the opportunity to tell us about their experiences living with a child with autism, we will have information that we can use to help professionals have a better understanding of what these families' needs are, and how to best support these needs. There is relatively little research on families of children with autism and their experiences. We hope that this research will help improve services for families of children with autism.

### What are the risks of taking part?

We do not believe that the families taking part in this study are being put at risk in any way. There is a small possibility however, that for some people, answering questions about their family member with autism may be distressing. If you take part in this study, you will be able to withdraw at any time, and there will be no pressure whatsoever to answer any of the questions. Information and advice about further support will be provided if requested. If needed, please contact Michael Petalas on the telephone number below.

All the information that you and your family provide will be treated as strictly confidential material, and will be kept securely locked in a filing cabinet without names attached. The researchers alone will have access to the telephone interview

recordings and questionnaires. The only exception to this, which is standard practice, will be if an individual discloses information relating to child abuse, intent to harm self or others, in which case the researcher has a duty to report such information.

**Do we have to take part?**

It is entirely up to you to decide if you would like to participate in this study. If you do decide to take part, please fill in the consent and contact forms enclosed and return them in the envelope provided. You may keep this information sheet for your records. You will have the freedom to change your mind at any time and without giving a reason. However, if you have sent back the initial consent form to say that you and your family will take part, and you have not sent back the questionnaires after one month, we may send you a reminder in the post.

**What will happen to me if I take part in this research?**

Once you have sent us your consent and contact form, we will send you a questionnaire pack to fill in. In addition, Mike, Louise, or Helen will telephone you (only if you have agreed via your consent and contact form) to talk about your child with ASD and your typically developing (without ASD) child that is closest in age to your child with autism - if there is one in the home. The phone call is expected to last for approximately 45 minutes and we will ask for permission to record part of the call when we phone you. You can refuse for call to be recorded and still participate in the study. Recorded information is purely to help the researcher in their data analysis and will be kept confidentially and destroyed at the end of the study. The questionnaire pack will contain one, two, or three questionnaires depending on the information you provide us with in your contact form. The yellow forms will be for the primary carer (this is the adult in the home that spends the most time caring for the child with ASD, i.e. a parent, partner, grandparent, foster parent, etc), The green forms will be for the secondary carer (this is the adult in the home that also cares for the child with ASD but spends less time doing so than the primary carer, i.e. a parent, partner, grandparent, foster parent, etc). Finally, the blue forms will be, for the typically developing sibling that is aged between 3 and 17 years and that is closest in age to the child with autism. You will be asked to choose only one typically developing sibling and make sure that both the primary carer and the secondary carer are reporting on the same sibling. We will give you a freepost envelope to return all questionnaires. If you are a primary carer of a child with autism we want to hear from you, even if there isn't a secondary carer or a typically developing sibling in the home.

While we are able to provide you with Welsh versions of some of the forms, regrettably, the questionnaires are available in English only. This is because the questionnaires have only been published in English and translating them would invalidate their use for research purposes. We appreciate your understanding.

For further details and if you wish to contact the research team, please contact Mike Petalas by telephone, email or post:



Michael Petalas  
Postgraduate Research Student  
Intellectual and Developmental Disabilities Research Group  
School of Psychology  
University of Wales, Bangor  
Adeilad Brigantia,  
Penrallt Road  
Bangor, Gwynedd  
UK  
LL57 2AS  
Tel: ++44 (0)1248 351151 extention: 8706  
E-mail: psp202@bangor.ac.uk

If you have any complaints about the way that this research is being conducted you are welcome to address unresolved concerns to:

Dr. Oliver Turnbull  
Head of School  
School of Psychology  
University of Wales, Bangor  
Adeilad Brigantia  
Penrallt Road  
Bangor, Gwynedd  
LL57 2AS

To be completed and returned to the Researcher if you agree to take part

**The Autism Families Research Study**

**Initial Consent and Contact Form to be completed by the main carer**

Signing and returning this form means that you agree to be contacted further about this research. It also means that you consent to receiving questionnaire packs. Please answer the following questions about your family and provide your contact details. This will allow us to send you the correct questionnaire pack for the study.

1. Please confirm that you are the main carer for a child with autism between the ages of 3 and 17 years. YES

How old is your child with autism .....years

What is your relationship to the child with autism (e.g. mother, father, grandmother, grandfather, foster parent, etc)?

.....

2. Is there a secondary carer living in the home? YES / NO

If YES,  
What is their relationship to the main carer (e.g. spouse, partner, mother, father, etc)

.....

What is their relationship to the child with autism (e.g. mother, father, grandmother, grandfather, foster parent, etc)?

.....

3. Does the child with autism have any siblings (brothers or sisters) that currently live in the home? YES / NO

If YES, please list the ages of the siblings below.

Sibling 1, age:	years	Sibling 5, age:	Years
Sibling 2, age:	years	Sibling 6, age:	Years
Sibling 3, age:	years	Sibling 7, age:	Years
Sibling 4, age:	years	Sibling 8, age:	Years

Please fill out your contact details. This allows us to send you the questionnaire pack for our study.

Name .....

Address:

Four horizontal lines for address input

Postal Code:

One horizontal line for postal code input

We will also need the telephone of the main carer to ask some questions about the child with autism and their sibling. We will ask for permission to record parts of this call when we ring. Please give details of the telephone number below and an indication of the best time for a researcher to contact the main carer.

Telephone no.:

One horizontal line for telephone number input

The best time(s) to telephone the main carer are:

(e.g. Evenings between 5pm – 7pm; Mornings between 10am – 11.30am)

Three dotted lines for time input

I have read the enclosed information sheet. I agree to be sent a questionnaire pack for my family to participate in 'The Wales Study of Families of Children with Autism' and to be contacted by telephone to talk about my child with autism and their sibling.

Signature:

Horizontal line for signature

Date:

Horizontal line for date

Name in Capitals:

Horizontal line for name in capitals

Please tick this box if you would like to receive information in Welsh/or bilingually in Welsh and English in future where this is available.

Welsh   
Bilingual

## Appendix 2

Annwyl Riant,

Diolch yn fawr i chi am fynychu'r rhaglen help!; roedd yn bleser eich cyfarfod. Er gwybodaeth rwyf wedi cynnwys gwybodaeth am adnoddau newydd a allai fod o help i chi a'ch teulu.

Ar nodyn gwahanol, ysgrifennaf atoch hefyd i roi gwybod i chi am ddarn o ymchwil a allai fod o ddiddordeb mawr i chi. Oherwydd y diffyg yma dros y ddwy flynedd ddiwethaf mae'r Gymdeithas Awtistiaeth genedlaethol wedi bod yn gweithio gyda Phrifysgol Cymru, Bangor i ddysgu mwy am teuluoedd. I'r perswyl hwn mae'r tîm ymchwil yn cychwyn ar astudiaeth fawr o frodyr a chwiorydd ar draws y DU. - Os oes gennych ddiddordeb mewn cymryd rhan yn yr astudiaeth neu os hoffech gael mwy o wybodaeth, llenwch y ffurflen datgan diddordeb amgaeedig a'i hanfon yn ôl at y tîm Ymchwil yn yr amlen barod. Rwyf yn ymwybodol efallai eich bod eisoes wedi cymryd rhan mewn astudiaethau ymchwil, a chi sydd i benderfynu a hoffech gymryd rhan yn yr astudiaeth.

Rydym yn gobeithio'n fawr y bydd y wybodaeth a geir o'r astudiaeth o fudd ymarferol i deuluoedd ag awtistiaeth, ac yn gymorth i'n gwaith. Byddem yn hapus iawn i rannu canlyniadau'r astudiaeth gyda chi, a gallaf eich sicrhau y bydd unrhyw wybodaeth a ddarparwch yn cael ei thrin yn gwbl gyfrinachol ac â'r parch mwyaf. Bydd yn ddarostyngedig i'r safonau onestrwydd proffesiynol uchel y mae Prifysgol Cymru yn mynnu cadw atynt, ac ni fyddwn yn eich enwi chi na'ch teulu mewn unrhyw ffordd.

Bydd y gwaith ymchwil yn cael ei wneud gan Michael Petalas, Louise Hall a Helen Joannidi, sy'n fyfyrwr ymchwil ôl-raddedig ym Mhrifysgol Cymru, Bangor. Bydd yn hapus i ateb unrhyw gwestiynau a all fod gennych am yr ymchwil a beth fydd yn digwydd.

Diolch yn fawr iawn i chi am roi o'ch amser i ddarllen y llythyr hwn.

Yn gywir

**Andrew Powell**

Pennaeth *help!*

## Taflen Wybodaeth i Deuluoedd

### Teitl yr Astudiaeth

Astudiaeth Ymchwil Teuluoedd ag Awtistiaeth

### Tîm y Project:

Michael Petalas, Myfyriwr Ymchwil

Richard Hastings, Athro Seicoleg

Alan Dowey, Seicolegydd Clinigol

Susie Nash, Swyddog Ymchwil Ôl-ddoethuriaeth

Helen Joannidi, Seicolegydd Clinigol dan Hyfforddiant

Louise Hall, Seicolegydd Clinigol dan Hyfforddiant

Partneriaeth yw'r ymchwil rhwng Prifysgol Cymru, Bangor a Chymdeithas Awtistiaeth Genedlaethol Cymru, sy'n ariannu rhan o'r ymchwil gyda Chronfa Gymdeithasol Ewrop. Hoffem glywed gan unrhyw deulu sy'n gofalu am blentyn gydag ASD (Anhwylder Sbectrum Awtistaidd) sydd rhwng 3 ac 17 oed.

### Beth yw pwrpas yr astudiaeth hon?

Mae gennym ddiddordeb mewn ymchwilio i sut mae'r profiad o fyw gyda phlentyn ag ASD (e.e. awtistiaeth, syndrom Asperger) yn effeithio ar deuluoedd. Yn enwedig, hoffem ddeall yn well safbwynt brodyr a chwiorydd a sut mae rhieni a gofalwyr yn ymdopi pan fydd plentyn ag awtistiaeth yn y teulu. Hoffem gael wybodaeth gan nifer o deuluoedd o amgylch y DU er mwyn cael syniad da o'r profiadau gwahanol maent yn eu cael. Byddwn yn rhoi adroddiad ar ganlyniadau ein hymchwil i'r Gymdeithas Awtistiaeth Genedlaethol a'r gobaith yw y caiff y wybodaeth ei defnyddio wrth gynllunio cefnogaeth i deuluoedd plant ag ASD yn y dyfodol.

### Beth yw manteision cymryd rhan?

Prif fantais yr ymchwil hon yw gwella'r wybodaeth sydd gennym am anghenion teuluoedd â phlant ag awtistiaeth. Trwy roi cyfle i deuluoedd i ddweud wrthym am eu profiadau'n byw gyda phlentyn ag awtistiaeth, cawn wybodaeth y gallwn ei defnyddio i helpu gweithwyr proffesiynol i ddeall yn well beth yw anghenion y teuluoedd hyn, a'r ffordd orau i gefnogi'r anghenion hyn. Cymharol ychydig o ymchwil sydd ar deuluoedd plant ag awtistiaeth a'u profiadau. Y gobaith yw y bydd yr ymchwil hon yn helpu i wella gwasanaethau i deuluoedd plant ag awtistiaeth.

### Beth yw risgiau cymryd rhan?

Nid ydym yn credu bod teuluoedd sy'n cymryd rhan yn yr astudiaeth hon yn wynebu unrhyw fath o risg. Mae posiblwydd bach, fodd bynnag, y bydd rhai pobl yn ei dechrau teimlo'n ofidus wrth ateb cwestiynau am yr aelod o'r teulu ag awtistiaeth. Os cymerwch ran yn yr astudiaeth hon, cewch dynnu'n ôl ar unrhyw adeg, ac ni fydd unrhyw bwysau o gwbl arnoch i ateb unrhyw un o'r cwestiynau. Darperir gwybodaeth a chyngor am gefnogaeth bellach os oes angen. Os oes angen, cysylltwch â Michael Petalas ar y rhif ffôn isod.

Bydd yr holl wybodaeth yr ydych chi a'ch teulu'n ei ddarparu'n cael ei thrin yn gwbl gyfrinachol, a chaiff ei chadw'n ddiogel dan glo mewn cabinet ffeilio heb enwau arni. Dim ond yr ymchwilydd fydd yn cael mynd at y recordiadau o'r cyfweiliadau ffôn a'r holiaduron. Yr unig eithriad i hwn, sy'n ymarfer safonol, fydd os bydd unigolyn yn datgelu gwybodaeth yn ymwneud â cham-drin plant, y bwriad i anafu'r hunan neu eraill. Mewn achos felly mae gan yr ymchwilydd ddyletswydd i adrodd am wybodaeth o'r fath.

### **Oes raid i ni gymryd rhan?**

Chi yn unig sydd i benderfynu a hoffech gymryd rhan yn yr astudiaeth hon. Os penderfynwch gymryd rhan, llenwch y ffurflenni cydsynio a chysylltu amgaeedig a'u hanfon yn ôl yn yr amlen a ddarparwyd. Gellwch gadw'r daflen wybodaeth hon at eich cofnodion. Byddwch yn rhydd i newid eich meddwl ar unrhyw adeg heb roi rheswm. Ond, os ydych wedi anfon y ffurflen gydsynio gychwynnol yn ôl yn dweud y byddwch chi a'ch teulu'n cymryd rhan, ac nad ydych wedi anfon yr holiaduron yn ôl ar ôl mis, mae'n bosib y byddwn yn anfon nodyn atgoffa atoch yn y post.

### **Beth fydd yn digwydd i mi os byddaf yn cymryd rhan yn yr ymchwil hon?**

Unwaith byddwch wedi anfon eich ffurflen gydsynio a'ch ffurflen gysylltu, byddwn yn anfon pecyn holiadur atoch i'w llenwi. Hefyd, bydd Mike, Louise, neu Helen yn eich ffonio (dim ond os ydych wedi cytuno trwy eich ffurflenni cydsynion a chysylltu) i siarad am eich plentyn sydd ag ASD a'r brawd neu chwaer agosaf mewn oedran ato neu ati (plentyn heb ASD ac yn datblygu yn ôl normau) - os oes un yn y cartref. Disgwylir y bydd yr alwad ffôn yn parhau am ryw 45 munud. Bydd y pecyn holiaduron yn cynnwys un, dau neu dri o holiaduron yn dibynnu ar y wybodaeth yr ydych yn ei rhoi i ni yn eich ffurflen gysylltu. Bydd y ffurflenni melyn ar gyfer y prif ofalwr (dyma'r oedolyn yn y cartref sy'n treulio'r cyfnod mwyaf yn gofalu am y plentyn ag ASD h.y. rhiant, partner, taid neu nain, rhiant maeth etc.) Bydd y ffurflenni gwyrdd ar gyfer yr ail ofalwr (dyma'r oedolyn yn y cartref sydd hefyd yn gofalu am y plentyn ag ASD ond sy'n treulio llai o amser yn gwneud hynny na'r prif ofalwr h.y. rhiant, partner, taid neu nain, rhiant maeth etc.) Yn olaf defnyddir y ffurflenni glas ar gyfer y brawd neu chwaer rhwng 3 a 17 oed sy'n datblygu'n arferol ac sydd agosaf mewn oedran at y plentyn ag awtistiaeth. Gofynnir i chi ddewis dim ond un brawd neu chwaer sy'n datblygu'n arferol a gwneud yn siwr bod y prif ofalwr a'r ail ofalwr yn adrodd ar yr un brawd neu chwaer, ac mai'r brawd hwnnw neu'r chwaer honno sy'n llenwi'r ffurflenni glas (ni fydd brodyr neu chwiorydd rhwng 5 ac 8 oed yn llenwi unrhyw ffurflenni eu hunain). Byddwn yn rhoi amlen radbost i chi i anfon yr holl holiaduron yn ôl. Os ydych yn brif ofalwr plentyn ag awtistaeth hoffem glywed gennych, hyd yn oed os nad oes ail ofalwr neu frawd neu chwaer sy'n datblygu'n arferol yn y cartref.

Er y gallwn roi fersiynau Cymraeg i chi o rai o'r ffurflenni, gwaetha'r modd, dim ond fersiynau Saesneg o'r holiaduron sydd gennym. Mae hyn oherwydd bod yr holiaduron wedi cael eu cyhoeddi mewn Saesneg a byddai eu cyfieithu yn eu gwneud yn annilys at bwrpasau ymchwil. Diolch i chi am ddeall hyn.

I gael rhagor o fanylion ac os dymunwch gysylltu â'r tîm ymchwil, cysylltwch â Mike Petalas trwy ffôn, e-bost neu bost:

Michael Petalas  
Myfyriwr Ymchwil Ôl-raddedig  
Grŵp Ymchwil Anableddau Deallusol a Datblygol  
Ysgol Seicoleg  
Prifysgol Cymru, Bangor  
Adeilad Brigantia,  
Heol Penrallt  
Bangor, Gwynedd  
DU  
LL57 2AS  
Ffôn: ++44 (0)1248 351151 estyniad: 8706  
E-bost: [psp202@bangor.ac.uk](mailto:psp202@bangor.ac.uk)

Os oes gennych unrhyw gwynion am y ffordd y mae'r ymchwil hon yn cael ei chynnal mae croeso i chi fynd i'r afael ag unrhyw bryderon sydd heb eu datrys i:

Dr. Oliver Turnbull  
Pennaeth yr Ysgol  
Ysgol Seicoleg  
Prifysgol Cymru, Bangor  
Adeilad Brigantia,  
Heol Penrallt  
Bangor, Gwynedd  
LL57 2AS

To be completed and returned to the Researcher if you agree to take part

**Astudiaeth Ymchwil Teuluoedd ag Awtistiaeth**

**Ffurflen Gydsynio a Chyswllt i'w llenwi gan y prif ofalwr**

Os byddwch yn llofnodi ac yn dychwelyd y ffurflen hon cymerwn eich bod yn cytuno i ni gysylltu â chi eto am yr ymchwil hon. Golyga hefyd eich bod yn cytuno i dderbyn pecynnau holiaduron. Atebwch y cwestiynau canlynol am eich teulu a rhowch eich manylion cyswllt. Bydd hyn yn ein galluogi i anfon y pecyn holiaduron cywir atoch ar gyfer yr astudiaeth.

1. Cadarnhewch mai chi yw'r prif ofalwr i blentyn ag awtistiaeth rhwng 3 ac 17 oed.  
IE

Beth yw oed eich plentyn ag awtistiaeth? .....oed.

Beth yw eich perthynas â'r plentyn ag awtistiaeth (e.e. mam, tad, nain, taid, rhiant maeth etc.)?

.....

2. Oes ail ofalwr yn byw yn y t□? OES / NAC OES

Os OES,

Beth yw eu perthynas â'r prif ofalwr (e.e. g□r, gwraig, partner, mam, tad etc.)

.....

Beth yw eu perthynas â'r plentyn ag awtistiaeth (e.e. mam, tad, nain, taid, rhiant maeth etc.)?

.....

3. Oes gan y plentyn ag awtistiaeth unrhyw frodyr neu chwiorydd sy'n byw yn y t□ ar hyn o bryd? OES / NAC OES

Os OES, rhestrwch oed y brodyr a'r chwiorydd isod.

Brawd/chwaer 1:	Oed	Brawd/chwaer 5, :	Oed
Brawd/chwaer 2:	Oed	Brawd/chwaer 6, :	Oed
Helen Joannidi	DClinPsy Thesis		1. 45



Brawd/chwaer 3:	Oed	Brawd/chwaer 7, :	Oed
Brawd/chwaer 4:	Oed	Brawd/chwaer 8, :	Oed

Llenwch eich manylion cyswllt. Mae hyn yn ein galluogi i anfon y pecyn holiaduron sy'n gysylltiedig â'r astudiaeth atoch.

Enw .....

Cyfeiriad: \_\_\_\_\_

\_\_\_\_\_

Cod Post: \_\_\_\_\_

\_\_\_\_\_

Bydd angen rhif ffôn y prif ofalwr hefyd i ofyn rhai cwestiynau am y plentyn ag awtistiaeth a'r brawd/ chwaer. Rhowch fanylion y rhif ffôn isod a syniad o'r amser gorau i ymchwilydd gysyllu â'r prif ofalwr.

Rhif ffôn: \_\_\_\_\_

Yr amser(oedd) gorau i ffonio'r prif ofalwr yw:  
(e.e. Nosweithiau rhwng 5pm – 7pm; Boreau rhwng 10am – 11.30am)

.....  
.....  
.....

Rydw i wedi darllen y daflen wybodaeth amgaeedig a chytunaf i dderbyn pecyn holiaduron fel y gall fy nheulu gymryd rhan yn "Astudiaeth o Deuluoedd ag Awtistiaeth yng Nghymru".

Llofnod: \_\_\_\_\_ Dyddiad : \_\_\_\_\_

Enw mewn Priflythrennau:  
\_\_\_\_\_

Ticiwch y blwch hwn os hoffech dderbyn gwybodaeth yn Gymraeg neu'n ddwyieithog yn Gymraeg a Saesneg yn y dyfodol pan fydd hyn ar gael.

Cymraeg

Dwyieitho

**3<sup>rd</sup> party copyright material excluded from digitised thesis.**

**Please refer to the original text to see this material.**

## Appendix 4

Dear Parent / Carer,

Thank-you very much for agreeing to take part in our research for families of children with autism. This is the pack you will need for the first part of the study.

This pack should contain:

- i) Questionnaires for all family members who have agreed to fill in a questionnaire.
- ii) Envelopes for each family member to seal his/her questionnaire in.
- iii) A large (expanding envelope) to return all the parts together back to us.
- iv) An information sheet for you to read if you wish (2 pages).

### Instructions for Filling in the Questionnaire Pack:

The Questionnaire Pack comes in *two* parts. Depending on the information that you sent us about your family in the initial consent form, we may have sent you one, two or three parts.

The *yellow* pack is for mothers or main carers\* to fill in. The *green* pack is for partners\*\* to fill in. You may not have received all the parts, depending on the information you gave us about your family from the initial letter we sent you. Each part has a separate consent form on the front that will be detached from the questionnaires by the researchers when they are sent back.

Please:

- 1) Give each part of the questionnaire pack to the relevant members of your family. *Yellow* for mothers or main carers and *green* for partners .
- 2) Each person filling in a part must sign the consent form and fill in the answers to the questionnaire.
- 3) They will then be able to seal the finished questionnaire in their own envelope.
- 4) The different parts to the questionnaire may then be all put together in the larger envelope provided and posted back to the research team.

### What will happen next?

---

\* The main carer is the person who spends the most time caring for the child with autism. This may be a mother, father, grandparent or foster parent. The main carer does not need to be a blood relative of the child with autism.

\*\* The partner is the second adult in the household, who spends less time caring for the child with autism. This may be a father, mother, grandparent, foster parent or a spouse or partner of the main carer. The partner does not have to be married to the main carer.

The questionnaires will be followed up with a telephone call between October 2007 and January 2008 for the mother or main carer of each family. The telephone interview will be with one of the researchers and will involve talking about your children, and answering some questions about your child with autism. Part of the telephone interview will be recorded. We will ask for your permission to do this before proceeding with the interview. You can still take part in the study if you refuse for the interview to be recorded.

All of the information that you give us will be treated as strictly confidential and kept securely locked in a filing cabinet/office without any information that can personally identify you. Consent forms will be detached from the questionnaires. All information is confidential and will not be passed on to anyone else. The only exception to this is if something is said during the telephone interview that sounds like a child is being hurt or is at risk of being hurt. In this case, it is our legal duty to pass this information on.

## **Information Sheet for Families**

### **Study Title**

The Wales Study of Families of Children with Autism.

### **Project Team**

Michael Petalas, Research Student

Richard Hastings, Professor of Psychology

Alan Dowey, Clinical Psychologist

Susie Nash, Postdoctoral research officer

Helen Joannidi, Trainee Clinical Psychologist

Louise Hall, Trainee Clinical Psychologist

The research is a partnership between the University of Wales, Bangor and the National Autistic Society (NAS) Cymru, who are funding part of the research along with the European Social Fund.

### **What is the purpose of the study?**

We are interested in listening to what families of children with autism have to say about their experience of living with a child with autism or Asperger's syndrome. We wish to better understand some of the issues that siblings (brothers and sisters) are most concerned with. We also wish to understand the needs that some children may have because of their experiences of having a sibling with autism. Finally, we wish to understand how parents and carers cope with having a child with autism. If future support systems are developed for families of children with autism, it is important that these families have the opportunity to have a say in the development of these services. We would like to get information from a number of families from or around the UK in order to get a good idea of the different experiences they have.

### **What are the benefits of taking part?**

The main benefit of this research is to improve the knowledge that we have about the needs of families of children with autism. By giving families the opportunity to tell us in their own words what it's like for them to live with a child with autism, we will have a information that we can use to help professionals have a better understanding of what these families' needs are, and how to help with these needs. There is relatively little research on families of children with autism and their experiences. There are also few formal support services for siblings of children with autism. Taking part in this research will help improve developments in this area.

We plan to keep the people taking part in this research up to date with the projects' progress through a website which will include links to relevant organizations. We will also post a newsletter to families taking part. If we publish any articles about the results of this study, you are also welcome to have a copy of these reports for yourself.

**What are the risks of taking part?**

We do not believe that the families taking part in this study are being put at risk in any way. There is the possibility however, that for some people, answering questions about their brother/sister or son/daughter with autism may lead them to becoming distressed. *If you take part in this study, you will be able to pull out any time, and there will be no pressure whatsoever to answer any of the questions.* Information and advice for further support will be provided if requested.

All the information that you and your family provide will be treated as strictly confidential material, and will be kept securely locked in a filing cabinet without the names attached. The researchers alone will have access to the telephone interview recordings and questionnaires.

**Do we have to take part?**

It is entirely up to you, to decide if you would like to participate in this study. If you do decide to take part, please fill in the questionnaires provided and return them in the envelope provided. You may keep this information sheet for your records. You will have the freedom to change your mind at any time and without giving a reason. However, if you have sent back the initial consent form to say that you and your family will take part, and you have not sent back the questionnaires after one month, we may send you a reminder in the post. If you have decided not to take part in the research, please ignore the reminder.

For further details and if you wish to contact the research team, please contact Mike Petalas by telephone, email or post:

Michael Petalas  
Postgraduate Research Student  
Intellectual and Developmental Disabilities Research Group  
School of Psychology  
University of Wales, Bangor  
Adeilad Brigantia,  
Penrallt Road  
Bangor, Gwynedd  
UK  
LL57 2AS

## Appendices

Tel: ++44 (0)1248 35 8706

E-mail: [psp202@bangor.ac.uk](mailto:psp202@bangor.ac.uk)

If you have any complaints about the way that this research is being conducted you are welcome to address unresolved concerns to:

Dr. E. Charles Leek  
Deputy Head of School  
School of Psychology,  
University of Wales, Bangor,  
Adeilad Brigantia,  
Penrallt Road,  
Bangor, Gwynedd,  
LL57 2AS

## Research Consent Form for Mothers or Main Carers

### The Wales Study of Families of Children with Autism

*Please complete the following and circle your answer:*

- 1) Have you read the all of the information on the Information sheet?  
YES/NO
- 2) Have you had an opportunity to ask questions and discuss this study?  
YES/NO
- 3) Have you received reasonable answers to all of your questions?  
YES/NO
  
- 4) Are you willing to take part in the questionnaire study, and for the information that you give us to be used in this research?  
YES/NO
  
- 5) Are you aware that you can change your mind and not take part in the study  
...at any time?  
...without giving a reason?  
YES/NO
  
- 6) Are you willing to be interviewed on the telephone, for part of the interview to be recorded, and for us to use this information for our research?  
YES/NO

Signature \_\_\_\_\_

Date \_\_\_\_\_

Name in block letters \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Telephone Number \_\_\_\_\_



**Research Consent Form for Partners**

**The Wales Study of Families of Children with Autism**

*Please complete the following and circle your answer:*

1) Have you read the all of the information on the Information sheet?

YES/NO

2) Have you had an opportunity to ask questions and discuss this study?

YES/NO

3) Have you received reasonable answers to all of your questions?

YES/NO

4) Are you willing to take part in the questionnaire study, and for the information that you give us to be used in this research?

YES/NO

5) Are you aware that you can change your mind and not take part in the study  
...at any time?

...without giving a reason?

YES/NO

Signature \_\_\_\_\_

Date \_\_\_\_\_

Name in block letters \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_ Postcode \_\_\_\_\_

Telephone Number \_\_\_\_\_

Annwyl Riant /Gofalwr

Diolch yn fawr i chi am gytuno i gymryd rhan yn ein hymchwil i deuluoedd plant ag awtistiaeth. Dyma'r pecyn y bydd ei angen amoch ar gyfer rhan gyntaf yr astudiaeth.

Dylai'r pecyn hwn gynnwys:

- v) Holiaduron i bob aelod o'r teulu sydd wedi cytuno i lenwi holiadur.
- vi) Amlen i bob aelod o'r teulu i selio ei holiadur ynddi.
- vii) Amlen fawr i anfon popeth yn ôl atom.

**Cyfarwyddiadau i Lenwi'r Pecyn Holiaduron:**

Mae'r Pecyn Holiaduron mewn tair rhan. Yn dibynnu ar y wybodaeth a anfonwyd gennych am eich teulu yn y ffurflen gydsynio gychwynnol, byddwn yn anfon un, dwy neu dair rhan atoch.

Mae'r pecyn melyn i'w lenwi gan famau neu brif ofalwyr\*. Mae'r pecyn gwyrdd i'w lenwi gan bartneriaid. Mae'n bosib nad ydych wedi derbyn pob un o'r tair rhan, mae hyn yn dibynnu ar y wybodaeth a roddwyd gennych am eich teulu o'r llythyr gwreiddiol a anfonwyd atoch. Mae ffurflen gydsynio ar wahân ar y blaen i bob rhan a gaiff ei datgysylltu o'r holiadur gan yr ymchwilwyr pan anfonir yr holiaduron yn ôl.

Os gwelwch yn dda:

- 5) Rhowch bob rhan o'r pecyn holiaduron i'r person priodol yn eich teulu. *Melyn i'r fam neu'r prif ofalwr, gwyrdd i'r partner a glas i frawd.*
- 6) Rhaid i bawb sy'n llenwi rhan lofnodi'r ffurflen gydsynio a llenwi'r atebion i'r holiadur.
- 7) Ar ôl gorffen yr holiadur dylent ei selio yn yr amlen briodol.
- 8) Yna dylid rhoi rhannau gwahanol yr holiadur gyda'i gilydd yn yr amlen fwy a'i phostio'n ôl at y tîm ymchwil.

**Bydd fydd yn digwydd nesaf?**

Ar ôl derbyn yr holiaduron byddwn yn ffonio'r fam neu'r prif ofalwr ym mhob teulu rhwng Hydref 2007 a Chwefror 2008. Bydd un o'r ymchwilwyr yn rhoi cyfweiliad dros y ffôn a byddwn yn gofyn i chi am eich plant ac yn gofyn rhai cwestiynau am eich plentyn ag awtistiaeth. Bydd rhan o'r cyfweiliad ffôn yn cael ei recordio os ydych yn cytuno.

Mae'r holl wybodaeth yr ydych yn ei rhoi i ni yn cael ei thrin fel gwybodaeth gwbl gyfrinachol a'i chadw'n ddiogel dan glo mewn cabinet ffeilio heb unrhyw wybodaeth a allai ddangos pwy ydych chi. Bydd y ffurflenni cydsynio'n cael eu datgysylltu o'r holiaduron. Mae'r holl wybodaeth yn gyfrinachol ac ni chaiff ei rhoi i unrhyw un arall. Yr unig eithriad i hyn yw os dywedir rhywbeth yn ystod y cyfweiliad ffôn sy'n swnio fel pe bai plentyn yn cael ei frifo neu mewn perygl o gael ei frifo. Mewn achos felly, ein dyletswydd gyfreithiol yw rhoi'r wybodaeth hon i rywun arall.

*Os ydych eisiau help gyda'ch ffurflen, cysylltwch â ni a byddwn yn hapus i'ch helpu i lenwi eich ffurflenni.*

## Ffurflen Gydsynio i Ymchwil i'r Prif Ofalwr

Astudiaeth o Deuluoedd â Phlant ag Awtistiaeth yng Nghymru

*Llenwch y canlynol a rhowch gylch o amgylch eich ateb:*

1) Ydych chi wedi darllen yr holl wybodaeth ar y ffurflen Gwybodaeth?

YDW/NAC YDW

2) Ydych chi wedi cael cyfle i ofyn cwestiynau a thrafod yr astudiaeth hon?

YDW/NAC YDW

3) Ydych chi wedi cael atebion rhesymol i'ch holl gwestiynau?

YDW/NAC YDW

4) Ydych chi'n fodlon cymryd rhan yn yr astudiaeth holiadur ac i'r wybodaeth a rowch i ni gael ei defnyddio yn yr ymchwil hon?

YDW/NAC YDW

5) Ydych chi'n gwybod y gellwch newid eich meddwl a pheidio â chymryd rhan yn yr astudiaeth

...ar unrhyw adeg?

...Heb roi rheswm?

YDW/NAC

YDW

6) Ydych chi'n fodlon cael eich cyfweld dros y ffôn, i ran o'r cyfweliad gael ei recordio, ac i ni ddefnyddio'r wybodaeth hon ar gyfer ein hymchwil?

YDW/NAC YDW

7) Os oes brawd neu chwaer i'r plentyn ag awtistiaeth sydd rhwng 5 ac 17 oed ydych chi'n cytuno iddynt gymryd rhan yn yr astudiaeth holiaduron, ac i ni ddefnyddio'r wybodaeth hon yn ein hymchwil?

YDW/NAC YDW

Llofnod \_\_\_\_\_

Dyddiad \_\_\_\_\_

Enw mewn priflythrennau \_\_\_\_\_

Cyfeiriad \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Cod post \_\_\_\_\_

Rhif ffôn \_\_\_\_\_

**Ffurflen Gydsynio Ymchwil i ail ofalwyr**

Astudiaeth o Deuluoedd â Phlant ag Awtistiaeth yng Nghymru

*Llenwch y canlynol a rhowch gylch o amgylch eich ateb:*

1) Ydych chi wedi darllen yr holl wybodaeth ar y ffurflen Gwybodaeth?

YDW/NAC YDW

2) Ydych chi wedi cael cyfle i ofyn cwestiynau a thrafod yr astudiaeth hon?

YDW/NAC YDW

3) Ydych chi wedi cael atebion rhesymol i'ch holl gwestiynau?

YDW/NAC YDW

4) Ydych chi'n fodlon cymryd rhan yn yr astudiaeth holiadur ac i'r wybodaeth a rowch i ni gael ei defnyddio yn yr ymchwil hon?

YDW/NAC YDW

5) Ydych chi'n gwybod y gellwch newid eich meddwl a pheidio â chymryd rhan yn yr astudiaeth

...ar unrhyw adeg?

...Heb roi rheswm?

YDW/NAC

YDW

Llofnod \_\_\_\_\_

Dyddiad \_\_\_\_\_

Enw mewn priflythrennau \_\_\_\_\_

Cyfeiriad \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ Cod post \_\_\_\_\_

Rhif ffôn \_\_\_\_\_

**Appendix 5**

Michael Petalas  
Postgraduate Research Student  
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E-mail: [psp202@bangor.ac.uk](mailto:psp202@bangor.ac.uk)

26th November 2007

Dear Primary Carer,

I am writing with reference to the questionnaire(s) we sent to you from the Autism Families Research Study. If you are still happy to complete the questionnaires then please send them using the freepost envelopes provided. If at the time you receive this reminder you have already sent the questionnaires to us, we apologise for this, please ignore our reminder. If you would now like more information about the study or help with completing the questionnaires, or would like us to send you another copy of the questionnaires please contact me. If you no longer wish to complete the questionnaires, please send them back in the envelope provided and I will not contact you again. I look forward to hearing from you soon.

Best Regards,

**Michael Petalas**

Postgraduate Research Student

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**Appendix 9**

**RISK ASSESSMENT 1: FOR POTENTIAL DISTRESS TO PARENT INTERVIEWEES**

**Name and Status of Assessor:** Michael Petalas (research student), Louise Hall (Trainee Clin. Psychologist ), Helen Joannidi (Trainee Clin. Psych.) **Date:** 10/07/06

**Activity/procedure being assessed:** The primary carer, secondary carer and typically developing sibling will be asked to provide information based on a number of measures as well as the five minute speech sample (FMSS; (Magna et al, 1986) - only the primary carer), during which they will be asked to talk, uninterrupted for five minutes about their relationship with their child with autism and their typically developing child. In addition a Semi-structured interview (based on the Vineland Adaptive Behaviour Scale -2nd Version (VABS II) (Sparrow et al, 2005)) will be conducted with the primary carer of the child with autism over the telephone.

**Known or expected hazards and estimated level of risk:** There is a very low but realistic possibility that being asked to complete questionnaires or talk about their child with autism or their typically developing child can evoke emotional content that might be distressing to the parent/caregiver/sibling. The assessor estimates the level of risk to be low.

**Person(s) at risk:** Interviewee parent(s)/caregiver(s)/typically developing sibling

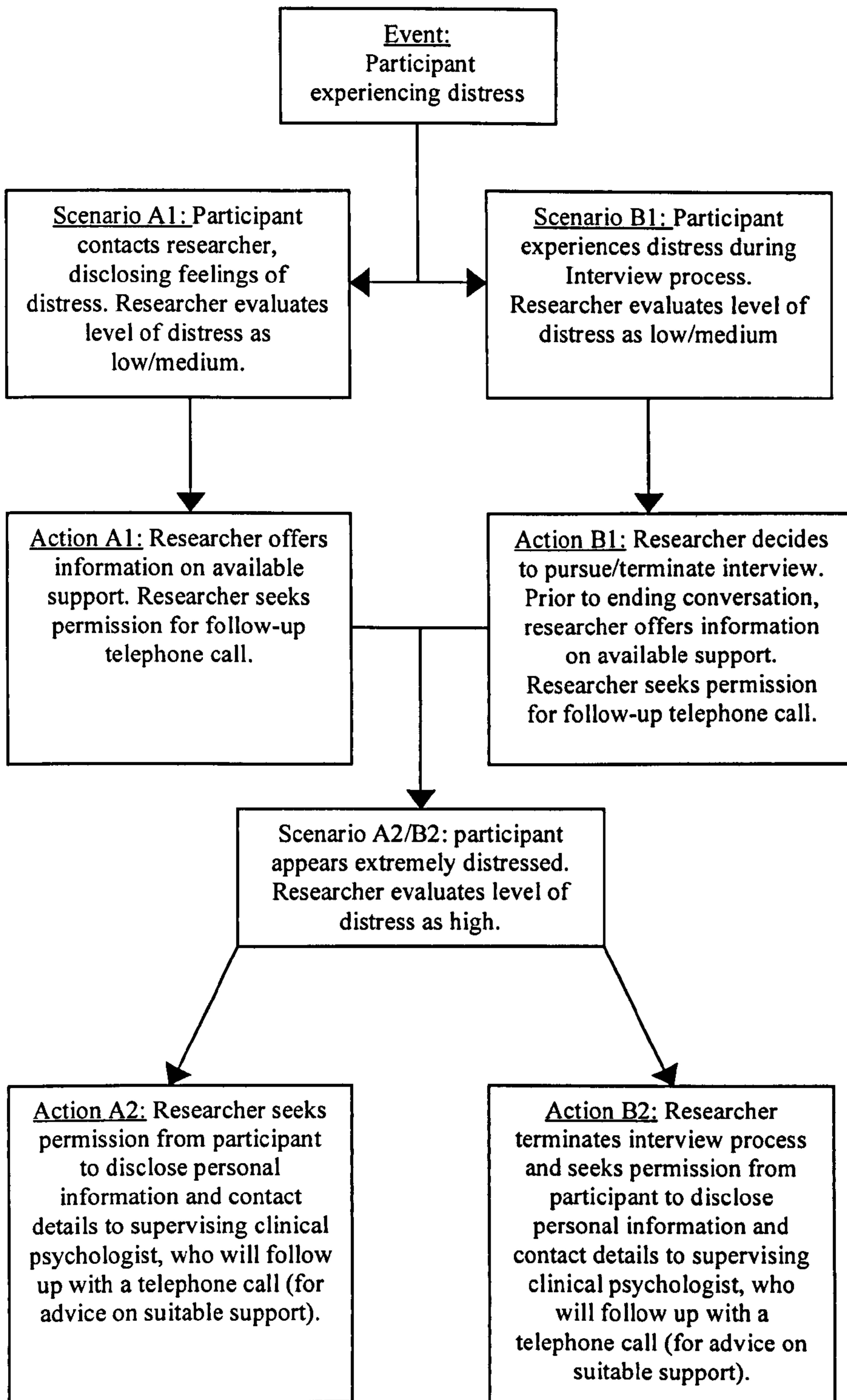
**Measures to be taken to reduce the level of risk:** Consent will be sought and parents/guardians will be informed prior to the interview of the possible risk of distress arising from the interview and the boundaries of confidentiality (see families info sheet). Brief assessment of immediate stress will be carried out (see Appendix 11 - evaluation protocol). Participants' will be informed of their right to withdraw and stop the interview at any point they wish. Verbal consent by the participating primary caregiver will be sought and recorded on tape prior to commencing the interview. A clinical psychologist who is a second supervisor to this project will be advising the researcher on any matters relating to risk of distress to participants. In the event of a participant becoming distressed, the member of the research team carrying out the interview will evaluate the situation and if necessary immediately terminate the interview process. Prior to the termination of the interview process (or at the end of the interview process depending on the evaluation of the researcher), permission will be sought from the affected participant for a follow up telephone call. 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 (see risk assessment -diagram 1).

**Training prerequisites:** All interviewers will be trained at delivering the interviews (see section 9 - Qualifications of the investigators to use measures)

**Level of risk remaining:** There is a remote possibility that despite the measures taken for preventing any experience of distress to participants there still remains a significantly low but possible risk of emotional distress.

**Action to be taken in an emergency:** In the event of severe distress of 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 (see risk assessment 1-diagram 1).

Risk Assessment 1 - Diagram 1





Appendix 10

**RISK ASSESSMENT 2: DISCLOSURE OF CHILD ABUSE/ INTENT TO HARM SELF OR OTHERS/ TERRORIST THREAT**

**Name and Status of Assessor:** Michael Petalas (research student), Louise Hall (Trainee Clin. Psychologist), Helen Joannidi (Trainee Clin. Psych.) **Date:** 10/07/06

**Activity/procedure being assessed:** The primary carer/ secondary carer and/or typically developing child have the opportunity to contact the researcher for further information and the primary carer will be interviewed by the researcher. During a conversation with the researcher the participant might disclose information that the researcher is obliged to report to local law-enforcement or health authorities.

**Known or expected hazards and estimated level of risk:** The level of risk is estimated to be very low. Although unlikely, there is the possibility that during conversation with the researcher a caregiver/sibling might disclose information such as child abuse, intent to harm self or others, or of a terrorist threat. In such an instance the researcher has a duty to report such information to local law enforcement/health authorities.

**Person(s) at risk:** Any

**Measures to be taken to reduce the level of risk:** This situation is classed as an extreme emergency over which the researcher has no control. No precautionary measures are therefore in place.

**Training prerequisites:** (No training prerequisites necessary) A clinical psychologist who is a second supervisor to this project will be advising the researcher on any matters relating to risk of distress to participants

**Level of risk remaining:** The possibility of this situation arising is very low, however, if such a situation occurs the risk to persons may be high.

**Action to be taken in an emergency:** In the event of such disclosure the interviewer will contact the relevant authority (GP, duty psychiatrist, social services, police) depending on the nature of the emergency. These extreme circumstances will have been discussed previously with the research team and the supervising clinical psychologist to pre-empt such occurrences as possible.

Appendix 11

*Evaluation Protocol*

- 1) Brief assessment of immediate stress conducted (How does participant feel on the day, are they still willing to have the interview?) - Researcher to establish whether participant is in reasonable mental health to continue with interview. If immediate stressors operate - reschedule interview.*
  - 2) Outline issues of confidentiality (all information will be treated as strictly confidential with the exception of disclosure of child abuse, harm or intent to harm self or others in which case information will be passed on).*
  - 3) If participant becomes distressed during the interview the researcher will probe to establish whether participant wishes to terminate interview (see risk assessment diagram 1).*
  - 4) Where risk is identified this will be assessed - level of immediate risk will be identified and researcher will take appropriate action (see risk assessment diagram 1).*
-

## Section Two : Reflections on the Process of Research

### Reflections on the Process of Research

I first became aware of the nature and impact of autism when working with a young boy with autism and his family eight years ago. Since then I have worked with numerous children and young people with autism spectrum disorders and their families. It was therefore important to me to be involved in a project that would be related to autism, and which would somehow capture the experience of families with a child with autism. In particular, I was interested in the impact of raising a child with autism on both parents, and how this might differ between mothers and fathers. Of the families that I have worked with, the mothers were mostly primary carers and the fathers the main earners, and I was interested to find if this was the case with most families. Many mothers I met had given up careers to look after their child, but fathers were sometimes under-confident in dealing with their child, because they did not have the same amount of time to practise strategies. I saw first hand the challenges presented to both parents by raising a child with autism, but was also able to witness how some families were able to grow together because of the experience. It was therefore also important to me to capture some positive aspects of parenting a child with autism.

This project has been a massive undertaking, especially for a clinical Large Scale Research Project. The size and scale of the project has been intimidating at times. This has been mostly because of the design of the study, including both questionnaires and telephone interviews, and the fact that it was carried out in conjunction with a PhD project. The hours undertaken in the data collection part of the project have been numerous. Conducting the telephone interviews alone

## Reflective Section

comprised more than 75 hours of data collection. It was definitely a challenge to undertake what has felt like a massive task in addition to doing clinical placements. An additional difficulty was the current job situation for newly qualified clinical psychologists. It was admittedly difficult to maintain motivation to finish this project and the doctorate when it may be difficult to find relevant employment at the end.

Despite taking up a lot of time and energy, and therefore being one of the most laborious parts of the project, the telephone interviews were also a rich source of qualitative and anecdotal evidence, which helped to bring to life the stories of some of the families who participated in the study. It was helpful to have had contact with main carers of families, even if in a limited way on the telephone, in order to highlight some of the issues that they felt were important in their experiences of raising children with autism spectrum disorders. Conversing with main carers (who were mostly mothers), I was able to find out details about their lives and their families' lives that were not captured by the questionnaire data. Some stories were touching. I spoke to a grandmother who was raising her granddaughter following the death of her daughter by cancer. She spoke of the challenges she faced daily raising an autistic child on her own, but was also driven by the love of her daughter. There was also a foster mother who had been the last in a long line of foster families who had failed to cope with a young boy with autism. Her and her husband had initially struggled with him, but she was glad that she had worked hard to understand him, and now felt that they had been able to give him a loving and stable home. Some stories about the children made me laugh out loud! They illustrated how literal the world is for a young person with an autism spectrum disorder. One such story was from a mother whose son had been bought a disposable camera for Christmas, and when he had used

## Reflective Section

it up taking photos, he had thrown it away straightaway. His mother pointed out that the film could not be developed as he had thrown it away, and he replied that, in that case, it was confusing for the camera to be called disposable!

The impact of talking to such large numbers of mothers has been to make me more aware of the difficulties associated with the diagnostic process. Although this was not a question that was specifically asked as part of the interview, it invariably came up again and again. Mothers had tales of not being believed by health visitors, G.P.s, and other professionals, who would reassure them that 'nothing was wrong'. In addition, most mothers also had difficulties in securing funding for their child to obtain extra support in school, or for their child to receive a statement of special educational needs. I was already interested in working in autism services, but having heard so many of these stories, I am now more motivated to make a difference by helping to train more primary care workers, such as health visitors and school nurses, in the early detection of autism.

In addition, although the study aimed to have as little impact as possible on the participants, I believe the interviews may have had some influence on the mothers I spoke to. This was mostly the case when asking mothers about how much help their children gave around the house. During this part of the interview, most mothers reflected that perhaps they did too much for their child, because it was easier than teaching them to do jobs around the house, and that maybe their child should be given more responsibilities. Many mothers seemed to feel a lot of guilt about their child with autism, and this was evident in this part of the discussion, where they would feel that they were not helping their child to develop as perhaps they could. At these

## Reflective Section

times, it was certainly helpful to have some therapeutic skills, as it often felt important to validate mothers' experiences and the difficulties of raising a child with autism. Most mothers, however, also seemed grateful to be able to have some time to talk about their child to someone who had experienced working with children with autism, as they often felt that they were judged by others who did not understand their situation. I was therefore grateful for my past experience that I believe helped to put many mothers at ease. I was also surprised at the extent that mothers were judged by others, even though it had happened to some of the mothers I had worked with in the past. This seemed to be mainly because autism and especially Asperger's Syndrome can be a 'hidden' disorder in that many children on the spectrum look like a typically developing child, and there is not always an obvious sign of their difficulties.

Several mothers that I spoke to displayed some signs of being on the autism spectrum themselves. Although this was only a handful of mothers, it meant that the phone interviews could be initially difficult, with a sense that introductory 'chat' was not wanted or tolerated. However, these mothers also tended to answer questions very efficiently and quickly and so these interviews were also often finished well on time! Many mothers also commented that their husbands had many of the same traits as their child with autism. For some families, this meant that the father understood his child with autism well, and this meant they had a good relationship. For others, this meant that the husband had difficulties in accommodating a child with some problems, and also that the marriage was strained. This project did not measure autistic symptomatology in parents and its impact on well-being and on the marriage, but this would be something that I would be interested in doing in the future.

## Reflective Section

I very much appreciated working with others on parts of this project. There were three of us who used the data from this study to produce different projects, and I felt very much supported by the two others. At times, this also made things more complicated, as everything had to be agreed on by the three of us, and it also meant relinquishing control of some aspects of the project, which was at times frustrating. However, even though things were not always done in a way that I would have chosen myself, overall I was still grateful to have others involved in some of the stages of this LSRP, and especially the support gained by being able to discuss different strategies and ideas.

This has been by far the largest piece of work that I have ever produced, and although daunting, it has also been rewarding. One of the many things that I have learnt has not been connected with the results of the data, the data collection or even the designing of the study. It has instead been a lesson learnt from the overall amount of work involved in the whole process of the study, in addition to doing clinical work, and how to cope with something that at first seemed overwhelming. Admittedly, this has also been something that the Clinical Psychology Doctorate in general has been good practice for. However, the sheer scale of this project has made me aware of the importance of remaining calm throughout a difficult time. In addition, I am acutely aware of how some of my outside activities have given me respite and breathing space from the project. I have discovered that doing martial arts has allowed me to cope by ensuring that this LSRP was simply not the only important thing in my life. In fact, I would go so far as to say that I have succeeded in making it just one of many things in my life, and although one worthy of attention, not one worthy of anxiety.



## Section Three : Literature Review

**Mothers and Fathers of Children with Autism Spectrum Disorders:  
A Literature Review**

Helen Joannidi

Richard P. Hastings

Bangor University, Wales

**KEY WORDS: AUTISM, ASPERGERS, MOTHERS, FATHERS,  
PARENTS**

Running head: Review: Mothers and Fathers of Children with Autism

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2DG, Wales, UK.

**Journal of Applied Research in Intellectual Disabilities: Notes to Authors**

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Top Author Guidelines

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### 2.1 Authorship and Acknowledgements

Helen Joannidi

DClinPsy Thesis

3. 1

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All manuscripts submitted to the Journal of Applied Research in Intellectual Disabilities should include:

**Cover Page:** The authors' details should be supplied and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

**Running Title:** A short title of not more than fifty characters, including spaces, should be provided.

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**Main Text:** All papers should be divided into a structured summary and the main text with appropriate sub headings. A structured summary should be given at the beginning of

each article, incorporating the following headings: Background, Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should proceed through sections of Abstract, Introduction, Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

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The reference list should be in alphabetic order thus:

- Emerson E. (1995) Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities. Cambridge University Press, Cambridge.
- McGill P. & Toogood A. (1993) Organising community placements. In: Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
- Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. Mental Handicap Research 5, 130-145

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## **Abstract**

### **Background**

Mothers of children with autism generally report more stress and mental health problems than fathers. A number of studies have investigated possible factors for why these differences may occur, including differences in perceived stigma and differences in coping styles.

### **Method**

A literature search was run using the search engines PSYCHINFO and Web of Science to obtain articles which reported on biological parents, foster parents or step-parents of children with autism, and which compared mothers and fathers. From an initial shortlist of 60, 17 articles were included in the review.

### **Results**

There is some evidence that mothers of children with ASDs have lower reported levels of well-being (especially depression) than fathers, that mothers are more affected by their child's behaviour problems than fathers, and to a much smaller extent, the child's level of autism, that mothers are likely to spend more time with their children than fathers, and that partner mental health, and different ways of coping, may be important factors in mothers' well-being.

### **Conclusion**

Services may have to support mothers and fathers differently in their different roles, and this needs to be born in mind by professionals. Overall, there is still much to be found out about the reasons why mothers of children with ASDs have lower levels of well-being than fathers and what else services can do to support mothers and fathers differently and effectively.

## **Mothers and Fathers of Children with Autism Spectrum Disorders:**

### **A Literature Review**

#### **Introduction**

There is an increasing body of literature to show that parenting a child with a disability can be stressful, and that therefore parents of children with disabilities report more stress than parents of typically developing children (Hastings & Beck, 2004). Turk (1996) outlined the difficulties that parents of children with intellectual disabilities face, including medical, cognitive, behavioural, educational and social difficulties. Emerson (2003) conducted a large-scale study into the social and economic situation, mental health status and psychological impact of raising a child with intellectual disability. It was found that mothers of children with intellectual disabilities were significantly economically disadvantaged when compared with mothers of children without an intellectual disability. Presence of mental health problems was associated with these children's difficulties having an increased social impact for mothers. Awareness of these issues suggests that it is important to explore the experiences of parents of children with intellectual disabilities, in order to determine what factors contribute to stress, and to discover how best services can support them.

Parents of children with Autistic Spectrum Disorders (ASDs) have, in some studies been investigated in comparison to parents of children with intellectual and other disabilities (eg Dumas, Wolf, Fisman & Culligan, 1991). It has been shown that, in general, parents of children with autism are at increased risk for stress compared to parents of children with other disabilities (eg Abbeduto, Seltzer, Shattuck, Krauss, Orsmond & Murphy, 2004). In looking at why some parents of children with ASDs may be more likely to be stressed than others, one variable, which has been shown to be important, is gender. There has been shown to be a difference in the amount of stress reported by mothers and fathers of children with autism, with mothers generally reporting

more stress and mental health problems than fathers (Hastings, 2003; Herring, Gray, Taffe, Tonge, Sweeney & Einfeld, 2006). There have been a number of studies looking at why these differences may occur, which include variables such as differences in perceived stigma (Gray, 2002) and differences in coping styles (Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005a).

The purpose of this literature review is to outline the findings of articles that have compared mothers and fathers of children with ASDs. The main focus of the review will be on what the literature in this area focuses on, which is stress, mental health problems, well-being and coping, and on similarities and differences between mothers and fathers. The literature on parents of children with ASDs reports on parents of children across the entire autistic spectrum. The review therefore looks at articles pertaining to children with all levels of ASDs from severe autism with an intellectual disability to high functioning autism / Asperger's Syndrome. The main purpose of the review is to evaluate the findings on mother/father differences in well-being, and to explore possible reasons for these differences. These include variables such as societal factors, coping differences, and possible personality differences. In addition, the implications of the findings for clinical support services for mothers and fathers will be considered, as well as suggestions for future research.

## **Method**

Articles were obtained which reported on data from mothers and fathers of children with autism. Those searched for were journal articles from English language publications only. It was decided initially to include articles which referred to either parents or carers, whether these were biological parents, foster parents or step-parents, as long as the parents were of different gender and were the main carers for the children with autism / ASD. The search was conducted using the following search terms for parents and carer variables: MOTHER\*, FATHER\*, PARENT\*, MATERNAL,

**PATERNAL, CARE-GIVER\*, FAMIL\*, CARER\*, CAREGIVER.** In addition, the following search terms were used in conjunction with the above parental terms to obtain articles that would be focused on parents/carers of children with Autistic Spectrum Disorders and Pervasive Developmental Disorders: **ASD, AUTIS\*, ASPERGER\*, PDD, PERVASIVE.** The search was run using the search engines PSYCHINFO and Web of Science for keywords and titles. This produced 548 articles, ranging in date from 1977 to 2006, the electronic records and abstracts of which were then searched individually for relevance. Articles were retained for the review if they directly compared mothers and fathers of children with ASDs. This may have been either on well-being variables, such as quality of life or stress, or on variables that have been suggested to be contributory to differences in coping and stress, such as personality differences, burden of care or perceptions about the child. Intervention studies which looked at a well-being measure as an outcome variable and which included data about mothers and fathers of children with ASDs were also included. If the electronic record suggested that there may be data on both mothers and fathers but this was not conclusive, the article was obtained and read. Of the 548 articles, an initial shortlist of 60 was found to contain data on mothers and fathers of children with ASDs. 32 articles were excluded after reading the abstracts and discovering that the reported outcomes were not always reporting on parents separately. After this selection process, 28 possibly relevant articles were retained and full copies of the papers were read. A further 11 articles were excluded after detailed evaluation, again due to lack of direct mother/father comparison. A further study was excluded as it used adult-age people with autism who were living at home with their parents as participants. A further four articles which appeared in the citation list of other papers were also obtained, of which 1 directly compared mothers and fathers. The final number of papers included in the review was therefore 17.

An issue in reviewing evidence on ‘parents’ of children with ASDs arises as to what constitutes a ‘parent’. Adult participants in the studies found were mostly described simply as parents, with five studies stating that the parents were either biological, or that the family contained at least one biological parent. One study mentioned that step-parents were recruited as well as biological parents, and the remaining 11 studies did not mention whether the parents were biological or not. Two of these remaining studies used postal surveys, and so it is likely that step-parents may have made up some of the participants. In order not to exclude evidence, and due to the relatively small number of studies directly comparing mothers and fathers, it was decided to include all studies of all main carers in this review, whether biological or not, providing they were of different gender. All 17 papers were therefore included in the review.

## **Results**

### **Mother/Father Well-Being Outcomes – Mental Health, Quality of Life & Stress**

Ten of the studies selected for the review directly compared mothers and fathers of children with ASDs on overall well-being variables such as mental health, stress and quality of life. Articles which looked at interactions between variables (eg child behaviour problems and stress), but which did not directly report the level of mother/father differences in terms of scores were not included in this section. Table 1 provides a summary of the ten articles.

Nine of the studies reported on either mental health or stress outcomes, or a mixture of the two, as a way of comparing mother/father well-being. The final study (Allik, Larsson & Smedje, 2006) used health-related quality of life (both physical and mental) as a measure of well-being. It was noted that nine studies showed a significant difference between mothers’ and fathers’ well-being on different outcome variables, with mothers scoring lower on well-being measures. The tenth

study did not report significance levels for mother/father differences (Hastings & Brown, 2002), but showed differences in the same direction as the others studies (i.e. with mothers having lower levels of well-being).

## Depression

Eight studies directly measured mother/father differences in depression (Dumas et al, 1991; Gray & Holden, 1992, Hastings, 2003; Hastings & Brown, 2002; Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005b; Moes, Koegel, Schreibman & Loos, 1992; Sharpley, Bitsika & Efremidis, 1997; Wolf, Noh, Fisman & Speechley, 1989). Six of these studies reported that mothers had significantly higher levels of depression than fathers (all but Hastings, 2003 and Hastings & Brown, 2002). Of the two studies that did not report significant findings, Hastings (2003) showed a non-significant difference with fathers reporting lower levels of depression than mothers. This study was conducted with 36 participants, and so it is conceivable that a higher-powered study may have found a significant difference. Hastings and Brown (2002) reported that mothers had higher levels of depression than fathers, and showed these differences in mean scores. However, as the study was not focused on these results as the main outcome, the level of significance was not reported.

Effect sizes were calculated by the present author for the studies which showed means scores and standard deviations for mothers and fathers on depression measures, as a way of determining how much of a sizeable difference there was between mother and father well-being scores. These sizes were calculated using Cohen's  $d$  (Cohen, 1988). Guidelines for effect sizes were as follows:  $d = .20$  or above – small effect,  $d = .50$  or above – medium effect,  $d = .80$  or above – large effect.

There were five studies, which quoted mean scores and standard deviations (Hastings, 2003; Hastings & Brown, 2002; Hastings et al, 2005b; Moes et al, 1992; Wolf et al, 1989). Two studies

showed a large effect sizes of  $d = .80$  and  $d = .86$  respectively (Moes et al, 1992; Wolf et al, 1989). One study showed a moderate effect size of  $d = .63$  (Hastings et al, 2005b). Two studies showed small effect sizes of  $d = .29$  and  $d = .18$  (Hastings, 2003; Hastings & Brown, 2002). The measures used for assessing depression are a consideration in the reliability of the above evidence. The measures used varied across the studies, but all studies used standardized measures that have been used previously in research. These included the Beck Depression Inventory (BDI; Beck, Steer & Brown, 1996), the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and the Zung Depression Scale (Zung, 1965). It was noted that these are all self-report measures, and that all eight studies relied on parents' reports of their feelings and symptoms. The studies therefore compare how well mothers and fathers perceived themselves to be and compared their reported differences, as opposed to those reported by others. Overall, there is some consistent evidence to show that mothers of children with ASDs report more depression than fathers.

## **Anxiety**

Five studies reported on mothers' anxiety (Gray & Holden 1992; Hastings, 2003; Hastings & Brown, 2002; Hastings et al, 2005b, Sharpley et al, 1997). One article did not find a significant difference in mothers' and fathers' anxiety, despite being quite well-powered with 82 participants (Hastings et al, 2005b). However, the trend found was towards mothers reporting higher anxiety than fathers. In three other articles, mothers' anxiety was reported as significantly higher than fathers' anxiety. The fourth article, (Hastings & Brown, 2002) reported mothers' anxiety scores as higher, but with no significance level conveyed. Of these four articles, only Hastings (2003) and Hastings & Brown (2002) showed mean scores and standard deviations. Effect sizes were calculated for the differences in mean scores, and both articles showed moderate effect sizes of  $d = .49$  and  $d = .69$  respectively. The measures used in these studies were reliable and validated

self-report measures, comprising of the HADS, the Zung Anxiety Scale (Zung, 1971) and the State-Trait Anxiety Inventory (STAI; Spielberger, Gorsuch, Lushene, Vagg & Jacobs, 1983).

However, overall the evidence for mothers reporting higher anxiety levels than fathers is quite sparse, and needs replicating to be more convincing.

## **Overall Mental Health**

Overall mental health was measured by Herring et al (2006) using the General Health Questionnaire (Goldberg & Williams, 1988), the overall score of which has been used as a screening measure of mental health problems. The study showed that mothers had a significantly higher score on the GHQ than fathers, equating to higher levels of mental health problems, and the effect size when calculated was a medium effect size of  $d = .54$ . The final study (Allik et al, 2006) looked at health-related quality of life as an outcome measure, which included both mental and physical quality of life. The results showed that mothers of children with high-functioning ASDs had lower reported levels of physical-related quality-of-life than both control mothers and fathers of children with high functioning ASDs (equating to a medium effect size of  $d = .58$ ). However, the study found no significant difference in mental health-related quality of life between mothers and fathers of children with ASDs. The outcome measure used was a validated questionnaire, the 12-item Short Form Health Survey (Ware, Kosinski & Keller, 1996). As this study was quite well-powered, the lack of difference between mother and father mental-health related well-being is not easy to explain. The results on gender differences in overall mental health related well-being is therefore currently inconclusive.



## Stress

Seven studies also looked at stress as well as mental health outcomes (Dumas et al, 1991; Hastings, 2003; Hastings et al, 2005b; Herring et al, 2006; Moes et al, 1992; Sharpley et al, 1997; Wolf et al, 1989). Of these, three articles showed no significant difference in stress between mothers and fathers (Hastings, 2003; Hastings et al, 2005b; Sharpley et al, 1997). Although Hastings (2003) had lower participant numbers (as previously mentioned), the other two studies had high numbers of participants (82 and 219 respectively), and so a non-significant result is unlikely to be attributable to lack of power. However, it was noted that the trend in all three studies was always for mothers reporting higher levels of stress than fathers. The other articles reported significant differences in gender stress, again with mothers reporting more stress than fathers. The effect sizes for Wolf et al (1989) was calculated as small at  $d = .28$ . The effect sizes for Herring et al (2006) and Moes et al (1992) were calculated as medium, at  $d = .70$  and  $d = .67$  respectively. The final paper (Dumas et al, 1991) did not show mean scores and standard deviations. The measures used for assessing stress were not all standardized measures. Reliable and validated measures used included the QRS-short form (Friedrich, Greenberg & Crnic, 1983) and the Parenting Stress Index (Abidin, 1995). However, Sharpley et al (1997) developed a stress measure for the study for which psychometric properties were not reported. In addition, Herring et al (2006) used a 'stress thermometer' to measure perceived stress levels, which clearly provides less robust evidence than validated measures. Overall, where gender differences in stress have been shown, mothers report greater stress. The evidence is patchy, however, and needs to be clarified with studies using more robust measures.

Overall, the generalisability of the above evidence is dependent upon the validity of the findings for parents of children with ASDs. One of the conditions for applicability to this population is whether or not children in these studies had confirmed official diagnoses of ASDs. Five of the

studies explicitly described how the recruited children had diagnoses of autism and were reassessed using either DSM or ICD criteria (Allik et al, 2006; Dumas et al, 1991; Hastings et al, 2005; Herring et al, 2006; Wolf et al, 1989). The other studies recruited children and their parents from autism-specific institutions such as schools, clinics and autism associations, but no information is given on how the children's diagnoses were confirmed. Two studies (Gray & Holden; Sharpley et al, 1997) used postal questionnaires sent to parents who were members of autism associations, and no information is given in either paper about the children's level of autism, or how this was measured. It is likely that any parent of a child with autism-type difficulties could join an autism association, and so data from these studies may be less likely than others to be generalisable. Postal studies are a cost-effective way to obtain high participant numbers, but it would be useful for future such studies to either obtain details of how and by whom diagnosis was made, or to include a measure of the level of the child's autistic symptoms. In terms of generalisability of the evidence, it was again noted that the age and severity of ASD of children differed across studies. It is, of course, possible that some findings may not therefore be applicable for parents of children of different ages or severity of symptoms.

Overall, then, if the evidence from different well-being variables is taken together, there is some reasonable evidence for differences in the reported well-being of mothers and fathers of children with ASDs. The most consistent and robust evidence was for a difference in depression, with mothers reporting higher levels than fathers. There is some evidence for reported differences in anxiety, again with the trend being for mothers to show higher levels than fathers, but more evidence is needed. The evidence for overall mental health is inconclusive, and the evidence on stress, although in the same direction as depression and anxiety, is patchy and needs more studies using validated measures to clarify the findings. Future studies of parents of children with ASD, especially postal surveys, also need to clarify how an autism diagnosis has been reached for each child, or provide a measure for autistic symptomatology.

## **Contributing Factors to Mother/Father Differences in Well-Being**

One possibility for mothers reporting higher levels of difficulties may be a general gender pattern, as reported in the mental health literature. Several studies have provided evidence for a gender gap in mental health (e.g., Dambrun, 2007; Emslie et al., 2002), for postulated biological, behavioural and social reasons, including gender differences in social roles (paid work versus domestic work), and perceived personal discrimination. In order to inform services it is important to explore whether gender differences in well-being of parents of children with autism are down to the reasons reported in the mental health literature or for additional reasons which are specific to parenting a child with autism. Possible additional contributing factors to these differences explored in the literature were therefore investigated. The second section of the review, therefore, looks at articles that attempt to investigate contributing factors in parents' experiences of rearing their children, and interactions between variables that may explain gender well-being differences. This section also includes some findings from articles reviewed in the previous section, if these articles also explored contributing factors rather than just measuring levels of differences between mothers and fathers. 14 articles were found which investigated possible reasons for mother/father differences, of which seven were reported on in the first section. In order to explore mother/father differences, the review explores what predicts mother well-being and what predicts father well-being, and how this may illuminate any reasons why mothers and fathers report different outcomes for parenting a child with ASD. For ease of reference, those articles which have already been referred to will be included again in this section. Table 2 shows the relevant articles, with those that have been referred to in the previous section marked with \*

The 14 studies found investigated the effect of coping, social support, carer roles / carer burden, stigma and partner mental health on maternal and paternal well-being. Three qualitative articles which explored mother and father coping (Gray, 2003) and stigma (Gray, 1993; Gray, 2002) were

also included for the themes that they uncovered in these areas. Ten studies (Allik et al, 2006; Dumas et al, 1991; Gray & Holden, 1992; Hastings, 2003; Hastings et al, 2005a; Hastings et al, 2005b; Herring et al, 2006; Konstantareas & Homatidis, 1989; Milgram & Atzil, 1988; Wolf et al, 1989) investigated relationships between variables in trying to understand mother/father differences. The other article discussed how level of involvement of mothers and fathers may contribute to well-being differences, but did not explicitly explore this statistically (Konstantareas & Homatidis, 1992).

### **Child Factors: Child Behaviour Problems**

Firstly it is useful to look at what variables are shown by the literature to contribute to parental stress. Four articles which have been looked at previously (Allik et al, 2006; Dumas et al, 1991; Hastings 2003; Hastings et al, 2005b) used measures of child behaviour problems in order to establish a relationship between level of child behaviour problems and parental well-being. The statistical analysis included correlation and regression analyses. Correlational analysis from two studies (Hastings, 2003; Hastings et al, 2005) showed significant correlations (from .32 to .59) between child behaviour problems and mother well-being variables (stress, anxiety, depression). The same two studies showed lower (.15 to .31) and non-significant correlations between child behaviour problems and father well-being variables. Regression analyses from two studies (Allik et al, 2006; Hastings et al, 2005b) showed initial significant relationships between child behaviour problems and mother well-being variables of  $\beta = .47$  and  $\beta = .62$ . Fathers' well-being did not show a significant relationship in these studies with child behaviour problems, with non-significant  $\beta$  weights of .17 and .28. The final study (Dumas et al, 1991) showed a significant relationship between both mother well-being variables and child behaviour problems ( $\beta=.43$ ) and father well-being and child behaviour problems ( $\beta=.28$ ), although for fathers the relationship was

much weaker. The measures used to establish levels of child behaviour problems were the Developmental Behaviour Checklist (Einfeld & Tonge, 1995), Eyberg Child Behaviour Inventory (Eyberg & Ross, 1978) and the Strengths & Difficulties Questionnaire (SDQ; Goodman, 2001) all of which have been validated and used before in research. These studies show that there is some evidence that mothers' well-being is more related to their children's behaviour problems than is fathers' well-being.

### **Adaptive Behaviour**

Adaptive behaviour is a measure of a child's abilities in daily living skills such as washing, dressing, eating, communication and social skills. The child's level of adaptive behaviour was measured in three studies (Hastings et al, 2005; Herring et al, 2006; Milgram & Atzil, 1988). The measures used were standardised and had been used in previous research. The measures used were either the Adaptive Behaviour Schedule (Lambert, Windmiller, Cole & Figueroa, 1974) or the Vineland Adaptive Behaviour Scales (Sparrow, Balla & Cicchetti, 1984). The effect of the child with autism's level of adaptive behaviour on mother and father well-being variables was only reported in two papers. Milgram and Atzil (1988) reported that parental, teacher and psychologist ratings of child behaviour problems did not correlate significantly with either mother life satisfaction (.23; .06; .16) or father life satisfaction (.20; .07; .05). Hastings et al (2005) also reported that adaptive behaviour did not correlate significantly with maternal stress (-.09), depression (.00), anxiety (.20) or paternal stress (-.02), depression (-.05) or anxiety (.01). Adaptive behaviour was also shown in Hastings et al (2005) using regression analysis, not to significantly predict maternal stress ( $\beta = -.04$ ) or paternal stress ( $\beta = .10$ ). Therefore the evidence so far suggests that the level of a child with autism's adaptive behaviour does not significantly contribute to either mother or father well-being.

## **Autistic Symptomatology**

Autistic symptomatology, or level of autistic symptoms, is another factor that has begun to be investigated as a possible contributor to mother and father well-being. The level of the child's autistic symptoms was measured by two studies (Allik et al, 2006; Hastings et al, 2006). Autistic symptomatology was measured using the High-Functioning Autism Spectrum Screening Questionnaire (Ehlers, Gillberg & Wing, 1999) and the Autistic Screening Questionnaire (Berument, Rutter, Lord, Pickles & Bailey, 1999). Allik et al (2006) reported that parental health-related quality of life was not related to level of autistic symptoms, although no statistics were reported. However, Allik et al (2006) used parents of children with high-functioning autism in their study. Hastings et al (2005b) used parents of pre-school children with autism, and reported that autistic symptomatology was not significantly correlated with maternal anxiety (.27), depression (.23) or paternal anxiety, (-.09), depression (.04) or stress (.26), but was significantly correlated with maternal stress, although the correlation was quite low (.32). When analysed using a regression model, child autistic symptomatology did not independently predict either maternal stress ( $\beta = -.04$ ) or paternal stress ( $\beta = .17$ ). More evidence is needed to explore the contribution of the child's level of autism to mother and father well-being, although the small amount of evidence so far suggests that this is not the most important contributory factor.

## **Parent Factors: Carer Responsibility**

Reasons for mother-father well-being differences were explored by investigating the contribution of parental variables. One such variable is that of carer responsibility, as defined by the amount of time a parent spends with their child, or the burden of care. Konstantareas & Homatidis (1992) asked parents to log the number of hours they spent doing various activities with their child, and reported differences in means. The results showed that mothers spent significantly more time than

fathers with their children with ASDs. Using *Cohen's d* the effect size ( $d = .66$ ) between mother and father means was moderate. Milgram and Atzil (1988) reported that mother's life satisfaction (as measured using a Likert Scale) was highly correlated to their share of parenting burden, whereas fathers' was lower. Whilst most researchers find that the main carer for child with ASDs is usually the mother, there have so far been no other studies that formally assess whether time spent with the child, or whether doing specific tasks (such as daily living tasks) with the child, and therefore more exposure to behaviour problems, is directly related to well-being variables rather than gender itself. Whilst two studies above used diagnostic criteria assessment for the children involved in the study, they used different measures to assess length of time spent with the child, and this included self-report logs. The evidence could be strengthened with recordings from observers. So, whilst carer responsibility may be an important factor in gender well-being differences, more evidence is needed to establish this. A related issue is the contribution of the societal or familial experience of carer roles to gender differences in well-being of parents of children with ASDs. Three qualitative studies (Gray, 1993; Gray 2002; Gray 2003) have uncovered themes about carer role whilst exploring parents' experiences of stigma and coping. These findings are not generalisable, but generate interesting themes to be followed up. For example, in all three studies, themes that arose for mothers were that they felt more responsible for the care of their children, and felt more judged by society because of this, and therefore experienced more stigma. In addition, fathers in these studies felt that their work gave them a separate role and identity away from the carer role. It has not been tested whether these themes are underlying differences in mother/father well-being in the wider population of parents of children with ASDs, but they pose interesting topics for further research.

## **Systemic Factors**

In terms of contributing factors to the picture of mother/father differences, three studies have looked at systemic relationships, and the effect of partner mental health on maternal/paternal well-being (Hastings, 2003; Hastings et al, 2005(b), Herring et al, 2006). These studies have all been described before in terms of their results on mother/father differences in well-being. However, all three studies also explore interactions between mother/father well-being variables as well as child behaviour problems as possible contributory factors. Two of these three articles (Hastings, 2003 & Hastings et al, 2005(b) showed a contribution of systemic variables to partner mental health. Hastings (2003) found significant correlations between paternal anxiety (.49), paternal depression (.69) and maternal stress when child behaviour problems were controlled for. However, the reverse was not true for fathers. Hastings et al (2005b) using regression analyses, found that paternal stress was predicted by maternal depression ( $\beta=.54$ ) and that maternal stress was predicted both by child behaviour problems ( $\beta=.62$ ) and paternal depression ( $\beta=.49$ ). Herring et al (2006), also using regression analyses, however found that partner mental health problems were not a significant contributor to either mother or father stress. However, Herring et al (2006) used children with pervasive developmental disorders (including children with ASDs plus children who had autistic-type difficulties but did not meet criteria for autism), rather than just children with autism. It may be therefore, with autism-specific samples, partner mental health is more important.

## **Coping**

Coping is another variable that has been explored in the literature, which may contribute to the ASD parent gender differences. Again Gray's (2003) qualitative study provides some themes as a way of an introduction to issues that arose for the parents in his study. These tie into earlier



themes about work providing a role for fathers, and therefore a means to cope. Fathers in the study also felt that they coped more easily than their wives because their child's autism did not affect them personally, due to their careers, but rather due to how their wives felt. Conversely, the mothers in the study had mostly given up their careers, and were more affected by referral and professional stresses. Again, these findings provide interesting variables for future research to explore. One other study has looked at differences in gender coping. Hastings et al (2005a) compared coping strategies in mothers and fathers of preschool and school-age children with autism. Mothers reported using significantly more active avoidance coping strategies as well as problem-focused coping strategies than fathers. Active avoidance for both mothers and fathers was significantly correlated with higher levels of stress (.56), depression (.43) and anxiety (.48). Positive coping was also significantly associated, although not highly (-.33), with lower depression in both mothers and fathers. This is the only quantitative study that has compared gender differences in coping of parents of children with ASDs. Although there is some evidence from this study that parents may adopt different coping strategies, more evidence is needed to replicate how this affects parents differently. The Hastings study used the COPE scale and extrapolated four factors of coping from this scale. Further studies could use a similar strategy to compare mother/father coping to build upon this evidence.

### **Social Support**

Social support as a coping strategy has also been explored in the literature. Gray and Holden (1992) showed a significant relationship between social support and lower depression (-.39), anxiety (-.49) and anger (-.44) in both parents, and that the levels of these well-being measures were lower for fathers than mothers. In a regression model in Wolf et al (1989), the inclusion of social support in the regression equation increased the amount of explained variance in depression from  $R = .24$  (24%) to  $R = .27$  (27%) for mothers, and from  $R = .18$  (18%) to  $R = .25$  (25%) for

fathers. Konstantareas & Homatidis (1989) found that both mothers' (-.25) and fathers' (-.32) stress was significantly negatively correlated with the degree of support reported. Support in all three studies was measured differently, using questionnaires designed for each study. This means that the evidence is difficult to compare, and no further studies have been conducted which look at how social support affects both mothers and fathers of children with ASDs. It appears from this small amount of evidence that social support may be important in the well-being of both mothers and fathers, but further studies which compare differences and which use standardized measures are needed.

Again, the quality of the research evidence from the additional quantitative papers can be analysed in terms of how a diagnosis of autism was confirmed in the children used. Of the four studies, three mention that DSM criteria were used in establishing childrens' diagnoses of autism, and the final study (Hastings et al, 2005a) does not mention how children were diagnosed. Most of these studies, therefore, provide reasonably generalisable evidence. In addition, all the measures used in these studies for mothers and fathers were self-report measures. It may be that professionals would have different views on parent's levels of well-being than parents themselves. An earlier study (Bebko et al, 1987) compared professional's views on parents' stress with the parents' views. The results showed that whilst parent and professionals agreed on the children's symptom severity, professionals judged parents to be more stressed by child symptoms than did the parents themselves. This would be an interesting finding to investigate, but is outside the area of interest of the present review

## **Discussion**

The literature on differences in well-being of mothers and fathers of children with ASDs is complex. If the evidence for the different well-being variables are taken separately, the strongest

evidence is for mothers reporting higher levels of depression than fathers. There is some, although less, evidence for mothers having higher levels of anxiety, and the evidence for differences in stress levels is mixed. There are also isolated studies on physical well-being and overall mental health which add to the picture of mothers' overall well-being as lower than fathers'. If all the evidence is taken together, there is some reasonable evidence that mothers of children with ASDs have overall lower levels of well-being than fathers. However, the evidence for why this may be is not completely clear. There is some evidence that child behaviour problems affect mothers' well-being more than fathers, and that the child's level of autism may be a factor, but whilst variables that may contribute to mother-father differences have been explored, there is no strong consistent evidence for which variables contribute most.

Intuitively, the difference in time spent with the child, or in the different tasks done with the child, seems to be an important factor. This is strengthened by the fact that even recent studies show that the burden of care falls mostly on mothers. This may be one of the most important factors in why mothers have higher levels of stress, but there has been no current research into whether gender differences in well-being are down to amount of time spent with the child, to additional factors that are more specific to gender differences in mental health, or to reasons specific to parenting a child with ASD. There have been several studies that have shown that mothers and fathers agree on both the level of the severity of their child's behaviour difficulties (Hastings & Brown, 2002; Bebko, Konstantareas & Springer, 1987; Konstantareas & Homatidis, 1989; Dumas et al, 1991), and on which child-related behaviour problems were most difficult to cope with (Konstantareas & Homatidis, 1989; Bebko, Konstantareas & Springer, 1987). Therefore, it may be that whilst both parents consider their child's behaviour to be equally difficult or distressing, mothers are more affected by the behaviour due to the greater burden of being the main caregiver rather than gender-specific variables.

Because of the above demographics, another variable that may be important in gender differences in well-being is the role provided by having a career away from the family, a theme which has emerged from the qualitative exploration of parents' different experiences. Hypothetically, the fact that most fathers have a full-time job may help in two ways: that fathers have a role which provides self-esteem outside the home, and/or the additional benefit of spending less time around the child's behaviour problems. It is unclear which of the two factors would contribute most to child behaviour problems affecting mothers more than fathers. However, this has not been investigated at all in the literature. Again, the qualitative studies showing that a common theme was mothers feeling more responsible for their child and reporting more experiences of stigma may be because of social expectations, or simply because for most mothers, they are still the caregiver most responsible for the child. It is therefore difficult to separate out whether these themes which may point to important variables are down to the caregiver role rather than gender-specific / cultural values.

The possible role of partner mental health is interesting to note, but needs more research to explain how it may contribute, as it has only recently begun to be investigated. Again, the possible importance of partner mental health has been mirrored in the qualitative literature in which fathers have reported their role as being one of supporting their wife emotionally (Gray, 2003) and that fathers felt that their child's difficulties affected their wife more than them. This again raises the question of whether or not this is down to the amount of time that mothers spend with their children, or to additional gender-specific variables.

There has been surprisingly little research that looked at different styles of coping between the genders, and how this contributes to differences in well-being. The initial finding that avoidance coping strategies are detrimental is a useful finding for services, but more investigation needs to be undertaken. Social support may also be an important variable, but the research on this is very

patchy and difficult to draw conclusions on. There are also other variables that have been shown to be important in the well-being of parents with disabilities, which may also be relevant for mothers and fathers of children with ASDs. These include the contribution of the quality of the marital relationship (Kersh, Hedvat, Hauser-Cram & Warfield, 2006) and the role of the support of other family members in parental well-being (Seligman, Goodwin, Paschal, Applegate & Lehman; 1997). These may be relevant to services in order to know where to concentrate help, and what constitutes risk factors for parents.

So far in the literature comparing mothers and fathers there has been no exploration of how the broader autism phenotype may contribute to differences in parenting and therefore well-being. Several studies have shown that fathers of children with autism have more 'autistic traits' than mothers, in that they perform less well than mothers on tasks that people with a diagnosis of autism find difficult, such as tests of facial recognition (Palermo et al, 2006), set-shifting (Wong et al, 2002) and other executive functioning tasks (Hughes et al, 2006). The implications for this in terms of coping are unclear, but it may be that parenting a child with autism is easier if you have autistic traits (i.e. you understand your child's difficulties better), or more difficult (i.e. you struggle to make the necessary changes and compromises needed to accommodate your child's difficulties). This has yet to be explored, but may well have implications for services which hope to support parents.

There has been little investigation in the literature of the 'buffering' effects of factors such as confidence in child-rearing and positive perceptions. One study, (Sharpley et al, 1997) found that, although mothers reported higher stress levels than fathers, they also showed higher levels of confidence in handling their child's major problems than did fathers (which was assumed to be due to greater day-to-day exposure to these problems and therefore greater proficiency in handling them – a positive side-effect of being the main carer). Hastings et al (2005b) also noted that

whilst mothers reported higher levels of depression than fathers, they also reported higher levels of positive perceptions than fathers. Other than these two studies, comparing mothers' and fathers' positive experiences of parenting a child with autism have not been explored. It seems, therefore, that much of the literature has historically focused on psychopathology and negative aspects of parenting, especially for mothers. For services, it would also be useful to understand what positive aspects help some parents to cope well, whether they differ between mothers and fathers, and how best they can be nurtured and supported by services.

The question of how best to intervene to support mothers and fathers has only been investigated by two intervention studies. The first study, by Sofronoff and Farbotko (2002) looked at the effectiveness of parent management training to increase self-efficacy in parents of children with Asperger's syndrome. The results showed that following the intervention, mothers showed a significant increase in self-efficacy, which was also maintained at a 3 - month follow-up, whilst fathers showed no change in self-efficacy at any assessment point. The authors concluded that future interventions need to be tailored more to fathers in order to help fathers' self-efficacy, but how this could be achieved was not mentioned. The second intervention study was conducted by Baker-Ericzen, Brookman-Frazee & Stahmer (2005). It examined the effect of a toddler inclusion programme on the stress levels and adaptability of parents of children with and without autism spectrum disorders. The results showed that the only significant changes in stress from assessment at programme entry to exit were seen in mothers of children with ASDs, who showed significant reductions in child-related stress, but not parent-related stress. The authors hypothesize that these results may be due to the less significant role that fathers play with their children, and that future parent education programmes need to address parent related stress for both mothers and fathers. Again, no advice on how to do this was presented. Whilst these intervention studies show that there may be a difference in how mothers and fathers benefit from training, there has also been no attempt thus far to provide evidence for why this may be the case, and how services

need to be different for each parent. In addition, the participants used in these studies may not be representative of parents in the general population, who may find themselves too stressed to be able to volunteer to attend training sessions.

A final point of note is whether or not mother/father differences in well-being is specific to parents of children with autism, or indeed whether there are general mental health differences by gender. Several of the studies used in this review had control groups consisting of either parents of typically developing children or children with other disorders, such as Down's syndrome. Wolf et al (1989), found some elevated levels of depression and stress for mothers of children with Down syndrome compared to fathers, but not as high as for mothers of children with ASD. Herring et al (2006) found that mothers of children with pervasive developmental disorders reported significantly more stress than fathers, as did mothers of children with other developmental delays. Allik et al (2006) found no significant difference in levels of mental or physical quality of life between mothers and fathers of typically developing children. In all studies, mothers of children with ASDs reported lower levels of well-being on different variables than mothers of other children. This evidence is interesting for services and suggests that parents of children with ASDs, especially mothers, may need more or different support from mothers of children with other disorders, and that specific services for autism may be needed.

Looking at the literature as a whole, then, there is some evidence that mothers of children with ASDs have lower reported levels of well-being (especially depression) than fathers, that mothers are more affected by their child's behaviour problems than fathers, and to a much smaller extent, the child's level of autism, that mothers are likely to spend more time with their children than fathers, and that partner mental health, and different ways of coping, may be important factors in mothers' well-being. The evidence on social support is patchy, and the contribution of many other variables such as the marital relationship, positive perceptions, the caregiver role and societal

expectations have not yet been explored. The challenge for services is to know how best to support mothers and fathers of children with ASDs, and at the moment, the literature mainly focuses on the psychopathology of parents, especially mothers, rather than on ways in which these difficulties can be alleviated. Some guidelines may be extrapolated, such as in order to support mothers, support services could concentrate on helping mothers use effective coping strategies, and also help to support fathers' mental health as a way to further support mothers. This may mean that services have to support mothers and fathers differently in their different roles, and this needs to be born in mind by professionals. Overall, there is still much to be found out about the reasons why mothers of children with ASD have lower levels of well-being than fathers and what else services can do to support mothers and fathers differently and effectively.

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Table 1

Author / Date	Parents / Recruitment	Children / Recruitment / Diagnosis	Topic	Measures	Outcome
Allik et al, 2006	31-mothers ASD, 30-fathers ASD; 30-mothers control 29-fathers control; control recruited via school nurses	School age-Asperger/high funct-already had diagnosis; PDD centres; ICD-10 criteria reassessment	Health-related QOL	Health Survey, High Functioning Autism Screening Questionnaire, SDQ	Mothers had lower physical QOL-related to hyperactivity / conduct probs
Dumas et al, 1991	30-ASD; 30-behavioural disorder; 30-Downs; 60-control; matched for gender & age; at least one biological parent for each child; control recruited from health clinics.	Autism; from a children's research institute. Initial MDT diagnosis then reassessment by psychiatrist using DSM III criteria.	Parent stress, child behaviour, dysphoria	Questionnaire: Parenting Stress Index, Eyberg Child Behaviour Inventory, BDI	Mothers of children with behaviour disorders & autism had more dysphoria. Mothers of young autistic children had more dysphoria
Gray/Holden 1992	172-ASD;	Autism; recruited from autism associations - no data on autistic symptoms	Psyco-social well-being	Postal Questionnaire Survey: Coping Health Inventory, Zung's Depression Scale, State-Trait Anxiety Inventory	Fathers had lower reported depression, anxiety/anger, & lower depression for parents receiving more social support
Hastings, 2003	18-ASD; biological parents	School age, autism; attended autism school - no information on original diagnoses	Child behaviour probs, partner mental health and stress	HADS, QRS-F DBC,	No differences in mother/father stress/depression but mothers had higher anxiety. Child behaviour & fathers mental health associated with mothers stress
Hastings / Brown, 2002	26 mothers; 20 fathers: from school for children with autism	Autism, attended autism school -no criteria	Behaviour problems, self-efficacy & mental health	DBC-teacher, Self-efficacy scales, HADS	Self-efficacy mediated mothers mental health & moderated father anxiety
Hastings et al, 2005(b)	41-ASD (pairs);	Pre-school, autism; childhood autism programme; already had clinical diagnosis of autism; also ADI-R by trained team member	Systems Analysis (including partner mental health) of Stress & positive perceptions	VABS, DBC, Autism Screening Questionnaire, HADS, QRS, Kansas Inventory of Parental Perception of Positive Contributions	Mothers had more depression & positive perceptions. Paternal stress/positive perceptions predicted by maternal depression. Maternal stress predicted by child behaviour & paternal depression
Herring et al, 2006	79-mother 72-fathers-PDD, 38 mothers 34 fathers-developmental difficulties	Toddlers, autism/PDD-NOS; DSM IV criteria-ADI-R & ADOS; recruited from specialist childrens service	Behaviour/emotional problems, mental health & family functioning	Psycho-educational Profile, VABS, Adaptive Behaviour Composite, Reynall Developmental Language Scale, WPPSI, DBC, GHQ, Family Assessment Device, Likert Scales	Behaviour/ emotional problems affected mothers mental health/stress & fathers mental health. Fathers had less stress. Partner mental health not associated with mother /father stress
Moes, Koegel et al, 1992	18-mothers; 12-fathers; from research project,	Autism, all age - no information on criteria for inclusion.	Stress profiles	QRS-short, Coping Health Inventory, BDI	Higher depression & stress for mothers
Sharpley et al, 1997	141-mothers, 78-fathers; parents & step-parents - newsletter for autism association	Range of children with autism - no information on original diagnoses	Stress, anxiety, health, assistance, depression	Postal Questionnaires: Zung anxiety & depression scales, Stress Questionnaire	Mothers had higher stress than fathers, but also higher confidence in handling child. Age of child no effect. Mothers also had higher anxiety & depression than fathers.
Wolf/Noh et al, 1989	31-ASD; 31-Downs; 31-control; At least 1 biological parent per child, matched for mental & chronological age & sex of child. Controls from GPs / clinics	Autism, all age; services from a development centre; Previous diagnosis by MDT & reassessment by psychiatrist using DSM III criteria.	Effects of stress (depression, social support)	Questionnaires: Parenting Stress Index, BDI, Kaplan Scale	Mothers of autistic children more depressed than others, not the case with fathers. Mothers & fathers reported same levels of stress. Higher parenting stress predicted maternal depression & paternal depression.

Table 2

Author / Date	Parents / Recruitment	Children / Recruitment / Diagnosis	Topic	Measures	Outcome	Potential Explanation for Mother/Father Differences
Allik et al, 2006 *	31-mothers ASD 30-fathers ASD; 30-mothers control 29-fathers control; control recruited via school nurses	School age-Asperger/ high funct-already had diagnosis; PDD centre; ICD-10 criteria reassessment	Health-related QOL	Health Survey, High Functioning Autism Screening Questionnaire, SDQ	Mothers had lower physical QOL-related to hyperactivity / conduct probs	Effect of child behaviour probs on mothers physical QOL
Dumas et al, 1991 *	30-ASD; 30-behavioural disorder; 30-Downs; 60-control; matched for gender & age; at least one biological parent for each child; control recruited from health clinics.	Autism; from a children's research institute. Initial MDT diagnosis then reassessment by psychiatrist using DSM III criteria.	Parent stress, child behaviour, dysphoria	Questionnaire: Parenting Stress Index, Eyberg Child Behaviour Inventory, BDI	Mothers of children with behaviour disorders & autism had more dysphoria, related to parent stress. Mothers of young autistic children had more dysphoria	Higher reported stress associated with higher child behaviour problems and higher depression for mothers. Higher stress associated with higher behaviour problems for fathers.
Gray, 1993	32-ASD;	School age, autism; diagnosed by staff at autism treatment centre	Perceptions of stigma	Qualitative: semi-structured interview	Mothers reported more stigma than fathers. Mothers felt greater responsibility	No
Gray, 2002	32-mothers, 21 fathers	High functioning autism; treated by state autistic association	Felt & enacted stigma	Qualitative: semi-structured interviews	Most parents experienced both types of stigma, but mothers more so, especially enacted stigma including avoidance, hostility & comments. Mothers felt more responsibility. Coped by ignoring & avoiding social contact & humour	No
Gray, 2003	32-mother; 21-fathers;	Asperger's/ high functioning autism; from autistic treatment centre; diagnosed by staff	Gender & coping	Qualitative: semi-struct interview	Fathers said child's autism did not affect them personally, but through wife's stress. Problems with marriage. Work important for role. Support for wife-worries re future. Mothers-career affected, referral problems.	No
Gray/Holden 1992 *	172-ASD;	Autism; recruited from autism associations - no data on autistic symptoms	Psyco-social well-being	Postal Questionnaire Survey: Coping Health Inventory, Zung's Depression Scale, State-Trait Anxiety Inventory	Fathers had lower reported depression, anxiety/anger, & lower depression for parents receiving more social support	Social support had negative effects on anxiety, depression, and also on anger for fathers.
Hastings, 2003 *	34-ASD; pairs of biological parents	School age, autism; attended autism school - no information on original diagnoses	Child behaviour probs, partner mental health and stress	HADS, QRS-F DBC,	No differences in mother/father stress/depression but mothers had higher anxiety. Child behaviour & fathers mental health associated with mothers stress	Affect of child behaviour problems on mother / father stress & mental health
Hastings et al, 2005(a)	26-mothers/20 fathers-school age ASD, biological; 48 mothers/41 fathers-pre-school children ASD.	School age & pre-school autism from childhood autism programme; clinical diagnosis of autism	Coping strategies	COPE, HADS, QRS,	Problem-focused coping not associated with higher stress/mental health. Avoidance associated with higher stress/mental health for mothers & fathers.	Correlations between maternal coping & well-being

Review: Mothers and Fathers of Children with Autism

					No effect of age.	
Hastings et al, 2005(b) *	41-ASD (pairs);	Pre-school, autism; childhood autism programme; already had clinical diagnosis of autism; also ADI-R by trained team member	Systems Analysis (Including partner mental health) of Stress & positive perceptions	VABS, DBC, Autism Screening Questionnaire, HADS, QRS, Kansas Inventory of Parental Perception of Positive Contributions	Mothers had more depression & positive perceptions. Paternal stress/positive perceptions predicted by maternal depression. Maternal stress predicted by child behaviour & paternal depression	Relationship between maternal & paternal stress, depression & positive perceptions
Herring et al, 2006 *	79-mother 72-fathers-PDD, 38 mothers 34 fathers-developmental difficulties	Toddlers, autism/PDD-NOS; DSM IV criteria-ADI-R & ADOS; recruited from specialist childrens service	Behaviour/emotional problems, mental health & family functioning	Psycho-educational Profile, VABS, Adaptive Behaviour Composite, Reynall Developmental Language Scale, WPPSI, DBC, GHQ, Family Assessment Device, Likert scales	Behaviour/ emotional problems affected mothers mental health/stress & fathers mental health. Fathers had less stress. Partner mental health not associated with mother / father stress	Affect of behaviour probs & partner mental health on stress/ mental health
Konstantaras & Homatidis, 1989	44 - ASD; matched with controls from previous study on age, sex & ordinal position of index child, family size, maternal employment status and socio-economic-status	Pre-school & school-age, autism; local clinic. DSM III criteria - child psychologist & psychiatrist	Child symptom severity, stress, support	CARS - administered by a professional & parents, Three - point scale of support and aggravations	Self-abuse best predictor for both parents, also older age/ hyperirritability for mothers	Correlation - stress & support
Konstantaras & Homatidis, 1992	16 - ASD; 16 - LD; 16 - control: Matched on child gender, age, birth order, mental age or chronological age	All age autistic: DSM III criteria enlisted through a clinic & control through advertisements	Involvement	Log book self-recording	Mothers had more involvement. Fathers of autistic children less involved than mentally delayed children.	No
Milgram & Atzil, 1988	46 - ASD	Autism:7-14; attending a day school for autistic children. DSM III criteria - no information on who administered this	Parenting stress	Adaptive Behaviour Schedule, Parent tasks, Fairness Questions, Life Satisfaction Questions	Where fathers stress is associated with the absolute burden of care; mothers stress is associated with the relative burden of care. Parents did not agree on what is good division of parenting.	Association between carer burden and stress
Wolf, Noh et al, 1989 *	31-ASD; 31-Downs; 31-control; At least 1 biological parent per child, matched for mental & chronological age & sex of child. Controls from GPs / clinics	Autism, all age; services from a development centre; Previous diagnosis by MDT & reassessment by psychiatrist using DSM III criteria.	Effects of stress (depression, social support)	Questionnaires: Parenting Stress Index, BDI, Kaplan Scale	Mothers of autistic children more depressed than others, not the case with fathers. Mothers & fathers reported same levels of stress. Higher parenting stress predicted maternal depression & paternal depression.	Social support as buffer of impact of stress on dysphoria for mothers, but no interaction effect. Paternal stress affected paternal dysphoria, & effect of social support was independent, but stress moderated with increased support.



## Section Four: Empirical Research Paper

**Comparison of Well-Being in Mothers and Fathers of Children with Autism:  
Predictors of Adjustment and Systems Analysis of Stress.**

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**KEY WORDS: AUTISM, ASPERGERS, MOTHERS, FATHERS,  
PARENTS, STRESS.**

Running head: Well-Being in Parents of Children with Autism

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**Journal of Applied Research in Intellectual Disabilities: Notes to Authors**

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**Abstract**

**Background**

Mothers of children with autism typically report lower levels of well-being than fathers. The present study compared the well-being of parents of children with autism, and investigated which variables were related to well-being, as well as which variables predicted well-being.

**Method**

100 mothers and 81 fathers of children with autism spectrum disorders reported on child characteristics, and their own mental health, stress, positive perceptions and marital satisfaction.

**Results**

Mothers were found to report higher levels of anxiety, depression and stress than fathers, whilst fathers reported higher levels of positive perceptions about their child than mothers. Regression analysis showed that maternal stress was predicted by child behaviour problems and employment status. Father stress was predicted by mothers' depression.

**Conclusion**

Future research needs to explore what other variables may be more predictive of both maternal and paternal well-being, and also by what mechanisms mothers and fathers become stressed. Future interventions will be more effective if targeted in a way that will make the greatest difference for mothers and fathers' well-being.

**Comparison of Well-Being in Mothers and Fathers of Children with Autism:  
Predictors of Adjustment and Systems Analysis of Stress.**

**INTRODUCTION**

Elevated rates of psychological distress indicative of serious mental illness have been found among mothers but not fathers of children at risk of disability (Emerson & Llewellyn, 2008). Present research has demonstrated that parents of children with autism report more stress than parents of both typically developing children and parents of children with other disabilities (Bouma & Schweitzer, 1990; Sanders & Morgan, 1997). The experience of raising a child with autism seems to affect mothers and fathers differently. In order to inform support services that assist parents successfully, it is important to investigate the differences in gender parenting experiences to make sure that resources are placed to be as effective as possible. It is therefore important to explore the outcomes for mothers and fathers separately. The research on mother-father differences has shown that mothers of children with autism report more negative effects than fathers, including higher levels of anxiety (Hastings, 2003), depression (Hastings, Kovshoff, Ward, Espinosa, Brown & Remington, 2005) and stress (Herring, Gray, Taffe, Tonge, Sweeney & Einfeld, 2006). The research on depression is currently the most robust, with other research, especially the stress literature, having methodological difficulties, such as lack of standardized measures used consistently. Possible factors in mother-father differences include differences in levels of parental responsibility, differences in coping and differences in levels of stigma experienced. However, there has been very little quantitative research into these factors and therefore there is no robust evidence base on their contribution to mother-father differences.

However, some variables that predict mother and father well-being have been investigated. Child behaviour problems, for example, have been shown to predict maternal stress, but not paternal stress (Allik, Larsson, & Smedje, 2006; Hastings et al, 2005). Adaptive behaviour, as defined by a child's level of skill in everyday living abilities (such as washing, dressing etc.) has been shown to be less predictive of maternal stress than behaviour problems (Hastings, 2002). The level of a child's autistic symptoms as a predictor of mother and father stress has been investigated by one study (Hastings et al, 2005) which showed that autistic symptomatology was not predictive of maternal or paternal stress.

There have been several studies into systemic issues as a contributor to parental well-being. Hastings (2003) found significant correlations between paternal mental health and maternal stress, but not maternal mental health and paternal stress. Hastings et al (2005) found that paternal stress was predicted by maternal depression and that maternal stress was predicted both by child behaviour problems and paternal depression. Herring et al (2006), however, reported that partner mental health problems were not a significant contributor to either mother or father stress.

The present study aims to investigate which variables predict mother and father adjustment (as measured by levels of mental health and stress) and to replicate mother-father comparisons of adjustment. Predictors of mother and father well-being are investigated separately rather than statistically compared. In addition, the study aims to explore systemic contributions to mother and father well-being by replicating the systemic regression analyses from Hastings et al (2005), which investigated the contribution of father mental health to maternal well-being and visa versa. The present study has improved on previous research by extending mother-father research to a larger sample, including children with autism spectrum disorders across the spectrum and extending the systemic variable exploration to school age

children. The study includes measures of the main areas of functioning of child with autism; behaviour problems, social behaviour, adaptive functioning and level of autism. In addition, the study includes a broader range of adjustment variables than previous research. These include the influence of dyadic adjustment (i.e. marital satisfaction) and positive perceptions of parents. There has only been one previous study that has investigated positive perceptions of mothers and fathers (Hastings et al, 2005) and there has been no previous research comparing the contribution of marital satisfaction to mother and father adjustment.

The study expected to replicate previous research showing that mothers of children with autism report higher levels of anxiety, depression and stress than fathers. Results were also tentatively expected to show that mothers would report higher levels of positive perceptions than fathers. There were no predictions about comparisons between mothers and fathers of satisfaction with the marital relationship, due to lack of previous research. It was expected that child behaviour problems would contribute to maternal well-being, and possibly not to paternal well-being, and, from previous research, that adaptive behaviour and child autistic symptomatology would be less likely to contribute to parental well-being than behaviour problems. It was also expected that maternal stress would be affected both by child variables and partner mental health, and that paternal stress would be affected by maternal mental health, as has been shown in the previous research.

## **METHOD**

### **Participants**

The data sample used for this study consisted of data from 100 families (100 mothers and 81 fathers) of children with autism spectrum disorders aged 4 – 17 years old. Of the 100

families that provided data, 55% of them had a total family income of less than £35,000, 42% had a total family income of over £35,000 and 3 families did not provide this information. The mean number of children in each household ranged from 1 – 5 ( $m=2.32$ ,  $SD=.72$ ). The number of adults (including children aged 18 or over) ranged from 1- 4 ( $m=1.92$ ,  $SD=.44$ ).

From the 100 families who volunteered for this study, data was collected from each family for one child with an autism spectrum disorder. Therefore data was collected for 100 children with an autism spectrum disorder, 84% of whom were male, and 16% female. The mean age of the children with autism was 9.68 years ( $SD=2.83$ ). According to parent report, 55% of the children had a diagnosis of autism, with 44% having a diagnosis of Asperger's Syndrome. There was no diagnostic information for one child. The mean time in years since the diagnosis was given was 3.24 ( $SD=2.27$ ). 28% of diagnoses were made by Clinical Psychologists, 39% by Paediatricians, 19% by a Multi-Disciplinary Team, and 7% by a Psychiatrist. There were missing data on who made the diagnosis for 7% of the autistic child sample. 17% of the children attended a mainstream school, a further 58% attended a mainstream school and had additional support, 15% attended a special school, 6% attended a specialist autism unit attached to a mainstream school, and 4% had 'other' educational arrangements. 99% of the children lived at home with their parents. 57% of children with autism had a total Vineland Adaptive Behaviour composite score below 70, which is indicative of significant developmental delay.

The mean age for mothers in the sample was 41.06 ( $SD=4.89$ ). 99% of mothers in this sample were biological mothers, and the remaining mother was an adoptive parent. 97% of mothers described themselves as White British, 2% as Other White, and 1 mother as British Asian. 86% of mothers were married or living with a partner, while the remaining 14% were

either divorced, formally separated, widowed or living separately from a partner. 38% of mothers had an education below university first degree level, with the remaining 62% having either an undergraduate or higher level university qualification. 61% of mothers had a job outside the home, and for 16% of the sample, this was a full-time job.

Of the 81 fathers in the sample, 93.8% were biological fathers, 3.7% were step-fathers, and the remaining 2.5% did not provide this information. The mean age for fathers in the sample was 42.81 years (SD=5.79). 92.6% of fathers described themselves as White British, 3.7% as Other White, 1.2 % as having a Black Background other than African or Caribbean, and 1.2% as British Asian. The remaining 1.3% did not provide this information. All fathers were living with a partner or married. 45.7% of fathers had an education below university level, with 54.3% having either an undergraduate or higher level university qualification. The remaining 2.5% did not provide information about their level of education. 92.6% of fathers had a job outside the home, and for 87.7% of the sample, this was a full-time job. 4.9% of fathers had a part time job, whilst the remaining 7.4% of fathers did not provide this information.

## **Measures**

Eight measures were used in the study, five of which were parent measures (including a demographic questionnaire), and three of which were child measures. All measures were sent to parents in the form of a postal questionnaire, except the Vineland Adaptive Behaviour Scale (VABS), which was completed during a telephone interview with the Main Carer from each family. The first parental measure, an in-depth demographic questionnaire, was completed by the Main Carer of each family, whilst the Secondary Carer completed a much

brief demographic section. All parent measures were completed by both carers in the family. Of the three child measures, the Main Carer completed the Vineland Adaptive Behaviour Scale (VABS) and the Social Communication Questionnaire (SCQ). The final child measure, the Strengths and Difficulties Questionnaire (SDQ) was completed by both parents.

### **Child Measures**

Child behavioural and emotional difficulties were measured using the Strengths & Difficulties Questionnaire (SDQ; Goodman, 1997). This questionnaire measures four problem domains (emotional problems, conduct problems, hyperactivity, and peer problems) as well as prosocial behaviour. Cut-off scores that suggest clinical levels of symptoms across the five domains are available, and a total difficulties score can be derived by summing the scores of the four problem domains. The SDQ contains 25 items (e.g. 'Is your child considerate of other people's feelings?'), which are answered 'not true, somewhat true or certainly true' by a parent. Items are scored 0, 1, or 2, and positively-worded items are reversed before scoring, except for those within the prosocial subscale. A total difficulties score is derived by adding the value of items in all subscales except for the prosocial subscale. The prosocial subscale total is derived by adding the value of the five items contained within it. The SDQ has excellent reliability and validity (Goodman, 1997). Internal consistency of the SDQ total difficulties domain was found in this study to be high, with a Cronbach's alpha co-efficient of .74 for mothers and .78 for fathers. The Cronbach's alpha of the prosocial subscale was .73 for mothers and .81 for fathers. The SDQ total difficulties score was used as a measure of the severity of behaviour problems displayed by the children, and the prosocial scale score as a measure of positive social behaviours.

## Empirical Study of Mother/Father Adjustment and Stress

The Vineland Adaptive Behaviour Scale-Survey Form (VABS, Sparrow, Balla, & Cicchetti, 1984) was used as a measure of adaptive behaviour. This semi-structured interview measure is composed of 297 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. The VABS is a standardized measure with well-reported internal consistency. The VABS composite score was used as an overall index of the child's adaptive skills.

The Social Communication Questionnaire (SCQ, Berument, Rutter, Lord, Pickles, & Bailey, 1999) is an autism screening instrument, which was previously known as the Autism Screening Questionnaire (ASQ). 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 based on the original Autism Diagnostic Interview - Revised (ADI-R) algorithm used for ICD-10 and DSM-IV diagnosis of autism. The SCQ contains 40 items (e.g. 'Does she/he have any particular friends or a best friend?'), which are answered 'yes or no' by a parent. The total score is calculated by adding the number of 'yes' responses. It has good discriminative validity with respect to the separation of Pervasive Developmental Disorders (PDDs) from non-PDD diagnoses at all IQ levels. The SCQ has well-reported internal consistency. For this study, the SCQ total score was used as an overall measure of the child's level of autistic symptomatology.

### **Parent/Carer Measures**

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. It has also been used specifically to measure anxiety and depression in parents of children with autism (Hastings, 2003). The HADS contains 14, four-point items, with seven assessing depression and seven assessing anxiety. Both the HADS anxiety and depression subscales contain seven items (e.g. anxiety: 'worrying thoughts go through my head'; depression: 'I feel as if I am slowed down'). Items have a response scored from 0-4, with different wording for each question. Positively-worded items are reverse scored. The total anxiety and depression scores are calculated by adding the value of the items within each subscale. The anxiety and depression sub-scales have been shown to have high internal consistency (Cronbach's alpha co-efficients of .80 and .76 respectively; Mykletun et al, 2001). For this study, the anxiety subscale of the HADS was found to have a Cronbach's alpha of .84 for mothers and .83 for fathers. The depression subscale of the HADS had a Cronbach's alpha of .81 for mothers and .77 for fathers. The HADS anxiety and depression subscale scores were used as a measure of levels of anxiety and depression in parents.

The Dyadic Adjustment Scale (DAS, Spanier, 1976) is a 32-item measure in a variety of response formats developed to measure dyadic adjustment. The abbreviated version of the scale (DAS-7) has seven items (e.g. 'my partner and I agree on philosophy of life'). The responses are scored from 0-5, with different wording for different items. The total score is calculated by adding the value of the items. Positive items are not reversed; therefore a high score reflects a strong satisfaction with the marital relationship. The DAS-7 has been shown to have good internal consistency (Cronbach's alpha of .79; Hunsley et al, 2001). The Cronbach's alpha co-efficient of the DAS-7 for this study was found to be .88 for mothers and .85 for fathers. The DAS-7 total score was used as a measure of parental satisfaction with the marital relationship.

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. For this study, one of the subscales of the short form of the QRS was used (QRS-F) (Friedrich, Greenberg & Crnic, 1983) - the Parent and Family Problems subscale. This scale consists of 20 items measuring stress experienced by the parent and family as a whole (e.g., 'I have given up things I have really wanted to do in order to care for...'). The items are scored true or false by parents. A total stress score is calculated by summing the score across all items. Positively worded items are reverse scored. Five items have been shown to constitute a depression measure in parents of children with disabilities (Glidden & Floyd 1997). These items were therefore removed in scoring, so that stress and depression measures were independent of each other. For this study, the internal consistency (Kuder-Richardson coefficient) of the QRS-F Parent and Family Problems subscale was high at .86 for mothers and .82 for fathers. The total score of the Parent and Family Problems subscale was used to measure parental stress.

The Positive Gains Scale (PGS) 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 (Pit-ten Cate, 2003). 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 (e.g. 'Since having this child I feel I have grown as a person') and two items relate to how the family has gained from the experience of having a child with a disability within the family system (e.g. 'since having this child, my family has become closer to one another'). Items are scored from 0 ('strongly agree') to 5 ('strongly disagree'). The total score is calculated by adding the value of the all items. Preliminary research findings indicate that the PGS has face and content validity and a Cronbach's alpha coefficient of .79 (Pit-ten Cate, 2003). For this study the internal consistency of the PGS was found to be high, with a Cronbach's alpha coefficient of .85 for mothers and .85 for fathers. The total score of the PGS was used as a measure of parents' positive perceptions of raising their child.

## Procedure

Participants were recruited through the National Autistic Society (NAS), a charitable organization that provides services for families of children with autism spectrum disorders. Parents were invited to participate if they had registered with the NHS Help database, having attended a 'Help' programme (Help is an NAS family support programme). 'Parents' recruited for the study could be biological, step-parents, foster-parents or other carers of children with autism. Parents were told that they were eligible for the study if their child had received a diagnosis of an autism spectrum disorder from an appropriate clinician. Information about the study, invitations to participate and contact detail forms were prepared by the research team and given to the NAS to distribute amongst families using the Help programme. Families were posted initial invitations to take part in research, and those that agreed to take part were sent out questionnaire packs consisting of the above measures. Mothers and fathers returned completed questionnaires in separate sealed envelopes. The VABS was also conducted over the phone with the main carer from each family. There is currently no overall information on response rates as the larger study is still ongoing, and the data for this study was taken from the first 100 families who had returned completed data and conducted the VABS by the time of writing. Only two primary carers from these 100 families were fathers, therefore analysis focused on mother-father comparisons rather than primary-secondary caregiver comparisons.

## RESULTS

Less than 2% of parental data was missing. Missing cells in the dataset were replaced casewise with weighted means for the remainder of the items completed for a sub-scale or overall scale score. The main child and parent variables were tested for normality of distribution using the Kolmogorov-Smirnov one-sample test. These were all non-significant, illustrating the data to be reasonably normally distributed. Therefore parametric statistical tests were used for analyses.

Initially, mothers and fathers scores on parental well-being measures were compared with previous norms where these were available. The data analysis that followed proceeded through several stages. The first stage investigated associations between demographic and parental well-being measures, in order to see what the relationships were between these variables. Any demographic variables which were found to have a relationship with well-being outcome variables were then entered into regression models in the final stage of data analysis as control variables. The relationship between child variables and parental outcome variables were then investigated. Any child variables that were associated with parental well-being outcome variables were also entered into regression models in the final stage of analysis as predictor variables. In addition, mother and father outcome variables were directly compared using paired *t*-tests. The final stage of data analysis was comprised of linear regressions, in order to investigate the contribution of child variables to parental well-being outcomes whilst controlling for demographic variables.

Parental Measure Norms and Cut-Off Comparisons

In the current study, 54% of mothers scored on or above the cut-off of 11 on the anxiety subscale of the HADS, which is indicative of clinical levels of anxiety, compared with 21% of fathers. 27% of mothers scored on or above the cut-off of 11 on the depression subscale, which is indicative of clinical levels of depression, compared with 7.4% of fathers. When compared with the results of a general population study, (Crawford, Henry, Crombie & Taylor, 2001), the figures for both mothers and fathers are much higher than a normative sample from the UK, which showed figures of 12.6% of the overall sample scoring above the cut-off for anxiety and 3.6% for depression. For mothers, this study showed that 16% of the normative sample scored above the cut-off for anxiety and 3% for depression. Table 1 shows the difference between norms drawn from a normal population sample and the sample of mothers and fathers from this study. The Table illustrates that both mothers and fathers for this study scored higher than those in the normal population, indicating higher levels of both anxiety and stress than in a normal population.

No other parental measures had cut-off scores or separate published means for males and females. However, Table 1 illustrates that both mothers and fathers in this study scored higher than the norm score for the QRS-F (Friedrich, Greenberg & Crnic, 1983), indicating a higher level of parental stress than those parents for whom norms were taken (parents of children with disabilities). In addition, both mothers and fathers scored lower than the norm score on the DAS (Hunsley, Best, Lefebvre & Vito, 2001), showing that the mothers and fathers were slightly less satisfied with their marital relationship than the average-scoring couples in the normal population. Finally, whilst mothers scored lower than the norm score on the PGS (Pit-ten Cate, 2003), fathers scored slightly higher, showing that the mothers in this study had fewer positive perceptions of raising their child than the average-scoring

mothers in the normal population, whilst fathers in this study had higher levels of positive perceptions of raising their child than average-scoring fathers in the normal population.

----- Insert Table 1 Here -----

### *Demographic Variable Associations*

Associations between demographic variables and parent outcome measures were explored.

These associations were explored with independent *t*-tests for dichotomous demographic variables and correlations for continuous demographic variables.

For mothers, the Positive Gains Scale Total (PGS) Score was significantly correlated with both the mothers' age ( $r=.24$   $p=.02$ ) and how long ago the autism diagnosis was given ( $r=.22$ ;  $p=.03$ ). Mothers reported more positive perceptions if mothers were older, and more positive perceptions if more time had elapsed since the diagnosis. No other significant correlations for mothers' demographic variables were found. The *t*-tests showed that mothers' HADS anxiety and depression scores differed according to their marital status (anxiety:  $t(26)=2.75$ ,  $p=.01$ ; depression:  $t(98)=2.30$ ,  $p=.02$ ), whether or not mothers had a university education (anxiety:  $t(98)=3.00$ ,  $p<.001$ ; depression:  $t(98)=2.94$ ,  $p<.001$ ), whether or not they had a job (anxiety:  $t(98)=2.12$ ,  $p=.04$ ; depression:  $t(98)=2.38$ ,  $p=.02$ ), and the total family income (anxiety:  $t(95)=3.32$ ,  $p<.001$ ; depression:  $t(95)=3.51$ ,  $p<.001$ ). Mothers had higher reported levels of anxiety and depression if they were divorced rather than married, if they did not have a university education, if they did not have a job in addition to being the main carer, and if they had a total family income of less than £35, 000. Mothers' QRS-F Total scores also differed depending on whether they had a university education or not ( $t(98)=2.04$ ,  $p=.04$ ), and whether they had a job or not ( $t(98)=3.39$ ,  $p=.00$ ). Mothers had higher reported levels of stress if they did not have a university education and if they did not have a job outside the home.

## Empirical Study of Mother/Father Adjustment and Stress

For fathers, the only significant correlation found was between the HADS anxiety score and the age of the child with autism ( $r=.27$ ,  $p=.016$ ). Fathers reported more anxiety, the older their child with autism was. There were no other significant correlations or differences in scores due to the other demographic variables. The above mothers' and fathers' demographic variables were therefore included in the main regression analyses as control variables.

### *Child Variable Associations*

Associations between child variables and parent outcome measures were also explored using correlations. The results are shown for both mothers and fathers in Table 2. For mothers, there was a negative relationship between anxiety and depression and high (good) prosocial behaviour in their child (SDQ Prosocial Score). Therefore mothers reported lower anxiety and depression when their child had more appropriate social behaviour. There was also a positive relationship between mothers' anxiety and depression and the total amount of difficulties that their child displayed (SDQ Total Difficulties Score). Therefore mothers reported higher levels of anxiety and depression, the more behaviour difficulties their child showed. Mothers' anxiety and depression was also positively correlated with the level of their child's autistic symptomatology (SCQ Score). Mothers reported higher levels of anxiety and depression the more autistic their child was. Finally, mothers' level of stress (QRS-F score) was positively associated with their child's total difficulties (SDQ Total), autistic symptomatology (SCQ score) and negatively associated with the level of their child's adaptive behaviour (VABS Total Score). Therefore mothers reported higher levels of stress when their child had higher levels of behaviour difficulties and autistic symptomatology, and when their child had lower levels of adaptive behaviour. For fathers, stress was positively correlated with the level of their child's total difficulties and autistic symptomatology. Therefore fathers reported higher levels of stress when their child had

higher levels of difficult behaviour and when their child was more autistic. There was also a negative relationship between fathers' positive perceptions and their child's autistic symptomatology. Therefore fathers reported fewer positive perceptions, the more autistic symptoms their child had.

Table 2 shows the results of child variables associations with both maternal and paternal well-being measures. It is noted that whilst the above described correlations were all significant, there were also paternal correlations which although non-significant were not greatly smaller in size than the corresponding maternal correlations. This suggests that the differences between maternal and paternal associations with child variables may not have been vastly different. However, no further statistical analysis was performed on these differences as this was not an aim of the study.

----- Insert Table 2 Here -----

#### *Mother/Father Comparisons on Well-Being Measures*

Differences between mothers' and fathers' scores on all well-being outcome variables were compared using paired *t*-tests. Mean scores for mothers and fathers on the HADS, QRS-F, DAS and PGS are shown in Table 3. Four significant differences were found, with mothers reporting significantly higher levels of anxiety, depression and stress than fathers, and also lower levels of positive perceptions than fathers.

DAS scores for mothers and fathers were highly correlated ( $r=0.76$ ,  $p<.001$ ), showing that there was a high level of agreement between mothers and fathers on how satisfied they were with the marital relationship (i.e. where mothers reported high satisfaction, fathers also reported high satisfaction).



----- Insert Table 3 here -----

### *Regression Analyses*

The final stage of data analysis used multiple linear regressions predicting parental well-being measures. Demographic and child variables which had been shown to be related to each outcome variable were entered into the regression analysis for that well-being score.

The first regression investigated the contribution of demographic and child variables to mothers' anxiety, as measured by the HADS anxiety scale. Overall, the variables shown in Table 4 contributed to 13 % of the variance of mothers' anxiety ( $R^2 = .18$ ,  $\text{adj } R^2 = .13$ ,  $F(6,90) = 3.31, p < .001$ ). However, none of the individual variables contributed independently to the prediction of mothers' anxiety.

The second regression investigated the contribution of demographic and child variables to mothers' depression, as measured by the HADS depression subscale. Overall, the variables shown contributed to 16% of the variance of mothers' depression ( $R^2 = .22$ ,  $\text{adj } R^2 = .16$ ,  $F(7,89) = 3.51, p < .001$ ). Again, none of the individual variables contributed independently to the prediction of mothers' depression.

The third regression investigated the contribution of demographic and child variables to mothers' stress, as measured by the QRS-F Parents and Family Problems subscale. Overall, the variables shown contributed 18% of the variance of mothers' stress ( $R^2 = .22$ ,  $\text{adj } R^2 = .18$ ,  $F(5,94) = 5.40, p < .001$ ). In addition, two variables made significant independent contributions to the prediction of mothers' stress. These were whether or not the mother had a job outside the home, and the child's total behaviour problems, as measured by the SDQ

total score. Mothers reported more stress if they did not have a job outside the home, and if their child had higher levels of behaviour problems.

Regression analyses were not carried out on any other mother well-being measures, as mothers' positive perceptions (PGS total) and marital satisfaction (DAS total) were not related to any child variables.

----- Insert Table 4 here -----

The only regression carried out for fathers investigated the contribution of child variables to fathers' stress, as measured by the QRS-F Parents and Family Problems Subscale. Overall, the variables shown in Table 5 contributed to only 8% of the variance of fathers' stress ( $R^2 = .10$ ,  $\text{adj } R^2 = .08$ ,  $F(2,78) = 4.24$ ,  $p = .02$ ). However, neither of the individual variables contributed independently to the prediction of fathers' stress.

No further regression analyses were carried out on the other father well-being measures, as father positive perceptions (PGS) was only correlated with one child variable, and the remaining variables of anxiety (HADS anxiety), depression (HADS depression), and marital satisfaction (DAS) were not correlated with any child variables.

----- Insert Table 5 here -----

#### *Exploratory Systemic Regression Analyses*

Finally, regression analyses were used to investigate whether systemic factors predicted mothers' and fathers' stress. The systemic regression analyses conducted in Hastings et al (2005) were replicated by repeating the mother and father stress regressions in Tables 4 and

5 but adding in partner mental health variables as additional predictors. The results showed that father mental health did not emerge as an independent predictor of maternal stress, but maternal depression was predictive of father stress ( $\beta=.30$ ,  $p=.03$ ). Fathers reported more stress when their partners reported more symptoms of depression.

## DISCUSSION

The present study replicated previous research which showed that mothers of children with autism report higher levels of anxiety, depression and stress than fathers. The findings of this study did not replicate previous findings on mothers' levels of perceptions of positive gains from raising their child (positive perceptions) as higher than fathers (Hastings et al, 2005). Instead, the results showed that mothers in this study reported lower levels of positive perceptions than fathers. Mothers and fathers reported similar levels of dyadic adjustment (marital satisfaction).

Different variables were found to be related to mother and father well-being. In line with previous research, using correlation analyses, child behaviour problems were shown to be related to mothers' well-being (anxiety, depression and stress) and less to fathers' well-being (stress only). Specifically, the level of the child's social abilities affected levels of mothers' anxiety and depression, but did not affect any paternal well-being measures. The child's level of autistic symptomatology was found to be related to more parental well-being than previous research has shown, in that autistic symptoms levels were related to mothers' depression and stress, and also to fathers' stress and level of positive perceptions. Adaptive behaviour was found, as in previous research, to be less important in parental well-being than

behaviour difficulties, in that adaptive behaviour was found to be related to mothers' stress, but not to any paternal well-being measures.

Regression analyses found few independent predictors, but these were that child behaviour problems were predictive of mothers' stress, which replicates the findings in Hastings et al (2005), and that employment status was predictive of mothers' stress, which is a new finding. In line with previous research, no variables were found to independently predict fathers' stress. The exploratory systemic regression found that, unlike in Hastings et al (2005), fathers' mental health did not predict mothers' stress along with child behaviour problems. However, fathers' stress was shown to be predicted not by child behaviour but by maternal mental health (depression), replicating previous findings.

The finding that mothers in this study reported significantly higher levels of anxiety, depression and stress than fathers, further strengthens previous evidence that this is a consistent actuality. However, the finding that mothers' positive perceptions of raising their child were lower than fathers, in contrast to Hastings et al (2005), is interesting. One possible hypothesis for this difference may be due to the differences in children ages (the Hastings study used pre-school children). It may be that mothers' positive perceptions of raising their child change over time. However, the present study did not show an effect of the child's age on mothers' positive perceptions of raising their child. The study also showed that dyadic adjustment did not differ significantly between mothers and fathers, and was also not related to any of the investigated variables. Further evidence is needed as to what other variables may predict dyadic adjustment, so that couples with children with autism can be better supported. Marital satisfaction may also need to be investigated as a contributory factor to parental well-being, as research from parents of children with disabilities has shown (Kersh, Hedvat, Hauser-Cram & Warfield; 2006).

The fact that mothers' mental health was found as a factor in fathers' stress has also emerged as a theme from qualitative research (Gray, 2003), and this in addition to the findings by Hastings et al (2005) adds to the evidence that this is an important factor in fathers' overall stress levels. However, father mental health was not found to be a factor in mothers' stress in addition to child behaviour problems (as in Herring et al, 2006). The contribution of paternal mental health in maternal stress therefore needs more investigation. The relationship of child autistic symptomatology to fathers' positive perceptions of raising their child would be interesting to combine with research on fathers' levels of autistic traits, to determine whether a father with more autistic traits would be more or less tolerant of a child with autism, and therefore more or less positive. The fact that autistic symptomatology did not contribute independently to mothers' stress, suggests that the level of the child's autism is just one among many variables which together contribute to mothers' stress, and is definitely less important than child behaviour problems in predicting stress levels. The same could be said of adaptive behaviour, which was related to mothers' stress but did not contribute independently to the prediction of mothers' stress scores, as in previous research (Hastings et al, 2005).

One final finding of note from this study was the relationship between mother well-being and being employed. Employment has also been shown to moderate the relationship between child maladaptive behaviour and maternal stress and depression in mothers of young adults with severe intellectual disability (Todd, Shearn & Jones, 2004). In the present study, having a job outside the home was related to lower levels of anxiety, depression and stress in mothers, and also contributed significantly to mother stress in the regression analysis. Most fathers in this study had a job, and therefore it would have been difficult to ascertain stress levels of the tiny percentage who did not. If, as the anecdotal evidence from the qualitative

research suggests (Gray, 2003), that for fathers, a job is a protective factor in stress, this study has shown that this may also apply to mothers. This is an interesting finding in that it is not entirely intuitive that having an extra responsibility outside the home would lower mothers' stress, but this is certainly a finding which may be worth investigating in future studies. More research needs to be carried out to investigate the importance of employment as a protective factor for mothers' stress and in order to inform future provision of support for mothers.

The methodological limitations of this study include those associated with much research in that participants were all volunteers, and therefore may not be representative of the population of families with children with autism as a whole. The high percentage of parents with university education illustrates this. In addition, being a postal survey meant that children with autism could not be assessed independently for the study. However, the questionnaire contained questions about time of diagnosis and professional who gave the diagnosis, in addition to the SCQ information about autistic symptomatology. It is argued that this has improved on the lack of any diagnostic information in previous postal survey studies. There is also a general difficulty of source variance for all the measures, in that, for example, mothers' reports about the child were used to predict mother well-being. It is likely that both mothers' and fathers' ratings would be affected by their well-being. An alternative effective method of avoiding the problem of source variance would have been to obtain multiple ratings of variables such as child behaviour, for example from teachers.

Clinical implications of the study include the importance of professionals understanding that mothers and fathers are affected differently by having a child with autism. The systemic findings are far from clear for the contribution to maternal well-being, but consistently mother mental health has been found to affect paternal well-being in several studies

(Hastings, 2003; Hastings et al, 2005). It therefore may be that professionals also need to take into account the mental health of both parents and how this may affect them both in order to develop the most effective interventions. It is clear that professionals would be wise to target interventions at helping mothers to cope with child behavioural problems, as this has been shown to be predictive of mothers' mental health in several studies as well as the current one (Allik et al, 2006; Dumas, Wolf, Fisman & Culligan, 1991; Hastings et al, 2005). In addition, the results from this study show that it may be useful for mothers to have additional employment outside the home. However, the regression analyses from this study also illustrate that a very low amount of both maternal and paternal adjustment were predicted by the study variables. Future research needs to explore what other variables may be more predictive of both maternal and paternal well-being, and also by what mechanisms mothers and fathers become stressed. Future interventions will be more effective if targeted in a way that will make the greatest difference for mothers and fathers' well-being.

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Table 1 – Means, Standard Deviations and Norms of Parental Measures

	Current Study				Norms			
	Mothers		Fathers		Males		Females	
Well-Being Measure	Mean	SD	Mean	SD	Mean	SD	Mean	SD
HADS anxiety	10.75	4.71	7.84	4.17	5.04	3.12	6.14	3.76
HADS depression	7.63	4.07	5.08	3.72	3.01	3.14	3.68	3.07
QRS-F Parent/Family Problems	7.67	4.02	6.27	4.03	4.9*	2.9*	4.9*	2.9*
DAS	21.29	6.23	21.49	5.69	25.8*	4.7*	25.8*	4.7*
PGS	13.95	5,12	16.16	4.64	15.3*	4.59*	15.3*	4.59*

\*These parental measures have no separate published norms for males and females

Table 2 – Correlations Between Child Measures and Parental Well-Being Measures

Child Variable	Mothers					Fathers				
	HADS anxiety	HADS dep	QRS-F	DAS	PGS	HADS anxiety	HADS dep	QRS-F	DAS	PGS
SDQ Prosocial	-.21*	-.22*	-.13	-.06	.05	-.09	-.12	-.15	.08	.20
SDQ Problems	.25*	.29*	.35**	-.02	.11	.10	.07	.26*	.09	.03
SCQ Total	.10	.28*	.29*	.05	-.09	.01	.05	.25*	-.01	-.29*
VABS Composite	.05	-.13	-.23*	.07	.01	-.04	.03	-.11	.07	.07

\* Results significant at  $p < .05$ .

\*\* Results significant at  $p < 0.001$

Table 3- T-Test Comparisons of Mother and Father Well-Being Measures

Measure	Mothers		Fathers		t-value	p-value
	Mean	SD	Mean	SD		
HADS anxiety	10.75	4.71	7.84	4.17	4.06	<.001
HADS depression	7.63	4.07	5.08	3.72	3.23	<.001
QRS-F Parent/Family Problems	7.67	4.02	6.27	4.03	4.01	<.001
DAS	21.29	6.23	21.49	5.69	.456	.65
PGS	13.95	5,12	16.16	4.64	3.33	<.001

Table 4 - Linear Regression Analyses of Mother Well-Being Measures

Predictor Variable	Mother Anxiety (HADS)		Mother Depression (HADS)		Mother Stress (QRS-F)	
	$\beta$	p	$\beta$	p	$\beta$	p
Marital status	.09	.41	.09	.36	na*	na*
University education	.11	.34	-.06	.60	-.02	.98
Employed or not	.10	.36	.13	.20	.27	.01
Family Income	-.18	.11	-.19	.09	na*	na*
SDQ Prosocial	-.13	.19	-.14	.17	na*	na*
SDQ Total	.12	.26	.13	.22	.22	.04
SCQ Total	na*	na*	.07	.58	.15	.21
VABS	na*	na*	na*	na*	-.07	.50

\* This predictor was not included in the analysis for this regression

Table 5 – Linear Regression Analysis for Fathers’ Stress

Predictor Variable	Father Stress (QRS-F)	
	$\beta$	p
SDQ Total	.20	.09
SCQ Total	.19	.10

## Section Five: Contribution to Theory, Clinical Practice and Learning

## **Contributions to Theory, Clinical Practice and Learning**

The main findings of this project include the replication of previous research results that mothers of children with autism report lower well-being than fathers. Variables that have been shown to be important in explaining mother and father differences in this study include child behaviour problems, systemic factors and employment.

Factors that have previously been investigated in the research include child variables such as adaptive behaviour and level of the child's autism as well as parental factors such as coping and social support, but there are few consistent findings about the contribution of these factors. Although child behaviour problems have been shown in previous research to consistently contribute to mothers' adjustment, and maternal mental health has been shown to contribute to paternal well-being, a substantial evidence base has yet to be developed to explain the variables which contribute entirely to either mother or father well-being.

This paper will discuss three main themes that have emerged from this project:

- 1) The implications of the finding that mother-father differences in well-being have been consistently reported in the literature and replicated in the empirical study.
- 2) The implications of the finding from previous research and this study that systemic partner variables have been shown to contribute to parental well-being.
- 3) The implications of the finding from this study that employment has been shown to contribute to maternal well-being.

These themes will be discussed in terms of theoretical, research and clinical implications.

### **Mother-Father Differences – Theory/Research & Clinical Implications**

The finding that mothers and fathers of children with autism report different experiences of parenting has been consistently reported in the literature, and was replicated in this study. Specifically, the fact that mothers report higher levels of mental health difficulties and stress than fathers poses the challenge for research to discover why these differences occur. Women report higher levels of mental health difficulties in the general population (Crawford, Henry, Crombie & Taylor, 2001), but it is unclear whether this is due to women experiencing higher levels of difficulties, or rather that women are more comfortable reporting difficulties than men. In this way, the gender differences found in parents of children with autism may simply mirror gender differences in the normal population. As has also been previously mentioned, the elevated levels of reported difficulties in women has been a central theme of previous research, as opposed to a focus on what interventions are helpful. However, from a more feminist theoretical standpoint, the higher levels of reported difficulties in women could in fact be a healthy expression of the struggles that parenting a child with autism may bring. The same standpoint would suggest that men may under-report whilst women express their problems more readily. Research into gender differences due to societal gender role expectations supports this perspective, in that men have been shown to have more difficulty than women in both reporting mental

health difficulties and accessing mental health services (Emslie, Ridge, Ziebland & Hunt, 2006; Smith, Peck & McGovern, 2004). Based on this standpoint, research into parental experiences could move away from the ‘psychopathology’ of mothers.

Indeed, taking the concept further, future studies could use measures that assess more typical male maladaptive ways of dealing with stress, such as alcohol consumption in order to measure difficulties in both genders. Hastings, Kovshoff, Brown, Ward, Espinosa & Remington (2005) in their analysis of coping in mothers and fathers of preschool children with autism concluded that mothers and fathers adopt different coping strategies and that “separate analyses of maternal and paternal (coping) data are needed in autism family research”.

A further factor in need of more research is that of societal and cultural factors in mothers’ well-being. The qualitative research themes that emerged for mothers included having more difficulties with services than fathers (Gray, 1993), and experiencing more stigma than fathers (Gray, 2002). These factors have yet to be measured in quantitative studies as contributory to mothers’ stress. Indeed, the fact that the variables that have been investigated so far do not contribute entirely to mothers’ stress levels suggests that other factors, such as societal factors, need to be investigated. The clinical implications of mother/father differences point to, at a basic level, the requirement for mothers’ and fathers’ needs to be considered separately.

From an assessment standpoint, it may be that different measures may be needed to assess mother and father well-being, especially if fathers are more likely to under-report and deal with stress by turning to maladaptive coping strategies. Specifically, this could involve assessing coping strategies, especially of fathers, in addition to



using mental health/stress measures, as this may provide a more accurate picture of paternal well-being than mental health/stress measures alone.

Intervention strategies would also have to be tailored differently for mothers and fathers based on the research. One of the most effective support strategies for mothers based on current findings would be moderating the effect of child behaviour problems on mothers. Interventions could be targeted at supporting mothers to become skilled in using behavioural principles to help their child learn more appropriate prosocial behaviours. Home-based intensive interventions programmes, for example, have been shown to be effective for autistic children's adaptive and prosocial behaviour (Sallows & Graupner, 2005). In addition, mothers would need support to build up adaptive coping mechanisms (for example, acceptance as an aid to adjustment; Lloyd & Hastings, 2008) and, where appropriate, be offered respite. For fathers, the methods of support would be more likely to be indirect. From the current research, any support that would benefit mothers' mental health would also be likely to benefit fathers. Therefore clinicians may find individual therapy with mothers, such as cognitive behavioural therapy for depression, would be a good use of their time. In addition, relationship therapy with couples could aid mothers and fathers in building their relationship in the face of parenting stress.

### **Systemic Relations - Theory/Research & Clinical Implications**

The small amount of research to date on the contribution of systemic factors to parental well-being suggests that parents may affect one another in addition to being

affected by their child. In fact, although the research on systemic contributions to mothers is less clear, fathers have been shown to be more affected by their partners' mental health than by their child's difficulties. The implications of these findings for theory and research centre around the need for a more systemic conceptualization of mother and father well-being, where it is recognized that not only does the child with autism affect parental well-being, but also that parents can affect one another's well-being. Systemic theory conceptualizes that all behaviour (normal or abnormal) occurs within the context of the systems and relationships of a person's environment.

Therefore, from a systemic standpoint, an individual's mental health problems occur within the context of their particular family, work and cultural environment.

Therefore the behaviour and mental health problems of one parent are determined by the patterns that connect all family members, and specifically the other parent.

In relation to the current findings, the need for looking at mother well-being outcomes in relation to father well-being would seem to be particularly important. It has been shown so far that these systemic variables affect fathers more than more direct variables such as child behaviour problems. This finding has mirrored the theme from qualitative research that emerged from fathers who felt that their child's difficulties affected their wife more than them (Gray, 2003). Systemic thinking could be taken further by examining the effect of all family members on each other, for example taking into account the effect that siblings in the family also have on mother and father well-being. Such research would be more likely to uncover further factors in mother-father well-being that have not been explored by the literature to date. Such an exploration would require a research design where measurements would need to be

taken from all family members, and the results could be analysed using systemic statistical analysis similar to the systemic regressions used in the present study.

A more systemic way of thinking about parental well-being would have some implications for clinical work. Assessment of a parents' ability to cope would need to include a full assessment of the adjustment and interactions of all family members (possibly even siblings) rather than just an identified parent. This could be carried out by assessing family members individually using mental health, stress and coping measures, but also by observing family interactions and patterns. A clinical formulation of a particular parents' well-being would also then necessarily include systemic factors as part of the overall picture for intervention. Such a formulation would include attention to familial patterns of interaction as ways of maintaining a particular family member's difficulties. Therefore, drawing on the current research, fathers' difficulties may be seen in terms of their relation to mothers' mental health problems.

In terms of interventions, fathers would be best supported by aiding mothers with their difficulties, again through individual cognitive behavioural work for mothers' depression or anxiety, or through exploratory couples work in order to uncover unhelpful interactions within the relationship. If systemic thinking were taken further, and further family factors were found to be important (such as dyadic adjustment and sibling mental health), targeted interventions would be likely to include support for all family members. Such interventions may include family therapy, in addition to the usual methods of intervention for the child with autism's behavioural problems, as described in the previous section. There has been little published research into the

effects of family therapy for families of children with autism. However, there have been some studies into the larger systemic root of difficulties of families of children with disabilities. For example, Woolfson (2004) proposed a psychosocial model of disability that shows how societal beliefs about disability might be translated at the level of parent beliefs which could be problematic for effective parenting, (and therefore lead to parental mental health problems). Clinicians may encounter difficulties in implementing family therapy with families of children with autism however, in that family members may well be very stressed and may not wish to take part in therapy. In addition, family therapy encourages family members to talk about their emotions towards each other and situations, and this may prove difficult for parents who themselves have a measure of autistic traits.

### **Employment as a 'Buffer' - Theory/ Research & Clinical Implications**

The final theme to be explored is raised by the finding that mothers' well-being has been found in the current study to be affected by whether or not they were employed. This finding has yet to be explored by further research, but has, as previously discussed, been uncovered as a theme for fathers in qualitative research (Gray, 1993; Gray, 2002; Gray, 2003). In these studies, fathers felt that their work gave them a separate role and identity away from the carer role. The 'buffering' effect of employment for fathers may also act in a similar way for mothers, and it would be interesting to explore and compare this further for both parents. There are a number of ways in which employment could affect both mother and father well-being, which could inform theory. It may be that by having a job, a parent just spends less time

around their child's behaviour problems, and this, especially for mothers, may be why working mothers are less stressed. It also may be that being in employment has an added effect for mothers as that reported by fathers above: that having a job outside the home means that a person has a role in which they can succeed that is separate from their role as carer, and so may contribute to increased self-esteem and self-efficacy. A qualitative study by Shearn and Todd (2000) which looked at mothers of children with intellectual disabilities found that for the mothers in the study, a lack of opportunities to engage in employment led to feelings of isolation, a lack of fulfillment and low self-esteem. Employment also provides a family with income, and as low income was related to lower well-being in this study, this may be the main effect of employment for mothers. Low income has been associated with both poorer health and elevated distress for mothers of children at risk of disability (Emerson & Llewelyn, 2008). Another possible benefit includes the social support network associated with employment. Social support has been found to aid adjustment of mothers of children with autism in several studies (Bromley, Hare, Davison & Emerson, 2004; Weiss, 2002). Future research could explore the role of employment for both mothers and fathers of children with autism, and what aspects of employment seem to have the most significant effects.

The implications for clinicians for the finding that employment may act as a 'buffer' for parental stress informs different areas for placing resources. For example, in addition to all the interventions described above, clinicians working with parents of children with autism may need to support mothers in remaining in work where appropriate, or even in finding employment. If employment is found in the future to be a significant and consistent contributor to well-being, services may need to target

resources towards supporting mothers to remain in employment or find employment, rather than supporting mothers to stay at home.

In conclusion, future research into the differences in well-being between mothers and fathers of children with autism needs to explore not just how parents differ on mental health measures, but to take into account a wider theoretical view of parental adaptation to include coping, societal factors and gender roles, as well as systemic variables and the importance of employment as a 'buffer' against stress. Such research will be able to inform clinicians in their work with families of children with autism, and also will be able to inform services where resources are best placed to support parents.

Clinicians may well have to adapt their work from traditional ways of supporting mothers to include supporting mothers to stay in work, and also working with partners and potentially the greater family unit as a whole.

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## Extended Discussion

Shearn, J. & Todd, S. (2000). Maternal employment and family responsibilities: the perspectives of mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 13* (3), 109-131.

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## Statement Of Word Count

<i>Section</i>	<i>No of Words</i>
Abstracts	625
Ethics Proposal	4652
Reflections on the Process of Research	1368
Literature Review	6402
Empirical Paper	4880
Contributions to Theory, Clinical Practice & Learning	2004
	<b>TOTAL 19931</b>
Appendices & References	<b>TOTAL 19980</b>
	<b>OVERALL TOTAL 39911</b>